

Research Paper

## Daily Care Giving Difficulties of Primary Care Givers of Persons with Schizophrenia in Kerala, India

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### ABSTRACT

Schizophrenia is a major mental disorder it affects the thought and behavior of an individual. The people affected with schizophrenia loses reality orientation also. The aim of this research is to understand the socioeconomic profile of caregivers of persons with schizophrenia and to analyses the multiple roles of care givers. Finally, the researcher is intended to understand daily care giving difficulties of care givers of person with schizophrenia. The study also analyses the problem experienced by care givers during the relapse of the patients. Caregivers of individuals with schizophrenia experience many problems inside the family. Sometimes the caregiver would have to take a dual role of generating income for the family and caring for the diseased. Most patients need assistance with brushing, to take bath, washing clothes, taking medicines, etc. Social mobility and the social gathering of caregivers are limited. Cultural dividend plays a dominant role in determining care givers attitudes and difficulties. Multiple roles and Multiple Challenges of care givers of Schizophrenia patients are identified. Care givers Personality traits, attitudes, believes in Almighty, age, health, social support, have a greater role in providing untired care. The study found that the main reason for relapse is not taking medicines on time by the patients and family conflict also a leading cause for relapse.

**Keywords:** *Schizophrenia, Relapse, Caregiving Difficulties, Multiple Challenges, Multiple Roles*

Schizophrenia is a major mental disorder it affects the thought and behavior of an individual. It is characterized by hallucinations, delusions, and negative symptoms. Caregivers of individuals with schizophrenia experience many problems inside the family and the family members of schizophrenics also undergo many problems due to the odd and eccentric behavior of the patient. The major aim of this is to analyze daily care giving difficulties of care givers of person with schizophrenia.

The Caregiver undergoes many problems in the financial, occupational, health, and social life. If the family's breadwinner becomes diseased, the other members have to find proper employment to run the family. Sometimes the caregiver would have to take a dual role of generating income for the family and caring for the diseased. Most patients need assistance with brushing, bathing, washing clothes, taking medicines, etc. Social mobility and the

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social gathering of caregivers are limited. The problems experienced by caregivers are, stigma, lack of social support, losing social relations, lack of social mobility, lack of social interaction and so on. As a result of the difficulties the caregivers experience highly emotional imbalance. The study found that some patients experience relapse also. Relapse is the reoccurrence of schizophrenia symptoms in the patients during treatment. In some cases, relapse needs re-hospitalization. Relapse creates an economic burden and caregiving burden as well. Hence identifying and understanding caregiver’s difficulty is a crucial thing in the mental health field and thereby this paper tries to find out the issues connected with relapse also.

## **METHODOLOGY**

For the purpose of understanding daily care giving difficulties the researcher collected data from 250 care givers of persons with schizophrenia from various hospitals of Kerala including private and government hospitals through simple random sampling. The universe of the study is the primary care givers of persons with schizophrenia who are taking care of a patient more than one year. The study followed explanatory sequential research design. Data collection was carried out by Structured questionnaire prepared by the researchers. Data collection was started after getting Ethical Clearance from the concerned authority. Informed consent form care giver was gathered for conducting data collection.

The following are the major objectives of the study

1. To analyses multiple roles of care givers and the challenges experienced by the caregivers.
2. To explain the daily care giving difficulties of care givers of persons with schizophrenia.

### *Analysis and Interpretation*

#### **Socio-Economic Profile of Care Givers of Persons with Schizophrenia**

The analysis of socioeconomic profile has given a complete picture of the respondents. This helps to understand how the basic features influence the care giving difficulties of caregivers. Caregivers of this study belong to different age group, education, financial stability, health, income, marital status. Gender plays an important role in understanding difficulties in care giving. Both male and female caregivers were participated in this study.

**Table 1 Socio-Economic Profile of Care Givers of Persons with Schizophrenia**

<b>Personal characteristics</b>	<b>Category</b>	<b>Frequency</b>	<b>Percent</b>
Gender	Male	104	41.6 %
	Female	146	58.4%
Age	18-25	10	4.0%
	26-35	26	10.4%
	36-45	30	12%
	46-55	62	24.8%
	56-65	64	25.6%
	Above 66	58	23.2%
Educational status	Below 10 <sup>th</sup>	175	70%
	Pre-degree	28	11.2%
	Degree	36	14.4%
	Post graduate and above	11	4.4%

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Personal characteristics	Category	Frequency	Percent
Marital status	Married	222	88.8%
	Unmarried	21	8.4%
	Divorced	3	1.2%
	Separated	4	1.6%
Income	No income	121	48.4%
	Below 5000	15	6%
	5001-10000	38	15.2%
	10001-20000	27	10.8%
	20001 and above	49	19.6%
Health	No health ailments	227	90.8%
	Have health ailments	23	9.2%
	Unemployed	135	54%
	Self –employed	24	9.6%
	Government	4	1.6%
	Private	71	28.4%
	Other	16	6.4%

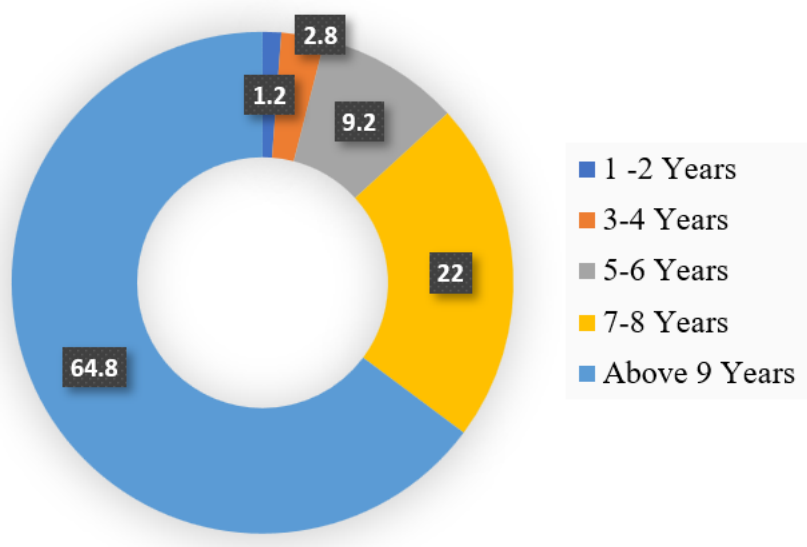
When we consider gender, this data very clearly suggests that women are the primary caregivers which aligns with global caregiving trends where women often take care of caregiving responsibilities. When we look at the age distribution, it is clear that the largest groups of caregivers fall within 46- 66 years and above. This indicates that most caregivers are middle aged or elderly either parents or spouses of individuals with schizophrenia. Younger caregivers from the age group of 18-25 years constitute only 4 percentage. Considering the educational background of the respondents, it is evident that 70 per cent of caregivers have very limited formal education and only 4.4 percent of respondents are post graduates. This means highly educated individuals are less likely to be caregivers or caregiving responsibilities are most often done by those do not have high income. In the present study spouses and parents are the primary caregivers and henceforth the emotional and social burden of caregiving which could affect marital relationship. It is revealed that nearly half of the caregivers have no income so, financial dependency of caregivers are visible in the study. Their hardship due to their full-time caregiving responsibilities is also prominently seen in the study result. Only a very small percentage of respondents are financially stable. From the table, it is very clear that caregiving responsibilities are mainly handled by older, married and female caregivers and most caregivers have low education levels indicates their economic vulnerability.

This shows how economic and social structures influence health outcomes and the quality of life for patients and their caregivers. High unemployment and the financial instability made the caregivers unable to access healthcare and medicines and it exacerbate health disparities. The caregivers need to spend high costs of medicines such as Rs 2000-3000 monthly makes their situation worse and the current study found that majority of the patients did not have insurance coverage or government support. This economic barrier lead them not to access health facilities and it reinforcing social inequalities. Some respondents opined that some patients' intake of food is high and there is a significant nutritional need which is very difficult to meet due to financial constraints. This caused lot of issues like malnutrition or the poor health outcomes further marginalize vulnerable groups. Additionally, the unemployment of caregivers and the high demand for resources place additional social and

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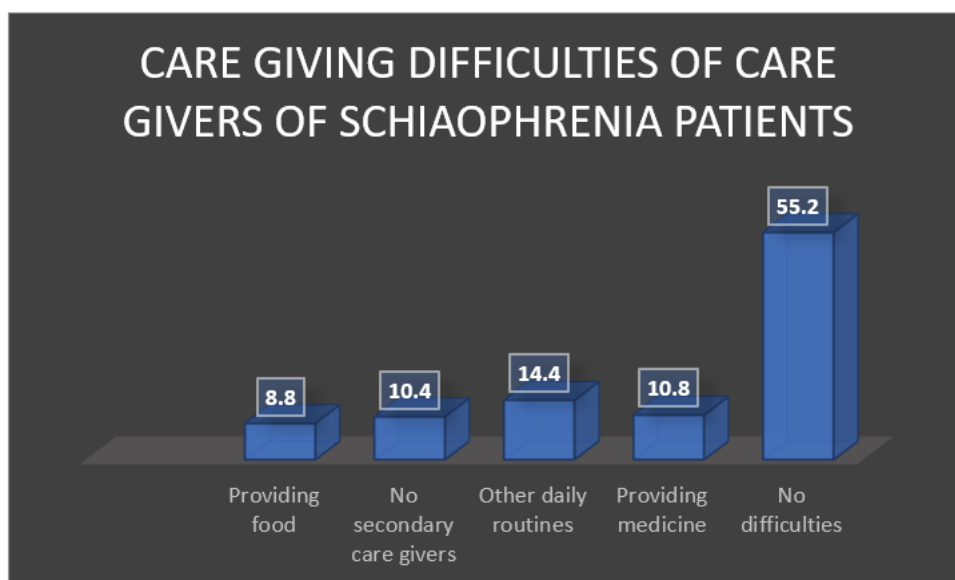
economic stress on families. This further caused strain in their social relationships, emotional stress and limit the capacity of caregivers to maintain their own wellbeing or participate in economic activities. Here it is explicit that structural issues such as poverty and unemployment disproportionately affect marginalized groups particularly from coastal population which needed systemic interventions aimed at reducing social disparities and improving healthcare access to marginalized communities.

This study found that families with little income and relying solely on government pensions face significant barriers to accessing healthcare. This situation exemplifies how economic deprivation constrains health choices and perpetuates health inequalities, often forcing families to prioritize immediate needs over medical treatment. The lack of additional caregivers and family participation in social or familial events lead the respondents to social isolation or breakdown of traditional support networks. Inadequate sanitation facilities and the caregiving support connected with their poverty. Therefore, it is very evident from this study that structural inequalities often force families live in poor conditions. So, in order to solve these issues, we need to improve the healthcare access, sanitation facilities and so on.



**Figure 1 Duration of Care Giving of Care Givers of Persons with Schizophrenia**

The above graph (Figure 1) illustrates the Majority (64.8 percent) of the caregivers have been caring their loved ones for more than 9 years. Most caregivers spend their valuable time in caring for the ill member of the family without considering their personal and familial matters. This is a remarkable and appreciable matter in the area of caregiving and also a matter of concern. As these care givers have spent a major part of their life in the process of care giving their physical energy, emotional health is also affected. Only a small percentage of care givers are in the initial stage of caregiving process. It is revealed that 22 percent of care givers are caring the patient for more than seven years.

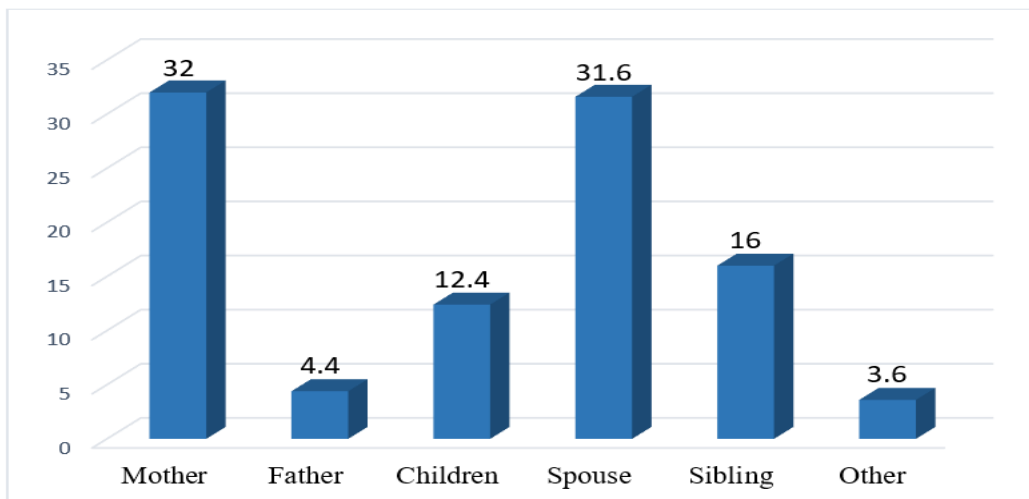


**Figure 2** Care giving difficulties of care givers of schizophrenia patients

The figure 2 shows that Providing medicines and foods on time, consulting psychiatrist, taking care of the patient, washing clothes are the major daily duties of the care givers. Most of the (55.2 percent) of the care givers reported that they were not facing difficulties while serving the patients. Majority of the patients are themselves able to take medicines on time, brushing and bathing which reduced the burden of care givers considerably. However, some patients need assistance in taking medicines and food. Most of the care givers consider their role as a care giver as a part of their life. They believe that it is ‘God given responsibility to look after the diseased one and they did not consider it as a burden. The care giving task is get aligned with their daily household chores and These care givers have to prepare food for the entire family, clean the rooms, washing, child rearing, attending other family members and sometimes they need to find the income also. Even though they are doing multiple roles in their everyday lives, they do not consider it as a burden. They cannot identify the time they are spending for the diseased one and they cannot identify it as a burden. It clearly reveals the old nation of family norms and the un breakable obedience to existing social system. The study reveals that the care givers first priority is family rather than individual priorities.

Caregivers face significant challenges in managing the daily routines of patients. Their primary tasks include preparing meals, assisting with brushing, bathing, and washing the patients' clothes. 10.4 percent of respondents face difficulty in securing a secondary caregiver for the patient. Employed caregivers often need to attend their jobs and as a result they require additional support for patient care. Sometimes, caregivers have to decline job opportunities due to the unavailability of a secondary caregiver for the patient. Some caregivers encounter difficulties in administering medicines, especially when patients show reluctance to take their medication. In these cases, caregivers must exert extra effort to ensure proper medication adherence. Providing food is not reported by the respondents as a problem as most patients are willing to eat on time. However, some caregivers reported issues related to overeating among male patients. Since timely food intake is often linked to medication schedules, caregivers put considerable effort into maintaining this routine to support the patients' health and treatment regimens.

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**Figure 3 Care givers Relationship with the Persons with Schizophrenia**

Figure 3 explains about care givers relationship with the person with schizophrenia. The graphs clearly depict that women are in front of care giving and it shows the gender disparity in care giving. As women are trained as home maker, care taker, caring for sick and children, here also women themselves are chosen and submit life as care takers. The multiple roles in care giving creates stress, strain, health issues in care givers especially in women. About 32 percent of care givers are mothers of the patient and 31.6 percent of them are spouses in which both husband and wife are as care givers. Only 4.4 percent of fathers are the care giver of their son or daughter with schizophrenia. From the opinions of care givers, it is understood that majority of men are reluctant in taking as role of primary care giver, hesitate to cook food, clean dishes, or taking care of the diseased or aged. Siblings and children are least care takers in the sample. As majority of the patients are un married most of them are cared by mothers and most of the married patients are assisted by their spouse.

**Table 2 Health Issues of Care Giver and Difficulties in Daily Care Giving**

Health issues of caregiver	Other daily routine	Absence of secondary caregiver	No difficulties	Providing Medicine	Providing food
No health issues	27 10.8%	24 9.6%	130 52.0%	27 10.8%	19 7.6 %
Have health issues	9 3.6%	3 1.2%	8 3.2%	0 0.0%	3 1.2%
Total	36 14.4%	27 10.8%	138 55.2%	27 10.8%	22 8.8%

**Chi-Square Tests**

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	16.043 <sup>a</sup>	4	.003
Likelihood Ratio	15.628	4	.004
Linear-by-Linear Association	5.125	1	.024
N of Valid Cases	250		

**Hypothesis 1:** There is association between caregivers’ health and daily care giving difficulties

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The above table summarizes the relationship between the practice of caregiving and its difficulties. The statistical analysis of the Pearson Chi-Square value of the two variables is .003 so significant at the 0.05 level. Health issues of care giver are associated with caregiving difficulties. The hypothesis(H1) stated the association ‘between caregivers' health and care giving difficulties’ is accepted. Healthy caregivers can provide better services to their loved ones. Care givers have to find time to maintain their health and well-being They need to consult regular health checkups for their better health maintenance. About 14.4 percent of care givers found difficulties, in caring for daily routine of the person with schizophrenia.10.8 percent care givers expressed the hardships in medication and keeping the patient alone in families. Healthy individual can earn, and look after the family member with schizophrenia with utmost care. Once care givers health deteriorates, it would affect in the care giving process and it also determine the recovery process of the patient.

**Table 3 Duration of Care Giving and Daily Care-giving Difficulties**

Duration of care giving	No difficulties	Providing Medicine	Other Daily routine	Absence of secondary care giver	Providing food
1 to 2 years	1	0	1	0	1
	0.4%	0.0%	0.4%	0.0%	0.4%
3 to 4 years	5	1	0	1	0
	2.0%	0.4%	0.0%	0.4%	0.0%
5 to 6 years	10	2	5	3	3
	4.0%	0.8%	2.0%	1.2%	1.2%
7 to 8 years	36	4	3	9	3
	14.4%	1.6%	1.2%	3.6%	1.2%
above 9 years	86	20	27	14	15
	34.4%	8.0%	10.8%	5.6%	6.0%
Total	138	27	36	27	22
	55.2%	10.8%	14.4%	10.8%	8.8%

### Chi-Square table

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	16.745 <sup>a</sup>	16	.402
Likelihood Ratio	18.705	16	.284
Linear-by-Linear Association	.151	1	.698
N of Valid Cases	250		

Pearson Chi-Square value calculated in the above table is .402. It means that there is no significant association between caregiving duration and caregiving difficulties. Around 64.8 percent of the care givers have been supporting the ill members of the family for more than 9 years. Care giving task hampers out most of the time of a care giver. Most of the (64 percent) of them are caring their family member with schizophrenia more than 9 years and within this 34.8 percent of care givers are not identify their problems of care giving. These care givers informed that it is their responsibility to take care the patient and they are happy to do it. They cannot see the restless care they are providing as a burden. All these years, the pain, stress, emotional issues, financial hurdles experienced by these caregivers are countless. Caregivers are not concerned about the span of time, but their concern is the well-being of the patient.

**Table 4 Socio-Demographic Features of the Care Givers and Daily Care Giving Difficulties**

Variable Source		Sum of Squares	df	Mean Square	F	Sig.
Age of care giver	Between Groups	23.631	4	5.908	3.029	.018
	Within Groups	477.873	245	1.951		
	Total	501.504	249			
Education of care giver	Between Groups	1.065	4	.266	.278	.892
	Within Groups	234.651	245	.958		
	Total	235.716	249			
Marital status of care giver	Between Groups	.821	4	.205	.810	.520
	Within Groups	62.095	245	.253		
	Total	62.916	249			
Job of care giver	Between Groups	3.760	4	.940	.419	.795
	Within Groups	549.316	245	2.242		
	Total	553.076	249			
Monthly income of care giver	Between Groups	10.458	4	2.615	.998	.409
	Within Groups	641.846	245	2.620		
	Total	652.304	249			
Relation with the person with schizophrenia	Between Groups	11.743	4	2.936	1.291	.274
	Within Groups	557.201	245	2.274		
	Total	568.944	249			

One-way ANOVA of the socio-demographic profile of the caregiver and their caregiving difficulties are shown in the above table. The 'F' value for age and care giving difficulties is 3.029 which is statistically significant at 0.05 level. This means difficulties in the practice of caregiving as care givers age varies. All other variables such as monthly income, job, education, marital status has no role in care giving difficulties.

80-year-old mother of a man with schizophrenia told that, *"I have been caring my son for 56 years. I feel difficulty or burden in caring for him as my health worse day by day. He was affected schizophrenia when he was 20. It's our fate, we cannot alter it. I am concerned about his life after my death. I considered my son a blessing after his father's death; he is the only asset I possess"*.

The women care giver of a male reported this, *"it's very difficult for me to clean his cloths as it always wet by urine. It is very difficult to make his routine properly. He always wants to be in bed or to watch TV"*.

All these explanations show that caregivers experience difficulties in the caretaking process. Especially aged mothers are not able to clean their diseased child, wash clothes, or prepare food for the patient; these tasks become a hurdle for them. As the age of the caregiver increases, the health also deteriorates, so the caregiving task becomes a herculean task for the caregiver. During old age, caregivers are not able to find time for themselves and are not getting proper rest either. As a result, they may experience increased stress and fatigue, which can further impact their ability to provide effective care. So, age is one of the crucial

factors that determines the quality of care one gives. The study shows that healthy caregivers in adulthood can provide quality care for their loved ones with schizophrenia.

***Relapse details of Person with Schizophrenia***

Relapse in schizophrenia means reoccurrence of schizophrenic symptoms while in the treatment and recovery phase. Relapse does not occur suddenly and they tend to follow a sequence of events based on family environmental triggers. Triggers are external things like people, places, and something that increase people's tendency to relapse. So, identifying the triggers need is the preliminary step while analyzing. Generally, there are three reasons for relapse, first one is avoidance of medicines, then consumption of alcohol and tobacco and emotions of care givers expressed during family conflict.

***Table 5 Relapse details of Person with Schizophrenia***

<b>Relapse details</b>	<b>Category</b>	<b>Frequency</b>	<b>percent</b>
Relapse of person with schizophrenia	Relapsed	63	25.72
	No Relapse	187	74.8
Last relapse in the last year	Last Week	12	4.8
	Last Month	34	13.6
	Before 5 Months	13	5.2
	5 months - 10 Months	4	1.6
Reason for relapse	Stopping Of Medicine	55	22.0
	Family Problems	3	1.2
	Others	1	.4
	No Reason	4	1.6

Table 5 describes the relapse of person with schizophrenia, only a small portion of patients experienced relapse. The table stipulated that that 74. 8 percent of respondent have not been experienced relapse yet. This shows that the care givers vigilance in providing medicines on time, timely consultation with the psychiatrist and mental health counsellor. These care givers are spending more than five hours daily on the care of family member with schizophrenia. The efforts taken by all these care givers are the main factor in preventing relapse in these patients. The reasons for relapse also quite interesting. Around 22.4 percent of relapse due to not taking medicine according to the prescription of doctors. Some families experience financial difficulties in buying medicine, as psychiatric medicines are very costly and some ignore the fact that their family members having a mental health problem that really needs medicines.

Government hospital of Kerala provides free of cost treatment and medicine to persons with mental illness but sometime some medicines are unavailable there. During the unavailability of medicine, the patient from lower economic class have to skip medicine intake. These reluctance in medicine intake is not deliberate, their economic problems and lower social class background is also a limiting factor in proper medicine intake. The study result shows that as these families have to find an income for food, medicines and other expenses, sometimes only option to sustain is to avoid expensive medicines, so as to get three-times meal a day. Some families run with the government pension and food items from ration stores alone.

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Family conflict also another reason for relapse in patients. Confrontation between members in family also create tensions in the patient that really affect their emotional health that in turn creates relapse in the patient. The respondents informed that one of the reasons for family conflict is economic issues and the prominent reason is lack of social support from other family members. It is revealed that families need a consist income, social and emotional support in the care giving process. So, avoiding family conflict has a crucial role in the recovery process of person with schizophrenia.

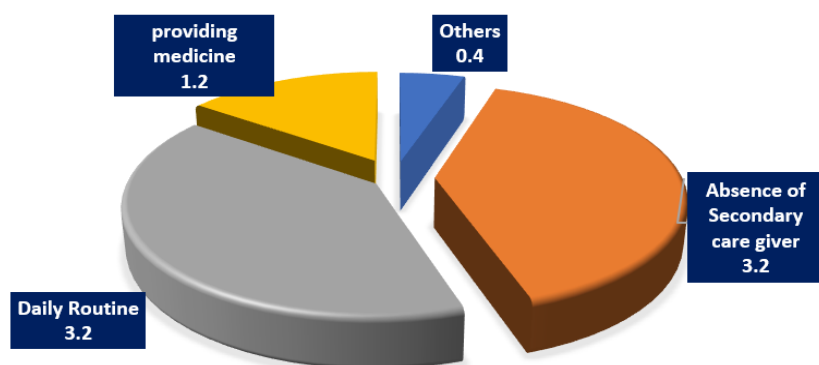
One of the caregivers said that,

*“I do consider it my first preference to give medicine to my husband. The doctor advised me not to avoid medications because it could result in a relapse. As a result, I never avoid giving medication intake.”*

One of the caregivers of a 25-year-old man said that,

*“When the bread winner of the family becomes ill, I have to find an income for the family. I have started working as a maid in a nearby house. I usually go work before 5 am and come back before my husband wakes up as there is no one in the home to care for him. Whenever I am not able to provide him medicine, he develops some symptoms of his disorder, so I borrow money from neighbours to give him medicine on time. so that his recurrent symptoms can be minimized”.*

From these words of care givers, it is understood that the care givers have awareness about the problem of avoiding medicines, about relapse and the difficulties there by, so most of them are vigilant in providing medicine for the patients. Care givers informed that medicine intake by the patient will help in managing the schizophrenia symptoms in patients as well. Thus, providing medicines on time is considered as the primary role of care givers.



**Figure 5 Care Giving Difficulties during Relapse of the Person with Schizophrenia**

During relapse the care givers burden level increases and they need support from others also. Care giver needed physical support, economic support and emotional support during the relapse of the patient. Around 4.4 percent caregivers have felt some difficulties in giving medicine during relapse of the patient and 3. 2 percent of the respondents said their difficulties is in getting a secondary care giver and maintain their daily routine, respectively. Thus, around 11.2 percent caregiver experienced difficulties during relapse. Relapse definitely creates additional burden for a care giver in terms of economic, social, emotional as well as physical dimensions of life. Physically it creates additional health issues due to constant hospital visit and strain in providing physical for the patient. In economic matters, hospital admission and leave from job also create troubles in buying medicine. All these physical and economic problem creates emotional imbalance in the care giver. Their social

life is affected by these frequent hospital visits also. During relapse of the patient the care giver is troubled by many problems. Thus, avoiding relapse is a major hurdle for care givers of schizophrenia patients. Overcoming relapse is a very crucial step in the process of recovery of a person with mental illness.

## DISCUSSION

Caregiving difficulties are encountered by a caregiver of a person with schizophrenia while dealing with the patient on a daily basis. Difficulties vary from person to person. Some factors, like age, health, education, and stress sometimes influence care giver's burden. Perceived burdens among family caregivers of patients with schizophrenia have been studied in various regions and cultures. In Europe, a study described several effects of caring, which included poor health of family members, disruptions to social and leisure activities and domestic routines, and a reduction in household income (Canive et al., 1996). Here in the present study researchers also noted three prominent factors that influence care giving are health of family care giver, reduction of income and age of care giver. Physical health definitely determines the care giver's capacity to provide quality care. In the case of caregivers with some health issues, the way of care giving, duration of care giving, attitudes, length of interaction with the patient were also affected. The way they treat the patients and the length and duration of interaction. The reduction of care giver's attention also caused issues in the recovery process for the schizophrenia victims. Household income reduction is another alarming issue for families of schizophrenia patients. The cost of psychiatric medicine was also another factor that reduces family income. Monthly hospital visits, counselling and travel expenses to hospitals also added the economic vulnerability of these families. Those living in a family with poorer functioning, poor health status, and minimal social support have the highest burden (Chien et al. (2007), this study result goes align with the study result of the researcher. Here the researchers also found that healthy care giver can provide quality care to the patients and family problems create relapse in patients.

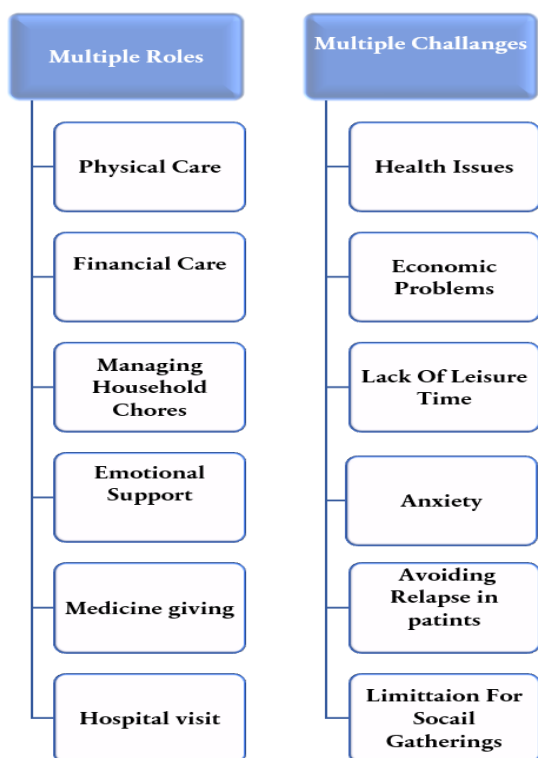


Figure 6 Multiple roles and Multiple Challenges of Care givers of Schizophrenia patients

Figure five shows the multiple roles and multiple challenges of caregivers of schizophrenia patients. The caregivers in this study provide round-the-clock care, often maintaining vigilance even during the patient's sleep. They monitor sleep duration, quality, and any sleeping difficulties. The multiple roles undertaken by caregivers include providing physical care, offering emotional support, seeking economic resources, assisting with hospital visits, and preventing relapse. Many patients require the physical presence of caregivers during the daytime as well. This continuous caregiving led to health issues for the caregivers themselves. Caregivers need a sufficient income to manage household responsibilities, but economic difficulties cause turmoil in their lives. Psychological support is essential for patients and caregivers as well, however access to professional counseling services is limited, which adds to the caregivers' anxiety about the patient's mental health. They assist with monthly hospital visits and ensure timely medication intake. The constant demand for caregiving and hospital visits often restricts caregivers' social interactions, limiting participation in social gatherings and family events. Another problem faced by the respondents are management of household chores such as preparing meals on time, sending children to school, interacting with family members, and making decisions regarding the patient and family. The burden of caregiving is often unrecognized, especially among those with low education and unemployed belong to a marginalised community. Many of these caregivers are not engaged in permanent employment and therefore spend most of their time at home and when the researcher asked about the nature of caregiving, the respondents responded that they often do not realize the amount of time and effort they dedicate to patient care. Most often the needs of caregivers such as proper nutrition, rest, and leisure activities, are frequently neglected. Some caregiver's express feelings of entrapment, highlighting the absence of support systems like secondary caregivers, which leaves them feeling overwhelmed and unsupported. Hence the caregivers become increasingly vulnerable due to the excessive burdens they bear in providing care to patients. Factors such as limited income, physical weakness, and emotional strain heighten their vulnerability. Along with those factors economic deprivation and educational backwardness, these social factors significantly impact the caregivers' quality of life. Such conditions restrict their happiness and confine their lives primarily to caregiving responsibilities.

The study found that the burden of caregiving often goes unrecognized, especially among female, uneducated, unemployed caregivers from coastal area. The majority of these caregivers are women serving as mothers, wives, or sisters, with traditional patriarchal norms heavily influencing family structures. Conventional family roles and patriarchal family functioning place the primary burden of caregiving on women's shoulders. The female caregiver exerts constant effort to sustain the family's functioning, which often limits their social and economic participation

### **CONCLUSION**

The caregiver's burden on day-to-day basis was analyzed in the study. The structural inequalities play a significant role in the marginalization of caregivers of persons with schizophrenia. Economic deprivation, debt, lack of insurance facilities, unemployment makes caregivers lives more vulnerable. Lack of social support, loss of social interaction feels them separated from the society. Constant hospital visit, interaction with psychiatrist, nurses and counsellors limit their role in economic and social events. Absence of leisure time activities and lack of rest makes their lives in a trapped state. Age and health determine the quality and quantity of care given by these care givers. The study result shows that age of care giver is also associated with difficulties in care giving as age increases care giver's ability to provide better care deteriorates. Health becomes a predictable role in determining

the care giving difficulties of the caregiver. Health issues of caregivers are associated with care giving difficulties. Healthy caregiver can provide sound services to their loved ones. Relapse in schizophrenia patients is a major obstacle in the recovery process of patients. It is found that the main reason for relapse in patient is not taking medicines on time and care givers burden increases during relapse events. The study results reveal that care givers need a consist income, social and emotional support in the care giving process.

This study found that the challenges faced by caregivers of individuals with schizophrenia are deeply embedded within the social and cultural fabric of their community and local context. The roles and responsibilities undertaken by caregivers are shaped by societal norms, cultural values and locality which particularly influenced their attitudes and coping mechanisms. That's how they even did not realise their job as a caregiver is not as a burden. These Cultural dividends play a crucial role in shaping caregivers' perceptions and responses to their caregiving roles. Along with cultural dividends, the individual factors such as personality traits such as age, physical health and family and social networks serve as key determining factors for care giving. Support from neighbourhood and community can alleviate the burden of caregiving and help them for sustained care. If caregiving is community responsibility, the caregiving would be effortless and less tiring. Proactive measures such as regular community-based health assessments and social interventions are vital for maintaining caregiver wellbeing. Socio economic support can be provided through financial ait though it is small by from the part of Government or non-governmental agencies. Engaging caregivers as active partners in community development not only help their infrastructural facilities but also it improves the sense of agency and social inclusion. In short, in order to improve the life of caregivers necessitates a holistic approach. Therefore, community networks, cultural competence in health care delivery and financial stability is vital for the improvement of the conditions of caregivers and enhance the overall well- being of families affected by Schizophrenia

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## **Conflict of Interest**

We have no conflicts of interest to disclose.

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