

STUDY ON THE RELEVANCE OF FAMILY CARE AND SUPPORT TO THE PERSON WITH SCHIZOPHRENIA

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ABSTRACT

Background

Schizophrenia not only influences the lives of those affected but also those around them, especially the caregivers. This study examines the different determinants that are relevant to the effective care and support to the person with schizophrenia.

AIM

The goals for this study were, to describe the Socio economic profile of the Persons with Schizophrenia and family caregivers, to examine the relationship between stigmatization of the illness and family caregivers' perception in defining the quality of care giving, to investigate into the problems experienced by the family caregivers of the Persons with Schizophrenia, to identify the coping strategies adopted by the care givers of the Persons with Schizophrenia, to design a model to suggest social work interventions to enhance the effectiveness of care giving.

MATERIALS AND METHODS

The study was conducted at Department of Psychiatry, Govt. General Hospital, Thiruvananthapuram, Kerala State after obtaining the necessary approval. 225 patients with schizophrenia and their caregivers attended the clinic during the year 2011 and 2012 were chosen for the present study by using the Census method. The data were collected with the help of a well-structured Interview Schedule and it was analysed by using the analytical software 'Statistical Package for Social Science' (SPSS) (Version 16). Pearson's chi-square (X^2) test, t-test and One-way ANOVA test was used to prove hypothesis

RESULTS

The care givers are having stigma which is leading to the poor care and support. The patient those whose are living with their spouse are getting more care and support than any other person in the family. The care givers are more worried about their children's future due the illness of the patient. Both the male and female patient is affected by schizophrenia. The patients, care givers and mental health professionals are given psycho education on time will helps in improving the standard of living of the patient and their family. The social worker is one of the important people in helping the caregivers and the patients in prevention of the illness and promotion of the health.

CONCLUSIONS

Intensified family and community based care improve the quality of life of the person with schizophrenia.

KEYWORDS: *Debilitating Psychological Disorder, Financial, Family Structure*

INTRODUCTION

Family members are the predominant providers of care and support to the day to day activities of the person with schizophrenia. The family members are extending a varied amount of time to bring the persons with schizophrenia to the real life. The relationship of the care recipient and care givers are very important in the health, wealth and opportunities of both categories. Families of people with schizophrenia often experience difficult challenges when it comes to dealing with this illness. Schizophrenia is a serious, debilitating psychological disorder which not only influences the lives of those affected but also his/her family. As schizophrenia tend to become chronic, the functional decline leads to loss of social functioning, alters communication patterns in the family, leads to occupational difficulties, and puts a burden in the family. Family responses to having a family member with schizophrenia include care burden, fear and embarrassment about illness signs and symptoms, uncertainty about course of the disease, lack of social support, and stigma. The caregivers have to deal with patient's symptoms, and help patients in activities of daily living. Caregivers look at several stressors including social, emotional, financial, family structure, and physical health demands among many others. Care giving could be stressful.

OBJECTIVES

General Objective

To study the effect of family environment on the quality of care and support giving to the persons with Schizophrenia.

Specific Objectives

- To describe the Socio economic profile of the Persons with Schizophrenia and family caregivers.
- To examine the relationship between stigmatization of the illness and family caregivers' perception in defining the quality of care giving.
- To investigate into the problems experienced by the family caregivers of the Persons with Schizophrenia.
- To identify the coping strategies adopted by the care givers of the Persons with Schizophrenia.
- To design a model to suggest social work interventions to enhance the effectiveness of care giving.

HYPOTHESES

The following hypotheses are to be put to test in the study.

- Unemployed bystanders remaining at home render greater care and support than the employed.
- There is a relationship between the gender of the caregiver and the type of care giving.

- The Persons with Schizophrenia who are married and living with their spouse receive better care and support than other categories.
- There exists an inverse relationship between perception of stigmatization and extension of care giving.

MATERIALS AND METHODS

Area of Study

The area selected for the study was the Department of Psychiatry, Government General Hospital, Thiruvananthapuram District, Kerala State. The researcher has conducted the present study among the persons with schizophrenia and their relatives, those who are attending the clinic.

Design of the Study

The researcher has adopted descriptive research design for the present study. The investigator tried to describe the characteristics of the respondents as well as their ill relative.

Selection of Sample

The study comprises of 225 patients with Schizophrenia and their caregivers attended the outpatient clinic of Psychiatric Department of Government General Hospital, Thiruvananthapuram, Kerala State for follow up during the year 2011 and 2012. The researcher has used census method for the selection of sample. **Statistical Tools Used**

The data collected was analysed by using the analytical software 'Statistical Package for Social Science' (SPSS) (Version 16). Frequencies and descriptives were calculated for all levels of data. Extensive data cleaning was conducted which consisted of rigorously checking for errors in data inputting. Further, for any missing data, missing value analysis was used which replaced missing data with analysed estimates. Pearson's chi-square (X^2) test was used to test for significant relationships between two or more categorical variables. Conventional statistical tools such as simple averages and percentage ratios are used for analysis and interpretation purposes. Besides, One-way ANOVA test was used to investigate the difference among the means of the population simultaneously and t-test was used to test the significance of the difference between the means of the sample drawn from the universe. Insights gained through observation have been incorporated into the text of the report at appropriate places.

Collection of Primary Data

Primary data are collected with the help of a well-structured Interview Schedule from the caregivers of 225 persons with schizophrenia who have availed outpatient treatment services from the Psychiatric Department, Government General Hospital, Thiruvananthapuram District, Kerala State. Prior to the data collection the researcher got approval from the ethical committee of the hospital.

Collection of Secondary Data

Researcher has used books, journals, magazines, previous research studies, internet data, newspapers, medical records, hospital registers etc. as a secondary source of data.

LIMITATIONS OF THE STUDY

- The respondents chosen for the study were restricted only with the patients and their caregivers and not included the health professionals/ health workers.
- The universe and units for the study was limited to the persons with schizophrenia and their caregivers attended the outpatient department of the General Hospital, Thiruvananthapuram, the rest of the hospital, patients and caregivers were excluded from the present study.

RESULTS

Demographic Profile of the Patient

Researcher has selected persons with schizophrenia from both of the genders for the present study. 52.4 percent of the patients fall under the category of male and rest of the patients belong to female Category. The patients of the study are adults and the majority of patients are between 30-40 years. Majority of the patients were married and only few are single. Education wise patients are more with degree qualification. Majority of the patients (32 percent) are unemployed due to the illness. But 24.9 percent are working for private firm and rest of them are having own business and working as labourers and few of them were studying. Spouse is the chief care taker followed by mother, daughter, father, brother, sisters and son. Majority of the patients were affected by Schizophrenia after their marriage (65.3 percent) rest is before marriage. Most of the patients (50.2 percent) of the patients were identified with relapse. Majority of the patients belongs to low income family. **Demographic profile of the caregivers**

Respondents selected for the study is male and female caregivers of the persons with schizophrenia. Majority of respondents are between 40-50 years(28percent), followed by 30-40 years(27.1percent). 96.6percent of the caregivers are married. Majority of the respondents (31.1percent) are have studied upto collegiate level and a same percentage have studied upto secondary level. Majority of the respondents (26.7 percent) are unemployed and 26.2 percent of them were labourers.58.2 percent of the caregivers falls under low income family. 93.8 percent of families are nuclear family.

Various Aspects of Caregiving

Respondents gave more importance in financial aspects of caregiving (66.7 percent). Around 64 percent of caregivers expressed moral and emotional/psychological aspects of care giving is more relevant. Whereas 58.2 percent of them stressed physical aspects are more important.

Table 1: Perception of Stigmatization by Kinship Relation of Caretaker with the Patient

Kinship Category	Respondents' Feelings of Stigmatisation		Total
	Yes	No	
	8 (34.7)	15 (65.21)	
Father	32 (72.72)	12 (27.27)	23
Mother	31 (32.97)	63 (67.02)	44
Spouse	10	12	94
Siblings	45 (45.45)	54 (54.54)	22
Son	7 (50)	7 (50)	14
Daughter	19 (67.85)	9 (32.14)	28

Table 1: Contd.,			
Total	107(47.55%)	118(52.44%)	225

Source: Primary data.

[Figures in the parenthesis denote percentage]

Stigma is more common among females than male i.e. mother with 29.9 percent, spouse (28.97 percent), daughter (17.75 percent). Only 7.47 percent are found with father rest with son and siblings.

Problems Faced in Management of the Patients

Majority of the caregivers are finding difficult in adherence to the treatment schedule (55.6 percent). 50.2 percent of having a problem in preparing the ill person for medical consultation. 47 percent of caregivers are struggling in controlling violent and emotional outburst and dietary schedule. Around 45 percent of caregivers are facing with giving counseling to the patient, grooming the ill relative, nurturing intimacy with ill person and to restrain the ill relative from misbehavior.

Feel Care Giving Blocks Achievements in Life

The caregivers (50 percent) feels caregiving blocks achievements in educational attainments, career opportunity/ career mobility, arrangement of marital alliance of family members, economic prospects and upbringing if children. 45% of respondents say caregiving blocks in development of health. Rest of then thinks caregiving is a barrier for caring other sick people and entertainment activities.

Feel Care Giving Reduce Social Contact

Around fifty percentage of the respondents felt caregiving will reduce contact with other.

TENSION AND QUARREL IN SHARING ROLE WORKS

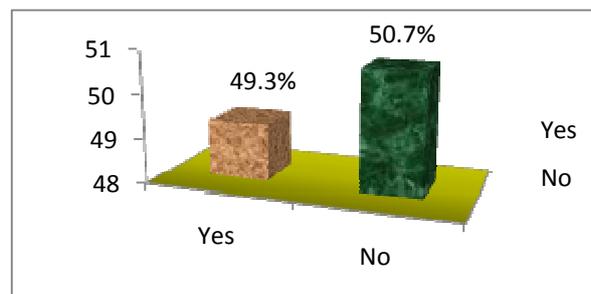


Figure 1

The care givers (50.7 percent) are having tension and quarrel in extending care especially in consultation with professionals, transportation, assisting for physical care, purchasing of medicine, daily routine of the ill relative and expenditure on treatment.

HYPOTHESIS TEST RESULTS

Unemployed Bystanders Remaining at Home Render Greater care than the Employed

This test was conducted through one-way ANNOVA test. The table value is 3.84 and calculated value is 3.547.

The table value is greater than the calculated value. Hence H_1 is accepted i.e. unemployed bystanders remaining at home render greater care than the employed.,

Gender of the Caregiver and the Type of Care Giving

This test was conducted through t-test. The significance of lower level is 2.576 and higher level is 1.282. Here the calculated value is in between these two. So the alternative hypothesis is accepted i.e. there is relationship between the gender of the caregiver and type of care giving.

THE PERSONS WITH SCHIZOPHRENIA WHO ARE MARRIED AND LIVING WITH THEIR SPOUSE RECEIVE BETTER CARE AND SUPPORT THAN OTHER CATEGORIES

The test was conducted through t-test. The significance of lower level is 2.576 and higher level is 1.282. Here the calculated value is in between these two. So the alternative hypothesis (H_1) is accepted. we can conclude that the patients living with their spouse are receiving grater care than other categories.

STIGMATIZATION AND EXTENSION OF CARE GIVING

The test which is conducted to prove whether there is a relationship between gender of the respondents and the stigmatisation possessed by them through Chi-square test. The results show that the table value is 3.841 and the calculated value is 0.463. The table value is greater than the calculated value. So the alternative hypothesis is accepted i.e. there is a relationship between perception of stigmatisation and extension of care giving.

FINDINGS OF THE STUDY

- Thenmale and female are affected by schizophrenia but the onset of the illness is earlier with male patients than female patients.
- The illness is affecting many people in getting marriage; it is not only with the unmarried patients but also with the other normal person from the family. Hence most of the respondents are worried about this and having a tendency to hide the illness from the society. Due to this reason the ill relatives are sometimes isolated in the family especially from the social gatherings.
- The education status of the patient as well as the caregivers is very important in improving the quality of life of the person with schizophrenia. Those family identified with higher education is more aware about the illness and have a good insight. They are able to find good solution to overcome the problem whenever needed.
- The caregivers with a job are less constrained with finance. In the present study majority of the respondents are either unemployed or labourers. Hence the money in their hand will be less and finding difficult to meet the need of the patients. The patients participated in the study is also in the same status. Many of them are not interested to go for a job.
- Majority of the respondents of the study are from the nuclear family and they wish to live in those family too. But when they have to move somewhere else they joint family is better than nuclear family because they can share their responsibilities with somebody else in the family. The number of person in the nuclear family to take care of the patient is less when compared with joint family.

- The patients those who are married and staying with their spouse are getting more care and support than others. The present study says that spouse is playing as a chief care giver of the patient than any other category. But the secondary care givers are either mother or daughter. From the observation researcher found that female care givers are extending more care and support from than male caregivers.
- The duration of the disease is one of the major issues with the caregivers. The persons involving in the long term care feel patient care as a burden for them.
- The respondents are giving more importance to the financial aspect of care giving than any other aspects. The care givers with less income are finding difficult to meet the need of the patient. Hence it is reflecting in the quality of life of the patient. The persons with schizophrenia sometimes need a long term treatment hence this can leads to be a burden for the family. One of the reason for the long-term treatment is because of poor drug compliance, quarrel between the family members in extending care, early diagnosis of the illness and initiation of medicine.
- The care givers are found to be stigmatized with the illness of the ill relative. The study says that female care givers are more stigmatized than male care givers. Presence of psychiatric case history, derecognition of status, social isolation, and avoidance by public are the major reason for stigmatization. Due to stigma the caregivers are hiding the illness and not giving or purchasing medicine regularly.
- The major problem facing by the caregiver with regard to the management of ill relative is with adherence to the treatment schedule. The caregivers also find difficult in preparing the patient for medical consultation.
- If the patient is not given medicine properly it will lead the patient to be symptomatic and become violent. The present study says that the majority of the patients are not allowed in decision making. The person with schizophrenia after starting treatment has to be given counseling. It will help to reduce the burden of the care givers. The present study says that the of the patients are not able to give counseling. Researcher observed that the reason for this is because lack awareness regarding the importance of counseling with the caregivers.
- The caregivers of the majority of the patient are identified with faith in god, piousness and belief in fortunes. Those care givers are always pray full. When the patient becomes symptomatic the caregivers are more tensed and are not able to tolerate the miserable situation. This is because of poor self-confidence and poor commitment and dedication. Those care givers with job and less number family members to support them in caregiving are facing a problem with time management. They are not able to give full care and support to the patient. The care givers of the study are not having enough ability to understand the people and the world view of life. A major number of caregivers are worried about the educational attainments and career of them or with their children.
- The caregivers those who are not married or having children to get married are worried more about their future. They feel due to this illness alliance from good family won't come to them. Hence there is a chance for hiding of illness with the unmarried patient and with the family members. A major number of caregivers of the person with schizophrenia are worried about their physical health. They feels that if they are contributing more for the wellbeing of the patient it is affecting in their health as well as in upbringing of children, caring the aged people as well as the other sick person in the family.
- Majority of the respondents are finding difficult to maintain rapport with their relatives, friends, co-workers,

neighbours and public since they have to be with the patient to take care of them.

- Some caregivers are found with quarrels and tension with sharing roles in caregiving. The major area leading for this issue is with consultation of professionals, transportation, assisting for physical care, purchase of medicine, daily routine of the ill relative and with expenditure on treatment.
- Unemployed caregivers are extending more care and support than employed towards the persons with schizophrenia.
- There is relationship between the gender of the caregiver and the type of caregiving.
- Spouses are extending more care and support than any other persons in the family.
- Degree of stigmatization is one of the factors for poor care and support.

CONCLUSIONS OF THE STUDY

The research findings based on the studies leads to the conclusion that, Schizophrenia is a serious mental illness characterized by positive, negative and cognitive symptoms that may affect almost all aspects of mental activity, including, perception, attention, memory and emotion in later stages especially if untreated. Though not we can irradiate the psychosocial problems of the person with schizophrenia, at least we can reduce the intensity and impact by taking enough precautions. The care and support towards the patient is the major area for their wellbeing. The care givers are having stigma which is leading to the poor care and support. The patient those whose are living with their spouse are getting more care and support than any other person in the family. The care givers are more worried about their children's future due the illness of the patient. Both the male and female patient is affected by schizophrenia. If the patients, care givers and mental health professionals are given psycho education on time will helps in improving the standard of living of the patient and their family. The social worker is one of the important people in helping the caregivers and the patients in prevention of the illness and promotion of the health.

REFERENCES

1. Addington J., Coldham E. L., Jones B., Ko T. and Addington D. *The first episode of psychosis: the experience of relatives. Acta Psychiatrica Scandinavica. 2003; 108: 285-289.*
2. Allebeck P. (1989). *Schizophrenia: A life-shortening disease. Schizophrenia Bulletin, 15: 81-89.*
3. Amaresha A.C. and Venkatasubramanian G. *Expressed emotion in schizophrenia: an overview. Indian Journal of Psychological Medicine. 2012 January; 34(1):12-20.*
4. Banerjee G. *The Law and Mental Health: An Indian Perspective. 2001. [Last accessed 2013 May 10]. Available from: <http://www.psypress.com/excl/lmhi.html>*
5. Bateson G, Jackson BD, Haley J, et al. *Towards a theory of schizophrenia. Behav Sci 1956; 1: 251-64.*
6. *Bipolar Disorder. National Mental Health Association. Accessed on 10 February 2015. Available at: <http://www.nmha.org/infoctr/factsheets/76.cfm>,*
7. Davies LM, Drummond MF. *The economic burden of schizophrenia. Psychiatr Bull 1990; 14(9):522.*

8. Khalifeh H. and Dean K. Gender and violence against people with severe mental illness. *International Review of Psychiatry*. 2010; 22(5):535-546.
9. Loganatha S. and Murthy S. Living with Schizophrenia in India: Gender Perspectives. *Transcult Psychiatry*. 2011 November; 48(5): 569-584.
10. Magliano L., Fadden G., Economou M., Held T., Xavier M., Guarneri M., Malangone C., Marasco C. and Maj M. Family burden and coping strategies in schizophrenia: 1-year follow-up data from the BIOMED I study. *Social Psychiatry and Psychiatric Epidemiology*. 2000 April; 35(3): 109-115.
11. Mari JJ, Streiner DL. An overview of family interventions and relapse on schizophrenia: meta-analysis of research findings. *Psychological Medicine* 1994; 24: 565-78.
12. Rajkumar S., Padvamati R., Thara R., Menon M.S. (1993). Incidence of schizophrenia in an urban community in Madras. *Indian Journal of Psychiatry*, 35: 18-21.
13. Rammohan A., Rao K. and Subbakrishna D.K. Burden and Coping in Caregivers of Persons with Schizophrenia. *International Journal of Social Psychiatry*. 2002 July-September; 44(3): 220-227.
18. Thara R. and Srinivasan T.N. Marriage and Gender in Schizophrenia. *Indian Journal of Psychiatry*. 1997 January-March; 39(1): 64-69.
19. Thara R. and Srinivasa T.N. How stigmatising is schizophrenia in India? *International Journal of Social Psychiatry*. 2000; 46(2):135-41.
20. Wong C., Davidson L., Anglin D., Link B., Gerson R., Malaspina D., McGlashan T. and Corcoran C. Stigma in families of individuals in early stages of psychotic illness: family stigma and early psychosis. *Early Intervention Psychiatry*. 2009 May; 3(2): 108-115.
21. Zahid A.M. and Ohaeri U.J. Relationship of family caregiver burden with quality of care and psychopathology in a sample of Arab subjects with schizophrenia. *BMC Psychiatry*. 2010 September; 10:10-71.

