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DETERMINANTS OF AN EXTENDED FAMILY SYSTEM HARBORING A CHRONIC SCHIZOPHRENIC PATIENT

Nadeem Iqbal[1], Haresh Kumar[2], Azra Shaheen[3], Mahira Shafi[4], Inam Rasool[5]

ABSTRACT

INTRODUCTION: Schizophrenia refers to a major mental disorder, the most severe and debilitating psychiatric illness, afflicting, roughly, 1% population, whose causes are still largely unknown, and which involves a complex set of disturbances of thinking, perception, affect and social behavior. So far, no society or culture anywhere in the world has been found free from schizophrenia. Typically, the illness occurs in young adults, having a lifelong course with decline in functioning be it personal, occupational or social putting great financial and emotional burden on family as well as the society in terms of disability and health costs. **OBJECTIVE**: To evaluate the core reasons for harboring chronic schizophrenia patients among extended families. **STUDY DESIGN:** Descriptive study. **SETTING:** OPD, Department of Psychiatry Jinnah Postgraduate Medical Centre. Karachi. **SUBJECTS AND METHOD:** This study was carried over a total of 100 patients who met the diagnosis or schizophrenia on ICD-10, having the duration on illness of at least 5 years, and one of the members of their extended family living together. It took six months to collect the data of the required number of patients. **RESULTS:** Extended family members harbor schizophrenia patient's are fear of God, kinship ties, responsibilities as family, sympathy, fear of harm to patient or others, social humiliation, symptom reduction, and poor living conditions in facilities. **CONCLUSION:** The biopsychosocial factors should include religio-cultural factors of harboring schizophrenia patients mentioned in the results. **KEYWORDS:** Chronic Schizophrenia, Extended Family System, Family Belief System

1. Assistant Professor / In-charge department of Psychiatry Karachi Medical & Dental College & Abbasi Shaheed Hospital Karachi
2. Associate Professor of Psychiatry, Khairpur Medical College, Khairpur Mirs.
3. Assistant professor of Clinical Psychology, Institute of Psychiatry, Baqai Medical University Karachi.
4. Assistant professor of Psychiatry, Institute of Psychiatry, Baqai Medical University Karachi.
5. Head of Institute of Psychiatry, Baqai Medical University Karachi.

Corresponding Author: **Dr. Haresh Kumar** Associate Professor of Psychiatry, Khairpur Medical College, Khairpur Mirs.Email: hareshmakhija@gmail.com Cell: +923337589901

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INTRODUCTION

One of a very complex mental disorder that has is present is Schizophrenia. The frequency of psychological disorders like schizophrenia based on 2013 survey is 1.7 per 1000 people [1]. The theorist who devised the name of the current disorder explained it as a distortion of cognition and emotions of an individual. Prior to the differentiation between neurology and psychiatry, schizophrenia was considered as a pathology stemming from brain. [2] The symptoms of schizophrenia includes both positive and negative which are delusions that are mostly of paranoid theme, different types of hallucinations, blunted affect and may include speech or motor distortions [3]. The indicators interferes with the patient's thinking, emotions, volition, conation and motor behavior. The illness can be triggered in late adolescence or in early adulthood. As per research, the pathophysiology of the present disorder is categorized in neurodevelopment disorder [4]. It is indicated that the disorder manifests between the ages of 18-25 however findings have suggested the psychosis is triggered much before in the course of life [5]. Genetic studies that schizophrenia has high heritable rate and may run in families [6]. As well as ecological factors come into play i.e., pre and post birth complications, malnutrition in mothers, second trimester contagions and more. Psychological and social influences are childhood trauma, loneliness, low socio-economic status, physical, emotional or sexual abuse, drug abuse, bereavement or loss, stress and problematic family relationships [7]. Schizophrenia is an uncurable yet manageable psychiatric pathology which is persistent and comes with many obstacles and negative outcomes [8]. Beside from personal miseries from the different symptoms of the disorder it imposes a substantial medical expense on the individual or the family as well as leads to burden of responsibility in on the caregiver, the household and indirectly to the community as there can be repeated hospital admissions and the family needs financial and emotional provision [9]. The individual is most likely unable to hold employment which results in life-time dependency. There are multiple domains that are affected with such kind of illness and by the degree of its severity i.e., social relationships, ability to learn, daily life skills, personal maintenance and professional life [10]. The current disorder also have risk of comorbidity with substance addiction, suicide and other mental ailments [11]. An extremely crucial role is played by the extended family as they have to provide a lifetime care and assistance with every aspect of the patient's life which effects the family as a whole. The whole unit is effected economically, socially and psychologically. However, findings suggests that patients with schizophrenia are better managed in developing countries as the family system is united through traditional and religious values [12]. The family's mental health who is taking care is impacted and feel high amount of pressure and trouble handling the patient. The responses of the families comprises of phenomenon of care burden, fear, shame of the symptoms, god's wrath, punishment for sins, supernatural themes, uncertainty about course of the disease, lack of social support, and stigma which may lead to families harboring the affected person [13, 14]. The current study is an effort to determine the core reasons which compel the extended family to harbor a chronic schizophrenia patient among them. The present research would prove to be helpful in treatment, rehabilitation and mental health care planning by integrating in the biopsychosocial model, both the casual beliefs regarding schizophrenia, and the main reasons for concealing a persistent schizophrenia patient in an extended family unit.

METHODOLOGY:

STUDY DESIGN: Cross-Sectional Study
STUDY SETTING: OPD Department of psychiatry Jinnah Post graduate Centre, Karachi.
SAMPLE SIZE: 100 Chronic Schizophrenic Patients and one of their extended family members living in the same house.
SAMPLING TECHNIQUE: Non-probability convenience sampling.

SAMPLING SELECTION INCLUSION CRITERIA:

1. Patients fulfilling the criteria of ICD-10(Schizophrenia).
2. Patients having duration of illness of at least five years.
3. One family member of extended family system of patient living in the same house.
4. Patients and families in nuclear families.

EXCLUSION CRITERIA:

1. Patients with psychiatric co-morbidity
2. Patients living in nuclear families

DATA COLLECTION

This descriptive study was conducted at the department of psychiatry, Jinnah Postgraduate Medical Center, Karachi. As outlines in the synopsis approved by CPSP, 100 patients were selected who fulfill the ICD-10 criteria for schizophrenia and had history of illness of at least five years, and their family members belonging to the same extended family system in the same house. Patients with psychiatric co-morbidity, and patients living in nuclear families were excluded.

Before taking history, informed written consent was taken from the patients. Sociodemographic data of such patients were taken on a semi-structured proforma , while patient's attendant were assessed for Belief System, Quality of Life, Stress and Tolerance, Religious Belief, Social Pressure, Inadequate Long Term Facilities and Stigma.

STATISTICAL ANALYSIS

Data analysis was performed through SPSS version-10.0. Sex distribution was presented by ratio (M:F) and age distribution by Mean and Standard deviation. Frequencies and percentages were computed to present all qualitative response variables. The P-value < 0.05 was considered statistically significant results. Continuous response variable like duration of illness and duration of treatment were presented by Mean and standard deviation.

OPERATIONAL DEFINATIONS

Extended family system: Set of biological relatives i-e, grandparents, fathers, mother, children, sibling, aunts, uncles and cousins.

Chronic schizophrenia: Disturbances specific to schizophrenia for more than two years duration.

RESULTS

Among 100 patients, 61 were males and 39 females participated in this study with 1.6:1 male to female ratio. Average age of patients was 34.74+ 8.21 (ranging from 24 to 60) years. The commonest age group was 31-40 years in which 45 patients were falling. Majority of the patients were unmarried (48%), followed by 30% married, 19% divorced and 3 patients had got separation from the spouse.

Relationship of the patient's attendant for full time care was asked. Father to 39 patients, mother to 9, brother to 33, sister to one, spouse to 13 and offspring to 5 patients were taking care of in their illness. History of tobacco use was the commonest substance use in family that was reported by 75% participants followed by paan by 51%, gutka by 47%, tranquilizer by 45%, cannabis by 19%, alcohol by 8%, opium by 2% and heroin by 1% participants.

When the participants of the study were asked that if they consider that the patient illness is caused by supernatural element, 96% responded positive. Out of 100, 46 were consistent with the opinion that the patient's illness was a psychiatric problem. According to 84% respondents that their patient' s illness is a trial from God for their. Fifty percent respondent considered their patient's illness as wrath of God. A 40% of respondent agreed with the assumption that their patient's illness was punishment against their sins, cent percent respondent described that their patient's illness in incurable but treatable (Table-1). Majority of the

respondents (98%) positively replied that if their patients were cause of shame in front of relatives, 93% agreed with the statement that the behavior of the other people towards the patient was, 92% described difficulty in matchmaking due to their patient (Table-2).

The 83% respondents reported that they were facing financial crisis, 92% described that their standard of living was affected and 95% reported significant effect on housing, education and marriage due to their patient' illness (Table-3). Majority of the respondent admitted that they were feeling anger and irritability due to patient's presence (83%) but 35% respondents described that quarrels among the family members were caused by the presence of patients. Fatigue due to patient's care was reported by 88% but only 16% were hopeless from complete cure while 88% participants were sharing responsibilities. (Table-4).

Majority of the participants described that they were harboring their patient due to fear of God (97%), due to blood relation/ kinship by 95%, all 100% told that they feel responsibility as family member , 98% participants were thinking that the patient might harm himself or may be harmed from others if they did not harbor their patient. 99% respondents said disrespect in society, 84% had belief for symptoms reduction in future and 98% of the respondent described the living conditions in long term institution as the reason for harboring their patients (Table-5).

TABLE – 1 BELIEF SYSTEM n = 100

Q	Factors	Response		
		Yes	No	p-value
Q1	Supernatural Causes	96	4	0.001
Q2	Psychiatric illness	46	54	0.424
Q3	Trail from God for your Family	84	16	0.001
Q4	Wrath of God	50	50	0.999
Q5	Punishment against sins	40	60	0.046
Q6	Incurable but treatable	100	0	-

TABLE – 2STIGMAn = 100

Q	Stigma	Response		
		Yes	No	p-value
Q7	Cause of shame in front of relatives	98	02	0.001
Q8	Criticism/derogatory remarks on patient	93	07	0.001
Q9	Difficulty in matchmaking due to patient	92	08	0.001

TABLE – 3QUALITY OF LIFEn = 100

Q	Factors	Response		
		Yes	No	P-value
Q13	Financial crisis due to patient's illness	83	17	0.001
Q14	Effect on standard of living	92	08	0.001
Q15	Effect on housing, education and marriage	95	05	0.001

TABLE – 4STRESS AND TOLERANCEn = 100

Q	Factors	Response		
		Yes	No	p-value
Q16	Anger and irritability due to patient's presence	83	17	0.001
Q17	Violence/quarrels among the family members	35	65	0.003
Q18	Fatigue due to patient's care	88	12	0.001
Q19	Hopelessness from complete cure	16	84	0.001
Q20	Sharing of responsibilities due to patient	88	12	0.001

TABLE – 5REASONS FOR HARBORINGn = 100

Q	Factors	Response		
		Yes	No	p-value
Q21	Fear of God	97	03	0.001
Q22	Blood relation/kinship	95	05	0.001
Q23	Responsibility as family member	100	0	-
Q24	Sympathy due to poor self-care/supervised living	99	01	0.001
Q25	Self-harm or harm from others	98	02	0.001
Q26	Fear of humiliation/disrespect in society	99	01	0.001
Q27	Symptoms reduction in future	84	16	0.001
Q28	Pathetic living conditions/poor facilities	98	02	0.001

DISCUSSION

Schizophrenia is a chronic disorder whose prevalence is roughly 1% and incidence ranges from 7.5 to 16.3 cases /per 100,000 of population.[1] It also takes its toll from the families of the patients in terms of stigma, stress, finances and quality of life.

Only 30% of the patients in our study were married while 70% were unmarried, divorced or separated indicating the inability of these patients to raise families. This could well be due to the downhill course of the illness and stigma which renders them unable to have good interpersonal relationship**.** It also shows that the majority of the patients were dependent on their extended families.[4] In our study, 90% of the attendants were found employed which could be due to the added burden of their patient's care. The extended family's belief system or explanation for this illness, 96% attributed supernatural causes, 84% saw the illness as a trial from God, 50% considered the illness as wrath of God, 46% said that the illness was a psychiatric problem, 40% described the illness as a punishment for their sins. Almost all the respondents were of the view that this illness is incurable but treatable in terms of symptoms. It is evident from the above results that the extended family's beliefs systems in our study is greatly embedded in the Islamic religion cultural model. Similar studies conducted in developing countries showed same pattern of family's belief system.

Regarding stigma, 98% of respondents in our study admitted that their patients were cause of shame among people. 93% reported criticism for patients by others. 92% reported difficulty in match making for family members. In one western survey of family members a vast majority of respondents reported that mental illness

stigma was present and had a negative impact on their ill relatives. About the quality of Life, 95% reported significant effect on housing, education and marriage due to their patient's illness, 92% mentioned their standard of living was affected, and 83% reported facing financial crisis..

Concerning Stress and Tolerance, 83% of respondents in our study were feeling anger due to patients, only 35% described quarrels among the family and 88% admitted fatigue due to patient's care. A Hongkong study reported family members experience most stresses related to the management of negative symptoms.

Concerning the reasons for harboring the chronic schizophrenic patients among the extended families, a significant majority of 97% of participants in our study described that due to fear of God. 95% blood relationship, 100% were of the opinion that the responsibility as family members. 99% reported sympathy as a reason as the patients were unable to care for themselves. 98% were thinking that the patient might harm himself or others. 99% described the fear of disrespect in society as reason for harboring. 84% hoped symptoms reduction in future while 98% of respondent attributed the pathetic living conditions in institutions.

International studies have demonstrated a far better long-term outcome for schizophrenia in developing countries. In the rural agrarian societies of south East Asia and Africa, showed better outcome than in the West. The common denominator in all these studies was extended family system.[8] Moreover, a supernatural casual attribution, which does not assign responsibility for the disorder to the family, may decrease the family's psychological burden. Cultural psychiatry has been an important contributor to the enhanced dialogue between psychiatry and religion in the past couple of decades.[2] During this time, religion have become more prominent in main stream psychiatry in a number of areas of study and clinical care.

CONCLUSION

The objective of this study was to evaluate the determinants of an extended family system harboring a chronic schizophrenic based in ICD 10 diagnostic criteria Overall, the main determinants were fear of God, blood relationship or kinship ties, responsibility as a family member, sympathy, fear of harm to patient or others, disrespect in society, hope of reduction of symptoms in future, and poor living conditions in long term psychiatric facilities were found to be statistically significant.

It was found that extended family's belief regarding schizophrenia and core reasons for harboring the chronic schizophrenia patients among extended family should be integrated into the bio-psycho-social model which will further enhance the efforts for treatment and rehabilitation of these patients.

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CONFLICT OF INTEREST

No conflict of interest is present in any of the authors.

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