ABSTRACT

Participation in the Community and Quality of Life of People Living with Schizophrenia

Schizophrenia (SZ) is a persistent mental disorder/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. The treatment for mental illness has a long history. It traversed from the period of witchcraft, isolation and physical restraining to a humanistic approach. Mental health services in India started as part of philanthropic concerns. Over a 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. Treatment plans for schizophrenia includes pharmacotherapy and psychosocial rehabilitation. 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.

The present 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. 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. Among the various mental illnesses defining quality of life of a person living with schizophrenia has always been the difficult task. 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.
The broad objective of the study is to understand the various dimensions of participation in the community and the extent to which that influences the quality of life of persons living with schizophrenia and the way people living with schizophrenia perceive their own quality of life.

Ethnography was the method chosen for data collection. This was done because the aim of the study was to understand the perception of PLS in the context of their everyday life. Case study method assisted in assembling the data and it helped in considering participant, her/his family, and rehabilitation process as a single case. The participants of the study were availing rehabilitation services at the NGO during the study. Family members and mental health professionals working closely with the participants were the other stakeholders of the study. In depth interview and observation were the techniques used to collect primary information from the participants. Key informant interviews were used to gather information from the stakeholders (family and professionals). Interview guide and observation guide were used to elicit information. The case files of participants and diaries (those who maintained one) have also been referred to get a complete picture.

Thematic analysis was used to analyze the data. The three major themes that have emerged in this study are living with schizophrenia, participation in the community, and quality of life. Chapter titled living with schizophrenia entails the perception of participants on their experience of living with schizophrenia. The chapter on participation in community looks into the aspects of participation of people living with schizophrenia in the community. The third analysis chapter is an attempt to understand the perception of people living with schizophrenia regarding their quality of life. Section on discussion tries to understand the interplay of participation of people living with schizophrenia in the community and their quality of life.

The participation of PLS in the community is mainly in the form of participation to self, participation in the family, participation at work place/education, and participation in the rehabilitation centre. The findings suggest that participation of PLS in the community helps in improving their quality of life. Quality of life of participants in the study is overshadowed by the fact of living with schizophrenia. Quality of life is expressed on the basis of time period. These periods could include past, present, and future expectations.
Quality of life of PLS also depends on the presence and extent of social support participants receive. Family support is a considerable aspect in improving quality of life of PLS. The study also found that better quality of life leads to a better participation of PLS in their community. However, since PLS in the study are attending a rehabilitation center it does not matter how much they participate in the community their quality of life is never complete.

Key Words: People living with schizophrenia, Participation in the community, Quality of life