

Lived Experiences of Caregivers' of Chronically Schizophrenic Patients: A Qualitative Phenomenological Study

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ABSTRACT

Increasingly, "health without mental health" underscores the fact that mental health is a fundamental and basic dimension of health. Mental disorders had a significant burden of morbidity and disability; whereas few illnesses expose the individual to extreme mortality as well. Different mental illness which are chronic in its course have lifelong effects, this influence lasts for a long time and gradually leads to a poor quality of life for these people and their families¹.

Qualitative approach was used to explore the experiences of caregivers of chronically schizophrenic patients. Non probability purposive sampling technique was used. The tool consisted of demographic profile and guidelines. The data was collected through one to one in-depth semi structured interview. Saturation of data was achieved with 14 samples. The pilot study was performed on 3 samples that had consented to participate in the study at Saishwari Clinic For Mental Health, Miraj from 12 December 2020 to 22 December 2020. The final study was conducted from 21st January 2021 to 3rd February 2021 at Bharati Hospital, Sangli and Saishwari Clinic For Mental Health, Miraj. Total 14 samples were selected and thematic analysis was based on the Collaizis method to analyse the collected data. Based on commonalities within the data, themes and categories were formulated. A total of 9 themes, 22 sub themes and 46 codes were generated. The conceptual framework was prepared by the researcher based on themes and sub themes generated.

Keywords: Explore, Lived experiences, Caregivers, Chronically schizophrenic patient.

INTRODUCTION

Better health is core to human happiness and wellbeing. As a result the healthy population survive longer, are more productive and save more by keeping integrity of physical, mental and social dimensions of health¹. Neglected mental health is now recognised as an essential need and is drawing attention of the policymakers, professionals, communities across India and around the world². Mental disorders generally begin early in life and are often intermittent and chronic in nature³. Supporting the family caregivers and the individual members is essential in addressing and learning about the roles during illness. It is clear that the pressure on the psychological improvements needs to be shifted from a patient centered approach to caregiver focus approach⁴. There is a need to raise awareness of the role of caregivers in taking care of the mentally ill⁵.

OBJECTIVE: To explore the lived experiences of caregivers of chronically schizophrenic patients

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REVIEW OF LITERATURE

The review is divided under following sections

SECTION A : LITERATURE RELATED TO SCHIZOPHRENIA

Varsha Jayaprasad Pune | May 26, 2019 INDIAN . The Indian Medical Association hosted a talk on mental illness and schizophrenia.” Schizophrenia, a psychiatric illness that commonly manifests in late adolescence or early adulthood, affects as many as 1% of the world's population. Schizophrenia affects about 1% of the world's population. The 24th of May is World Schizophrenia Day. Hallucinations, delusions, and other cognitive disorders are commonly seen in schizophrenic patients, and it can be a lifelong challenge⁶.

Indian express Lifestyle Desk | New Delhi | May 24, 2020 “Due to lack of awareness about mental illnesses, general people may perceive a threat from those suffering from Schizophrenia due to their actions and social inappropriateness in their behaviour”. Schizophrenia typically affects adults between the ages of 15 and 25, although it may strike as young as five years old. Childhood schizophrenia (COS) is a rare disorder that starts before the age of 13 and grows steadily in adolescence and peaks in early adulthood⁷.

Section B : Literature related to family caregivers of schizophrenic patients

Masunga K. Iselelo, Joel Seme Ambikile, 2020. "Promoting Recovery in Mental Illness: The Perspectives of Patients, Caregivers, and Community Members in Dar es Salaam, Tanzania. They conducted four focus group discussions (FGDs), two with mentors and two with community members. There were also six in-depth interviews with mentally ill patients. Both focus groups and in-depth interviews were digitally captured and transcribed. The data in qualitative research was analysed using content analysis. The study described four subjects: encouraging patient involvement in home activities, improving patient support services, encouraging patient self care, and protecting and sustaining patients with mental illness. One of them is ensure. The patient care system, on the other hand, has evolved to provide educational and therapeutic resources⁸.

Nao Shiraishi, Jacqueline Reily 2019, had conducted the study “Positive and negative impacts of schizophrenia on family caregiver”, to offer a detailed description of the positive and negative effects of schizophrenia on family caregivers The interactions of family caregivers with a schizophrenic sibling were explored via qualitative research⁹.

MATERIAL AND METHOD

A qualitative research approach was considered to be acceptable and used in order to achieve the study's desired objectives. The methodological framework was phenomenology. Non probability purposive sampling technique was used. The tool consisted of demographic profile and guidelines. The data was collected through one to one in-depth semi structured interview. Saturation of data was achieved with 14 samples.

RESULTS

A thematic analysis was based on the Collaizis method to analyse the collected data. A total of 9 themes, 22 sub themes and 46 codes were generated. The conceptual framework was prepared by the researcher based on themes and sub themes.

SECTION I: FINDINGS RELATED TO DEMOGRAPHIC VARIABLES OF CAREGIVERS OF CHRONIC SCHIZOPHRENIC PATIENTS

TABLE No. 1: FREQUENCY AND PERCENTAGE DISTRIBUTION OF DEMOGRAPHIC VARIABLES (N=14)

S.N	Demographic Variables	Category	f	%
		20 – 40	4	28.57

1	Age (in years)	41 - 60	6	42.85
		61 - 80	4	28.57
2	Gender	Male	8	57.14
		Female	6	42.85
3	Marital status	Married	12	85.71
		Unmarried	2	14.28
4	Type of family	Nuclear	13	92.85
		Joint	1	7.14
5	Education	Primary	3	21.42
		Secondary	5	35.71
		Higher Secondary	2	14.28
		Graduate	1	7.14
		No formal education	3	21.42
6	Monthly income in (rupees)	5,001/- to 10,000/-	2	14.28
		10,000/- to 15,000/-	9	64.28
		15,001/- and above	3	21.42
7	Relationship with the patient	Parents	7	50
		Spouse	4	28.57
		Sister	2	14.28
		Father in law	1	7.14
8	Occupation	Retired	1	7.14
		Business	4	28.57
		Farmer	6	42.85
		Driver	1	7.14
		Housemaid	2	14.28
9	Years of experience in caring	3 - 5	6	42.85
		5 and above	8	57.14

The data provided in table 2 reveals that, out of 14 participants, the age group of 41-60 years, were 6 (42.85 percent).

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8 (57.14%) were male, with 6 (42.85%) female caregivers taking care of their chronically schizophrenic relative.

12 out of 14 (85.71%) were married and 2 (14.28%) were unmarried.

It was noted that 13 (92.85 percent) lived in nuclear families and 1 (7.14 percent) in joint families when gathering their experiences.

3 out of 14 (21.42 percent) had primary and no formal education. 5 (35.71 percent) were secondary, 2 (14.28 percent) were higher secondary and 1 (7.14 percent) was a graduate.

9 (64.28 percent) caregivers per month income ranged from Rs10,000/- to Rs15,000/-, 2 (14.28 percent) between Rs 5,001/- to Rs10,000/- and 3(21.42 percent) were earning more than Rs15,000/-.

7 (50 percent) out of 14 were parents, 4 (28.57 percent) were spouse, 2 (14.28 percent) were sisters and 1 (7.14) were parents.

Data related to the occupation of caregivers showed that 6 (42.85 percent) of them worked as farmers, 4 (28.57 percent) had their own business, 1 (7.14 percent) were drivers and retirees, and 2 (14.28 percent) were home maids.

As reported by the participants, years of caregiving is the main issue in caring for chronic schizophrenic relatives. Most 8 (57.14 percent) have been caring for more than 5 years and 6 (42.85 percent) have been caring for since 5 years.

SECTION II

Analysis of data among the samples attending the psychiatric hospital with chronic schizophrenic relative

This section deals with the study of information accumulated from 14 participants through face-to-face interviews. The information collected was translated into the dialect caught on from the participants, and to create credibility/validity, the transcript was given back to the participant. The terms utilised by the participants to depict the diverse experiences they experienced during their care time of treatment were analyzed.

Each item/word verbalised by the participants was characterised by the researcher in order to formulate themes that could further clarify the experiences under different diagrammatically represented titles.

TABLE NO.2: Analysis of data among the samples attending the psychiatric hospitals with their chronic schizophrenic relative.

Description of the themes generated

N=14

CAREGIVING EXPERIENCE	<p>THEME</p> <p>BURDEN OF PATIENTS HOSPITALISATION</p> <p>CONCERNS RELATED WITH TREATMENT OF PATIENTS</p> <p>PHYSICAL IMPACT</p> <p>PSYCHOLOGICAL IMPACT</p> <p>SOCIAL IMPACT</p> <p>FINANCIAL IMPACT</p> <p>ALTERED RESPONSIBILITIES</p> <p>NEED FOR INFORMATION</p> <p>COPING STRATEGIES</p>
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TABLE NO 3: Description of the sub theme generated from the theme.

N=14

CAREGIVING EXPERIENCE		
SR.NO	THEME	SUB THEME
1	Burden of patients hospitalisation	a. Struggle
		b. Length of stay
		c. Distance
2	Concern related to treatment of patient	a. Patients adherence to treatment
		b. Patients non adherence to medication
3	Physical impact	a. Tiredness b. Health problems c. Inadequate sleep
4	Psychological impact	a. Uncertainty of future b. Fear c. Psychological problems d. Worry
		e. Sad
5	Social impact	a. Cooperation
		b. Social stigma
6	Financial impact	a. Dependence on family and friends
		b. Burden on financial expenses
7	Altered responsibilities	a. Dual responsibilities
8	Need for information	a. Wanting to know more
9	Coping strategies	a. Faith
		b. Hope
		c. Religious practices
		d. Acceptance

Table No.3 defines a total of 9 themes, of which 23 sub-themes and 46 codes have subsequently been clarified in additional tables. Each theme is grouped into sub themes so that it can be better understood.

TABLE NO. 3.1: Description of theme burden of patient's hospitalisation

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N=14

SUB THEME	CODES
Struggle	<ul style="list-style-type: none"> a. Kasrat karava lagatay b. Taqlif hoti hai c. Khota bolun anto d. Khup traas hoto e. Hath pai bandhun anlo
Length of stay	<ul style="list-style-type: none"> a. Bahut din rehna padta hai b. Kholumba honar c. Sagla vel davakhanyat gela
	<ul style="list-style-type: none"> a. Khup diwas rahayala lagatay mhanun kadich admit nahi kelo b. Dhavpal hoti c. Saglancha hal hoto d. he sagl thodasa avagad hot ahe
Distance	<ul style="list-style-type: none"> a. Antar khup jast aslyamule b. Lambcha rasta aahe c. Velet pohchu shakat nahi d. Door hai

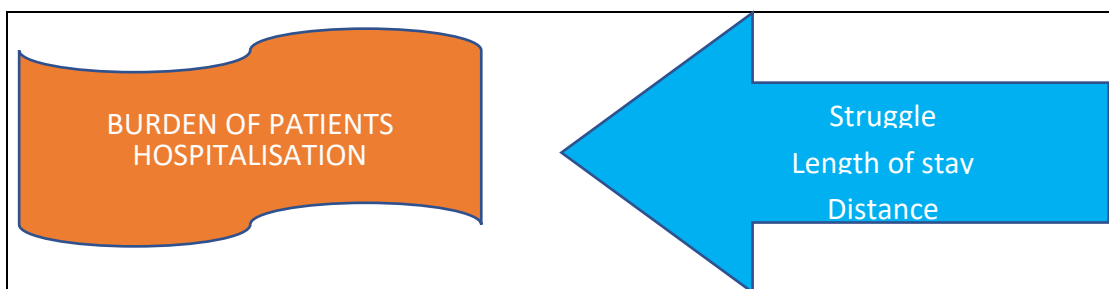


Fig No 2 Sub themes used to depict the burden of patients hospitalisation.

Table No 3.2: Description of theme concern related to treatment of patient

N=14

SUB THEME	CODES
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Patients adherence to medication	<ul style="list-style-type: none"> a. Aushad vyavastit ghetat b. Aushad velevat ghetat c. Goli dene ki taqlif nahi lagi d. Goli ghenyayasathi Kahi traas det nahi e. Goli ghe mhanun sangava nahi lagat
Troubles with non adherence to medication	<ul style="list-style-type: none"> a. Golya chukavate b. Uliti karun golya baher kadate c. Goli takun yayacha d. Khup traas dete

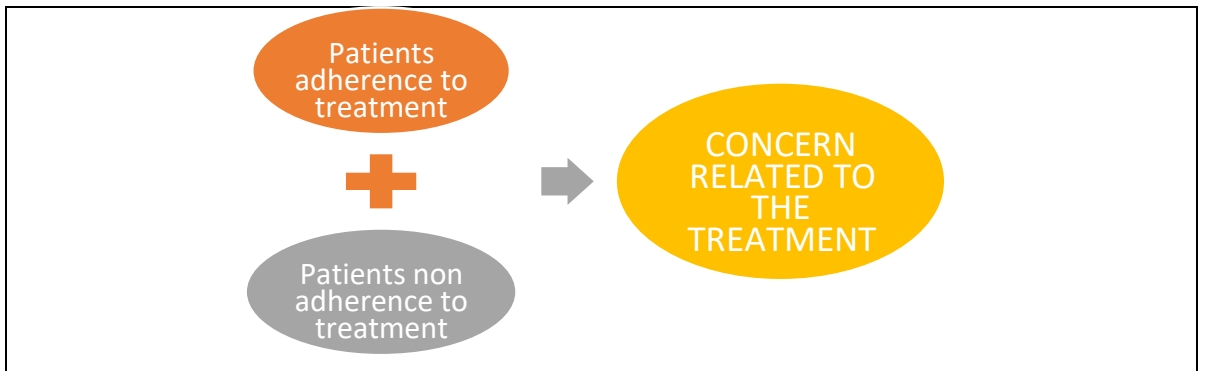


Fig No 3: Sub themes used to depict concern related to the treatment

Table No 3.3: Description of the theme physical impact

N=14

SUB THEME	CODES
Tiredness	<ul style="list-style-type: none"> a. Thakayala hote b. Kiti kantala aala tari kay
Health problems	<ul style="list-style-type: none"> a. Bhook Jast lagat hoti aani tahan hi jast b. Chakkar yevun padlo c. Kamrecha traas d. Dokh dukhat hota e. Uliti zhali
Inadequate sleep	<ul style="list-style-type: none"> a. Zhop nahi lagat b. Neend na aata hai

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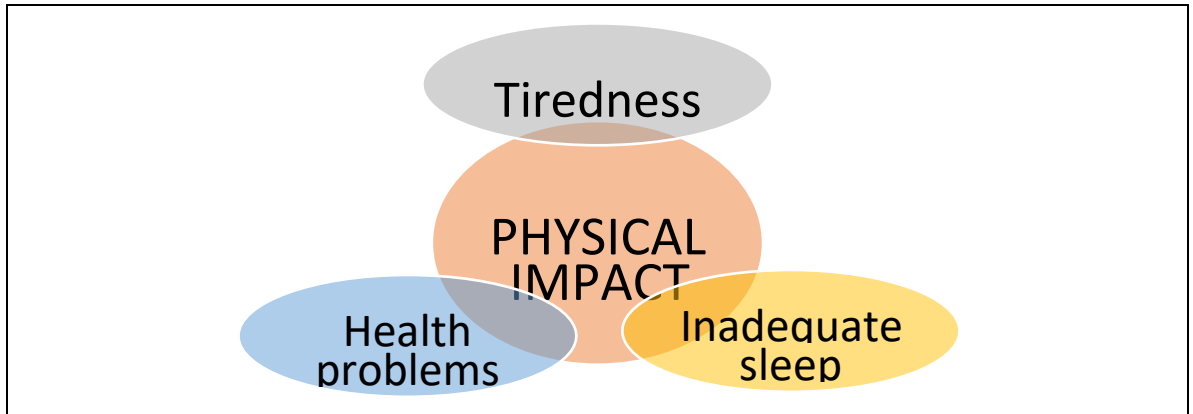


Fig No 4: Sub themes used to depict physical impact

Table No. 3.4: Description of the theme psychological impact

N=14

SUB THEME	CODES
Uncertainty of future	<ul style="list-style-type: none"> a. Bhavishyacha kay b. Iska aage kaisa honewala c. Mazhya nantar kay honar d. Tila kon karun ghetil e. Mazhya nantar ticha kalaji kon ghenar
Fear	<ul style="list-style-type: none"> a. Maarne ka darr b. Bhiti vatate
Psychological problem	<ul style="list-style-type: none"> a. Mansik problem vadala b. Tension aahe
Worry	<ul style="list-style-type: none"> a. Satat vichar
Sad	<ul style="list-style-type: none"> a. Manala vait vatala

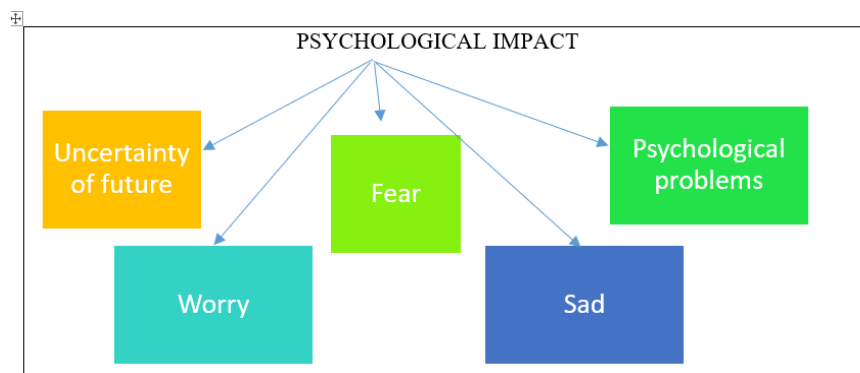


Fig No 5: Sub themes used to depict Psychological impact

Table No 3.5: Description of the theme social impact

N=14

SUB THEME	CODES
Cooperation	a. Sambhalun ghetat
Social stigma	a. Khuli aahe b. Kiti diwas hichya barobar asnar dusra lagna karun ghe

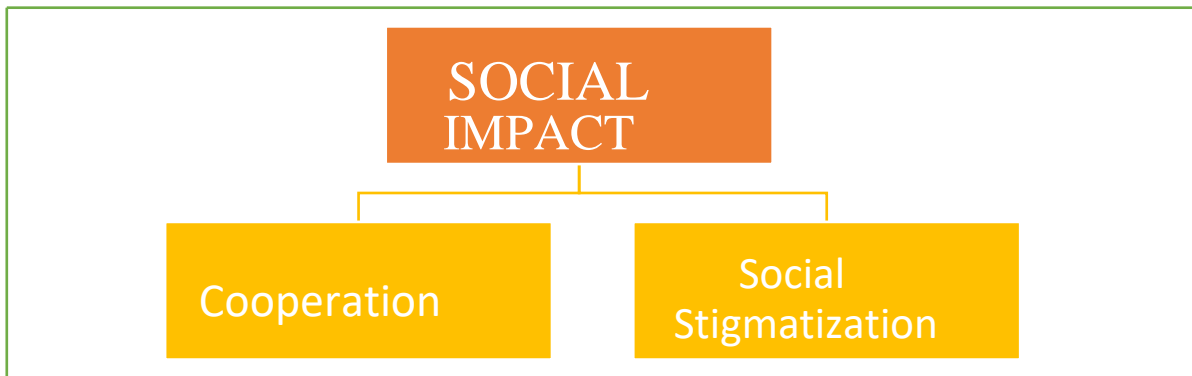


Fig no 6: Sub themes used to depict social impact

Table No 3.6: Description of the theme financial impact

N=14

SUB THEME	CODES
Dependence	a. Mazhya mulinvar avalambun rahava lagatay b. Karz bazari zhalo c. paishyachi adchan aahe
Burden of financial expenses	a. Aushadanche karch b. Khupach kharchik c. Davai ka kharcha d. Injection (ECT) cha karch

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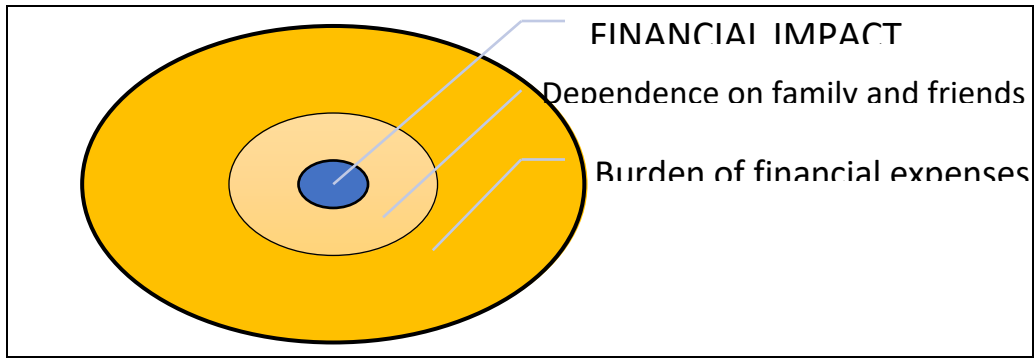


Fig No 7: Sub themes used to depict financial impact

Table No 3.7 Description of the theme altered responsibilities

N=14

SUB THEME	CODES
Dual responsibilities	<ul style="list-style-type: none"> a. Gharach, bahercha kam karava lagtay b. Hya vayat mule aai vadilanchi kalaji ghetat pan mazhya babbat ulta aahe c. Hila asa kahi traas zhala tar sagle mala aai ani vadil mhanun karayala lagatai. d. Davakhanyat ghevun java lagtay

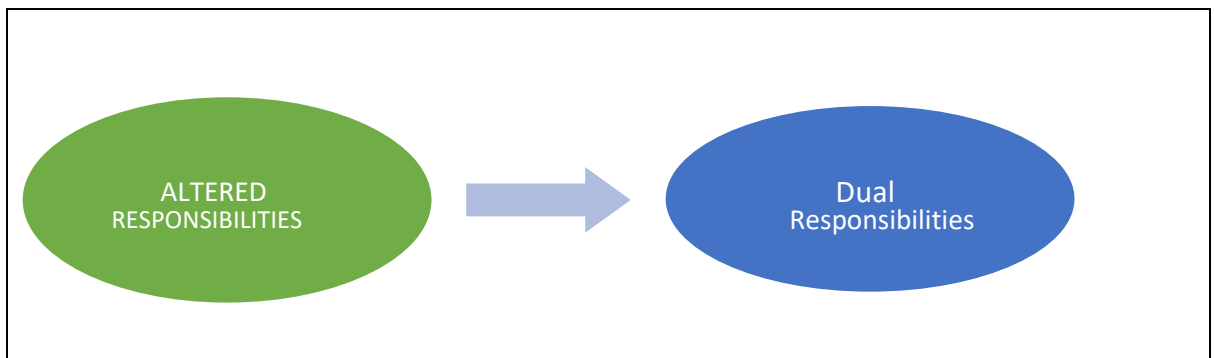


Fig No 8: Sub themes used to depict altered responsibilities

TABLE NO 3.8 DESCRIPTION OF THE THEME NEED FOR INFORMATION

N=14

SUB THEME	CODES
Wanting to know more	<ul style="list-style-type: none"> a. Bimari ke bare aur thoda malumat milegi b. Farsa kahi mahit nahi c. Poornapane bara honyasati kiti diwas lagnar d. Satat hya ajarabaddal mahiti ghet asto

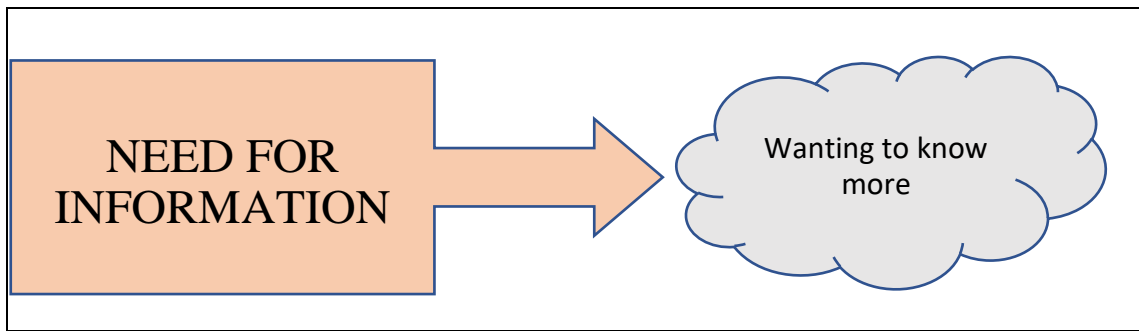


Fig No 9: sub themes used to depict wanting to know more

TABLE NO 3.9: DESCRIPTION OF THE THEME COPING STRATEGIES

N=14

SUB THEME	CODES
Faith	a. Devavar vishwas b. Allah pe barosa
Hope	a. Bara hoil hi ashe b. Didi acchi ho jayegi
Religious practices	a. Devdharma kartoy b. Devakade hath jodun magto c. Koni kay sangtat sagla kahi kartoy
Acceptance	a. Manya karun tyanchi kalaji ghene hech mahatvache aahe

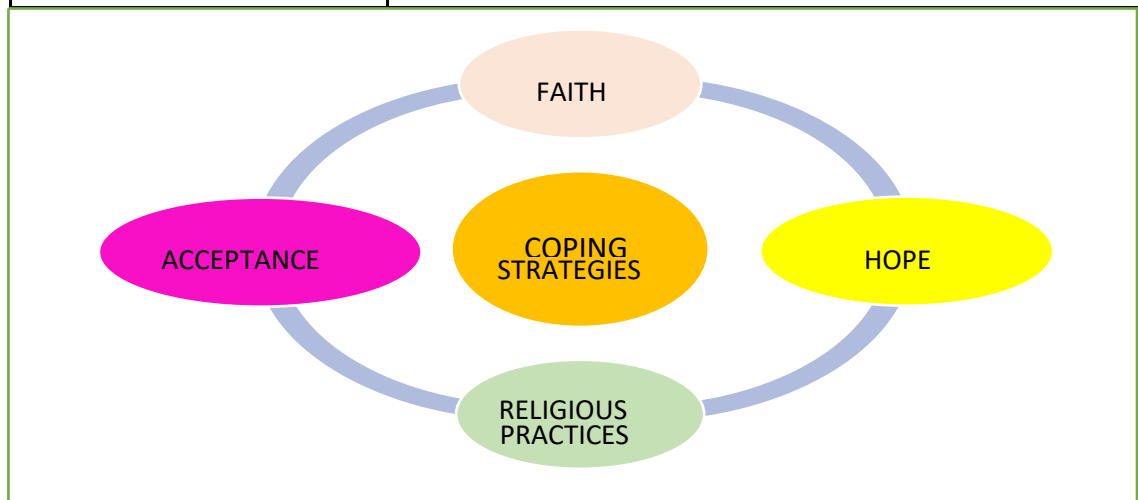


Fig No 10. Sub themes used to depict Coping strategies

DISCUSSION

The researchers were able to infer basic impressions by utilising the phenomenological approach, and endeavoured to explore and decipher those meanings.

The first theme burden of patient's hospitalisation further categorized as struggle they had in bringing the patient to hospital, the length of stay in the hospital was key point because many of the relatives

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faced problems with their relative's hospitalisation and the distance which made them difficult to get the treatment in time.

The second theme concern related to treatment further categorised as patients adherence to treatment, caregivers were happy to see that their schizophrenic relative were very much eager to take the medicines regularly and properly. Patient's non adherence to treatment was very much hurting to the caregiver because they are trying their best to treat the illness but their ill relative take the medicine in front of their caregiver and spit or vomit it out.

Category of physical impact was sub categorised as tiredness they had while caring their schizophrenic relative. Caregivers suffered the health problems such as hypertension, high blood sugar level, headache, acidity and so on. Majority of the care givers had inadequate sleep due to the illness of their relative because many of their ill relative would not sleep during night times and trouble them and also they used to think about the recovery of the illness.

The study conducted by Souzan Abd El-Menem Abd El-Ghafara , Amal A. Abd El-Nabic , Hosam El-Din Fathalla have revealed that as a result of prolonged trouble and the physical requests of caregiving; the family caregivers' physiological working is compromised. This will increase their chance for physical well being issues and increased mortality (Saarni, 2010). Additionally, stigma toward mental illness is still a incredible issue for patients who are suffering with mental illness and their families. It is considered a risk to the self-esteem and relationships for the patients with schizophrenia as well as their family members. It may moreover debilitate family caregivers from looking for support.⁶

Psychological impact has been further classified as future uncertainty plays an important role in making caregivers feel insufficient. Few of the caregivers had doubts about their sick relative's future. Some caregivers were fearful that their sick relative were abusing them. Two of the caregivers had the mental stress and tension they had been treated for it and they are doing well now.

Jennifer Way conducted the research study on Lived Experiences of Caregivers for Individuals with Serious Mental Illness in Rural Communities. Caregivers for grown-ups, in comparison to caregivers of children, had differing opinions and contemplations about the future. All three caregivers communicated that endeavouring to modify their individuals were challenging. Infact inspite of the reality they felt their individuals required to be employed and possess their own housing, they did not appear confident this would happen. They does not predict the individual finding a work, accepting treatment, or living on her own⁷.

The social impact was categorized as cooperation given by the members of the family, friends and the authorities where they work. Social stigma: The stresses of stigma and ridicule was not surrendered by caregivers living with members suffering from schizophrenia.

The study was conducted by Hui-Man Huang 1 , Yu-Chih Jen 2 and Ya-Fen Lien 3 After the patients were discharged and returned home, they were avoided within the participants' communities. The isolation and community ridicule inflicted ceaseless pain upon the participants, profoundly ingrained inside them⁸.

Another theme financial impact was categorized by dependence i.e caregivers' reliance on their family members and friends for hospitalization and treatment bills. Some have taken debts from the tenants for their debilitated relative's care. The caregivers talked approximately the truth that their mentally ill relative was frequently unable to hold or maintain a job.

Altered responsibilities is another theme categorised by dual responsibilities. This conventional concept of family roles with the parents forming the primal unit and the children as dependents was not always realised owing to the inability of members suffering from chronic schizophrenia: failure to satisfy their roles secondary to the devastating effect of schizophrenia. Similarly also some parents experience role

reversal of having to take care of their grown up children and their off spring because schizophrenia has crippled them.

Need for information is categorised as wanting to know more about the disease condition, medication and recovery. The need for information helps the caregivers to receive assistance from the community, government or health care institutions. As primary caregivers for their mentally ill adored ones, many of the interviewed family members felt they needed information about diagnosis, prognosis, therapy, and schemes that can be used by those who cannot afford to pay their bills. Caregivers will be able to use the information they receive to lessen the burden of care as well as the financial burden.

Coping strategies: Coping is the strategy of tending to outer or inner needs that go beyond the capacity of an individual and through which a person battles to decrease, relieve, or eliminate tension with a condition.

Faith is also very important in coping. Some participant reported that they have faith in God one or other our patient will be perfectly alright. Hope for the future looks for future changes in the conditions and symptoms of the patient. In order to promote the state of the patient, caregivers who remained hopeful attempted to find better doctors and experimental medications and found professional assistance. In spite of a long caregiving era, some caregivers are still hopeful about the future and the patient's progress.

CONCLUSION

The suggestions of caring for a relative with chronic schizophrenia were discussed in this study. Participants offered intimate and narrative accounts of their experience dealing with hospitalization, concern related to treatment, impact on caregivers, altered responsibilities and strategies for coping.

Through this research, it has become clear that the suffering of a relative with schizophrenia has a significant impact on families, especially those who provide day to day care. As mentioned in the literature, the burden of caregiving can restrict the freedom and personal lives of caregivers.

Various pressures and shortcomings, such as restricted social lives, were noted by the participants of this research. In part, the limitations of their own opportunity are due to emotional challenges, such as depression, regret, and disgrace, but also because of the many caretaking duties.

A number of responsibilities were defined by participants in this study, such as daily living assistance, medication supervision, securing and organizing resources and appointments, and advocating for their relatives.

The findings of current research regarding perspectives of caregivers of chronically schizophrenic patients can be discussed by nursing professionals who are working with mentally ill patients in psychiatric units. Psychiatric nurses should receive professional training in mental health care so that they can assist caregivers of people with schizophrenia. Majority of them expressed financial burden while caring their schizophrenic relative, hence financial variable can be researched both qualitatively and quantitatively. Nurse researchers should keep up-to-date with recent trends and technologies so that we prove ourselves in the ever increasing techno savy world timely and again.

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