

# Living with a disability: A perspective on disability in people living with schizophrenia (PLS)

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## Abstract

Schizophrenia is devastating of all mental illness. Disability arising out of schizophrenia is as disastrous as any physical disability. This illness affects all areas of functioning and impairs basic living skills. Disability in carrying out everyday life activities and social functioning is the prominent aspect of schizophrenia. It affects the productivity and capability of the person living with it. It prevents people living with schizophrenia from carrying out even the least complex activity. Symptoms are such that it prevents the individual from focusing on any activity. Their involvement in social activities decreases over the period of time. Their participation in community activities tends to be minimal. People living with schizophrenia show a tendency to avoid contact with other people. This is a major reason for complete social isolation and non-active social life. Studies show that medication and psychosocial rehabilitation are helpful in reducing disability. The time, money, and effort required for psychosocial rehabilitation process are the challenges. The data used in this article is part of a larger ethnographic study.

**Key words:** schizophrenia, disability, psychosocial rehabilitation

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## Introduction

Mental health is considered as a state where an individual is able to carry out his/her activities independently, maintain relationships, face struggles of daily life effectively, and contribute to the community. In this sense mental illness can be considered as a state; where an individual does not realize her/ his abilities, not able to cope with stressors in life, unable to work productively, and not able to contribute to the community. Mental illnesses were traditionally categorized as neurosis and psychosis but currently they are grouped into themes according to the similarities in their manifestations. Schizophrenia is the most severe among all the mental illnesses. Schizophrenia is manifested in the form of positive symptoms and negative symptoms. It drastically affects various areas of life. This disorder disrupts the day to day life functioning of the person. Self care, interpersonal relationships, social involvement, and vocational life are all affected (Thara 2005). Disability occurring due to mental illness is one of the major causes increasing the global burden of disease (Chaudhury et al. 2006). Disabilities in various areas such as educational performance, vocational activities, independent living skills, activities of daily life are recognized as part of psychotic illnesses. Disruption in social functioning also adds to the burden of disability.

Under the framework of Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995 mental illness is any illness related to mind that may dismantle a person's thought, perception, and feelings resulting in disruption of abilities to function in various areas of life (Chaudhury et al. 2006). A general understanding of disability is that of a situation where the person is not able to engage or carry out the socially and culturally expected roles. World Health Organization has developed a tool called WHODAS (Disability Assessment Schedule) to address the question of measuring the degree of disability. In India disability arising out of mental illness has been recognized as disability since the conception of People with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995. The Indian Disability Evaluation and Assessment Scale (IDEAS) have been developed by the Rehabilitation Committee of Indian Psychiatric Society to measure the disability level in various areas of functioning. This tool is used by mental health professionals to assess the level of disability in people living with mental illness and plan rehabilitation as per the outcome.

Assessing disability in schizophrenia is yet again a very difficult process since all areas of life are affected. Disability in schizophrenia is not as visible as physical disability. Most of the time the lack of interest in activities of daily life is misunderstood as laziness, but studies has shown that this is a part of schizophrenia (Holmberg and Kane 1999). As per International Classification of Functioning (ICF 2001, 3) definitions of 'functioning' and 'disability', this lack of interest is considered as a disability. Therefore the present article attempts to understand the different kinds of disability experienced by people living with schizophrenia. How these disabilities influence their quality of life? And how over the period of time disability becomes a part of their life? This paper also tries to identify existing theoretical assumptions on disability and rehabilitation procedures to counter disability in schizophrenia. To strengthen the arguments personal narratives of people living with schizophrenia are used to substantiate the literature. The data used in this article is part of a larger ethnographic study 'participation in the community and quality of life in people living with schizophrenia' conducted at a rehabilitation center from May 2010 to February 2011. The data collection was part of doctoral research work. Method of data collection was in depth interviews with people living with schizophrenia and observations during data collection. Before starting the interview participants were informed about the academic use of the data, and a written consent was obtained from each participant.

## Disability in schizophrenia

There are studies showing neurocognitive impairments as the main reason for disability in schizophrenia (Bowie et al. 2010). As per International Classification of Disorders Tenth Revision or popularly known as ICD 10 schizophrenia is a disorder in which thought, affect, and perception are severely affected (ICD 10

1994). Schizophrenia is the ninth leading cause of disability among the major causes of disability (Thrithalli et al. 2010). In schizophrenia disability mainly occurs in social functioning and cognitive ability though other areas are also affected (Velthorst et al. 2010). The reason for considering disruption in social functioning as a severe disability is due to the inability in maintaining a minimum level of social involvement. Person living with schizophrenia finds it extremely difficult to initiate and pursue any form of social activity. Cognitive deficits have been identified as one of the prominent characteristics of schizophrenia (Alptekin et al. 2005). Studies show that these deficits remain consistent for a longer period (Krishnadas et al. 2007). The extent of disability will be different for each individual living with schizophrenia. In order to understand disability we need to know what functioning means.

As per International Classification of Functioning (ICF) 'Functioning is an umbrella term encompassing all body functions, activities and participation; similarly, disability serves as an umbrella term for impairments, activity limitations or participation restrictions' (ICF 2001, 3). In simple words functioning depicts a fully fledged activity level whereas disability refers to difficulties and limitations in performing any activities. Schizophrenia is considered as a severe psychotic disorder with major impact on the person's functional capacity. It eventually results in functioning deficits which is difficult to recover (Viertiö 2011; Harvey et al. 2007). These deficits are manifested in the areas of self care, relationships, work, and social life. Interest in self care decreases as the person does not take care of personal hygiene activities such as brushing teeth, taking bath, changing clothes, combing hair, and cleaning nails. It is very difficult for a person living with schizophrenia to harbor interest in self care when she/he is floridly symptomatic. The Individual have to struggle every day for sustaining interest in daily life activities and responsibilities. In most instances she/he need motivation and personal assistance along with regular medication to perform these activities.

*...I lost interest in personal hygiene activities. My mother used to give me bath and dry my hair, she used to comb my hair...they [parents] took care of me like a baby.... (Narayani is living with schizophrenia for past 12 years)*

Relationships with the spouse, family members, friends, and relatives are strained due to the illness. It becomes difficult for the person to sustain a relationship when the individual is confused about the state she/he is in. The symptoms are such that sometimes PLS are suspicious that family is against her/him, or people are talking about her/him. They find it difficult to initiate conversation with others when it is tiring to put thoughts together. Conflicts with family members are quite common. Schizophrenia affects not just the individual but his/her family (Canavan 2000). Studies show that expressed emotions by the family members are one of the main causes for relapse (Pharoah et al. 2003). If the family is not supportive it affects the improvement and results in frequent relapses. Relapses pose biggest challenge to treatment and rehabilitation. Even though the PLS is on medication relapse may occur, to avoid such instances regular follow up is necessary. The need for regular follow up is not correctly understood by the PLS or family. Stigma also prevents them from approaching for treatment on a regular basis. Studies on effectiveness of antipsychotic medications show that maintenance therapy is required for a longer period (Barnes et al. 2011).

*...I used to ill treat my mother sometimes like shouting at her beating her...I used to beat my brother....it affected my studies also I couldn't get nice marks as I was getting earlier before the attack of schizophrenia, I finished my schools once on supplement, up to MA I did but still regrets I couldn't perform well only got sixty percent for BA and second division for MA....I lost my intelligence completely, I am not able to think like before I used to, I can grasp but I can't understand some....schizophrenia devastated my career completely. I am not leading life like normal people....this illness has affected my quality of life.... (Jayamala is living with schizophrenia for last 15 years)*

Disability is visible in vocational activities; PLS find it difficult to perform well in work (Harvey et al. 2007). Studies show that work is a crucial factor influencing quality of life in people living with psychiatric disability-

ies. If the onset is at a very young age for example fifteen or sixteen then their educational achievements are severely hampered. This prevents from building a good career or earning a better job. There are a few studies exploring the relationship between cognitive deficits, educational achievements, and work (Krishnadas et al. 2007). Those who are in job have difficulty in being consistent with it. This is due to the unpredictable nature of schizophrenia resulting in frequent absences from work. Finding out a job is difficult since most of the employers are not open to hire people living with mental illness in general. Most of the time people living with schizophrenia had to hide the fact of their illness, but that becomes even more complicated. Though the symptoms will recede over the period of time, the decreased ability in performing activities persists, and this is the biggest challenge for PLS in carrying out any work.

It is like challenging the world, challenging the people, I don't like speaking, and otherwise I would have kept mum if people were not speaking to me....we started a factory making corrugated cardboard cartons... I used to do the field work, getting's payments, getting orders, and getting deliveries done... then my brother was giving me some jobs on the computer for data entry... This went on for some time; I stopped it because I was hospitalized in between that. The reason I was hospitalized was because of the result of stress the work had on my nerves. I began to have obsessions and compulsions, typing out sentences and erasing them dozens of times before I got it in a perfected manner, shouting every time, the obsessions became too much and the work was going haywire... maybe the medication was not working, I was earning only 10,000 a month.... I worked for 10 years, without any problem, but now my condition is not suited for work, I am now not interested in work. No, stamina, interest is not there, I cannot sit for more than 5 minutes on the computer (Govind is living with schizophrenia for last 40 years)

Social life especially social relationship of PLS is severely affected (Mulvany 2000). PLS distance self from the society and society alienates them due to schizophrenia. PLS isolating self from society could be due to the fear of isolation from the society once the diagnosis is known. Another reason is fighting with symptoms on everyday basis takes a toll on the individual and prevents her/him from approaching people. People living with schizophrenia withdraw from all the social activities they used to engage before they had schizophrenia. Their interaction with relatives, friends, and colleagues gradually decreases and ceases. It has to be noted that isolation and discrimination based on schizophrenia is widespread among general population. The stigma associated with schizophrenia is mainly due to the manifestations of aggression, genetic predisposition, disability, and unpredictable nature of the illness (Thara 2005). The literature shows that social disability is a prominent feature of schizophrenia. It also suggests that social dysfunction affects the course and outcome of schizophrenia (Wolff 2011). Family too faces the wrath of society especially from relatives and neighbors. Therefore most of the time family members conceal the fact of illness from everyone. This can adversely affect the treatment and rehabilitation.

*....So far being in a rehabilitation center is okay, once I am out of here I don't know how it is going to be. Mental patients words are like written in water no one listens to us....i feel people doesn't share much with me, they don't mingle with me, unless I go and mingle with them they don't open up. Who ever come to me I talk. Unless and until they are not interested in me I don't talk. I talk to my sisters and mother.... (Pazhani is living with schizophrenia for last 20 years)*

### Theoretical assumptions in disability

There are various theoretical assumptions regarding disability due to health conditions. ICF is considered as a comprehensive framework for evaluating the functioning level and disability related to health domains (ICF 2001). ICF framework focus on 'health and health related domains' (ibid 3), it explains the health situation of a person. This model explains structure and functioning related to the body, and capacity for participation and performance in activities. This model explains the functioning and disability associated with various health conditions specified in ICD 10. Functioning is the positive aspect and disability is the negative aspect of a

health situation. ICF model considers functioning and disability as an outcome of the interplay between disease and environmental conditions. Schizophrenia as mentioned earlier affects the personal and social areas of the individual. The domains quoted under activities and participation in ICF framework are affected by this health condition. It also gives scope to compare the functioning and the capacity of the person to perform these activities. Therefore this framework is very relevant while discussing disability due to schizophrenia. It also discusses the relevance of environmental support for countering disability. Family and societal support is necessary for a person living with schizophrenia to function effectively.

The social model of disability was introduced after realizing the drawbacks of looking disability from a medical point of view. The drawback of medical model of disability was the absence of voice of people living with disability. It became essential to address the issue of disability from a broader point of view consisting medical, social, and cultural aspects (Barnes 1998). Social model of disability theory focuses on social and cultural factors in aggravating mental illness (Mulvany 2000). Social model of disability helped in bringing out the perspective of people living with disability regarding their living with a disability. This theory also tries to distinguish between impairment and disability (Tregaskis 2002). 'Impairment is the functional limitation within the individual caused by physical, mental or sensory impairment. Disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers' (Barnes 1991, p. 2 cited in Tregaskis 2002). This difference helps to understand the functional limitations that an illness causes, and the barriers in using the opportunities available to participate in the community. These two theoretical assumptions have helped in understanding that disability in schizophrenia should be perceived within the framework of physical, psychological, social, and cultural contexts.

## Treatment and Rehabilitation to reduce disability

The focus of health services earlier was on the elimination of illness. Traditional health practices did not focus on the well being of the person. It took a long time to shift the focus to the after effects of illness, especially the disability occurred due to any physical or psychotic illness. This led to the need for considering the first person account of illness experience in order to build a more comprehensive approach towards the illness (Solkanki et al. 2010). The problem in psychiatric arena was the reluctance to come out of the realm of medical model. The realization that psychological and social aspects also needs to be considered while planning for treatment led to the introduction of social model of mental illness. Social context of a person is as equally important as her/his physical aspects in causing mental illness (Pullen 1986). The treatment for PLS consists of pharmacotherapy, and psychosocial rehabilitation. Pharmacotherapy consists mainly of antipsychotic medication. If the symptoms consist of depressive features antidepressants are also used to counter those symptoms.

Antipsychotic medicines are helpful in reducing the symptoms and thwarting relapses. Problem with antipsychotic medicines are their inefficiency in countering negative symptoms. A study by Thirthalli et al. (2010) suggests that antipsychotic medication in fact reduces the amount of disability in schizophrenia but depends on the quality of family support they receive. Over the period of time it became clear that medication alone is not sufficient to counter the impacts of schizophrenia. It is here rehabilitation of people living with schizophrenia gained more attention. Rehabilitation of PLS aims to reduce the disability and improve their functional ability. There could be confusion on when and where rehabilitation should begin. Rehabilitation starts the moment a person is diagnosed with schizophrenia (Pullen 1986). Hume (1986) explains the term rehabilitation as 'the process through which a person is helped to adjust to the limitations of his disability' (43). This is the simplest way of explaining rehabilitation in a person with psychiatric illness. 'Psychosocial rehabilitation is often the key to reintegration' (Crosse 2003, 77).

Medicine is helping me to reduce symptoms. I was referred by my psychiatrist to a rehabilitation center, here I have a routine at home I used to sit idle here I am busy and that is helping me, I started interacting with

others...I am attending courses related to my educational background so that I can start working once I have acquired the skills to be in a job. My family supports me both financially and emotionally. I share my problems with them they console me. Their support makes me feel that they can understand me.... (Vimal is living with schizophrenia for last 17 years)

The focus is mainly on redeveloping the impaired skills and strengthening their coping abilities. Theoretically the patient should be treated as a person and her/his opinion should be given due importance (Pullen 1986). In reality this rarely happens, and most of the time rehabilitation in the literal sense does not happen. In the words of Pazhani

*...Mental patients' words are like written in water no one listens to us...*

It is not necessary that people living with schizophrenia turn violent all the time. When symptoms are florid people living with schizophrenia finds it difficult to carryout minimal self care activities. Therefore, the first step in rehabilitation is to reduce the intensity of the symptoms. This calls for regular medication and follow up. Most of the time PLS give up medication once they feel better or are able to take care of self. This poses the biggest challenge for rehabilitation planning. Any rehabilitation process aims to improve the quality of life of the person receiving the services. Rehabilitation services tries to help the person to reduce the disability and be independent in all areas (Hume 1986). The duration of rehabilitation for people living with schizophrenia depends on the needs and extent of the disabilities in her/him.

The concept of recovery from severe mental illness like schizophrenia has two different positions. A service based definition of recovery depicts improvement in symptomatic behavior and impairments caused by illness. People living with mental illness view recovery as personal growth and attaining a meaning full life (Schrank & Slade 2007). The user's definition of recovery points at the need of a life with some purpose and growth. Service definition focuses on reducing symptoms and thus in turn improving in their day to day life functioning. These definitions show that treatment for schizophrenia needs to be clubbed with pharmacotherapy and psychosocial therapies. The disability in schizophrenia (as discussed earlier) is widespread to all the areas of functioning. Retraining various skills in personal, interpersonal, vocational, social, and spiritual areas are primary aspects of rehabilitation planning. PLS due to the impairments in function abilities loses their capacity to function independently. Rehabilitation planning ultimately focuses on turning the individual into an independently functioning person. Pharmacotherapy is considered as a significant element for effective rehabilitation services. Pharmacotherapy is essential for a successful psychosocial rehabilitation program. Unless the symptoms are under control psychosocial interventions cannot be successfully implemented.

The rehabilitation plan turns successful when the person is resettled back in the community. Resettling back in the community needs support from the community. There are different ways in a person living with schizophrenia can function in the community. Staying with the family is the ideal situation for reducing disability and function effectively. In India most of the time PLS stays with their family. Studies shows outcome of schizophrenia is better in developing countries since most of them stay with their families (Thrithalli et al. 2010). There are researchers questioning this assumption and suggests that more concrete studies are required to prove this assumption (Patel et al. 2006). In a country like India, where the population is high and services are limited majority cannot avail rehabilitation facilities. The facilities available are concentrated in urban areas. Only a few are located in rural areas. Studies have shown that through better treatment and rehabilitation disability in people living with schizophrenia can be countered (Barbato 1998).

### Quality of life and disability in people living with schizophrenia

It is difficult to define the concept of quality of life in a person living with schizophrenia. Schizophrenia affects the overall personality of an individual. Living with schizophrenia is a challenge in every ways. It rips the

person out of their functioning in various areas of life. This illness is currently popular as a brain disease due to the changes it causes in neuro-chemical components in the brain (Thara 2005). The model of quality of life used in people living without mental illness therefore cannot be applied in people living with schizophrenia. This is because the parameters used to identify quality of life of people living without schizophrenia or any mental illness is different. The issues with self care and personal space eventually affect their social involvement. Interaction with family members, friends, colleagues, and relatives decreases. Interaction becomes minimal or stops completely. Communication with others turns out to be need based. Studies show that the performance of the person before the onset of schizophrenia is not good (Cannon et al. 1997; Strous et al. 2004). Their performance further deteriorates after the onset of illness. From this point of view quality of life becomes a meaningless concept.

Schizophrenia results in major economic burden for the family. It also contributes to the global burden of disease (Rossler et al. 2005; Jablensky 2000; Barbato 1998). It is important to understand the economic situation of the person living with schizophrenia while assessing the disability. Amartya Sen's capability approach has been useful in developing a framework for identifying and understanding the disability in an economic perspective (Mitra 2006). Work brings in satisfaction and confidence in people living with schizophrenia. Work with a remuneration can help them to become financially independent to a certain extent. Financial dependence on family members is an issue that affects the choices made by PLS. Independent decision making is a problem when an individual is dependent on family for everything. Research works on living with schizophrenia are not enough to draw any conclusions. We need more studies to understand the lived experiences of disability in schizophrenia and economical ways to counter it.

As mentioned earlier the experience of schizophrenia will be different for each person. The level of disability may differ in individuals. There are people living with schizophrenia who may function well in all areas, some may be able to maintain a minimum level of functioning with or without support, whereas a small group need constant support to carry out even small activities. Disability and everyday life activities have a tumultuous relationship. For a person living with disability performing everyday life activities is a challenge. They have to continually fight with their state of disability to carryout activities that are easily carried out by a person without any disability (Locker 1983). This is same for people living with schizophrenia. Their day begins with reminders and coercions to perform activities of daily life . It takes a long time to get into the habit of developing a routine and follow it without failure. Most of the families are concerned about the performance of PLS in everyday life activities. The expectation of family from rehabilitation is that person living with schizophrenia should be able to carry out their activities of daily living without any motivation and support.

## Conclusion

The disability arising out of schizophrenia doubtlessly has severe impact on various areas of life. The article attempted to look at the perspective of people living with schizophrenia on disability. The disability resulting from schizophrenia spreads across all the areas of functioning. It is difficult to make some general criteria for measuring the extent of disability in schizophrenia since it will be different for each individual. Studies show that through medication, better rehabilitation services, and community support disability can be minimized and the person living with schizophrenia can lead a near normal life. The challenges are the years of investment required for recovery and chances of relapse. Though PWD Act 1995 and various studies have recognized disability in mental illness, more studies are required to establish the fact that disability arising out of schizophrenia is as severe as any physical illness. Since the primary objective of the study was not to explore the extent of disability in schizophrenia further explorations are required to reach a concrete conclusion.

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