

ONSET OF SCHIZOPHRENIA; FAMILY CARE GIVER EXPERIENCES IN KERALA – QUALITATIVE ANALYSIS

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ABSTRACT

Mental disorders were the second leading cause of disease burden in terms of years lived with disability. Schizophrenia is a major mental disorder characterized by distortions in thought and behavior. Onset of schizophrenia would be a challenging event in a family. The person with schizophrenia needs care and concern from the caregiver for taking medicines, daily activities, assistants in hospitals, and support in various activities. Thus caregiving becomes a more responsible, time-consuming duty. This article explores the family changes during the onset of schizophrenia and the necessary social work interventions for dealing with the problem. Catharsis and case work will be the most useful intervention for care givers of family member with schizophrenia. The family interaction between family members should be cordial. Proper communication will enable the family to function smoothly. Family problems should be addressed for building a sound society

KEYWORDS: schizophrenia, care giver, family, social work interventions, society

INTRODUCTION

Health is the most valuable asset a man possesses. Health includes many dimensions such as physical, social, occupational, spiritual, and mental health. Mental health is a state of emotional health in which an individual realizes his or her own potential, has a good interpersonal relationship, adjusts, and solves problems of life. Mental health includes the holistic well-being of the individual. Disruption of mental health leads to mental health disorders/ mental illness or psychiatric disorders. Mental disorders were the second leading cause of disease burden in terms of years lived with disability and the sixth leading cause of disability-adjusted life years globally. (Rajesh Sagar et al, 2020). A family having a person with mental illness needs enormous adjustments inside the family, especially in the case of schizophrenia, a major mental illness. Caregivers of persons with schizophrenia experience many challenges inside the family environment. The person with schizophrenia needs care and concern from the caregiver for taking medicines, daily activities, assistants in hospitals, and support in various activities. Thus caregiving becomes a more responsible, time-consuming duty. The caregivers must be active and vigilant in caregiving along with other family roles. It is in this background the present study aims to find out the nature and extent of problems, and difficulties experienced by caregivers of persons with schizophrenia.

In India, 988 people are affected by schizophrenia as per the report of the India state-level disease burden initiative. The prevalence of schizophrenia ranges from 0.2 to 0.4 percent across countries. It is estimated that 20 million people in the world had schizophrenia in 2017. In Kerala, 12.43 percent of the adult population is affected by mental health issues. The prevalence of psychosis was 0.7 percent in the Kerala population. Lifetime prevalence rate for schizophrenia is 0.23 percent (95 percent (1:0.26 – 0.32).– (K.S. Shaji, et al, 2017)

METHODOLOGY

This is an exploratory study which is exploring the family circumstances in dealing a family member having schizophrenia. The objectives of this study to explore family changes during

the onset of schizophrenia and the necessary social work interventions for dealing with the problem. For conducting the study ten family care givers were selected through purposive sampling technique. Interview guide was used to collect data from care givers. Data analyzed on thematic basis. Study conducted after getting ethical clearance from university level ethics clearance committee.

ANALYSIS

The study has mentioned that people with schizophrenia can experience difficulty engaging in everyday life. As the behavior of the person changes the care giver undergoes difficulty in managing the patient creates interpersonal problems with other family members. Schizophrenia is a major mental disorder characterized by distortion in thinking and behavior. It means split mind (Niraj Ahuja, 2006) page no 57). It is a very serious psychological disorder characterized by severe distortions in thought, language, perception, and emotions, hallucination, delusions. Its onset may be gradual or acute depending on many factors such as heredity, and life events. In some cases, there may be life events such as death, bereavement, economic deprivation, etc., to trigger the causes of Schizophrenia. Loss of life of near and dear ones, loss of love, etc., maybe the main contributing factors to worsening anyone's mental health. Families must identify the symptoms to tackle Schizophrenia from its first episode to help them from worsening the symptoms and reducing the treatment burden.

SOCIAL REASON FOR SCHIZOPHRENIA

A Care giver of a 52 year old female patient said that,

“After my younger brother’s death, the entire behavior of my mother had changed to a large extent from very talkative, very clean person to total silent, gloomy and un tidy. Now it becomes difficult to manage her. Her untidy nature created some problems in our family. Due to her behavior I have to make extra effort in the home. I become frustrated, as sometimes become late for office. I quarrel with my younger sister about this”.

Mother of 39 year old female patient said that,

‘After rejecting my daughter’s marriage proposal the noted change is in her personality is that, her sudden change to reluctant, violent angry nature. Till then she was very obedient and calm after that she began to shout at her father and thrown appliance. Her change in bahaviour had made me to think about her emotional imbalance. Thus, we approached the hospital for treatment. Due to these reasons problems in-between me and husband become usual”.

Mother of a 32 year old male patient has said that,

“When my son was cheated and looted money by his best friends, he slowly avoided to go outside and was getting closer to his surroundings. He always shut inside his room. After his diagnosis, my journey is limited to hospital and home only. Neighbors on my request bought the groceries.”

From all these responses it can be understood that there may be a life event that surely alter a person's mental health. Death of loved one, loss of money, rejections like any other negative event would become a responsible factor in predicting one's psychological well being.

SOCIAL CHANGES IN PERSONS WITH SCHIZOPHRENIA

If a person is affected by schizophrenia some behavioural as well as social change occur in that particular person.

Brother- in- law of 60 year old patient has said,

"After losing money of my brother in law, he become depressed and failed to go to his job. He stopped all of his contacts and even refused to call his wife or brother. He was terminated by his employer and returned to his home after long assistance from his friends abroad. He was sent to hospital and my sister had spent days looking after him until her death. I have lack of time to deal with my business as I have to do things for my brother-in-law."

One of the care giver of a 35 year old man said that

"my son was diagnosed with the disorder when he was 23 years old. That becomes a hurdle stage for us. We have to lose all our friendship and relation with neighbours' also. He uses to say abusive words to my neighbours and that worsen our relationship".

65 year old mother and 68 year old father of a 38 year old female patient said that that,

"When we saw certain behavioral changes in our daughter, we brought her before the priest and offered some rituals. We visited some of the temples to get relief to our daughter. We had expended about 3 Lakh rupees and after three years, one of our friends insisted we to consult a doctor and we started treatment and now she is getting well".

When a person is hit by schizophrenia the morrow of the entire family changes. The person experience difficulties in day-to-day life. There will be changes in attitude, affect, and feelings of the person ant it will show in their behaviour also. Self-grooming and social interaction will be reduced. Patients with schizophrenia, for example, display poorer social skills and report fewer close relationships than patients without schizophrenia (Green et al., 2008, Hooley,

2008). This study result supports the study result of Burns DD, Sayers. Poor marital relationship has an adverse impact on both physical and mental health as well as the quality of life (QOL) of individuals Burns DD, Sayers (1994) Few studies have reported the high rates of poor marital adjustment and divorces in schizophrenia. Thara R, Srinivasan TN (1997)

FAMILY CHANGES

The care giver of 38 year old assistant professor informed that,

"When my daughter was diagnosed with schizophrenia, the whole family atmosphere changed. I have to take a long leave from my job."

My husband, who is also my daughter's stepfather, discontinues his visits to my home. She has problems with all family members. That affects my relationship with others also”.

The problems occurring in a family while taking care of a person with Schizophrenia are numerous. In most cases, the caretaker may be the female in the role and responsibility of a mother, wife, daughter, or daughter-in-law. It becomes a triple role for her and all the household chores like cooking, cleaning of vessels, cleaning clothes, house cleaning, rearing of young ones, and caring for a person with Schizophrenia are done by a single member of the family. The caretaker goes through many stressful events, as she may lose her personal caring and resting time. It, in turn, affects the caretaker's physical and mental health. The main attention needed in the family, along with the person with Schizophrenia, is the family's primary caretaker. The health of the caretaker has due importance for the overall wellbeing of the family.

ECONOMIC CHANGES AFTER SCHIZOPHRENIA DIAGNOSIS

Economic capacity and stability of a family has important role in providing high quality health care for a person with schizophrenia. Economically well settled families can easily cope with financial problems inside the family, when a family member is affected by a major mental disorder.

One care giver of a 34 year old man told that,

“When my son becomes ill, he is not able to go to work for months. When he became normal, his job was gone, and no one was willing to give him a job. After that, he stops job searching. "Now we are living with government pensions of mine and my son”.

The care giver of a 40 year old man said that,

“My son was working in a shop before he was diagnosed with schizophrenia." After his treatment, his owner is unwilling to give him a job as he has mental illness. He has approached many others also, but no one is willing to give him a job. After some years, he stopped job searching and living with the government pension”.

The care giver of another patient informed that,

“My uncle is a blacksmith. He runs his own shop. The shop was closed for 3 years as my uncle was not well. He reopened the shop when he became normal, and he is getting work and good payment also”.

Cousin of a 34 year old woman informed that,

"When her owner of the shop scolds her for no reason, she becomes upset and leaves her job."

Schizophrenia brought drastic economic changes in any family. The disorder become a reason for losing one's job, and a reason for economic paucity. Some people in society doesn't consider their difficulties as humble human being. Some families are running only with the help of government pensions along with food items supplied through government ration store.

IGNORANCE IN GIVING MEDICINES

Even though we have achieved hundred percent literacy some people in our society is ignorant of the importance of giving medicines for the patient. They never accept the disorder condition. They rationalize the symptoms of schizophrenia as anormal thing.

Other caregiver of a 50 year old and 45 year old female patients have explained that. Said that,

“Our daughters are doing well, and they need not have medicines, and they are capable of doing their daily activities. Getting money from some farming activities and we are happy”.

One of the caregiver of 65 year old male patient has said that,

“We have not giving him medicines for about one year as he was normal and not showing any symptoms . Now we are not planning to continue his medication, and now he is suffering from old age health ailments”

ROLE OF CARE GIVERS

Mother of a 43 year old male patient has said that,

“I do compulsorily give him medicines, otherwise he will not intake. Usually I ask him to take bath and wash his cloths. Sometimes he tried to avoid all these and most of the time he used to have his bath without soaps. His uncle offers some help in his daily routine. He has no difficulty in having food in time. He demands food whenever he is hungry.

The care giver of a 54-year old man said that

"I will do all things for him. I don't want to make him worried about anything. I am giving medicine for him, washing his clothes, giving food and all."

The mother of a 37-year old lady patient said that,

"Her father doesn't want to hurt or worry her, never allowed her to do any things. He wants to care for her like a one-year old child." So I am doing all the things for her, like washing her clothes, giving medicine, etc.

Caregivers may experience stress, and exhaustion while caring for a family member having an illness. The burden of caregiving leads to emotional outbreaks and problems in the family. Expressed emotion is the emotions, feelings, and behaviors expressed by a caregiver or family member towards a person with schizophrenia while caring for a person with schizophrenia. These attitudes and emotions of caregivers determine the course of illness, relapse, and treatment duration of the person with schizophrenia. Expressed emotion arises due to failed social interactions arising from the misunderstanding between a person with Schizophrenia and other non-ill members of the same family. The interactions were determined by each individual's emotional state, which will determine the relapse of the person with Schizophrenia. The words coming from each individual create emotional turbulence in the home environment. Their emotions may be coming from their irritations, frustrations, lack of mobility, caregiver burden, financial difficulties, etc. These comments

may be critical or hostile, igniting relapse in people with Schizophrenia. The critical comments may be due to their thinking that their comments will help the patient to change their abnormal character to normal behavior. Family members are helped to accept the person with schizophrenia to provide them a quality of life.

SOCIAL WORK INTERVENTIONS

The caregiver of the person with schizophrenia must educate and acknowledge handling the patient for better family functioning and well-being of the patient. So that burden in caregiving can be reduced. The caregiver needs proper physical and emotional health so that quality of care can be assured. The caregivers must get adequate time for her/his personal matters along with caregiving duties. Proper ventilation of feelings and appreciation for their caregiving will give strength to their roles. The person with schizophrenia needs care, concern, and affection from all family members. Acceptance from family members will help the patient to recover from the illness quickly. The family interaction between family members should be cordial. Proper communication will enable the family to function smoothly. Family problems should be addressed for building a sound society. Case work will be conducted among care givers for proper understanding of each case. Care givers are unique, so their problems and intervention are also unique. Case work enables in identifying each care givers strength, weakness, awareness about schizophrenia , and role as a supportive family member.

FINDINGS

The study result shows that Life tragedies have a greater role determine an individual's mental health. Schizophrenia affects all areas of personality, it brings behavioural and social changes in individual. Family undergoes enormous changes while accommodating a family member with schizophrenia. Economic change is the most threatening problems in the family of a person with schizophrenia.

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CONCLUSION

The present Kerala society, family is giving prime importance to their ill family member. If a family member is affected by schizophrenia, the whole family equilibrium is changed. All family members have to make enormous adjustments in economic, social, interactions. Family relations also affected. These changes would reflect in family functioning and family wellbeing. All family members are involved in the process of care giving .Care givers are expressing more positive attitude than negative emotions .The care givers have to be vigilant and alert in all matters related to the patient as well as family. Care givers time, money, and health have to invest for the betterment of the patient. Timely giving of medicine, making daily routine of the patient, safe guard of the patient and assisting patient in hospital are become the responsibilities of care giver.

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