CHAPTER 4

ANALYZIS AND DISCUSSION

This section of the thesis deals with analyze and discussion of the themes that have emerged in the present study. The process of analyzing the data started with reading the interviews and identifying the themes. The three major themes that have emerged in this study are living with schizophrenia, participation in the community, and quality of life. These three themes are elaborately explained and interpreted in the following three chapters. The discussion chapter tries to compare the major themes with the existing literature.

The chapter on living with schizophrenia entails the perception of participants on their experience of living with schizophrenia. This chapter attempts to look at the various aspects of living with schizophrenia from the perspective of PLS, their family, and professionals. The chapter on participation in community looks into the various aspects of participation of people living with schizophrenia in their community. This chapter focuses on the perspective of people living with schizophrenia on their participation in the community. It also tries to identify the ways in which the rehabilitation facility encourages participation in the community. The third analysis chapter is an attempt to understand the perception of people living with schizophrenia regarding their quality of life. It also tries to look at the views of the family and professionals on the quality of life of the PLS. The discussion chapter tries to understand the relationship between participation of people living with schizophrenia in the community and their quality of life.

The attempt is to examine each analysis chapter without any overlapping of the concepts. This seems extremely difficult as each theme is intrinsically connected to each other. The challenge is to avoid repetition and bring the nuances of each theme. The issue of repetition is not a challenge in the chapter on living with schizophrenia since it deals with the experience of living with schizophrenia. Participants used the same concepts interchangeably to denote their perception on participation in the community and quality of life. The framework of activities and participation provided by ICF is used in the
chapter ‘participation in the community’ to get more clarity on the concepts. In the chapter ‘quality of life’ models of quality of life proposed by Calman’s (1984), Lehman (1988), Bigelow et al. (1982), and Awad et al. (1997) has been used to clarify the concepts.
SECTION A
LIVING WITH SCHIZOPHRENIA

Introduction

This chapter attempts to understand the experience of ‘Living with Schizophrenia (LS)’ from the perspective of ‘people living with schizophrenia (PLS)’, with supportive information from family members and professionals. The effort is to voice out participants’ experiences of living with schizophrenia and the way schizophrenia has changed their lives. There are various components that played part in aggravating the difficulties and also reducing those difficulties. It is not easy to live with such a severe mental illness where symptoms are always present though the intensity may differ. The experience of living with schizophrenia is of pain and isolation. This chapter explores the various facets of living with schizophrenia. The purpose is to locate the struggle and effort PLS put in to achieving a recovery. Matrix 4 gives a glimpse of various aspects of living with schizophrenia.

Matrix 4. Aspects of living with schizophrenia

<table>
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<tr>
<th>Living with schizophrenia</th>
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<tr>
<td>Duration of living with schizophrenia</td>
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<td>Knowledge/ understanding schizophrenia</td>
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<td>Manifestations of schizophrenia</td>
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<td>Accepting schizophrenia</td>
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<td>Treatment</td>
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<td>Family support</td>
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<tr>
<td>Implications of schizophrenia</td>
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20 Since participants uses the term illness to refer schizophrenia the same term will be used interchangeably in chapter
Duration of living with schizophrenia (onset and years of living with schizophrenia)

Duration of illness (in this study) comprise the period of living with schizophrenia. It covers the onset of schizophrenia, years lived with schizophrenia, and present state of living with schizophrenia. The period of living with the schizophrenia has a profound influence on the perception of PLS. Duration of schizophrenia is an important component that influences decision making of people living with schizophrenia. In this study the duration of schizophrenia of the participants can be categorized into; less than five years, five to ten years, ten to twenty years, twenty to thirty years, and more than thirty years. This categorization is important since chronicity\(^1\) influences various aspects of schizophrenia such as their outlook towards life, attitude towards treatment and rehabilitation, effectiveness of rehabilitation, participation in various areas, and quality of life. Data reveals that there is a variation in the time of diagnosis and time of onset of schizophrenia. Most of the participants were diagnosed with schizophrenia during their SSLC or PUC or under graduation days, whereas some were diagnosed while on a job.

There are participants who believe that schizophrenia might have occurred during their childhood. They could not identify it at that point of time. Today participants are capable to understand that because they are aware of the symptoms of schizophrenia. The age of onset of illness is another important aspect of living with schizophrenia. In terms of ‘age of onset of illness’ participants can be categorized into three groups; fifteen to twenty years old, twenty-one to twenty-five years old, and above twenty five. Data shows that there are participants who did not experience any disturbances related to the illness in their childhood. Matrix 5 gives a brief picture of duration of living with schizophrenia.

\[\ldots\text{till I was 14 years old I did not have schizophrenia and because of that I was a bright student in the school. Continuously I got good marks and all. I studied till}\]

\(^1\) Long years of living with schizophrenia are probably living with schizophrenia for ten to more than ten years. This is how the NGO differentiate the participants living with schizophrenia for longer duration from participants with shorter duration.
10th standard after that I got schizophrenia. I was perfectly healthy till 14 and no schizophrenia.... I got schizophrenia at the age of 15 now I am 45, 30 years back. After a few years I came and joined half way home and then long stay home.... (Mynah)

Matrix 5: Duration of living with schizophrenia

<table>
<thead>
<tr>
<th>Rehabilitation facility</th>
<th>Duration of participants’ illness</th>
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<tbody>
<tr>
<td>Half way home</td>
<td>less than five years</td>
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<tr>
<td>Day care</td>
<td>five to ten years</td>
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<tr>
<td></td>
<td>ten to twenty years</td>
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<tr>
<td></td>
<td>twenty to thirty years</td>
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<tr>
<td>Long stay home</td>
<td>More than thirty years</td>
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</tbody>
</table>

In the present study duration of living with schizophrenia of participants at long stay facility is different from half way and day care facility. Long stay facility accommodates people living with chronic schizophrenia; therefore the duration of illness is more than thirty years. There is an exceptional case of Ammal who is living with schizophrenia for the last 28 years attending day care facility as her family does not want to send her to any residential rehabilitation facility. Family members’ (in some instances) have only an approximate idea regarding the duration of schizophrenia. This is in case of those participants who have spent a considerable amount of time living with schizophrenia.

...for more than sixteen years he has been behaving like this. He was okay in childhood, after high school I think, now he is thirty-six, I think twenty years it has been, at the age of twenty it started.... (Ali’s Father)

Over the years families learned to observe participants carefully and identify when they become disturbed and what should be done at that time. This enabled families of people living with chronic schizophrenia to understand the nature of illness and seek
professional help whenever necessary. Family members of participants with acute\textsuperscript{22} schizophrenia find it difficult to handle the situation since they are not very familiar with the course of schizophrenia. They are also not open to seek professional guidance due to stigma and discrimination from relatives and friends. Professionals’ says that they find it easy to work with chronic PLS and their families. This is because people living with chronic schizophrenia and family have a better understanding of illness and maintains a minimum activity level. Professionals also feel that acute PLS are mostly in a state of denial\textsuperscript{23}. Therefore, it is difficult to make them understand the need for treatment and rehabilitation. Their families also share the same state of denial for a long time which adversely affects the treatment.

Duration of illness is an important aspect in determining the rehabilitation procedure. Rehabilitation plans are different for participants with three years of illness compared to a participant with twenty years of illness. This is because the needs of participants with three years of illness are different from those with twenty years of illness. Even though organization A does not consider age as a criterion for admission, long stay facility accommodates PLS above forty years. This is because people living with chronic schizophrenia require long term care and LSH is meant for long term care. It is also because as the people living with schizophrenia grow older more care is required in psychiatric and physical issues such as diabetes, cholesterol, blood pressure which family finds difficult to provide. The amount of time spent on living with schizophrenia influences other areas of life, and their understanding and acceptance of the illness.

**Knowledge/ understanding schizophrenia**

Participants’ knowledge about schizophrenia is based on three aspects; their own experience of various psychological disturbances and symptoms, explanations by psychiatrist or therapist or family, and from sources such as the internet, books, or palm

\textsuperscript{22} Organization A uses this term to represent shorter period of living with schizophrenia probably less than five years.

\textsuperscript{23} Participants refuse to accept the fact that they are diagnosed with schizophrenia or living with schizophrenia.
lets. Participants agree that they do not know the exact definition of schizophrenia or how it is defined in the books. Some of them are curious to know about schizophrenia and its manifestations. This lack of knowledge is due to two reasons. First reason is that the explanations from the psychiatrist or other professionals are not satisfying. Second reason is that participants are not very keen to know about their illness. There are also instances of participant forgetting the information psychiatrist shared about schizophrenia. A few participants refuse to discuss about schizophrenia since they do not believe that they have schizophrenia. Even though they are ready to discuss how the label of schizophrenia changed their lives, they are not ready to accept self as living with schizophrenia. Participants recollect the moment of awareness\textsuperscript{24} with shock and distress.

\textit{...I was suffering but I asked....they never told me that, doctor also did not let me know that I am suffering from schizophrenia, they used to think I have mania depression....then he told my father probably she is suffering from schizophrenia....then they told she is schizophrenic then I came to know about that I am schizophrenic, I was shocked very much such a major disease I am suffering from (Hasini)}

\textit{Schizophrenia is a mental illness that much I know. It is like the mind is not functioning the way it should...it is quite common to hear voices, talk to people, talk to yourself, and be aloof from everyone else...also at the same time you can be quite, you hear voices but you do not harm anyone, and you can be aggressive and not aggressive also. So I am not the aggressive type. So that much I know...this [knowledge] from watching movies and all (Avinash)}

During the initial stages of schizophrenia participants were aware of certain difficulties they experienced such as hearing voices, fear, depression, getting angry for small things, violent towards family members, but they were not able to understand what went wrong with them. Though they knew something was wrong they never thought it was schizophrenia.

\textsuperscript{24} The moment and day they came to know about their diagnosis of schizophrenia
Participants felt that the understanding that something was wrong with them became the breakthrough for searching the reason behind it. They started searching for an answer on what went wrong with them, and how to overcome it. Mynah identified her distressing experiences as symptoms of mental illness after reading a pamphlet issued by an NGO. She convinced her family members to take her for treatment and followed treatment rigorously. She experiences less distress at present and attributes it as the effect of medication, care and counseling. Mynah’s case is different from other participants. Other participants living with chronic schizophrenia did not notice the symptoms initially, which was one of the reasons for not accepting illness at that point of time. Accepting the disturbances as a manifestation of schizophrenia was not easy. Data revealed that participants irrespective of their gender initially refused to accept the fact that they have schizophrenia. There were instances where participants were not informed about their illness for a long time. They came to know about it after many years and did not take it very well when they were told. There were participants who did not want to know about schizophrenia because it made them feel bad about self. Participants were hesitant to discuss about what they think of schizophrenia, but they were ready to explain how that labeling affected their lives.

Knowledge as mentioned earlier is mainly based on the participants’ experiences. Participants who wanted to know more details about schizophrenia accessed internet or read books, which gave more information on schizophrenia. Then they compared this information with their own experiences. Family history also played a role in understanding and accepting self with schizophrenia.

*My eldest brother was suffering from schizophrenia I did not know that... actually I do not know properly but royal family my mother's side has this because they marry within relations at that time.... I think it is in the blood (Avni)*

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25 Participants called schizophrenia as a label attached to them and it changed their lives.
26 There were people in the family who suffered from any form of mental illness other than the participant.
The explanation by the psychiatrist that schizophrenia is the result of a chemical imbalance in the brain is easily accepted by the participants. This explanation gives them a confidence that schizophrenia is a physical illness and also gives a hope for cure from schizophrenia. In participants’ opinion understanding positive and negative symptoms also helps in relating own symptomatic behavior. Participants’ says that changes in appetite, sleep, interaction, cognitive abilities, interest in work, and suicidal thoughts are recognized once they are aware of the features of schizophrenia.

Families of those participants who have a clear understanding and acceptance about schizophrenia\textsuperscript{27} find it relieving that they do not have to remind participant to take medication and go for follow-up. This alleviates the family members concern of medication compliance\textsuperscript{28}. At the same time, family members of participants who do not have proper understanding and acceptance of their illness reports a tough time keeping up with treatment and follow-up. They need to motivate and at times force participants to take medicines, follow routine, attend rehabilitation center, and help at home. This is extremely difficult for family members who are not able to provide personal support and monitoring\textsuperscript{29}. The family’s knowledge regarding schizophrenia is also important in regular treatment and follow-up. Family members say that most they rely on the explanations of psychiatrist. If family consists of medical professionals, then their knowledge level is different and better.

\textit{Very few of the clients that I have come across have tried to know what schizophrenia is. One due to the fact that they all come after meeting many psychiatrist, psychologist and counselors (they are chronically ill). As you know they go to doctor shopping for a long time and until all is exhausted they do not come for rehabilitation. This does not apply to all the clients but at least eighty percent of them. However, when clients who are recently diagnosed and come for rehabilitation they often ask questions on their illness and that too depends on}

\textsuperscript{27} Clear understanding and acceptance of schizophrenia is referred as insight by the professionals’ which is explained later in this chapter.

\textsuperscript{28} Medication compliance refers to regular intake of medication without force or motivation.

\textsuperscript{29} This is difficult in case if the care taker is old, or is the only bread winner of the family.
their education level, understanding and the symptoms. Please understand this is pertaining to the rehabilitation set up (Kalyani mental health professional)

Doctor told this is because his brain is weak. He has mental illness (dimag ki bimari) that needs medicines….whenever he stops medicine he becomes disturbed…. (Ali’s father)

Professionals use the term ‘insight’ to refer the level of awareness in people living with schizophrenia about their illness. They also differentiate between clear insight, partial insight, and no insight. Participants who are completely aware of their diagnosis and accept it as part of their lives has clear insight. Participants who know about symptoms and take medication, but do not accept it as schizophrenia have partial insight. Participants who do not know anything about schizophrenia, not accept self as diagnosed with schizophrenia, and take medication with motivation/force has no insight. In HWH and LSH professionals are able to supervise medication intake, but for day care participants’ it is the responsibility of their family members. Family members (mainly care takers) and professionals have to remain alert in ensuring medication compliance, routine, improvement, and report it to the psychiatrist. They also have to keep track of the symptomatic manifestations.

**Manifestations of schizophrenia**

In the present study most of the participants are diagnosed with paranoid schizophrenia. Manifestations of illness are also termed as symptoms by mental health professionals. There are participants who reported of hearing voices (auditory hallucinations) as a prominent feature of their illness. They say that this is manly in the form of a voice commanding them to do certain things, or a conversation between two voices talking about the participant. The voice threatens them that something bad will happen to their family members if they do not follow the instructions. Delusions**30** are mainly in the form of others are talking about the participant, or plotting to kill the participants, or film stars are in love with the participant, or she/he posses some special

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30 A firmly held belief or set of beliefs which may not be true or rational. (see introduction chapter)
kind of power to predict future, or is god. Talking to self or laughing to self is usually a response to the voices heard. Participants are not aware of this behavior until the family or professional tells them about this. All these symptoms create distress in people living with schizophrenia to such an extent that they sometimes turn aggressive or violent, especially when paranoid symptoms are floridly present.

These symptoms disrupt cognitive functions, specifically concentration, attention, memory, and comprehension affecting participant’s daily life activities. It is difficult for participant to focus on any activity when she/he is disturbed, particularly when hallucinations are present. Lack of motivation to engage in any productive activity is often misunderstood as laziness. Participants report that they find it difficult to find interest in any activity and are unable to find happiness in anything. They have experienced various difficulties such as hearing voices, unknown fears, concentration and attention problems, suicidal thoughts and attempts, sleeplessness, and increased amount of smoking. In their opinion these experiences brought unhappiness, loneliness, misunderstanding, and eventually led to withdrawal from everyone and everything. Participants had difficulty in recollecting their behavior during floridly symptomatic period, but they could clearly remember the distress experienced before the full blown symptoms. They had a vague memory of the events happened during hospitalization\(^{31}\).

\[\text{from beginning there was some problem, I understood that in PUC only....later I started feeling eye problem, staring eye, I can’t understand, couldn’t grasp what they say, I felt blank, I used to sit alone not mingling with people...after that I suspected everybody, they are talking about me my brother took me to hospital I was not willing to take medicine....whole world was watching me in television, they used to follow me in bike, everybody was watching me...before only I knew that something was wrong with me, nobody noticed. I could not talk to anybody. Something was going on (Prema)}\]

\(^{31}\)Therefore, the information gathered from the families, professionals’, and case reports have been useful to understand the symptomatic behavior of people living with schizophrenia.
Families report that during the symptomatic period various areas of functioning are affected. This starts with trouble in sleeping, participant either sleep less or sleep excessively, her/his appetite decreases, and the individual become more irritable and lethargic. Eventually, personal hygiene and self care deteriorates. Interaction, even with the intimate family members reduces and after a point of time ceases completely resulting in a state of social withdrawal. Participant becomes inconsistent in work or loses interest in work or quit the job. Cognitive problems add more troubles to the existing issues. Motivation to perform any activity diminishes to such an extent that the participant loses interest even in performing daily life activities. As mentioned above self care is the first area that gets affected and professionals face tough time in retraining those skills. Participants’ involvement in treatment decisions is limited. They take medicines, but do not know the name of the medications they consume. In professionals’ observation this depends on the education, insight, and motivation of the participant.

....I had hallucinations about an Australian girl whom I wanted to marry and all it was just imagination. I was fed up of what was happening in my life. And this doctor was good but every time I had consultation with him something negative always came up. Like violent to his father or not getting up on time, not following a routine, doing nothing with his[his own] life...this place[current rehabilitation center] is better and psychiatrist is good, here I started preparing my own medication so I know what I am taking and why I am taking it....(Avinash)

...twenty-four hours he will be at home lying....looking at the ceiling and he will never respond to you....he never comes out of the house, he used to go to his room and lock, he doesn’t come out not even for taking a bath or even any relatives come to home.... (Kumar’s brother)
The difference between participants with positive symptoms (prominent) and negative symptoms\textsuperscript{32} has also been mentioned by the professionals. In their opinion participants with positive symptoms have difficulty in concentrating on the work assigned. These participants find it very difficult to divert attention from distressing symptoms. Whereas it is easy to get participants with negative symptoms to work since they are able to sit and work for a longer period. The only concern while working with these participants is that their interaction and communication is need based. One aspect professionals observed while working with the PLS is that their symptoms do not subside completely. At times, some delusions creep in, but do not interfere with participants' functioning.

**Accepting schizophrenia**

Acceptance of illness did not come at once; it took several years to come in terms with the illness. After the initial refusal it took many years of struggles and strain to understand the illness, its manifestation, and treatment. Participants living with illness for more than two decades say that they have come in terms with the fact of living with schizophrenia. Age and duration of schizophrenia thus plays a role in understanding and accepting schizophrenia. In participants' opinion acceptance of the illness occurs when they are completely aware of their illness; how it manifests, what the illness does to them, how to overcome it, and realize the need for treatment. Participants start taking medication on their own once they realize the need for treatment and stick to it until the psychiatrist asks them to stop. This awareness depends on many factors such as educational background, family support, and certain individualistic characteristics of self awareness. Only a few participants feel this awareness, other participants are either confused on this matter or hesitate to consider self as living with schizophrenia. For example, Varun is a medical graduate, this helps him in accepting the fact that he is living with schizophrenia though he is not happy with it. Navneet is living with schizophrenia for last thirty years. He refuses to accept his diagnosis, but takes medication.

\textsuperscript{32} Professionals’ explains symptoms under two categories of positive and negative symptoms. Positive symptoms refer to hallucinations, delusions, etc., and negative symptoms refer to lack of interest, withdrawn, etc. (These are explained in the introduction chapter)
I never consider myself as schizophrenic, I feel schizophrenia even if I have a bit of it, it is curable....There are many definitions of it according to one dictionary it is periodic manifestations of stupor and anxiety, I do feel depressed at times....during childhood period there was no signs of schizophrenia, these signs occurred when I was in college and when I failed in my BA....I want to remove the label of schizophrenia....I feel more you know [thinking for sometime] it is a better sky with medicines (Navneet)

Participants with a family history of illness are ready to accept their illness compared to those who do not have any family history. This is due to the reason that they have seen what it means to live with mental illness and knows its impact on life. The acceptance of illness gives participants a hope for recovery\(^{33}\). While explaining the reasons for not accepting schizophrenia participants made it clear that stigma, dependency on medication, and side effects played a role in it. Sharing the fact of living with illness with outsiders is still a problem for participants. This is mainly due to the fear of discrimination and isolation. Participants are hesitant to reveal their illness even with relatives. Participants do not completely rule out the possibility of schizophrenia. They believe that if they have schizophrenia then it is curable and that is why medication is important. On the other side taking participants and professionals feel that medication is also a precaution to avoid relapses\(^{34}\). Nevertheless, taking medication is not always an indication of acceptance of illness. It can be due to family pressure, demand from the employers, or suggestion by the psychiatrist.

Participants shared their views on what could have caused schizophrenia. In their view, there were no specific reasons attributed to the onset of schizophrenia. They feel that many factors have played part in the onset. For example, Malleswaran felt that staying away from family for a long period of time and started working at a very young age might have led to the illness. The pressure of job added stress to the wound created

\(^{33}\) Being regular in taking medication is assumed to help in controlling symptoms and thus enabling participants in their daily functioning. (Field observation report)

\(^{34}\) This results from the previous experiences of relapse. (Field observation report)
by loneliness leading to a breakdown. The lack of opportunities for socialization and friends hindered sharing troubles with others. Kavya and Nalini felt that the burden of studies and failures in exams created frustration and might have caused the illness. Family atmosphere filled with chaos and conflict between parents, financial troubles, physical and sexual abuse, and loss of parents might have triggered the illness. The change in environment, drug abuse, failure in relationships, and fear about the future were also quoted by participants.

"my illness actually according to me schizophrenia had when I was in America...at a very early age I am subjectified nature the environment made me ill, the environment in America. It is usually, for example when the village people come to city know they experience a lot of difficulties, from Bangalore, India to America is a very tough kind....it is not the stay in the country the environment and life in America is very tough (Arthi)

"....during graduation I fell sick, before that my father got business or financial loss, financial side was upset. I couldn’t see my father suffering during that time. Slowly depression started.... (Nalini)

Some participants felt that schizophrenia just happened without any specific reason. There were no particular incidences that they could remember as a possible cause for schizophrenia. Family members shared similar views as the reason for the onset of schizophrenia. Professionals explained the causal factors quoted in various psychiatric textbooks.

**Treatment: Medications, side effects, psychosocial therapies, and physical issues**

The data shows that during the course of illness changing psychiatrist was not a new phenomenon. This was mainly due to dissatisfaction with the treatment PLS received. When the results were not in favor of the participants then both the participants and the
family wish to change the psychiatrist. The phenomenon of changing psychiatrists continued until the expectations were met at least in terms of minimizing the symptoms. The shift in residence due to change in caretakers’ job was also a reason for changing current psychiatrist. In such instances, previous psychiatrist referred a psychiatrist in the new place. Participants who were happy with the outcome continued their treatment under one psychiatrist. There was also an instance of ‘Dargha’ (traditional healers) treatment during the initial years. Since the ‘Dargha’ people were not able to bring any change in the symptoms they suggested for medical treatment. Data revealed that initially participants used to keep track of their medications. After a point of time they lost the interest in knowing medicines and started taking medicines without checking the name and effects. This could be due to the trust on psychiatrist and confidence in the medication prescribed by her/him.

Medication for schizophrenia mainly consists of antipsychotics. This is sometimes combined with antidepressants when depressive features are present or mood stabilizers in case of mood fluctuations. Participants agree that as long as they take medicines symptoms are under control. In those participants who have persistent symptoms medication helps to attain more focus without the interference of symptoms in their daily life functioning. The effect of medication and psychosocial interventions works in different ways. Participants are able to maintain self care on a regular basis. They can independently carry out daily activities without any motivation or supervision. There are participants who are able take up small jobs and continue with their studies. Case files show that relapses happen primarily due to non compliance of the medication or irregular follow-up with the psychiatrist. It also points out that after participants’ admission to rehabilitation center relapses occurred chiefly due to non compliance of medication. This

As per the case history records (feedbacks from participants collected during the admission to rehabilitation center) participants were aware of the medications prescribed by their psychiatrist during the initial stage of treatment. During the interview most of the participants did not remember the names of medications. They said that the name of medication did not bother them anymore and they trust their psychiatrist.

I used to attend classes organized by the organization A. The classes were taken by psychiatrist and he explained different type of medications for people living with schizophrenia.

Symptoms may be mildly present there is not an instance where participants felt complete freedom from symptoms.
non compliance of medication happened while participants went home on a vacation. In certain instances changes\textsuperscript{38} in medication can trigger relapse. The impact of medication and psychosocial interventions varies for each individual.

\textit{...in last year I forgotten medicine, I got relapse now I know I should take medication regularly that is very important.... (Avni)}

\textit{medications are important but small dosage of medicines should be given otherwise it affect memory loss....long term medication has really affected, I feel very disgusted but it is inevitable, I have to take...I have accepted the fact that I have to take medication lifelong because this medication helped my nervous system.... (Arthi)}

The question of whether participants like to take medication does not arise. It seems participants do not have any choice, but to continue with the medication for a long time. Participants are willing to take medication in the belief that it will cure schizophrenia after sometime. Participants with chronic schizophrenia have almost accepted the fact they have to continue with medication for the rest of their lives. Participants with acute schizophrenia feel that once schizophrenia is cured there is no need for medication.

The major issue with medication is its’ severe side effects. The most common side effects are gastritis, constipation, obesity, diabetes, tremors, involuntary facial movements or Tardive Dyskinesia\textsuperscript{39} (TD), drowsiness, and excessive salivation. Side effects of medications can be distressing than symptoms, especially for those participants with TD. This is because TD causes social embarrassmment and is also a barrier for

\textsuperscript{38} Sometimes the change in medications also did not work out resulting in relapses. Sagar was taking medication regularly but his symptoms did not reduce even after changing medication. He feels that his medication was not effective in countering his symptoms and ended up in hospital.

\textsuperscript{39} Tardive dyskinesia (TD) is a side effect of antipsychotic medication where the person experience involuntary facial movements. TD causes embarrassment in the individual while interacting with people. They experience pain while speaking so it is difficult to continue conversation for a long time at a stretch. Participant with TD had difficulty during interview as it was painful talking for a long time and required breaks in between. (field notes)
interaction. There are certain side effects, which require periodic blood checkups\textsuperscript{40}. There are participants who are relieved from side effects due to the combination of medication prescribed by their psychiatrist. For some participants’ side effects persist despite the changes in the medication. Physical illnesses are the biggest challenge to the treatment since it is difficult to deal with the physical problems along with complications of psychiatric illness. Diabetes restricts participants from enjoying certain food and they also have to take medication to control their blood sugar level. Stiffness, back pain, high blood pressure, weight gain, and cholesterol are common forms of physical discomforts. Participants with multiple physical complications have a tough time. Maria was treated for breast cancer in the past. She also suffered from epilepsy and water clogging in knees. A few years back she fell from a staircase and injured her spine which resulted in restricted physical movement. At present, she is dependent on an attendant for carrying out almost all the daily life activities.

\textit{...and then throughout my days of taking medication, I had tardive dyskinesia, very severe. Earlier it was more and I was very conscious of it. The recent medication made it less, but it is still there and causes slurring of speech....} (Akhil) [While speaking it looked like he is making faces, but it was due to TD, with much difficulty he expressed his view]

Participants with physical issues such as diabetes, cholesterol, overweight, and high blood pressure have to take precautions to control it. Regular checkups are inevitable to monitor blood-sugar level, pressure level, and cholesterol. Increase in weight is a major health concern. Weight gain is mainly a side effect of medicines and lack of exercising (observations from field notes). Exercising and diet control are part of the routine at HWH and LSH. There are participants’ in LSH and HWH who go for long walks. In day care exercise is a part of the routine, but diet control is the responsibility of the family. Though participants are concerned about weight gain, they are not keen on exercising. Professionals suggest that exercising is an important aspect in reducing weight. Family

\textsuperscript{40} This is for participants who are on clozapine. This medication may lead to a drop in the count of white blood cells in the blood which calls for regular blood tests. (field notes)
insists on continuing medication as it helps participants in their daily functioning. While on medication, it is easy for the family to manage participants at home. There are families who find it difficult to convince participants to take medicines regularly. Therefore, psychiatrist prescribes depot injections. Families acknowledge that when participants are regular in medication it reflects in a better behavior towards family members. This gives family a hope for improvement, and they imply the need of medication to function well.

he is okay now, actually he is like if he has got a little bit ‘I am okay’ kind of attitude, I can manage myself when he feels like that he stops medication, again relapse, this continues repeatedly....medicine part is the biggest. We only want him to take it properly.... (Sourav’s sister)

Professionals feel that medication is the base for a successful rehabilitation process. The concern for professionals is the side effects of antipsychotic medicines. They think that certain side effects are distressing for participants. In their opinion medication non compliance, physical issues and substance use (smoking) are the challenges in the rehabilitation process.

.... at that time he was not having control over smoking. There was no control over his diet, both of them are pretty serious condition, when he smokes more he goes more paranoid actually when he doesn’t smoke he is not so paranoid...now he has controlled, he has quota, he might smoke a little over his quota also, but not as more as he was earlier. When he came here we had put contract type of thing that he should follow these types of things....none of his medicines were working psychiatric and general...now everything is under control even his sugar

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41 This is because medication helps in controlling the symptoms and thus enable participant to take care of self. This relieves family from the effort and pain in forcing the participant to take medication. (field notes and interviews)
42 Depot injections are mainly for individuals who have issues of medication non compliance. These injections are effective and prevents relapse. The effect of injection will remain for a longer period even if the individual skips medication for a day or more. Most of the depot injections are administered twice a month. (field notes)
Regularity in medication is important in treatment, most of the time participants are regular in medication after a relapse. Relapse is a matter of worry not only for PLS, but also for family, employers, and professionals. This is because after relapse, the individual has to put double effort in attaining a level of functioning they maintained before the relapse. It is here insight becomes a crucial part in treatment and rehabilitation. Even though participants understand the importance of medication somehow they fail to confirm with it. It can be due to their inner conflict of dealing with the fact of living with schizophrenia. After a few relapses and hospitalisations they start to acknowledge the importance of medication though they may not accept the fact of schizophrenia. Sourav is very intelligent and have achieved a better position in the company where he joined after recovery. His work is well appreciated by his employer and is complemented by a raise in his salary. Sourav’s employer insists on regular medication because relapses happen when Sourav skips his medication. Kumar needs no reminder to take medication, his family and professionals are impressed with his dedication to take medicines on time. He ensures that medicines are seen by the professionals before he takes it. Mynah, Kumar, Maria, Vikrant internalized the fact that they have to take medicines.

….he is okay with taking medication, he does not say he does not want, he realizes it is important...insight in the sense he does not really have any insight about his delusion, he instead says you people call it delusion I know....initially when he came he was reluctant to take medication, when he came for trail stay for a week or so...his issue was he is not going to take medicine, he had to be put in the closed ward because he was aggressive and argumentative...somewhere now he understands medication is important. he does not refuse medication he even remembers his injection...he does realize it is important to keep track, plus his job is very dependent on the fact that he is on medication, his employer has made it very clear that moment you stop medication you are out of job so it is an added factor....( Professional Sagarika about sourav)
Family situation

Family situation of most of the participants is favorable and supportive. The family is the main source of economic and emotional support for participants. Family support seems to be an inevitable part in recovery and management of their illness. There are participants whose family is the only source of support. Parents are the primary caretakers and in their absence, responsibility is taken up by siblings or a relative/guardian. There are two sides for this aspect; on one side there are instances of abuse and negligence from family members and on the other side family members devote their lives to take care of the participant. Sometimes family atmosphere has played a crucial role in aggravating schizophrenia such as conflict between parents, abuse from parents, hostility from siblings or in laws, or marital conflicts. In the past adjustment issues with maternal relatives were a big issue for Mynah. Her parents died when she was three years old since then she was at the mercy of her maternal cousins. Due to the nature of illness they could not tolerate her. Mynah's paternal relatives were not interested to take care of her. At present she feels fortunate that her parents left enough money, so she could afford to stay at long stay home. Once she got a permanent place to stay her insecurity regarding future vanished. Her maternal cousins became ready to provide the monthly expenditure at the rehabilitation facility. Earlier, she had a stormy relationship with her cousins due to schizophrenia. After her improvement, Mynah’s behavior towards cousins and their behavior to her also changed.

....I am close to my elder sister...they enquire about my health. My parents call up almost every week and keep checking my health (Varun)

my father used to beat me....he used to be angry with me and he used to beat me without any reason... my mother did not beat me she has always supported me....my maternal uncles’ give me financial support....they give love and affection, they reassure me that everything will be fine....(Arthi)

Only four female participants have the history of marriage. All of them are divorced. Their marital life lasted only for a short period.
Participants agree that during the course of illness their family also equally suffered and took them everywhere possible to get a relief. They feel that if the family is not supportive, they will not attain any improvement. After admission to Half Way or Long Stay facility family keeps in touch through phone calls, personal visits, and emails. This gives participants a confidence that family is keen in their improvement. There are uncertainties regarding the future of participants’ whose parents are aged. Though siblings may take care of the participant, a fear of being sidelined exists in both participant and their parents.

Some of the families did not know what to do at the initial stage of illness and this delayed in seeking treatment. Families agree that they initially did not know about the schizophrenia and were shocked to know about it and found difficult to accept. The treatment and rehabilitation brought a lot of changes in the relationship between family members and the participants, especially in communication and sharing. In the past, participants showed aggressiveness and violent behavior towards family members, but during the course of time these behaviors reduced. Though suspiciousness is still present it is lesser than earlier. Family members are cautious not to force participants to do any activity when they are in a bad mood. If participants are in a bad mood, they do not listen to family members.

Nobody in our family has this illness...I do not why he got this, he was good in studies, he might have got the stress due to effort he put in his studies...we are ready to move to this place [near to the rehabilitation center] if he wants to work here, we just want to see him leading a respectable life.... (Varun’s father)

He is very much attached to them....they emotionally support him like they never scold him for small things they discuss it with us rather than blaming him. They are very supportive.... (Professional Aliya about Varun)
Professionals consider family involvement as an important factor in treatment and rehabilitation process. It is difficult to deal with over involved families, and it is easy to deal with families who understand the situation. The situation in the family is also an important aspect influencing the improvement. Attachment with family members' acts as a buffer in facing the daily life issues of living with schizophrenia.

**Implications of living with schizophrenia**

The impact of schizophrenia on various areas of participants' life was massive. It affected self care, everyday life functioning, relationships, work, and social life. Cognitive difficulties, psychological distress, inter personal issues, isolation, dependency on others were just a few to name it. During the interview, some participants broke down while sharing how schizophrenia affected their lives, how happy they were before they had this illness, and how better they functioned before it struck them. Participants found it difficult to assess how schizophrenia affected their lives.

> *I can’t measure, there is a coin in a water there is a displacement of water, I did not know how much water displaced in my life….just like a wood I laid there (Malleshwaran)*

> *I can’t state clearly how it has affected my life….friends used to call me mad in college there was no reason to believe that I was mad…. (Navneet)*

After the onset of schizophrenia, every aspect of their lives, every incident of their lives are influenced and sometimes determined by the illness. Even though each participant has had a unique experience of schizophrenia, there are certain common areas affected by the illness. They are education, relationships with family and friends, marital life, career, social involvement, failure, suicide attempts, relapses, hospitalizations and rehabilitation attempts, medication side effects, dependency, cognitive difficulties, and stigma and

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44 Professional’s knowledge regarding the past situation in family is limited to what family and PLS says. Since they are able to observe the present interaction their knowledge regarding the present situation is better.
discrimination. In order to give a picture of how schizophrenia affected their lives participants compared their performance before the onset of schizophrenia with their performance after the onset of schizophrenia.

Matrix 6: Implications of living with schizophrenia

<table>
<thead>
<tr>
<th>Implications of living with schizophrenia (areas)</th>
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<tr>
<td><strong>Activities of daily life</strong></td>
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<td><strong>Relationships with family, spouse, relatives, friends</strong></td>
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<td><strong>Cognitive difficulties</strong></td>
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<td><strong>Hospitalizations, and rehabilitation</strong></td>
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<td><strong>Education and work</strong></td>
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<td><strong>Emotional distress</strong></td>
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<td><strong>Discrimination</strong></td>
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Activities of daily life

Activities of daily living consist of self care, maintaining personal space, and routine. Self care is the first area affected by schizophrenia. Activities for maintaining personal hygiene such as brushing teeth, bathing, changing and washing clothes deteriorates over the period of time. Participants report that their personal hygiene became poor after the onset of schizophrenia. The interest in brushing, combing hair, bathing, changing clothes, grooming, washing, drying is lost in the due course of time. The disinterest in maintaining basic hygiene activities affects the maintenance of personal space too. The activities such as folding clothes, arranging cupboard, making bed, cleaning bedroom and shoes are considered as activities of maintaining personal space. PLS requires reminder for carrying out self care and personal space maintenance. The performance in daily activities drops down. Participants start to depend on the family members to carry out daily activities. In certain instances, family has to force the participant to perform personal hygiene activities. There is no routine to follow and case files records shows that participants either sleeps throughout the day or sit idle without doing any activities.

Avinash clarifies that it is not laziness but inability to focus on anything that stops him from performing the basic activities. Whenever he tries to do any activity negative thoughts creep in and stop him. He reveals that it happens all the time and is difficult to function when such thoughts are present. Participants feel that losing interest to such an extent leads to dependency on others to perform even a simple task.

....I lost interest in everything....my mother took so much care, she used to comb my hair, feeding me, giving me head bath, simply because I lost interest in everything. My personal hygiene (sic) was poor so they cared me like anything....
(Nalini)

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45 Independence in this context is used to refer the ability in motivating self to take perform personal hygiene activities. Dependency is where participants need some motivation or reminder or support either from family or professionals to perform activities which makes them dependent on family.
I was able to sleep but not able to take food, no appetite….at home I will be sleeping all day…. (Ali)

….before I used to think that he makes excuses but now I know that it is a disease, he is not able to keep his room clean, he is not taken care of laundry for a whole week, and it has piled up on but it is probably because of the disease, he doesn’t take care of it easily like how we would, I mean he has to be told, remind it and remind it and told it all the time…. (Avinash’s Mother)

Family shared it was tough to deal with such a situation since they did not know what to do. Initially, they thought it as excuses to avoid work, but later realized that it was part of schizophrenia.

Reinstating skills of self care is the biggest challenge for professionals. Therefore, their primary focus in the process of rehabilitation is to motivate self care activities. Once this aspect is in place they start giving training skills in everyday life activities, and then to develop a routine. Constant motivation is required for participants who are not very keen on following the instructions. Once they have a schedule to follow participants are able to follow the routine most of the times.

Relationship with family, spouse, relatives, friends

Schizophrenia affects participant's relationship with her/his family. Case file reports showed conflicts with family members in the past. Emotional outburst towards family members sometimes coupled with physical aggression added more strain on the fragile relationships. Since family was unequipped to understand these behaviors as part of schizophrenia (at least initially) they were incapable of tolerating it. Symptoms, especially suspiciousness on family members made daily interactions difficult resulting in hostility reciprocated by family members. Sometimes these suspicions were directed to relatives also, which made cracks in those relationships too. Families who could take a
sympathetic stand attained the trust of participants while others could not. Marriage ended abruptly without even getting a chance to revive it. Marital life was also pictured with physical abuse, lack of love and sexual life, and mistreatment from in-laws.

Family members reports that they still have difficulty in dealing with the conflict.66

....before this illness I was happy, I had many friends, I interacted with many friends, I was liked at home, mother prepared good food, I interacted with cousins, I had school mate friends. After sister got married I had misunderstanding, brother in law wanted sister to be with him. She changed after marriage. I got misunderstanding fight started failing in subjects...I felt like a wooden block in my head....become more dependent on mother....I started suspecting my father since last two to three years, I feel he is ill treating me, he gets angry with me most of the time when I talk to him, I feel he purposely does that (Kavya)

Making new friends and maintaining friendship becomes difficult and thus ending up in complete desertion from that circle. Participants shares different opinions on this issue. Friends' circle consists mainly of school mates or childhood friends. Once school life gets over the contacts become less. After the onset of schizophrenia, it becomes difficult to maintain any kind of relationship. Ali shares that his friends do not know about his illness and there is no need for them to know about it. He is worried about their reaction once they come to know about it. Hasini shares a different experience at school. She was bullied and isolated when she was in her school. She did not have any good friends and was scared to make some. Bullying at school and college has an impact on participants’ social involvement. This results in withdrawing from everyone eventually resulting in social isolation.

66 Though families are given psycho education it is difficult to deal with conflict on a daily basis. The conflict mainly arises when PLS does not perform their basic activities and responsibilities as a family member. For example Shivani still has issues with her mother and her mother does not understand the need to avoid conflicts. This creates issues in while sending her home as part of rehabilitation process as both of them are fighting with each other. (field notes).
Participants also shares instances where they received support from friends. Professionals agree that one of the areas affected by the illness is the relationship with family members and their roles in the family. Failure to perform roles in the family worries both the participant and the family members. Evidence of hostile behavior from siblings is also present. This resentment is also a result of over protection by parents in the past. On the other side, there are siblings who try to understand and control the situation when a parent is over involved.

*high school friends they supported me, they have given notes to me, in school my headmistress helped me a lot she was supportive, in my college my friends used to support me and lecturers used to support me. And I had shivering because of side effects of medicine....in the college I went to bathroom my friend used to tie pants, they used to take me to temple....they used to give me notes, notes means lecture notes....*(Arthi)*

*...though her elder sister passed away her children are there, they are not all that close. They are younger to her and they are scared, she used to beat them once she becomes restless, all those things have happened but here never, she is fond of me and if I tell her to do this know at least she will listen to me (Mini’s Sister in law).*

*His relationship with family members is good; mother is very over involved; his sisters are busy with work other times they are okay. When they take him for a break at home his sisters keep complaining that mother is over pampering him...he go eat everything without control [Malleshwaran has diabetes]....*(Professional Jeevan about Malleshwaran).*
Cognitive difficulties

As explained earlier the cognitive difficulties consist mainly of lack of concentration and attention, inability to understand things, and poor memory. It is difficult for most of the participants to concentrate on any activity for a slightly longer period. Since they also become restless paying attention to anything is a tiresome process. The capacity to retain whatever they read, taught, or learned is affected badly. This has an impression on the rehabilitation activities too47. In the past disruption in cognitive functions affected participants’ education and work. Participants reports of facing cognitive difficulties at some or the other point of time during their course of illness. It becomes extremely stressful when hallucinations are present along with cognitive difficulties. Participants cannot concentrate on any work or divert their attention from hallucinations. This also affects their interaction with others as they fear that people may come to know about their illness. In the past those participants who had undergone Electro Convulsive Therapy (ECT) later reported of problems in remembering things.

I had auditory hallucinations now relieved, commanding hallucinations and self muttering are still there, these divert my concentration and difficult to talk to people like what they think, how to hide it [hide the hallucinations since he react to his hallucinations], how to control it (Varun)

I can't interact with people, I feel drowsy all the time....I was admitted in another rehabilitation centre in Tamil Nadu earlier, there too I used to work very well but I used to forget everything memory was poor. I used to do everything well but no memory.....I do not understand anything, getting scared; over and over again illness is coming.... (Rani)

47 Malleswaran is enthusiastic to learn and keep notes of everything he learns. He forgets what he learned on the previous day, but he tirelessly learns that again. His spirit to learn is well appreciated by the professionals and they encourage him to try again and again. His inability to remember does not stop Malleswaran from working hard (field notes).
...his communication is need based, but suddenly he will get this thing and he will start talking to people, but not on a regular basis need based communication....he is restless he cannot sit down anywhere for long time, a little bit concentration has improved. Once he is able to sit down then he is able to do things.... (Professional Kalyani about Kumar)

Problems in cognitive skills pose the biggest challenge for pursuing higher education and work. It also affects the interpersonal relationships as participants are not able to communicate effectively. Communication with everyone becomes need based\textsuperscript{48}. The other effect of schizophrenia is the problems in comprehension. Participants who have issues with comprehension are not able to put their thoughts together. This creates problems in communicating with family and others. Family feels that the lack of communication between them and participant is the main issue. No matter how hard family tries to interact with participants it become arduous to get her/him to interact with family\textsuperscript{49}. Professionals find it laborious to put the rehabilitation plans into action due to the difficulties in getting participants to focus on activities. They have to monitor participants regularly and urge them during the initial stages of rehabilitation process. Professionals succeed in getting them to focus in activities once symptoms are under control. A lot of time is apportioned to retrain cognitive skills through various activities that stimulate cognitive abilities.

*Education and work*

All the participants in the study are educated, but only a few could pursue higher education. The educational level of participants in the present study varies from

\textsuperscript{48} Communication happens when there is a dire need for something otherwise it is difficult to make those participants to speak even during group activities. (field notes)

\textsuperscript{49} Communication with family is always either of the extremes; very aggressive and intimidating, talking irrelevently, excessive talking etc., or complete silence, need based, limited to a few words. A medium level of interaction is present among the participants, but not between participants and family or professionals. (interviews and field notes)
Secondary School Certificate (SSC) to professional and higher education. Disruption in cognitive functioning has an influence on the academic performance. In case of participants whose illness started at an early age education level has not crossed SSC or Pre University Course (PUC). The onset of illness during SSC or PUC may probably be a reason for low educational qualifications. Participants who took a break from studies in the past due to illness continued their studies once they were able to concentrate on studies. Participants who pursued their education despite the illness took many years to complete it. Completing education was a herculean task, and participants were not satisfied with their performance. Some of them had to spend a few additional years to complete their graduation or professional courses. Though repeated failures affected their self confidence they tried to achieve as much as they could. Instances of drop outs, failures and under achievement hindered the desire for further academic achievement. Drug abuse and alcohol aggravated the existing problems.

Obtaining a job is difficult than finishing studies. Participants due to the nature of illness are either not able to find a job or kept switching jobs. Only a few participants have history of employment. They have experience in some or the other vocational activity. Even if participants have educational qualification, lack of work experience hinders their efforts to get a job. There is another difficulty in acquiring a job and that is revealing the fact of living with schizophrenia. Participants do not want to take the risk of losing a job due to this. Professionals are confused while planning for a liaison program to reveal or not to reveal the fact to employers, but they have to follow the interest of the participant. Participant's inability to sustain interest in work is also a challenge for professionals while locating a job for her/him. On the other side, employers are not very keen on retaining a participant if he/she does not show any interest in work. Economic dependence on family members is a matter of concern for the participants.

50 There are participants who passed SSC and did not pass SSC; participants who could not complete PUC and participants who completed their PUC, but could not finish graduation; participants who finished graduation, but could not pursue post graduation; participants who finished post graduation, but could not stick to a job; participants who finished professional education such as medicine or engineering, but could not practice. (Case files and interviews).

51 Avinash went for higher education abroad and got into drugs. He could not finish his education and had to return home. He believes drug use aggravated his illness.
Family is quite concerned about the employment opportunities available for participants. This concern is mainly because participants do not have enough educational qualifications and work experience to find an appropriate work. Academic qualification plays an important role in identifying prospective jobs. Participants’ with lesser educational qualification finds it more difficult to get a well paid job. Participants from wealthy families are able to find work in their family business, thus employment is not an issue for them. For participants who have financial difficulty, joblessness is a significant issue.

....I went to Scotland for tertiary education. I studied there for about two years , there I was not into studies and more into drugs and partying...but I did manage my study a bit I finished two years at least two years without failure. I felt rotated but when I attempted the subjects, I passed.... so I finished one and half months in Scotland....Then my education in America went completely out of the roof, I wasn't attending classes, in the first semester I was drinking alcohol (Avinash)

....one year I failed...I came back to Bangalore....one year I studied distant education...I studied in house and passed the exam...I did not get good marks....I told my father I will not write....so he told okay after that I studied and completed computer. In computer also once I failed and after that I got good marks placement also I got....there they told me I am not taking interest so I left the job and came back. I left like this so many jobs....I am interested to go for a job, but that people are not giving me a job (Shivani).

Hospitalizations, suicidal attempts, and rehabilitation attempts

When symptoms become florid participants are hospitalized. Sometimes these hospitalizations are expanded to a longer period. Several relapses and consequent hospitalizations decrease the effect of improvement. In the past some participants were administered ECTs during their hospitalization period due to severity of the symptoms. Most of the time relapses are the result of medication non compliance. This is also a
reason behind families’ insistence to continue rehabilitation until participants are convinced about the importance of regular medication. Rehabilitation process gets tough due to switching between home, hospital, and rehabilitation facilities during the periods of recovery and relapses. Substance abuse (in the present study it is smoking) is an additional burden to the existing hurdles in the rehabilitation process.

Smoking increases during relapses hindering the treatment. Case file reports show that smoking in male participants starts after the onset of schizophrenia. There are instances of suicide attempts, and case reports show that these attempts are either by consuming overdose of medication or by electrocuting self. Suicide attempts are mainly during the initial years of schizophrenia, which is possibly a result of emotional distress. Though at present participants who had the history of suicidal attempts do not show any such tendencies, professionals and families are alert on this matter. The difficulty in pushing away suicidal thoughts lies in the fact that participants are constantly disturbed by negative thoughts.

Actually my brother had schizophrenia and my mother’s side of the family had schizophrenia, and I have Paranoid Schizophrenia. Many times I attempted suicide but always was unsuccessful, we have on mothers side sons of the family my cousin had same illness he committed suicide when he was around 25 and my brother committed suicide, all boys (Maria)

I skipped medicines….I was hospitalised last year I told doctor that can’t take any injection and I had a very bad relapse, I was not aware of it…hospital I was okay but when they give shock treatment six times or something….I felt that shock treatment was so bad…. (Avni)

….1984 she had attempted suicide, after that we came to know about the illness, before that she was doing well…. (Hasini’s Father)

Families of participants with suicidal ideations and failed attempts became conscious of the seriousness of schizophrenia after these suicide attempts.
In the past participants were admitted to various hospitals, and changed a few rehabilitation facilities. As mentioned earlier relapses are the main reason for hospitalizations, until the symptoms come down hospitalization is necessary\textsuperscript{53}. Case file reports show that hospitalizations are not voluntary all the time. Participants have to be forced to go to the hospital, most of the time they are not even aware of when they got admitted to a hospital. With the help of effective medication and constant supervision participants are able to come out of relapses and eventually leave the hospital. Participants who have been in and out of many rehabilitation facilities know how it works. This helps them to get into the routine faster than those who are admitted for the first time in a rehabilitation facility. Relapse can happen even if participants are regular in medication. This causes worry and questions the effectiveness of medication. It seems that sometimes medications are not much of help and participants require regular psychiatric consultations until symptoms are stabilized.

\textit{...personal hygiene her attender was helping her, actually since her relapse an attender was appointed was appointed, she used to give away her things and attender used to go and collect it. That was one of the issues she faced while hospitalisation that has come down with medication... (Professional Diana about Avni)}

\textit{I will get craving for cigars ....while I walk I start talking to myself and neighbor saw it, I was picking up cigar buds from the road from trashcans from ashtrays which stand in out they put outside footstalls and all that and I was talking to myself a lot of weird things happened that time many bad things I can’t remember what happened in fact my memory was so bad…I ate a lot of food and ate my meals also then I started hallucinating and talking to self. So then they put me in a hospital they said you are hearing voices.... (Avinash)

\textsuperscript{53} It is difficult for the family to manage PLS at home when they are floridly symptomatic. In hospital they receive professional care and supervision required until the symptoms are under control and manageable. It does not mean that hospitalization do not happen after attending rehabilitation centers. Whenever there is a severe relapses PLS are hospitalized (field notes and work experience).
Emotional distress

Living with schizophrenia is not easy. Psychological distress of being a person living with schizophrenia has an adverse effect on the improvement. Illness creates a sense of insecurity and fear in the participant eventually leading to a breakdown or relapse. Depressive feeling, suicidal thoughts, and an inability to find happiness make life more complicated. Sometimes negative thoughts come and prevent participants from carrying out any work/responsibilities. Living in a rehabilitation facility far away from home is stressful for HWH and LSH participants. Participants with relationship issues say that they are confused about how to deal with it. Absence of family life in terms of marriage, children, love, and caring creates a vacuum in their lives. For participants who are divorced bitter experiences of marriage life still creates an emotional crisis. There are participants who worry about their sexual life. They say it is difficult to control such thoughts at times and are scared to share it with anyone. At the end of the day staying in a rehabilitation facility (DC, HWH and LSH) is not something participants are happy about. Fear and insecurity about the future have takes a toll on their emotional functioning. Though participants know family and professionals are there to support them, sometimes it is overpowered by the thought that they have schizophrenia.

Since schizophrenia was unexpected families were not prepared to face the situation. This created a lot of stress within the family itself. Later, family members recognized that participants need family support to deal with stress and pain due to the illness. Family members express their willingness to take additional effort to provide any possible support to the participants. Having fewer friends and lack of social circle makes family also feel lonely and distressful. Professionals acknowledge the fact that participants and family are going through a lot of emotional strain. Therefore, they are careful in dealing with both of them. Professionals assist participants to engage self in activities that will help to divert their attention into productive activities. Counseling services are provided to participants, but sometimes even these could not help them to find a relief. Fear of isolation and discrimination also brings distress and worry among participants.
Family support gives participants’ a hope for leading a better life. Participants keep comparing to their previous self, and this makes them feel inferior. The thought that they are a burden to family affects their confidence level which in turn undermines the hope for recovery. Anxiety is present in most of the participants. It prevents them from participating effectively in any activities that require social involvement.

"...no marriage, no love, I will be thinking of sex at times...I am dependent on my sisters. I am of no use to them; I live at their mercy, a burden to them. Since they provide me everything I am here, I do not know what will happen once they are not there (Malleshwaran)"

"...she was isolated, my husband’s job...he has to be outside....she shouldn’t feel that she is alone or it is like she is handicapped because of the illness it is there in her mind, morning she was telling me ‘mein kyon why I am still living’ something sort of, I asked her why would you talk like this? I do not know she says.... she is sensitive she talks to me about her parents [Mini’s parents passed away].... (Mini’s sister in law)"

"...since I have come I had seen her, she is anxious, very anxious....starting it was not at all good...in the sense that’s all because of she was not able to put out her views and she was not able to participate well in the group because of her anxiousness (Rehania professional about Kavya)"

**Discrimination**

The label of schizophrenia does not go away no matter how hard participants and their families try to overcome it. Stigma and schizophrenia are interconnected. Participants expressed that isolation and ridiculing due to schizophrenia was part of life during the initial years of living with schizophrenia. This was not only due to the revelation of schizophrenia to outsiders, but also the behavioral changes in the participants. The level of discrimination increased when the fact of schizophrenia was
revealed. Therefore, fear of rejection prevents participants from sharing it with the outside world\textsuperscript{54}. In the past, they had certain experiences of discrimination even from mental health professionals. These experiences are also a reason for not sharing the fact about living with schizophrenia to people outside the family and trusted professional circles. Side effects of medication such as TD, overweight, rigid posture affects a person’s appearance which is not taken very generously by others. Marriage proposals are rejected due to schizophrenia\textsuperscript{55}. Divorce happened when living with schizophrenia was revealed to the spouse and his family. Before marriage neither participants nor family revealed the detail of schizophrenia to the groom or his family. In the past bullying by relatives was not uncommon. Relatives did not consider participant’s opinion seriously and treated them with disrespect. Some families hesitate to take participants to social functions due to the fear that relatives will observe the participants\textsuperscript{56}.

Participants hesitate to share their intimate feelings with family since they feel that family has been through enough trouble because of their illness. Discrimination from professionals, friends, relatives, and from the workplace (in the past) has affected the process of recovery\textsuperscript{57} and rehabilitation. Family is concerned about the attitude of relatives who are not supportive and isolates them from social circle. Professionals at the current rehabilitation centre are more sensitive, but they are not able to devote more time\textsuperscript{58} to the participants. Participants expressed their concern regarding this aspect. Professionals agree that stigma and discrimination are in fact one of the major hurdles in the process of rehabilitation. The only way to reduce stigma is by spreading the awareness about schizophrenia and familiarizing PLS in the community.

\textsuperscript{54} The questions here are what will happen if people know my illness? How will they react? Will they take advantage of me? These thoughts are a reason for constant worry because PLS feel people will not accept them if they come to know about schizophrenia. Some of them have previous experience of rejection.
\textsuperscript{55} There were instances of marriage cons which were more painful than rejecting proposals.
\textsuperscript{56} This is not the case of everyone; some families take participants for outing and social functions. It depends on the family’s attitude towards participant and her/his illness.
\textsuperscript{57} The term recovery is used to denote symptom reduction and ability to carry out daily chores with self motivation.
\textsuperscript{58} Professionals are overburdened with various works. Therefore, they are not able to give adequate time to participants. Field notes observations
due to this illness I was forfeited by a shopkeeper...got scolding from family members and relatives (Raju)

once police arrested me an found some schizophrenic (sic) medicine in my pocket so they asked me are you schizophrenic (sic)? I said sir I am under treatment for schizophrenia, I am on a very low stage of treatment...they said there is medication in your pocket and we will have to arrest you. They took me to the police station and they telephoned my father we have found boy with medication in his pocket, so my father said unke saath zaberdasthi math karna voh bimar hai, do not be harsh with him he is ill.... (Navneet)

see sometimes what happens is some patients come here, in our application form, this is a simple example there is a number they need to give us of any relative in case of any emergency, many of the family members refuse to give us that. Why because they say they give many reasons, one of them is see madam our relatives do not know that he is mentally ill...if they find out we will be shunned from the family. So we do not want to give the number. Second thing they say is no madam if they come to know then they will ridicule us and all that so we do not want to give.... (Kalyani - professional)

Case summaries

Case 1

Akhil is a 45-year-old unmarried male hailing from an upper-middle-class urban family settled in one of the northern states of India. He was a good student at school, and a creative person before the disturbances appeared. His educational performance started deteriorating while he was in the high school. Any form of mental illness was not diagnosed until the age of eighteen. Family noticed a few changes in his behavior such as

Data source is case history and personal interviews.
withdrawal, aggressiveness, carelessness, tiredness, and in appearance. Later parents took him to different psychiatrists, but they did not diagnose any psychotic features in him at that point of time. With much difficulty, he passed his graduation, in his own words.

...First year I got through, second year I failed, third year I had a relapse and could not give my exam the next year because of my acute condition. Then they could not take into the same college so I went to another college in another course, B com course. Fourth year I failed again, fifth year I passed my second year, and sixth year I passed 3rd year. It took 6 years to pass my graduation course....

He could not succeed in any of the jobs he took, which badly affected his self-confidence. He did not know that the difficulties in studies and work were due to schizophrenia. Though he had difficulties in studies, he managed to finish a three-year computer course while he was in a rehabilitation facility. He tried many jobs, but could not pursue any of them for a longer period. Parents were supportive and helped him in all the ways they could. He started attending a day care in his native place, and it was there he realized that he has schizophrenia. Twice he attempted to commit suicide, but was saved in nick of time. Parents were worried that he may try it again so they admitted him to a rehabilitation center for professional care.

They did not tell me for 15 years. They did not tell me I had schizophrenia, they told me I had some problem, that's all. Only when I joined a daycare center, did I get to know I had schizophrenia and that was in 1987. My parents never told me that first...they told me you are being given some medication. I thought it was an appetizer. I did not know it was going to be such a drastic medication because it put me to sleep for 6 hours and I woke up with a stupor I walked clumsily all over the place in a stumbling gait, very slow and staggered... I could not interact much. Also I was not good at interacting; all this is because of schizophrenia. I could never be myself; because I could never find an identity.

The impact of schizophrenia on his life was drastic. His interaction with others was fine until the attack of schizophrenia. He was good in sports but later lost his interest in
all those activities that used to make him happy. Side effects of medication were severe and still continue in the form of Tardive Dyskinesia. He used to work as a transcriptionist and used to earn a decent amount of money. Due to relapse, he had to quit his job and could not get back to that level of productivity since then. He had to be hospitalized during the relapse due to the severity of relapse.

At present, the level of distress is much better than earlier. His understanding about his illness is good. He still requires professional support, and therefore he prefers to stay at Long Stay facility. His family remained supportive during all these years and is still supporting him financially and emotionally. He is unmarried and not employed.

Case 2

Malleswaran is a 46-year-old unmarried male from a middle-class urban family settled in a southern state of India. He is the elder of four siblings. Family had financial difficulties. Therefore, participant had to work immediately after finishing school. He was in a central government job during the first episode of schizophrenia. He continued in the job for quite some time. He had to stay away from family and felt isolated. Slowly, he got paranoid about his colleagues and started acting on it. His interaction level reduced and was hospitalized several times in a period of two years. This affected his performance at job and had to quit the job. Since he left the job before completing the stipulated period he could not claim the benefits. Due to his paranoid ideas, he could not sustain in any job he undertook. His brother had schizophrenia and committed suicide. Later, his father passed away, and this affected him severely. During this time, he showed some psychotic features such as laughing at self, talking to self and social withdrawal. He was hospitalized for a short period and was referred to a rehabilitation center. In his own words

My family’s financial background was not good. My father told me to continue work and settle debts and then come home. So I stayed away from family for a longtime. I did not know what to do and wanted to be with family. Nobody wrote a letter except my father…lot of pressure was there, job was hectic when time passed I got illness…I was not socializing. I followed the routine at work but did
not interact with people. As days passed happiness was not there, a kind of loneliness...I was not knowing what was happening, doctor did not tell me anything...I can’t measure there is a coin in a water there is displacement of water, I did not know how much water is displaced in my life....

He showed improvement in symptomatic behavior, self care, and interaction with family and other areas after started attending rehabilitation centers. He kept on changing rehabilitation centers because his mother was never happy with the improvement. Over involvement of mother has created problems in the rehabilitation process. Due to this his siblings decided to send him to the present rehabilitation center. There is a family history of mental illness from maternal side and paternal side. Parents did not have a healthy relationship with each other, but the children did have a healthy relationship. Family does not have any social support from the relatives. Malleshwaran is aware of his illness and believes that it is treatable.

**Case 3**

Rani is a 36 years old unmarried female hailing from an upper middle class urban family situated in one of the southern states of India. She is the younger of four siblings and currently under the care of brother since her parents are not alive. She was apparently functioning well until the age of seventeen. Her father’s death and financial issues at home had an adverse effect on her. She failed in secondary school leaving exam and completed in the second attempt. The symptoms were not visible during that time. It was during her Pre University Course family observed certain changes in her behavior. She was crying vigorously, complained about hearing voices. She started talking to self and became restless. Rani also has a history of attempted suicide. Family took her to a psychiatrist for treatment. She was administered with Electro Convulsive Therapy a couple of times along with antipsychotics. She responded well to the medicines, and her condition was improved. Due to non compliance of the medication the symptoms returned. During that episode, she turned aggressive towards her mother. Again, she was on medication for the next couple of years. In her own words
...nobody knew I had this illness not even me. No one knew when it started...twice I was attacked by this illness...second attack occurred when I was in my native place. I was worried so much; scared and shivering....I was able to follow till tenth standard...after that I couldn’t study. I lost interest and concentration, I used to beat my mother, break things at home....everyone at home scolds me that I am lazy, always lying down...I am not interested in anything I do not know why....

She was shifted to a rehabilitation facility in her native place after her mother’s demise. There she was trained in tailoring works as part of the vocational rehabilitation program. She was later shifted to ladies' hostel for some time, and then she started staying with her brother. Her brother was married during this time, and Rani had issues with the sister in law. Therefore, she was shifted to another hostel. After some point of time brother divorced, and he was transferred to a different city. Her brother remarried after a year. She does not have any issues with the present sister in law. Rani currently stays with her sister in law and attends the rehabilitation center regularly. She has improved over the period of time, but still has problems in concentration and motivation. Rani does not have an employment history. Though she got training in tailoring she had no plans to take it as a job. Her family is supportive of treatment and rehabilitation. She is aware that she has a severe mental illness, but does not know the name. She is regular in medication and follow-up.

Case 4

Lalita is 42-year-old unmarried female hailing from a middle-class urban family situated in one of the southern states of India. She has two sisters, and they are her caretakers at present. She was functioning well until graduation. She started experiencing symptoms during the third year of graduation. This happened after she failed in the final exams due to fever. She started showing symptoms such as impulsive behavior, hearing voices, cutting eyebrows, and aggressiveness. Lalita was taken to a psychiatrist and was on medication. The symptoms reappeared when her father passed away, and she was hospitalized. During that hospitalization period, her brother also expired due to some physical illness. It was during this hospitalization, she became aware of her diagnosis. After discharge she could function considerably and was also regular in medication. She
functioned properly for almost two years and then had a small relapse. During this time, she was aggressive, restless, started over eating and showed hatred towards the family members. She was taken to a psychiatrist and continued medication.

*After father’s death I started beating my mother, threw things on the floor, and started throwing things so they hospitalized me. I was in the hospital for two months...I do not have an idea about those incidents...first doctor did not tell me about my illness, they gave medicines, when I came to city hospital only I came to know about my illness is schizophrenia....I lost interest in everything, not mingling with others except my family, not reading book, studies affected. It destroyed my life altogether. No constructive activities I am able to do because I am always restless. It affected my career also...*

Family decided to keep her occupied and thus found a job for her. She could not continue in the job for a long time. Whenever she experienced slight disturbances, family took her for consultation, and psychiatrist changed medication as per the symptoms. Conflicts with the employer led into discontinuing medication and resulting in severe relapse. Family hospitalized her and there she was administered with Electro Convulsive Therapy. Even after discharge her behavior towards family members continued to be of abomination. She physically abused her mother resulting in mother’s hospitalization. It became difficult for the family to manage her at home. As per psychiatrists’ suggestion, she was admitted to the rehabilitation center. She is aware of her illness and follow treatment instructions rigorously. Her family provides economic support but is not ready to take her back home and wanted to keep her in any rehabilitation facility.

Schizophrenia affects all areas of functioning adversely and brings many changes in participants’ lives. The present chapter shows that living with schizophrenia is an unpleasant and distressing experience. It deprives the chances of a better life in terms of proper self care, good relationships, employment, and active social life. The way participants perceive their own life in terms of their involvement in the community and quality of life is impacted by their experience of living with schizophrenia. Participation of people living with schizophrenia in their community is influenced by schizophrenia in various ways and leaves a far-reaching impression on their quality of life.
SECTION B
PARTICIPATION IN THE COMMUNITY (PIC)

Introduction

This chapter attempts to explore the perspective of people living with schizophrenia on their participation in the Community. The theme PIC includes the participants' view on their participation in the community. Information has been collected from the participants, their families, and professionals. Data collected from family and professionals are used to support the data from participants. Observations from the field and information from case records have been used wherever required. This chapter is presented in four sections. The first section deals with understanding the concept of participation in the community from the perspective of the participants. The second section identifies the areas and components of participation in the community. The third section deals with the outcomes of participation in the community. The fourth section looks at the various supportive factors and challenges to the participation of people living with schizophrenia in the community. Participation ranges from taking part in daily activities to a broader range of community activities. The ways in which participants participate in their community differs. The fact that participants are living with schizophrenia does not stop them from taking part in community they live. The terms' participation and community (in the context of a person living with schizophrenia) itself requires a clear understanding. International Classification of Functioning (ICF 2001) is used as a guide to understand the difference between various concepts such as activity, participation, activity limitations. There is a possibility of concepts overlapping.

60 There is a possibility of concepts in the analysis chapter ‘living with schizophrenia’ overlapping in the present chapter. I have tried to minimize the overlapping as much as possible. Since all three themes are interconnected overlapping of concepts to a certain extent are unavoidable.
Participation in the community (understanding the concept)

The idea of participation in the community is expressed as the activities done in various facets of community life. It encompasses all the activities participants undertake in their day to day life. There could be a confusion regarding what are the activities that constitute participation. It is essential to understand participant's perception on the terms ‘participation’ and ‘community’ to clear the confusion on the usage of the terms ‘participation’ and ‘community’. Participation of a person living with schizophrenia is difficult to define due to the perplexity on what can be considered as an activity and as participation. Participants share their understanding on participation and the activities they consider as participation. As per their understanding participation is involving self in something, or taking part, or engaging in some activities or programs.

What are these activities\textsuperscript{61} or programs that embody participation\textsuperscript{62}? In participants’ view activities include activities of daily living (ADLs) such as self care and maintaining personal space, household chores, helping at home, works and responsibilities at office, and various activities organised by the rehabilitation facilities. These activities form the basic areas where participation\textsuperscript{63} takes place. There are other aspects that are considered as participation, but these are more of characteristic features than activities. This characteristic features help the participant to take part in the activities\textsuperscript{64} effectively. The characteristics are initiative to interact and communicate, take up responsibilities and duties, and supporting and helping each other.

\textsuperscript{61} According to International classification of functioning (ICF) ‘Activity is the execution of a task or action by an individual’ (ICF 2001, 123)
\textsuperscript{62} According to International classification of functioning (ICF) ‘Participation is involvement in a life situation’ (ICF 2001, 123)
\textsuperscript{63} It is difficult to differentiate between participation and activities since it is used interchangeably. As per ICF guidelines of activities and participation this is one of the ways in which these two aspects (participation and activities) are structured.
\textsuperscript{64} The characteristics are mostly the aspects supporting or required to take part in activities. For example if the person does not initiate or is not willing to take up responsibilities at the rehabilitation center or home their participation in such activities will be absent.
Participation is including yourself in all the activities...programs, being a part and parcel of society, being involved in social skills of life (Akhil)

Participation means showing interest in a particular kind of program...and participate means to study and to do some research in community work, participation in social activities, participation in music teaching, i teach music...that is also a participation, serving patients (Arthi)

Interaction and communication with people closer to the participants are crucial in receiving and extending support. Initiative and willingness to take up responsibilities at rehabilitation centre and home and putting full effort to complete the task is considered as participation. Therefore, participation is taking part in any activities starting from performing self care activities to involvement in social activities. Participants describe community based on two facts 'people' and 'interaction'. Community is where a group of people interact with each other and participate in various activities. The basic element of community is the interaction between people who may or may not live in the same place. Thus, community consists of people who have close contact with participants such as family members, supportive relatives, professionals, para-professionals, and people living with mental illness attending rehabilitation facilities. Therefore, community in this context comprises of family, relatives, friends, mental health professionals, religious organization, and rehabilitation facilities. It is framed with interaction, communication, and adjustment with each other. Community keeps on expanding to the extent participants expand their participation. Since participants have gone through many experiences of stigma and discrimination, they mentioned that community should stop discriminating people living with schizophrenia. Data shows that participant’s perception on community is also based on the rehabilitation facilities they are in.

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65 It depends on their participation in various areas of life. Family friends, childhood friends and neighbors, colleagues at work place, college mates, religious organisations, and society at large can constitute community as far as they extent their participation.

66 In Navneet’s opinion his community is not a bunch of handicapped people.
A gathering of people whether it is a group of people inside your home or outside. A commune of people who harmonize with each other, get along well, interact and participate in community based activities. Despite others fault they adjust with each other. They do not discriminate between each other. They talk to each other. Community can be family also (Akhil)

Matrix 7: PLS perception on participation in the community

<table>
<thead>
<tr>
<th>Rehabilitation facility</th>
<th>Community (comprises of)</th>
<th>Participation in the community</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day care (DC) participants</td>
<td>Self, family members, relatives, friends, Day care clients, Professionals and para-professionals, Neighbors, Well-wishers, HWH and LSH members, Office colleagues of the guardian, and Religious organisations</td>
<td>Self care and grooming, Maintaining personal space, Interaction with fellow members, Communicating with others, Outings with family members, helping at home, Attending social functions, Following rehabilitation centre activities, and Education and work</td>
</tr>
<tr>
<td>Half way home (HWH) participants</td>
<td>Self, family members, relatives, friends, Half way facility residents, Professionals, Students coming for field work, Day care clients and staff, Religious organisation, Work place colleagues, Society in general</td>
<td>Attending day care, Self care and grooming, Maintaining personal space, Interaction and communication, Outings with family members, support from family, Following rehabilitation centre activities, Education and work</td>
</tr>
<tr>
<td>Long stay home (LSH) participants</td>
<td>Self, LSH residents, Professionals Attenders, Family members, relatives, friends</td>
<td>Attending day care, Self care and grooming, Maintaining personal space, Interaction and communication, Support from family and outings with family members, Following rehabilitation centre activities, Education &amp; work</td>
</tr>
</tbody>
</table>

A detailed analysis of participant's perception on the concept of community gives us some understanding on what forms community irrespective of the rehabilitation facility
they attend. Family members, relatives, friends, and other members at the rehabilitation center including professional and para professional staff and psychiatrist forms their community. In the instances of employed participants\(^\text{67}\) workplace colleagues are part of community. For participants who are pursuing education, their class mates are also considered as part of their community. Religious organisations are also quoted as a part of the community\(^\text{68}\). It is quite clear that community is defined based on participants' close contact with its members. It is interesting to note that ‘self’ forms a part of the community. This is due to responsibilities of participants to self in the form of self care and maintaining personal space. Day care participants consider HWH as part of his/her community. This is because some of the DC participants initially stayed at HWH and when psychiatrist and family felt that he/she has achieved a level of independence, they shifted participant to day care. These DC participants meet HWH and LSH residents attending vocational activities at day care and interact with them. HWH participants attending various vocational activities in the day care consider daycare members (those who interact with them) as part of their community.

Though interaction is the aspect determining community, it is limited to family, other members at the rehabilitation facilities (HWH, LSH, and DC) professionals, relatives, colleagues, classmates, field work students, and in certain occasions' friends outside rehabilitation facility. The closeness in relationships determines the interaction and participation of participants with other stakeholders. Participation in activities such as duties in and around rehabilitation facility, self care, group activities, household works, job (for those who are employed), and classes (for those attend college) constitute major portion of their participation in the community. It is either extended or limited to the immediate settings they live in\(^\text{69}\). Participants’ behavior and performance at home and

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\(^{67}\) There are instances of care and support from employers and office colleagues of the guardian. Sourav’s employer is very supportive and concerned about his treatment. Rani’s guardian’s colleagues are very supportive and caring toward the participant. Thus they are quoted as members of their community.

\(^{68}\) Though religion does not play a role in determining the interaction or relationship between participants it constitute a part of their community due to the religious activities participants’ follow and support a few participants’ receive from such organisations. Ali’s family and Arthi receive moral support from their religious organizations. (interview notes)

\(^{69}\) It seems more social contacts in the community make better participation in community.
rehabilitation facility is of utmost importance for family members. Families define participants’ participation in family in terms of overall conduct towards family members, initiative in performing household works, and performance at the rehabilitation center. The aspect family feels as influencing symptomatic behavior is medication intake. If the participant is on medication, then her/his demeanor is better since symptoms are under control. Therefore, in family members opinion participation is better when PLS are on medication. Families also quote that at times participants need a little bit of motivation to carryout activities otherwise there is no need of any motivation. Family expect participant to learn some vocational skills that will help her/him to develop some work habits. This will assist the participant in future to get a job and perform well in it. Family points out that attending day care has helped participants in acquiring some vocational skills

*I am participating, I interact with other people, participate in group sessions and individual sessions, in all activities at the rehabilitation centre, I talk to my sister over the phone...i try to listen to others if they are facing any problems which I can help them in anyway, I try to do that. I am not participating in my own family, they are not telling me anything...day care facility I attend classes on embroidery and computer. I am enjoying both of them. I am expecting this will help me in future (Lalitha)*

*I think...I have four responsibilities, one is towards my body soul whatever you call it towards my existence, second is towards my family, third is towards my office work which gives me bread and butter, fourth is towards the whole world...so first one will be carrying out personal hygiene, having proper food, and tea, sleep etc...participation with myself I told your right that whatever responsibilities I have and whatever I can do best in my responsibilities for example my office work that is also participation towards myself in a way because only out of that some output is coming which is helping them and me also and as I grow in the organisation that is one thing i take life as it comes, do it without any expectations....participation in the family is only as far as I can give money to whoever needs it....then another is participation in the community in terms of*
world affairs I really haven’t thought about it in between I was having an idea whether I should go and join UN, UNESCO something like that…. (Sourav)

Matrix 8: Participation of PLS in the community from families’ perspective

<table>
<thead>
<tr>
<th>PIC: family perspective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavior towards family</td>
</tr>
<tr>
<td>Initiating household works</td>
</tr>
<tr>
<td>Performance of activities at rehabilitation center</td>
</tr>
<tr>
<td>Medication</td>
</tr>
</tbody>
</table>

Professionals explains PIC in three areas; participation to self, participation to family, participation at work. Participation to self includes self care, grooming, taking medication regularly, maintain personal space, and performance of expected roles\(^{70}\). Participation with family is important and consists of relationships with family members, communication with family, and fulfilling roles and responsibility in the family\(^{71}\). Participation at work can be by being punctual and regular in work along with performing well in works assigned. Professionals conceptualize the term participation in the community based on participant’s performance in various areas of functioning. Professionals have to prioritize their intervention process to enhance participation as per the capacity of the participants. Therefore, in many instances, professionals have to focus primarily on self care and maintaining personal space. Professionals agree that self care indeed forms the basic element of participation in the community. In case of those participants with appropriate self care professionals shift focus on areas where participants have difficulties in performing.

he is communicating well, only thing I still find that he is still reserved about communicating with other people and he prefer rather to be alone than with

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\(^{70}\) Roles assigned in the rehabilitation center.

\(^{71}\) Role as a daughter, son, sibling, spouse, mother, father etc., are carried out without much difficulty.
people, so I keep calling him there [when relatives visit home]...I deliberately make that (Avinash’s Mother)

I expected she should [paused] have full confidence, she should absolutely able to stand on her feet, I told the staff I want her to stand on her feet but that did not happen....(Hasini’s father)

In my opinion involving in day to day activities, giving their opinions and ideas may be communication, decision making in their personal life, daily activities, or some issues regarding community. Participation in the family perspective there is much more involving them in medication, providing information about their day to day improvements that we see and families participation in terms of following whatever we do here, or they coming here or communicating over the phone as and when required, taking to the hospital, looking at the medication, taking home on a break, and doing whatever activities we do in HWH following that same at home, so that and all I will call it as a participation from family point of view. If it is work then what is the participation or motivation that resident shows and what is the reaction and response from the employer's side for the efforts these people are taking. Some residents go to study so their participation will be how best they get adjusted to the activities there as well as the activities here, that also I would call participation.... (Nila mental health professional)

Participation can be active or passive. Active participation in present study context refers to performance of daily life activities with self motivation. It consists of initiating for a conversation, taking up responsibilities, involving in house (both rehabilitation and home) activities, and sharing problems with professionals. Passive participation refers to participation in activities of daily life with motivation from professionals or family members. Learning vocational skills and spending time productively is equally important in PIC. The significance of taking medication regularly is one aspect professionals and family consider as essential for better PIC. Most of the time participants require
motivation to carry out these activities, specifically during the initial period of rehabilitation. Even though participants need motivation and supervision at times, they learn to stick to the schedule over a period of time. Self care activities include activities such as brushing, bathing, washing and cleaning. The participant who faces difficulty in structuring her/his everyday routine is provided with a timetable consisting of activities to be performed and time limit for each activity. This schedule is meant to enhance their ability to use time effectively. After achieving progress in self care and routine, then focus is shifted on improving interpersonal relationship. For this purpose cooperation of participants and family is essential.

Matrix 9: Participation of PLS in the community as per professionals’ perspective

| Participation of PLS in the community as per professionals’ perspective |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Day to day activities    | Decision making          | Interaction and communication | Medication               | Family                   | Education                |
|                          |                          |                          |                          |                          |                          |
|                          |                          |                          |                          |                          |                          |
|                          |                          |                          |                          |                          |                          |

As per professionals’ opinion community is anything beyond individual and is limited to the people participants’ interact with. Professionals suggest that the concept of community can be arranged into four levels/categories as per participants' perception: immediate family members in the first level; relatives, friends, professionals at second level; third level consists of acquaintances, friends of friends, workplace and colleagues, classmates; and fourth level is the larger world. Here community is identified based on
two aspects; closeness to participants and society they live in. Closeness to participants decides the level of participation. The reason for participants less involvement in any particular level of the community is their lack of closeness to the people in that level. Professionals also feel that community participation is equally important in the participation of people living with schizophrenia in the community. They think that community support is an inevitable aspect for participants’ functioning in the larger community.

![Diagram of different levels or tiers of community from the perspective of participants]

**Figure 3**: Different levels or tiers of community from the perspective of the participants

### Areas of participation in the community

Participants feel that there is a demarcation between areas where participation in the community\(^{72}\) should take place and areas where participation actually takes place. This demarcation is because the areas where PIC should take place always point to an ideal situation of PIC. The actual participation of PLS in the community may be different from the ideal situation. The area where PIC actually takes place is different from one individual to the other. Participants have identified the areas of PIC where participation

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\(^{72}\) Participation and PIC are used interchangeably under this section.
should take place and where they really participate. In their opinion, participation should take place with oneself, family, work, and society, but this may not be possible all the time. There is a variation in the areas participants actually take part. The areas where PIC happens are self, family, rehabilitation centers, and work (for those who are employed). The difference shows the need to participate in various areas of life, but the limitations in taking part due to living with schizophrenia. Participation in work is limited to participants who are engaged in any productive vocational activities. Society is replaced by the rehabilitation centre since it has become an integral part of participants’ lives. Living in a rehabilitation facility plays a significant role in differentiating participation of person living with schizophrenia and a person without any mental illness.

Matrix 10: Areas of participation (ideal and actual)

<table>
<thead>
<tr>
<th>Areas PIC should take place</th>
<th>Areas PIC take place</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self</td>
<td>Self</td>
</tr>
<tr>
<td>Family</td>
<td>Family</td>
</tr>
<tr>
<td>Work</td>
<td>Work/job/education</td>
</tr>
<tr>
<td>Society</td>
<td>(limited to those employed, studying)</td>
</tr>
<tr>
<td></td>
<td>Rehabilitation centers</td>
</tr>
</tbody>
</table>

Areas of PIC can be divided into four sections as per the above matrix. It starts with 'participation to self' which includes taking care of oneself without any assistance, maintaining personal space, having a routine, shopping own requirements, and taking care of health. Any work related to self care, personal space, and health care is the basic aspect of participation to self. Participation in self becomes important since schizophrenia primarily affects the area of self care. There are occasions where a participant has to take help from an attender (paid service) to carry out self care activities. This assistance is required mainly due to physical complications or severe relapse. Participants feel that in such instance participation in the community is limited. For participants with physical
complications self care is the only area where participation takes place. Second component of participation to self is having a routine or a structured life. In participant's opinion routine ensures participation to self and other areas. Routine becomes an important element since it will build the ability to carry out day to day life activities regularly. It is also the best way to use time efficiently. During the symptomatic period participants used to spend their time sleeping, sitting idle, or roaming around without a routine. Therefore, developing a routine is an important aspect in participation to self.

The component of 'participation in family life' comprises of maintaining healthy relationship with family members and relatives. For day acre participants helping family in household chores is part of involvement in the family. There is a need for maintaining a better relationship with family members through interaction and communication besides staying with them. Kumar spends time with his mother and sister while at home. He goes for shopping with his mother and sister. He helps mother in the kitchen and plays with her whenever she is free. Another aspect of involvement in the family is the fulfillment of roles and responsibilities expected from the participant by her/his family. In the present study, this aspect of participation in the family is limited to carrying out minimum responsibilities assigned by the family. It also consists of attending various functions held at own house and their relatives house. HWH and LSH participants' involvement in the family is limited to occasional visits, mails, phone calls, and letters. Day care participants' involvement in the family is comparatively active in terms of regular presence of family in their day to day life.

Participants stay at HWH, LSH, and DC has an influence on their participation in the family. Participants' stay at the rehabilitation center makes that a part of their community and thus an area of participation in the community. Taking part in activities at respective centers is equally important for participation. Participation in the rehabilitation center

73 This term is used by the participants to refer to their state of illness when symptoms are floridly present. They also used the term ill to refer to that point of time. Therefore these terms will be interchangeably used.

74 This aspect is expressed mainly by the professional rather than people living with schizophrenia.
takes place in various aspects. It includes taking part in the activities at the centers, interacting with other participants or members of rehabilitation facility, professionals and para professionals, and consultation with the psychiatrist. There are activities that are therapeutic and leisure in nature. Rehabilitation centers day care, halfway home, and long stay home has designed various activities to ensure participation. Participation includes interacting with other residents, or clients at rehabilitation center, and following routine at the respective centers. Work, college, and artistic ventures\textsuperscript{75} are not pursued by everyone. Vocational activities also act as a small source of income for participants who are interested and engage in such activities. Some of the day care participants assist their parents in family business which helps them to develop some work habits.

Participants, who go to college for continuing their studies, choose professional courses which will help them to get a job in the future. Participants who have friends outside the rehabilitation facilities are countable. And participants who have friends outside rehabilitation center are childhood friends, family friends or workplace colleagues. Since participants’ and their community members are part of the larger society, it forms an area of participation even though participants consider their contribution to it as minimal. Figure 4 gives an idea on levels of participation of PLS in the community based on the rehabilitation facility they are in.

\textsuperscript{75} By artistic ventures what is implied here is singing, painting, or handicraft and embroidery
Components of participation in the Community

Components consist of activities in each area of PIC such as self care, routine, life at rehabilitation facilities, interaction and communication, family and professional support, work and college, medication, and prayer and religious activities. Participants regard self care as the most important component of participation in the community, especially activities of personal hygiene and routine. Participants identify routine as helping to engage in productive activities and in diverting' negative thoughts. Routine is different for day care participants, and HWH and LSH participants. Interaction and communication with family, relatives, psychiatrist, and people close to participants is considered as an important factor promoting their involvement in the community. Family and professional provide support, motivation and encouragement as well as family is the main source of financial assistance and emotional support. Each rehabilitation center activity is different and designed to cater to the needs of participants. Religious activities, including prayer, visiting devotional places, and rituals are also a part of participation in the community. Participation to self is the base to all other forms of participation.
Matrix 11: Components of Participation in the Community

<table>
<thead>
<tr>
<th>Components of PIC</th>
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<tbody>
<tr>
<td>Participation to self</td>
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<tr>
<td>Participation in family</td>
</tr>
<tr>
<td>Participation at rehabilitation facility</td>
</tr>
<tr>
<td>Participation at work or college</td>
</tr>
</tbody>
</table>

**Participation to self**

The components of participation to self are explained in detail in this section. As mentioned above it consists of personal activities one performs to make oneself participate in the community. Matrix 12 shows the components of PIC.

Matrix 12: Components of participation to self

| Self care,                              |
| Maintaining personal space,             |
| Routine                                 |
| Health care and medication              |
| Prayer, and religious activities        |

**Self care**

Self care is the primarily affected area when schizophrenia strikes. As a result, self care deteriorates, and participants lose interest in maintaining it. They may become preoccupied with hallucinations or delusions, which eventually pave way to ignore self care activities. Taking care of self thus becomes a responsibility to self. Participants consider activities related to self care as involvement to self. For them, self care activities include brushing, bathing, washing, changing, cleaning hair, and nail care. It is explained as the way one participates to self. Participants agree that in the past they had difficulty in maintaining self care. At present, they consider the situation differently. Participants feel
that looking after him/her self is a part of their participation in the community. However, participants expressed different opinion about maintaining self care activities.

There are participants who consider self care as a very important aspect of PIC, whereas there are participants who do not feel the same. Participants who are reluctant to consider self care as involvement to self are those who are maintaining it well. For them, there are other things more important than self care. The participants who have issues with self care activities consider self care as a significant component of PIC. The participants are conscious about their personal hygiene activities since they are part of a group76. Since HWH and LSH participants are living in rehabilitation facilities professionals ensure regularity in self care by motivation and supervision. Day care participants are motivated and supervised by their family members.

*I am taking part in the community, looking after me is a form of participation in the community (Akhil)*

*...taking care of myself that is also participation, participation to myself, like taking bath, attending to my personal hygiene...and in washing machine I put clothes, and I wash dishes or vessels, I fold clothes (Arthi)*

*Saturday and Sunday same routine, but do not take bath in morning, wash clothes in washing machine, I help in cooking, I do not take bath at all. I forget to take bath. I do not take bath every day. Combing hair I usually do, I have a separate bedroom...so ask my maid servant to clean the double cot, she sometimes ignore to clean the cot...only when I tell she does that.... (Ammal)*

*....Mynah needs lot of reminders and coxing for maintaining hygiene, exercise, and all these things, we have prepared a checklist for her to follow, after*

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76 Here the group consists of other HWH, DC, and LSH participants who are there to correct and direct them about responsibilities. (field notes)
performing each activity she marks it herself and by a professional so that she can ensure she did it…. (Vinaya professional)

All participants do not require guidance and motivation. Participants found it difficult to explain the reason behind losing interest in self care activities. They feel that lose of interest and negative thoughts are implications of schizophrenia. The primary focus of rehabilitation is to initiate interest in activities of self care. Through constant self and external motivation, training by professionals and support from family participants over the period of time develops the ability to perform self care. Families have some expectations from rehabilitation. The priority is given to self care because it is a tedious task for family members to motivate participants to perform self care activities when they are symptomatic. Self motivation is not present in all the participants. Attending day care and staying at HWH and LSH is helpful in gaining this motivation. Participants have to take care of self otherwise has to face criticism from other residents. In order to stay away from criticism and present self in appropriate manner participants are cautious about following self care activities. Self care is closely followed by maintaining personal space.

**Maintaining personal space**

Maintaining personal space includes activities such as making bed, folding and arranging clothes in the cupboard, cleaning shoe racks, cleaning and organizing the room. In participants' opinion, they have difficulty in maintaining their individual space especially in organizing things. They feel that following self care activities is not an issue once it becomes regular, but maintaining personal space requires a lot of effort. Folding and arranging requires a huge amount of energy and time as it turns out to be a time

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77 Self motivation plays an important role than external motivation in sustaining self care activities. Participants agree with the fact that self motivation plays a crucial role in participation in the community.

78 There were instances where other members at the rehabilitation center pointed at someone’s poor self care. (field notes)
consuming\textsuperscript{79} activity. Participants find it easy to do the cleaning works at the center and home than maintaining personal space. HWH and LSH participants have to follow a certain schedule\textsuperscript{80} which includes maintaining individual space. Every day, they have to clean their room after performing self care activities. Participants sometimes feel that there is no need to burden the supporting staff by changing bed sheets every week. Participants clean the shoe racks provided to them since they feel it is part of the duty. Professionals assist those participants who find it difficult to do carryout activities for maintaining personal space. Participants who are able to do it without help and motivation performs their work and also assists those who have problems in it [field observation notes].

\begin{quote}
Arranging things are difficult, my cupboard is always a mess….inside whatever is there sweeping the floor, downstairs lounge, vegetable cutting, cleaning after breakfast that kind and all is very good. I will do it, cleaning after dinner that and all is very nice (Shivani)
\end{quote}

\begin{quote}
...I feel linen they change quickly within one week they change. We are taking bath every day. It is a big burden to cleaning staff. We are not dirty we wash our clothes every day…. (Malleshwaran)
\end{quote}

In order to strengthen skills in maintaining personal space HWH and LSH organize maintenance duties as part of the schedule. Maintenance duties are meant to enhance skills in coordinating and systematizing things. These duties include room maintenance, house (HWH and LSH) cleaning, and arranging. The role of professional (HWH and LSH) is important in this aspect as they have to teach participants and personally supervise maintenance activities. For day care participants’ families have to take up the

\textsuperscript{79} It takes a lot of time for participants to fold and arrange those in the cupboard. Maintaining personal space is a part of schedule at HWH and LSH. During a visit to Hasini’s house for interviewing her father I was able to see her room. She didn’t make her bed in the morning bed sheets were still unfolded and her clothes were lying around the room. (field notes)

\textsuperscript{80} Each resident is provided a cupboard to keep their belongings such as clothes, cosmetics. They are also given a shoe rack on sharing basis. (field notes)
role of supervising with regular feedback and assistance from professionals. Self care activities and maintenance activities constitute the major part of routine.

Routine

Routine is another significant aspect identified as contributing to participation to self. In retrospect, most of the participants led a comparatively uneventful life before the onset of schizophrenia\textsuperscript{81}. Participants' agree that they need a routine that will enhance their participation. Participants' have a clear opinion on why routine is so relevant. They think routine is important because it keeps them occupied. Earlier at home participants used to sleep, or sit idle throughout the day and would not listen to the family’s suggestion to help in household work or do something than sitting idle. Participants quote that this idleness increases the intensity of pessimistic thoughts. Participants also feel that these negative thoughts stopped them from performing anything. In their opinion, routine is necessary to keep self engaged in productive activities and thus avoiding negative thoughts. Once participants develop a routine, they no longer waste time by sleeping. They spend time in acquiring skills required for a job or start pursuing education. Routine activities gradually boost participant's confidence in self. Both genders share same opinion regarding the need of routine.

Routine at HWH and LSH consist of rising at a particular time, performing self care activities, prayer, exercise, breakfast, medication, activities at rehabilitation facilities and home, lunch, medication, group activities, doing homework, prayer, dinner, medication, and going to sleep. Day care participants routine consist of rising early, attending day care, activities, helping in household activities, medication, doing homework, and sleeping on time. Day care participants have to plan a set of activities for Sunday and Saturday as they spent these two days at home. Participants and families feel that after coming to rehabilitation facility they have a structured routine.

\textsuperscript{81} Case history reports show that most of participants had an uncomplicated life before the onset of schizophrenia.
... always negative comes by its own when am not doing any activities...am relaxed on when it comes to washing my clothes, I wait till last minute and left the stain, it did not go and taking bath all that personal hygiene is very bad very bad like even now I can tell I need to brush my teeth like I ate food I smoked I drank tea, no I did not drink tea, but all everything in that just everything I had onions and all the garlic and everything the smell is coming (laughing hysterically) so I know all that so am very relaxed with that...Yeah like I have lost interest like even I won't dress properly I wear different matching socks and all that and I won't iron my clothes. I do not know something like that for a while, now I can see that coming (Avinash).

....I help at home, cook, take care of my father and brother, come regularly to day care attend different activities all these are participation in the community, also I go to temple to pray, sticking to my culture and beliefs (Hasini)

....he wake up early now otherwise he used to get up at ten or eleven in the morning, then have breakfast again sleep till two thirty or three, night he takes dinner and medication then go to sleep...this was his routine. Now he gets up, his timings are adjusted. He gets up, brush teeth, earlier he used to brush for twenty to thirty minutes if there is no water then one hour or one and half hour. Now that has reduced he will fill water in the bathroom, brush in ten minutes wash face and get ready to go to day care... (Ali’s father)

Case files show that before the onset of schizophrenia participants were engaged in one or the other activities. It could be education, job, or marriage, but they were doing some productive activities. Participants feel that after the onset of schizophrenia, they lost that rhythm and drifted away from every aspect of life. Eventually, it came to a state where they spent whole time/day without doing anything. Avinash thinks that something holds him back from doing any activity at the right time, so he keeps pushing it for later. If he is not engaged in any activities, negative thoughts keep coming in and prevents him from doing anything. Earlier family/guardian was concerned about participant's lack of
interest and level of inactivity. At present, they are not much worried since participants are attending rehabilitation center and follows a routine. Professional supervision helps participants to perform activities on time. There are participants who have issues in following routine rigorously and within the time limit. Professionals allow those participants do it at their own pace, but keep reminding them of it. The activity structure at HWH, LSH, DC is different, but it ensures that participants spend their time fruitfully. This helps to engage themselves in one or the other activity.

Health care and Medication

Maintaining physical health is important for both younger and older participants. Participants show utmost care in maintaining their physical health. They feel it is important to maintain physical health for better functioning. Participants feel that taking food on time and going for a walk or doing exercise is necessary to maintain good physical health. Participants express their concern over increasing weight. Therefore, they maintain a weight check. There are participants who have severe problems with blood sugar and blood pressure levels. Professionals assist them in checking sugar and cholesterol level in order to keep a watch on it. Participants do not forget their checkups and consultations. The menu at HWH and LSH is decided by both participants’ and professionals. This menu is prepared keeping in mind the nutritional needs and affordability. Exercise is part of the schedule and attendance is compulsory for all the participants. Participants who are not satisfied with exercise at rehabilitation facility either go to gymnasium or go to the park, or make individual exercise plans. Though participants are apprehensive about medication it is an inevitable part of their lives. Participants appreciate the effect medicines brought in their functioning, but are not happy with the concept of lifelong medication. Participants also suggests for smaller doses of medication than a heavy dose.

82 Participants are particular about their health checkups and psychiatric consultations. There are participants who take depot injections due to problems in medication compliance. When it is time for the next dose of injection family has a tough time convincing them to take the injection, but after meeting with their psychiatrist participants takes the depot. (field notes)
I put on weight….I go for walk in the morning…I do jogging…whatever exercise I do in day care that I do several times at the park. I practice dance and music….medicines are important but small dosage of medicines should be given otherwise it affect memory loss….I have diabetes so I have to go for regular blood tests....(Arthi)

Families insist on taking medication regularly since it is important in symptom control and better participation. Professionals share the same opinion, but are concerned about the side effects of medicines. Staying healthy both physically and psychologically is a relevant aspect in participation to self and thus for participation in the community.

Prayer, beliefs, and religious activities

Visiting various religious institutions such as temples, mosque, church for performing prayer and other rituals is a part of participants’ life. Participants expressed prayer as an inevitable part of their life. Participants feel that it helps to ease their struggle and considers prayer as a refuge to sort issues in life. Prayer is considered as participation to self since participants think it gives them hope for improvement. At HWH and LSH, prayer is part of the routine and prayers of different religions are included in the prayer schedule. Female participants go together to the nearby temples to worship. Maria considers prayer as a consolation since she thinks her death is near.

....I couldn’t pray, I did not pray at home, I am feeling guilty, I should have prayed then I could have had a better day calm and peaceful like that, I do not know whether god gives everything whenever you pray but things become easier when you pray to god...I feel that god is real, when I started praying I feel less distance of god that god is with me so troubles and tribulations and very hard

83 It was difficult to discuss about religious activity and prayer with the Sourav who had the idea that he is a reincarnation of Vishnu. The challenge while talking to him was to not to discuss about god since he tries to explain his idea in detail. His psychiatrist has given strict instruction on not to discuss any topics related to God while talking to him since it may strengthen his delusional ideas.
times I felt god is with me, god made me let pass very easily he made me easier to pass through this crisis.... (Hasini)

...actually I am fully into prayer, death can come anytime to me because if that I confessed to two priest according to my religion’s rule.... (Maria)

It is admirable that difference in religion and caste does not influence participants' relationship with each other. Participants in fact discuss their religious rituals and prayer with each other. Rehabilitation facility allows HWH, LSH, and DC participants to celebrate various religious festivals.

**Participation at rehabilitation facilities**

Participation at rehabilitation facilities consists of taking part in various activities at each center. Each rehabilitation facility has different short-term and long-term goals. Various groups and individual activities are designed to furnish these goals. Since half way home and long stay facility offers residential care their activities are different from those of day care. The priority in HWH is to enhance an organized life for the members. In order to organize activities HWH have a structured schedule. LSH follows a flexible routine to ensure the basic functioning of the participants since most of them plan to spend the rest of their lives in LSH. Day care facility offers vocational training and group activities to the participants. Members from HWH and LSH attend day care for vocational training.

Participants’ consider their interaction with other members as an important aspect of participation in rehabilitation centers. Participants' agree that interaction is an important aspect in determining their social involvement. They also regard interaction as one of the best ways to get support from others and rekindle relationships. Participants feel that their

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84 Majority of the members at rehabilitation facility belongs to Hindu religion, but all religious festivals are celebrated. Organization A uses every such occasion to add some color and happiness to participants lives. These are the occasions where members at each centers (HWH, LSH, and DC) enjoy happiness and harmony. (field notes)
interaction level has improved over the period of time because of attending rehabilitation facilities.

...I have started interacting, I try to talk to people more than I used to. In the group I used to be shy, but now I try to speak. The more I interact the more personality will improve (Varun)

Interaction is mainly in the form of conversation, and the topics are related to interests, hobbies, and life in general. Living in a rehabilitation facility helped participants to identify people with similar issues and concerns. This identification also helps in interacting without the fear of isolation and discrimination. Interaction takes place in two ways; by initiating a discussion and/or replying when others initiate a conversation. Inhibition to engage in conversation is a well-known factor in people living with schizophrenia. Therefore, improvement in social interaction is an important milestone in rehabilitation. There are other aspects of involvement in the rehabilitation facility, but participants consider interaction as the most important aspect.

Matrix 13: Participation in rehabilitation facilities

<table>
<thead>
<tr>
<th>Rehabilitation facility</th>
<th>Schedule and Activities</th>
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</thead>
<tbody>
<tr>
<td>Long Stay Home (LSH)</td>
<td>Relaxed schedule and activities</td>
</tr>
<tr>
<td>Halfway Home (HWH)</td>
<td>Structured schedule and activities</td>
</tr>
<tr>
<td>Day Care (DC)</td>
<td>Structured activities and vocational training</td>
</tr>
</tbody>
</table>

Long stay home

Long stay facility participants follow a relaxed routine. They engage in various activities to keep themselves busy. Though, the schedule is not very rigid participants get up early in the morning and engages in various activities. After rising they perform personal hygiene activities, prayer, exercise, and breakfast. Participants consider each of these activities as their involvement in long stay home which they treat as their family
and community. Participants who need to attend vocational training at day care gets up earlier than other participants. This is because of the day care activities begin at nine thirty in the morning, and the bus leaves at eight thirty from the LSH. Only Avni attends day care regularly and she attends tailoring unit. Mynah goes occasionally when she has any doubts in her craft work. Due to her physical disability Maria is unable to attend DC. Other participants are not interested to go to day care since they do not find it productive.

Participants who stay back in LSH are relaxed and spend their daytime doing various activities. They watch television programs or chat with other members. Participants may go for a walk or shop for daily/monthly requirements of LSH or for them. Those who have consultations go for their consultations. Participants who are interested in cooking help the kitchen staff in preparing food. Each participant is assigned with house duties or responsibilities. They spend time on fulfilling house responsibilities. House responsibilities include cleaning rooms, arranging newspaper, cleaning table after food, vegetable cutting, and group activities held once in a week. One member is selected as the chairperson for a week or two for leading the house. She/he will look into the matters regarding house activities and performance of the members in carrying out those house responsibilities. Participants feel that the freedom they get in the center is really good compared to the earlier rehabilitation centers. They are allowed to go out for a walk and buy things whenever they want to, this ensures a level of freedom one enjoys at home.

Participants think that though LSH is not like own home, they consider it like their home. They express that they are able to follow a routine which helps participants to carry out the daily life activities without any failure. Participants who are engaged in some form of vocational activity feel that they spend their time in a packed schedule that enhances their participation. For those participants who do not engage in any vocational activity feel that they are not productively participating. The participation at LSH

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85 There is a bus service arranged by the rehabilitation facility to pick up members in the morning and drop them in the evening.
86 The number of members at LSH is less compared to HWH therefore members can help in preparing food. (field notes)
activates again is influenced by the physical health of the participant. Maria has severe physical health issues. She feels that her participation is limited to self care activities due to her physical condition. Participants find the routine at long stay facility helpful in maintaining self care, keeping self occupied, regular medication, and maintaining proper health care. Mynah initiated to get a timetable from the staff since she had difficulty in planning a day’s activity. She makes sure staff checks the timetable and her performance. Her skills in embroidery and craft work are widely appreciated by professionals and other members at the LSH. Mynah attends private classes to learn new patterns in embroidery and craft work.

I have a routine here I participate in other activities also. Morning I get up at 7.30 am, brush my teeth, comb my hair, go for prayers, take breakfast, come down have a bath then I clear up my room neatly and arrange it, and then I sit and do my embroidery work till lunch time. Lunch time I go up fill the drinking water drum, keep the plates, these are my house duties, then have tea come down say my prayers, after that again sit and do my craft work. 4.00 pm I again go up for tea and snacks, vegetable cutting is there, then I come down, after that I am free, that is free time but am not free i go for walk from 4.15 pm to 5.00 pm. Once I come back from that that is the end of my working day like all my activities are over, so after 6.00 pm I sit and relax either I watch TV, or read the novels, or listen to music that is it. At night 7.00 pm we go for prayer then dinner at 7.15 pm take medicine some times for half an hour, no ten to fifteen minutes I watch TV and then I go to sleep by 8.00 pm... (Mynah)

I wake up in the morning, have breakfast, take medication, take a bath if I miss a bath then i do it in the evening, then I go for walk in the afternoon or in the evening, i go to the cricket ground in my tracksuit and sometimes i watch cricket.... (Niranjan)

am not able to take up house responsibility due to my physical problems, otherwise I watch TV, go to my room and pray or read some good books, take
Participants take part in the group activities conducted in LSH. Group activities are organized once in a week, but it is not very rigorous as it is in HWH or DC. Community meeting is regularly conducted to assess the performance of the chairperson and LSH members. It is also an occasion to allocate duties for the next week. Participants think that community meeting is an opportunity to express their opinion in the matters regarding duties, issues, and activities at LSH. Group therapy is not rigorously followed. Most of the time group games are organized to lighten the mood of members and ensure full involvement. Participants have a different approach regarding the money matters. Participants feel that they have to spent money cautiously. The financial background of the LSH participants is stable enough to afford the expenditures.

Participants feel that their interaction and communication are in good shape. Arguments do occur among participants, but they solve it by themselves. In case if participants are not able to handle the arguments, they take help from professionals. Subjects for argument are issues with roommates on keeping bathroom and bedroom clean, or interference in personal matters. Mynah feels happy about her regular participation in the kitchen. She does it regularly whereas Avni says she is interested in helping kitchen staff, but only if she feels to do something in the kitchen. Though Niranjan says he is interested to work his therapist (the mental health professional) working with him has a different opinion. Professional observes that he is inconsistent in

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87 Group therapy is generally intended to bring some therapeutic results. Therapeutic discussions happen once in a while. Professionals and participants prefer games so that it will strengthen the compatriot spirit among the members. Professionals and LSH members take part in the games so that there is no hierarchy in group participation.

88 A certain amount of money is allotted for each resident to buy their daily requirements and snacks. Though the purpose is to teach them to handle money efficiently, it is not rigidly followed. The reason professionals quoted (during an informal conversation) is that the only thing LSH members can enjoy is food and it does not give a nice feeling to restrict food, but can ensure that it does not affect their physical health.
his interests and he also has sleeping troubles\(^9\). Therefore, planning vocational rehabilitation for Niranjan is difficult. His participation in house activities is also very limited due to odd hours of sleeping. He is interested in reading books and going for long walks in the park. Akhil feels his participation become limited due to his last relapse. He used to work in a medical firm and he had to quit the job after relapse. For the past one year, he is trying to achieve the level of productivity he possessed before relapse.

*I interact with everybody, socialize, I participate in all the activities organized by the institution, I take part in skits, write skits, direct them for the community, not disturbing anybody, looking after people and they can look after you. Adjusting with everybody, trying for a job, taking medication, trying to help people, following rules and regulations, being committed to my work or task which has been given to me* (Akhil)

*In house activities vey less, minimum participation because most of the time he is sleeping or smoking or goes off for a walk and comes back, but in the house he doesn’t do much…groups he attends by force, he is not that interested, doesn’t like to do anything with interest in the house….he is not consistent in anything so we can’t get him a job…he has too many things in his mind, he likes to be standing and doing a salesman’s job, sometimes he likes to be an insurance agent, sometimes he like to go and study something….sometimes he likes to be in some shopping complex distributing palm lets...for a product....he is not consistent at all.... (professional Vinaya about Niranjan)*

There is no pressure on participants to take part in all the house activities, but participants feel it is necessary to keep self-busy. Psychiatrist, families and professionals strongly suggest participants to take part in all the activities since it will help participants

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\(^9\) Niranjan sleeps during the day and is wide awake the whole night. Psychiatrist and the therapist tried various ways to modify his sleeping habit, but did not work out. Since his family is not very keen on his vocational rehabilitation professional does not have pressure to find a job for him. (Informal conversations with professional, interview, field observation, and case records)
to engage in some work than sitting idle. Except those who have physical disability or floridly symptomatic. Most of the LSH members take part in house activities. In those instances, attenders are hired to assist participants in carrying out activities of daily living.

*Half way home*

Half way home has a structured schedule for its members. Participants consider taking part in these activities as involvement in the community. This is because HWH is referred as their ‘community’\(^{90}\). HWH is aimed at promoting self care, cognitive, social and interpersonal skills of the members. Therefore, there are various activities in the schedule such as routine, cognitive retraining activities, group activities, house responsibilities, shopping, individual counseling services, consultations, friendly chats, college, work, meeting families, exercises to ensure participation. Participants’ day begins with getting up early in the morning and performing the personal hygiene activities. Personal hygiene activities are followed by exercise, breakfast and morning medication. Group activities start with morning feedback meeting, and vegetable cutting. In between participants carry out their individual house responsibilities and maintenance duties. Therapeutic group activities start at eleven in the morning. Each day participants have diverse group activities catering to the different needs or areas of intervention. After lunch and medication participants attending vocational activities go to day care. They return in the evening and take part in the exercise. Tea and snacks are served at four in the evening which is followed by evening exercise. Participants who are assigned to buy fruits for dinner go to get the fruits. Prayer is before dinner and medication. By nine thirty, HWH members go to bed. This is the usual day to day life structure of each participant in the center.

\(^{90}\) HWH activities are based on the concept of therapeutic community. Therefore, they use the term ‘community’ while referring to HWH members and atmosphere. (field notes)
by 6.00 or 6.30 am I get up. I go to brush my teeth and attend my personal hygiene, then coffee, sometimes attend exercise, breakfast, medicines, planning meeting, maintenance duty, group sessions.... (Lalitha)

at home I was restless, here it reduced. I did not maintain a routine. I did not take bath on time, here I have a routine (Varun)

'staying at short stay facility helped me a lot, it made me active, alert, and helped me to take care of my personal hygiene activities on time. I do not feel lazy now and I am fast in doing things than earlier, so my parents are also happy....I felt controlled, I was able to manage myself, I was able to look after myself within time, not left loose like that, I felt restricted. I did not misuse freedom; here I am in a controlled atmosphere, same I was able to at home [when she went home on a vacation].... (Kavya)

Participants before their admission to HWH have to face an interview and a trial stay of 10 days. In their opinion, trail stay helps them to understand and adjust to the routine. Participants express that the activities at the center helped them to take part promptly in the daily activities, work, and education. They feel time is spent effectively by doing productive activities. During free hours' participants spend time on chatting, reading, playing games, or watching television. They feel that there are no restrictions in the activities they can do during leisure time. Participants have to keep self occupied in one or the other activity. The structure is designed in such a manner that the members do not stay idle. Participants observe that their interaction and communication level has improved over the period of time. This they feel is because of the rigorous group activities at the center. These group activities aim at both individual and group learning.

Group activities are meant to enhance social skills such as interaction level, communication pattern, sharing, and recreation. These group activities are categorized based on social-skill training, group therapy, art therapy, recreational activities, and

91 This was expressed during the informal conversations with participants during tea breaks.
money management. Group activities are primarily meant for therapeutic interventions. Group activities are planned and implemented to improve various skills in participants to deal with real life situations. Participation can be active or passive. Active participation refers to begin a conversation, taking up duties and responsibilities, approaching for counseling (whenever required), and expressing their opinion in the group without external motivation. In passive participation, members do not volunteer to involve in all the activities. They have to be motivated by the professionals.

Participants do not discuss anything related to schizophrenia with each other. Arguments are common but if they can solve it themselves, participants will not let it reach the professionals. If it becomes difficult to sort it out, then they approach the professionals. All the participants expressed their happiness to take part in recreation activities. Recreation activities such as going out for lunch, snacks, movie, or picnic are planned for each week. In the participant's opinion, this is the best of all activities at the center since she/he gets a chance to go to different places and enjoy the food. Participant's involvement in activities varies as per her/his interest.

Community meeting is a group activity where participants are actively involved. The purpose of this group meeting is to select a chairperson for each week and assign house duties to members. Participant's performance for the previous week is assessed and rewarded. Maintenance duties are assigned based on the capacity and initiative from the participants to perform it. Participants who are not initiating to take any duties are assigned duties by the professionals. Performance in every duty is scrutinized by other HWH members and professionals. Those participants who have performed well receive appreciation and those who did not perform are criticized. Criticisms are not harsh, but in the form of suggestions and guidance. Most of the time feedback does wonders to the members. Participants try to improve their performance during the next week.

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92 Group participation is one of the prominent aspects of HWH life.
93 Participants’ conversations are never related to their illness. The topic of conversation would be anything other than their illness. There seems to be an understanding among participants that they will not discuss about schizophrenia or whatever their diagnosis is. (field notes)
….what I feel like doing I do it, like reading, writing letters to my mother and friends. I do my own exercise other than they have here. I go for walking. I watch television, film, songs, serial...listening to good Tamil songs, read good joke books, keep writing some good thought for the day from books of proverb and find good ones, I get phone calls from family...i go to see my doctor...once in a month for consultation, and stay at home for a few days...i sing prayer songs.... (Malleshwaran)

....she was not able to participate well in the group. She just used to participate but later...slowly...after participating in talents day and all these things...very enthusiastically she used to participate and especially art and movement therapy she was participating very well and...role play she was participating well...sometimes she will not put out her thoughts or views or voice out her opinions but even if she says she will give a prompt point...

(Professional Rehania about kavya)

There is an incentive for attending exercises. Participants who attend regularly get the whole amount. Each absence from the exercise results in a cut in the incentive money. This is not applicable to those members who are excluded from exercise due to physical issues. These participants are provided with daily allowance instead of incentive. Participants purchase their daily requirements with the incentive money. The purpose here is to enhance money management skills such as wise spending, control expenditure, maintain an account, and saving money. Participants have different opinions on this activity. There are participants who feel that the incentive money is sufficient to buy the snacks for a week. Other participants feel that it is too small an amount to buy their weekly snacks. They report that the problem is in finding out the snack which is sufficient to last a whole week with that small amount. All members have to attend the group activities whether they like it or not. Participants are cooperative in group activities and attend group without hesitation. The involvement of participants in HWH activities is

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94 Incentive amount and daily allowance amount are same. The aim of incentive money is to encourage participation in exercises.
motivated by the fact that it will help them in getting well soon and go back to the family, work, or education

Avinash initially had problems in attending group as he thought it was worthless. Later, he started feeling that it is helping him in distracting his negative thoughts and also to present his ideas to other group members. Sourav used to attend and participate actively in groups before he got his job. He felt that his contribution was helping other members in the group. His participation in the group was not restricted to voicing out his opinion or initiating responsibilities. He encouraged other residents to contribute their ideas and express opinions.

Day care

Day care facility has a structured routine for the participants. Participants spend the daytime at the facility as per the schedule prepared by the professionals. Day care starts at 9.30 am, with a morning group meeting of participants, students and professionals. This is followed by exercise for fifteen to twenty minutes. After the exercise, participants go to vocational training sessions as per the timetable allotted to them. Vocational activities include computer classes, printing classes, tailoring classes, art and craft sessions, and plastic molding sessions. Computer classes impart basic computer knowledge in participants. In printing class participants are taught to make paper covers and bags, receipt books, and notices. Plastic molding is technical in nature and in this section participants assist in making files and file clips. The tailoring sections give training for females in stitching, embroidery, crochet, greeting cards, and book marks. Art and craft session aims to enhance cognitive abilities in clients who have difficulties in concentration, memory, and attention.

Vocational sessions are continued until three in the afternoon followed by group therapy. The working hours ends with evening group sharing where members share their feedback about the day. Participants consider taking part in each of these activities as their participation in the community. For them each of the activity at DC enables to learn
a new skill or sharpen their existing skill. Participants' interest is also taken into account when she/he initiate/volunteer to work in a particular vocational session. This is allowed when there is no work at other sessions or participant is unable to focus in the allotted session. For example, Prema usually works in plastic molding, but if there is no work in that session she finds work in other sessions. Prema initiates to find work rather than waiting professionals to allocate work for her.

day care I go to all the sections, in computer section I do MS word, excel, power point everything I do, and in printing section bags, envelopes, covers, visiting cards, medicine covers we make, and some design cards that greeting cards you know that designs, I will make or alter envelope cover outside you know that cover we put outside in all that, I help the instructor before I used to do now no order, then screen printing and all that vouchers here we will do, all the things I do. In all the things I help her. And in plastic molding section we pass the files, putting clips in the files, I can operate the machines both the machines, I can do that also. Art and craft before I used to do now madam told no need now I spend that hour in plastic molding section. I am not going for art and craft (Prema)

in tailoring I do book marks, embroidery, satin stitch, stem stitch, French knot, filling with color thread and anger thread, hand embroidery on cloth, and crotchet telephone mats. I repair my mother's blouse on sewing machine. Some days I attend computer sessions, I have to be in tailoring session since I have a lot of work there, sometimes the instructor is not there then I have to look after tailoring session. I argue with computer instructor for putting me in computers, he allows me to go to tailoring session. I attend and learn these two sessions, only through these two I can feel happy, and curious to learn, and anxious that I can become a tailor and that makes me cheerful.... (Ammal)

95 This is done for participants who initiates for doing work at sessions. There are participants who need a lot of motivation to take part in vocational or any activities. In such instances professional decides the type of session that participant should attend. (field notes)
when she comes she participates. She is very caring towards other clients...she knows how to do problem solving...at least for others, I do not know about herself but others she does very good....she is very forgetful...other things logical, reasoning and all that is very good. She writes stories...she has a good command on language both Hindi and English (Professional Kalyani about hasini)

Group activities consist of morning feedback session, group therapy, games/recreation, community meeting, music therapy, and evening sharing meeting. Participants’ interaction with other members and professional and paraprofessional members of the facility is comparatively good. They feel their interaction with other members has improved compared to their earlier state. Participants say they spend time with other members at the center so that they can share a good relationship with them. During the tea breaks and lunch hour participants sit together and chat. The topic of conversation varies from family to work. They crack jokes, correct others (in a polite manner), help each other, and share food. There are participants who keep to themselves and show less interest in interacting with others. They feel to interact with people whom they are comfortable with.

Professionals agree that there are participants with limited interaction and need based communication. The level of understanding is high among participants, and they patiently help other people. Participants find it difficult to guide or teach others in vocational sessions if the instructor has other works. They feel that carrying out work at vocational sessions is fine but teaching other people is difficult. For example, participants in tailoring session are able to carry out their work, but find it difficult to teach other clients. They are not able to show the patience to explain more than once and get irritated quickly. Therefore, instructor is apprehensive about giving the charge of the session to

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96 Though day care participants’ are able to interact with others without much trouble, communication at times becomes difficult. They find it difficult to express accurately what they want to convey. Participants take time to put their ideas into words.
97 Participants listen to other member patiently, reassure them, and sometimes guide them in personal issues. Participants only difficulty is to assist or guide other members in the vocational session.
client members when she goes out for some other work. Instructors maintain cordial relationship with the participants. They are closer to participants than professionals. Participants’ interaction with instructors is pleasant and jovial. Instructors are of the opinion that participants gradually learn the skills.

*Ktailoring session in the beginning she didn't know any work properly, in the sense she talks a lot so whatever we try to teach her she will keep telling that she is not able to do it. Gradually she improved and started learning different works, slowly improved and learned skills; she is doing as she possibly could. (Instructor Mozhi about Prema)*

Professionals assign home work and participants’ show interest in doing the home work. Participants feel that home work*98 keeps them engaged even after reaching home and sharpen their memory. Typing on a type writer is not common these days, but in day care it is used as a better way to increase concentration. Participants who have experience in typing are assigned this work to improve their concentration and attention. Personal hygiene and self care are closely observed by professionals and para professionals. If the participant is not maintaining her/his personal hygiene well then they instruct family to keep check. Participants feel that attending day care makes them cautious about their dressing and grooming. Other participants and members at day care take note of the dressing and grooming. They openly tell the participant if she/he is not maintaining proper self care. Community meeting is for evaluating clients’ performance for the previous week and assign duties for the present week. Duties assigned to clients are arranging the room (after sessions are over), safe keeping (materials), and hygiene monitoring. Monitoring of duties and report writing is chairperson’s duty. In the absence of chair person assistant chairperson takes up this duty. Participants usually initiate to take up responsibilities and fulfill it without failure. They give creative feedback and

*98 The home works in tailoring sessions are crochet work and embroidery. In art and craft home work consists of puzzles, short story writing, basic writing, and word power. It is not possible in other three sessions to assign homework due to the nature of work.*
observations about others work during the feedback session. Participants analyze positive and negative aspects while giving feedback.

Group therapy sessions consist of games, and occasionally discussions and therapeutic interventions. The reason for using games is to ensure participation of all members. In professional's opinion individuals with intellectual disability\textsuperscript{99} would find it difficult to involve themselves in discussions and other therapeutic interventions. Therefore, to ensure participation of all members, they choose games than other therapeutic activities. Participants share a good relationship with other members at the center by reassuring and supporting whenever needed. They encourage each other in work and motivate those who find it difficult to follow. Professionals organize various programs for participants to enhance their inner talents. Participants perform well in programs with adequate practice and support from professionals. Arguments do occur between participants, but they resolve it among themselves. In case if they could not take care of it by themselves, professionals and paraprofessionals help them to sort it out. Participants express that they are performing well in their day to day life activities since they have to attend day care regularly. There are participants who find it difficult to balance participation at day care and home. Their participation depends on the amount of support they get from family members.

**Participation in the family**

Involvement in family is different for HWH and LSH participants, and DC participants. LSH and HWH participants feel that their involvement in family is limited. They have regular contact with their family members through phone calls and /or emails. Participants’ idea of involvement in the family includes active participation in family matters, decision making, and providing emotional and economic support to the family. Participants feel that in this sense, their participation is minimal or not at all there. They

\textsuperscript{99} \url{https://arcmass.org/Portals/0/renamingMRIDDApril2007.pdf}, accessed on 10-10-12, Professionals still use the term mental retarded to refer to people living with developmental disability.
want to participate in the family, but impossible due to schizophrenia. Though family members visit HWH participants every month, and participants spend time with them involvement is limited to that. Those who are able to visit family help them in household activities. Their participation in the family extends to that level. Arthi’s family stays nearby the rehabilitation center. She goes to stay with the family during the weekends. Therefore, in the opinion of HWH participants their involvement in the family is not good. Half way home participants have the option of going on a vacation with family. This vacations help participant to spend time with family members so that family can understand the areas of improvement and where help requires. Another advantage is that participants are able to identify to what extent they can actually follow the routine at home. Vacation is planned when participants' express his/her desire to visit home, and family and psychiatrist agrees for the same. Participants' from Bangalore or anywhere in Karnataka can visit home or family can visit them whenever they feel like.

...they [sisters] inform me about whatever happens at home when I ask them...they do not ask my suggestions/opinions about family decisions. I am far away from home otherwise they used to ask. I did not go home but went to Mysore. I stayed with sister and mother. It was a good experience.... (Varun)

his communication is very nice, he is joking...he is better than earlier, he share his problem with us, he speaks now...his participation is limited, he is here under treatment he can’t do much for us, we do not expect him to take care of us.... (Varun’s father)

LSH participant's contact with family is lesser than HWH participants. Family meeting is held twice in a year to help LSH participants and their family to share their concerns, expectations, and improvements with professionals. Those participants whose family stays outside of India do not get a chance to meet family even during family meeting. Therefore, participants’ do not get frequent chances to interact with family. Niranjan’s father stays abroad and has not visited him for a long time. Niranjan express

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100 There are participants’ whose family stays in Bangalore and they visit participants frequently.
his dissatisfaction in not meeting him, though he receives calls regularly. He has expressed his wish to spend a vacation with his family, but not materialized yet. He gets annoyed during family meetings since nobody is present for him. Though he has a local guardian, he contacts his guardian only when required. This is not same for other participants in the LSH. Mina has regular contact with her maternal cousins. After her parents demise her maternal cousins take care of her. Maria’s guardian is her paternal relative who occasionally visits her. Her guardian could not visit due to his ill health. She does not have a good support system as her sister in law refuses to take care of her. Akhil’s parents are old but visit him whenever possible. Avni last vacation with family ended up in relapse and hospitalization. Her brother is apprehensive about taking her for another visit. In short, LSH participant's involvement in the family is limited to communication over phone, emails, and occasional visits. Over the period of time, participants have accepted long stay home as their own home.

...this [long stay home] is the place I live and these are people I interact with, staff, but previously my family was the prominent part of my community and I did not know about my illness....now I consider myself at home.... (Avni)

Day care participants’ participation in the family is more active since they stay with their family. They help parents at home, assist in household chores, and go for shopping daily life requirements. Participants feel their involvement in household activities is equally important as their participation at day care. They find going out with family relieving and making them feel self as a part of the family. Participants consider their interaction with family members as another aspect of participation. They go out with family and spend time together. Participants feel that their interaction with relatives has improved over the period of time. They also feel that attending social functions help them to maintain a relationship with relatives and friends. There are issues between participants and family members. Participants feel that they are able to resolve these issues and stay together. The difference in the participation of day care participants in their family compared to HWH and LSH participants is the constant presence of family in their day to day life. Involvement of family in day care participants’ life is more visible
than HWH and LSH participants. Therefore, day care participants’ level of participation on a continuous basis in their family can be said as higher than HWH and LSH participants.

*Helping my mother I buy things from shop, put water in the front yard during festivals so that she can clean it* (Raju).

*My father is a retired supervisor, he is at home, and my brother is working and paying. They provide me food, clothes, bus expenses etc., in every way they are supporting getting medicines, taking for consultation. I share my feelings with mother. My father is old, he forgets so I do not share with him* (Ali).

...after leaving half way home regularly he comes to day care...we can find a lot of improvements in many areas like in food habits, then taking care of himself, then going out, going for walk, going for shopping...he interacts with relatives and family...*(Kumar’s brother)*

Family members attend psycho education classes and survivors sharing organised by day care. HWH, and LSH centre organize family meetings to assist family in enhancing their participation in the rehabilitation process. This helps family to participate effectively in the process of treatment and rehabilitation. Interaction and communication with family members are important areas of participation in the community and the area where participants feel they contribute less. Family is the major source of economic and emotional support for people living with schizophrenia. Except Sourav other participants are dependent on their family for everything. Since Sourav is financially independent he does not face this issue. Therefore, participants are of the opinion that their participation in this area is less and insufficient. Emotional support is other factor participants expressed as equally important as financial support. Participants consider the interest of

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101 Recovered people living with mental illness discharged from the rehabilitation center share their experiences of living with mental illness to the client members at day care.
family in their improvement as a positive sign for better participation in family. Professionals act as a resource and a source of emotional support at the same time. Participants feel that they are able to share their concerns, and seek advice and guidance from them.

**Participation to work and education**

Finding an employment opportunity for a person living with schizophrenia is considered as a big achievement in the process of rehabilitation. Participants’ perception on participation in the community also includes being on a job and pursuing higher studies. Participation in work basically consists of being punctual to work, putting whole effort in work, and working as a team. Participation in education is mainly in the form of attending classes regularly, work hard, and pass exams with good marks. Work is an area where participants’ finds it extremely difficult to take part. Participants acknowledge that rehabilitation centre inculcated a work habit in them. Vocational area is severely affected by schizophrenia and the attempt to revive it is a tedious process. Sourav is the only person who could achieve a well paid job. Hence his participation in vocational area is active than all the other participants. He feels that work is also participation to self as it helps him to be independent.

Mina and Avni turned their vocational skills in tailoring into an income generating activity. For them, it is a source of income and at the same time a hobby that keeps their time and confidence in place. Arthi goes for music concerts, but she does not consider it an income generating occupation. This is because she does not go regularly and it is not giving her any income. She is happy that she can take part in such occasions since it gives an opportunity to exhibit her singing talent. Varun after a long struggle started going for training courses related to his medical profession. He feels that attending medical courses will help him to take up a job that will pay him to meet his basic expenditure. Varun also expressed his hope of practicing his profession once he finds a rhythm in the present
work. His family is ready to do anything possible to help him to lead an independent life.

*My office work that is also participation towards myself in a way because only out of that some output is coming which is helping them and me also....* (Sourav).

....we only want him to take it [medicine] properly....on the job he is very good...the job people also they have sustained him for a long time...he has a kind of support system....he has got tremendous will power...if he set to achieve something then he does it.... (Sourav’s sister)

....am not working as you know, education is something I wanted to pursue...because education is like I participate in because I am keen on doing something with my life because I want to learn.... (Avinash).

....medical transcription is one thing which will support him financially...this job will help him financially I think that is good part because his parents are retired, in long run financial support also become very important for him. This will also help him to support his parents...after a point of time. To become a full fledged practitioner may not be possible.... (Professional Aishwarya about varun)

Other participants have expressed their wish to attain a job and become independent. Participants’ will power and determination also play an immense role in achieving a job or pursuing education. Avinash cannot complete his education which remains as a huge pain for him. He decided to join a professional course related to his earlier education. His counselor helped him in locating the college that offers the course and enrolled him there. Avinash’s mother is supportive of his endeavor and is ready to provide financial assistance. Shivani express her desire to continue with education, but she is not sure about what she wants to learn. Her father is supportive and is ready to support her in all

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102 He works as a transcriptionist in a medical firm. His performance seems to be good at the firm. (feedback by professional)
the ways possible. The biggest challenge to participation in this area is the ability to sustain interest their job, studies, or the efforts to achieve either of it. Day care provides client members an incentive at the end of the every month after analyzing their performance for each month. This helps in boosting their confidence and creates a sense of achievement. The aim of this procedure is to make client members aware of their improvement and performance in activities at the centre. HWH and LSH home does not follow this since the vocational training is not their main activity.

**Outcomes of participation in the community**

Outcome and improvement are used interchangeably. Improvement in various areas of participation can also be considered as outcomes of participation in the community. Participants identify that their level of interaction has improved compared to the earlier state. They feel that training in vocational skills has helped in acquiring work habits. Participation in the community has also improved their self confidence and decreased their anxiety level. Participation helps them in diverting negative thoughts and focus on some productive work. They are occupied in some activity rather than sitting idle and have a routine to follow compared to their past. Participants’ cognitive skills, especially concentration level and memory are better. These changes they feel are a result of both participation in the community and medication compliance. Participants feel that their social involvement in terms of attending social functions, visiting relatives, going out with family, and pursuing work and education are in a better shape. They also feel the need for understanding other person's feelings. The level of physical activity is better than earlier since participants are taking part in many activities. Participants feel that this helps them in knowing about self and expressing their feelings effectively. Taking part in groups assists in improving language, interaction with other members, and their thought process\(^{103}\). Participation motivates them in taking care of their personal hygiene effectively and regularly. This awareness makes participants aware about the surroundings.

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\(^{103}\) Participants think that they are able to form an opinion on various aspects and voice out that opinion. They consider this as a result of participating in group activities since group activities demand interaction.
The participant feels that she/he is better in facing social situations and can maintain a good relationship with family members. Earlier money management was a huge issue. After adequate training participants feel they are able to spend money fruitfully. Participation also brought a feeling that they are not just a patient or a person with mental illness, but an individual with productive life. There are participants who feel involvement in the community has not brought any changes in their lives. Sourav feels that since he always participated well in community schizophrenia does not matter in anyway. Participants who had difficulty in initiating a conversation in the past are able to initiate a conversation with others at present. Participants now share everything with family and seek help from professionals. They also started helping other residents’ and clients who are in need of help. Confidence in speaking, taking up responsibilities and fulfilling it, and seeking help whenever required are a few noticeable changes in the participants.

...neatness and all I improved a lot, before I was not that much neat after coming here I improved in neatness, everything I improved...sports and all, earlier i was not playing sports I won in carom board and then running race (Prema).

All these activities are helping me, I am keeping busy, it is not hectic, and it is good for me. I am happy doing all these activities (Virat).

At home I will lie down and sleep. After coming to day care facility I am working, I have a routine, speaking with other members, playing, attend group meetings, recreation, therapy etc., I have got a routine due to this. At home also it is helping (Ammal).

because they are living in a community...that is why participation is important...so that community living has some purpose....if they are interacting with others, participate with others they will understand about other human beings, if they are able to understand [other human beings] they will be able to
adjust well in the family, well adjusted in the work they go for. So participation plays an important role in deciding their goal, where they want to go, or what they want to do after they go from here...participation is important but how much you take it depends on the individual...staff has to involve...or family (Professional Nila)

It is difficult to say whether the training in vocational activities will help participants to secure a job. There is no doubt that it will certainly instill certain working habits in the participants. These working habits may help them to perform well in a job. The professionals and participants do not believe that vocational activities by themselves will help them to attain a job. Another aspect of vocational training is that it will increase the confidence of the individual to search for a job. Increase in self confidence is the eventual outcome of participation in the community. Participants had difficulty in concentrating, grasping, and memorizing things. This is a big hurdle for participants as well as professionals, since cognitive skills in a person with schizophrenia are generally disrupted. Through various cognitive retraining activities such as grain sorting, building blocks, puzzles, and word power these skills are regained to a certain extend.

Medication compliance can be considered as an outcome as well as a supporting factor for participation in the community. Participants, family members, and professionals feel that medication is helpful in reducing the distressing symptoms and enabling participants to take part in activities. Participants believe that the achievements and outcomes of participation in the community is the product of many aspects. An overview of the areas and level of participation in the community shows that participation in the wider community is inadequate. Participants feel that the biggest challenge for a better participation in the community is the lack of involvement in the wider community. There are various issues and challenges for effective participation in the community.
Supporting factors and challenges to participation in the community

In the present study supporting factors of participation in the community are family support and professional support. Family plays the most important role in enhancing participation in the community. They provide participants the motivation and hope to overcome the implications of schizophrenia and face day to day life struggles. Family support encourages participants to view treatment and rehabilitation confidently and comply with medication. The understanding that family is spending a lot of money for treatment and rehabilitation is distressing for the participants. This understanding acts an inspiration for better participation in the community. Professionals through guidance and assistance help participants to surmount various obstacles in participating. They plan activities that will encourage participants to take part in various areas of life. Participants usually share their concerns and plans with professionals during the counseling sessions. Participants also approach professionals whenever they need some help in day to day life events.

Professionals also act as a mediator between participants and their family. Attending rehabilitation facility helped participants to understand that they are not alone in living with a mental illness. They realized that there are people who live with schizophrenia or other severe mental disorders. Participants identified that they are in a better state than other people living with schizophrenia or mental disorder. This knowledge helps them to support and understand each other’s feelings. There are other supportive factors contributing to participation in the community such as support from relatives, fellow rehabilitation members, friends outside rehabilitation facilities, and employer. Participants consider other members at rehabilitation facility as friends. Friends outside the rehabilitation center are rare, even if participants have friends they have not revealed the fact of living with schizophrenia. In certain instances family friends and childhood friends continue to provide support.

Relapses and medication non compliance are the two biggest challenges for participation in the community. When a functional individual gets relapse, all those
achievements so far drops and the person goes to a floridly symptomatic state. It takes quite a bit of time to get the symptoms under control and achieve a minimum level of functioning. The data shows that usually medication non compliance and relapses go hand in hand. There are incidents were relapses occurred even with regular medication. Therefore, relapses are not only the after effect of medication non compliance. For example, Akhil in spite of regular medication ended up in a severe relapse. He used to do medical transcriptions; his striving for perfection led him to constant worry. Eventually, he had a relapse and quit the job. Even though he was able to come out of the relapse he could not return to his old job. The experiences of relapse affected his self confidence and urge to work. Avni had to hire an attender to perform the self care activities during relapse. She had to retain the attender till she became self dependent to perform day to day life activities.

_Actually I had a relapse I told you, so I saw the atmosphere which was not well that is why I kept an attender. She does all the work, wash my clothes, earlier I used to do all my work but now I can't do. When she comes she gives bath to another resident then she monitor my bath and all that, washing clothes, keeping my things arranged so I get more time for handicraft work.... I want to do something else I feel like going to a family and help them out, not my family, family over here those who need help...bringing or shopping for them...take them for walk [smiling], I myself need someone's help...[laughing] (Avni)

I was taking lots of medication olanzepine, clonazepam and all.... then I stopped taking all of it for two weeks when I was there without any instructions from doctor I stopped medication, my mom trusted me that I was having it after dinner or after breakfast in the morning but I stopped...I started having a few symptoms like hearing voices again going for long walks very long walks talking to myself (Avinash)

I have experience when I was in Madhya Pradesh that time my illness was more, I was telling some things and my counselor was not understanding, she is not
getting my point, then she scolded me telling this is not my cup of tea like that, there are people who doesn’t understand, now I am better than earlier, I was not so good in conversation and all, I was suffering from illness and that affects your mind set…they will gossip on your back (Hasini)

...we do not have case managers, but we do that [liaison work between employer and clients] sometimes. Like for some of our clients they go out and we go to the employer and tell them but here also we face an ethical issue because some of our clients say not to tell the employers that they are mentally ill…when our client is saying that we have to go by it...we have to lie to the employer we can’t do that...but some employers are very open...which makes it all the more easier.... (Professional Kalyani)

Stigma plays a major role in hindering participation in the community. It is impossible to share anything related to schizophrenia with an outsider due to the fear of discrimination. Hasini experienced discrimination from a mental health professional during the initial years of her treatment. Applying for a job without revealing the fact of schizophrenia is a risk. The two risks are the unpredictable nature of schizophrenia and the reaction of employer if she/he comes to know about living with schizophrenia after hiring for the job. This is also a major barrier for the professionals while seeking employment for participants. Informing the employer regarding schizophrenia may not helpful if she/he is not able to understand the nature and course of it. Another problem is participant’s position on sharing the fact of schizophrenia. If the participant does not want professional to share it with employer then she/he has to follow the interest of the participant.

Participants expressed that they want to get rid of the label of schizophrenia. They understand the importance of participation in the community. Participation to self is the area where participants are able to involve. They feel their participation in the family is not that good since they are not making any financial contribution or emotional support or physical assistance to family. Participants express the urge to do something for the
society, which they feel is hindered by the fact that they are living with schizophrenia. Participation in the community is also influenced by the perception of participants regarding their quality of life. The following chapter deals with the quality of life of participants in general and in various areas of life.
SECTION C
QUALITY OF LIFE

This chapter deals with the perception of people living with schizophrenia (PLS) on their quality of life\(^{104}\) (QOL). The chapter explores questions such as what does the term QOL mean to people living with schizophrenia and how do participants view their QOL. Therefore, focus of the chapter is to elicit the perspective of people living with schizophrenia on their quality of life. Narratives from PLS along with information from family and professionals are used to substantiate the subthemes. The data from family and professionals, and field observation notes helped in attaining a comprehensive picture of quality of life of PLS. This chapter is divided into four sections with each section providing various aspects of QOL. First section gives an overall picture of participant’s understanding on the concept of QOL.

The effort is to know how participants understand the term quality of life in general. This section also deals with numerous components of QOL which helps in enhancing participants’ quality of life. It is necessary to consider a time\(^{105}\) based segmentation in understanding the quality of life. Therefore, for the purpose of analyzing, quality of life has been divided into three segments based on time. These segments are quality of life in the past, present, and the future expectations on quality of life. Second section of the chapter narrates participant’s perception regarding her/his QOL in the past. Third section entails the perception on QOL in the present situation. And fourth section deals with the expectations about QOL in the future.

\(^{104}\) Participants’ used terms such as life quality, good life, or life with quality to refer to their quality of life. These terms are interchangeably used in this chapter.

\(^{105}\) Time becomes important in quality of life since the perception regarding quality of life may not be same over the period of time. The intention here is to use time as a criterion for understanding quality of life at different period of time also to compare the differences in quality of time over the period of time. Participants used time as the criterion to explain their quality of life.
Matrix 14: Participants’ perception of QOL at a glance

<table>
<thead>
<tr>
<th>Participants’ general understanding/aspects of QOL</th>
<th>Components that enhance participants’ QOL</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Happiness</td>
<td>• Being in a job or vocational activities</td>
</tr>
<tr>
<td>• Simple life</td>
<td>• Performing activities of daily life without failure</td>
</tr>
<tr>
<td>• Independent/self dependent</td>
<td>• Carry out household works without motivation</td>
</tr>
<tr>
<td>• Participating in community</td>
<td>• Adequate family care and support</td>
</tr>
<tr>
<td>• Standing for family</td>
<td>• Professional support</td>
</tr>
<tr>
<td>• Speedy recovery or cure</td>
<td>• Marriage and kids</td>
</tr>
<tr>
<td>• Meet basic needs</td>
<td>• Regular medication</td>
</tr>
<tr>
<td>• Good things</td>
<td>• Appropriate behavior</td>
</tr>
<tr>
<td>• To do best in any activities</td>
<td>• Following routine regularly</td>
</tr>
<tr>
<td>• Achieve something</td>
<td>• Attending day care regularly</td>
</tr>
<tr>
<td>• Successful in life</td>
<td>• Better cognitive functioning</td>
</tr>
<tr>
<td>• No stigma and discrimination</td>
<td>• Financial stability</td>
</tr>
<tr>
<td>• Respect and dignity</td>
<td>• Working hard</td>
</tr>
<tr>
<td>• Honest and punctual</td>
<td>• Keeping self occupied to avoid negative thoughts</td>
</tr>
<tr>
<td>• Guidance</td>
<td>• Engaging in leisure activities</td>
</tr>
<tr>
<td>• Serving own country</td>
<td>• Interaction with family, professionals, and others</td>
</tr>
<tr>
<td>• Being optimistic</td>
<td>• Take part in talent shows</td>
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<tr>
<td>• Go ahead in life</td>
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Understanding the concept of QOL and the components enhancing Quality of Life

This section deals with participants’ understanding on the concept of QOL in general and the components enhancing their quality of life. This includes both subjective and objective aspects. The general understanding of quality of life includes qualities, objects, and aspirations and desires a person may prefer in leading a good life. Understanding the concept of quality of life from the individual’s perspective is important in recognizing the
subjective elements of QOL. This is also done to respect the individual differences in valuing a person’s life quality. Participants express that their quality of life is overshadowed by the fact that they are living with schizophrenia. At the same time, they are of the opinion that living with schizophrenia does not indicate a life without quality. Participants feel that their quality of life varies from time to time and it is not static. There are many factors influencing their quality of life such as nature of illness, family atmosphere, social support system, employment opportunities, and rehabilitation. In participants’ opinion quality of life exists when surrounded by good people especially people who love, support, and care for them. There is quality in life when participant enjoys good food without worrying about the physical issues. Participants recall that each day is a struggle to stay out of symptoms and therefore, each day is a combat with self.

Participants’ understanding on the concept of quality of life has helps in identifying two things. It helps in understanding various aspects of their QOL and the meaning participants attach to it. Participants consider happiness as the key in leading a life with quality. Staying happy and leading a peaceful life is the foundation of QOL. Participants agree that it is not necessary to have all factors in one individual, but they believe these as the general aspects of QOL. In participants opinion a person will have quality of life if her/his life is free of worries and is filled with happiness. A happy life with fewer things to worry about is the simple way in which participants describe their quality of life. Therefore, staying away from worries and enjoying a happy life is the best way to achieve a better quality of life.

As mentioned earlier QOL is subjective in nature and is different for each participant. Participants feel that a simple life without many complications is the strength of quality of life. Simple life in this context refers to carrying out their day to day life activities, take care of relationships, and maintain social life besides struggling with schizophrenia. For example, Malleswaran is able to carry out his daily life activities independently. His smoking has come down, his symptoms have decreased, and he maintains a good relationship with his family members. A physical illness in addition to living with
schizophrenia hampers the individual’s QOL. It is challenging to explain what constitute QOL in a person living with schizophrenia. Participants feel that the priority is always given to cure.

*For me quality of life is that, [thinking for a second] you enjoy everything you do, you take interest in everything you do, whichever you do, do it to the best of your abilities, keep improving yourself over the period of time. Try to become a perfectionist as much as possible and enjoy the fruits of the efforts you put in, have negativities as less as possible and just be happy at work...the important thing is dignity of labor....treat everything as your responsibility.... (Sourav)*

*For me quality of life is that I should have a personality, personal hygiene, actively participate in society, take initiative in talking to people, communication with others, lead a disciplined behavior, get up on time, maintain daily life activities, not depending on others in terms of livelihood, job...establish myself in the society (Varun)*

Participants feel that support from family is a vital ingredient of quality of life. Standing for family is equally important as support from family. Along with participants’ family members have also endured a lot of pain during the course of schizophrenia. Participants think that this understanding is important for supporting and standing for family. Family support is essential for a better life quality. Participants realize that they may not be able to contribute financially or emotionally but they can reduce caretaker’s burden by taking care of self. Since participants are dependent on family for emotional and financial needs being self dependent is treated as a crucial element of quality of life.

Participating in the community by taking part in various activities organised at rehabilitation centers, house hold activities, social functions, office work or vocational activities helps participants in attaining a better quality of life. All these activities give a structured routine for participants which develop a confidence in self. This is the main reason participants demand for speedy recovery or cure from schizophrenia, so that they
can take part in various activities. Though, at present their basic needs are met, there are participants who are worried about the same in the long run. Therefore, meeting basic needs such as food, a place to live, and wearing good clothes gains attention. Participants quoted that enjoying good things such as good food, good clothes, good place to stay, good books, good job etc., are components of quality of life. The term good is used to refer to better price, quantity, and quality of the objects or services they avail. Performance level in any activities is another aspect of quality of life that closely follows participation in the activities. Participants feel that if they are able to put maximum effort to do their best in any activities then that result in a better quality of life. In their opinion the output do not matter, but the amount of dedication a person shows, in doing any activity (big or small) is what matters.

Participants quote success as another aspect of QOL. Success in this context refers to achieving something and doing well in life. Participants express that achieving everything a person wants such as care, freedom, love, affection, independent living, and security are all part of quality of life. Professional guidance and support in dealing with symptoms of schizophrenia, side effects of medicines, day to day life issues and behavioral issues increased their confidence and optimism in self. Prema feels that she is not able to contribute for the country even then serving her country is a part of her QOL. However, participants feel that moving ahead in life despite all the troubles looming from schizophrenia determines a person’s QOL. Stigma and discrimination are part of living with schizophrenia.

Participants feel that there should not be any stigma and discrimination based on schizophrenia. In their opinion participation in the community becomes difficult if stigma and discrimination are prevalent in the society. Hasini approached a health center for the purpose of reducing her weight. The health center as part of the admission procedure enquired about medication intake (since some medications have the side effect of weight gain this is significant information). Hasini had to disclose her illness and the health center did not approve her application. She felt depressive and complained that she became hesitant to approach any other place due to the fear of ridicule. This kind of
discrimination affects the level of achievement of the participants which will reduce their quality of life. Participants express the need for respect and dignity in leading a better QOL. Virtues of being honest, caring, loving, and punctual in performing duties and responsibilities are also a part of their life quality.

*his quality of life is very bad. He can’t do what he wants to do. He is very intelligent and has lot of abilities but not able to lead a life which a person without mental illness has... (Akhil’s brother)*

*...what can I say about his quality of life, he is here and has this illness. He is better than earlier, he talks to us more now, closer to his sisters, he is going for class and started working...it is better than earlier....*(Varun’s father)*

According to a family member QOL of participant has deteriorated after the onset of schizophrenia. Families generally consider quality of life bad because participants are not able to do what they want to do in life. Family explains better quality of life in terms of improvement in illness and better outcome from rehabilitation attempts. They compare participants earlier and current behavior, performance in various areas, and involvement in household activities as the base for explaining quality of life. Family feels QOL of PLS lies in their ability to lead a normal life. While explaining their ideas on quality of life, families did not make a clear cut differentiation between participation in the community and quality of life; there is only a thin line of difference between both the concepts. In fact they feel both are interrelated and participation in the community is a part of QOL. This is somewhat similar to participants’ understanding on QOL. However, families are happy about the changes in the participants and they attribute this to medication and rehabilitation efforts.

The changes are visible in three areas; living with schizophrenia, self care and activities of daily life, and social involvement. Changes occurred in the area of living

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106 Normal life here refers to cure from illness, employed, married, and able to live like any other person in the society. This according to the family members’ is the idea of leading a life with quality (filed notes and informal conversations).
with schizophrenia includes the reduction in severity of symptoms and relapse. In the opinion of the families this is due to the medication compliance and regular follow up with the psychiatrist. They also feel that reduction in symptoms has helped in leading a better life. Caretakers\(^\text{107}\) think that participants are happier than earlier because of these changes. Changes in self are visible in terms of improvement and sustenance in self care, relationships with the family, and their social involvement. Social involvement\(^\text{108}\) here refers to interaction with relatives, attending social functions, and spending time with family.

Matrix 15: QOL of PLS from the perspective of families

<table>
<thead>
<tr>
<th>Aspects of QOL</th>
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<tbody>
<tr>
<td>QOL is bad</td>
</tr>
<tr>
<td>QOL deteriorated after illness</td>
</tr>
<tr>
<td>Changes over the period of time</td>
</tr>
<tr>
<td>• Illness</td>
</tr>
<tr>
<td>• Self</td>
</tr>
<tr>
<td>• Social</td>
</tr>
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...quality of life we need to compare with someone or with himself, compared to earlier his quality of life is much better....his professional quality of work that we are working on it...he has many options, his quality of life is very good (Professional Aishwarya about varun).

The professionals look at participants’ QOL in terms of improvement in their symptomatic behavior, self care, social skills, and relationship with family, and work life. In their opinion QOL of PLS is how well participants live despite the fact that they have

\(^{107}\)Caretakers here include parents, siblings, sister-in-law, or a distant relative (Case histories and field notes).

\(^{108}\)Social involvement is compared with the present state to the earlier state (field notes and informal conversations).
schizophrenia. Are participants able to find happiness in whatever they do or enjoy their life as any other person in the society? If yes, then participants enjoy a good quality of life. Professionals think that one has to consider participants’ overall performance in various domains of life while assessing QOL. In their opinion defining QOL of people living with schizophrenia is the most difficult thing. The presence of distressing symptoms though in a mild form reduces the chance of having a better quality of life. Therefore, in their opinion medication is important in controlling symptoms. The fact that participants have to depend on antipsychotic medication for better functioning is not very well appreciated by mental health professionals. However, professionals accept that medication is inevitable in reducing symptoms. They also feel that if possible putting participants on a maintenance dose would be a better option. The aim of medication is to bring down the symptoms so that participants can focus on their daily life activities. Functioning with the support of medication raises issues of side effect. Professionals expressed that the ideal state of QOL is a situation where PLS are no longer a burden for the family or society.

Participants and professionals agree that psychiatric medication has severe side effects. According to the professionals’ these side effects has an adverse influence on participants’ daily functioning. Professionals feel that participation in all the activities is an important aspect of QOL. They insist that participants should take part in activities of daily living, work at home, duties and responsibilities at rehabilitation centre, and office work to improve their QOL. The role of employment is crucial in improving QOL. Professionals believe that lack of employment opportunities for PLS is the biggest challenge in attaining financial independence. There are certain areas where participants, family, and professionals share similar opinions. They are self care, relationship with family members, medication, work, and performing well in daily life activities. Participants shares that they want to be in a job. They also prefer to have a married life. Professionals and family have a different stand on these two aspects. They feel that

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109 The psychiatrist had a different opinion that medication should be administered in order to reduce the difficulties of the individual living with schizophrenia and their family members (key informant interview).
though job and marriage are definitely a part of quality of life, it would be difficult for participants to maintain the responsibilities due to the nature of schizophrenia.

<table>
<thead>
<tr>
<th>Aspects of QOL</th>
<th>Aspects of QOL</th>
</tr>
</thead>
<tbody>
<tr>
<td>• How well people living with schizophrenia live</td>
<td>• Personal life</td>
</tr>
<tr>
<td>• Should enjoy life like any other person</td>
<td>Self care-grooming, cleaning, neatness</td>
</tr>
<tr>
<td>• Function within their own space, various domains of life</td>
<td>Happy in life</td>
</tr>
<tr>
<td>• Away from symptoms or subsided</td>
<td>Satisfied in self,</td>
</tr>
<tr>
<td>• Not a burden to family or society</td>
<td>Able to cope with deficits</td>
</tr>
<tr>
<td>• On a maintenance dose</td>
<td>independent/self dependent</td>
</tr>
<tr>
<td>• Participation in all activities</td>
<td>Occupied in something, distract negative thoughts</td>
</tr>
<tr>
<td>• Source of income</td>
<td>• professional life</td>
</tr>
<tr>
<td>• Good physical health</td>
<td>Occupation/work, pursue some interest and talents, good job, vocational training</td>
</tr>
<tr>
<td>• Strong support system</td>
<td></td>
</tr>
<tr>
<td>• Social life</td>
<td></td>
</tr>
<tr>
<td>Staying or at least spending time with family (LSH)</td>
<td></td>
</tr>
<tr>
<td>good family,</td>
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Previous section explained the nuances of participants understanding\textsuperscript{110} on QOL. It also threw some light on families and professionals perspective on QOL of people living with schizophrenia. There are many components quoted by HWH, LSH, and DC participants’ which will help in enhancing their QOL. These components are based on participants’ real life situation, and activities and things that enhance their QOL. Need for employment has been expressed as an essential component of quality of life. The motivational factor for participating in vocational activities is the wish to get employed. Care and support from family has instilled confidence in participants. Helping in household activities without any motivation or reminder from the family members helped

\textsuperscript{110} At times it became difficult to differentiate between ‘understanding QOL’ and ‘components of quality of life’. The effort was to separate both the concepts but sometimes they overlap.
in improving participants’ relationship with family. Interaction with the family members brings positive effects and is valued by participants as contributing to QOL. On the other hand there are participants who quotes that conflicts with the family members adversely affect their QOL. Criticisms from family members cause friction in the relationship and reflect in their interaction. HWH and LSH participants quoted that staying away from family has a negative impact on their relationship reducing their QOL.

....I do not like my elder sister that much, she keeps blaming me, I like my younger sister....when I talk with my friends, family, elder people, when I go outside I see environment or nature I feel very happy then my life quality is better not when fights are there.... (Prema).

...So far I am protected by family, medication, and staff....I am safe and sound so my life has quality but once they are not there I do not know about what will happen to me.... (Malleshwaran).

HWH and LSH participants do not spend much time with the family since they are at the rehabilitation facility. Therefore, participants feel that their quality of life in this area is not as good as it should be. If the family is in Bangalore or in Karnataka meeting them on a regular basis is not an issue. For those participants whose families are staying outside Bangalore it is difficult to meet on a regular basis. LSH participants spend time with the family occasionally that is whenever family comes to visit them. Therefore, they feel that quality of life in terms of their closeness with family is not good. Since their families reside outside Karnataka or India it is difficult for them to come every now and then. In half way facility family visits are more frequent compared to long stay facility. Whenever the family visits long stay home or halfway home participants go out with them. At times family prefer to stay at the rehabilitation facility to observe the routine at the centre. This also helps them in understanding participant’s performance in various activities. DC participants feel that since they stay with the family quality of their relationship with family is better. Participants are of the opinion that presence of family in their day to day life enhances their quality of life.
Going for a vacation with the family serves a few purposes. It helps family to understand the improvement in the participant. Participant feels that they can spend time with her/his family. Most importantly participant can verify the feasibility of the routine (HWH) at home. If they are not able to follow the same routine some alternative activities at home are identified to fit in the routine. The reason behind sending participants home on vacation is to enable them to function well within the family and thus enhance their quality of life. There are DC participants who stays with their family, but do not share a healthy relationship. This has created a negative attitude in them resulting in poor adjustment with the family. Since family is the sole support system participants have to depend on the family for everything. There are families who have devoted their life to take care of the participant and ready go to any extent possible to help and support her/him. Kumar’s sister and brother have decided not to marry, but to take care of Kumar for the rest of their life. Participants who realized that they have a good family support have shown tremendous improvement over the period of time.

Marriage is expressed as a component of quality of life. Regarding marriage participants have different stands. There are participants who do not want to get married for they think it will be another burden. On the other side there are participants who plan to get married once they are settled in the belief that it will add quality to their life. Participants who were married, but divorced have other concerns. Maria is concerned about who will take care of her once her guardian passes away. Avni is concerned about her relationship with her daughter and their future. Arthi wants to get married because she needs a companion. Participants are happy with their psychiatrist for prescribing effective medication. In their opinion medication has been quite helpful in functioning and improving quality of life. Even though side effects are still present medication has been helpful in bringing down the symptoms. The concern here is how long participants should continue with the medication. They are not in favor of continuing medication for rest of their life.

\[\text{111 Once participant recover from schizophrenia, find a job, start living independently and then get married (field notes-informal conversations).}\]
...I think medication most importantly that made a big difference, now I realized the need for medicine, I started taking and it started working on my brain, started giving effect so now I am ninety nine percent better this has improved my quality in life.... doctor says schizophrenia is curable completely some says we have to depend on medications throughout life and if you take medicine regularly you will be more or less normal, but to maintain that normality or good health you have to continue medication what do you say? Is schizophrenia completely curable or you should take medicine permanently? (Mynah).

Participants consider routine as improving quality of life since it keeps them occupied and helps in avoiding negative thoughts. This has also helped them in carrying out the activities of daily living without any reminders. Participants feel that carrying out activities without reminders gives a confidence of being self dependent. Physical illness is a concern affecting quality of life due to the complications it brings such as high blood sugar and pressure level, and problems in mobility. It is an additional burden to the existing problems. Participants reports that they have physical health issues such as diabetes, hypertension, and cholesterol. This can be due to genetic/hereditary factors, or side effects of medication, or inappropriate eating habits. Hasini has diabetes and is under medication to control it. Her diabetes is considered as hereditary because her mother had diabetes. Arthi got diabetes after taking psychiatric medication. Therefore, maintaining a good physical health is as important as any other components of QOL. Varun believes that developing a good personality and maintaining a good behavior will also help to improve QOL.

Participants are of the opinion that meeting one’s basic needs such as food and having a place to stay is an essential component of QOL. Though participants are concerned about their future at present they are happy with whatever they have. In a floridly symptomatic state participant has to depend on someone for everything. Therefore, avoiding relapse is important to stay independent. The other component in quality of life
is independent living\textsuperscript{112}. Even though participants at long stay home prefers to continue under the care, they have expressed their wish to move out and live on their own. Independent living is not much of a concern for day care participants as they stay with the family, but self dependence is valued. Halfway home participants’ goal is to eventually move out and live in a hostel, or as a paying guest, or stay with the family. Those HWH and LSH participants attending day care facility feels that they should continue with it. This is because attending day care regularly will help in sharpening their vocational and social skills. Therefore, achieving skills in any of the areas such as vocational, social, or interpersonal is an integral part of quality of life.

Participants find professional support as another important component of QOL. Participants receive various forms of support from the professionals. These services include counseling, guidance, sharing, therapeutic interventions, family counseling, and help in daily activities (whenever required). HWH and LSH participants are close with the professionals than their families. This is due to their close proximity with the professionals. Participants feel that counseling helps to find alternatives to resolve adjustmental problems, worries, family issues, work, future, and illness. Participants expressed their discomfort in changing the therapist\textsuperscript{113} at times. This is because participants manage to build a good relationship with one therapist over a period of time and wishes to continue with the same, sudden change and adjusting to a new therapist takes time. Dissatisfaction in professionals approach is mentioned as an adverse aspect to QOL. There were occasions when participants felt that they were deprived of a chance to talk to the professionals. This happens when professionals are not able to spend time with participants due to other works at the centre. Sometimes as a strategy to develop emotional independence and to make participants stop worrying about same issues professional cut short conversations with the participant. There were instances where professionals showed little empathy to participants.

\textsuperscript{112} Independent living is in terms of carrying out activities independently (self dependent) and living outside rehabilitation centre as a paying guest or in own house or a flat (field notes, informal conversations, and interview)

\textsuperscript{113} The organisation has a policy to change therapist (counselor) at particular intervals so that participants will get acquainted with other professionals in the respective centers (field notes).
Cognitive functioning of people living with schizophrenia is adversely affected by the illness. Participants faced problems with concentration, attention, and memory adversely affecting their QOL after the onset of schizophrenia. Therefore, better cognitive abilities were considered as a component for a better QOL. Participants feel that poor cognitive functioning is a barrier to employment. They are of the opinion that unemployment makes them economically dependent on their family which is a negative aspect of QOL. The families are fine with providing support as long as they can, but participants do not prefer to be a burden on their family. Participants’ who are dependent on family have concerns about their future. Participants who are financially stable do not have that worry. Financial stability is a crucial component of QOL.

Participants have to spend for medication, rehabilitation services, and other needs. Participants who have finished their formal education are at advantage while searching for a job. Sourav was able to find a well paid job due to his intellectual ability and educational qualification. Avni and Mina engage in tailoring and embroidery work and sell it with the help of the professionals. The nature of illness, medication, payment, and reluctance from employer to hire a person living with schizophrenia are some of the constraints in getting a job. Interaction and communication is considered as integral part of leading a life with quality. Participants feel their level of interaction and communication with the family and others was not good earlier. They feel that through participating in various activities at rehabilitation centers they were able to develop a minimum level of interaction and communication.

*Earlier I was scared to talk to people….I am participating in activities, getting confidence in life, and I can speak in front of a group now which I couldn’t do earlier...this definitely has improved my quality of life (Lalitha).*

Avni and Mina think that helping other members at the LSH who are in need makes them happy. Therefore, helping others is a component of quality of life. HWH and DC participants feel that staying in a rehabilitation center do not improve quality of life in the
long run. As long as they are in a rehabilitation center and availing its services to recover from schizophrenia, it is fine to stay in a rehabilitation center. Ali feels that discharge from the rehabilitation center and opening a small business is important to improve his quality of life. Malleshwaran is of the opinion that beauty of life is what QOL indicates. LSH participants have a different opinion on their stay at rehabilitation center. They find it comforting and secure to live in a protected and caring environment, but they have issues with the label of schizophrenia. In their opinion it is better to stay at an old age home than a rehabilitation center to remove the tag of schizophrenia. Older participants’ feel that aspects such as peace, happiness, care, security, and staying with the family are important components of quality of life than job and other achievements. For younger participants being successful in life in terms of job and assets are important components of quality of life. Influence of age and duration of living with illness is evident in participants understanding about QOL. Irrespective of their age participants felt that QOL is enjoying everything a person have and do in her/his life.

Participants consider routine, maintaining proper self care, employment, family support, professional assistance, financial stability, and anything that makes their life better as components of QOL. Some among these aspects are also considered as participation in the community. How then participation in the community is different from quality of life? Routine, self care, rehabilitation center activities, family involvements, social involvement, active life are the areas of life where participation takes place. These areas and activities become a part of quality of life when participants are able to have all these aspects in place. If they are able to perform these activities without failure and sustain it for longer period then that adds to their quality of life. In a way we can assume that participation in the community enhances quality of life. This also depends upon the way participants compare their quality of life at various point of time in their life.
Quality of Life in the past

Past is colored with the onset and episodic attack of schizophrenia. Participants (chronic) believe that schizophrenia ruined their life and denied them their right to lead a dignified life. This has created hatred towards schizophrenia and self. Participants believe that if they were not suffering from schizophrenia they could have had a better life. They could have had a career, a married life, and lot of friends. Living with schizophrenia has affected their QOL in the past. QOL in the past can be divided into two stages. First stage is before the onset of schizophrenia and second stage is life after the diagnosis of schizophrenia. Life before schizophrenia is the period before the onset and diagnosis of schizophrenia. Participants or their family were not able to recollect the exact time of onset of schizophrenia. Akhil recollects the emotional distress and cognitive difficulties he has undergone during his school days. These distresses made his childhood miserable. Though his parents were highly supportive Akhil could not find solace in them. He had issues with himself for not being as good and efficient as his parents or brother.

*Quality of life in past was not good at all....I became very paranoid that people are talking about me...I could not concentrate on my studies...I had to do ten times more studies than the average person had to do...economic honors course in the college, first year I got through, second year I failed, third year I had a relapse and could not give my exam...then they could not take me into the same college so I went to another college in another course B.com...fourth year [first year of B.com but fourth year in a college] I failed again, fifth year I passed my second year, and sixth year I passed third year. It took six years to pass my graduation course....I am just left disillusioned. My brother was a topper, my father was a topper and my mother was a topper... (Akhil).*

As far as Hasini’s memory goes she was a good student till the onset of schizophrenia. Her life before schizophrenia was also not a happy picture. It was pictured with the mother’s mental illness, conflicts between parents, sexual assault from the
relatives, and worries about her looks. These took a toll on her and at the age of fourteen she attempted suicide. She had a few romantic relationships, but none of it worked in her favor. After a few years she was diagnosed with schizophrenia. She felt that her quality of life in the past was bad since she had a miserable life. Varun had a quiet and less eventful childhood. His family remained supportive and caring all the time. As a child he was introvert and had a few friends. He spent his time reading books than playing with his friends. He was good in studies and topped in all classes. Things were fine until he went for medical studies where he failed in a subject in his second year. He was highly upset with the fact that he had to appear for a supplementary exam for the first time in his life [observations in the case file]. The course of schizophrenia started after this incident. Each participant in this study had a different life before the diagnosis of schizophrenia. Some were eventful some were not very eventful. Sourav’s parents used to fight, but it did not affect him. He agrees that he did not receive much care and love from parents due to their conflicts with each other.

* ...I have no emotions [laughing loudly]. I am beyond all that. I think from childhood there was no much affection for me because of my parents issues...I used to have thinking right from my childhood so I never accept any belief so easily...so quarrels between parents...did not affect me much...my quality of life was never an issue in that way [laughing again] (Sourav).*

Life after the onset and diagnosis of schizophrenia\(^{114}\) was quite eventful. Participants while looking at QOL in the past recollected many aspects as either contributed to their QOL or deprived them off QOL. This section deals with how schizophrenia affected their QOL after the diagnosis. Once officially\(^{115}\) diagnosed with schizophrenia, participants’ life took a drastic change. Symptoms such as hallucinations and delusions did not become active initially. Participants think that it all started with the cognitive difficulties and troubles in coordinating their thoughts. Their productivity level came down over a period of time. It became difficult to perform even the basic activities of living. This is relevant

\(^{114}\) It is essential to mention that most of the aspects explained in analysis chapter ‘living with schizophrenia’ are applicable in this context.

\(^{115}\) Participants consulted a psychiatrist and started medication as per her/his prescription.
in assessing QOL in the past since participants’ feel that their performance in activities of daily living was better before the onset of schizophrenia. They did not depend on the family members for carrying out daily activities. After the onset of illness they had to depend on someone to carry out daily activities, especially when symptoms were florid. Depending on someone else for carrying out basic functions affected their self confidence. This reduced their quality of life in the past.

All participants in this study are educated\textsuperscript{116}. Hasini was able to finish her masters in literature while managing to live with schizophrenia. Sourav’s illness started at the age of twenty-four but the manifestation of full blown symptoms happened during his early thirties. Therefore, his education period was not affected by schizophrenia. He completed Masters in Business Administration (MBA) and joined for a job immediately after completing MBA. Varun completed his bachelor of medicine though he took a few additional years to finish it due to schizophrenia. Akhil also took more than four years to finish his bachelor in commerce.

Maria finished her graduation in stipulated period despite the troubles of schizophrenia. Shivani finished her graduation successfully, but could not finish masters and failed in all subjects even after many attempts. Prema could not finish her bachelor of medicine due to frequent episodes of schizophrenia. Participants’ Kumar, Raju, Ammal, Navneet, and Lalitha experienced symptoms during their college days and had to discontinue their studies. Other participants in the study managed to reach secondary and higher secondary level of schooling. Participants expressed that educational under achievement was another aspect that adversely affected their quality of life in the past. They consider educational achievement as an important aspect in building one’s career. In that sense they feel that their quality of life in the past was not good. This issue extends to the present state of quality of life as it is difficult to apply for a well paid job with low educational qualifications.

\textsuperscript{116} Education in this context refers to formal education. SSC (Secondary School Certificate) is the minimum educational level achieved by the participants in the present study. There was no intentional selection of participants who have a minimum level of education. Most of the participants in the rehabilitation center had the minimum education level.
Participants who managed to finish their higher education amidst the symptoms had a tough time. They are happy that though it took a few more years to finish graduation or masters, at the end they achieved it. Participants expressed that life after the onset of schizophrenia was not completely a sad picture. They did not feel that they were completely deprived of any quality in their life. On the other side participants’ who could not continue with their studies expressed their disappointment. There were instances where participants could not sustain in one job for more than a few months. Hasini could not pursue her teaching job due to fear and anxiety. Though she is happy with her educational achievement she could not make use of it in building her career in teaching. She remained jobless after quitting her job as a school teacher.

Shivani could not sustain her call center job due to restlessness and eventually she lost the job. Since then she is under treatment and started attending the rehabilitation center. She is happy that her family remained supportive and caring which helped to retain some quality in her life. Except Maria all the other participants have a good family support system. Maria lost her parents at a young age. After the death of her parents she stayed with her brother. A few years back she lost her brother in an accident. She does not have a cordial relationship with her sister-in-law. She was married and divorced within a short span of time. She suffered from various physical ailments such as seizures, cancer, swelling knees, and injury in the back along with schizophrenia. When asked about quality of life her question was how to decide quality of life in that context.

Participants are thankful to their family for supporting them during all these years. They agree that family also has gone through pain due to their illness. Conflicts within the family and between participant and family members adversely affected participants’ QOL. In the opinion of families when participants are on medication symptoms are under control and the behavior to family members is good. In the past medication compliance was the major issue in the treatment resulting in frequent relapses and hospitalizations. Avni was administered Electro Convulsive Therapies during her relapse. This she considers as the worst thing that has ever happened to her. She feels this affected her life quality badly as she experiences memory lapse. Sourav’s employers were kind enough to
understand his situation and admitted him to a hospital during the relapse. His refusal to take medication resulted in further complications. He was kept in the closed ward\textsuperscript{117} of the psychiatric hospital. The reason for relapse was medication non compliance. He later told that he felt that it was unnecessary to take medicine.

\begin{quote}
My quality of life was affected in many ways the worst was hospitalizations….in the hospital I was okay but when they give shock treatment, six times or something, I do not remember but the last one I did not go inside only...I felt that shock treatment was so bad....it affected my memory, my entire functioning I would rather die than taking shock treatment.... (Avni)
\end{quote}

\begin{quote}
I stopped medicine twice because I felt it is not needed....I was admitted in mental hospital...they kept me in closed ward where you are not allowed to go out, you are in a ward only just a big square room with gate and locks. I told them I am not going to take medicines and then they said they will sedate me then I said okay I will take it…. (Sourav)
\end{quote}

Akhil managed to attain a job and performed well in that job for almost ten years. After a severe relapse he slowly lost the amount of productivity he showed in his work. He quit his job due to restlessness and problems in concentration. The job timings were flexible and the job itself was less stressful. His relapse was due to fear and excessive concern about accuracy in the work. After the relapse Akhil could not go back to the same job. In his opinion this affected his quality of life in the past. He also expressed that his life quality was good when he was able to work but not after the relapse.

Participants who attempted suicide felt that it actually reduced their quality of life. Suicide attempts were due to dissatisfaction with life and label of schizophrenia. Another aspect that reduced QOL was the process of shuttling in and out of rehabilitation centers. These stints at rehabilitation centers had a toll on participants’ quality of life. Mina had

\textsuperscript{117} Closed ward is where patients are kept in a ward under lock and key. They are not allowed to go out and are supervised by nurses. (field notes and informal conversations)
no choice, but to stay in a rehabilitation center since she had no place to live on. She used to stay with her aunts and this created a sense of insecurity in her which she felt as worse than anything. She had to shift from one relative’s house to the other every three or four months. She felt fortunate that her parents left enough money so that she could afford to stay in the long stay facility. After she shifted to the long stay home she felt secured as no one will ask her to go out of that place. She has been in long stay home since its inception. Other aspect participants expressed as improved their quality of life was the financial stability. Economic stability helped some participants to use better treatment and seek better facilities. In participants’ view QOL in the past in comparison to the present state was unsatisfying.

*If we look at his quality of life earlier it was not that good...when he came here he was very symptomatic. He had commanding hallucinations. Even we were afraid to send him out because his hallucinations were such that it will tell him to cross the road when the bus is coming so he used to be in the centre...his social skills were very poor, his communication with staff and other residents was very little.... (Aishwarya professional about varun)*

Professionals’ observation about participants’ quality of life in the past consists of many factors. In their opinion it was the nature of schizophrenia that severely affected participants’ quality of life in the past. The symptoms were severe and participants required utmost care. Symptoms played a major role in reducing social involvement. Professionals also felt that shifting\textsuperscript{118} from one rehabilitation center to another had also adversely affected participants’ QOL. Due to this shifting participants could not adjust to any rehabilitation center. Another aspect that professionals considered as barrier to QOL in the past was frequent hospitalizations. These hospitalizations affected participants day to day functioning, family life, work, and social activities. Hospitalizations extended as per the severity of relapse. Deterioration in the cognitive abilities happened to such an extent that it became difficult for participants to carryout daily life activities.

\textsuperscript{118} Participants shifted from one rehabilitation centre to another when they were not satisfied with the previous one. (case files)
Professionals felt that medication non compliance resulted in relapses. This has also negatively influenced life quality. Family and the professionals share the same views on this matter. Family expressed that they found it very difficult to manage when participants were reclusive and stopped interacting. This social reclusion has affected participants’ quality of life in the past.

**Quality of life in the Present**

Participants’ feel that their quality of life in the present is better compared to their QOL in the past. This is primarily due to the improvement in the symptomatic behavior and better daily functioning. Participants feel that medication and other therapies have worked well in bringing down the symptoms and improving their social skills. Participants appreciate their psychiatrist for prescribing right medication. They consider medication as an important element in helping their daily life functioning. Participants find themselves as less symptomatic and more functional. They feel that regular medication has helped in stabilizing the symptoms. The amount of distress from symptoms have reduced to a great extend which improved their QOL at present. Even though participants are reluctant to accept medication as part of their life, they acknowledge that medication is useful in many ways. There are participants who feel that they should take medication for the rest of their life. Other participants want to discontinue the medication once schizophrenia is cured\(^\text{119}\). They believe that QOL can be completely achieved when they are cured and live without the support of medication. Side effects from medications have been an issue for participants, but they feel that at present the amount of side effects is less than earlier. Participants expressed their will to challenge side effects and work hard to attain a better level of functioning and QOL.

*I have recovered considerably and feeling stronger than before. I am fighting the illness; well I am continuing fighting with illness. I am going steady with illness*

\(^{119}\) Participants believe that schizophrenia is curable and that is why medication is necessary (interview and informal conversations).
as long as the medication I am taking...quality of life at present is good due to this... (Virat)

Though symptoms are still present that does not interfere in their daily functioning. Routine and participation in various activities keep participants engaged throughout the day. Participants feel that this helps them in diverting attention to various productive activities and thus avoid negative thoughts. At times it becomes difficult to avoid symptoms in that instance participants seek professional help\textsuperscript{120}. Follow up with psychiatrist is regular even after discharge from rehabilitation center. Participants feel that their cognitive abilities such as concentration, attention, and memory have improved. They are able to engage in various activities and focus in whatever activity they do. Participants are of the opinion that improvement in cognitive abilities helped them in attaining a confidence in self. They learned new skills in vocational activities. This brought a new hope in participants’ life and eventually boosted their life quality. Participants feel that their social interaction became better over the period of time. They can interact with other HWH, LSH, and DC members, professionals and para professionals, supporting staff, family, and people outside this circle such as shopkeepers and fieldwork students without any inhibition. They are happy about their performance in daily activities.

Participants are able to maintain a good relationship with the family which they consider as improvement in their QOL at present. Family and professionals keep themselves alert to notice any changes in participants.

My family support is quality of life...my brother is working and paying for me. They provide me food, clothes, bus expenses etc. in every field they are supporting; getting medicines, taking for consultations. I share my feelings with my mother...she understand me (Ali)

\textsuperscript{120} If the distress is severe and cannot managed by counseling professionals take participants for psychiatric consultation. (field notes)
There are participants who still have issues with the family members for example Prema has issues with her sister-in-law and she is worried about it. She feels that due to this problem her quality of life in this area is not that good. She stays with her elder brother and he supports her financially. Other siblings are not ready to take the responsibility of looking after her. Lalitha’ sisters are both working outside Karnataka. In the past, during the symptomatic period, her relationship with mother and siblings were strained. At present she is able to understand things and is ready to work hard to mend the relationships. The strained relationship with her siblings is better at present and she considers it as one of the aspects contributing to her QOL.

Family is the primary care provider. Family provides both emotional and economical support. Interaction of HWH, LSH, and DC participants’ with their family is good at present. HWH and LSH participants receive calls from family on a regular basis. They are able to call their family whenever they want to talk to the family. Participants quote this as an important feature improving their quality of life at present. Participants are also able to maintain relationships with their relatives. Acceptance from the relatives has also made it easier to rebuild the relationships. This helps in improving their social involvement. Day care participants help family members in the household activities whenever there is work, they also initiates to do own chores. Families consider this as the positive outcome of rehabilitation services. For HWH and LSH participants staying away from the family is still an element reducing their QOL. Long stay facility participants feel this stronger than HWH since they are not going back to reside with family.

*My quality of life is better than earlier because earlier at home I will lie down and sleep. After started attending day care I am working, I have a routine, interacting with clients, playing, attending group activities. I have got a routine due to this; at home also it is helping....so life is good now (Ammal).*

*My concentration has improved since I am attending art and craft sessions...English class helped me to improve my English speaking. games are*
also a good exercise. Group therapy also I like, it engages me in something....many psychosocial problems get solved (Kumar).

Participants feel that though living in a rehabilitation facility is not a happy thing, it has contributed to improving QOL in various ways. There are participants who managed to engage themselves in some sort of employment, either self employment or working in firms or helping in family business. This is due to the training they received at the rehabilitation center. The improvement in cognitive and vocational skills has increased their confidence level to attain a job in the future. Participants who attend the day care facility for vocational training expressed their happiness in learning many activities. They also have a packed schedule starting early in the morning till late in the evening which keep them occupied whole day. Participants feel that their self care is better at present and their ability to maintain personal space has also improved. They are able to take care of themselves without anyone's assistance. Participants feel that since they do not have to depend on any one for their day to day needs there is a sense of independence. They also initiate to participate in the group activities which helped them to interact with others and communicate more clearly.

Participants feel that improvement in interaction has helped in getting to know people, making friends, and improving their communication skills. In short their social involvement level has increased. This is a major achievement for participants since social withdrawal is one of the implications of schizophrenia. In participants’ view the biggest advantage of attending rehabilitation facility is that they came to know people with similar or bigger issues. This gave participants a confidence that they are not alone in fighting with schizophrenia or any other mental illness. HWH and LSH participants who had adjustmental issues with roommates overcame this with the help of professionals. Participant Mynah feels that the sense of security she feels at LSH has improved her quality of life at present. Navneet feels that the facilities provided by the rehabilitation centre is not enough and need more sophistication. He feels that LSH is overcrowded and he wanted to stay in a place where people are less. Therefore, his quality of life at present is alright, but not as good as it should be.
...in aunt's house I had a sense of insecurity I go to every aunt's house after two months they would say go to other aunt's house we had enough of you, I was insecure that time but in long stay permanently I got a place to stay nobody will tell me go from here this is my home I stay here happily, so this sense of security is there... that made a very big world of difference for me and improved my quality in life.... (Mynah)

Participants identifies that their self confidence is better than earlier and this might have increased their QOL. Participants are able to motivate self to take part in activities without any reminders. Self motivation thus is a factor contributing to their present QOL. DC participants think that attending day care regularly has contributed to a better QOL. HWH and LSH participants consider taking part in activities at their respective centers as contributing to their life quality. This is because they feel that participation in all activities at the center is the only way to attain a better QOL. Family and professionals consider improvement in self care and managing personal space as a major achievement. Since professionals spend a lot of time with participants they are able to identify the slightest change in participants. HWH, LSH, and DC participants acknowledge professional support as equally important as family support. Support from psychiatrist in the form of appreciation for improvement and encouragement is considered as important. Participants also expressed that they feel happy when psychiatrist spend more time listening to their issues and concerns.

.....my counselor is good, our communication is good. He understands my problems. He tells me to be punctual not to get absent, and concentrate in work like that...my psychiatrist listens to my worries and talk to my family which I feel is good... (Ali)

For DC participants spending time on various productive activities contributes to QOL. For HWH and LSH participants taking part in activities at the respective centers contributes to their quality of life at present. Participants are concerned about how they
spend their time effectively once they are discharged. Participants who believe in positive thinking feel that it is the reason for their better state of QOL. Most of the participants quote prayer as an inevitable part of their life. They visit temples, churches, and mosque and feel that this has contributed to QOL. Participants are pleasant and happy in whatever activities they engage in, be it small or big. This ability to find happiness in whatever they do has a huge impact on their quality of life.

Health issues are very high among HWH, LSH, and DC participants. Most of the times PLS are not allowed to eat all kinds of food due to concerns about physical issues such as diabetes, cholesterol, and blood pressure. This is because maintaining physical health becomes an issue in treatment and rehabilitation. Participants with the health issues mentioned above have to be cautious and take medicines to counter it. Diabetes is present in most of the participants who are above thirty five years old. High blood pressure is present in participants who are above forty five years old. This is an additional burden with the psychiatric medications they take. Along with the psychiatric medications they have to consume general medicines and insulin shots. This is quite a distressing experience for participants and they feel that it affects their quality of life adversely. Since diabetes restricts the food intake it deprives participants of that happiness too. Exercising is insisted by the psychiatrists and the other mental health professionals. Participants also feel that exercise is good, but only a few of them are actually ready to make it a part of life. Even though participants (who are overweight) are concerned about weight issues still they are reluctant to follow exercise with rigor.

*My quality in life is affected by my diabetes and blood pressure level. Diabetes is worrying me I have to take five injections a day, my vision is going down, doctor asked to maintain diet and take insulin, it is tiring me I am not able to involve actively in anything....now it is okay under control...taking insulin is distressing. It bothers me when I can't take sweets (Malleshwaran).*

Participants who are unmarried are of the opinion that it was a good decision that helped them to maintain their QOL. They feel that marriage would have added more
burdens in their life. Participants who are at a marriageable age decided not to get married because they are not quite confident about the responsibilities that they will have to take. They are not in a position to take up such a huge responsibility because that may cause more stress leading to another relapse. Hasini’s father while searching for a prospective groom came across many marriage cons. This has created a fear in him and he finally decided to drop the idea of marrying her off. Her father felt that it is better to remain unmarried than getting into such troubles. Participants’ agree on one aspect that having a family with a husband/wife and kids is an important component of QOL. However, they feel in their present circumstances it is not a wise thing to get married. Avni is a divorcée and a mother. She is not able to spend time with her child. These distresses have made a negative impact on her QOL. She expressed that this separation has created a lonely feeling in her.

....As long as you are able to cater to your day to day needs...and your requirements what all they are and save some money for the future...then it is decent quality of life... (Sourav).

Participants' feels that at present their basic requirements are taken care by the family. Their family is providing them with all the basic needs. Therefore, in terms of meeting basic needs participants QOL is better. In their opinion only thing that they have to be concerned at present is their recovery. Participants expressed that as long as living in a rehabilitation facility they are less burdened with other responsibilities of a son/daughter/sister/brother. Depending on an attender for carrying out daily needs has decreased the QOL, but Avni and Maria feels that it helps them to maintain a minimum QOL. Avni hired an attender during her relapse which turned to be more severe than ever. Maria hired an attender due to her physical disability. While the former is able to maintain a good relationship with her attender, the latter is not able to do so and keep complaining about the attender. Interactions with attender since participants’ are in close contact with them influences their relationship.
My quality of life is not so good as you can see, I make a crippled, there is little I can do around here. I am dependent on my attendant. One night I cannot be without my attendant, and am paying a lot of money for them, my cousin anyway did not hesitate to keep an attendant for me, since I badly need help. Nobody comes to visit me now, earlier my guardian used to come now he too is ill, am not happy about my life....(Maria).

One aspect participants insist as increasing quality of life is dedication towards whatever work a person does, be it house responsibilities, office work, or any kind of work. Taking up responsibilities at rehabilitation facility, home, and group activities is important in improving one's quality of life. This encourages participants to take up responsibilities and perform it well so that it is valued while assessing their improvement. Participants initiate to take up duties while assigning duties during community meeting. There are certain factors participants consider as affecting their QOL adversely. Unemployment is their biggest concern since it increases the dependency on family. Participants are of the opinion that employment even if it provides only a nominal income is essential. They consider being in a job as more important than a higher payment. For those participants who have some income generating vocational engagements are not very satisfied with their present vocation. They quote the need for a better option in terms of more pay and recognition is significant for a better quality of life. Long stay facility has supported female participants by opening a small boutique to sell their handmade products. The products are mainly sold to visitors at the centers and also during exhibitions.

Psychiatrist assesses improvement not only on the basis of symptom reduction, but also on the basis of performance in various activities at the facilities. Therefore, participants’ says that they are keen to take up the responsibilities and perform it well. Professionals encourage day care participants to assist the family members in their household work. Professionals collect feedback from the family on how day care participants behave at home. Professionals then decide the intervention strategies as per the feedback and need. Prema had financial difficulties and therefore could not pay fees
at day care. She received a concession in fees as a result of which she is able to attend the centre without fail. Since Prema has shown good improvement in behavior and performance after attending day care, the management felt that continuing at day care will help her to maintain a better level of functioning. Participants from financially sound background do not face difficulties since the families have made adequate arrangements to meet the financial requirements. However, this is not same for those participants from less financially sound background. They have uncertainties about the future though they are able to get everything at present.

Sourav has taken a house on loan which he has to repay and this actually played as a motivating factor to attain his job. Participants are concerned about the lack of confidence they experience at times, they feel that this is affecting their QOL. The concern is due to the fact that this lack of confidence prevents participants from performing well in any activity. Karan expressed his worry about losing his family's trust in him by not utilizing the opportunities they gave him. It is now a challenge for him to gain his family’s confidence and prove himself to the family. He also feels that by proving himself he will also be able to maintain a better quality of life. Maria has no immediate family support; her guardian is one of her distant relatives who used to pay occasional visits. At present the guardian is not well and is not able to visit her any more. This has created a vacuum in her life as she feels lonely. Since her physical mobility is less Maria cannot take part in most of the house activities.

In Professionals opinion present state of quality of life of participants is better than earlier. They observe that participants are open to learn new things which help them in planning intervention activities. They find that at present participants do not spend time idle and keeps self occupied in some activities. Professionals feel that there are changes in participants’ behavior and overall personality. Behavior towards family and professionals has improved. Professionals feel that participants are able to maintain a better relationship with their family. Participants were able to adapt the routine at the respective centers and followed it rigorously. Their physical health issues are under control due to monitoring and diet control. Professionals decide the quota of cigarettes
after consulting with the male participants. This has helped in controlling excessive smoking. They also feel that participants are less demanding than earlier. Through counseling and guidance participants are able to understand their situation clearer than earlier. Participants carry out the responsibilities successfully and express a sense of achievement. They are kind to each other and help other participants in need. Initially professionals had to supervise every activity, but later supervision came down to a once in a week. HWH and LSH participants realize the importance of medication and take it without any motivation from the professionals. DC participants (some of them) still have issue with the medication. Family feels this as a problem in recovery and a negative aspect to QOL.

Her quality of life is not very good...she has the basic comfort zone....I would say it is okay not too great...she still needs to be independent, be on her feet, the family still needs to take her in...they do not take her out anywhere. She is inside those four walls all the time.... (Professional Kalyanai about Prema)

There are factors professionals consider as challenges to QOL of people living with schizophrenia. It is true that participants’ level of dependency has come down, but they are not completely independent. Participants have to depend on their family for everything since they do not have a job. Dependence on family limits the amount of freedom in decision making which reduces their quality of life. Long stay participants are not going back to their family. Long stay home (no matter the quality of facilities provided) cannot offer the sense of belongingness of a home. The only option available for LSH participants is to spend holidays with the family. Rehabilitation centers offering more freedom and mobility will help in improving quality of life.

The issue of inconsistency in performance and nature of illness are the challenges professionals face in helping participant to attain a better QOL. Initiating a conversation is still a trouble for most of the participants. Their interaction level is limited to the people whom they are close with. Participants sometimes are not able to retain their interest in work even though they want to do the work assigned to them. They are not

121 Only male participants were reported to be smoking. (field notes)
able to identify why it happens, but they somehow manage to complete the work. Sourav do not have any complaints about his quality of life because he believes in facing life as it comes. On the other side participants feel that their QOL is not complete and have to try hard to achieve it. This is the motivation behind the plans for improving quality of life in the future.

**Expectations of quality of Life in future and planning for future**

Future is always looked with expectations and hope. Participants express their first and foremost goal for future is to sustain the improvements that they have attained. Improvements in self care and routine are the result of hard work and perseverance. The future goal is to try and improve this achievement further so that participants will be able to manage their time in a better way and taking up more responsibilities. Taking care of personal space without support and reminders is other area participants’ feels will add more value to their future life. HWH participants feel that their QOL in future will be better if they get discharged from the rehabilitation centre and go home or live independently. LSH participants’ thinks it is better to stay in the facility since it ensures professional care and support. Navneet feels it is better to stay at an old age home so that the label of schizophrenia can be removed. Mina plans to stay at LSH for the rest of her life.

*My life quality depends on my family support I am dependent on my sisters. I am of no use to them; I live at their mercy and is a burden to them. Since they provide me everything I am here, I do not know what will happen once they are not there'* (Malleshwaran).

*I think to get a better quality in my life I have to study further, take MBA, and get a job this will add value to life. Continue my education and becoming qualified, getting good marks in B.Com. Avoiding negative thoughts by thinking everybody loves me* (Kumar).
For the participants at halfway home and day care discharge from those centers is what a better quality of life indicates. This is the motivating factor behind their good performance at the rehabilitation facility. HWH participants’ whose family is in and around Bangalore wants to shift to day care once they are able to follow a routine. Participants understand the need for both emotional and financial support from family in future also. They accept the fact that family is the ultimate source of support. Going home and living with the family, following a routine at home, and supporting family are important for participants. Hasini feels it is also important to take care of the family by assisting members of the family in their household works. If discharge is not possible in a near future, then at least spending time with family once in a while is also anticipated. Independent living has become the ultimate aim of recovery. The plan to move out is decided with psychiatrist’s approval and family's consent. Participants are quite confident that they can live on their own once they finish training at the rehabilitation facility.

Participants' seems to have come in terms with the fact that they have to continue medication until psychiatrist suggests to discontinue. Continuing medication as long as required is therefore an important element in deciding future quality of life. It is a distressing experience to continue with the medication, but under their present circumstances participants are not quite confident to take the risk of discontinuing medication. Experiences from the past have taught them to be extremely cautious with the aspect of medication and follow up. Side effects can create problems, but since the psychiatrist is supportive participants are confident that they can always share it with her/him. Speedy recovery from the illness, cure form illness, and finishing treatment are participants’ expectations for future. Recovery is not just reduction/absence of symptoms but complete removal of schizophrenia.

Employment is pursued by the participants so that they can be financially independent. This can be by practicing a profession as per their educational background or by starting a small business or trying to find a less stressful job. For this purpose participants' who have left their education unfinished have decided to start afresh. Training in computer is the most preferred course or skill since knowledge in computer is
one of the requirements for job application. Participants believe that being in a job is the indication of being productive. Participants are scared of unemployment and concerned about their future employment status. Even though rehabilitation centre is offering various vocational activities other than computer participants do not consider those as useful in getting a job. Education is valued by younger participants and they have plans for pursuing education. Most of the female participants' are concentrating in tailoring or computer skills which they feel can later be transformed into an income earning activity. Financial instability is a matter of concern and thus attaining economic independence is considered as important.

Arthi is talented in music and plans to open a music academy for children. She also wishes to go abroad since it would help her earn more money and recognition. Arthi wanted to be a classical singer since childhood, but due to schizophrenia she could not accomplish her dream. She is aware of the difficulties in starting own music academy, but is ready to put that effort. This cannot be considered as an impossible dream since the only area schizophrenia has not affected is her talent in music. She takes part in musical concerts and has a good social support though her parents are not alive. Her maternal uncles are quite supportive and are ready to support her for the rest of her life. Even at the day care facility her performance at music therapy is well appreciated. Participants stress the importance of maintaining a good physical health.

The plans for maintaining physical health includes reducing weight, maintaining blood sugar and blood pressure level, regular health checkups, and exercising. The question here is to what extent participants will be able to actualize these plans. Since most of the participants have one or the other physical ailments this concern need to be addressed. The issue is not only sticking to the plans, but also doing it without motivation and supervision. While sharing expectations and anticipations for future Kavya and Ammal expressed their wish to lead a carefree life. They wish to lead a lavish life style of attending parties, wearing expensive dresses, and not worrying about any problems.

122 Professionals assigned Veena as the instructor for music therapy. She brings new songs at each session and teaches the other day care members. (field notes)
Whereas, Mina wants to use quality things be it clothes or any daily requirements. Avni, Lalitha, and Malleshwaran wish to stay in a peaceful environment where they can focus more on their life than getting into unnecessary quarrels with fellow members.

The areas PLS think that they need further improvement are socializing, cognitive skills, language proficiency, career, and marriage. Participants are not satisfied with their current interaction level. They are of the opinion that unless there is an improvement in socializing it is difficult to attain a better level of functioning. Participants feel that interaction plays an important role in acceptance from the society. Social acceptance is the crucial aspect in improving quality of life. Cognitive skills need to be sharpened in order to develop a work habit. Participants recognize the need for developing a work habit since it is important while pursuing a job or education. At the same time participants understand that a stressful schedule can be problematic to their functioning. Therefore, most of them prefer a less stressful job. Marriage is an area where participants seem perplexed. On one side there are participants who want to get married, but worries about the responsibilities. On the other side there are participants who do not want a marriage as it is a huge responsibility which they may not be able to comply with. Arthi wants to get married for she needs a companion, a security, and a family of her own. Those who do not want to get married in future decided so to avoid the complications and responsibilities associated with it.

Same routine, same work, there is no change, so I need a change in my quality of life, same routine life I do not like, I want more change in my life, again I want to go abroad, after studying music, there are lot of Indian schools there.... if I am successful in career naturally somebody will come forward to marry me.... according to me marriage is very important....it is a security, and after parents' husband will take care....I want a companionship, I want to get support, lots of love, a family....that is how I plan to improve my life quality for the future (Arthi).

Lalitha wishes to have a small music player. Karan wants to travel to distant places. Navneet wants to go on a holiday with his family in US. These are all small wishes, but
very important for the participants. Participants are not quite sure to what extent their wishes will be fulfilled. For Sourav future is not a concern since he believes in living in the present. He is not quite sure about what future has in store for him. Therefore, his expectations about the future are less and he is ready to accept whatever happens. Maria is tired of her physical complications and loneliness so she expressed her desire to die. She wants to perform all the religious rituals before death. Perception about future quality of life is dependent on the participants past and present experiences.

Family members are able to understand that it is difficult for PLS to be completely independent. They also realize the need for lifelong support in one or the other form. Keeping this in mind families has formulated certain future plans. The most important among the plan is to help participants to maintain the improvement achieved till date. Therefore, regular treatment and follow-up is the primary goal. Families of day care participants have no intention to send them to HWH/LSH. Whereas, families of HWH participants wish to keep them there till they are able to sustain their improvement. They also want participants to move out and stay as a paying guest or in a rented house. This is only when participants are independent enough to take care of themselves. Participants who are able to take care of themselves do not pose a big problem for the family. Families are not planning marriage for participants because marriage is a big responsibility. They feel that participants at present are not in a position to take that responsibility. Families of young participants have kept an option for marriage provided participants meet two conditions. The marriage is possible only if participants recover completely and if family is able to find a person who will understand the nature of illness and will be ready to marry despite the existence of schizophrenia.

*His quality of life will improve if he is able to maintain this improvements... we want him to maintain himself... at least by the end of this year...my sister also said he can come to her office and do some small work... (Kumar’s brother).*

*If he has to improve his quality of life then...immediate plan will...be to move out into a PG facility I hope he is ready to take that step where he has to be responsible to take his medication and visit the doctor on a monthly basis, he’ll have to take other minor responsibilities which come with living on his own, like*
not doing excess of smoking and not too much television or develop any bad habits or make such friends who can influence him in a bad way. One major part will also be to be able to handle his money, keep his diary in which he can record how much he has to spend and how to make it last through the month (Karan’s mother).

Financial stability is an issue for Malleswaran’s family. They feel that the fee at HWH is very high and worried about how long they can keep him there. Keeping Malleswaran at home is difficult since his sisters have to go for work and mother is too old to take care of him. His smoking also creates an issue because he is not ready to give up. Earlier Malleshwaran showed an interest to get married and family was worried when he insisted. After a point of time he stopped asking. Even though families do not want participants to get married there is a worry on who will take care of them once parents passes away. This is the reason for sending participants to rehabilitation facility to achieve a level of independence. Families staying in Bangalore plans to transfer participants to day care when they finish training at HWH. This will help participants to keep self occupied until they find a job. This will be decided after consulting with psychiatrist and professionals.

Families of those participants who have dropped their studies want participants to pursue it again. There is a question of providing support for participants. There are families who are ready to move into the city to stay with participants if required. On the other side due to personal commitments some families cannot afford to stay with the participants. Families do not want to exert pressure on participants, but are worried about how long they will be able to support. The success stories of survivors have inspired Varun’s family to have faith in him. Families do not wish participants to earn and support them, but to take care of self. They want participants to work hard so that they can earn to meet their own needs and lead a respectful life.

Quality of life in terms of future...mother is not well so they cannot keep him at home. She is over involved and they won’t be able to manage him, in case of any emergency they won’t be able to manage both of them....they would be looking at
the option of long term care….two sisters are younger both are working, they are the only financial support…. (Professional Jeevan about Malleshwaran).

Professionals after working with the participants for a long time prefer a practical approach in planning future. They would suggest participants to focus on areas such as self care, communication, and interaction. This is because professionals feel that the participants have to maintain self and build a social network. The ultimate aim is to help participants to lead an active social life. Participants still have issues with the decision making. The confidence to take a decision on their own is a big challenge to most of the participants. Professionals are not in favor of large amount of medication, but they insist it is better to take a maintenance dose of medication until the psychiatrist decides to discontinue medication. Medication helps to reduce the severity of symptoms. Therefore, medication non compliance will affect the improvement. Professionals have concerns about the employment of the participants. Lack of motivation and interest are the constraints in finding a job. Also finding employers who knows and understand mental illness is another concern. Professionals insist the need to reduce smoking among male participants. For example Malleswaran becomes more suspicious when his smoking increases. Therefore, it is better if he could control his smoking to avoid such troubles.

Matrix 17: Time line indicators of quality of life of a few participants

<table>
<thead>
<tr>
<th>Participants</th>
<th>Excerpts from narratives</th>
<th>QOL in the Past</th>
<th>QOL in the Present</th>
<th>QOL and future expectations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mynah (LSH)</td>
<td>Sense of Insecurity, No home to stay</td>
<td>Sense of security, Permanent place to stay, Good psychiatrist and treatment, Using good things</td>
<td>Worried about increasing fees at the rehabilitation center</td>
<td></td>
</tr>
<tr>
<td>Hasini</td>
<td>Could not achieve a job, conflict between parents, schizophrenia</td>
<td>Sometimes better sometime not good, improved than before, routine,</td>
<td>Job, earning, maintaining improvements, help</td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td>Condition</td>
<td>Improvement</td>
<td>Challenges</td>
<td></td>
</tr>
<tr>
<td>--------</td>
<td>---------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Prema</td>
<td>Incomplete education, no career, lost parents</td>
<td>Improvement after attending day care, good treatment, help at day care, improved self, conflicts with family</td>
<td>Improve self confidence, regular treatment</td>
<td></td>
</tr>
<tr>
<td>Lalitha</td>
<td>lost interest in everything, poor self care, schizophrenia, fought with family</td>
<td>Meeting basic needs, participating in the activities, got confidence in life, improved interaction, family issues</td>
<td>Meet basic needs, routine, family support, music player, reading good books, simple life</td>
<td></td>
</tr>
</tbody>
</table>

Quality of life is a complicated concept to define especially in people living with schizophrenia. Living with schizophrenia is the greatest barrier for a better quality of life. Any discussion regarding quality of life is overshadowed by the impact\textsuperscript{123} of schizophrenia. Therefore, quality of life of participants in this study shows that all the aspects required for a better quality of life are intertwined with living with schizophrenia and their participation in the community.

\textsuperscript{123} I use the word impact to represent the drastic changes schizophrenia brings in participants life.
SECTION D

DISCUSSION

Introduction

The analysis chapters explained the various aspects of the experience of living with schizophrenia, participation of PLS in the community, and their quality of life. Each chapter is closely linked with the other yet unique in its own way. Chapter on living with schizophrenia discussed the aspects related to the experience of living with schizophrenia and the implications of schizophrenia on participants’ life. The second analysis chapter titled participation in the community discussed the participation of PLS in their community. Participants’ perspective on the concept of participation and community in the context of living with schizophrenia is the focal point of understanding participation of PLS in the community. Living with schizophrenia and participation in the community changed the quality of life of the participants. Chapter on quality of life of a person living with schizophrenia explains participants’ perception regarding this aspect. As per participants’ observation their quality of life is not good compared to people living without any mental illness. The present chapter discusses the interface between living with schizophrenia, participation of PLS in the community, and quality of life with the support of various studies taken place in each of these areas. The chapter looks into different aspects: participants’ perception on living with schizophrenia, participation of PLS in the community, and quality of life and the studies supporting and opposing their views; inter linkages between various concepts; and conclusion.

Living with schizophrenia

Participants’ idea of living with schizophrenia differs from each other. One aspect they all agree is that living with schizophrenia is a great challenge. There are various hurdles participants have to overcome for leading a productive life since they fight with their symptoms and distress on a day to day basis. Living with schizophrenia is described on the basis of years of living with schizophrenia. The data shows that the years of living with schizophrenia changes the way PLS makes decisions regarding her/his life, ambitions, and outlook towards life. The study reveals that people living with
schizophrenia for a long duration shows more interest in treatment and rehabilitation. This is because they understood the need for treatment from their experience of living with schizophrenia for many years. The functioning level of chronic PLS is affected during the initial stages of illness, but they are able to regain a better functioning later. Participants with shorter duration are hesitant to continue with treatment and rehabilitation. This is mainly due to the reluctance of accepting their diagnosis of schizophrenia. The need of a person with a few years of living with schizophrenia will be different from those who are living with schizophrenia for many years.

Data reveals that there is a gap between the diagnosis and actual manifestation of symptoms. This is due to the fact that treatment is sought after a few occurrences. Participants and family considers the possibility of any mental illness as a last option. Therefore, family sometime finds it difficult to remember when schizophrenia started. Data indicates that years of living with schizophrenia is an important aspect determining rehabilitation plan. Schizophrenia is generally categorized\textsuperscript{124} into chronic and acute on the basis of duration of living with schizophrenia. Chronic is a word used to represent the longer duration of an illness or its persistent reoccurrences\textsuperscript{125}. In schizophrenia this term is also used to denote impairments or deficits occurring over the course of illness especially negative symptoms. Generally the word chronic is used to represent a state of inactivity. After analyzing various studies Harding et al. 1992 says that this usage is wrong and people living with schizophrenia can be active participants in the process of recovery. Therefore, in their opinion prolonged is a better term than chronic. It is clear that longer duration of illness does not always deprive a better functioning (Harding et al. 1992).

Data shows that longer duration of living with schizophrenia helps in understanding the illness. The knowledge regarding schizophrenia is different for each participant. The question of knowledge about schizophrenia is interesting because most of the time

\textsuperscript{124} The organisation where the study took place categorize living with schizophrenia based on the time spend on living with schizophrenia. Therefore, chronic schizophrenia is where the individual spend a considerable time living with it. Acute is used to refer short period of living with schizophrenia. (field observation notes)

\textsuperscript{125} http://www.netdoctor.co.uk/diseases/facts/schizophrenia.htm, accessed on 16-10-12
participants are aware of their diagnosis, but not the details of it. The data shows that except one or two participants others have not even attempted to ask the psychiatrist about their diagnosis. Study also reveals that there are participants who refuse to accept the fact they are diagnosed with schizophrenia. These participants take medications since they have ‘some issues’ which requires medication. Those participants who are completely aware about schizophrenia and recognize the symptoms accept their diagnosis. This depends on the participants ability to assess own behavior/distress and compare that with the knowledge they acquired. These participants accept the fact that they have to take medication to reduce the symptoms.

The fact that medication helps in reducing the distressing symptoms is appreciated and acknowledged by the participants. The question participants raise is how long they have to depend on medication. Participants revealed that the consumption of medication is on the belief that it will cure schizophrenia. The study reveals that biopsychosocial model is helpful during the rehabilitation process since it helps to look at various aspects that play part in living with schizophrenia. The highest criticism for biomedical model is its inability to find a cure for schizophrenia or any mental illness and not recognizing the relevance of psychosocial aspects in treatment (Engel 2004). It is here biopsychosocial model of George Engel (1977) is utmost important. This model points at the importance of considering the biological, psychological, social, and cultural aspects that contributes to the course of schizophrenia (Engel 2004). Gilleen et al. 2011 tested the awareness of PLS regarding various domains of schizophrenia and reported that PLS are aware of illness, but not the details of it.

Living with schizophrenia is expressed in different ways. It consists of completely denying the possibility of having schizophrenia, considering the possibility of having schizophrenia, and accepting schizophrenia and taking treatment. In this context it is not surprising that among the twenty one participants only three are completely aware of schizophrenia. Data shows that the level of insight varies from complete insight to

126 Participants are not ready to call it schizophrenia, but some issues which needs treatment. They did not hesitate to give the interviews, but was not happy with the fact that they are diagnosed with schizophrenia. (field observation notes)
127 Insight is an individual’s awareness about self as living with schizophrenia (Amador and
partial insight. The presence of insight is high in participants living with schizophrenia for many years compared to those with shorter duration. Insight definitely plays an important role in improving the daily life functioning of PLS. Data shows that participants’ awareness about what is happening with them and around is less during the symptomatic phase. Hospitalisation is the ultimate choice for family and rehabilitation facility if they are not able to handle the situation. More research is required to explore the role of years of living with schizophrenia in improving insight.

The role of insight in treatment outcome in schizophrenia is a broad area of research. There are studies showing relationship between insight, treatment compliance, and functioning (Lysaker et al. 1994; Crumlish et al. 2007; Gilleen et al. 2011). Wilson et al. 1986 shows that lack of insight is higher in people living with schizophrenia (cited in Schwartz 1998). Lysaker and Bell (1998) points out that people living with schizophrenia tends to refuse having schizophrenia despite concrete evidences suggesting the presence of schizophrenia. This issues regarding insight could be due to various reasons. Lysaker and Bell (1998) put forth the various possibilities for issues in insight. Authors consider that PLS may be using it as a coping strategy, poor medication compliance, cognitive deficits, or neuropsychological impairment. There have been various studies pointing out the importance of insight in treatment. If the person who is in need of treatment refuses to accept the illness then a long term treatment goal will not work out. Therefore, the relationship between insight and treatment outcome details requires further exploration (Schwartz 1998).

The data shows that even family members are also not very much aware about the details of schizophrenia. They know that the participant has schizophrenia, but not what schizophrenia is. Family is concerned about the treatment and improvement of participants rather than the knowledge regarding schizophrenia. Family history of mental illness also plays a role in understanding and accepting schizophrenia. Professionals insist the need of insight for both participants and their family members since it is important in treatment. Stigma is another aspect affecting participants’ perception on accepting schizophrenia. Participants have experienced discrimination due to living with

Kronengold 1998)
schizophrenia. They fear to disclose the fact of living with schizophrenia to anyone other than close family members, professionals, relatives, and friends. Studies show that there is substantial evidence that psycho education for family is relevant in the improvement of schizophrenia (Dixon and Lehman 1995). Family support and awareness are two important aspects in attaining better treatment results (McFarlane and Lukens 1998). Stigma plays a crucial role in the underutilization of mental health services. Caregivers often find isolated after disclosing the fact of mental illness in the family (Thara and Srinivasan 2000; Menon 2009).

Source of knowledge regarding schizophrenia is most of the time psychiatrist and PLS’s experiences of living with schizophrenia. There are instances where knowledge is acquired from pamphlets or books, and browsing internet for details. Here the question is why most of the participants are not very keen in knowing their diagnosis. Data shows that the lack of interest in knowing more about schizophrenia is due to the increase of worry and fear about illness. Studies related to this aspect are insufficient to make a conclusion on whether people living with schizophrenia actually refuse to know more about schizophrenia because the knowledge causes them worry and fear. Though, the present study results show a disinterest in PLS to understand schizophrenia, it is better to know what schizophrenia is so that they will be able to handle it effectively. The debate on whether to tell diagnosis to the person with mental illness especially schizophrenia and who should tell it still goes on (Atkinson 1989; Clafferty et al. 2001). Atkinson 1989 suggests that it is better for the person to know what her/his diagnosis is so that they may be able to deal with it positively.

The study shows that self care activities and other daily life activities are changed due to schizophrenia. Data shows that early onset of schizophrenia especially during school or college years lead to academic under achievement. This prevents participants from attaining a better educational qualification. Educational underachievement deprives PLS from getting any employment opportunities. The onset of schizophrenia while on a job is a critical situation for the participant, employer and the family. Rehabilitation process is arranged according to the disability requirements of the participants. Data reveals that along with symptomatic manifestations problems such as cognitive deficits and
functional impairments are more challenging. Difficulties in concentration, attention, comprehension, and memory lead to impairments in social functioning. Cognitive functioning is an important aspect influencing social involvement. Data shows that functional impairments are present in the areas of self care, education, work, and interpersonal relationships.

The study findings are similar to the outcomes of various studies on living with schizophrenia. People living with schizophrenia find it difficult to organize their daily life activities (Austin 2005). Studies have shown that cognitive deficits remain steady for a long time (Isaac et al. 2007). Impairments in cognitive functioning adversely affect social functioning (Hatashita-Wong et al. 2002). Occupational functioning and studying capability are adversely affected (Nations for Mental Health 1998). Vocational disability is a prominent feature in schizophrenia. Functioning at work is affected by the course of illness (Harvey et al. 2009). Social disability is an underlying effect of schizophrenia (Williams and Collins 2002). Studies also show that functional disability is severe in people living with chronic schizophrenia (Velthorst et al. 2010). Thara (2005) wrote that the disabilities as part of schizophrenia occurs in various areas of functioning such as self care, maintaining personal space, function in a job or relationship, and cognitive deficits. The studies related to educational underachievement in PLS are yet to be explored in detail.

The present study reveals that the first plan in rehabilitation is enabling participants to focus on self care activities. Once self care activities are in place slowly focus is shifted to developing a routine. The study also shows that in the past participants’ were completely dependent on medication before attending the rehabilitation facility. They followed the antipsychotic medication prescribed by the consultant psychiatrist for a long time. Most of the participants attend rehabilitation facility as per psychiatrists’ suggestion. The realization that medication is not enough for better functioning is the motivating aspect to explore psychosocial treatments. Data reveals that medication non compliance is considered as the biggest challenge to treatment and the reason for relapse. Data also reveals that the main reason for dropping medication is that participants feel it
unnecessary to take medicines once the symptoms have subsided. The realization that schizophrenia requires lifelong medication is also not accepted easily.

Putten et al. 1976 studied about drug refusal and found out that there could be various reasons for medication non compliance. They suggested that lack of insight about illness, refusal to accept the illness, no supervision and monitoring of medication, and attitude towards treatment are the reasons for non compliance of medication. If the person living with schizophrenia is not seeking treatment voluntarily then chances of medication compliance is high. Schizophrenia is featured with decreased self care activities (Tara 2005). Personal hygiene is usually poor and requires regular monitoring. Recent studies show that the treatment for schizophrenia should be coupled with medication and psychosocial rehabilitation. Treatment for schizophrenia should be designed to tackle both acute and chronic incidences of schizophrenia. Therefore, it is appropriate to combine medicines and psychosocial rehabilitation to achieve better results (Gelder et al. 1983; National Collaborating Centre for Mental Health 2003).

Participants in the study belongs to the category of those who voluntarily seeking treatment. The concept of ‘voluntary’ is again confusing since a few participants express the view that they are taking treatment because of family pressure. The admission at the rehabilitation centre is voluntary in the sense participant has to agree without any pressure to stay at the centre. There are two sides for this aspect; on one side participants who voluntarily come forward for treatment and on the other side those who take treatment due to family pressure. Recovery is the motivating aspect behind seeking treatment. In schizophrenia recovery is an ambiguous concept, but in the present study participants use it as a synonym to complete removal of schizophrenia and leading a dignified life.

Recovery could probably be relief from symptoms and manage to function even symptoms are mildly present (Lysaker and Buck 2008). This can be considered as a narrow explanation of the concept of recovery in people living with schizophrenia. The conceptualization of recovery in mental health system by Jacobson and Greenley (2001)

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128 In the context of the present study a person is ready to take treatment on her/his own not under any external pressure. (field observation notes)
consist of the individual’s outlook and the circumstances. In their opinion recovery is a process and an element that support and change the individual and circumstances. Recovery from mental illness should not be limited to relief from symptoms, but participants’ ability to function well in day to day life, take part actively in family and social functions and work, and sense of belongingness and hope.

Data shows that most of the participants take medicines in the belief that it will cure their illness. Relapses are another major challenge in treatment. Data shows that relapses occurred mainly due to medication non compliance. Relapse most of the time ended up in hospitalizations. Sometimes hospitalizations expand for a longer period putting both participant and family in difficulty. Relapse takes away all the improvement achieved so far. Therefore, relapse is fearful especially for family members. The reason for relapse is always not medication non compliance. In certain instances relapse occurred even with regular medication. It can happen due to stress, irregular consultations (though medications are regular), and family situations. Family is the primary caretaker of almost all the participants in the study. Therefore, burden lies entirely on the family than anyone else. It seems that professionals have to put more effort to help participant after relapse to attain a minimum level of functioning. Rehabilitation attempts at a rehabilitation facility are expensive and may extend for longer periods. Data shows that family atmosphere was conducive in aggravating or reducing illness.

Families insist on continuing medication and are very supportive for treatment. Since families are the primary care takers, in most instances they are the only source of financial support. The economic burden on participants and family during relapse is very high. This is because during relapse as mentioned earlier due to hospital admissions and medical complications expenditure shoots up (Thara 2005; Kazadi et al. 2008). Relapse is the result of medication non compliance leading to hospitalizations (Kulhara 1998). The rate of relapse rates in people living with schizophrenia on medication is ‘40 percent in 2 years’ compared to ‘80 percent in 2 years’ (Sadock and Sadock 2010, 153) in people without medication (Sadock and Sadock 2010). Expressed emotions in the family are considered as a threat to improvement and leading cause of relapse (Hultman et al. 1997).
Since the present study did not attempt to explore caregiver burden, the effect of caregivers’ stress in relationship with PLS is not clear.

The study reports that there are instances where certain participants are excluded from social gatherings at home. Ridiculing from relatives is mentioned as the reason for such measures. This creates a negative attitude in participants towards self and their family. Participants who have such experiences tend to reflect that negative attitude in their behavior towards family. The implications of schizophrenia are damaging. Degree of impact varies, but areas affected are similar. Self care, maintaining personal space, interpersonal functioning, social functioning, vocational functioning, and cognitive functioning are severely affected. Data indicates that frequent hospitalisations and rehabilitation attempts are part of the picture. Hospitalizations cannot be avoided during severe relapse (floridly symptomatic) since family is not able to handle it.

Rehabilitation attempts at different voluntary care organisations forms part of the cycle. Deficits in various areas, stigma and discrimination, lack of social support and social security are certain aspects ruling the life of a person with schizophrenia. In professionals opinion skill impairments are the biggest challenge in dealing with schizophrenia. Relationship with parents, siblings, spouse, children, relatives, friends, and colleagues deteriorates over the period of time. Educational and work performance drops due to cognitive deficits and distressing symptoms. Stigma and prejudice towards people living with mental illness is high and influence their everyday life (Walton 1995). Studies have contributed evidences on disabilities arising due to schizophrenia (Harvey et al. 2009).

The use of IDEA Scale (Indian Disability Evaluation and Assessment Scale)\(^{129}\) (see appendix 5) to assess the extent of disability helps to plan activities as per the ability of the person. Once participants are able to perform well in activities of daily life she/he is encouraged to participate in activities that need more focus, for example, vocational

\(^{129}\) [http://www.bpaindia.org/ENApril-June06.htm](http://www.bpaindia.org/ENApril-June06.htm), accessed on 28-03-13
activities. The barriers in effective\textsuperscript{130} participation are basically in the form of symptoms, cognitive deficits, and side effects of medication. It takes time to reduce the effect of these limitations in their performance. There are instances where participants are kept away from social functions to avoid embarrassment. In such circumstances participation in social area becomes limited.

Emotional distress of being labeled as mentally ill has its implications on participants. Experience of stigma and discrimination hampers any attempts of socialization. Dependence on family members is another feature of living with schizophrenia. Independent living is just a distant dream for most of the participants. Day to day life activities are disrupted without any routine leading to more inactivity. Western literature shows that people living with schizophrenia lives either alone or with friends and not with family (Walton 1995). Indian studies shows that people living with schizophrenia stays with family (Thara and Srinivasan 2000). Therefore, the concept of independent living needs to be redefined according to the cultural differences. Eklund et al. 2009 points out that loneliness and lack of meaning in life are associative features of schizophrenia (cited in Eklund et al. 2012)

Continued professional care is advised for participants who need both psychiatric and medical care. Data shows that participants who have physical ailments need more attention than those who does not have any physical illness. This is one of the reasons LSH participants decides to stay at LSH for the rest of their life. Other reason is that family also prefers to keep participants in LSH. Participants at long stay home experience various physical ailments which require close supervision. Family feels that they may not be able to provide this kind of care. Therefore, it is better for participants to stay at LSH. Family cannot provide the professional supervision and care LSH\textsuperscript{131} provides to the

\textsuperscript{130} Effective is used to depict full participation where participants enjoy the activity and find it productive. There are times when participants take part in an activity since it is part of the schedule at the rehabilitation facility and not they enjoy it. Here participation cannot be called effective since it does not give any happiness or satisfaction to the participant. (field observation notes)

\textsuperscript{131} Only one family member in long stay home participated in the study. Other families did not respond to emails or phone calls.
participants. A critical reflection of this thought is that this may actually reinforce the use of institutionalization.

Institutionalization deprives participants’ right to live with their family and enjoy life as any other human being. The care and support can also be provided under the care and supervision of family. The over emphasis and influence of biomedical model of illness hinders participants choice. On the other hand it is difficult to completely withdraw from the treatment due to the role it plays in effective functioning. Linszen et al. 2001 suggested the need of prolonged care and assessment of improvements for better treatment results. This was based on the results of a study where the better treatment results after the initial episode of schizophrenia was not present in participants after a period of time (cited in Economou et al. 2011).

**Participation in the Community (PIC)**

After the deinstitutionalization movement the focus is on providing community care for people living with schizophrenia. Community participation became a prominent concept in mental health as a result of this development (Lloyd and Deane 2007). Various attempts have taken place to enable people living with schizophrenia to take part in community activities. Studies have shown that people living with schizophrenia has limited involvement in community (ibid). The present study shows that participation of people living with schizophrenia in the community is mainly in the form of participating in activities towards self and interaction with people close to the participants.

Data reveals that schizophrenia has affected every aspect of life therefore maintaining a minimal functioning in those areas is considered as the basic aspect of PIC. Community sometimes refers to a particular group of people with specific needs or interests, for example people living with physical disability. It is used to denote a therapeutic community or a community of people admitted in a hospital with specific needs (Report of the Richmond Fellowship Enquiry 1983). In the current study participation towards self, participation in family, participation in treatment and rehabilitation, participation in work, and participation in society are the various tiers of participation in the community.
These areas of participation in the community are identified by the participants. All the areas are intertwined with the various segments of the community.

Data reveals that self care and other activities of daily living is a part of PIC because these are the first areas affected by schizophrenia. Therefore, first and foremost area where PIC takes place is self care activities. Participants feel that the need for focusing on self care activities is the importance of keeping self healthy, clean, and presentable in the community. People living with schizophrenia experience cognitive, social, and behavioral disabilities of chronic nature which impairs their self care practices (Holmberg and Kane 1999; Lehman 1999; Thara 2005). Literature pertaining to self care practices in people living with schizophrenia is limited. Norma MacDonald (1960) has written very clearly that it is difficult to carryout daily activities when symptoms are even mildly present. Daily life activities are difficult to perform and adequate motivation is required. Studies show that psychosocial rehabilitation aims at enhancing a routine and structure in daily living. Professional helps in preparing a checklist of activities and monitors the performance (Lehman 1999; Nagswami 2004). Data reports that participants’ gives due importance to self care and other activities of daily living. Since they have impairment in these areas it is important to get some professional assistance to get those skills in place.

Literature covers self care, maintaining personal space, routine, health care, and prayer and religious activities under the term activities of daily living (ADLS) or basic living skills (Murali et al. 2001; Nagswami 2004). As per the data participation towards self comprises of activities of daily living. Studies regarding the involvement of subjective perception of people living with schizophrenia in these aspects are less. Since relapses results mainly from medication non compliance participants consider regular medication as participation to self which in turn enable them to participate in the community activities. Participants accept that regular medication will help them in functioning well. Health care is another aspect participants consider as part of participation to self and community. Health care involves both psychiatric and physical health care. Physical health issues are equally burdensome for people living with schizophrenia (Burns and Kendrick 1997).
Diabetes and high blood pressure are the common physical illness present in the participants. Health checkups and follow-ups are rigorously carried out for participants living with chronic schizophrenia. Medication side effects also result in physical complications for example obesity, tardive dyskinesia (Strathdee and Kendrick 1966; Kulhara 1998). Substance abuse especially excessive smoking (in males) is a challenge since it paves way for further complications. Literature shows people living with schizophrenia tend to smoke more than general population and people living with other mental illness. The effect of nicotine in enhancing brain functioning is considered as the reason for increased smoking in schizophrenia (Marder et al. 2008). Participant who smokes confessed their inability to reduce or stop smoking and are not ready to quit smoking. In their opinion smoking helps to get a kick so cannot or do not want to stop it. Researchers consider smoking in PLS as a double edged sword. Though smoking may bring some changes, it is an unhealthy habit and a cause for concern (ibid).

Length of stay at the rehabilitation facility is different according to the need of participants. Each center provides services as per the requirements based on the disability of the participant. Data shows that referral for rehabilitation is mainly by psychiatrist or psychologist. In rare instances participant or family has initiated to explore the possibilities of rehabilitation services. Participation in rehabilitation centre is mainly in the form of involvement in the various activities organized by each centre. Each facility is different in nature and offers diverse services according to the requirements. Half way home is a residential setting that provides various social skills training to the participants. Earlier the idea of half way houses was to provide a shelter for people living with mental illness to keep them away from trouble (Soddy and Ahrenfeldt 1967). Later half way houses started providing temporary shelters where people living with mental illness can stay and receive training in various skills (Murali et al. 2001).

The HWH in the present study follows the same principle where participants are provided with residential and psychosocial facilities. The activities at the centre are designed on the basis of therapeutic community principles. The decisions on the activities at house are shared by the professionals and the participants. Participants’ involvement in decision making is mainly in the form of what activities they should take part in the
centre. Their participation in family matters is minimal or not present in most of the instances. Participation in treatment and discharge is not beyond explaining symptoms and distress to the psychiatrist and family.

Participation in group activities such as community meeting, group therapy, social skills training, recreations, shopping provisions, and art therapy forms the major part of participation at half way home. These group activities are mainly therapeutic in nature. The aim is to promote interpersonal interactions among participants. The aim of therapeutic community treatment is to enable social living in people living with mental illness (Rapoport 1960). Half way homes service provides twenty four hour services to the participants and other members and thus increase the efficiency of the rehabilitation process and achieve better results (Maggie 2006). Kumar and Srinath (2009) study on the therapeutic community treatment offered in Athma Shakti Vidyalaya explored the organization’s structure and functioning as a therapeutic community and its effectiveness in psychosocial rehabilitation. Their study shows that the autonomy of the patients is high in the organization and activities.

The HWH participants at the present study do not share the same level of autonomy as in Kumar and Srinath (2009) study. Their involvement in decision making at the center revolves around daily schedule to be followed at the center. The concept of therapeutic community aims to use community as a method of treatment and at the same time it is the context where change takes place. Here in the present study community is used as a treatment method, but the involvement of the participants is not present in all the decisions regarding the rehabilitation facility. Most of the time professionals make decisions regarding the group activities and responsibilities. The role of professionals in therapeutic community approach is intense and important, sometimes this may lead to make PLS dependent on professionals.

Maintenance duties are carried out with two purposes; to be self dependent and to take part in household works after discharge. In order to check the effectiveness of rehabilitation participants are send on occasional vacations to home as part of the intervention plans. Participants have to prepare a list of their daily requirements and purchase it from the nearby shops on their own. Apart from this a certain amount of
money is allowed as weekly allowance for purchasing snacks. This is meant to enhance their ability to manage money and expenditure. The other aim is to enable participants to independently interact with outsiders. Traditionally transitional half way houses were considered as the platform for building relationship between the people living with mental illness (or with any illness living in a hospital) and the community (Lehman and Newman 1996). The activities at HWH are designed to enable participants to maintain a contact with the community. Interaction between the participants and other members at the center is good. They spend a lot of time chatting with each other. Conflict does occur, but participants are able resolve it own their own though at times they may need help from staff. Vocational training is not provided at HWH since DC is the place where it is offered. Participants who need to develop a work habit and vocational skills attend day care center to avail those services.

Group activities are usually guided by the professionals. Active participation in group activities is seen only in a few participants while others require motivation. Professionals ensure that every member in the group has participated in the activity. The role of professional is crucial in ensuring participation of every member (Misra and Misra 2008). Vocational training is carried out in different ways. Participants attend day care for training in various sessions or find out the activities of their interest outside the rehabilitation center and attend those. Vocational training outside rehabilitation facility depends on the level of functioning of the participants. Professionals do not force participants if they find that day care activities are not contributing to rehabilitation plans.

Participation in the group activities at respective centers is compulsory. Participation in vocational activities initially requires professional supervision. Over the period of time professional supervision will become minimal. Rennie et al. 1950 suggested that vocational activities should be considered important for those participants who did not get any chance of employment due to mental illness. Chalill 2010 found that vocational activities assist PLS in different ways such as keeping them engaged, ‘getting better’ (144), enhance their ability, and economic support. Most of the participants in the study do not have a work history. Therefore, the training in vocational activities is believed to help them in acquiring skills required to be in a job. Vocational activities keep PLS
engaged in some productive activity that enhances their cognitive abilities. It also helps people living with schizophrenia who have a history of employment to assess where they stand in the future prospectus of a job.

Day care facility offers care services during the day time. The emphasis on community psychiatry paved way for the development of day care for people living with psychiatric illness (Cross et al. 1972). Day care facilities were traditionally meant for providing therapeutic services during the day time for people living with mental illness who are less symptomatic (Murali et al. 2001). Day care participants schedule is different from HWH and LSH participants. Participants are generally less symptomatic and functional. This is also because center does not take PLS who are not able to follow DC schedule due to distressing symptoms. Their participation is mainly in vocational training though they do have group activities.

The group activities consist mainly of community meeting, group therapy, and music therapy. Group activities mainly consist of games, discussions or role plays. These activities are part of therapeutic interventions. The participants at day care centre consist of people living with different mental illness and intellectual disabilities, therefore, group activities are planned to cater the needs of each and every participants. This diversity in the illness does not affect interaction between members at the center. Their participation in activities at the center is good\textsuperscript{132} and active. Participants at day care are keen in attending computer classes at it provides some scope for job in the future. Females and males show more interest in learning computer than other vocational activities due to this reason. The study did not intend to look at the performance of female and males separately. Therefore, gender differences in participation have not been taken into account.

A case study on continuing day care treatment program for people living with schizophrenia in New York shows that focus of day care program should be in improving interpersonal skills, behavior, and controlling symptoms (Handa et al. 2009).

\textsuperscript{132} The involvement level in each activity is present. Participants initiate to attend the sessions. They also voice out their opinions and suggestions. There are participants who require a slight encouragement but involvement level is good. (field observation notes)
Participants’ interactions with other members differ in terms of the initiation and frequency. Data show instances of initiating a conversation with fellow members without any motivation from professionals or para professionals. On the other side instances of interaction with motivation is also present. Though interaction level varies participants are protective of each other and stands for each other when occasion arises. This is seen more among day care participants than LSH and HWH participants. The communication and understanding among and between day care resident and day care members are good. The structured routine keeps participants busy and focused in the activities.

Group therapy and games help to improve the interpersonal relationships. Professionals provide therapeutic interventions and para professionals give training in vocational activities. The interaction with para professionals is relaxed and jovial whereas professionals share formal relationship with participants. This could be because participants spend more time in the vocational sessions taken by para professionals. If they have difficulty in attending any vocational session participants are free to share the issues with professionals. This freedom influences their participation in vocational activities. Interest in vocational activities plays a crucial role in participation in vocational sessions. The level of functioning is a significant aspect in making such choices. Since schizophrenia is such an illness that may lead to lose interest in work and bring some cognitive difficulties professionals has to constantly motivate participants to take part in different the activities at the center.

Long stay home participants have more autonomy in terms of daily routine. The purpose of long stay houses is to provide care for people living with mental illness who cannot take care of themselves for the rest of their life (Murali et al. 2001). Long stay care usually is provided in long stay hospitals for people living with chronic schizophrenia (Upadhyay 1987). In the present study LSH is a group home where participants have autonomy. The participants at LSH are older than HWH and Day Care participants. At times they need supervision in certain areas, but most of the time they are able to take care of themselves.

Participants’ age is an aspect for concern due to the presence of physical illnesses such as diabetes, cholesterol, blood pressure, and other illness. Since they are going to
spend rest of their life at LSH the restrictions are minimal. This helps participants to feel at home in LSH. The difference from a mental hospital is the freedom participants have to go out, work, and contact\textsuperscript{133} family members. The participation is mainly in form of self care activities and vocational activities. Activities at the centre are not rigorous and structured as in HWH and day care. Group activities are minimal and participants ensure their participation without any motivation from professionals. Group activities are minimal, but all LSH members take part in it. Interaction and communication between participants and other members at the center is good.

Participants at LSH have been living with schizophrenia for more than two decades. This is the reason for considering their state as chronic. The aim of LSH is to enable participants to take care of self and keep self occupied. The long term plan is not to send them back to family, but to provide adequate professional care. This is different from a hospitalised care in the sense of freedom participants have in their daily life activities. Studies suggest that long term hospitalisation is not an appropriate choice for chronic schizophrenia since it increases the disability in long run (Upadhyay 1987; Taiwo et al. 2008). The studies on length of stay at mental hospital show that family’s preference for prolonged care is a reason for opting long term hospital care (Talbott and Glick 1986).

Long stay facility and long term hospitalisation should not be confused as same. Long stay facility in the present study focus on rehabilitation. Hospitalization happens only when participants are in a symptomatic phase since it is difficult to manage them at the rehabilitation center. The reason for availing long stay facility service is the inability of family members to provide continued care at home. Participants’ age, nature of illness, medication, care giving burden are certain aspects influencing the decision to avail long stay home facility. Participants from LSH, HWH, and DC knew each other and maintain a cordial relationship. The difference in the form of rehabilitation facilities does not affect their interaction.

Family support is an important element in participation of people living with schizophrenia in the community (Thara 2005). Participation in the family differs for

\textsuperscript{133} Contact with family members are through phone, letter, emails, and occasional visits by family.
HWH and LSH participants, and DC participants. LSH and HWH participants’ involvement in family is limited to phone calls, emails, and occasional visits from the family members. Whereas DC participants take part more actively in household works. Their interaction with family members is regular since they stay with the family. However LSH, HWH, and DC participants’ involvement in decision making regarding family matters is limited. Though participants did not show any remorse feeling for not being able to take part in decision making, they felt it is an important part of participation in family.

Participants feel that family does not consider their opinions and suggestions due to their illness and stay at rehabilitation center. Since the presence of HWH and LSH participants in the family is less, their participation in decision making in family matters is limited or does not exist. DC participants feel that though they stay at home their opinion on family matters is rarely consulted. They express happiness in helping parents at home, going out with family, and attending social functions. Participants acknowledge the fact that they are dependent on their family and will need family support in everything. Participants are not happy about their financial contribution to the family. Since most of the participants are not earning they are unable to contribute any money to the family.

Schizophrenia affects educational achievement and vocational skills which in turn deprives people living with schizophrenia of a good career (Mueser et al. 2001; Honkonen et al. 2007). In the present study participation to work and education is limited to those who are employed or attends college respectively. Therefore, enabling participation in these areas is critical in the process of rehabilitation. Participants who attend college are keenly interested in their studies. This shows the participants’ understanding on the importance of education. Participants at HWH shows more interest in continuing their studies. They take help from others who are capable of assisting them in the facility. At times self motivation becomes less and professionals and family has to motivate the participants to help at home. Participants who are engaged in some income generating activity participate well in those activities. Females seem more successful in finding out some vocational activity especially tailoring and handicraft than males. The
reason for this may be because females use tailoring work sessions to learn and later convert it into some source of income. Whereas male participants find it difficult to take up small jobs that they can carry out on a regular basis. They feel that small jobs have less social status and pay.

Participation of people living with schizophrenia in the wider community is limited. This is due to the drastic implications schizophrenia has on the life of people who live with it (Bellack et al. 2007). Participation of people living with schizophrenia in their community is important in reconnecting with the community. In the present study prominent areas of participation include activities of daily living, treatment, interaction, vocational skills, money management, and family relationships. Improvement in these areas is important since these are the areas severely affected by schizophrenia. Community in the context of PLS in the present study consists of people closer to participants. Participants’ involvement in the community other than close relationship is very limited. Considering schizophrenia as an illness has helped them to stick to medication. This is also a result of going through many relapses.

The influence of biomedical model is visible, but this model has helped in functioning despite the implications. Medication has helped in gaining better outcomes from rehabilitation process. Though HWH and LSH participants and DC participants differ in their level of participation they are participating in their community. Family support and professional assistance are considered to be the crucial elements in encouraging participation. Stigma, unpredictable nature of illness, chances of medication non compliance, and possibility of relapses are the aspects challenging participation in the community. Participants especially females are more vocal about prayer and religious beliefs than male participants. Prayer is considered as a source of relief and support. Participants’ performance in various areas of life is important in understanding their quality of life.

134 Community here refers to those tiers where participants are actively taking part which includes self, rehabilitation center, family, education, and work.
Quality of life

Conceptualizing quality of life in people living with schizophrenia always raises several questions. The major question is regarding the measurement of quality of life in schizophrenia. This question is still relevant while considering the impairments resulting from schizophrenia. However, the purpose of the present study is not to measure the quality of life of people living with schizophrenia. The purpose is to understand quality of life from the perspective of the person living with schizophrenia. Quality of life depicts both objective and subjective aspects (Rajkumar 1999). Narvaez et al. 2008 explains subjective indicators as satisfaction in life and objective indicators as participation in daily activities and relationship with family and others. World Health Organization’s (WHO) definition of quality of life points at the importance of individual’s perception on her/his own quality of life (cited in Division of Mental Health and Prevention of Substance Abuse 1997). Individual perception is important since each individual’s experience and the way they look at life is different from one another (Felce 1997). WHO’s definition underlines the importance of individual’s perception on her/his life which helps in conceptualizing quality of life in this study. Participants’ perception of quality of life consists of both objective and subjective aspects.

Happiness is the key to a better quality of life. Happy in whatever participants do or have in their life is the foremost aspect of quality of life. Finding happiness in whatever a person does is something participants consider as adding to quality of life. Hedonistic theories explain happiness, pleasure, satisfaction as part of quality of life (Brock 1993). The concept of happiness in schizophrenia is relevant for many reasons. One of the biggest problems faced by people living with schizophrenia is their inability to experience pleasure (Austin 2005). Therefore, being happy is an achievement in the rehabilitation of people living with schizophrenia and improving their quality of life. Corten et al. 1994 explains the importance of hedonistic features in quality of life.

Satisfaction with life is a widely discussed aspect of quality of life. The satisfaction in life depends on the way a person perceives and accepts her/his life. The study shows that participants have problems with accepting self as living with schizophrenia. Therefore, recovery from schizophrenia is crucial to have a better quality of life. For this reason
participants quoted optimism as a component of quality of life. Optimism is essential for recovery from the illness. The faith that symptoms will come down and participants will eventually be able to lead a less eventful life increases their hope to have a better quality of life. Hope for recovery and to lead a better life acts as a boosting aspect in the treatment of schizophrenia (Littrell 1996). Fighting with symptoms on a day to day basis is tiresome and tedious. Therefore, participants prefer a life less complicated and simple. Simple here refers to a state where symptoms are non active, relationships are less chaotic, a daily routine, and take care of self independently. Schizophrenia is that illness in which symptoms never goes down completely. Symptoms are always present though the intensity differs as per the effect of medication. The outcome of schizophrenia is not very favorable even with adequate treatment facilities (Srivastava et al. 2009).

It is important to note that cure from schizophrenia is the biggest dream participants’ pursue. They realize that cure is not a possibility at least in the current scenario. This realization hampers participants’ spirit to look at the future positively. The aim of treatment is to enhance maximum level of functioning and attain a meaningful existence (Goodman and Smith 1997). The issue participants raise here is taking medication for an indefinite period. This they believe will affect quality of life in the long run. It is true that medication is helpful in preventing relapse to a certain extent, but it has not been successful in eliminating the symptoms completely. There is a lack of clarity in how long participants should continue with the medication (Nations for Mental Health 1998). This is significant since QOL is also influenced by distressing influence of antipsychotic medications (Awad et al. 1997).

The illness has affected participants’ ability to lead an independent life. Depending on family for everything is not an ideal situation. Participants’ distress in depending on family for everything is evident in their narratives. Family is the primary support system for participants. Since the family is ready to provide support as long as they can, participants are able to avail the rehabilitation services. Indian studies show that family provides support and care for people living with schizophrenia (Thara et al. 2007; Stanley and Shwetha 2006). Family support act as a solace and relief, but participants feel that depending on family is a distressing and affects their quality of life.
Stigma and discrimination against people living with schizophrenia is a universal phenomenon. Studies show that stigma often affects both participants and family (Ertugrul and Ulug 2004; Corrigan and Watson 2002; Byrne 1997). Stigma also plays a crucial role in not approaching for treatment (Thara and Srinivasan 2000). Participants’ quality of life is affected by stigma and discrimination. The fear of being ridiculed, isolated, and discriminated is not a situation where quality of life is good. The experiences of discrimination created pain and prevented participant from trusting anyone. Research shows that such kind of painful experiences aggravate self stigma (Pan 2011). Since schizophrenia affects all areas of life, maintaining a minimal level of functioning in all the areas is the criteria of determining a good quality of life. A better quality of life is when participants participate in the community by involving self in the community activities. For participating in the community participants need the support and confidence of not just the family, professionals, and friends, but the wider community. To get an in depth understanding about the quality of life of people living with schizophrenia, it is essential to entail their perception on quality of life in the past, present, and the future prospectus (Calman 1984).

Quality of life in the past starts from the point of onset of schizophrenia and passes through various attempts of rehabilitation and covers till the period of data collection. The reason for looking at quality of life from three different period of time is to get the nuances of that trajectory. It will also help to understand the variations in the components of quality of life over the period of time. The period of life before onset of schizophrenia was better since participants were able to function well. They were able to make friends at school and outside. Participants’ relationship with relatives was pleasant. They were able to study and pass the exams till the onset of illness. Emotional distresses, conflicts with family members, lose of interest in studies or failures, and slow changes in cognitive skills embarked the journey of schizophrenia. In participants’ opinion quality of life before the onset of illness was somewhat good since they were able to take care of themselves. Study on quality of life in first episode schizophrenia shows a diminished quality of life, but early treatment brings favorable outcomes (Browne et al. 2000).
Under achievements in education was the most striking aspect that affected participants’ quality of life. Failure in studies affected their self confidence and scope for a good career. Daily activities became very difficult to perform. Participants had to depend on someone else for performing basic living activities. Medication helped in reducing symptoms and preventing relapse, but added more stress in the form of side effects (Awad et al. 1997). Depressive feelings, negative thoughts affected quality in life adversely. Relationship with family also deteriorated in the past. The inability to contribute to the family either financially, emotionally, or physically was another aspect that lowered the quality of life. Data shows that medication non compliance, relapses and hospitalizations were the common features in the past for most of the participants. Suicide attempts by participants made a setback in treatment and improvement. Cognitive deficits in schizophrenia are an established fact and have severe implications on the quality of life (Alptekin et al. 2005; Ritsner 2007). Cognitive impairment is a major challenge in vocational rehabilitation. Participants without a work history have a few chances of employment in the present and future. For participants those who finished education felt that as a relief and a pleasant achievement.

Accepting schizophrenia was a big challenge for participants and family. Inability to continue in a job for a long time was an issue for participants who were employed. Switching from one job to another due to dissatisfaction and inability to cope with situations at the work place fuelled more discrepancies. Analysis of the reports of participants about their past experiences showed that disability in various areas especially in job performing adversely affected quality of life. The challenge was to sit and work for a long time which participants were unable to do. This prompted for taking up jobs that have flexible timings. Rehabilitation activities seem to have a good impact on quality of life though shuttling in and out of rehabilitation facilities is not a pleasant aspect. Being in a protected environment (rehabilitation center) acted as a major component of quality of life for some participants. Support from family was a crucial element in improving quality of life. Marriage life was not a pleasant experience and so was divorce.

Participants’ quality of life in the present situation is comparatively better than past situation. There are many aspects that played part in improving their quality of life.
Participants attribute this achievement to medication compliance. Medication helps in reducing symptoms thus enabling them to take part effectively in rehabilitation activities (Wolters et al. 2010; Slade 2009). Social skills training, group therapy, vocational training, cognitive retraining techniques, and individual therapies contribute to improving performance (Liberman et al. 1998). Improvement in daily life activities and a daily routine to keep self busy are the most notable changes. Routine helps in diverting thoughts and attention to productive areas. Living in a rehabilitation facility helps in interacting with people who have similar issues. Being part of group that does not stigmatize each other for mental illness contributes to a better quality of life and functioning. Ability to initiate a conversation helps to build confidence in interpersonal relationship. Support from family members is a great relief for the participants who have a regular contact with family members (Mathiesen 2001). Lack of emotional support from family deprives of a better quality of life though family provides the financial support.

Participating in various activities at the rehabilitation center, household chores, other daily activities, interaction with family and relatives has improved during the course of time. Rehabilitation helps in improving the interaction level of people living with mental illness (Lung et al. 2001). Group activities not only helped in improving communication skills, but overcoming anxiety while facing social situations. Their interaction skills improved resulting in a better social involvement. Social involvement in this context refers to participants’ interaction with other members at the rehabilitation facility, relatives, and guests. It also points at going for shopping or bank with or without assistance. Looking at the past events these are the changes that adds value to their life.

The difference in the present circumstances of HWH and LSH participants from DC participants is the constant physical presence of family in DC participants’ rehabilitation process. In that instance DC participants appear to be in a more advantageous position in terms of quality of life. This finding is not a conclusion on the quality of life of HWH, LSH, and DC participants, but an indicator that physical presence of family is much valued by the participants for a better quality of life. There are aspects that are not favorable for attaining a better quality of life. Physical health issues such as diabetes,
high or low blood pressure, cholesterol, and medication side effects are the main concerns. Since most of the participants are not very keen on making exercise a part of their routine, weight issues will continue to remain an issue.

One aspect which needs appreciation is the effort of female participants at long stay home to pursue tailoring skill as a source of income. They have managed to convert vocational training into a part time job and earn a decent sum of money. This job is good in the sense that they do not have to go outside to do it. Male participants have issues with pursuing a tailoring job since it is a female job. It is tough to find a job suitable for the male participants. They are not interested in low paid jobs. Finding an appropriate job in a suitable place is a challenging affair for the professionals. Employment always acts as a motivating aspect in treatment (Bejerholm and Eklund 2007; Solanki et al. 2008). Solanki et al. 2008 pointed out that the unemployment rate in people living with schizophrenia in that study was only 29.8 percent compared to global rate of 70-85 percent. They also said that this may be due to the complicated nature of jobs in developed countries which people living with schizophrenia in developing country do not face.

Study data shows that having a job is essential for a better quality of life even for participants who are economically sound. Improvement in cognitive skills has boosted the confidence in focusing vocational activities. Regular medication and good use of services has helped to stay out of symptoms. This gave the hope of recovery from illness. This hope is present in participants and adds more quality to their life. The basic needs of participants are taken care by their family which is an indicator of quality of life. Assistance in performing daily life activities has hampered the spirit of the participants, but is a necessity for those who are not able to carry out activities by self. Being independent is considered as a crucial aspect of better quality of life. For participants economic and emotional independence both are very important in determining quality of life.

Level of independence is an issue while living with schizophrenia. Independent in this context refers to participants’ ability to take care of self, but may not always refer to the ability to live independently. Some level of supervision is required in most of the
instances to ensure medication intake and good physical health. Being in a rehabilitation facility ensures regular intake of medication and a minimum level of functionality. This is the underlying principle for opting long stay care for people living with chronic schizophrenia. Participants’ report of a sense of achievement while taking up and fulfilling responsibilities at rehabilitation center or at home indicates a better state of life quality. Excessive smoking still remains a major health problem for male participants who smoke. The question of dependence of medication is one question that remains unanswered. The whole idea of maintenance medication is to reduce the amount of medication but to keep a minimum level of medicine to prevent relapse (Chan and Ungvari 2002). In the opinion of psychiatrist, if medication actually helps to function well in the community and improves quality of life, then it is better to depend on medication.

Future is looked with the hope of recovery and better functioning. Quality of life in future is based on their present state of life. Among the various aspects that contribute to quality of life maintaining the present state of stability is the most important one. Symptoms under control and a better level of daily functioning are the two crucial elements for a better quality of life. Therefore, medication compliance is considered as important. Continuing at a rehabilitation facility is not an option for HWH participants and DC participants. Since discharge is not an option available for long stay participants, they prefer moving into an old age home. It should be assumed that no matter how better services are provided at rehabilitation facility, participants do not wish to stay at a rehabilitation center. Discharge definitely is an important aspect in deciding quality of life in the future. Though participants have to put a lot of hard work attaining a job that has a better pay scale is a priority for quality of life. Physical health issues are common in schizophrenia and needs careful monitoring to avoid complications. Maintaining good interpersonal relationships is important in better social functioning (Mubarak 2005). Financial worries and uncertainty about future are causes of concern.
Theoretical Framework

In order to understand the process of living with schizophrenia it is essential to look at the biological, psychological, and social aspects operating at different levels. The current study focused on the experience of living with schizophrenia which paved way for looking at the perceptions of the participants. The biopsychosocial approach by George Engel (1977) assisted in understanding the perspective of people living with schizophrenia on their experiences of living with schizophrenia. This approach helped in considering participants as a unique individual who is the right person to tell about her/his life with schizophrenia. The experience of the person living with schizophrenia is very important in understanding the whole process of living with schizophrenia.

The biopsychosocial approach is useful in understanding the process of mental illness in the study context. The role of mental health professional is crucial since she/he has to differentiate the influence of each aspect in the process of schizophrenia (Leigh 1997). The biggest challenge here is the time and effort required for each PLS when time and resources are limited. Though the role of psychosocial and cultural aspects in the onset, course, and outcome of schizophrenia is been recognized, the effort to incorporate this in treatment is still a long way from reality. This approach can be used in reintegrating the individual back in the community since it takes social and cultural aspects into consideration. The focus here must be to enhance and encourage the participation of PLS in various areas of community life. Figure 5 shows the various aspects of living with schizophrenia.
Figure 5: Aspects of living with schizophrenia

Therapeutic community approach (1963) has been used in HWH facility. Therapeutic community model is used here to enable the members to refine their socialization skills through living in a community. Here the community consists of other people living with mental illness, professionals, para-professionals, supporting staff, students, and volunteers. The various activities are organised to create a feeling of a community living. Participation in the activities is compulsory for all the members. The focus is on the recovery of the individual and group as a whole. Along with schizophrenia and recovery this approach has enabled participants to acquire some right living attitudes. In this context community is used as a method of treatment. This is to ensure that participants are able to function at home and work place after discharge (Leon 1994).

As per International Classification of Functioning (ICF) 2001 activity is the performance of any deed or work by the individual. There are various activities participants undertake and perform. Activities such as self care, other daily life activities, work at rehabilitation facility and home. These activities help participants to keep self occupied and regain the skills impaired. These also impart various basic and social living skills in them. As per participants’ perception participation is taking part in anything. Participants are taking part in various activities in different situations. ICF 2001 explains participation as the involvement of the participants in activities or different life situations. Activities at rehabilitation facility are designed according to the capacity of the participants. Therapeutic community approach and International Classification of
Functioning helped in understanding the need for looking at participants’ capacity to function despite the severity of schizophrenia.

Quality of life is explained in terms of the past situation, present life, and expectations for future. Calman (1984) points at the need of a time frame to consider quality of life as a concept. The same pattern has emerged in the present study. Participants compare their perception on quality of life at various point of time. Therefore, participants explain their quality of life in the past situation compared to their present life. They also share their expectations in achieving a better quality of life in future. Participants shared that quality of life does not remain the same over the period of time. QOL is good at times and it is bad at times. The change in the QOL depends upon various aspects such as nature of illness, level of family support, productivity, routine, medication, etc.

Lehman’s A General Model of Quality of life (1988) is based on the assumption that quality of life is a subjective concept. This subjectivity is based on certain aspects such as personal characteristics, objective and subjective quality of life indicators in several domains of life. (cited in Angermeyer and Kilian 2006). The present study shows that both subjective and objective aspects are considered to be equally important in determining quality of life of people living with schizophrenia. Lehman suggests that quality of life covers three aspects, sense of well being which comes under the broad category of subjective quality of life. The other two aspects are functional status, and access to resources and opportunities which is covered under the category of objective quality of life. He developed a tool called Lehman Quality of Life Interview (QOLI). This is a scale used to assess ‘global life satisfaction, and objective and subjective quality of life in eight life domains: living situation, daily activities and functioning, family relations, social relations, finances, work and school, legal and safety issues, and health’ (Center for Mental Health Services Research, nd, 1).

QOLI is considered as appropriate in assessing quality of life of people living with severe mental illness in community settings. The domains mentioned under this scale are

135 http://www.ohsu.edu/xd/education/schools/school-of-medicine/departments/clinical-departments/psychiatry/faculty/upload/schizophrenia.pdf, accessed on 23-07-12
very much of relevance to the present study. Living situation of the participants in this study is crucial in determining their quality of life. A better performance in daily activities and well functioning is in fact an inevitable aspect of life quality. Family is the only source of economic and emotional support. Educational status is not great due to illness and diminishes the chances of getting a better job. Social security for people living with schizophrenia in India is still a dream. Health issues such as diabetes, blood pressure, obesity, cholesterol, etc., are alarming.

As per Bigelow’s model on mental health services (1982) it is important to provide opportunities for people living with schizophrenia and identify their capacity to meet the requirements of the society. This model is based on the assumption that quality of life is the result of interaction between need fulfillments and coping with societal demands placed upon each individual in the society. Here mental health services are meant to compensate the disabilities of people living with psychiatric disorders, their participation in the life through altering the intensity of societal demands, alternatives opportunities, and restoring their abilities (cited in Bobes and Gonzalz 2006). The participants of the study are availing rehabilitation services from a voluntary organization. The various rehabilitation programs are planned according to the deficits in the participants. These activities or programs are meant to enhance their participation in various life situations through restoring their impaired abilities. Participants are provided with opportunities to regain their skills and thus meet the requirements of the society to a certain extent.

The challenge is in identifying the opportunities in the society that a person with schizophrenia would be able to take up and make use of. Stigma against people living with mental illness is still a big barrier in reintegrating them back to the society. Awad’s integrative model for quality of life of schizophrenic (sic) patients receiving antipsychotic treatment (Awad et al 1997) discusses the relevance of the interaction between the ‘severity of psychotic symptoms, side effects (including subjective responses to antipsychotic drugs), and level of psychosocial performance’ (Bobes and Gonzalz 2006, 169).
The subjective perception of a person living with schizophrenia on her/his quality of life is an outcome of these three aspects and is also influenced by the resources available, strength of social network, and values and attitudes (Bobes and Gonzalz 2006). In the present study participants are under antipsychotic treatment. The participants in the present study were not symptomatic during the data collection period. There are various side effects that affect their day to day life functioning. Since the rehabilitation services in the facility are aimed at improving psychosocial performance professional observe medication side effects and report it to the psychiatrist immediately. Participants’ accepts antipsychotic medication as part of the treatment, but are not happy to continue it lifelong. Family support and professional assistance are the major resources available for the participants. Social network is limited to family, professionals, relatives, and in certain instances employers. The values and attitudes of the participants have played a role in treatment and thus in turn their quality of life.

Matrix18. Quality of life concepts (theory and data)

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<td>Lehman’s A general Model of Quality of life (1988), and</td>
<td>subjective and objective aspects</td>
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<tr>
<td>Bigelow et al. Quality of Life as a mental Health Service Outcome (1982),</td>
<td>Living situation, daily activities and functioning, family relations, social relations, finances, work and school, legal and safety issues, and health mental health services, fulfillment of needs and coping with societal demands,</td>
</tr>
<tr>
<td>Awad’s An Integrative model of Quality of Life for Schizophrenic Patients</td>
<td>severity of psychotic symptoms, side effects (including subjective</td>
</tr>
</tbody>
</table>

Happiness, achievements and success, Security, Meeting basic needs, Living with schizophrenia Living in a rehabilitation facility Performance level in various areas of life, Medications and health concerns, Employment status and economic stability Independent living, Moving out of rehabilitation facility, Family and professional support, Marriage and kids.

136 PLS who were not symptomatic for a period of six months to one year before data collection were chosen for the study.
New insights in theoretical framework

The outcome of the present study points at the relevance of a few theoretical perspectives such as Ecological Perspective in Social Work by Carel B. Germain (1973), Strengths Model in Social Work (1989), and Maslow’s Hierarchy of Needs (1943) that were not the part of the original theoretical framework. Therefore, these theoretical perspectives are considered as the new insights in to the existing theoretical framework. Data shows that various segments of community consist of self, family, relatives, friends, college, work place, rehabilitation centre, neighborhood, and the larger society.

Figure 3: Different levels or tiers of community from the perspective of the participants
(copied from analysis chapter ‘Participation in the Community’)

137 Though these theories were referred during the proposal writing stage it did not seem relevant at that point of time. After analysis of data it became evident that these theories are relevant with the findings of the study.
The levels/tiers of community and the areas of participation in the community from the perspective of participants can be related to ecological perspective used in social work practice. The ecological perspective introduced to social work by Carel B. Germain (1973) represents the interplay between the individual and her/his environment. Later environment was replaced by the term social determinants. The advantage of ecological perspective in social work is that it gives value to the individual’s concern. The ecological perspective also gives scope to the influences of environment on individual decision making.

In the present study individual, family, relatives, friends, college, work place, rehabilitation centre, neighborhood, and the larger society forms the different layers of community. The interaction with these various levels of community and the reciprocity from the community decides the level of participation of the individual in her/his community. The participation of participants who are able to take care of self, communicating with family, have a good family support system, engage in vocational activities or have a job, have better work environment, and friends outside the rehabilitation center is better than participants who lack these aspects. The involvement of community is also an important aspect determining the level of participation in the community. In certain instances though participants want to participate in the community it becomes difficult due to the negative behavior of the member in the community. This behavior can be from any member from the various tiers of the community. As per participants’ perspective their participation is limited to those people with whom they interact well.

The data shows that participants who have a well knit support system such as family, friends, professionals, religious organization, and relatives participate well in the community compared to those who do not have these layers of community. Another important aspect of the study is that participants try to adjust with the surroundings they

139 http://ecologicaltheory.tripod.com/, accessed on 13-03-13
140 http://www.uncp.edu/home/marson/348_ecological.html, accessed on 13-03-13
are in and use the resources available to improve their participation. Once participants settle down in the rehabilitation centre, then they start adjusting with their roommates, find courses suitable to continue studies, attend vocational activities, take help from the professional whenever necessary, and try to resolve conflicts on their own. The issue with this perspective in the context of people living with schizophrenia is the interaction between PLS and the larger community. Study shows that participants fear stigma to such as extent that they are cautious not to interact with people outside their immediate community. The question on what ways the participation of PLS in the larger community and attain support from the larger community still remains unanswered. (see case summaries in chapter ‘Living with Schizophrenia’)

The ways in which organization A and professionals try to encourage participation in the community is by focusing on the strength of the participant. This we can consider as an application of strength perspective (1989) which recognize the strengths, needs, and resources of the person and use those to bring the change in the individual\(^\text{141}\) (cited in Earley and GlenMaye 2000). In the present study professionals try to understand the needs of the participants. The need of the participants may be to impart self care habits, structure daily life activities, enhance cognitive skills, interpersonal interaction and family role functioning, developing confidence in self, develop work habits, and vocational skills training. The intervention is based on the skills which are already in place and use those skills as a resource to develop other skills. It is a step by step process where participants are able to identify the changes in various areas over a period of time.

If the participant has difficulty in maintaining self care and personal space then that is the area professional has to focus. In such instance continuous supervision and motivation is provided until the individual is able to maintain self care and personal space on her/his own. The interpersonal issues between family and the participant are another challenge. Here professionals focus on the ability of the individual to adjust with other members at the rehabilitation facility and stress that during the individual counseling sessions. Professionals also assess the family members’ behavior and approach towards the participant. In participants with cognitive difficulties professionals using various

\(^{141}\) [http://www.socwel.ku.edu/strengths/about/index.shtml](http://www.socwel.ku.edu/strengths/about/index.shtml), accessed on 13-03-13
psychological tests and tools to identify what skills are in place. If the participant’s ability to comprehend or communicate or concentrate or pay attention is in place then focusing on that skill professionals decide on the intervention plan. If the participant has difficulty in most of the cognitive skills then they are assigned to art and craft sessions and cover making sessions to improve those skills. When cognitive skills are in place professionals assign work in other vocational sessions. The challenge here is in planning the intervention. If the participant has full insight then professionals plan the intervention along with the participant. Whereas, professionals has to decide certain intervention plans in the instance of participants with partial insight or no insight.

The concept of quality of life has been explained based on various theories. WHO have developed a tool to assess health related quality of life. Lehman (1988), Bigelow (1982), and Awad et al. 1997 have done path breaking studies to understand and define quality of life in people living with schizophrenia and developed tools to assess quality of life. The theoretical framework of QOL in this study is heavily drawn from these studies. After analyzing the outcomes of the present study A.H. Maslow’s Hierarchy of Needs (1943) also appears relevant in determining the quality of life or expectations of future quality of life.

Maslow’s Theory of Need Hierarchy (1943) is explained in terms of human needs (Maslow 1964); Green 2000). According to Maslow there are five categories of needs for human beings; physiological needs, safety needs, belongingness and love needs, esteem needs, and needs for self actualization. These needs are a continuum, without fulfilling the first set of needs it is not possible to move forward to the next need (Green 2000). The data shows that the physiological needs are taken care of and participants are happy about it. Participants have a place to stay either with the family or at the rehabilitation facility. Their basic needs are met at present and there is a concern about future. The second need for safety is in place for all the participants for the moment since participants stay with family or in a rehabilitation facility.

Participants who do not have a stable relationship with the family and financial backing are worried about their future. Participants with a good family support and financial stability are not at all worried about their future. The level of Love, affection
and belongingness is different for participants with a good family and professional support, friends circle, and cooperative relatives. For participants without positive family support and lack of friends outside rehabilitation facility this level is not in place. Depending on family for everything lowers self esteem. For participants with a job and good interpersonal interactions, self esteem is achieved to a certain level. Living with schizophrenia and stigma goes side by side. The last or the highest in the hierarchy the need for self actualization is very limited and most of the time ceases to exist.

![Diagram](image)

**Figure 6:** The perspective of the participants’ quality of life based on Maslow’s need hierarchy theory

**Participation in the Community and Quality of Life of people living with schizophrenia**

The main objective of the study is to understand the interplay of participation of PLS in the community and their quality of life. Data shows that there are two positions regarding the interplay of participation in the community and quality of life. Most of the participants agree that participation in the community improves quality of life. There are participants who feel that participation in the community does not bring any changes in their quality of life. The concepts discussed under PIC are more or less similar to the
concepts in QOL. The difference is in the ways these concepts are perceived. Participation in the community refers to participation in various areas of functioning. Quality of life stands for participants’ subjective feeling about overall life situation. A careful scrutiny of both the themes revealed the intertwined aspects of PIC and QOL. Participation in the community is contributing to improve quality of life. Participation basically stands for taking part in various activities whereas quality of life encompasses activities, feelings associated with it, outcomes, and changes in participants’ lives. As per the data quality of life is a broader area and participation in the community is one of the aspects determining a better or worse quality of life.

The components of participation in the community are performing activities of daily life, maintaining communication with family, taking part in activities at rehabilitation facility, leisure activities, interaction with others (family, friends, clients and residents, relatives, students, office colleagues, attenders, shop personals) taking medication and regular consultations, keeping self busy or occupied, regular in job, take part in social functions, and helping others. Quality of life components are happiness, security, meeting basic needs, family and professional support, performance level in various areas of life, living with an illness, medications and health concerns, employment status, independent living, moving out of rehabilitation facility, marriage and kids, achievements and success, stigma and discrimination, economic stability, and prayer. Also quality of life is a comparative analysis of past and present status of life, and plans for future. There is a clear difference between the two, but are interconnected with each other. In fact we can assume that both the themes influence each other.

Participation in the community improves quality of life and a better quality of life enhances more participation in the community. Quality of life of a person living with schizophrenia is affected severely and so is her/his participation in the community. Data shows that participation in activities of daily life is the primary focus in psychosocial rehabilitation since it is foremost area affected by schizophrenia. It is not possible to carry out other interventions until participants’ daily activities are in place. Inability to perform daily activities affects participation in the community and quality of life. Sometimes assistance is required to perform these activities which decrease participants’
quality of life. In order to improve quality of life it is essential to focus on enhancing participation in daily life activities independently. Each of the areas affected by schizophrenia needs to be addressed to ensure a better quality of life. Ensuring participation in the community is important in achieving a better quality of life. Each of the activities mentioned under participation in the community eventually enable participants to lead a better life. The ultimate quality of life is to lead a life where the individual is happy with her/his own life. Individual’s hope to lead a better life is considered as a primary element of recovery (Jacobson and Greenley 2001).

Participants recognize the need of being a part of the community for a better quality of life. The study by Corring (2002) reported that being a part of the community is important for a better quality of life. Living with a severe mental illness does not deprive the right to live with dignity and respect. A life where PLS are accepted the way they are, and treated without stigma and prejudice is a life with quality. Though only a few participants expressed that participation in the community does not influence quality of life it is important to know why. They agree that their participation in the community is in place, they are self dependent and functioning well. Living with a severe mental illness like schizophrenia is a big barrier to quality of life. More than half of their life participants with chronic schizophrenia have been struggling with schizophrenia. They live in a rehabilitation center and do not know when they will be able to move out of it. Participants do not have a job and are dependent on their family for everything. Participation in community does not indicate a better quality of life when participants’ live in a rehabilitation facility and away from their family. The areas affected by illness are in a better state than earlier, but there are many aspects that deprives of a better quality of life. This is the reason for believing that PIC does not influence QOL.

The discussion chapter gives details of how study findings and literature complements and contrast each other. There are areas that need more research studies to make a conclusion on the relevance of looking at the subjective aspects of QOL. The findings cannot be generalized as that was not the purpose of study. The study findings point at the importance of understanding the perception of PLS regarding their life experiences. It also showed that the participation of PLS in their community is different
from people living without mental illness in certain ways and similar in certain ways. Quality of life is again different from one participant to the other. It is expressed in terms of past, present, and future. This comparison helped in assessing the level of quality of life during various periods of time. The change participation of PLS in the community brings on their quality of life is quite evident. Participation of PLS in the community has helped in improving their quality of life. The study also found that a better quality of life leads to a better participation of PLS in the community.
Figure 7: Conceptual Map: Participation in the Community and Quality of Life of People living with Schizophrenia

**People living with schizophrenia**

- **Before the onset of schizophrenia**
  - Self care, Education and work, Relationships

- **Living with schizophrenia (LS)**
  - Schizophrenia, Self care and ADLs, Relationships, Cognitive difficulties, Hospitalizations and rehabilitation, Education and work, Emotional distress, Discrimination

**Living with schizophrenia changes the nature and extend of PIC**

**PIC**
- **Self**:
  - Performing activities of daily life, Keeping self busy or occupied, Helping others, Taking medication and regular consultations,

  - Family:
  - Communication with family, helping family at home, Attend social functions

  - Work:
  - Job

  - Rehabilitation:
  - Taking part in activities at rehabilitation facility, Leisure activities, Interaction with others,

**Living with schizophrenia lowered QOL**

**QOL**
- Past: Stigma and discrimination, implications of living with schizophrenia

- Present: Living with an illness, living in a rehabilitation facility, Medications and health concerns, Family and professional support, Better performance level in various areas

- Future Expectations: Medications and health concerns, Employment status, economic stability, Family and professional support, Independent living, Discharge, Marriage and kids, Achievements and success, Happiness, security, Meeting basic needs, Dignity and respect

**Better PIC and QOL help to adapt ways to improve living with schizophrenia**
CONCLUSION

This section is an overall summary of the study and its findings. The study was an attempt to understand the perceptions of people living with schizophrenia (PLS) on their participation in the community (PIC) and quality of life (QOL). The initiative was to explore the perception of PLS on their participation in the community and quality of life.

Participation and community has been defined in the context of people living with schizophrenia. Participation is the involvement in any activity or program. Community is defined on the basis of closeness to the participants. In that sense community involves family, HWH or LSH resident members, DC clients, relatives, professionals, friends, colleagues, neighbors, and class mates. The wider community or society did not have a place in the definition of immediate community. The stigma existing against people living with schizophrenia is the main reason for less presence of wider community in participants’ lives. The participation of PLS in the community is mainly in the form of participation to self, participation in the family, participation at work place/education, and participation in the rehabilitation centre. Participation to self consist of self care, maintaining own space, taking medication, having a routine, health care and medication, and prayer and/or religious activities. Participation in the family is through regular contact with their family members (HWH and LSH), participation in family matters, decision making, and emotional and economic support. Participation at work and education involves performing well in work and studies respectively. Participation at the rehabilitation centre revolves around taking part in activities at the centre. Participation of PLS in the community has a positive outcome on their quality of life.

Quality of life of participants in the study is over shadowed by the fact of living with schizophrenia. Quality of life is expressed on the basis of time period such as in the past, present, and future expectations. Since the aim was not to measure the level of quality of life, the study has not attempted to generalize the quality of life in people living with schizophrenia. A certain level of comparison in quality of life of participants at HWH, LSH, and DC naturally emerged out of the data. This comparison was based on a few aspects such as the constant physical presence of family members in daily life, employment status, improvement in schizophrenia, participation in the community, and
daily life performance. It does not indicate that the life at any one of the centre is better than the other. It shows the various ways of quality of life of PLS. The data showed that quality of life of two individuals is difficult to compare, but there are areas where quality of life is better for one person than the other. Though participants are not happy about their quality of life in the past, they feel quality of life is better at present than in the past. Participants expect to improve their quality of life in the future through regular treatment, family and social support, and hard work. Quality of life depends on the presence and extent of social support participants receive. Family support is a considerable aspect in improving life quality. The data shows that participants with good family support have shown sizeable progress in their functioning.

Participation of people living with schizophrenia in the community has helped in improving quality of life. The various forms of participation in the community paved way to improve numerous areas of life. PIC helped in improving self care which participants consider as an important element in QOL. The data shows that whenever participation in the community declined that resulted in poor quality of life. Interestingly there is an opinion that PIC does not improve quality of life. This is because of the absence of participation in the wider community. Participants felt that since they are living with schizophrenia and attending a rehabilitation center, it does not matter how much they participate in the community, their quality of life is never complete. Though this opinion was expressed by two participants, it is important to note that PIC and QOL is whole when the community accepts PLS. The study shows the significance of involvement of community in improving the participation in the community and quality of life of people living with schizophrenia.

The study considered people living with schizophrenia availing the services of the rehabilitation centre. It would have broadened the scope of the study, if the perception of PLS living in the community has also been considered. The study also points at the relevance of providing rehabilitation services to enable the participation of PLS in the community and thus in turn improve their quality of life.