International Journal of Science and Research (IJSR)
ISSN (Online): 2319-7064
Impact Factor (2012): 3.358

Knowledge, Attitudes and Practices among Caregivers of Patients with Schizophrenia in Western Maharashtra

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Abstract: ***Aims: This study aimed at assessing the knowledge, attitude, and practices among caregivers of schizophrenia patients in western Maharashtra. Settings and Design: Cross-sectional study design was used which was carried out in mental health institute. Methods –A semi-structured questionnaire was used to obtain the required data from caregivers accompanying the schizophrenia patients. Convenient samples of 50 caregivers were selected. Most of the caregivers (30%) had no prior knowledge about schizophrenia. The fathers (24 %) and relatives (24%) were the major caregivers for the patients. Caregivers considered medical intervention to be the most important, but they also advocated supportive interventions such as counseling and family support. Financial problem was one of the factors that impacted negatively on follow-up of patients. Conclusion- Educational programmes for the relatives of patients by developing psycho-educational intervention and sensitization campaigns are needed.***

Keywords: Schizophrenia, Caregivers, Knowledge, Attitudes, Practices

1. Introduction

Schizophrenia is a severe form of mental illness affecting about 7 per thousand of the adult population, mostly in the age group 15-35 years. Though the incidence is low (3-10,000), the prevalence is high due to chronicity.

Facts

- Schizophrenia affects about 24 million people worldwide.
- Schizophrenia is a treatable disorder, treatment being more effective in its initial stages.
- More than 50% of persons with schizophrenia are not receiving appropriate care.
- 90% of people with untreated schizophrenia are in developing countries.
- Care of persons with schizophrenia can be provided at community level, with active family and community involvement.

There are effective interventions (pharmacological and psychosocial) available and the cost of treatment of a person suffering from chronic schizophrenia is about US$2 per month; the earlier the treatment is initiated, the more effective it will be. However, the majority of the persons with chronic schizophrenia do not receive treatment, which contributes to the chronicity.
Pilot programmes in a few developing countries (e.g. India, Iran, Pakistan, Tanzania, Guinea-Bissau) have demonstrated the feasibility of providing care to people with severe mental illness through the primary health care systems by:

- Appropriate training of the primary health care personnel;
- Provision of essential drugs;
- Strengthening of the families for home care;
- Referral support from mental health professionals, and
- Public education to decrease stigma and discrimination [1].

The schizophrenic disorders are characterized in general by fundamental and characteristic distortions of thinking and perception, and affects that are inappropriate or blunted [2. Clear consciousness and intellectual capacity are usually maintained although certain cognitive deficit may evolve in the course of time. The most important psychopathological phenomena include though echo; thought insertion or withdrawal; thought broadcasting; delusional perception and delusions of control; influence or passivity; hallucinatory voices commenting or discussing the patient in the third person; thought disorders and negative symptoms. There are sub types of schizophrenia; paranoid, hebephrenic, also called disorganized, catatonic, undifferentiated, simple and residual schizophrenia. Paranoid schizophrenia is dominated by relatively stable, often paranoid delusions, usually accompanied by hallucinations, particularly of the auditory variety, and perpetual disturbance. Catatonic schizophrenia is dominated by prominent psychomotor disturbance that may alternate between extremes such as hyperkinesias and stupor, or automatic obedience and negativism. Hebephrenic schizophrenia is a form of schizophrenia in which affective changes are prominent, delusions and hallucinations fleeting and fragmentary, behavior irresponsible and unpredictable, and mannerisms common. Undifferentiated schizophrenia is psychotic conditions meeting the general diagnostic criteria for schizophrenia but not conforming to any of the subtypes, or exhibiting the features of more than one of them without a clear predominance of a particular set of diagnostic characteristics [2].

Residual schizophrenia is a chronic stage in the development of a schizophrenia illness in which there has been clear progression from an early stage to the later stage characterized by long term, though not necessarily irreversible, "negative" symptoms, e.g., psychomotor slowing; under-activity; blunting of affect; passivity and lack of initiative; poverty of quality or content of speech; poor nonverbal communication by facial expression, eye contact, voice modulation and posture; poor self-care and social performance. Simple schizophrenia is a disorder in which

there is an insidious but progressive development of oddities of conduct, inability to meet the demands of society, and decline in total performance. The characteristic negative features of residual schizophrenia (e.g. blunting of affect and loss of volition) develop without being preceded by any overt psychotic symptoms [2].

The study of attitudes has occupied and continues to occupy a central place in social- psychological research. Knowledge of attitudes and their functioning is of interest both theoretically and practically. No theory of social behavior can be complete without incorporation of attitude functioning, and it is doubtful that complex social behavior can be predicted without knowledge of attitude. To study attitudes requires that they be measured [3].

2. Need for the Study

Families are a primary care giving resource for person with mental illness, yet they often lack the knowledge and skills needed to assist their relatives. Studies show that families routinely request information on basic facts about mental illness and its treatment, behavior management skills, and the mental health system in order to better cope with their relatives' illness. It is well recognized that the maximum impact of a psychiatric disorder is borne by the family and often leads to a complete disruption in its functioning [4]. Patients had always stressed about the role reversal with spouse and had also always the stress about the role reversal with children. Sometimes stress of changes in family responsibility [5].

Regarding knowledge and attitude about mental illness, reviewed studies showed that in the Japanese general population, few people think that people can recover from mental disorders. Psychosocial factors, including weakness of personality, are often considered the cause of mental disorders rather than biological factors. In addition, the majority of the general public in Japan keep a greater social distance from individuals with mental illness, especially in close personal relationships [20].

There is a misconception that people with mental illness are violent, which contributes to the significant of mental illness. The majority of people with mental illness are not violent, and the majority of violent acts are conducted by person who is not mentally illness [7].

Knowledge of attitudes and their functioning is of interest both theoretically and practically. No theory of social behaviour can be complete without incorporation of attitude functioning, and it is doubtful that complex social behaviour can be predicted without knowledge of attitude. To study attitudes requires that they be measured [10].

Keeping in view these important aspects of public opinion about mental illness, this study on “knowledge, attitude, perception and belief (K.A.P.B.) of patients’ relatives towards mental illness” seems meaningful so that various mental health programmes could be formulated and organized. This will also help in proper rehabilitation of the patient.

3. Literature Review

3.1 Studies Related to Care Givers

A study was conducted on Caregiver strain in a community sample of Korean elders with cohabiting caregivers, and factors associated with this were comparing between groups classified by cognitive and functional impairment. Caregiver strain was significantly associated with cognitive impairment. In the group without cognitive impairment, caregiver strain was significantly associated with participant characteristics (Daily activity impairment, and symptoms of depression and alcoholism). In those with cognitive impairment, caregiver strain was associated with both participant status (depressive symptoms and Daily activity impairment) and caregiver characteristics (a child caregiver, lower social support, and urban environment) [9].

Typically, the caregiver for the older adult is female, married, and middle aged. Half of all women caregivers are employed, 35% are over 65 years old, and those caregivers who are over 65 may also have a number of chronic illnesses [18]. Similarly, caregiver educational needs differ based on gender. Vanetzian and Corrigan [11] reported that male caregivers’ highest priority was to learn how to assist the disabled adult; female caregivers required information regarding health and human resources. Education, combined with practical, supportive counseling addressing the resolution of daily issues was more conducive in aiding post-stroke family adjusting. Family members routinely accept the major responsibility of care giving [12], financial worries and reduced social activities add to feelings of burden [13].

3.2 Studies Related Knowledge, Attitudes, Practices

A study was conducted to assess knowledge, confidence and attitude towards mental health for nurses direct and the effects of training. They found that confidence increased in nurses who received mental health training. After training, attitudes towards depression had shifted in that nurses now felt positive towards their role in treating depressed patients [14].

In previous study knowledge and attitude of the general public regarding symptoms, etiology and possible treatments of depressive illnesses, eighty percent of the populations consider antidepressants to be addictive, and 69% were convinced that the use of antidepressants would lead to personality changes. Future information campaigns should aim at describing depression as an often chronic disease similar to hypertonic or diabetes. Public knowledge about antidepressants must be improved. [15].

A study was conducted on police officers' knowledge and attitudes towards, mental illness in southwest Scotland. They found there was a good knowledge of relevant legislation, but most officers felt they did not have sufficient training in mental illness, and were keen for more. Improved liaison between sector psychiatrists and local police may be of value in the earlier identification and treatment of the mentally ill. [16].

A study was conducted on attitude towards people with mental disorder in Australia. The sample consisted of 2031 member of Australia public, 872 general practioners, 1128 psychiatrists and 454 clinical psychologists. The result shows that many of the samples have more negative attitudes towards mental illness. [17].

3.2.1 AIM

A study to assess the knowledge, attitude and practices among caregivers of patient with schizophrenia in western Maharashtra

4. Research Methodology

Research methodology involves the systematic procedure by the researcher which starts from the initial identification of programme to its final conclusion [8].

4.1 Research Approach:

Pre experimental research approach as appropriate to describe knowledge, attitude and practices of caregivers' of patient with schizophrenia.

4.2 Research Design

The research design, the plan, structure and strategy of investigation of answering the research questions, is the overall plan or blue print the researcher selects to carry out the study [8].

Keeping in view the objective of the study, the research design selected for present study was descriptive survey design.

4.3 Setting of the Study

The study was conducted at various mental health institutes of western Maharashtra.

4.4 Sample

Samples refer to a selected proportion of the defined population [8].Sample for the present study was caregivers who were staying with admitted schizophrenia patients.

4.5 Sample Size

The sample size for the study was 50 caregivers of schizophrenia patients.

4.6 Sampling Technique

Sampling refers to the process of selecting a portion of the population to represent the entire population. In the present study convenient sampling technique was adopted for selection of samples.

5. Criteria for Selection of the Sample

5.1 Inclusion Criteria

1. Caregivers of schizophrenias who can understand Marathi, Hindi, English language.
2. Caregivers of schizophrenias who were above 18 years age (adult).
3. Caregivers belong to patient family.

5.2 Exclusion Criteria

1. Health team members were excluded.
2. Caregivers of patients who were not willing to participate in the study

5.3 Time of study

The study was carried out from October 2013 to April 2014.

5.4 Tools

Self designed semi-structured questionnaire was used to collect quantitative and qualitative data by interview technique. Demographic information collected included: age, sex, level of education, religion, relationship of caregiver to patient. Information about knowledge, attitude and practices were collected by structured questionnaire.

5.5 Interview Procedure

Aim of the study was explained to each subject and proper instructions were given. Written consent was also obtained from caregivers before the interviews were conducted. The statements were read out before each of them individually. Subjects expressed their views for each statement which was documented.

5.6 Analysis of Data

The quantitative data were analyzed statistically using EPI-Info. 6.02. The qualitative data were analyzed using Thematic Method.

6. Results and Discussion

6.1 According to Demographic Profile

Table 1: Demographic descriptions of caregivers by frequency and percentage

Characteristics	*Frequency*	*Percentage*
Age in years		
18 Yrs-27Yrs	10	20.0
28Yrs-37Yrs	9	18.0
38Yrs-47Yrs	12	24.0
48Yrs-57Yrs	9	18.0
>57Yrs	10	20.0
Sex		
Male	45	90.0
Female	5	10.0
Religion		
Hindu	47	94.0
Muslim	2	4.0
Other	1	2.0
Education		
University	8	16.0
Primary	20	40.0
Secondary	13	26.0
No Formal Education	9	18.0
Relationship with caregiver with patient		
Father	12	24.0
Mother	1	2.0
Brother	8	16.0
Relative	12	24.0
Husband	7	14.0
Son	5	10.0
Wife	5	10.0

Above table No. 1 shows the following findings

Age: Total 20 % of subjects were in the age group of 18 – 27 years. 18 % of subjects were in the age group of 28 - 37 years[19], 24 % of subjects were in the age group of 38 - 47 years[4], 18 % of subjects were in the age group of 48-57 years and 20 % of subjects were in the age group of more than 57 years.

Sex: - Total 90 % of subjects were male and 10 % of subjects were female. Findings were contradicts with previous studies [4].

Religion:- The study shows that, total 94% of subjects were Hindus, 4% of subjects were Muslims and 2% of subjects were from other religion. Findings were contradicts with previous studies [6].

Education:- Total 18% of subjects were illiterate, 40% of subjects had primary education, 26% of subjects were secondary and 16% of subjects were having university education. Findings were supported to Shinde M, study [4].

Relation with patient:- The parents (24%) were the major caregivers, with the fathers (24%) playing the leading role compared to the mothers (2%) [21].

Table 2: Describe the symptoms of the illness of the patients

	Percentage
Abnormal belief	6.0(3)
Scared	26.0 (13)
Sleep a lot	10.0 (5)
Verbal aggressive	28.0 (14)
Abnormal speech	20.0 (10)
Smoking	12.0 (6)
Insomnia	74.0 (37)
Abnormality of mood	8.0 (4)
Roaming/ wandering	20.0 (10)
Self neglect	6.0 (3)
Isolation/withdrawn)	26.0 (13)
Hearing voices/taking / laughing to self	22.0 (11)
Antisocial behavior	46.0 (23)
Physical aggression	42.0 (21)

When caregivers were asked about their knowledge of schizophrenia and the source of their information, 30% had no prior knowledge about the illness and got the information first hand by patients experience; however 10.0% got the information from friends, 30.0% got it from health workers and 3.0% from the local newspaper. When the caregivers were asked if the illness is only one type or different types, 76.0% indicated that there were many types of the illness, 15% indicated that there was one type and 7% were not sure.

Table 3: What supportive intervention is needed for the patient?

	Percentage
Finance	10.0 (5)
Give smoke	2.0 (1)
School	4.0 (2)
Counseling	72.0 (36)
Awareness	0
Stop smoking	2.0 (1)
Rehabilitation	10.0 (5)
Family support	78.0 (39)

All items are multiple response so do not add up to 100%

To assess their knowledge of recognizing schizophrenia, caregivers were asked to describe the different symptoms of their patients. It shows the different symptoms indicated by the caregivers. Insomnia (74%) and antisocial behavior (46%) were the most frequent, followed by physical aggression (42%), verbal aggressive (28.0%), isolation and withdrawal (26%). The supportive interventions that caregivers recommended for the patients. Family support (78%) and Counseling (72%) were highly recommended, followed by others such as, rehabilitation, finance, stopping smoking and awareness.

Table 4: Caregivers responses to attitude towards the patients

How do you feel about discussing the illness of the patient with others?	
Discuss if asked	20 (10)
Ashamed	20 (10)
Relieve pressure	10 (5)
No discussion	22 (11)
Discuss for assistance	0
Awareness	4 (2)
Comfortable to discuss	36.0 (18)
Which people do you feel comfortable talking to about the patient?	
Bosses	2.0 (1)
Health workers	22 (11)
Church members	0
Relatives	36.0 (18)
Communities	12.0 (6)
Family members	38 (19)
How do you react when the patient makes bizarre statements, comments or action?	
Give medicine	10 (5)
Scared	18 (9)
Ashamed	2 (1)
Sad	44 (22)
Upset	8 (4)
Feel responsible calmly correct them	22 (11)
How do you feel about caring for the patient?	
Upset	**0**
Repay what he has done	0
Happy	40 (20)
Burden	12 (6)
No problem	18 (9)
Tiring	0
Our responsibility	42(21)

All items are multiple responses so do not add up to 100%. The response of caregivers on questions relating to their attitude to the patients shows most of the caregivers (36%) felt comfortable discussing the illness of the patient with others. The caregivers feel more comfortable talking to the family members (38%), relatives (36%) and health worker (22%) when the patient relapses [21].

It also show the attitude and reactions of caregivers when the patients make bizarre statements or bizarre actions. Being sad, upset, calming and giving medication to the patient making bizarre statement or acting abnormally were highly expressed by the caregivers. The question, "How you feel about caring for the patient?" was use to partly assess the attitude and responsibility of the caregivers towards caring for the patient. Most (42%) of the caregivers said that they were responsible to the patients.

It shows the responses of the caregivers when they were asked who do they see first when the patient relapses. The health worker was the first person seen by most (70%) of the caregivers, only 5.0% indicated that the police was seen first. The responses of caregivers for the questions related to willingness and problems or barriers to attending consultation clinics. Fifty five percent of caregivers said they attended the clinic always, compared to 60.0% who attended most times and 10.0% that only attended sometimes. The major problems that prevented some caregivers from bringing their patients to the consultation Clinics, included transport (30%) finance (28%), and refusal by the patients (26%). Aaggressive behavior of patients (14%) and having surplus of antipsychotic drugs at home (10%) were other problems mentioned. Responses to supervision of medications for patient at home were (56%) caregivers, respondent (48%) and parents of patients (28%) were mostly responsible for the supervision of medication at home. The patients themselves supervised their own treatment in 6% of cases. The responses of caregivers to questions about the difficulties they faced and suggested activities to support recovery of the patients. Money (36%) was the most common difficulties faced by caregivers and also non compliance with medication (23%). Aggression and violence (4%) demand for cigarettes (2%) were other difficulties mentioned. Finance (50%), Medicine (40%), family support (38%) and school (36%) were seen to be the most support activities for recovery.

7. Conclusion

In conclusion, a key suggestion is for educational interventions aiming specific target groups, with prior identification of their attitudes. Family is a target group, the starting point for all target groups and at every level is education. The results of this study underlined the need for educational programmes for the relatives of patients. These findings also help the need for a continuous psycho-educational input from mental health professionals in order to sustain and improve this level of awareness in the caregivers and in the general public.

Research suggests that one of the most effective ways to positively affect attitudes is to deliver relevant messages that will resonate with target audiences, encourage the public to recognize, acknowledge and disclose their own problems or those of family members, and provide information that will help the audience to access help.

Media coverage of these interventions will be essential to disseminate positive mental health messages, while challenging current misinterpretations. Further programmes must be developed which reach out to diverse communities and tailored to their specific needs.

8. Scope of Study

8.1 Nursing Practice

As a psychiatric nurse she should have knowledge regarding mental illness among schizophrenia patients & thus need to impart knowledge to caregivers of schizophrenia patients so they can identify the schizophrenias with mental illness at primary level. For imparting knowledge self instructional materials, pamphlets, booklets can be distributed to the caregivers regarding mental illness. Nurse can support people with mental illness, usually in a multidisciplinary team and also concerned with their clients health in the widest context. She can help clients of all ages to live their lives as fully and

independently as possible, while respecting their rights and dignity. She can work with clients and their families to assess their needs and draw up care plans. She can monitor the implementation of recommendations. She can works with other nurses and health and social welfare professionals to help clients and their family members with basic living skills and social activities to ensure that they can lead a life as normal as possible.

8.2 Nursing Education

The nursing curriculum can be modified with more emphasis on mental illness among schizophrenia patients. Nursing personnel should give an opportunity to update their knowledge periodically. The nurse educator when equipped with proper knowledge then she can develop students & staffs competent in care of mental ill patients and she can give proper health education to caregivers of mentally ill patient. Conferences, workshops, seminars can be held for nurses on mental illness.

8.3 Nursing Administration

The nursing administrator should give more emphasis on training of psychiatric & community nursing. The administrator should give the opportunity to the nurses to work in community setting. They can arrange workshop, seminar special lecture etc. for caregivers of schizophrenias on mental illness so, they can be familiar with the mental illness & this knowledge they can be apply in their day to day care of patient. Nurse administrator should encourage to staff and students to carry out similar study in different population and setting to find out the knowledge and provide necessary help.

8.4 Nursing Research

A profession seeking to improve the quality of its practices and to enable its professional status would strive for continuous development of its body of knowledge. There are only few studies are conducted on Knowledge of mental illness among caregivers of schizophrenia, there is necessity of more studies in this field. The findings of the study have added to the existing body of the knowledge in the nursing profession. Other researcher may utilize the suggestions & recommendations for conducting further study. The tool & technique used has added to the body of knowledge & can be used for further references.

8.5 Limitations

1. The study is limited to the caregivers of schizophrenia patients in western Maharashtra.

8.6 Recommendations

1) A comparative study can be done among caregivers of mentally ill patients in different geographical settings.

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