

# **OUTCOME STUDY OF DISABILITY MANAGEMENT FOR PERSONS WITH SCHIZOPHRENIA LIVING IN THE COMMUNITY**

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## **ABSTRACT**

Schizophrenia is a major mental illness affecting the normal functioning of the brain that has a measurable impact on many aspects of the life of those who are affected by it. Among many areas of impairment, severe deficits in functioning are observed in daily living, family life, social interactions and employment.

The aim of the study was to examine the outcome of a brief intervention package (on disability management) for the persons with Schizophrenia (PWS) living in the community.

Criteria-based sampling technique was employed to derive a sample of 31 participants who attended OPD of Institute of Psychiatry, Kolkata. This was an outcome study, pre-post experimental design without a control group. Participants were initially assessed with Indian Disability Evaluation Assessment Scale and Social Occupational Functioning Scale, after which, a structured intervention was conducted. Soon after the intervention, post- assessment was done in the same parameters and data was analyzed.

It was found that PWS has a significant impairment in the socio-occupational functioning area and has a moderate percentage of disability before the intervention. After the psychosocial management, significant improvement has been noticed in socio-occupational functioning and the level of disability also decreased.

The present study demonstrated the feasibility and efficiency of a psychosocial intervention package on the management of impairment and disabilities for PWS which helped them improve impairment and disability.

**Key words: Psychosocial management, Disability, Socio-occupational functioning, Schizophrenia**

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## **INTRODUCTION**

Schizophrenia is a severe, chronic and incapacitating brain disorder that affects various aspects of behaviour, thought and emotion. Schizophrenia occurs in 1 per cent of the general population making it the most common of the severe mental illnesses (Pennington, 2002). It is considered as a major psychotic disorder with impact on the person's functional capacity, eventually resulting in functional deficits which are difficult to recover (Viertio, 2011; Harvey et al., 2007). These deficits are manifested in the areas of self-care, relationships, work, and social life, which in turn, affect the individual's ability to understand and act according to social norms (Devaramane, 2011). Severe disability is the result of both positive and negative symptoms of schizophrenia. It not only causes personal diminution for the PWS but it also disturbs their family members, peer group and anyone associated with them. Disability arising out of severe mental illness is defined as an inability to perform at a desirable level in activities such as self care, social relationship, work and situational appropriate behaviour (WHO, 2001). Some of the fundamental areas that disability affects in an individual's functioning includes personal hygiene, social interaction, money management, work habit, leisure time activities, interpersonal relationship, time management, communication, crisis management, household activities, emotional expression and decision making (American Psychiatric Association, 1997).

Even though schizophrenia can be disabling, with effective treatment, including good access to proper medications and psychosocial intervention, PWS can live reasonably normal lives. The key phrase here is 'reasonably normal'. So, despite the widespread misconception that PWS have no chance of recovery or improvement, the reality is much more hopeful. In many countries, there are various government programs and community services that may be helpful as part of schizophrenia treatment, management and recovery. In the current scenario of Kolkata (India) the facilities are available in a scattered way, and private care is still costly. Even if facilities are available, the level of awareness and utilization of the resources is not yet properly developed. Most of the psychiatric hospitals and nursing homes here primarily prefer the pharmacological treatment over non-pharmacological one. Hence this present study is an attempt to establish the feasibility and efficacy of psychosocial management of disability among PWS. The aim of the study was to examine the outcome of a brief intervention package (on disability management) for PWS living in the community.

## **METHOD**

Pre-post experimental design without control group was adopted for the present study which was a hospital-based outcome study conducted at a tertiary care centre in Kolkata, India. Forty PWS were diagnosed as per ICD-10 (WHO, 2007) criteria in the age range

of 18 – 50 years of either sex with minimum 6 months of illness duration and clinically stable; living in the community and attending OPD of a tertiary care centre were selected through criteria-based sampling. Out of forty, 31 participants who completed both pre and post intervention assessment were taken for final analysis. In cases where there were major changes in drugs or hospitalization during the study period, these were also not included in the final analysis. PWS with any major physical illness or disability, mental retardation, neurological disorder and substance dependence except nicotine and caffeine were excluded. Family members of PWS with any major mental or physical illness or disability, mental retardation, neurological disorder and substance dependence except nicotine and caffeine and those who have severe family conflict were excluded as well.

After taking Informed Consent from PWS and their family members, initially socio-demographic and clinical data was taken from all the participants using a specially designed proforma for the study, then Indian Disability and Assessment Scale (IDEAS,2001), Social Occupational Functioning Scale (SOFS)(Saraswat et al.,2006) were administered to assess the level of disability and socio-occupational functions of the PWS. Subsequently, need-based psychosocial interventions were conducted and after the intervention, the post intervention assessment was done using IDEAS and SOFS. Data was analyzed using Statistical Package for the Social Sciences 16<sup>th</sup>version (SPSS 16). Descriptive statistics were calculated along with correlation and comparative profile in pre and post intervention was done by using Wilcoxon signed rank test.

Intervention package included initial full length clinical assessment of PWS and their family members, monitoring compliance for intervention, psychoeducation, activity scheduling, skill training to address communication and interpersonal relationship problems, intervention to address impaired socio-occupational functioning, engaging in any vocation or productive work, referral counselling and post intervention assessment.

A pilot study on 3 cases was conducted to check the suitability and feasibility of the tools to be used in the study before the actual study.

**Ethical Clearance:** Taken

## **RESULTS**

### **Socio-Demographic Profile of the PWS**

The Mean age of PWS in the present study was 33.19 ±8.70. More than half (52%) of the PWS were male and a large majority of them were Hindus (84%) followed by Muslim (16%). There were equal number of married and single PWS- 15 (48%) each, and only 1

(3%) person was a widow. Less than half of PWS hailed from the rural area (48%), followed by the same number of the sample hailing from the urban and suburban area (26% each). Almost one-third of the PWS i.e., 10 (32%) were educated up to the fifth standard, followed by equal numbers 5 (16 %) of each who were educated up to eighth, tenth and up to graduation. Less than half (48%) of them belong to nuclear families, followed by those in joint families (36%) and the rest of them from extended families (16%) with an average of 5 family members in each household. With regard to the occupation, most of the PWS were unemployed (45%), followed by 10 (32%) homemakers, 1 (3%) each involved in service or trade occupation, skilled, semi-skilled and unskilled occupation, industrial work and crafting and rest 3 (10%) of them involved in some other professions. Their mean income was Rupees 1838.7+ 5.62

### **Clinical Profile of the PWS**

The mean age of onset of illness was 26 years. Mean duration of illness and duration of treatment were 85.74 ±76.11 months and 79.16 ±76.69 months respectively. A large number of PWS (80.6%) were not undergoing any psychosocial intervention. Mean of number of hospitalizations was 0.19± 0.65. Whereas 18 (58.1%) PWS had no side effects, 13 (41.9%) of them still had some side effects, 21 (67.7%) had no positive family history of psychiatric illness.

### **Socio-Demographic Profile of the Family Members of PWS**

In terms of the relationship with family members of PWS, 12 (39%) were parents, 10 (32%) persons were spouses, 7 (23%) were siblings and 1 (3.2%) each were off-springs. Mean age of family members was 45.03±1.8 years. A majority of family members were males (58%) and a majority (90%) of them were married. In terms of education, 23% were educated up to the tenth standard, 6 (19%) persons were educated up to eighth standard and 5 (16.1%) persons were educated up to twelfth standard. Among them, 11(36%) were homemakers, 6 (19.4%) were involved in business and 4 (12.9%) in agricultural work. Mean family income was Rupees 7138.70±6.45. Mean duration of family members having contact with PWS was 25.64±8.92 years. Mean time of family members spending time outside the family was 6.83±6.50 hours every day.

**Table 1: Comparative Profile of Impairment on Pre and Post Intervention**

Areas of Impairment	Negative Ranks	Positive Ranks	Ties	Z
Bathing and Grooming	10	1	20	-2.673**
Clothing and Dressing	8	1	22	-2.333*
Eating, Feeding and Diet	8	2	21	-2.153*
Neatness and Maintenance	14	0	17	-3.416**
Conversational Skills	22	1	8	-4.153***
Social Appropriateness/politeness	17	1	13	-3.572***
Social Engagement	23	1	7	-4.290***
Money Management	8	1	22	-2.326*
Orientation/Mobility	20	2	9	-3.751***
Instrumental Social	16	1	14	-3.532***
Recreation/Leisure Activity	26	0	5	-4.604***
Work	27	0	4	-4.640***
Respect	10	0	21	-2.970**
Independence/Responsibility	19	1	11	-3.440**
Total Score	30	0	1	-4.788***

\* Correlation is significant at the 0.05 level (2-tailed).

\*\* Correlation is significant at the 0.01 level (2-tailed).

\*\*\*Correlation is significant at the 0.001 level (2-tailed).

Table 1 shows the comparative profile of impairment in different areas of socio-occupational functioning in the pre and post intervention group among the PWS which was done by using the Wilcoxon signed rank test. All the areas of impairment in socio-occupational functioning has statistically significant difference on the pre and post intervention groups (0.05 level in clothing and dressing, eating- feeding- diet and money management domains; 0.01 level in bathing and grooming, neatness-maintenance activities, respect for property & independence/responsibility domains and 0.001 in conversational skills, social appropriateness/politeness, social engagement, orientation/mobility, instrumental social skills, recreation/leisure, work and in total score domains).

**Table 2: Comparative Profile of Disability on Pre and Post Intervention**

Areas of Disability	Ranks	N	Z
Self-Care	Negative Ranks	11	-3.127**
	Positive Ranks	0	
	Ties	20	
Interpersonal Activities	Negative Ranks	21	-4.041***
	Positive Ranks	1	
	Ties	9	
Communication & Understanding	Negative Ranks	19	-4.065***
	Positive Ranks	0	
	Ties	12	
Work	Negative Ranks	25	-4.452***
	Positive Ranks	0	
	Ties	6	
Global Score	Negative Ranks	30	-4.800***
	Positive Ranks	0	
	Ties	1	
Severity of Disability	Negative Ranks	20	-4.379***
	Positive Ranks	0	
	Ties	11	

\* Correlation is significant at the 0.05 level (2-tailed).

\*\* Correlation is significant at the 0.01 level (2-tailed).

\*\*\*Correlation is significant at the 0.001 level (2-tailed).

Table 2 shows the comparative profile in different areas of disability on pre and post intervention among the PWS which was done by using the Wilcoxon signed rank test. All the areas of disability have a statistically significant difference on the pre and post intervention groups (0.01 level in self-care domain and 0.001 in interpersonal activities, communication & understanding, work , global score and the severity of disability domains).

### **Psychosocial Issues**

Apart from the above findings on impairments and disability measured with two tools IDEAS and SOFS, some psychosocial issues were found on the qualitative clinical assessment as well. Poor compliance to medicine and psychosocial intervention was fairly apparent. There were also stigma and discrimination experienced by PWS and their family members from the society which affects their self-esteem and confidence. A common finding was in the form of misinformation or lack of information about

mental illness among family members. A significant barrier to employment of PSW was employer's attitude. Many employers underestimated their ability or feared the PWS's unpredictable behavior. A few family members complained that employers may be unduly concerned that individuals with serious mental illnesses like schizophrenia will have poor attendance, will perform poorly or will need accommodations that will be too costly. In some cases, the family itself lacked belief that PWS can work or can be engaged in any productive work (even in their own household work). All these issues were addressed with adequate concern during the course of the intervention and subsequently, the improvement was also measured in the post intervention assessment.

## **DISCUSSION**

The overall functioning of schizophrenia can have a very limited view when interpreted only in terms of psychopathology (Luckoff, 1987), so instead of just symptoms, socio-occupational functioning impairments and disability were assessed and psychosocial management was provided in order to address areas of impairments and disability.

In the present study, the mean age of PWS was 35.18 years which indicates that a majority of the participants were in their mid 30s with 16 male and 15 female PWS which is almost equal in number. Though the study did not use a random sampling method it could still be considered as an indication that schizophrenia is equally prevalent in men and women, which is reflected in many other studies as well (Saha et al., 2005; Bhugra et al., 2005; Versola-Russo, 2006; Ochoa et al., 2012). It was also found that 45.2% of the participants were unemployed and most alarming fact is, among the unemployed participants 78.6% of them are unemployed because of their illness (schizophrenia) which is consistent with the study by Chowdhury et. al. (2018). Another supporting finding to the present study is by Anthony (1995) where it was found that only 25% of PWS were employed. Even though some studies do have different findings, like the one by Srinivasan & Thara (1998) wherein they found an annual rate of employment of 63-73% in the first 10 years of follow-up in people with first episode schizophrenia.

The mean age of onset of illness in this study was found to be 26 years which is consistent with the study done by Sham et al. in 1994, who found that schizophrenia is a disease that typically begins in early adulthood; between the ages of 15 to 25. The majority of the PWS, 25 (80.6%), were not undergoing any psychosocial treatment. It may be one of the reasons for the presence of higher level of disability or impaired socio-occupational functioning. Another reason for not undergoing any psychosocial treatment could be limited availability of psychosocial treatment services in different parts of the country (Hazra et al., 2012).

From the present study, it was found that the PWS had impairment in the different areas of functioning especially in the areas of work, respect for property, recreation/leisure activities, conversational skills, social engagement and instrumental social skills which play a very important role in daily living. It is consistent with several previous studies (WHO, 2001; Hansley, 2000), that revealed schizophrenia affects the individual's functioning such as social interaction, money management, work habit, leisure time activities, interpersonal relationship, personal hygiene, time management, communication, crisis management, household activities, emotional expression and decision making.

While intersecting the areas of difficulties, one major and most common issue found among the PWS in the present study was difficulty in communication and a deteriorating interpersonal relationship. Through brief communication enhancement training, the difficult areas of communication and interpersonal relation of the PWS with their family members were addressed. Stigma and discrimination experienced by family members from society were again an issue found in many cases which affected the self-esteem and confidence of both the PWS and their family members. Different studies such as Shrivastava et al. (2011), Gonzalez-Torres et al. (2007) and Jackowska (2009) have supported the same finding. In the intervention package, these issues were addressed in the form of ways of handling the stigma and discrimination coming from society, tactfully. Focusing on and utilizing the positives rather than the negatives responses of the society was considered. In Psychiatric Social Work such approaches have been shown to be effective by Sahu (2015). Poor compliance to medicine and psychosocial interventions was also a common issue which was found in the form of misinformation or lack of information about mental illness from family members. Keeping that reason in mind psychoeducation was included in the intervention program. Magliano et al. (2006) and Bauml et al. (2006) in their study supported the efficacy of psychoeducation in schizophrenia. Difficulty in the areas of daily living and maintaining personal hygiene was found in some PWS. Through activity scheduling, their day-to-day lifestyle is helped to change by targeting their self-care, personal hygiene, time management and the like. Planning a balanced activity schedule was the target for each individual. Dogra et al. (2009) in a study found that activity scheduling does have an impact on the negative symptoms of the PWS. Apart from these significant areas of target, most of the PWS were found to be unemployed or facing difficulties in the area of work. This area was related to difficulty in the area of communication, understanding and making relationships. So, as these areas were addressed, special focus was given to the area of work as well. For those who were unemployed they were made to identify potential sources of income, their level of interest in working, their work-related abilities and



disabilities, learning job skills, advantages of working, facilitating brainstorming about all the skills and abilities that would help him/her to be successful in any job that was focused on.

From the present study, significant improvement was found in all the domains of socio-occupational functioning especially in the areas of conversational skills, social appropriateness/politeness, social engagement, orientation/mobility, instrumental social skills, recreation/leisure activity and work which are important for daily living. In the post intervention assessment of disability, significant improvement in all the domains of disability especially to the interpersonal activities, communication & understanding and work domain were found as well.

Among many, one supportive study by Kern et. al. (2009) promoted functional recovery in schizophrenia through psychosocial treatments. It has been studied overall that these treatments provide a range of promising approaches to help PWS achieve better outcomes far beyond symptom stabilization. This finding was consistent with a study by Thara et al. (1998) where management of social disabilities in PWS were evaluated in terms of negative symptoms, social disabilities and psychological impairments and after one year, a significant decline in some negative symptoms and improvement was found in certain disabilities.

The present study findings suggested positive outcomes in managing different socio-occupational functioning impairments and reducing overall severity of disability with an adequate psychosocial intervention.

## **LIMITATIONS**

Small sample size, the absence of a controlled group and the inclusion of drug naïve samples were some of the limitation of the study.

## **CONCLUSION**

The present study demonstrated the feasibility and efficiency of a psychosocial intervention package on the management of impairment and disabilities for PWS which helped them to live a less disabled and impaired life than before.

The present study which is among the very few intervention-based outcome studies on management of disability in West Bengal and specifically in Kolkata can be considered as an evidence of effectiveness and viability of the psychosocial intervention as a part of the management plan in a tertiary care setting for the PWS.

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**CONFLICT OF INTEREST:** None

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