Original Article

Effects of Coordinated Support Services through Primary Caregivers in Improving the Functionality of Persons with Schizophrenia

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Abstract

Background: Schizophrenia is a disabling disorder affecting social and occupational functioning and daily living skills. **Aim:** To develop caregivers as co-therapist for support services to enhance functionality of people with schizophrenia. **Methods:** People with schizophrenia attending outpatient services were randomly divided into experimental and control groups. The validated intervention programme was provided to the caregivers of the participants in the experimental group. Both the groups were assessed for functionality at base line and post intervention period of six months. Brief Psychiatric Rating Scale (BPRS), Clinical Global Impression (CGI), Social Occupational Functioning Scale (SOFS) were used for assessment. **Result:** After 6 months of intervention, only experimental group showed a trend towards improvement in the BPRS score, even though RMANOVA shown a statistically insignificant finding (F df=1,66 =3.39; p= 0.07). However, a significant improvement was observed in the adaptive skills sub-score of socio occupational functioning (F 1,67 = 25.37; p<0.001)). In addition, a significant difference was observed for relative change in global illness severity on the CGI score (Mann Whitney U=243.00; p < 0.05). **Conclusion:** This study results suggest that involvement and training of caregivers is feasible and may help improve functionality in patients with schizophrenia.

Keywords: Psychosocial intervention, Training of caregiver, Co-therapist, caregivers, Involvement, Ilness severity

Introduction

Schizophrenia is a severe mental illness which leads to significant social and occupational dys-function. Many studies have also reported that people with schizophrenia experience cognitive deficits, worsening their social impairment (Couture, Penn, Roberts, 2006, Fett, Viechtbauer, Penn, et al., 2011) It is well researched that people with schizophrenia experience social deficits and have poor activity of daily living (ADL) skills, which come in the way of their engagement in productive work and in reintegration to community life (Bellack 2004, Perlick, Rosenheck, Kaczynski et al., 2008). Antipsychotic medications do reduce positive symptoms but psychosocial care programmes need to be added as adjunct to pharmacotherapy for dealing with the negative symptoms (Lieberman, Stroup et al., 2005. Liberman, Kopelowicz 2005). It is been

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shown that psychosocial intervention has a significant role in enhancing productivity, inter personal relationships and re-joining in family or household activities.

Family holds a significant role in caring for persons with mental illness; previous studies suggest discrimination and stigma experienced by patients and caregivers (Kavitha, Raguram 2013). Stigmatizing experiences may influence interpersonal relationships between patients and caregivers and further, it may aggravate the strained relationship between them (Hanzawa , Bae, Tanaka , Bae , 2010).

In previous studies demonstrated that, Poor knowledge and negative attitude towards psychiatric illness can influence the prognosis (Oyefeso 1994, Prabhu , Raghuram, Verma , Maridass 1984). Many studies show that high expressed emotion among the relatives of persons with mental illness affects schizophrenia relapse and poor outcome (Leff, Sartorius, Jablensky, et al., 1992) High expressed emotions have positive correlations (Wang , Chen , Yang 2017).

Families extend emotional, social, and economic support to their ill family member. High functional family always helps and supports mentally ill family member to cope with distress and extend helps in problem-solving (Sawant, Jethwani. 2010). In the recent past, the family environment has been given importance as a contributing factor for relapse or rehabilitation (Vaughn , Leff 1976).

Literature suggests that "work brings clear health benefits for persons with schizophrenia" (WHO, 2001, Yerxa 1998). Involvement in productive activity should be simultaneously started along with pharmacotherapy. Research also confirms that persons involved in productive work will have better functional outcome (Halford, Harrison, Moutrey, Simpson 1998, Mairs, Bradshaw 2004).

Research in India and in other countries have reported that people with schizophrenia have difficulties in maintaining ADL skills (Boronow,1986 Henry, Coster, 1996). For long it has been recognized that activities and routines form an important aspect of treatment and social integration (Kumar, Singh 2015 Suresh, Kumar , Thirthalli 2012). In this context, caregivers' involvement is very important. Lack of caregiver support and involvement affects functionality and quality of life of persons with schizophrenia (Schulz, Tompkins. 2010 Creado, Parkar, Kamath, 2006).

Various studies demonstrated that psychosocial interventions are effective and used for schizophrenia treatment. The current intervention module, family psychoeducation, social skills training, communication training, and self-care treatment, were not tested in the Indian family. However, most of these approaches in the western counties' have effectively reduce the level of positive and negative symptom, improving functionality, and prevent relapse. Their implementation in the Indian family with schizophrenia has not been tested. With the increasing deinstitutionalization of patients, the family has to assume a co-therapist's role as a mental health professional performed in the psychiatric hospital. Families have been the substitute for the scarcity of therapeutic and residential resources. Therefore, there is a great challenge for families to be accepted as co-therapist. Thus, the current study aimed to develop caregivers as co-therapist for support services to enhance people's functionality with schizophrenia. This study adopted a quasi-experimental pre-and post-controlled group design.

Methods:

Sample: The study was conducted in the outpatient adult psychiatry services of National Institute of Mental Health and Neuro Sciences (NIMHANS), Bengaluru from February 2018 to January 2020. In total, 78 caregivers and their family member with schizophrenia were recruited in the study. Male and female caregivers living with the person with schizophrenia, in the age group of 18 to 45 years, able to speak Kannada, Hindi and English were included

for the study.

Design: This study followed a quasi-experimental design with a control group and performed repeated measures in baseline time (1st assessment) and six months post intervention (2nd assessment). The caregivers and their family member with schizophrenia were randomised into two groups of 39 each using block randomization. The experimental group received psychosocial Interventions, and the control group received routine care.

Recruitment Procedures: The recruitment procedure was followed as per diagrammatic flow chart given below (adapted from CONSORT guideline)

Both intervention and control groups had received pharmacotherapy and treatment as usual in the outpatient department (OPD) and in addition to that the experimental group was provided the psychosocial intervention module (details given below). Data was collected at two time points, at baseline and after post intervention follow up after six months at OPD. Caregivers in the experimental group received 10 intervention sessions along with as usual care, lasting for 60 minutes as given in figure 1. Resource person for the intervention was research assistant appointed for that purpose under the supervision of Principal Investigator/Co -Principal Investigator. Methodology of the intervention program were discussion. lecture, exercise, poster presentation and demonstration. The intervention programme aimed at making caregivers a change agent to monitor the activities of their family member with schizophrenia.

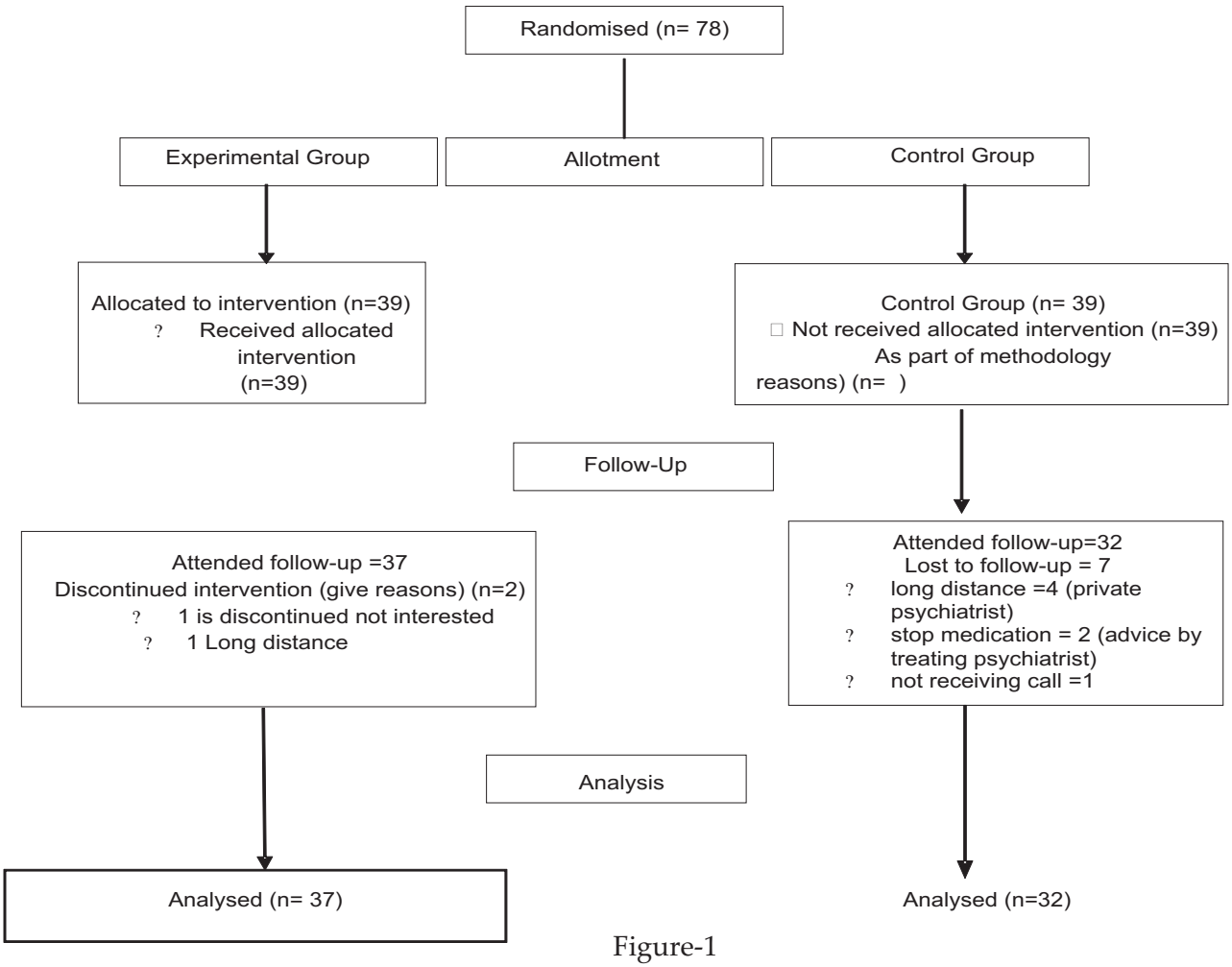

Figure-1

Interventions: The content was developed and validated by multidisciplinary professionals including clinical psychologists, psychiatric social workers, and psychiatrists. The programme consisted of 6 modules including (1) Rapport building & Baseline assessment (2) Family Psycho Education (3) Social skills training (4) Communication Skills; (5) Self-care; (6) Closing session and final assessment. Intervention module was designed to impart training to caregivers of persons with schizophrenia. This model can be applied at clinic at OPD level during follow-up session (or in homecare settings) with an objective to enhance and deliver better coordinated care to their family members with illness at their home, which would enhance their functioning and quality of life. Each module consisted of segments or "skill area", and each skill area includes specific educational objectives. The details of the intervention programme is given in Table 1

Tools:

1. **Socio-demographic & Clinical data sheet:** It was prepared by the researchers to collect personal data and clinical history of the people with schizophrenia.

Table 1

Therapeutic Interventions for Experimental Group

Intervention	Objective	participants	No. of session	Content	Outcome Indicator
Introduction, Rapport building & Baseline assessment	To establish therapeutic relationship	Patient/caregiver	1	Rapport establishment	baseline assessment
Family Psycho Education	adherence Identifying benefits of the treatment Reduction of Stigma, reduced EE, etc	Caregiver &Patient	2	Stigma reduction strategies, motivation for treatment adherence Communication skill training	Increased follow up, reduction in drop out. Decreased negative symptoms Increased communication in the family Reduction of stigma
Social skills training	Importance of soft skills in everyday life	Caregiver & Patient	2	Activity scheduling Importance of reinforcement Role plays	Involvement in productive activities, maintaining activity schedule, Taking responsibility for personal hygiene and medication adherence.
Communication Skills	Enhance positive communication and decrease negative communication	Caregiver & Patient	2	Importance of Language Voice, tone Expression Eye contact. Positive and negative communication	Increased positive communication in the family Reduced conflicts at home Supporting for personal goal
Self-care	Self-care in a group home	patient	2	ADL skills	maintaining self-care
Closing session	To close the intervention and		1		final assessment

ADL = Activity of daily living

2. **The Brief Psychiatric Rating Scale:** (Overall , Gorham 1962) It is a rating scale to measure psychiatric symptoms such as depression, anxiety, hallucinations and unusual behaviour. The presence of symptoms is rated on a Likert scale from 1(not present) to 7(extremely severe) depending upon the version between a total of 18-24 symptoms are scored. The scale is the one of the oldest, widely used scales to measure psychiatric symptoms.

3. **The Clinical Global Impression Improvement: (**Spearing, Post, Leverich et al., 1997)[8] The Clinical Global Impression (Improvement) rating scales is commonly used measure for symptom severity, treatment response and the efficacy of treatment for people with mental disorders (Guy, 1976)[9] It is 7-point scale that requires the clinician to assess how much the patient's illness has improved or worsened. It is rated as: 1). Very much improved; 2) Much improved; 3) Minimally improved; 4) No change; 5, Minimally worse; 6). Much worse; or 7). Very much worse.

4. **Social Occupational Functioning Scale:** (Saraswat, Rao , Subbakrishna , Gangadhar 2006)[10] This scale used to measure the social functioning of people with schizophrenia patients. It is a 5-pointscale. It has good reliability and validity scores.

5. Caregivers rated weekly about the activities undertaken by their family member with schizophrenia in a checklist which was submitted during their monthly follow-up.

Procedure: After taking informed consent, those patients who met the criteria of schizophrenia according to International Classification of Diseases-10 (ICD -10) as well as the inclusion criteria were included in the study. Informed consent was also obtained from the caregivers. The study has obtained ethical clearance from NIMHANS Ethics Committee (Ref. No. NIMHANS/IEC (BEH.SC.DIV)5th MEETING/2017, Date: 10/4/2017).

Subjects were randomized according to the block randomization and allocated into experimental/ control group according to the random sequence generated prior to the recruitment. We used block randomization to maintain equal number of subjects for intervention as well as control group. Personal and clinical data were collected from the respondents. Primary outcome measures were assessed at baseline and post-intervention (after 6 months) including Brief Psychiatric Rating Scale (BPRS), Clinical Global Impression (CGI), and Social Occupational Functioning Scale (SOFS), to understand the effects of intervention from the selected samples. In this connection, one research assistant with a qualification of Master of Social Work with Medical and Psychiatric Social Work with 2 years' experience in the field of mental health was appointed to undertake assessment and intervention on the selected sample. Research assistant was given training to perform assessment and intervention. However, Post assessment was not carried out for 9 participants (7 control and 2 experimental groups) as they could not attend follow-up.

Statistical Analysis:

All analysis was done using Statistical Package for Social Sciences software version 22.0 (IBMSPSS Statistics for Windows, Armonk, NY: IBM Corp). Distribution of demographic characteristic of the sample were presented as frequency analysis for categorical variables and mean (standard deviation) for quantitative variables. Shapiro-Wilk test was administered to check for normality of the data. For CGI score, the relative difference was calculated using [Baseline Score-Post score/ Baseline score] and the difference in average score between experimental and control group was tested with Mann Whitney U test. Repeated measures analysis of variance (RMANOVA) was used to test the mean difference between groups. Relationship between different domains of SOFS with CGI was assessed using Spearman's rank correlation. For all tests, the level of significance was fixed at 5%.

Results:

Table 1

Demographic and clinical characteristics of the participants

Variables		Experimental group (n1=37) Frequency (%)	Control group (n2=32) Frequency (%)
Age of the respondents*		33.6(9.14	33.3 (8.06)
Sex	Male	24 (64.9)	18 (56.3)
	Female	13 (35.1)	14 (43.8)
Marital Status	Married	23 (62.2)	16 (50.0)
	Single	14 (37.8)	16 (40.0)
Religion	Hindu	30 (81.1)	29 (90.6)
	Muslim	6 (16.2)	3 (9.4)
	Christian	1 (2.7)	0 (0.0)
Education	SSLC	9 (24.3)	5 (15.6)
	PUC	26 (70.3)	25 (78.1)
	Graduation	2 (5.4)	2 (6.3)
Occupation	Student	2 (5.4)	2 (6.3)
	Farmer	5 (13.5)	7 (21.9)
	Business	2 (5.4)	1 (3.1)
	Professional	6 (16.2)	
	Other	22(59.5)	19(59.4)
Socio-economic status	Lower	12 (32.4)	3 (9.4)
	Lower Middle	3 (8.1)	17(53.1)
	Upper middle	22(59.5)	12(37.5)
Habitat	Rural	12(32.4)	8 (25.0)
	Urban	3 (8.1)	3 (9.4)
	Sub Urban	22(59.5)	21(65.6)
Family Type	Nuclear	36 (97.3%)	32(100.0%)
	Joint	1 (2.7)	0(0.0)
Clinical Variables	Past history of psychiatric illness	37 (100)	32 (100)
	Duration of illness (in year) *	5.9 (5.68)	4.7 (3.08)

The average age of the respondents in the experimental and control groups was 33.6(SD: 9.14) and 33.3 (SD 8.06) years respectively. Majority of the respondents drawn in the experimental and control groups are similar in demographic characteristics. However, differences are in socio-economic status distribution 59.5 % upper middle class and 53.1 % lower middle class from experimental and control group respectively. 37 of the 39 subjects recruited came for the follow-up and were re-tested with the measurement scales. The subjects were guided and regular instructions were given to perform activities at home. They had the freedom to take assistance from caregivers to help them complete the assigned tasks. However, in control group only 32 subjects came for follow-up.

Table 2.

Distribution of Baseline and 6 months Follow-up intervention of study groups

Variables		Experimental group (n_1 =37) (Mean ± SD)		Control Group (n_2 =32) (Mean ± SD)		Test statistic	p value
		Baseline	Post	Baseline	Post		
BPRS		28.9± 2.29	25.2 ± 2.41	26.9 ± 2.64	28.7 ± .34	3.39	0.07
CGI	(Relative change in CGI score)	3.1± 0.92	0.25±0.49	3.18±0.78	0.62±.13	243.0#	0.001
SOFS	Adaptive Skills	9.0 ± 1.93	7.1 ± 1.36	8.7 ± 1.75	8.2 ± 1.60	25.37	0.001
	Appropriateness	5.1 ± 1.12	4.2 ± 0.70	4.6 ± 1.08	5.4 ± 1.13	0.01	0.097
	Interpersonal Skills	7.1 ± 1.62	5.1 ± 0.98	6.6 ± 1.58	7.8 ± 1.99	1.99	0.163

Abbreviations: BPRS: Brief Psychiatric Rating Scale, CGI: Clinical Global Impression

SOFS: Social Occupational Functioning Scale. *P<0.05, # Mann Whitney U

Effect on Symptom Recovery: There was a trend towards significant difference between experimental and control group with regard to psychiatric symptomatology, although it did not reach statistical significance

Effect on Global Improvement: Subjects in the experimental group showed significant improvement in clinical global impression (Table3) after the intervention programme as compared to the control group.

Effect on Functional Status: There was significant change in adaptive skills, but not in social appropriateness and interpersonal skills among people in the experimental group

There was a significant positive correlation between adaptive skill scores and CGI.

Table 3 Correlation between Social Occupational functioning scale and Clinical Global score

Variables	**Spearman's rho Correlation coefficient**
Adaptive Skills vs CG	0.326**
Social Appropriateness vs CGI	0.095
Interpersonal skills vs CGI	0.192

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

Discussion

The current study provided a structured intervention for primary caregivers to act as co-therapist in motivating their family member with schizophrenia to regain their functionality in ADL. The caregivers attended 10 sessions, each of 45 to 60 minutes duration during their outpatient follow up. Family psycho-education, social skills training, communication skills training and self-care training were provided.

Majority of the participants recruited in the present study were male, married, educated up 12 years, which confirms the findings of the previous studies (Chien , Mui , Cheung , Gray 2015). In present study majority of the participants were unemployed or semi- unskilled workers, or home makers; and living in nuclear families. The average duration of illness of the patients in the control and experimental group was 4.9 years and 5.4 years, respectively. All of them were on pharmacological treatment (Leaf, Bruce, Tischler. 1986, Wells, Burman, Camp 1995). Many studies have confirmed that course and outcome are largely determined by the psychosocial intervention received in the last two years which determines the long-term outcome for people with schizophrenia (Birchwood, Todd, & Jackson 1998, Harrison, Hopper, Craig, Laska 2001).

Both the groups were comparable in terms of the severity of symptomatology. However, after the intervention, the experimental group had significantly lower global severity of illness as compared to the control group. The coordinated support programme for the caregivers in the experimental group seems to have been successful in gaining skills as a co-therapist to encourage and motivate their family member with schizophrenia to engage in productive activities. This possibly has had an effect on the reduction of psychiatric symptomatology. Various studies conducted in east and west confirm that pharmacotherapy along with psychosocial interventions, psychoeducation, and building the skills of caregivers in dealing with their ill family members would facilitate the person with severe mental illness to regain their cognitive skills and improve their ability to reintegrate into the community (Banfield, Gardner, McRae, 2013 Craig , Eby , Whittington 2011).

The current research supports the research evidence that building the skills of caregivers to act as co-therapist may help the family member with schizophrenia to engage in productive activities, take up responsibilities, reduce illness severity and improve overall functioning of persons with schizophrenia (Pharoah , Mari, Rathbone, Wong. 2010 Penn , Mueser , Tarrier, Gloege 2004). This study also suggests that such training for caregivers is feasible on an outpatient basis with the involvement of a multidisciplinary team.

Some useful feedback was given by the clients during the monthly follow-up sessions. They reported that employing family member as a co-therapist has great benefits like helping in performing assigned duties, ensuring drug adherence, improving communication within family unit, building self-esteem, reducing stigma and bridging the trust deficits which emerge due to illness, and enhancing relationship and bonding within the family. Caregivers during the feedback session shared their experiences of being self-reliant and empowered in managing symptoms of the illness and gained skills to overcome stigmatizing beliefs about mental illness. In summary, the training programme not only helped participants to organise their life systematically but also it helped to construct daily life and functioning independently (Giron, Fernandez-Yanez, 2010, Mueser, Deavers, Penn, Cassisi 2013).

Recommendations

Based on these findings, the following recommendations are made: 1. Long term studies using functional parameters and social outcomes are required to assess whether such intervention modules are effective in improving functionality

such as reintegration with the family, friends and social relatedness; 2. Multidisciplinary teams are important to improve understanding from different perspectives/disciplines using a biopsychosocial model and help clients get access to holistic treatment.

Strength of the study: Samples recruited had wide range of background with response to age, ethnicity and sociocultural background. Intervention program can be conducted both in clinical and home setting. It is cost effective and easy to practice by general population.

There are some limitations in the current study. Double blinding was not strictly adhered. As assessor himself allocated subjects to the experimental and control group which may have inadvertently influence the outcome. This study was restricted to quantitative analysis but both quantitative and qualitative methods would have been useful to get comprehensive knowledge and understanding about the effectiveness of coordinated support service intervention program. This study used only ten sessions of intervention due to time and cost considerations. However, our experiences suggest that this may not be sufficient to enhance social functioning among persons with schizophrenia. Also, routinely monitoring and documenting the activities of the ill family member by the caregiver is a cumbersome job as most of the caregivers are shouldering multiple house hold responsibilities.

Conclusion

A coordinated support service package is a feasible intervention module for building the skills of caregivers to act as co therapist for persons with schizophrenia, and appears to help improve functioning of patients with schizophrenia. However, this requires confirmation by well-designed multi-centre trials. Such activities would also help in bridging the gap between pharmacological interventions and psychosocial interventions, and enhancing long lasting therapeutic relationships in people with schizophrenia.

Conflict of interest: None

Contributors: All authors have made contributions with regard to 1. Conception and design of the study 2. Collection of data, analysis and interpretation of data 3. Reviewed and given valuable suggestion for improvisation of the content.

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