INTRODUCTION: CONCEPTS OF STUDY AND THEORETICAL FRAMEWORK

The present study is 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 study explores the various facets of participation of people living with schizophrenia in their community. It delves into the perception of people living with schizophrenia regarding the various aspects that contribute to their quality of life. This chapter is an attempt to explain the various concepts used in the present study. The endeavor is to introduce the concepts of the study as existing in the literature. The various concepts in the study are schizophrenia and living with schizophrenia, participation in the community, and quality of life. The concepts are followed by the theoretical framework of the study. Theoretical framework basically consists of biopsychosocial model (1977); therapeutic community approach (1963); International Classification of Functioning, Disability, and Health (ICF 2001) model by World Health Organization; Calman’s Gap Theory (1984); QOL theories in schizophrenia Lehman (1988), Bigelow (1982), and Awad et al. (1997); and Sociocultural theory.

Concepts of the study

Schizophrenia and living with schizophrenia

Schizophrenia (SZ) is a persistent mental disorder/illness. The term schizophrenia was introduced by Swiss psychiatrist Eugen Bleuler in the beginning of 20th century.

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1 The term ‘schizophrenia’ is questioned by prominent research bodies due to the stigma it causes. Since the term has not been replaced by another less stigmatizing term I have no choice but to use it in my research work.

2 ‘In DSM-IV, each of the mental disorders is conceptualized as a clinically significant behavioral or psychological syndrome or pattern that occurs in an individual and that is associated with persistent distress (e.g., a painful symptom) or disability (i.e., impairment in one or more important areas of functioning) or with a significantly increased risk of suffering death, pain, disability, or an important loss of freedom…Whatever its original cause, it must currently be considered a manifestation of a behavioral, psychological, or biological dysfunction in the individual’ (Diagnostic and Statistical Manual of Mental Disorders IV TR 2000, xxxi).
Before that schizophrenia was known as dementia praecox, a term introduced by Morel in 1857 (cited in Smith 1966). Though Kahlbaum (1863), Hecker (1871), and Falret (1878) provided various categorizations, it was Emil Kraepelin (1896) who defined dementia praecox as a single entity of disease (ibid). Bleuler used the term ‘schizophrenia’ to depict a split in the mind. Bleuler used the term schizophrenia since he believed that individuals experienced a split in various activities of mind such as perception, thought, and emotion. As per Bleuler’s conceptualization this split is the reason behind the bizarre behavior in PLS (Nagaswami 2004). Though Bleuler agreed with Kraepelin in the organic causation of schizophrenia, he disagreed with Kraeplin on many other aspects in understanding the illness. He categorized the symptoms of schizophrenia into two; fundamental symptoms and accessory symptoms. He believed that life experiences have a significant influence on the illness. He also brought a humanistic view to schizophrenia and broadened the scope of psychosocial aspects in the course and treatment of schizophrenia (Shean 2010).

International Classification of Diseases and Related Health Problems 10th revision (ICD-10) defines schizophrenia as

> ‘The schizophrenic disorders are characterized in general by fundamental and characteristic distortions of thinking and perception, and affects that are inappropriate or blunted. Clear consciousness and intellectual capacity are usually maintained although certain cognitive deficits may evolve in the course of time. The most important psychopathological phenomena include thought echo; thought insertion or withdrawal; thought broadcasting; delusional perception and delusions of control; influence or passivity; hallucinatory voices commenting or discussing the patient in the third person; thought disorders and negative symptoms’ (ICD 10 2010, 92).

This definition helps to understand the various areas affected by schizophrenia such as perception, thought, and emotion. It also gives an account of symptoms present in people

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3 This split is different from the split in a split personality disorder.
living with schizophrenia. PLS experience various distressing symptoms such as hallucinations, delusions, and thought disturbances. These symptoms destroy the rhythm of their daily life functioning. The definition indicates that there is a higher possibility of losing cognitive abilities over a period of time. Schizophrenia also affects the social life and work performance of the individual. ‘…For a significant portion of the time since the onset of the disturbance, one or more major areas of functioning such as work, interpersonal relations, or self-care are markedly below the level achieved prior to the onset…’ (DSM-IV-TR 2000, 312). Schizophrenia affects all the areas of functioning of the person living with it. There are various guidelines offered by ICD-10 and DSM-IV-TR for diagnosing schizophrenia. The present study is not covering the diagnostic process of schizophrenia.

Schizophrenia is characterized with positive and negative symptoms. Positive symptoms consist of ‘delusions’, hallucinations, and disorganized behavior’ (Sadock and Sadock 2010, 149). Negative symptoms include ‘affective flattening, alogia’,

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4 ‘Delusions…are erroneous beliefs that usually involve a misinterpretation of perceptions or experiences. Their content may include a variety of themes (e.g., persecutory, referential, somatic, religious, or grandiose)….The distinction between a delusion and a strongly held idea is sometimes difficult to make and depends in part on the degree of conviction with which the belief is held despite clear contradictory evidence regarding its veracity’ (DSM-IV-TR 2000, 299).

5 ‘Hallucinations…may occur in any sensory modality (e.g., auditory, visual, olfactory, gustatory, and tactile) but auditory hallucinations are by far the most common. Auditory hallucinations are usually experienced as voices, whether familiar or unfamiliar, that are perceived as distinct from the person’s own thoughts. The hallucinations must occur in the context of a clear sensorium….Certain types of auditory hallucinations (i.e., two or more voices conversing with one another or voices maintaining a running commentary on the person’s thoughts or behavior) have been considered to be particularly characteristic of Schizophrenia…’ (DSM-IV-TR 2000, 299-300)

6 ‘Grossly disorganized behavior…may manifest itself in a variety of ways, ranging from childlike silliness to unpredictable agitation. Problems may be noted in any form of goal directed behavior, leading to difficulties in performing activities of daily living such as preparing a meal or maintaining hygiene. The person may appear markedly disheveled, may dress in an unusual manner (e.g., wearing multiple overcoats, scarves, and gloves on a hot day), or may display clearly inappropriate sexual behavior (e.g., public masturbation) or unpredictable and untriggered agitation (e.g., shouting or swearing). Care should be taken not to apply this criterion too broadly’ (DSM-IV-TR 2000, 300).

7 ‘….Affective flattening is especially common and is characterized by the person’s face appearing immobile and unresponsive, with poor eye contact and reduced body language. Although a person with affective flattening may smile and warm up occasionally, his or her range of emotional expressiveness is clearly diminished most of the time…. ’ (DSM-IV-TR 2000, 301).
avolition\textsuperscript{9}, and anhedonia\textsuperscript{10}. Schizophrenia is also pictured with various dysfunctions in cognitive and emotional functioning. It is not necessary that a person living with schizophrenia may have all the positive and negative symptoms. Sometimes negative symptoms may be prominent than positive symptoms or vice versa. Both types of symptoms affect the level of functioning, cognitive abilities, and interpersonal interactions of the individual. Functioning in daily life declines and the person shows a tendency to withdraw from the community. Schizophrenia is categorized into various subtypes based on the symptoms present in an individual. There are mainly five subtypes of schizophrenia. They are ‘paranoid type, disorganized type (earlier known as hebephrenia), catatonic type, undifferentiated type, and residual type’ schizophrenia (DSM-IV-TR 2000, 303). ICD-10 offers three more categories of schizophrenia ‘post-schizophrenic (sic) depression, simple schizophrenia, and other schizophrenia’ (ICD 10 2010, 100-103).

In paranoid schizophrenia delusions of paranoid nature accompanied (sometimes) by auditory hallucinations are the prominent features. Disorganized schizophrenia is characterized with delusions, hallucinations, irresponsible and unpredictable behavior, inappropriate mood, disorganized thought, incoherent speech, and social seclusion. Psychomotor dysfunction is the core feature in catatonic schizophrenia. These psychomotor disturbances can be either hyperactivity or stupor. Undifferentiated schizophrenia follows the general diagnostic guidelines for schizophrenia but do not fall under any subtypes. In residual schizophrenia negative symptoms are prominent and are characterized with a chronic (long term) stage of illness (DSM-IV-TR 2000; Cooper 1994). Post-schizophrenia depression as the name suggests is a state of depression after

\textsuperscript{8} ‘….Alogia (poverty of speech) is manifested by brief, laconic, empty replies. The individual with alogia appears to have diminution of thoughts that is reflected in decreased fluency and productivity of speech….’ (DSM-IV-TR 2000, 301).

\textsuperscript{9} ‘….Avolition is characterized by an inability to initiate and persist in goal-directed activities. The person may sit for long periods of time and show little interest in participating in work or social activities’ (DSM-IV-TR 2000, 301).

\textsuperscript{10} ‘….Anhedonia is common and is manifested by a loss of interest or pleasure….’ (DSM-IV-TR 2000, 304).
an episode of schizophrenia. People diagnosed with simple schizophrenia shows strange behavior, and a decrease in their personal and social performance (Cooper 1994).

There are various theories and models explaining the causes of schizophrenia. These models or theories elucidate the causes of schizophrenia and treatments plans. Some of the well versed models and theories in causation of schizophrenia are: Biological model, psycho-social model, socio-cultural model, anti-psychiatric model, labelling theory, double-bind theory, and schizophrenogenic mother (Warner et al 2009; Aritie 1997 Neill 1990 cited in Pinder 2006; Carson and Butcher 1992; Coercrham 1981; Peacock and Mathews 1985; Roberts 2001). In the field of psychiatry schizophrenia is considered as an illness. Considering schizophrenia as an illness is due to the influence of biomedical model that still rules the discipline of psychiatry. Biomedical model points mainly at the changes in biological process as the causal factor of schizophrenia. Psycho-social model explains the influence of psychological and social aspects in the occurrence and treatment of schizophrenia. Socio-cultural model points at the relevance of cultural aspects along with other aspects in causing schizophrenia. Anti-psychiatry model oppose the notion of viewing schizophrenia as an illness.

Most of the rehabilitation approaches are influenced by these theories and models. Each model is rich in explaining its own notions on causal factors, but none of them are able to give a comprehensive image of the concept of schizophrenia. Each theory suggests a way to deal with one or the other aspect of schizophrenia. At present biopsychosocial model introduced by George Engel (1977) is considered as an extensive explanation for cause and treatment of schizophrenia (cited in Lakhan 2006). This has helped professionals in planning and designing an appropriate rehabilitation model as per the needs of a person living with schizophrenia. This to a certain extent has helped in resettling PLS back in the community.

Nations for Mental Health (1998) reports that the incident rate of schizophrenia vary between 0.1 and 0.4 per 1000 population per year. Estimates made by WHO in 2002 shows that 25 million people suffer from schizophrenia worldwide. As per the ‘Epidemiological Study of Prevalence of Mental Disorders in India’ conducted in 2001 by Murali S. Madhav, the prevalence rate of schizophrenia is 2.3/1000 population. The
WHO collaborative study report indicates that the annual incidence rate of schizophrenia per 1000 population in rural and urban Chandigarh is 0.42 and 0.35 respectively (Eaton 2006). Gender does not play a significant role in ‘age at the onset of schizophrenia’ (Angermeyer and Kuhn 1988, 351). Vijay and Sinha (2009) found out that there is no significant gender difference in schizophrenia symptom profile. They also found that paranoid schizophrenia is the most common subtype closely followed by undifferentiated schizophrenia. The life expectancy rate in people living with schizophrenia is lesser than the general population (Thara 2005). Paranoid schizophrenia was prevalent among females and undifferentiated type among males (Vijay and Sinha 2009).

**History of mental health services** for people living with mental illness

The development of psychiatry as a separate area of medicine started in late eighteenth century. The approach was to keep people living with schizophrenia in institutions. The interest was to protect community from people living with schizophrenia. Protection of people living with schizophrenia was not the concern. During this period they were kept in mental asylums for treatment. The treatment in mental asylums composed of medication and physical restraints. All this created a fear in society that people living with schizophrenia are dangerous. This fear prompted to keep PLS away from the society. Over the years attitude towards people living with schizophrenia has changed a little bit. ‘The development of psychiatric services started with the era of moral management, later it became asylum movement which gradually gave way to social psychiatry and ultimately reached in community care’ (Gelder et al. 1983, 645-7). The treatment for mental illness has a long history. It traversed from the dark period of witchcraft, isolation and physical restraining to a humanistic approach. The development of psychiatric services was influenced by various movements in the field of mental health. These movements had an impact on the rehabilitation approaches for people living with schizophrenia. Therefore, it is important to have an overview of the history of psychiatric services worldwide and in India.

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11 In this study the term mental health services will be used to represent psychiatric and rehabilitation services. ‘Mental health service, a group of government, professional, or lay organizations operating at a community, state, national, or international level to aid in the prevention and treatment of mental disorders’ (http://medical-dictionary.thefreedictionary.com/mental+health+service, accessed on 08-06-12).
The changes in the field of psychiatry was the result of several movements starting with moral treatment movement, mental hygiene movement, deinstitutionalization and the community care movement, the community reform movement, and the recovery movement (Openshaw et al. 2008). The moral treatment movement was associated with the enlightenment era. The history of psychiatric services shows that people living with severe mental illness/schizophrenia was also treated by traditional healers. This treatment most of the time turned brutal and inhuman. People who were against such inhuman treatments argued that humanistic approach can help people living with severe mental illness/schizophrenia to attain a dignified life. This thought paved way for the moral treatment movement in the beginning of nineteenth century. Philippe Pinel was known to be the main proponent of moral treatment movement (Geniuses 2010). The philosophy behind this movement was to provide respect and care to people living with severe mental illness/schizophrenia. The focus was to encourage doctor-patient interaction with a humane approach to care (ibid). The care was again custodial rather than community or family care. Though in the beginning this approach was successful, it became insufficient when the number of people living with severe mental illness/schizophrenia started increasing. The quality of care declined and dropped due to lack of resources. This inadequacy paved way for a new approach called Mental Hygiene Movement.

The Mental Hygiene Movement (MHM) was inspired by the ideologies of dynamic psychiatry proposed by Adolf Meyer. This movement was also influenced by the book ‘The Mind that Found Itself” written by Clifford Beers. The book narrated his experiences in various mental hospitals. The focus of mental hygiene movement was more on prevention than treatment of mental illness. Therefore, children and education system were the focus of this movement (Mental Hygiene 2008). MHM emerged as a response to the need for quality of care in the asylums. The quality of care provided in asylums was insufficient due to the overcrowding of people living with mental illness and lack of financial support from the local government (Openshaw et al. 2008). The main challenge was to reintegrate people living with mental disorder back into the community. The major difficulty in placing them back to the community was the nature and course of
illness since the symptoms were unpredictable in nature. MHM motivated community based care and services for people living with severe mental illness/schizophrenia in the asylums. Providing care for people living with mental disorder in non-institutional settings became the focus of attention after the World War II.

The community mental health movement started in late 1940s and early 1950’s. The need for a community based and accessible health care became relevant during this era. The introduction of Lithium and Chlorpromazine was a breakthrough in the development of community based care. This approach was also known as ‘community psychiatry/community mental health movement/ non institutional care’ (Murthy 1992, 111). In 1960s deinstitutionalization of people living with severe mental illness/schizophrenia became rapid. British mental health acts in 1959-60 changed the conception of asylums. They made it mandatory that people who have recovered (who did not require constant supervision and care) should be discharged from asylums. The problem was where to accommodate discharged individuals if families were not ready to accept them. In such instances local authorities were liable to make arrangements for their living (Affleck 1975). The deinstitutionalization movement was motivated by the invention of antipsychotic, antidepressants, and neuroleptic medications. These drugs helped in reducing and controlling the symptoms. It enabled people living with severe mental illness/schizophrenia to stay with their family in the community. The philosophy behind the change was that along with the protection of the community protection of people living with mental illness/schizophrenia became equally important.

A major contribution of community care was the development of community mental health teams (CMHT). CMHT was meant to provide care in the community than a hospital or an institutional setting (Effective Health Care 2000). It was also a time when laws governing people living with mental illness underwent a reform in various developed countries. The aim of community mental health movement was not only to reduce institutionalization but also to provide adequate resources to make a living. However, the failure in providing resources for a living resulted in the community reform

12 http://www.mnpsychsoc.org/history%20appendix.pdf, accessed on 07-06-12
movement. The Community reform era during 1975 was based on the recognition that people living with severe mental disorder may lead a productive life if provided with treatment, medications, housing, vocational assistance, and medical care. These developments helped in considering community care as an integral part of psychosocial rehabilitation. All the above four movements were mainly focused on the curative part of mental illness rather than the preventive aspect. This paved way for the fifth movement referred as recovery movement. The recovery movement is consumer driven, started in 2002 in USA with the formation of President’s New Freedom Commission on Mental Health - 2003 to recommend improvement to the USA mental health service system (Openshaw, et.al 2008).

The advent of community psychiatry gave a new face to the rehabilitation of people living with severe mental illness. Community psychiatry also known as the third psychiatric revolution started after the era of deinstitutionalization in developed countries. This approach emphasized the importance of discharging people living with severe mental illness from mental hospitals, and bringing them under the care of community mental health care centers (Ahuja 1990). Mental health gained momentum after World Health Organisation accepted it as an integral part of health care. Prevention of mental illness and promotion of mental health practices were recognized as equally relevant as cure. Prevention of mental disorder and promotion of mental health became a key factor in reducing stigma on mental illness. The effect of stigmatization of mental illness was not limited to people living with mental illness, but extended to their family members and significant others. Family was often viewed as the source of the mental illness (Encyclopedia of Mental Disorders 2010). Stigma also lead to the refusal of treatment both by the individual and the family. Family found it difficult to approach professionals for help due to the fear of isolation.

The Indian Scene

The worldwide developments in the field of mental health services had its influence on Indian psychiatric arena. Mental health services in India started as part of philanthropic concerns. Over the period of time it turned into a professional service. The
history of Indian psychiatry gives a picture of ongoing struggle to provide accessible and affordable mental health services to people living with mental illness. It was after independence mental health care and people living with mental illness got a significant place in health policy. This was clearly mentioned in National Mental Health Program report by Ministry of Health and Family Welfare. During the mid of 20\textsuperscript{th} century mental health care became an integral part of national concern.

‘Before Independence, there were no clear plans for the care of the people living with mental disorder. The approach was largely to build ‘asylums’ which were custodial rather than therapeutic. Around the time of independence, the situation in regard to mental health services is best presented in the recommendation of the Bhore committee (1946)’ (Ministry of Health and Family Welfare 1989, 2).

It was around late 1970s and early 1980s a realization occurred that existing facilities were not adequate to treat people with severe mental illness. Another aspect was the scarcity of trained mental health professionals in the existing facilities to provide adequate care. These concerns led to the formulation of National Mental Health Program (NMHP). The development of services in the field of mental health seriously started with the introduction of NMHP (India) in 1982. NMHP was the after effect of the workshop held in New Delhi for mental health and related professionals on providing accessible and affordable mental health care (\textit{ibid}).

In 1987, Mental Health Act (MHA) was drafted by the parliament which came into effect in April 1993. In comparison to its predecessor ‘the Indian Lunacy Act (1912)’ MHA brought major changes. It suggested modifications in various terminologies used to represent people living with severe mental illness. For example, in an attempt to reduce stigma, the term mental asylum was replaced with mental hospital. Though these attempts were helpful in reducing stigma to a certain extent, the real challenge was to provide affordable and accessible mental health services to the community. The establishment of General Hospital Psychiatry Units (GHPU) helped in meeting this challenge to some extent. The understanding that mental hospitals cannot be solely relied for care of people living with mental disorder motivated the introduction of GHPU. Foundation of GHPU brought a belief that mental disorder is like any other physical illness and can be
successfully treated. This initiative also assisted in reducing the stigma on mental illness. Integration of mental health services in primary health care was another mile stone in the development of mental health care services. Experience in Bangalore and Chandigarh showed that services of primary health personnel’s were effective in the management and care of people with severe mental disorder (Rao and Kuruvilla 1997).

Post independence history of psychiatry in India illustrates the development of new mental hospitals, GHPUs, training professionals and para professionals, implementation of MHA 1987, and introduction of various rehabilitation programs for people living with mental illness and their family (Nizamie and Goyal 2010). In India mental hospitals formed a vital part of mental health services and still continue to be a major player in disseminating mental health services (Krishnamurthy et al. 2000; Nizamie and Goyal 2010). During the pre independence era mental health care was restricted to mental hospitals. Even in the present era mental hospital forms a crucial part in the treatment of mental illness. Earlier mental hospitals acted as a custodial care facility. Later it started outpatient care which proved to be beneficial for both people living with severe mental illness and their family. In the 1980s, a few mental health clinics became operational in some parts of the country. The Schizophrenia Care and Research Foundation (SCARF), an NGO in Chennai established a community clinic at Thiruporur in 1989 which functioned till 1999. During this period various programmes such as training of the primary health center staff, setting up a referral system, setting up a Citizen's Group, and self-employment schemes were initiated (cited in Thara et al. 2008). ‘According to recent survey conducted by Ministry of Health, Government of India, at present, there are about 39000 inpatients in 38 mental hospitals in India, giving an average of more than 1000 patients per hospitals’ (Sharma and Kala 1999, 5). The specific problems faced by the mental hospitals were paucity of resources, people living with persistent mental illness, stigma attached to mental hospitals, and lack of good leadership (Sharma and Chadda 1996). Attempts were made to improve the services at mental hospitals, but still most of the mental hospitals lack basic facilities.

It became evident that government alone cannot tackle the mental health care requirements of the population. The growing awareness on the lack of resources to
address the mental health needs of the population led to the development of NGOs in mental health care. It is here Non Governmental Organisations (NGOs) became a crucial supporter in providing mental health care services. NGOs act as a catalyst between government and community without the direct control of the government. The concept of partial hospitalisation was a very important and innovative alternative to hospitalization. This later transformed into day care centers and half way homes. NGOs have played and still continue to play a significant role in filling the gaps between mental health needs and resources. They also had a role in innovating new models of health care in poorly served populations (Patel and Thara 2003). After NGOs became active in rendering mental health services community care approach became significant in rehabilitation and reducing stigma. NGOs started various intervention programs for people living with mental illness. The difficulty in implementing these programs was the disability emerged from living with a severe mental illness especially schizophrenia. Prevention of disability and enhancing self reliance became the primary aim of NGOs working in this field (ibid). Thus the treatment and rehabilitation of people living with severe mental illness has been passed through various stages, and was also influenced by different treatment approaches. The treatment and rehabilitation process for people living with mental illness should be flexible enough to incorporate the best components of existing mental health care services.

**Treatment and Psychosocial Rehabilitation (PSR)**

Treatment plans for schizophrenia includes pharmacotherapy and psychosocial rehabilitation (Castle et al. 2008). Pharmacotherapy consists of antipsychotics, antidepressants (if depressive features are present during the episode), and medicines for anxiety (if anxiety is present). Another treatment method which is not commonly recommended is Electroconvulsive Therapy or ECT. The use of ECT is controversial and not an integral part of the treatment plan. It is used as the last resort when antipsychotic medications are least effective (Tharyan and Adams 2009). Psychosocial rehabilitation is a combination of behavioral therapy, supportive psychotherapy, individual and family counseling, group therapy, social skills training, occupational therapy, vocational training, and support groups (Jones and Marder, 2008). Treatment plan is designed as per
the requirements of the person living with schizophrenia. It is chosen on the basis of severity of symptoms and extent of impairments in various areas of functioning. Rehabilitation is a process of rebuilding the lost abilities and skills of the person affected with schizophrenia. ‘Rehabilitation is an educational process. The patient must learn to use the capabilities he has and to discount those he may have lost’ (Deaver 1959, 1278).

Rehabilitation is the process through which a person is assisted to adjust with the limitations of her/his disability. This process takes place through the combined effort of people living with schizophrenia, their family, friends, relatives, and professionals and paraprofessionals. Factors influencing the rehabilitation process are communication, knowledge, skills and attitudes of professionals, and socio-economic factors. The focus of rehabilitation is on the quality of life of the person, how he/she lives and works (Hume and Pullen 1986). ‘Psychiatric rehabilitation refers to efforts to restore persons with psychiatric disabilities to optimal states of constructive activity’ (Pratt et al. 2007, 14). Rehabilitation of people living with schizophrenia is focused on improving their psychological and social functioning. Psychosocial rehabilitation (PSR), therefore, focuses on reintegrating PLS back into their social life. ‘Psychosocial rehabilitation is often the key to reintegration’ (Crosse 2003, S77). PSR gained attention when the relevance of providing care after discharge from the hospital was recognized. Earlier treatments were limited to antipsychotic medication and prolonged hospitalizations.

The terms psychiatric rehabilitation and psychosocial rehabilitation are used interchangeably. However, literature shows that there is a difference between both the terms. Psychiatric rehabilitation model is influenced by biomedical model where as psychosocial model draws its philosophical grounding from social rehabilitation model. The efforts to distinguish psychiatric rehabilitation from psychosocial rehabilitation were given up due to the problems of separating rehabilitation from treatment for mental illness (Corrigan et al. 2008). In case of severe mental illness the term psychosocial rehabilitation is more frequently used. ‘Psychosocial rehabilitation refers more specifically to restoration of psychological and social functioning and is most frequently used in the context of mental illness’ (King et al. 2007, 3). Psychosocial rehabilitation consists of various components to assist PLS in attaining a minimum level of functioning.
PSR plan generally consists of training in basic living skills, independent living skills, money management, interpersonal relationship, time management, and social skills (Murali et al. 2001). These components are decided on the basis of the need and extent of cognitive and functional deficits in PLS.

The reality that pharmacotherapy was not sufficient for proper functioning of PLS in the community/society motivated mental health professionals to consider after care services. During the deinstitutionalization movement in the United States many people living with chronic schizophrenia were discharged from the hospital and placed in the community. Community was least prepared to accommodate these discharged PLS. Thus the attempt was damaging and most of the PLS ended up living in the streets. The concept of community based rehabilitation services has its roots in providing care for PLS in the community. However, the disability emerged out of schizophrenia was devastating and disconcerting. Psychosocial rehabilitation was formulated to reduce the disability in PLS. The challenge for the mental health professionals was to design an appropriate community based PSR plan. This paved way to the development of various alternatives for care such as day care, halfway homes, long stay homes, shelter homes, day hospitals, and night hospitals (Nagaswami 2004; Soddy and Ahrenfeldt 1967).

Generally, there are two broad types of rehabilitation facilities for people living with schizophrenia. They are residential rehabilitation facility and non-residential rehabilitation facility. As the name constitutes residential facility is where accommodation facility is provided during the treatment process whereas non-residential facilities offers care during the day time (Murali et al. 2001). Hospitals, halfway homes, foster homes, and long stay homes fall under the category of residential rehabilitation facility. Day cares, sheltered workshops, partial hospitalisation, and vocational training centers are various non-residential rehabilitation facilities. Most of the rehabilitation services falling under the category of residential rehabilitation facility are based on the therapeutic community approach. Therefore, it ensures that PLS are equipped with skills necessary for appropriate community functioning.

PLS accessing non residential rehabilitation services stay with the family and the wider community while utilizing the services. Hence, they are constantly in contact with
the community. This approach is recognized as more effective than residential rehabilitation facility due to the constant presence of family and community in the process of treatment, management, and rehabilitation of PLS. Social support plays a crucial role in determining the success of rehabilitation activities. Chapman and Chapman (1978) says that ‘social support includes caring and sustenance provided by the social environment, as well as the emotional and material support that people obtain from their social relationships’ (cited in Bellack et al. 2007, 817). Literature explains social support as a causal aspect and a supporting aspect in the recovery of an illness (Cohen and Syme 1985). However, for those who are in need of continuous medical and psychiatric care, and supervision residential facility with the persistent support from family members is appropriate.

**Participation in the community**

Participation of people living with schizophrenia in the community is a least explored area of research. Oxford dictionary defines the term participation as ‘the action of taking part in something’\(^\text{13}\). As per Oxford learner’s pocket dictionary participation is to ‘take part or become involved in an activity’ (Oxford learner’s dictionary 2008, 318). Participation can be taking part or involving self in any big or small activity. It is an act of engaging self into various activities such as activities of daily living, social activities, occupational or work related activities, or philanthropic activities. Human beings are participating in one or the other activity throughout their life. The importance of participation in any activity depends on the individual’s need and perception about that activity. Participation is a broad term and its meaning changes as per the situation in which it is used. The concept of participation in a person with schizophrenia may be different from a person without any mental illness. In the similar way the notion of community may also be different for a person living with schizophrenia.

Generally, community is a broader concept and defining it is quite a difficult task. There are many sociological explanations for a community. A few definitions of community give a comprehensive picture regarding the term.

\(^{13}\)http://oxforddictionaries.com/definition/participation?q=participation, accessed on 13-06-12
MacIver defines community as ‘an area of social living marked by some degree of social coherence. He further says “whenever the members of any group, small or large, live together in such a way that they share, not this or that particular interest, but the basic conditions of a common life, we call that group a community (cited in Bhushan and Sachdeva 2001, 9).

Blaire E. Merca defines ‘a human community is a functionally related aggregate of people who live in a particular geographic locality at a particular time, share a common culture, are arranged in a social structure, and exhibit an awareness of their uniqueness and separate identity as a group’ (cited in Bhushan and Sachdeva 2001, 9). These two definitions give a general idea regarding the concept of community. Hawley (1950) defines community as ‘the structure of relationship through which a localized population provides its daily requirements’ (cited in Beshers 1962, 14). As per these definitions community is a place where people live together and share a common life. They share the identity of the group they belongs to. From these definitions we can assume that community has two characteristics; it is a social entity and a territorial unit.

The term that is commonly used to refer participation of general population in their community is ‘community participation’ (CP). Oakley (1985) defines community participation as ‘as active process where intended beneficiaries influence programme outcomes and gain personal growth’ (cited in Rifkin and Kangere 2001, 41). The concept of community participation used in community based rehabilitation (CBR) is ‘Community participation is the organisation of activities by groups of persons who have disabilities (or their family members/friends), in conjunction with others who do not, to increase their ability to influence social conditions, and in doing so to improve their disability situations’ (Boyce and Lysack nd, 45). This definition explains CP as an organized activity by the people who are affected by disability, their families and significant others (friends, relatives, guardian, etc.). This can be in collaboration with others who are not affected by any disability. The purpose behind CP in CBR is to improve the life situation of the beneficiaries.

The idea of participation in the concept of ‘community participation’ is an active process where a person takes part with a purpose. Participation is not limited to the mere
presence of the person in the meeting or activity, but involving self in it (Boyce and Lysack nd). Pateman (1970) suggests that suitable definitions of participation must include four elements - participation by someone, participation with someone, participation in something, and participation for some purpose’ (cited in Boyce and Lysack nd, 45). Is it possible to apply the concept of community participation to represent the involvement of people living with schizophrenia in the community? Though it looks similar it is not the real case. Community participation has a broader meaning and application. It is mainly used to represent the participation of any community in activities related to their lives. Community participation is a collective action by the community on matters regarding their life. Whereas participation of PLS in the community they live calls for a detailed analysis. The question here is what does ‘participation’ and ‘community’ means to a person living with schizophrenia. Are they participating in the community? How do they participate in the community while living with such a disabling mental disorder? What are the different ways in which they participate in their community? The concept of community in this context refers to relationship between people in groups with a common aim, for example, therapeutic community. This type of community is known as community of interest and used to refer community in people living mental illness, disability, etc (Report of the Richmond Fellowship Enquiry 1983).

The ideas mentioned above gives a general picture of the term community. Is this same for a person living with schizophrenia? The rationale behind this question is the stigma and discrimination faced by PLS in the community. The assumption is that PLS are participating in the community and this has a connection to their quality of life. The questions that needs further exploration are how do they define the term community and what are the various ways they involve self in that community? If the meaning of participation and community is different for PLS, it is essential to understand that difference from their perspective. Once these two concepts are in place then it is easy to explore how PLS participate in their community. Let us assume that the term community is same as the definition above. Then in what ways do PLS participate in that community? The current research is an attempt to explore these questions. These questions are relevant because studies show that schizophrenia drastically affects social functioning. The aim of psychosocial rehabilitation is to restore these functional abilities
and skills. The burden of schizophrenia on individual, family, and society is higher compared to any other physical and mental illness. With all these difficulties how do they participate in the community? The literature on participation in the community of people living with schizophrenia is limited. Participation in various areas of life is a crucial aspect in determining an individual’s quality of life.

**Quality of life**

The word quality of life means various things to individuals. What does the word quality of life stands for? A very interesting explanation is given in the Handbook on Quality of Life for Human Service Practitioners ‘….quality makes us think of the excellence or “exquisite standard” associated with human characteristics and positive values such as happiness, success, wealth, health, and satisfaction; of life indicates that the concept concerns the very essence or essential aspects of human existence’. (Schalock et al. 2002, 1). It can range from material possessions to psychological satisfaction. Quality of life is considered as a multidimensional concept (Felce 1997). It consists of both objective and subjective elements. Subjective elements include happiness, well-being, and satisfaction whereas objective elements include basic living facilities, safety, accessibility to services, and financial stability. These two elements form the foundation of QOL measurement (Korr and Ford 2003). In short objective QOL consists of involvement in ‘activities and relationships’ and the subjective aspect of QOL refer to ‘life satisfaction’ or ‘subjective well-being’ (Narvaez et al. 2008, 201-2)

The definition of QOL by Department of Environmental Planning (2009) has a macro level applicability. It encompasses different areas of life and the interaction between these areas. ‘Quality of life (QOL) is seen as the product of the interaction of a number of different factors – social, health, economic, and environmental conditions – which cumulatively, and often in unknown ways, interact to affect both human and social development at the level of individuals and societies’ (Department of Environmental Planning 2009, 1). This definition is useful to measure quality of life of a population rather than an individual’s quality of life. For example, a person’s quality of life is determined by various factors such as finding happiness in life, meeting the basic needs, good relationships, acquiring a job, attaining economic independence, enjoying luxuries.
If the individual is suffering from any physical ailments recovery from that illness can be the primary element of her/his quality of life. According to Felce and Perry (1996) ‘Quality of life has been defined as an overall general well-being that is comprised of objective and subjective evaluations of physical, material, social, and emotional well-being together with extend of personal development and purposeful activity, all weighted by a personal set of values’ (cited in Corring 2002, 350).

WHO’s definition on quality of life in the field of health is considered as a comprehensive definition. It covers various aspect of an individual’s life. WHOQOL is a sensitized tool to capture cross cultural nuances in well-being (Skevington et al. 2004).

WHOQOL Group defines health-related QOL ‘as the individuals’ perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by a person’s physical health, psychological state, level of independence and the relationships to salient features of the environment’ (cited in Zikmund 2001, 529).

Health related quality of life (HRQOL) consist of different broad domains such as financial status, employment status, physical health, functional abilities, subjective wellbeing, social life, and psychological functioning. Health related quality of life is used in assessing quality of life of people living with schizophrenia (especially chronic and severe). There are various reasons for using HRQOL in people living with schizophrenia. The main reason to use this tool is that the focus of treatment and rehabilitation has been shifted to community care due to the process of deinstitutionalization (Cramer et al. 2000). The question here is does quality of life remain same for the individual over a period of time?

Quality of life of a person living with mental illness (PLMI) is different from a person living without any mental illness. It is complicated to identify what can be considered as quality of life for a person living with mental illness (PLMI). The attempt always was to assess or measure quality of life. Generally, in people living with mental illness quality of life is measured using various scales, it is generally a process of evaluation. The scales
for measuring quality of life in PLMI were developed keeping in mind the various features of the illness. There are various instruments for measuring QOL in people living with severe mental illness. These instruments are useful in giving a general picture of QOL domains. They do not explore the perceptions of the person living with severe mental illness on their QOL. Other issues of using scales for measuring QOL are related to conceptualization, psychometrics, and the extent of domains assessed (Korr and Ford 2003).

The breakthrough in measuring quality of life of people living with severe mental illness was the development of Quality of life interview by Lehman et al. (1988). Cross sectional studies by Lehman et al. (1982), Baker and Intagliate (1982), Shadish et al. (1985), Pinkney et al. (1991), Sullivan et al. (1991), and Skantze et al. (1992) paved way to the development of scales to measure quality of life in various domains of people living with severe mental illness (cited in Barry and Zissi 1997). The limitation of these scales was that it gave less scope for the perspective of the individual living with mental illness. Katsavdakis et al. (1999) have developed ‘The how are you? Scale: A quality-of-life outcomes measure for routine practice’ (cited in Korr and Ford 2003, 23). It is a 55-item scale that gives emphasis to PLMI’s perspective. It uses the language familiar to the PLMI, and the mode of administration is basically conversation between the PLMI and interviewer. This scale also consists of QOL domains that are relevant to the PLMI. The design of the scale is such that it can be used during the clinical practice and ensures PLMI’s participation in assessment and progress. Preliminary studies regarding the administration of this scale points to a better psychometric properties (Korr and Ford 2003). Though this scale looks at the perception of PLMI it is still limited in covering the perceptions of PLMI/PLS.

Among the various mental illnesses defining quality of life of a person living with schizophrenia has always been the difficult task. Schizophrenia is a severe and damaging mental illness that affects various areas of functioning. It will not be exaggerating to say that schizophrenia destroys the quality of life of the individual. The complication in defining the quality of life of a person living with schizophrenia is in identifying the aspects she/he considers as contributing to quality of life. Studies that explore the
perceptions of PLS regarding their life in general are limited. Schizophrenia and the
disability arising out of it still remains an enigma for mental health professionals. The
challenge is in promoting quality of life of people living with schizophrenia in touch with
the nature of illness and disability. The scales for measuring quality of life in people
living with schizophrenia were developed considering the nature of illness, disability, etc.
The scales can give only one side of the picture. It is important to understand the
perception of people living with schizophrenia regarding their quality of life. The idea of
allowing the person living with schizophrenia to talk about her/his life is over looked by
researchers.

The present study does not attempt to measure quality of life and therefore do not
propose to use any scales. It is necessary to understand the perception of people living
with schizophrenia regarding their quality of life. The aim of the study is to know the
perception of PLS about their quality of life. This will help in identifying the insider’s
(PLS) perspective rather than trying to evaluate their life. Another focus is to understand
the relevance of participation in the community on quality of life. The initiative is to
explore the perception of PLS on their participation in the community and quality of life.
What are the various ways in which PLS participate in the community? Does this
participation influence their QOL in any ways?

Theoretical framework of the study

The theoretical framework for the present study consists of the theories that will
support in explaining the concepts of the study. It also explains the relationship between
the concepts and limitations of the study\textsuperscript{14}. Theoretical framework strengthens the web of
relationship between the concepts. Four main theoretical models are used in the present
study:

- Biopsychosocial model (1977),

\textsuperscript{14} \url{http://libguides.usc.edu/content.php?pid=83009&sid=618409}, accessed on 04-06-12 and
\url{http://bold-ed.com/framework.htm}, accessed on 04-06-12
• Therapeutic Community Approach (1963),

• International Classification of Functioning, Disability, and Health (ICF) model by WHO (2001)

• Calman’s Gap Theory (1984)

• Quality of life models by Lehman (1988), Bigelow (1982), and Awad et al. (1997),

• Sociocultural theory.

**Biopsychosocial** model (1977)

Biopsychosocial (BPS) model is the contribution of George Engel (1977) as an alternative for biomedical model. Biomedical model did not consider the psychological and social factors that influence the illness experience. Biopsychosocial model considers the biological, psychological, social and cultural aspects in the process of illness. In psychiatric illness and the person living with psychosis the relevance of biological, psychological, and social factors are equally important (Engel 1977; Leigh 1997). Though BPS was developed as an alternative to biomedical model, it can also be used as a supportive model to biomedical model as per the context in which it is used. In the present study two sub sections of BPS model are given priority:

• Biopsychosocial model of psychiatric illness: the psychiatric illness is the focus of attention. The psychiatric illness is considered as a result of biological, psychological, cultural and social factors operating at the biological, personal, and environmental level respectively. Here the mental health professional has to differentiate the influence of each factor in the process of illness (Leigh 1997).

• Biopsychosocial model of patient: the experience of the person living with illness is given priority in this section. The person’s social and cultural background, personality, intelligence level, etc., are focused (*ibid*).
This theory is relevant in the present study for it encompasses social, cultural and psychological aspects along with biological aspect. The psychosocial rehabilitation process of PLS is based on the similar idea. Since the study involves PLS undergoing rigorous rehabilitation process, this model will help in understanding the structure and rationale of treatment and rehabilitation methods used.

**Therapeutic Community Approach**

‘Therapeutic Community (TC) is a term coined by Tom Main in 1940s’ (Dolan et al. 1992). The idea behind the concept was to help soldiers suffered from war neurosis by introducing groups in hospitals. Later this concept was popularized by Maxwell Jones and Stuart Whiteley. Therapeutic community is used as a treatment approach for people living with psychiatric illness (cited in Lees et al. 1999). Therapeutic community derived its philosophical root from social therapy. The method used in therapeutic community was group psychotherapy influenced by psychoanalytical approach (Clark 1981).

‘Tom Main defined therapeutic community as an attempt to use a hospital not as an organization run by doctors in the interests of their own greater technical efficiency, but as a community with the immediate aim of full participation of all its members in its daily life and the eventual aim of resocialization of the neurotic individual for life in ordinary society’ (cited in Kumar and Srinath 2009, 40).

The term ‘Therapeutic Community Approach (1963)’ (TCA) was coined by David Clark. Therapeutic community approach is an extended version of therapeutic community proper concept. This approach was developed for people living with mental illness in asylums (cited in Campling 2001).

The common philosophy behind therapeutic community is that a therapeutic environment is essential in the process of treatment. The principles guiding therapeutic community are responsibility to self, combined decision-making, and open communication. The strength of therapeutic community is the belief that all community members’ professionals, paraprofessionals, and residents or clients are active participants in the process of healing (Wright and Wendi 2000). Therapeutic community approach is different from other modes of treatment in two ways. First it is used as a method to
facilitate change and second it is the context where change takes place. The community is used as the primary agent of change and growth. This approach follows a systematic treatment perspective; it gives focus to the person, her/his illness, recovery and appropriate living. Therapeutic community approach differs according to the severity of the illness (Leon 1994).

Therapeutic community model focuses in four areas; person, illness, recovery, and respectable living attitudes. The mode of treatment is community, where community is both a tool and the context. Schizophrenia causes deficits in psychological, cognitive, vocational, familial, and social life of the individual. In order to curb these deficits therapeutic community offers various intervention programs. These programs enable individual to lead a productive and socially active life. The most important part of therapeutic community is the use of community as a method to bring change. Using community as a method helps PLS to meet other people with similar issues. This enables them to learn from each other and help self in recovery. Creating a peer network is important to sustain interactions and growth. TC suggests a schedule to follow so that participants’ day is tightly packed with structured activities. Feedback from the members helps the individual to assess their performance. It is a process of helping each other through the means of learning. The role of professional is intense and important. In case of people living with schizophrenia professional has more involvement in the process (Leon 1994).

**International Classification of Functioning, Disability, and Health (ICF) model by WHO (2001)**

ICF model (2001) consists of all aspects related to health. It encompasses various components of health related well-being. ICF is a structured body of information about health and health related functionings. ICF is divided into two parts; components of functioning and disability, and components of contextual factors. Functioning and disability covers various functions of the body, and activities and participation. Contextual factors consist of a list of environmental and personal factors that influence the functioning and disability. ICF has a wider applicability, it is not just a model for people living with disability. Functioning and disability aspect holds interest since it
explains the various activities a person with disability performs. It also helps to understand how a person living with disability participates in activities. The term activity is defined as the performance of any task. Participation is defined as the involvement of the person in any life situations. The activities and participation are qualified by two aspects; capacity and performance of the person. Capacity is defined as the ability to carry out a task. Performance explains what a person does in her/his current environment. ICF has also given definitions of activity limitations and participation restrictions. Activity limitations are problems a person experience in carrying out the activities. Participation restrictions are difficulties a person faces in involving in the life situations (ICF 2001).

![ICF model](image_url)

**Figure 1: ICF model-Components of functioning and activities**

This model gives a comprehensive picture of functioning and activities in various life situations. Most importantly the model has defined each of these terms in a simple language. The part consisting of functioning and activities is very important for the present study. Schizophrenia affects functioning in various areas of life. It limits a person from involving in her/his life situations. ICF explains various areas of functioning and the levels of participation in each of the areas.
**Calman’s Gap Theory (1984)**

Calman (1984) placed an interesting argument in measuring QOL which is known as gap theory. In this concept he says that time plays an important role in determining quality of life. He gives importance to individual’s aspirations and experiences at a point of time or over a period of time. These time periods (the present situation, the past experiences, and future expectations) play a crucial role in understanding an individual’s quality of life (Cited in Bowling 2001). The other aspect in QOL is the gap between reality and goals of the individual. Calman’s idea was to propose a hypothesis in defining quality of life of people living with cancer. His idea was that quality of life can only be explained by the concerned individual and should consider many areas of life (Calman 1984).

‘The term 'quality of life' extends not only to the impact of treatment and side-effects, but to the recognition of the patient as an individual, and as a whole person, body, mind and spirit. A study of the quality of life is difficult for two reasons. Firstly, there is a real problem in defining what is meant by ‘quality of life'. Secondly, even if this were possible, there remains the difficulty of quantifying 'quality of life' and of comparing one individual with another. There is also the related, but equally important fact that measurement may not be important from the point of view of the patient’ (Calman 1984, 124).

Though Calman used gap theory in cancer patients this theory is relevant in people living with schizophrenia because it gives importance to the individual’s interpretation about her/his QOL and also consider the element of time. Gap theory recognizes that quality of life in an individual do not remain same over a period of time, it keeps changing.

**Quality of life models by Lehman (1988), Bigelow et al. (1982), and Awad et al. (1997)**

When we consider quality of life as a theory it is important to take into account the term subjective well-being (SWB). QOL and SWB are sometimes used interchangeably. Kozma and Stones (1980) says that subjective well-being includes ‘happiness, life
satisfaction, and morale’ (cited in Kozma et al 2000, 13). Sirgy M. Joseph (2002) quotes ‘that subjective well-being involves both positive and negative affect as well as affective and cognitive experiences’ (cited in Joseph 2002, 1). Micheal B. Frisch (2000) in his article ‘Improving mental and physical health care through Quality of Life Therapy and assessment’ comments that ‘In Quality of life theory life satisfaction is equated with quality of life and refers to a person’s subjective evaluation of the degree to which his or her most important needs, goals, and wishes have been fulfilled’ (italicized in the original document) (cited in Frisch 2000, 220). In short quality of life theory gives a picture of relationships between people’s subjective experiences and their quality of life. This is the basis of theoretical framework governing the present study.

Quality of life theories are vast and each theory addresses different aspects. The present study is focused on the QOL of people living with schizophrenia. Therefore, three theoretical models are used in understanding quality of life of people living with schizophrenia.

- Lehman’s A general Model of Quality of life (1988),
- Bigelow et al. Quality of Life as a mental Health Service Outcome (1982),
- Awad’s An Integrative model of Quality of Life for Schizophrenic Patients Receiving Antipsychotic Treatment (Awad et al 1997)

Lehman’s A General Model of Quality of life (1988): the basic assumption of this model is that ‘Quality of Life is a subjective concept which depends on the personal characteristics, objective quality of life indicators in several domains of life, and subjective quality of life indicators in several domains of life’ (Angermeyer and Kilian 2006, 20). The subjective indicators in this model composes of ‘how people living with illness feel about their lives and are influenced by expectations, prior experiences and perceptions of current conditions of life’ (Bobes and Gonzalz 2006, 167). ‘Objective indicators reflect norms of function and life style’ (ibid, 167). These aspects of objective and subjective indicators are important in the present study for it gives importance to both feelings and functions. This feeling is highly influenced by their expectations and experiences in life. The subjective indicators help in understanding the meaning people
living with schizophrenia attach to their life. The objective indicators help in identifying the accessibility and affordability of the services, and the resources available. Lehman’s model helps in understanding the subjective and objective factors associated with an individual’s QOL.

Bigelow’s ‘Quality of Life as a mental Health Service Outcome’ (1982) aids in identifying the importance of providing opportunities to people living with schizophrenia and their capacity to meet the requirements of the society. The basic assumption of Bigelow’s model is that quality of life is the result of interaction between the fulfillment of needs and coping with demands society places upon its members (Bobes and Gonzalz 2006). Bigelow’s model considers mental health services as trying to compensate for the deficit in the abilities of people living with psychiatric disorders. It also tries to reimburse impaired participation in the normal opportunity structure through moderating social demands, supplementing opportunities, and restoring abilities (ibid). This model is relevant in this study due to the importance it gives to mental health services. The present study tries to look at mental health services provided by an NGO to enhance participation as an opportunity to fulfill their basic needs through regaining their abilities. Thus in turn enable them to meet the demands society placed on them. This is another way of bringing people living with schizophrenia back to the community by helping to minimize their disability through various activities organised for them. It is done with the help of individual’s family and other community support system.

Even if Bigelow’s model (1982) helps in understanding the opportunities provided by the society and capabilities of the person living with mental disorder, it does not mention the importance of symptomatic behavior and its influence on their perception. The model introduced by Awad et al. (1997) known as ‘integrative model for quality of life for schizophrenic patients receiving antipsychotic treatment is based on the assumption that the patient’s subjective perception is the outcome of an interaction between three major determinants; severity of psychotic symptoms, side effects (including subjective responses to antipsychotic drugs, and level of psychosocial performance’ (Bobes and Gonzalz 2006, 169). The quality of life of the person living with schizophrenia’s subjective perception is an outcome of these three major factors which also influenced by
resources, social network, and values and attitudes (ibid). It is important to consider the nature of illness of people living with schizophrenia which has an influence on their perception on participation in the community and quality of life. Severity of the psychotic symptoms may color their perception. This eventually may affect their psychosocial performance. The side effect of medicines causes distress to the person living with schizophrenia which affects their subjective responses. This study would consider the severity of symptoms and the level of psychosocial performance of people living with schizophrenia since these two aspects are closely associated to their involvement in participation in the community and the perception on quality of life.

**Sociocultural theory**

Sociocultural theory is based on the work of psychologist Lev Vygotsky. He thought that ‘parents, caregivers, peers and the culture at large were responsible for the development of higher order functions’ (Cherry 2012, 1). It is important to consider the social and cultural background of the people living with schizophrenia. These aspects have an influence on their involvement in the community they live, their day to day life experiences, the way they perceive these experiences, and the influence of the significant people in their life. Socio cultural theory views people living with schizophrenia as a component of their social system in which they live (Peacock and Mathews 1985). This theory would be used to get an insight into the culture and its influence on PLS perception on their quality of life. Their perception on quality of life is influenced by support from the community and interactions with the community. In India this approach has been used in the study ‘The Great Universe of Kota Stress, Change and Mental Disorder in an Indian Village’ by G.M Carstairs and R. L. Kapoor (1976). They says

‘It stands to reason that if the frequency of occurrence of an entity in two different situations is to be compared the entity should be defined in the two situations. This is very difficult to accomplish in the case of mental disorder since the very concept of what is psychologically normal or abnormal is dependent on the beliefs, values and codes of human interaction which characterize a given cultural group, and therefore varies from one group to another. Each culture has its own
criteria of reality, and a symptom regarded as indicative of mental abnormality in one may not be so regarded in other’ (Carstairs and Kapoor 1976,11).

The above mentioned theories help researcher to identify the various areas of participation in the community, general parameters of quality of life of people living with schizophrenia and its significance on the their perception of quality of life.

**Conclusion**

Biopsychosocial model is used to understand the structure of rehabilitation process. Therapeutic community approach will help to explore the role of community as a treatment method. ICF model is used to guide in structuring functioning and activities of PLS. Calman’s gap theory is useful to understand the differences in QOL over a period of time. Quality of life models is used to direct the literature in assessing objective and subjective aspects of quality of life in people living with schizophrenia. Significance of cultural background is well recognized in the present research. Socio cultural model is known for its contribution in understanding the cultural and social components of people under study.