

Benefits of Family Support Groups – Subjective Perception of the Care-givers of persons with Schizophrenia

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Abstract: Family members of persons with schizophrenia experience significant distress and burden in the caring process. The illness in itself has high chances of relapse and exacerbations and is often associated with cognitive and social deficits/ disabilities. This compels the family members to devote increased time and energy in the process of providing care and support to their family members with a serious mental illness. The incredible amount of stress experienced by family members, if, not understood and handled carefully, may be so overwhelming that they may be unable to care for themselves or their ill family members.

While individual family interventions may also be used, family support groups may be more beneficial in many aspects as it is based on the premise that people with a shared condition come together to help themselves and each other to cope with the problem at hand. Family Support Groups create a platform for family members to discuss and share information regarding the illness, their own distress and burden, seek support and advice from one another and also ensure adherence and overall improvement in their family members with severe mental illness.

This study aims to discuss the subjective perception of the care-givers in terms of the benefits by them by being a part of the Family Support Groups facilitated by the Psychiatric Social Work team at IHBAS, a neuro-psychiatric tertiary care hospital.

Key words: caregivers, family support groups, subjective perception.

I. Introduction

Schizophrenia is the most common disabling mental illness with a poor prognosis and is also accompanied with significant deficits post treatment. It is the third most debilitating mental illness with a prevalence of 0.4%, accounting for 1.1% of the total disability adjusted life years (DALYs), and 2.8% of the years lost due to disability as per the global burden of disease. The stigma of Schizophrenia is much greater than some other mental illnesses like depression and people, including the families affected, generally know next to nothing about it. The lack of insight common to Schizophrenia often throws many families into extreme turmoil as they struggle with obtaining treatment that their son or daughter is refusing to comply with.

A substantial body of research suggests that in a caring role, the care givers experience considerable ongoing burden and psychological distress^[1]. Despite their central role in the healthcare of their relative with a mental illness, only a minority of care givers receive services from mental health agencies^{[2] [3]}.

Despite advances in antipsychotic medication for schizophrenia that have alleviated side-effect burden, it has become clear that medications alone are not sufficient for recovery and adaptive adjustment. Psychosocial treatments that enable persons with schizophrenia to cope with the disabling aspects of their illness and achieve personal goals are a necessary complement^[4].

Psychosocial treatments are considered important as they focus on long term goals of recovery and rehabilitation of persons with Schizophrenia. Psycho social treatments help improve the quality of life of disabled individuals by assisting them to assume as much responsibility over their lives and to function as actively and independently in society as possible. They also ensure that the disabled person possesses the physical, emotional and social skills needed to live, learn and work in his/her own particular environment.

With deinstitutionalization, the burden of care giving has shifted to the family members. Many families who have their family members suffering from severe/chronic illnesses feel distressed and distraught at the need for significant and long term care of their family members. Alcohol dependence, Schizophrenia, Bipolar Affective disorder, dementia, cancer and such other medical or mental health conditions place tremendous stress and burden on their care givers. These family members, over a period of time may become so overburdened

with the continuous and increased demands of care giving, that they may neglect their own existence and needs and over time, may not remain being ‘supportive’ carers.

Carers are often thrown in the deep end, with no formal training in mental illness^[5]. They also face a lack of information about the disorder and its medication, a lack of resources and treatment facilities, and a lack of responsive professionals. These very real obstacles place both objective and subjective burdens on family members^[6]. Care givers often face feelings of anxiety, stress, guilt, shame, self-blame, depression, fear, anger and confusion^{[5] [7] [8] [6] [9]}. Other experiences include lowered self- esteem and increased isolation and withdrawal due to stigma and reduced social networks^{[8] [9]}.

Psychiatric Social Workers provide various interventions at the individual, group and family levels. Individual interventions believe in the value of uniqueness of individuals and assist them in identifying and resolving problems in their environment by utilising their own internal strengths and resources. Group interventions are those wherein the group members are guided/ facilitated by a social worker about interaction within the group; to relate to others and experience growth in accordance with their needs and capacities. In a group process, the group members have an experience of belonging in the group and this group experience becomes the means of individual development and growth.

Three models may be distinguished^[10]:

1. Remedial: Where the aim on the part of the work/agency is individual adaptation.
2. Reciprocal: Where the aim is to strengthen mutual aid and to mediate between individuals and society.
3. Social Goals: Where the concern is to foster social justice often through collective, social action.

Group work methods and interventions that are practised in health settings mainly follow the reciprocal model. When there are patients with some major or chronic medical or mental health problems who need long term medications or follow-up, when their problems require adequate strength and endurance to cope with them or when their conditions compel them to face with bodily changes due to surgery or other interventions (like in the case of mastectomy for breast cancer patients), group interventions are the preferred choice of intervention. More often, it is the families that undergo severe pain and stress in caring for these persons with long term illnesses and also face severe emotional and physical burden due to the demanding nature of care-giving.

Family members play an important role in helping to keep their relatives with mental illness supported and oriented. Patients are often incapacitated and there is a drain on family energy and resources, which is not intentional on their part. They are more victims in that situation than anything else.

Such families need the assistance of mutual- aid groups or ‘support groups’ wherein they are able to interact with other families facing similar problems and experiencing similar stress, to seek information and advice and also derive support from them.

Support Groups, also often known as mutual aid groups are often used to assist individuals and/or families undergoing or experiencing stress associated with the illness. These groups are formed by persons facing similar problems, wherein the group members provide support to one another in the form of understanding and empathy. They also assist in providing support through gentle confrontation and allow members to experience conflict in a positive manner and see the members through the eyes of others.

In the field of mental health, Support groups are usually practised with persons recovering from schizophrenia, bipolar disorder, anxiety, personality disorder etc. and also with families of these clients. Support groups originally started as a self help movement due to the lack of long term institutional facilities for those with severe mental illnesses and also with the advent of ‘de-institutionalisation’, the family had nowhere to go but engage themselves full time in caring for their ill relatives^[12]. The family members were left with no option other than to get together and find solace in fellow care-givers as they could discuss and share experiences related to care giving and the burden they experienced.

II. Methodology

Hospital Setting

The Institute of Human Behaviour and Allied Sciences is a tertiary care neuro-psychiatric hospital situated in Delhi catering to more than one thousand clients with mental health problems daily. Most of these clients belong to lower socio-economic strata and access the services from as near as half a kilometre to as far as beyond 200 kilometres. A majority of the persons seek treatment at the hospital on an out-patient basis with just a few of them getting in-patient admission. The most common illness for which treatment is sought is Schizophrenia followed by Bipolar Affective disorder.

Rationale

It is well recognised that the caregivers carry a great deal of burden of care, are often under tremendous stress due to the sick member of the family and have often been given negative signals in terms of being blamed

for the misfortune of the patients. They may also have frustrations, despair and a fear that things will not work out well. Working with such families is not easy. It may be difficult to engage them in any therapeutic plans as they may be pessimistic about the outcome or may perceive the therapeutic process and their 'involvement' too demanding. ^[11] It was felt that a majority of the clients seeking treatment at the tertiary care hospital at the Institute of Human Behaviour and Allied Sciences do not get the benefit of the multidisciplinary treatment approach that include psychosocial, family and group treatments. The huge crowd at the out-patient services on an everyday basis leaves little time for family members to discuss their queries and doubts regarding the illness with the medical professionals and also share their difficulties associated with care-giving.

The Psychiatric Social Workers at the tertiary care government hospital, IHBAS respond to the needs of these clients by planning and implementing psychosocial interventions suited to individual needs. However, in view of the large number of consumers who require these interventions and the difficulty in providing these to all who need them in the limited time, it was felt that an alternative to this needed to be thought of. An intervention that catered to many clients in a short time, but was also going to be more comprehensive and useful to clients was devised in the form of Support Groups for families of persons with Schizophrenia.

Objectives

The Support Groups were planned with the following objectives in mind.

- To provide a platform to share experiences, information and advice,
- To improve drug compliance in patients suffering from Schizophrenia.
- To reduce stress and burden of family members associated with care giving.
- To encourage mutual support and acceptance.
- To help reduce negative feelings of isolation and fear and conflict.
- To create a group situation for exchange of ideas and views.
- To strengthen the group to handle the problem on their own
- To promote the feeling of universalization
- To equip caregivers in daily living skills like coping, communication, time management, management of emotions, problem solving.
- To provide a platform for participation and acceptance.
- To help deal with one's own burn out.

Frequency of Sessions

The Support Groups were held once every two weeks for about 60 minutes by each of the two multidisciplinary team units respectively; thereby this intervention being made available once weekly to clients on every Thursdays for Unit 2 clients and on Fridays for Unit 1 clients. After much thought, the groups were kept open, in that, new members could join as and when they wanted.

The criteria for joining the support groups were determined:

- Those care givers, both men and women, who had been primary care givers (who were predominantly taking on the role of care giving) of persons suffering from Schizophrenia
- Those who had the family member suffering with the illness at least for the past one year
- Those who had been following up regularly for the last six months at the hospital, IHBAS.

The caregivers were referred to the Support group programme by the treating team members of Psychiatry, Clinical Psychology and Psychiatric Social Work. Though most of the family members seeking help had their relatives suffering from Schizophrenia, only those family members who had significant issues with care giving and who had experienced significant distress were taken in to the Support Groups. There were nearly 20 members in each Support Group programme in each Unit (a total of 40 persons) which slowly got reduced to 30 members over a 6-8 sessions, i.e., three to four month period.

These care givers mostly belonged to both rural and semi –urban households and came from within Delhi as well as from nearby states like Uttar Pradesh and Haryana. Nearly 90% of the clients were from lower socio-economic strata and were availing free medicines at the hospital. Their expenses mainly included their travel and food expenses which ranged from nearly Rs.40/- to Rs.200/- depending on their distance. The subsidized food provided at the hospital canteen also helped reduce their expenses on food.

Duration of the Support Group Program

The Support Groups were held over a two year long period from November, 2011- October, 2013. Each session was for duration of 50-60 minutes. A total of 60 group meetings were held during the period which included holidays, non availability of some members on some days, festival seasons etc.

Content of the Sessions

The sessions were a mix of didactic and interactive nature. The content of the Support groups was structured to include:

1. Basic information regarding the Illness
2. Psycho-education components
3. Reasons for relapse
4. Need for treatment adherence
5. Experiential sharing of difficulties and different ways of management
6. Success and failure stories
7. Need for rehabilitation and after care
8. Handling one's own emotions
9. Tips for daily living
10. Crisis management
11. Information on related issues like financial budgeting (money management)
12. Information on related issues like legal rights and guardianship of their ill family members
13. Legal assistance
14. Future plans in respect of the patient like formation of a Trust etc.

Sessions 1,2,3,4,7,8,9,10,11,12 and 13 were in the form of a short informative/educational session for 20 minutes followed by interaction with the group members involving queries, experiences, difficulties faced, guidance expected, ventilation and group support. The remaining sessions were predominantly facilitated and managed by the group members themselves.

The Process

The Support Groups were primarily facilitated by the Psychiatric Social Workers, with the support of the psychiatrists. In the beginning, the group members were hesitant to discuss with one another about their problems and looked upon the facilitator to ask them specific questions. Initially, the hesitation to be a part of the group with similar problems and the fear of sharing their issues with new acquaintances was evident as the group members restricted their interaction to exchange of greetings within the group. It took a minimum of five sessions for the members to become familiar with their group members who later started interacting with them even outside the group environment, on their way to related facilities within the hospital or on their way home.

The Support Group members became active participants in the group after nearly six sessions and the role of the Psychiatric Social Worker was mainly restricted to being a facilitator. The Group members shared their experiences, their difficulties in care giving, their anxieties and the stigma they faced among their other relatives and the community around them and also shared their own psychological distress. Gradually, the members started finding solace within the group as they waited for the other members to join once they reached the hospital. They also began coordinating with them over phone as to their availability and time of arrival.

As the out- patient services catered to nearly one thousand clients daily, the members of the Support Groups found it difficult to access the Pharmacy services as they had to stand in the queues after their meetings and felt that they were getting very much delayed. To ease this difficulty, the out-patient cards of all the Support group members were collected along with their case files and medicines were prescribed just before the group meeting and their medicines from the Pharmacy were arranged at their venue of the group meetings.

III. Results

Benefits perceived by the support group members - Qualitative statements/quotes

"I have been provided adequate information about the illness, which I never knew about in this detail, though I was managing my son with illness for the last four years" said, the father of a 28 year old son with Schizophrenia.

"I have not only understood the nature of the illness, but also learnt how to handle my wife", said the husband of a 32 year old lady suffering from paranoid schizophrenia.

"I never knew that a group of other family members, (and not doctors) could have helped me in dealing with this illness to this extent" a senior care giver stated.

"This group has helped me to be bold and go out as I am not the only one having a person with mental illness in my home as there are others too" a literate person from a semi- urban area said.

"I have been able to accept my son's illness better after I have met this wonderful group" said a 50 year old father who had severe difficulties in dealing with this truth for many years.

"I had always felt alone in this battle. I am feeling stronger now as I know these other members will be there for me" a care giver said.

“I always worried about what would happen to my kin when I would be no more. The sessions on legal guardianship and ‘how to form a Trust’ has made me feel comforted”, an aged care giver taking care of his 45 year old daughter with Schizophrenia said.

“We never realised that our own health and happiness were also important” said many care givers.

“I had always felt angry and irritated at my husband as he was abusive and aggressive and many times I have abused him verbally and also felt like leaving him. I have also felt guilty about it and never disclosed it to anyone so far. This group has been very understanding of my feelings and have supported me and advised me correctly” said the wife of a person suffering from Schizophrenia for the last 14 years.

IV. Discussion:

The Support Groups held at IHBAS for the family members of Schizophrenia was perceived as meaningful and beneficial by the members attending them. They felt ‘more confident’ in dealing with the illness, ‘more equipped’ ‘less burdened’, and felt ‘more accepted’ by others facing the same problem. By participating in a shared mission, members of the support groups felt a sense of power and confidence. Many of the care givers who were continuing to attend the Group meetings for a considerably long time felt they could better guide other care givers who had less understanding and experience in dealing with the demands of care giving. They felt better equipped to cope with their psychological distress. Many family members felt that information provision and the gaining of support and self understanding from the group process was helpful^[13]. Also, for those who were long term participants, the belonging to the group itself was the perceived benefit.

Studies found that behavioural family management was effective in reducing re admission rates in discharged patients^{[14][15][16]}. Studies show that family intervention is effective in reducing relapse rates in such patients.^{[17] [18] [19] [20]} Family interventions have also been shown to reduce burden of care, improve patients' functioning in social areas and are cost effective to the extent that these are less expensive than conventional therapies^{[15],[21] [22] [23] [24] [25]}. Studies reported that family interventions are beneficial in most cases but under used.^{[26] [27] [28] [29] [30]}

Apart from pharmacological treatments, family interventions are found to be efficacious and robust in relapse prevention^{[27] [31] [32]}. Relapse frequencies for patients who received psychosocial treatment in addition to somatic treatment were consistently lower than for patients who received only somatic treatment.^[33] Family interventions also showed significantly fewer relapses 5 and 8 years after family intervention; and also lower family Expressed Emotion.^[25]

V. Conclusion

As the carers play an important role in the overall improvement and well being of persons with severe mental illnesses, they are to be considered as significant stakeholders in the over- all care process. Their involvement and participation in the mental health care service is essential to chalk out better and more effective family intervention strategies. Support Group is one such intervention programme designed to help groups of families with similar problems in a more cost effective way. The paucity of mental health or after care services increase the demand and need for more involvement and support of the care givers in the overall recovery of persons with severe mental illnesses.

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References

- [1]. Cuijpers, P, The effects of family interventions on relatives' burden: a meta-analysis. *Journal of Mental Health*, 8(3), 1999, 275-285.
- [2]. Dixon, L., Luckstead, A., Stewart, B., & Delahanty, J, Therapists' contact with family members of persons with severe mental illness in a community treatment program. *Psychiatric Services*, 51(11), 2000, 1449-1451.
- [3]. West, J.C, Wilk, J. E., Olfson, M., Rae, D. S., Marcus, S., Narrow, W. E., et al, Patterns and quality of treatment for patients with schizophrenia in routine psychiatric practice. *Psychiatric Services*, 56(3), 2005, 283-291.
- [4]. Kern S. Robert., Glynn M. Shirley., Horan P. William., and Marder R. Stephen, Psychosocial Treatments to Promote Functional Recovery in Schizophrenia, [http:// www.ncbi.nlm.nih.gov/ pmc/ issues/ 177484](http://www.ncbi.nlm.nih.gov/pmc/issues/177484), 2009
- [5]. Abramowitz, I.A & Coursey, R.D, Impact of an educational support group on family participants who take care of their schizophrenic relatives. *Journal of Consulting and Clinical Psychology*, 57, (2), 1989, 232-236
- [6]. Chapman, H, Self-help groups, family carers and mental health, *Australian & New Zealand Journal of Mental Health Nursing*, 6 (4), 1997, 148-155
- [7]. Berry, D. *Living with Schizophrenia*, (Institute of Psychiatry, London, 1987)
- [8]. Brady, A, *A Study on the Effects of Schizophrenia on Carers* (Thesis), Department of Psychology, University of Dublin, M.A.1996
- [9]. Wintersteen, R.T & Young, L, Effective professional collaboration with family support groups, *Psychosocial Rehabilitation Journal*, 12(1), 1988, 19.

- [10]. Papell, C and Rothman, B, Social Groupwork models: possession and heritage <http://infed.org/mobi/what-is-groupwork/> 1966, last accessed on 19th December, 2014
- [11]. Kulhara, Parmanand, Review Article- Management of Schizophrenia: An Update, *Indian Journal of Psychiatry*, 40(2) 1998, 120-134
- [12]. Reay-Young, R, Support groups for relatives of people living with a serious mental illness: an overview, *International Journal of Psychosocial Rehabilitation*, 5, 2001, 147-168
- [13]. Citron, M., Solomon, P. & Draine, J, Self-help groups for families of persons with mental illness: Perceived benefits of helpfulness, *Community Mental Health Journal*, 35 (1), 1999, 15-30
- [14]. Anderson, C.M., A Psychoeducational model of family treatment for schizophrenia. In Stierlin, H., Wynne, L.C. & Wirsching, M., (Eds.), *Psychosocial Intervention in Schizophrenia* (New York : Springer Verlag 1983), 227- 235.
- [15]. Falloon, I.R.H., Boyd, J.L., McGill, C.W., Ranzani, J., Moss, H.B., and Gilderman, A.M, Family management in the prevention of exacerbation of schizophrenia: A controlled study. *New England Journal of Medicine*, 306: 1982, 1437-1440. <https://books.google.co.in/books?isbn=9622097251>
- [16]. Falloon, I.R.H. & Shanahan, W. J, Community management of schizophrenia, *British Journal of Hospital Medicine*, 43, 1990, 62-66.
- [17]. Leff, J.P., Berkowitz, R., Shavit, N., Strachan, A., Glass, I., and Vaughn, C, A trial of family therapy versus a relatives' group for schizophrenia, *British Journal of Psychiatry*, 154, 1989, 58-66.
- [18]. Leff, J.P., Berkowitz, R., Shavit, N., Strachan, A., Glass, I., and Vaughn, C, A trial of family therapy versus a relatives' group for schizophrenia: Two-year follow-up. *British Journal of Psychiatry*, 157, 1990, 571-577.
- [19]. Hogarty, G.E., Anderson, C.M., Reiss, D.J., Kornblith, S.J., Greenwald, D.P., Javana, C.D., and Madonia, M.J, Family psychoeducation, social skills training and maintenance chemotherapy in the aftercare treatment of schizophrenia: I. One-year effects of a controlled study on relapse and expressed emotion. *Archives of General Psychiatry*, 43, 1986, 633-642
- [20]. Hogarty, G.E., McEvoy, J.P., Muncz, M., Di Bdray, A.I., Bartone, P., Cather.R., Cooky, S.J., i Ulrich, R. Carter, M & Madonia, M.J, Dose of fluphenazin, familial expression of emotion and t outcome in schizophrenia: results of two-year controlled study, *Archives of General Psychiatry*, 45, 1989, 797-805.
- [21]. Falloon, I.R.H., Boyd, J.L. & McGill, C.W, Family management in the prevention of morbidity in schizophrenia: Clinical outcome of a two year longitudinal study. *Archives of General Psychiatry*, 42, 1985, 887-896.
- [22]. Tarrier, N., Barrowclough, C, Vaughn, C.E., Baurah, J.S., Procceddu, K., Watts, S. & Freeman, H, The community management of schizophrenia: a controlled trial of a behavioural intervention with families to reduce relapse, *British Journal of Psychiatry*, 153, 1988, 532-542.
- [23]. Tarrier, N., Barrowclough, C , Vaughn, C.E., Baurah, J.S., Procceddu, K., Watts, S. & Freeman, H, Community management of schizophrenia in a two year follow-up of a behavioural intervention with families. *British Journal of Psychiatry*, 154, 1989, 625-628.
- [24]. Tarrier, N., Lowson, K. & Barrowclough, C, Some aspects of family interventions in schizophrenia. II. Financial considerations, *British Journal of Psychiatry*, 159, 1991, 481-484.
- [25]. Tarrier, N., Barrowclough, C., Porceddu, K., and Fitzpatrick, E, The Salford Family Intervention Project: Relapse of schizophrenia at five and eight years. *British Journal of Psychiatry*, 165 1994, 829-832.
- [26]. Mari, J.D.J., and Streiner, D.L, An overview of family interventions and relapse on schizophrenia: Meta-analysis of research findings. *Psychological Medicine*, 24:565-578, In Lisa B. Dixon and Anthony F. Lehman (1995), Family interventions for schizophrenia, *Schizophrenia Bulletin*, 21 (4), 1994, 631-643
- [27]. Dixon, L.B & Lehman, A.F, Family intervention for schizophrenia, *Schizophrenia Bulletin*, 21, 1995, 631 -643.
- [28]. Schooler, N.R, Integration of family and drug treatment strategies in the treatment of schizophrenia: a selected review. *International Journal of Clinical Psychopharmacology*, 10, 1995, 73-80.
- [29]. Perm D & Mueser K, Research update on the psychosocial treatment of schizophrenia. *American Journal of Psychiatry*, 153, 1996, 607-617
- [30]. Anderson, J & Adams C, Family intervention in schizophrenia. *BMJ*, 1996, (7056): 505–506.
- [31]. Pitschel-Walz, G., Leucht, S., Bauml, J., Kissling, W., Engel, R.R., The Effect of family interventions on relapse and rehospitalisation in schizophrenia: a meta-analysis. *The Journal of Lifelong Learning in Psychiatry Winter II (1)*, 2004, 78–94
- [32]. Pharoah, F., Mari, J., Rathbone, J & Wong, W, Family intervention for schizophrenia. *Cochrane Database of Systematic Reviews 12*, doi:10.1002/14651858, 2010, CD000088.
- [33]. Mojtabai, Ramin., Nicholson, Robert A.,and Carpenter, Bruce N, Role of psychosocial treatments in management of schizophrenia: A meta-analytic review of controlled outcome studies. *Schizophrenia Bulletin* 24, (4), 1998, 581.