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A Study To Associate Relapse With Attitude Towards Medication, Explanatory Models Among People With Schizophrenia And Their Care Giver Knowledge Regarding Schizophrenia.

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I. Introduction

Schizophrenia is a severe mental disorder affecting more than 21 million people worldwide. It is associated with considerable disability and may affect educational and occupational performance. **(WHO, 2016).** It is a chronic mental illness which requires consistent and long term support from carers, which means it is stressful not only for patients, but also for their family members. **(Doval, Sharma, Agarwal, Tripathi and Nischal, 2016).**Pharmacological and non pharmacological measures are being used to treat the mental illness. In reality, effective treatment for mental illness is a big challenge due to issues with adherence. Readmissions to psychiatry wards & acute care room are a source of frustration, not only to the treating team but also to patients and families. Relapse may leads to re-hospitalization, and is distressing to patients and their caregivers **(Nandhini C, Charles A, 2006).** Caregivers who are the primary interface with the health care system often receive inadequate support from health professionals and frequently feel abandoned and unrecognized by the health care system **(Lilly MB, Robinson CA 2012).**

Repeated hospitalisations in a psychiatric unit, affecting primarily the seriously mentally ill, are a substantial problem. Between 40 percent and 50 percent of patients with a history of repeated psychiatric hospitalisations are readmitted within 12 months. Key factors in decreasing the likelihood of subsequent psychiatric readmissions include rendering sufficient inpatient care to address adequately the acute presenting problem and stabilize the patient's psychiatric status, ensuring adequate discharge plan and delivery of sufficient support services and continuing adequate outpatient services to allow the individual to remain in the community **(Williams, Csipke, 2014).**

Positive attitude toward medications has contributed to patients staying on treatment for longer periods. It is also possible that longer treatment duration helped patients to gain better insight, and thus have a better perception of the medication. Similarly, positive patient attitude and behaviour may have contributed to improved psychopathology **(Liu-Seifeit et al., 2010).**

Caregivers' negative experiences and lack of knowledge may affect their ability to care for the patients and considering caregivers' Quality of Life and indirectly affects the patients' health. Improvement of caregivers' Quality of Life may have a direct impact on the psychotic symptoms of patients and indirectly on patients' Quality of Life. So caregivers' Quality of Life is a major concern and mental health professionals and policy makers should consider the establishment of routine and ongoing family interventions in Latin America (**Alejandra Caqueo- Urizar, Marine. A 2017)**

Srinivasan and Thara (2010) assessed the beliefs about causation of schizophrenia among Indian families of patients with schizophrenia. They reported that only 12% of the families named supernatural cause and psychosocial stress was most commonly cited cause, followed by personality defect and heredity. Among the families, 14% could not name any cause and 39% named more than one cause.

Need for the study:

Increased frequency of relapse and admissions negatively affect patients and families quality of life **(Gbiri, Badru, Ladapo, & Gbiri, 2011).** Inadequate insight with discontinuation of medicines (non-adherence to treatment) are factors associated with relapse. **Shobalakshmi (2006)** ,**(National Institute of mental health, 2007).** A study done in the same setting among patients with schizophrenia and their care givers identified that they held multiple and contradictory beliefs about the causation and treatment of illness (**Charles,**

Manoranjitham and Jacob 2007). Improved understanding of illness and more positive attitude towards medication results in better community functioning **(Mohamed et al 2009)** and also influences their ability to care for patients **(Alexandra palli et al, 2015).** Hence, the researcher felt the need for conducting a study to associate relapse with attitude towards medication, explanatory models among patients with schizophrenia and their care givers' knowledge regarding schizophrenia.

Aim of the study:
Aim of the study was to identify factors associated with relapse in patients with schizophrenia

II. Methodology

A Cross sectional study was used for the study. This **s**tudy was carried out in the Department of Psychiatry, CMC, Vellore which caters to patients with severe and minor mental disorders. Patients with schizophrenia in relapse and their care givers who attended the outpatient department or were admitted to the inpatient facility of the department were approached for suitability of inclusion in the study. They were recruited after obtaining the informed consent. A total of 100 patients with Schizophrenia and their caregivers who had consented to participate in the study were included in the study.

a) To estimate the prevalence of patients with negative attitude towards drug and patients with relapse the required number of samples for the study was estimated to be 75 patients **Chakraborty N, Aryiku. (2006)**
b) To estimate the knowledge of caregivers assuming that 35% will have correct knowledge (≥ 10) about schizophrenia; the numbers of care givers to be studied was estimated as 91 **Economou M, Clive.(2009)**
The sample size was calculated based on the $n=4pq/d^2$. Hence sample size for the present study included 100 patients and 100 care givers .

Sampling technique:
The study was incorporate a cross sectional survey design to recruit consecutive patients with schizophrenia who were currently suffering with relapse along with their care givers based on inclusion criteria at the Department of Psychiatry, Christian Medical College , Vellore. Clinical Global impression scale-Severity (CGI-S) was used to assess the severity of illness. If the patients were found to have severe mental illness (CGI-S suggestive of severe mental illness and above) and hence judged unable to give a valid informed consent for the study, then the patients and care givers were excluded from the study. IRB permission was obtained and protection of human rights was ensured.

Description of the instruments:
Part I: A) Socio demographic variables of the patient and Care givers
B) Clinical variables of the patient

Part II: Drug Attitude Inventory Scale (DAI-10)
This is a standardized questionnaire to assess the attitude towards drug compliance. This scale was adapted from a self report scale predictive of drug compliance in Schizophrenia: reliability and descriptive validity. This scale has a total of 10 items; 6 items that were scored 'true' and 4 'false'. If the person was fully compliant, it shows positive subjective response.

Part III: Knowledge about Schizophrenia Interview (KASI) has been shown to be an effective tool in the assessment and evaluation of the functional knowledge about schizophrenia (33). It is quick, easy to administer and has been reported to be reliable with good face validity for the caregivers. The KASI questionnaire has been translated into Tamil by Schizophrenia Research Foundation [SCARF], Chennai, India. KASI is a self-report
The questionnaire contains questions that are divided into 6 sections of diagnosis (4 questions), symptomotology (5 questions), etiology (4 questions), medication (7 questions), course and Prognosis (3 questions) and management (4 questions).

Part IV: Short explanatory model interview (Lloyd, Jacob, Patel, Bhugra, & Mann, 1980) SEMI consists of 24 questions. The components of SEMI include the following:

- Questions on health behaviour
- Nature of the problem, reason for consulting, name of the problem, perceived causes, consequences and overall effect
- Help seeking especially with non medical and traditional healers
- Questions on causes for the illness
- Questions on reason for the visit to the physician
- Questions related to their beliefs (using Vignettes of schizophrenia)

Scoring: The qualitative data generated by SEMI was examined. Items were enumerated and broad categories (facets) were identified. The items which occurred frequently were allocated independent numerical codes. Subsequently EMIC items 28 were coded dichotomously (yes/no) which allowed quantitative analysis. The frequency distribution of data generated was used for statistical analysis. This scale is routinely employed in the department for clinical work.

Validity and reliability:

All the instruments were standardized except the interview guide for collecting socio –demographic and clinical details of the patient. Adequacy of the demographic and clinical details to be assessed was scrutinized by experts in the field. All the questionnaires that were translated into Tamil language were translated back and tested during the pilot study and found suitable for Indian setting. Thus, it was concluded that the study would be feasible and the tools are reliable.

Data analysis

Descriptive statistics were carried out for the sample. Independent t test, Pearson's co-relation co-efficient and Chi-square tests were used to find the association between socio demographic variables with relapse, models of illness, attitude towards drug and the care givers knowledge about Schizophrenia.

III. Results

Majority of the patients (85 %) belonged to the age group of 18-40 years. A major proportion were males (52%), Hindus (78%), from rural (53%), single(58%), studied up to higher secondary(35%) and not working (46%).
Majority of the patients (82%) had history of relapse, recovered from the past episode (78%) and had minimal improvement (55%).

Table 1: *Description of care givers according to socio demographic variables* (N=100)

Variables	n	%
Relationship with the Pt		
Parents	70	70%
Spouse	7	7%
Children	9	9%
Others	14	14%
Gender		
Male	41	41%
Female	59	59%
Education		
Primary	11	11%
Secondary	66	66%
Graduate	23	23%
Occupation		
Employed	44	44%
Unemployed	18	18%
Home maker	38	38%

Table 1 shows that majority of the care givers were parents, female, studied up to higher secondary level, and not working.

Table 2: *Distribution of Patients according to belief models about illness* (N=100)

Variables	**n**	%
Other health behaviour **Getting Help from** Temple/ Church	38	38%
Black magician	31	31%
Healer	27	27%
Doctor	67	67%
Anyone else has given advice about seeking health care Hospital	14	14%
Friends	20	20%
Family	41	41%
Church	19	19%
Healer	6	6%
Are you treating yourself with supplementary therapies Alternative system of medicines	21	21%
Counsellor	9	9%

Magico-religious	6	6%
Nil	64	64%
Reason of onset		
Internal	21	21%
External	38	38%
Natural	15	15%
Man made	26	26%
Perceived severity		
Yes	52	**52**%
No	48	48%
Expectations from health care provider		
Medicines	42	42%
Injections	10	10%
Natural	12	12%
Spiritual	21	21%
Counselling	36	36%
Consequences		
Social	70	70%
Interpersonal	14	14%
Personal	58	58%
Occupational	26	26%
Family	87	87%

Table 2 reveals that majority of the patients believed that the illness is caused due to evil spirit (25 %), followed by black magic (15 %), punishment from God (12 %) and karma (11 %). 37 % of them believed the illness is due to biochemical causes (brain problem, chemical changes in the brain, genetic).This shows that majority of the patients (63 %) held non-medical model. Majority (38%) of the patients had reported that the reason for the onset of illness was external like evil spirits, black magic and karma. However, 21% of them expressed to be internal like mind confusion, head injury and excessive stress.

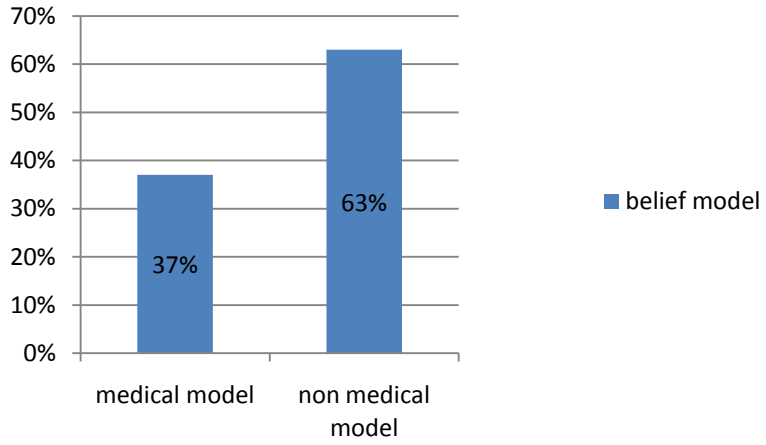

***Figure 1*:** Distribution of patients according to illness model

Figure 1 : Shows that majority of the patients follow non medical model

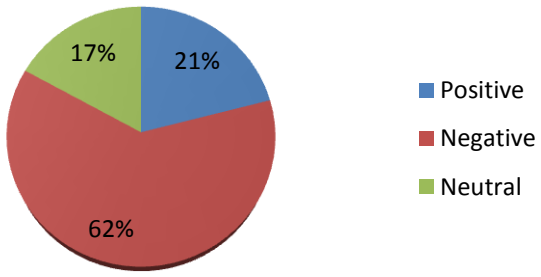

***Figure 2*:** Distribution of patient's attitude towards antipsychotic drugs

Figure 2: Shows that majority (62%) of the patients had negative attitude towards taking antipsychotic drugs.

Table: *3* *Distribution of care givers according to the knowledge about Schizophrenia* (N=100)

Variables	**n**	**%**
Diagnosis		
Personality	32	32
Some mental illness	49	49
Severe mental illness	14	14
Correct information	5	5
Signs and symptoms		
Below 2 score	28	28
Do not know	44	44
Aware of signs and symptoms	26	26
Complete awareness	2	2
Etiology		
Non medical	45	45
Bio chemical	26	26
Psycho social	28	28
Complete information	1	1
Medication		
Incorrect/ do not know	42	42
Aware of frequency	27	27
Acceptable responses	25	**25**
Complete detail	6	**6**
Prognosis		
Do not know	47	47
Aware of recurrence	42	42
Aware of other factors causing relapse	10	10
Complete information	1	1
Management		
Emotionally/ over-involved	24	24
Over protective/ foster dependence	32	32
Willing to spend time with Pt	30	30
Supportive/ encouraging	14	14

Table 3: shows that most of the care givers (49%) said that the diagnosis is "some mental illness", 44% of them were not aware of the signs and symptoms , 45% of them believe the illness is due to non medical causes (black magic, loss of loved ones, adjustment problem, financial problem, stress, love failure, failure in examination ,marriage related problems, ancestral spirit etc), 42 % of them were not aware of the medicines taken by their caregivers (name, frequency, dosage etc.,), 47 % of them were not aware of recurrence, prognosis and many of them were over protective and 14% has ideas about supportive therapy.

Table 4 : *Distribution of patients according to the reasons for help seeking to hospital(N=100)*

Reasons for help seeking	n	**%**
Suicidal attempt	38	38**%**
Hearing of voices/ commanding voices	12	12**%**
Assaultive/abusive behavior	13	13**%**
Anger / irritability	12	12**%**
Sleep disturbances	9	9**%**
Poor nutrition	4	4**%**
Altered ADL	3	3**%**
Poor self care	3	3**%**
Others (over familiarity, excessive speech)	2	2**%**
Wandering / absconded from home	4	4**%**

Table 4 reveals that majority gave the reasons for help seeking to hospital are suicidal attempts (38%) followed by hearing of voices(12%), anger and irritability (12%), assaultive behavior (13%), sleep disturbance(9%), other reasons are not taking food, altered ADL, poor self care , excessive speech and wandering.

IV. Discussion

CARE GIVERS KNOWLEDGE: Most of the care givers (49%) reported that the patients' diagnosis was 'some mental illness', 44% of them were not aware of the signs and symptoms , 45% of them believed that the illness was due to non-medical causes (black magic, loss of loved ones, adjustment problem, financial problem, stress, love failure, failure in examination ,marriage related problems and ancestral spirit), 42 % of them were not aware of the medicines taken by their relative(s) (name, frequency, dosage etc.,), 47 % of them were not

aware of recurrence, prognosis and many of them were over protective and 14% of them had an idea about supportive therapy.

In this study caregivers' education is significantly associated with awareness of diagnosis **(p value- 0.000)**, signs and symptoms **(p value- 0.001)**, and etiology of illness **(p value- 0.004)**. Occupations of caregivers are significantly associated with awareness of diagnosis **(p value is- 0.019)** , etiology of illness **(p value is- 0.011)** and prognosis **(p value- 0.080)** .Which is supported by a study done by Thara, Padmavati, Aynkran & John, 2008. Caregivers' knowledge about etiology is associated with recovery of the patient from the past episode **(p value is- 0.004)** and knowledge about medication is significantly associated with recovery in the past episode **(p value is-0.010)** Some care givers expressed that they did not want the neighbours, relatives friends and extended family members to know about the psychiatric problems of patients. Therefore, they did not seek psychiatric treatment, though they knew the client would get better soon if they did so.

ILLNESS MODEL: Majority of the Patients believed that the cause of illness was evil spirits (25 %), followed by black magic (15 %), punishment from God (12 %) and karma (11 %). 37 % of them believed that the illness is due to biochemical causes (brain problem, chemical changes in the brain) or genetics .This shows that majority of the subjects (63 %) held non-medical model ,which is supported by a study done by Manasi A et.al (2011) which reveals that the most often mentioned factors for psychiatric illness were stress (63%). There no significant association between demographic variable and expressed explanatory model.

PATIENTS ATTITUDE TOWARDS ANTIPSYCHOTIC DRUGS: Majority (62%) of the patients had a negative attitude, 21% of them had positive attitude, while 17% of them had a neutral attitude towards the consumption of antipsychotic drugs which was consistent with a study that was done in Tanzania Mbatia & Jenkins (2010). Previous studies done by Kazadi, Moosa & Jeenah(2008), have also found that non adherence to medications appear to be one of the factors most likely to increases the risk of relapse in schizophrenic patients . Several patients stated that the reason they sometimes do not take their medication is because of the side effects of drugs, which cause drastic changes in their lives, robbing them of the ability to perform certain activities efficiently. In this study, the attitude of patients towards antipsychotic was not significantly associated with any of their socio demographic variables.

Many caregivers expressed their concerns regarding patient's non adherence to treatment as follows:

"He didn't take his medication as prescribed as he felt that he has been cured. When he stayed without medicines his illness aggravated".

"My relative failed to take medications as he felt drowsy and sedated most of the time during the day".

"She forgets to take medicines most of the times. This is the reason why her condition has become this way"

"My husband stopped taking medicines because he feels that he not able to perform sexually".

"My relative's illness worsened when his/her medication dose was reduced and the drug was changed"

Some of the patients expressed their concerns as follows:

A 35 year old, female patient, expressed: *"I used to take medications regularly but when I felt that I was cured, I stopped taking medicines and stopped attending OPD".*

A 30 years old newly married female patient claimed: *"My in laws talk a lot about me, I live in joint family. They tell me, "You are very lazy, sleeping all the time and not doing any work also said they were planning to apply for divorce".*

Many patients, both male and female expressed *"Medications make me drowsy and sleepy. I am unable to do simple daily activities. So, I stopped taking medicines".*

"Since I didn't have enough money on many occasions, I chose to adjust my medicine myself. This was the reason my illness worsened".

Some of the caregivers and patients gave few suggestions to reduce relapse:

1) Mental health team members should try their best to spend enough time and talk to the patients and care givers in their own language.

2) Communicate with them through cell phones, if possible video calls and enquiring health condition , medication side effects, and next appointment.

3) Video assisted teaching regarding relapse and medications can be given especially during the waiting time in OPD.

Psychosis Vignette

Mrs A is a 30-year-old housewife with three small children. Her husband is a manual labourer. For the past 6 months she has stopped doing household work. She does not interact with her children or look after their needs. Her personal care is poor. She has been socially withdrawn and prefers to be alone. Her family has noticed that she smiles to herself and admits to hearing voices of strange people speaking to her. She is convinced that others will harm her. Her sleep is disturbed and her appetite is poor. Her in-laws live next door but are not supportive.

Responses of most of the patients to the following questions:

1) Does she have a problem? *"Yes, she has some problem".*
2) If so, what is her problem? *"There is something wrong with her mind. She doesn't talk to others. She is smiling and talking to self".*
3) Does she have a disease? *"I know something is wrong with her brain. This might be due to excessive tension. She also has to raise 3 children with financial problems".*
4) What are the causes of her problem? *"She has 3 children; husband's income is insufficient and has no support from her in laws. This can be the reasons for her problem".*
5) Do you think that the problem is caused by black magic? *"Yes, I believe someone cast an evil spell on her and her family."*
6) Is her problem caused by evil spirits? *"Yes, she has spirits in her body which threaten her and it is the spirits she is talking to."*
7) What should she do to overcome her problems? *"She should approach an oracle (poojaari) for help ".*
8) Should she contact a doctor or a nurse for treatment? *"Yes, she should go to see the doctor if approaching the oracle does not help."*
9) What should the doctor / nurse do to help her overcome her problem? *"I feel counselling is enough for her".*

V. Conclusion

This study highlighted the patient's negative attitude towards antipsychotic drugs their perceptions about illness and lack of care givers knowledge about schizophrenia that mostly influence relapse. The most common reasons that increase the risk of relapse are the irregularities in taking antipsychotic drugs, medication side effects, belief of being cured, cost of antipsychotic medications, poor family support, stressful life events and substance use.

Responses of caregivers give the picture that they are not aware of the psychiatric illness, its causes, medication and treatment modalities. This implies that there is an urgent need to educate the people at community level about the disease and its treatment so that the stigma they hold will be abolished and they will be free to seek mental health services at the correct time.

By identifying such factors the Nurses and Mental health team members can plan for health education programme for all such patients who get discharged and thus improve compliance to antipsychotic medications and follow-up. Furthermore, this knowledge would be useful for nurses to structure their nursing care plan, plan for psycho educational interventions, which may reduce the relapse and readmission

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