

## Disability and Rehabilitation Needs of Persons with Schizophrenia

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### ABSTRACT

**Background:** Schizophrenia is a major mental illness. It imposes significant disability which has a measurable impact on many aspects of a person's life. Rehabilitation need is a major aspect of needs of persons with schizophrenia. The present study intended to assess the disability as well as to assess the rehabilitation needs perceived by the persons with schizophrenia. **Method and Materials:** The present cross-sectional institution based descriptive study was conducted at a tertiary care centre. Fifty individuals diagnosed with schizophrenia fulfilled inclusion and exclusion criteria were taken up for the study. The data was collected by administering Indian Disability Evaluation Assessment Scale (IDEAS) and Rehabilitation Needs Assessment Schedule (RNAS) after taking informed consent. **Results:** Findings revealed that most of the persons with schizophrenia had a mild level of disability; most disability was seen in the area of interpersonal activities and least in the self-care. Skills training were the most preferred area of rehabilitation needs followed by a need to finding employment, people's or family's/friend's/neighbour's attitudes modification and providing help for families. **Conclusion:** This present study contributed to the knowledge of studied areas and given a new insight which can be used to plan and develop and psychosocial rehabilitation services.

**Keywords:** Disability, rehabilitation, need assessment, schizophrenia


### INTRODUCTION

Schizophrenia is one of the most severe mental illnesses which affect one per cent of the general population.<sup>[1]</sup> It imposes significant disability which has a measurable impact on many aspects of a person's life. Disability is the disadvantage or restriction of activity caused by a society which takes little or no account of people who have impairments and thus excludes them from mainstream activities.<sup>[2]</sup> A person with schizophrenia

(PWS) experiences deficits in a variety of functional domains of everyday life.

People with milder forms of schizophrenia are able to work and live independently. Unfortunately a large percentage of PWS experience severe to moderate symptoms which can be helped with medical treatment partially only.<sup>[3]</sup> Lifelong disability of varying degrees can significantly affect both persons with schizophrenia and their families.<sup>[3]</sup> Severe disability is the result of both

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positive and negative symptoms of schizophrenia. This in turn affects the individual's ability to understand and act according to social norms which would diminish markedly.<sup>[4]</sup> Persons with schizophrenia experience unemployment, social isolation, homelessness and dependency on family members and peer groups changes partly because of their unexplained behaviours and the stigma associated with the illness. Similarly, cognitive deficits like decreased attention, concentration and lack of motivation lead to deterioration in their work capacity and are responsible for unemployment among these patients which further leads to social maladjustment.<sup>[5]</sup> Disability has been found to be affected by characteristics like age of onset, duration of illness, severity and type of symptoms, duration of untreated psychosis, cognitive deterioration and intellectual functioning. But most of the PWS have moderate disability.<sup>[6]</sup> Moreover, schizophrenia is associated with considerable economic burden due to the loss in productivity as well as the costs of treatment, hospitalization, and rehabilitation.<sup>[7]</sup>

The rehabilitation needs of patients with mental illness have been highlighted in various studies. Here rehabilitation needs refers to the needs perceived by a person with schizophrenia. There are few attempts in India to assess rehabilitation needs of persons with mental illness in general and PWS in particular. The present kinds of studies are needed for the planning of any psychosocial rehabilitation services. So, the present study is intended to assess the disability in the persons with schizophrenia as well as the rehabilitation needs perceived by them.

#### METHOD AND MATERIALS

This was a cross-sectional hospital based descriptive study conducted at a tertiary care centre, Kolkata, India. Fifty persons with schizophrenia diagnosed as per ICD-10<sup>[8]</sup> criteria between the age range of 18 – 65 years of either sex with minimum 6 months illness duration and clinically stable, living in the community and attending OPD of a tertiary care centre were selected purposively for the study. PWS with any major physical illness or disability, mental retardation, neurological disorder and substance dependence except nicotine were excluded. Primary caregivers with any major mental/physical illness or disability, mental retardation, neurological disorder and substance dependence except nicotine were also excluded. After taking informed consent from

the caregivers and the persons with schizophrenia, socio-demographic data sheet, Indian Disability Evaluation and Assessment Scale<sup>[9]</sup> and Rehabilitation Needs Assessment Schedule<sup>[10]</sup> were administered. Statistical analysis was done using Statistical Package for the Social Sciences version 17 (SPSS 17).<sup>[11]</sup>

#### RESULTS

##### Socio-demographic Variables

Mean age of PWS was 35.18 + 9.73 years. Majority of them were Male (58%), Hindu (84% and rest Muslim) and general category (74%). In regard to area of residence 21(42%) PWS were hailing from urban and 20 (40%) rural background. Majority of the PWS 23(46%) were educated up to primary level followed by 13(26%) PWS were educated up to secondary education, 6(12%) PWS were educated up to higher secondary education, 5(10%) PWS were graduate and only 1(2%) PWS was educated up to post-graduation. Little less than half 23(46%) PWS were married and another 23 (46%) were unmarried and 4(8%) were widow. Majority of PWS 32(64%) were coming from nuclear family, 14 (28%) were from joint family and 4 (8%) were coming from extended family, the mean no. of members in their family were 4.68 + 2.30. Most (88%) of the PWS had no vocational or technical Training or Education. Mean of income was Rs. 1866+4886.45.

Majority 25(50%) of the primary caregivers of PWS were a parent and 16(32%) were spouse. Mean age of primary caregivers was 49.28 + 15.20 years. Majority of them were male (52%). Majority of them 22 (44%) were educated up to primary level followed by 10(20%) were educated up to secondary, 6(12%) were educated up to graduation, 4(8%) were educated up to higher secondary and 2(4%) were educated up to post-graduation. Majority of primary caregivers, 38(76%) persons were married. Mean of family income was Rs. 6884+8187.18. Mean of the duration of contact with PWS was 24.52 + 11.73 years. Mean of time spend outside the family was 4.1 + 4.71 hours per day.

##### Clinical Variables

Majority (74%) of PWS were diagnosed as paranoid schizophrenia followed by 7(14%), 5(10%) and 1(2%) PWS were diagnosed as hebephrenic schizophrenia, undifferentiated schizophrenia and catatonic schizophrenia respectively. Mean age of onset was 25.40 + 10.25 years. Mean of the duration of illness and

Table - 1 : Level of Disability

Areas of Disability	Mean±SD	0	1	2	3	4
Self Care	0.80 ± 1.16	30(60 %)	8 (16%)	5 (10%)	6 (12%)	1 (2%)
Interpersonal Activities	1.96 ± 1.21	6 (12%)	14 (28%)	11 (22%)	14 (28%)	5 (10%)
Communication & Understanding	1.66 ± 1.24	11 (22%)	12 (24%)	14 (28%)	9 (18%)	4 (8%)
Work	2.3 ± 1.34	7 (14%)	7 (14%)	11 (22%)	14 (28%)	11 (22%)
Total Score	6.76 ± 3.97	-	-	-	-	-
Duration of Illness	2.26 ± 1.01	-	-	-	-	-
Global Score	9.02 ± 4.10	0 (0%)	22 (44%)	21 (42%)	7 (14%)	0 (0%)

0 = no disability, 1 = mild disability, 2 = moderate disability, 3 = severe disability and 4 = profound disability

Table - 2 : Occupation before and after the Onset of Illness

Occupation	Before n (%)	After n (%)
Housewife	9 (18%)	10(20%)
Student	16(32%)	1 (2%)
Professionals (eg. Doctor), high level executive or administrator	1 (2%)	-
Agricultural worker / Self employed farmer	1 (2%)	-
Service or Trade occupation – skilled (eg. Nurse)	4 (8%)	2 (4%)
Service or Trade occupation – semiskilled or unskilled (eg. street vendor, shop assistant etc.)	7 (14%)	4 (8%)
Industrial Worker – Skilled (eg. Foreman)	3 (6%)	1 (2%)
Industrial Worker – Unskilled or Semiskilled	-	4 (8%)
Unemployed	5 (10%)	24(48%)
Other	4 (8%)	3 (6%)
Not Applicable	-	1 (2 %)

duration of treatment was 118.42 + 94.00 months and 101.16 + 82.61 respectively. Majority 42(84%) PWS were not undergoing any psychosocial intervention. Mean of no. of hospitalization was 1.98 + 0.14 in last 1 year. Large majority 46(92%) of PWS had no side effects through in 38(76%) PWS some symptoms were persisting. More than half (60%) persons with schizophrenia had no positive family history of psychiatric illness.

#### Level of Disability

Table 1 shows the level of disability in persons with schizophrenia. It was shown that most (88%) disability was in interpersonal activities area followed by communication & understanding (78%), work (76%) and least disability (40%) was found in the area of self-care. The mean of the global score was 9.02 + 4.10. Overall, 22 (44%), 21 (42%) and 7 (14%) PWS were having a mild, moderate and severe level of disability respectively because of the schizophrenia.

#### Rehabilitation Needs

From the table 2, it was shown that 90% PWS were engaged in some kind of productive work before the onset of the illness which reduced to 52% after the onset of their illness. It means 48% of persons with schizophrenia continued to remain unemployed even though they were taking treatment or medications.

Out of these 24(48%) PWS, 60% attributes the reason for the same to their mental illness. With regards to paid employment, only 6(12%) PWS were involved in a full-time permanent employment, 4(8%) PWS were involved in temporary employment, 3(6%) PWS were involved in a part-time permanent employment during the time period of the study.

The persons with schizophrenia were asked “If an agency were to offer help to you, what would you require regarding employment?” help in finding

employment was most preferred (34%) followed by need for vocational training (10%), vocational guidance (2%), other specific needs (2%) and more than one in above (4%).

Regarding the condition of work required, 22% persons with schizophrenia need work in full-time normal condition, 2% wanted part-time normal condition and the same percentage of PWS needs some full some part-time work in normal condition. Only 4% PWS need work with full time in sheltered condition, 6% part-time in sheltered condition and 8% some full some part-time in sheltered condition. Few (4%) PWS require work with the condition of the combination of the above. Regarding the nature of employment required, 26% PWS required unskilled manual labour, followed by 8% require craftwork, 4% each required unskilled agricultural work/professional work, 2% each requires unskilled or semiskilled clerical works/unskilled or semiskilled service or trade job/ skilled clerical work/skilled service/trade work/ other types of employment. As a nature of vocational training 8% persons with schizophrenia required semiskilled, repetitive work like beedi rolling, baking etc., 4% required craftwork like carpentry, 2% persons with schizophrenia required skilled work like screen printing, packing, tailoring, etc./domestic craft like needlework, 8% persons with schizophrenia required other type of vocational training.

Most of the persons 84% PWS stayed in their own house and therefore do not require an accommodation. Very few (6%) PWS required accommodation like hospital or institutionalization and 4% Independent lodging. Largely (94%) persons with schizophrenia said they did not require organized leisure activities. Almost half (46%) PWS required no help in the areas of people's attitudes modification followed by 18% each needs modification in the attitudes of immediate family's members or friends and neighbours and 8% in the distant relatives. Almost two third of the PWS required help for finding employment for someone in their family and 24% PWS seeking other kinds of help for the family. With regards to skills, 26% and 28% of PWS required learning social skills and personal skills respectively.

#### Correlations

##### Socio-demographic Variables & Disability

There is a significant negative correlation ( $r = -0.316$ ) at

the 0.05 level between age and work. There is a significant positive correlation ( $r = 0.313$ ) at 0.05 levels between self-care and religion as well as category. There is a significant negative correlation at 0.05 levels between no. of family members and self care ( $r = -0.268$ ), communication and understanding ( $r = -0.348$ ), duration of illness ( $r = -0.363$ ), global score ( $r = -0.382$ ).

##### Clinical Variables and Disability

There is a significant negative correlation between age of onset and self care ( $r = 0.334$ ), work ( $r = 0.350$ , global score ( $r = 0.371$ ) at 0.01 levels. There is a significant positive correlation ( $r = 0.344$ ) at 0.01 levels between duration of treatment and duration of illness.

##### Socio-Demographic Variables of the Primary Care Givers and Disability

There is a significant negative correlation ( $r = 0.369$ ) at 0.01 levels between a relationship with the PWS and inter-personal activities. There is a significant positive correlation ( $r = 0.272$ ) at 0.05 levels between self-care and sex. There is a significant negative correlation ( $r = 0.308$ ) at 0.05 levels between self-care and education. There is a significant negative correlation ( $r = 0.312$ ) at 0.05 levels between family income and work.

##### Socio-Demographic Variables and Rehabilitation Needs

There is a significant negative correlation ( $r = 0.294$ ) at 0.05 levels between age and current employment status. There is a significant positive correlation ( $r = 0.500$ ) at 0.01 levels between sex and current employment status. There is a significant positive correlation between occupation and occupation prior to illness ( $r = 0.280$ ), need of help for family ( $r = 0.280$ ) at 0.05 levels. There is also a significant positive correlation between occupation and current employment status ( $r = 0.691$ ) at 0.01 levels. There is a significant positive correlation ( $r = 0.388$ ) at 0.01 levels between vocational training and reason for unemployment. There is also a significant negative correlation ( $r = 0.268$ ) at 0.05 levels between vocational training and need of modification of people's attitudes. There is a significant positive correlation between marital status and current employment ( $r = 0.281$ ), need for organized leisure activities ( $r = 0.278$ ), need for other area ( $r = 0.279$ ) at 0.05 levels. There is a significant positive correlation ( $r = 0.493$ ) at 0.01 levels between marital status and satisfaction with the current living arrangement. There is also a significant negative

correlation ( $r = 0.344$ ) at 0.01 levels between marital status and requirement of accommodation. There is a significant positive correlation between domicile and reason for unemployment ( $r = 0.438$ ), the requirement of vocational training ( $r = 0.307$ ) at 0.05 levels. There is a significant negative correlation between domicile and nature of employment required ( $r = 0.438$ ), leisure activities ( $r = 0.369$ ) at 0.01 levels. There is also a significant negative correlation ( $r = 0.282$ ) between domicile and nature of vocational training required on 0.05 levels. There is a significant positive correlation ( $r = 0.277$ ) at 0.05 levels between the type of family and occupation prior to illness. There is a significant negative ( $r = 0.704$ ) at 0.05 levels correlation between the type of family and current living arrangement. There is a significant negative correlation ( $r = 0.704$ ) at 0.01 levels between no. of family members and current living arrangement. There is a significant negative correlation ( $r = 0.533$ ) at 0.05 levels between income and required organized leisure activities.

#### Clinical Variables & Rehabilitation Need

There is a significant positive correlation ( $r = 0.311$ ) at 0.05 levels between the age of onset and reasons for unemployment. There is a significant positive correlation ( $r = 0.333$ ) at 0.01 levels between duration of illness and current occupation. There is a significant negative correlation ( $r = 0.349$ ) at 0.05 levels between psychosocial intervention and need for other areas. There is a significant positive correlation ( $r = 0.284$ ) at 0.05 levels between side effects and nature of employment required. There also is a significant positive correlation ( $r = 0.352$ ) at 0.01 levels between side effects and type of accommodation required. There is a significant positive correlation ( $r = 0.792$ ) at 0.05 levels between symptoms and help regarding employment. There is a significant positive correlation ( $r = 0.663$ ) at 0.01 levels between family history and occupation prior to illness.

#### Socio-Demographic Profile of the Primary Care Givers and Rehabilitation Needs

There is a significant positive correlation between relationship and occupation prior to onset of illness ( $r = 0.269$ ), current accommodation ( $r = 0.274$ ), leisure activities ( $r = 0.321$ ) at 0.05 levels. There is also a significant negative correlation between relationship and current occupation ( $r = 0.277$ ), help regarding

employment ( $r = 0.285$ ) at 0.05 levels. There is a significant positive correlation ( $r = 0.335$ ) at 0.01 levels between the age of the primary caregiver and help the family. There is a significant negative correlation ( $r = 0.410$ ) at 0.01 levels between the age of the primary caregiver and nature of employment required. There is a significant negative correlation ( $r = 0.181$ ) at 0.05 levels between sex of the primary caregiver and current employment status. There is a significant negative correlation ( $r = 0.381$ ) at 0.01 levels between sex of the primary caregiver and type of accommodation required. There is a significant positive correlation ( $r = 0.325$ ) at 0.05 levels between the marital status of the primary caregiver and current occupation. There is a significant negative correlation ( $r = 0.366$ ) at 0.01 levels between the marital status of the primary caregiver and type of accommodation required. There is a significant negative correlation ( $r = 0.355$ ) at 0.01 levels between duration of contact with the persons with Schizophrenia and occupation prior to illness. There is a significant negative correlation between duration of contact with the persons with Schizophrenia and occupation prior to onset of illness ( $r = 0.322$ ), current occupation ( $r = 0.288$ ), reasons for unemployment ( $r = 0.286$ ) at 0.05 levels. There also is a positive correlation ( $r = 0.321$ ) at 0.05 levels between duration of contact with the persons with Schizophrenia and current employment status.

#### DISCUSSION

Psychopathology gives only a limited view of the overall functioning of schizophrenia<sup>[12]</sup> Therefore, instead of symptoms disability was measured in the present study. Several studies<sup>[13,14]</sup> have been done with the aim of assessing the needs of the persons with mental illness/schizophrenia using different tools e. g. 'The Camberwell Assessment of Need - Research'<sup>[15]</sup> but here the scale used for measuring subjective rehabilitation needs was Rehabilitation Needs Assessment Schedule<sup>[11]</sup> since it specifically assesses the needs related to rehabilitation; moreover this tool has been used in Indian population<sup>[16-20]</sup> so, it is a more appropriate tool.

The mean age was near about 35 years which indicates that age of majority of persons included in this study. It was revealed from the present study that age of the PWS has a significant negative correlation with work. Elderly PWS have less disability in the area of work than younger which is contradictory finding with a previous

study<sup>[21]</sup> which revealed that efforts to find work, and interest in work decreases with increasing age.

More than half male and little less than half female persons with schizophrenia participated in this study. Schizophrenia is equally prevalent in men and women<sup>[22-26]</sup> the present study also supports this statement through the sample was not drawn randomly still it could be considered as an indication.

All most half of the PWS were educated up to primary level, around the one fourth secondary level and rest higher secondary or higher. Ten per cent of the PWS was having no formal education.

In the present study, most of the persons were married. In a previous study<sup>[27]</sup> it was observed that more than half persons with schizophrenia were married, had a good marital outcome in terms of getting married and keeping the marriage intact it was associated with a number of clinical and socio-demographic variables and several other domains.

In the present study majority of the sample belongs to Hindu religion and general category which could be explained by sampling area. Religion and category have a significant positive correlation with self-care. It means the Hindus in comparison to the Muslims and PWS belongs to general category than other backward class, scheduled caste and tribes were having less disability in the area of self-care. It could be due to their socio-cultural practices. Every individual lives with their family.

A person with schizophrenia with a joint family and a circle of friends who are ready lend a helping hand is much better off than alone man afflicted with the illness, whose relatives are in some far off land, and who has no one to turn to. WHO data showed a better outcome for patients managed in extended families. The functional disorder was found high in subjects living in nuclear family or living alone.<sup>[28]</sup> The present study finding also supports this, it has been seen that most of PWS were coming from nuclear family and who lives with more number of family members has less disability in the areas of self-care, interpersonal activities, communication & understanding and, global disability.

Three-fourths of the PWS was diagnosed as paranoid schizophrenia which is a most common subtype of schizophrenia as mentioned in a previous study.<sup>[29]</sup> In the present study, though most of the PWS started treatment

within a short period of time after the onset of illness, they were not undergoing any psychosocial treatment, which has a very important role in the treatment of schizophrenia. It could be one of the reasons for the presence of a disability and another reason could be limited psychosocial treatment services availability like other parts of the country.<sup>[30]</sup> The present study findings suggest that young age of onset have more disability in the area of self-care, work and overall disability which is an obvious finding.

From the correlation of the socio-demographic profile of the caregivers with disability of PWS, it was evident that if the parents were the caregiver disability in the area of inter-personal activities was the minimum which increased in case of sibling, spouse, offspring and other progressively which is obvious that parents are more tolerant than anyone else in among relatives of PWS. One more interesting finding was when caregivers were women or more educated disability was found less in the self-care domain. When family income was more disability in the area of work was found to be more this could be due to less importance is given to earning or income generation activities by the family having god income.

In the present study, in the area of self-care has the least disability among the PWS. As most of the persons had negative symptoms, like anhedonia, avolition, it is expected that they have a disability in the area of work, interpersonal activities and sometimes in the area of communication and understanding also.<sup>[31]</sup>

Almost half of the study samples were unemployed. Generally, high employment rates up to two third have been found in India<sup>[34]</sup> but present study does not support this finding. This could be due to their limited opportunity. In another study<sup>[35]</sup> among untreated Indian PWS, almost one-third was employed. In a study<sup>[36]</sup> found only one-fourth PWS was employed which is consistent with the present study. Unemployment was increased after the onset of the illness among PWS. Majority of them have attributed it to their illness. Advanced age, female gender, early onset and long duration of illness had a negative impact on employment of PWS. In a previous study<sup>[37]</sup> among a large group of PWS suggested that overall employment may be impeded by clinical problems, including symptoms of schizophrenia and poorer neurocognitive and intra-psycho functioning which could be true for

the present study also. From another previous study<sup>[38]</sup> it was shown that whether a PWS seeks employment will be a function of the correspondence between the work-needs and the work-reinforces actually experienced. It seems most likely that PWS who had been out of work for a long period will not be able to do this well. This finding is consistent with the present study as well.

More than one-third PWS wanted some help in finding employment, one-tenth vocational training and other vocation related needs. Work provides financial remuneration and is a normalizing experience, allowing individuals to participate in society, and may promote self-esteem and quality of life. Furthermore, the vast majority of persons with severe mental illnesses identify paid employment as one of their goals.<sup>[39]</sup>

A large majority of PWS did not require any kind of accommodation since they reside in their own house. Further, it was found that married, single, widow and widower PWS had increasingly accommodation need and satisfaction with their current living condition. This finding is underlining the important role of the Indian families which was established by the previous study.<sup>[40]</sup> Carling<sup>[41]</sup> had also observed that mental health consumers prefer to live independently in their home with a friend or loved one, rather than in a therapeutic facility.

Leisure is not perceived as a major need by the majority of the PWS. Most of the persons opted for passive recreations like listening to the radio, watching TV, and reading books. Further, it was found that married, single, widow and widower PWS needed for increasingly organized leisure activities.

In the present study, more than two third of primary caregivers had asked for some kind of help in finding employment for some on in the family particularly when they were aged or there ward (PWS) were unemployed which obvious. The help was needed in other areas as well. In another study<sup>[17]</sup> it was revealed that they need help for educating other members of the family, looking after of family members' health, financial help, etc which merely reflects the social problems of poverty and unemployment. The study concluded that it would be impossible to rehabilitate the family as well unless voluntary care agencies are sufficiently motivated in this direction. Not only the persons with schizophrenia, their

family members were also be affected during the time of taking care of the ill persons so PWS need help for family members.<sup>[37]</sup>

More than half primary caregivers wanted social skills and personal skills to be taught to the patient. This could be probably due to the persistence of disability in various areas which can be attributed to the persistence of negative symptoms when negative symptoms persist, it is conventional to recommend the use of psychosocial interventions such as token economies, social skills training, life skills training, self-instructional training and problem-solving.<sup>[42]</sup>

#### Limitations

Small sample size, purposive sampling, no comparison with any other group of mental illness or controlled group and symptoms were not considered for correlation with disability and rehabilitation needs were some limitations of the study.

#### CONCLUSION

Most of the persons with Schizophrenia participated in the present study had a mild level of disability with most disability in the area of interpersonal activities and least in the self-care. Assessment of rehabilitation needs indicated that skills training was the most preferred area, followed by employment, modification of psychological environment, providing help for families, leisure activities, vocational training. This study suggests that there are relationships between one's socio demography profile and disability and rehabilitation needs.

This present study contributed to the knowledge of studied areas and given a new insight which can be used to plan and develop and psychosocial rehabilitation services.

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