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Original Research Article

Burden and Needs of Primary Family Caregivers of Schizophrenic Patients: A Qualitative Study

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ABSTRACT

Background: Caregivers need to look after all the requirements of the mentally ill person which become very tiresome and challenging. The study aimed to explore burden and needs of primary family caregivers of schizophrenic patients.

Methodology: A qualitative study was conducted using phenomenological design. A total of 17 primary family caregivers of schizophrenic patients from Psychiatric Department of Gauhati Medical College & Hospital, Guwahati were selected using purposive sampling technique. Data were collected by conducting one to one interview using semi-structured interview schedule. Data analysis was done by thematic analysis.

Result: Five major themes and twenty sub-themes were identified. The five major themes were: Challenges encountered, Psychological impact, Unpleasant experiences, Requirements of caregivers and Emotional impact.

Conclusion: The findings of the present study clearly confirmed that the family caregivers faced a lot of challenges while caring for the individual with schizophrenia.

Keywords: Burden of caregivers, needs of caregivers, schizophrenia patients, family caregivers.

INTRODUCTION

Mental disorders are highly prevalent globally, affecting people across all regions of the world.[1] Schizophrenia affects approximately 24 million people or 1 in 300 people (0.32%) worldwide. Approximately 50% of the people in mental hospitals have a schizophrenia diagnosis.[2] Individuals diagnosed with schizophrenia vary widely in terms of their disabilities, presentations, and quality of life. Although schizophrenia is treatable but it is not curable and is a chronic and severe mental illness.[3] Schizophrenia is likely responsible for longer hospitalizations, greater chaos in family life, more exorbitant costs to individuals and governments and more fear than out of all the mental illnesses.[1] Research indicates that most caregivers were under emotional burden, suffered economic loss, had difficulties in meeting basic living needs, interrupted work life, deteriorations of family and social relationship and assumed new responsibilities.[4] Studies revealed that needs of the caregivers includes information about the disease, need for meeting family members who had the same illness as their patients, rehabilitative needs and need for mental health services near home.[5]

Therefore, the study will explore the burden and needs of primary family caregivers of the schizophrenic patients as very less numbers of qualitative studies have been conducted in Assam on these areas. Studying burden and needs of the caregivers will highlight the challenges and requirements of the caregivers to the decision makers, mental health professionals and researchers and also will help the nurses and healthcare providers to take appropriate measures that can lessen caregivers burden and improve the quality of life.

MATERIALS & METHODS

Research approach: Qualitative research approach.

Research design: Phenomenological research design.

Sample: The sample includes primary family caregivers of schizophrenic patients.

Sample size: Sample size is 17.

Sampling Technique: Purposive sampling technique.

Setting: Psychiatric department of Gauhati Medical College & Hospital, Guwahati.

Analysis of data

The qualitative data were organized manually and thematic analysis was done using Braun & Clarke’s six phases of thematic analysis.

RESULT

The demographic information of the participants is presented in Table 1 and Table 2 includes major themes and sub themes of the analysed data.

Table 1: Socio-demographic characteristics of the primary family caregivers

Serial No.	Variables	Category	Frequency	Percentage
1.	Age	29-39	6	35.3
		40-50	8	47.1
		51-60	3	17.6
2.	Gender	Male	8	47.1
		Female	9	52.9
3.	Religion	Hinduism	13	76.5
		Islam	4	23.5
4.	Educational level	No formal education	4	23.5
		Primary School	1	5.9
		Middle School	3	17.6
		High School	6	35.3
		Higher Secondary	2	11.8
		Graduate and above	1	5.9
5.	Occupation	Home maker	5	29.4
		Daily wage earner	5	29.4
		Self employed	1	5.9
		Govt. employed	1	5.9
		Privately employed	5	29.4
6.	Monthly income of family	68,967-92,185	1	5.9
		9,232-27,648	10	58.8
		≤9,226	6	35.3
7.	Marital status	Married	13	76.4
		Unmarried	2	11.8
		Widow /widower	2	11.8
8.	Type of family	Nuclear family	14	82.4
		Joint family	3	17.6
9.	Relationship of participants to the patients	Parents	6	35.3
		Spouse	4	23.5
		Siblings	2	11.8
		Children	2	11.8
		Relatives	3	17.6
10.	Any physical illness of caregiver	Nil	13	76.5
		Hypertension	4	23.5
Total			17	100

Table 2: Major themes and sub themes

Major themes	Sub themes
Difficult situations encountered	Strain on physical health Economic burden Household chores affected Increased responsibility Affected social life Lack of time Affected worklife Medication non-compliance
Psychological impact	Helplessness Tensed Worries about patient's future Mental issues
Unpleasant experiences	Unusual behaviour of the patient Discrimination and criticism
Requirements of caregivers	Free medication and transportation facilities Need for more information Support from family and relatives
Emotional impact	Sadness Anger Fear

Five major themes and twenty sub themes emerged from the data analysed.

1. Difficult situations encountered

Eight sub themes were identified under the major theme difficult situations encountered.

1.1 Strain on physical health

Most of the caregivers expressed that taking care of patient with schizophrenia had a great impact on their physical health as they need to be a full time carer. Caregivers had to look after each and every needs of the patient, manage patient's unusual symptoms, stay with patient during hospitalization and worry about patient which affected their physical health as they had no rest and sleep.

"We didn't had peace at all. Even while eating I had to leave my food and run after him. Initially my sleep was affected a lot thinking what if he goes out of the house at night. So the entire night I had to stay awake and look after him". (C4)

"My sleep got affected because he keeps on going out of the house at night, repeatedly goes to washroom and opens the door frequently. He stopped eating food with me which made me sad as we always had food together. So I started skipping my meals too." (C16)

1.2 Economic burden

Most of the caregivers expressed that they faced economic burden due to various medical and non medical costs. The main factor attributed to economic burden was expenditure on treatment and medications.

"I had to sell my land as I was unable to afford the expenses of his treatment. Now I have shifted to a hilly area and started staying in a bamboo house which is also deteriorating day by day. I cannot even think of repairing the house. With such a little amount of money shall I repair the house, treat my son or spend on our meals?" (C7)

"Due to financial crisis, I couldn't bring him to hospital on time. Even I had to borrow money to buy his medicines and sell cows for his treatment expenses". (C12)

1.3 Household chores affected

Most of the caregivers reported that they could not do household chores wholeheartedly as they had to manage the patient's symptoms and stay in hospital whenever the patient got admitted.

"since I had to be in the hospital with him I cannot look after my house. At present there are few cattle but one was killed by wild animals or maybe by people in my absence." (C1)

"I could not do my household works as much as I should have done. I had to spend most of my time looking after him and managing his illness related behaviour. Whenever he got admitted in hospital, I had to be with him". (C4)

1.4 Increased responsibility

Caregiving comes with lots of responsibilities as stated by most of the caregivers. A caregiver role is very challenging because apart from caregiving there are lots of other responsibilities that they need to look after. The role played by a caregiver is multiple which adds on more burden in caregiving process.

"I had to manage everything alone. I had to support my family financially, go to work, bring him to hospital for regular follow up and even stay in hospital whenever he got hospitalized as our parents were old and illiterate and do not understand hospital procedures". (C3)

"My elder daughter's husband expired and she got married for the second time. But her present husband didn't accept the child so she stays with me. Now I had to take care of my grandchild, look after all her expenses, take care of my son, go to work and manage household chores too." (C7)

1.5 Affected social life

Caregivers reported that they had to give up their social life due to caregiving process. Social relationship of the caregivers is negatively affected as they cannot go anywhere and had to be with the patient most of the time. They had to perform multiple other responsibilities apart from caregiving which makes it difficult for the caregivers to spend time with their friends and relatives. Sometimes patient themselves did not allow the caregivers to go out due to their illness related behaviour.

"I cannot go anywhere. If I go out he suspect me of having extramarital affair. I cannot attend any occasion like birthday or marriage party of my family members or in our neighbourhood. Even he does not allow me to go to my mother's house. I hardly talk to people nowadays." (C14)

"I need to take care of her, do household chores and then go to work. After returning back from work I need to be with her again and left with no energy. I can't even visit my mother's house." (C6)

1.6 Lack of time

Caregiving process is time consuming. Most of the caregivers had very little time for themselves, their children and other activities as they are engaged in caregiving. Caregivers had to take care of the patient as they are left with no other choice. Also they had less family time which adds on to their burden.

"I am unable to spend time with my children. When I stay in the hospital with him I cannot take care of my children. They cannot keep themselves clean, do not take bath or have food on time. I cannot even look after the cattle and few of them died too." (C4)

"I can no longer take care of my child. I had to go to work and after returning back home take care of her. I can hardly spend time with my child and husband." (C6)

1.7 Affected work life

Caregivers reported that caregiving has disrupted their work life. To provide uninterrupted care to the patient sometimes caregivers had to give up their job and be with patient as it becomes difficult to manage both work and caregiving. Most of the time it is the illness related behaviour of the patient which act as a hindrance to work life making it difficult for the caregiver to go to work.

"I had to give up my job I took leave to be with my mother but got repeated calls from office to join back as my leave was getting over. Her condition was deteriorating so I could not join and finally had to resign. I was jobless for 2-3 months. Luckily I got another job and started working from home. But I started getting calls to join again but was unable to go. So they have reduced my salary". (C8)

"because of him I cannot step out of the house. I cannot go to work. If I go to work for one day, the next few days I had be at home because of his suspiciousness. So nobody wants to hire me now and I have lost my job. " (C14)

1.8 Medication non-compliance

Caregivers expressed that when there is little improvement in the patient's condition they hardly want to continue the medications thinking that it may further deteriorate their condition and make them dependent on the drugs. It becomes very difficult on the part of the caregivers to make the patient understand the importance of continuing medications to prevent relapses.

"He stopped taking his medications as he thinks that he recovered and there is no need to continue his medicines. If we insist him to take medicines he says that it's our plan to make him go insane and gets angry on us." (C12)

"She will take the tablet and put it inside her mouth in front of me but later throws the tablet as soon as I move away. Initially I was unaware of that but later I found out." (C13)

2. Psychological impact

Four sub themes were identified under the major theme psychological impact.

2.1 Helplessness

Caregiving process can be overwhelming making the caregiver feel lonely very often. The main reason which makes the caregiver helpless is no improvement in patient's condition even after doing every possible thing. Seeing the patient suffer infront of their eyes makes them feel worst.

"I tried to do everything people said that would cure my brother's illness. We took him to a faith healer, spend a lot on him and even sold half of our land with a hope that he will be cured soon but all my attempts failed. I don't know what else should I do?" (C3)

"I felt very bad when his father denied to take him to the hospital because he does not want people to know that his son is mentally ill. I had to see my son suffer in front of my eyes. I feel that it would have been better if he dies soon." (C11)

2.2 Tensed

Most of the caregivers were tensed due the unpredictable behaviour of the patient associated with schizophrenia. Caregivers thought that other people might not understand the patients condition and may cause harm to them. Caregivers even wonders whether other family members would support or take care of the patient or not as it is challenging to look after a mentally unstable person.

"….I am under constant mental strain. Even if I am at work thoughts about her recovery and well being comes repeatedly to my mind. My son supports and take care of her now. But how long he will be able to support? Now he is able to do so because he is not yet married but will his wife accept to live with a sister in law who is mentally unstable?" (C2)

"Even when I am at work my mind keeps on thinking about her. I keep on thinking what he is doing, what if he goes out of the house, what if he is being beaten by others, what if he harms anyone or destroys others property? Until and unless I return back home my mind is occupied with such thoughts" (C7)

2.3 Worries about patient's future

Most of the caregivers expressed that they are concerned and worried about the patient's future after they pass away as no one would take their responsibilities. Some of the caregivers also expressed that the patient might not get married and will be left all alone throughout their life.

"I am worried that if I die how will he survive? His father will not take him to the hospital even if he suffers because mental illness is still a stigma to him. He will not even give food to my son or take care of him properly." (C11)

"I know that he will not be able to marry. Nobody would marry their daughter to a man who is mentally unstable. What will happen to him when I am no more? May be he will wander in the streets or go from one house to another in search of food. I don't know how he will survive?" (C16)

2.4 Mental issues

Caring for a schizophrenic person for longer duration affects the caregivers mentally. Few of the caregivers reported that caregiving have affected them to such an extent that they themselves are mentally exhausted. They were in need of therapy and were on medications too.

"I feel like I am not well mentally. I don't feel like talking to people and want to stay alone. I feel as if I am no longer active. So I thought of going for a counseling session or may be psychiatric consultation. I keep on wondering why am I living such a miserable life? It is better to commit suicide rather than living such a bad life. There is no happiness in my life. " (C10)

"I used to think a lot about my son. I felt like why should I live? Many a times I think of drowning myself and taking away my life. I felt so sad. I went for psychiatric consultation and was diagnosed with depression. I was on medication for one year." (C11)

3. Unpleasant experiences

Two sub themes were identified under the major theme unpleasant experiences

3.1 Unusual behaviour of patient

Caregivers reported they had to manage various illness related behaviour of the patient which makes caregiving process more struggling. Reduced income, loss of property and paying for the loss to others have negatively affected their life. Caregivers mainly had trouble dealing with the aggressive behaviour and harm or injury inflicted to others.

"I had to go to work. When I returned back home I saw he had burned down the household things and threw away all our clothes outside. He does not allow me to stay at home and tried to kill me. Gradually his symptoms increased and one day he destroyed our neighbour's property too. I had to bear all the expenses for the damage made by him." (C7)

"….she will not prepare food or do any household works and would get angry when asked to do so. She will verbally abuse me and sometimes hurt me physically. Once she hit my head with a brick and tried to kill me with a machete." (C15)

3.2 Discrimination and criticism

Caregivers shared that they had to face criticism and were held responsible for patient's mental illness. People were unable to accept a person with mental illness in the society. They mocked and discriminated them which made the caregivers felt hurt and devastated.

"I heard people saying that we were not good parents. They said that we have done wrong to others so now our daughter is suffering because of our sins. It really hurts me a lot when people say such things." (C2)

"After knowing that she is mentally ill people laugh at her. They said that nobody would marry her now. Our neighbours are not at all good. They does not even understand that she is undergoing treatment and should not be mocked." (C6)

4. Requirements of caregivers

Three sub themes were identified under the major theme requirements of caregivers.

4.1 Free medication and transportation facilities

Caregivers expressed that free medications and transportation facilities from hospital would have been beneficial for them as it would help them in proving better care to the patient and come regularly for follow up and treatment.

"The medicines are quite expensive. It becomes difficult to afford it every month. Also we need to pay for all the investigations. Free medications and investigations would have been of great help.” (C3)

“I know that people with mental illness need to continue their medications life long. I don’t know for how long I will be able to pay for his medicine? I need free medicines for him or at least reduced price of the medicines.” (C17)

4.2 Need for more information

Caregivers expressed that more information would have been helpful in dealing with the patient’s illness and managing their behaviour. They should be given information about the illness patient is suffering from and different ways that can be adopted to manage patient’s condition.

“It would have been of great help if somebody could have explained to me about the illness in details illness. There should be sessions for all the caregivers where explanation about the illness, patient’s symptoms management and ways to behave with the patient is explained. At least one session per week would have been useful.” (C2)

“I would like to know more about the illness. What exactly is the condition he is suffering from? Whether he is recovering or not?” (C3)

4.3 Support from family and relatives

Most of the caregivers expressed that support from the relatives and family members like visiting the patient, talking over phone with the patient, helping financially and sharing some responsibilities of the patients would have made caregiving process a bit easier.

“I have two more son but none of them supported me financially. Even they do not look after their brother instead they take advantage of his illness and make him do all the household chores.” (C5)

“None of our relatives came to see my son. They don’t even call me. I have two brothers but they never came forward to help me. It also happened that we could not afford a meal for days and ate rice with salt. Even my children had to eat the same.” (C14)

5. Emotional impact

Three sub themes were identified under the major theme emotional impact.

5.1 Sadness

Caregivers reported that they feel sad because their dreams for better future of their patient were shattered, patient being not accepted by other family members, affected relationship of the caregiver with other family members and repeated sufferings of the patient.

“My sister started disliking her kids. She will always scold them and does not want them to come near her. She cursed them to die. It’s really painful and sad to hear such words from her.” (C9)

“I feel sad when I look at my son. I was hopeful that my son will earn someday, look after the house and family members, get married and have his own family. But I don’t have any such hopes now.” (C16) 2572

5.2 Anger

Caregivers expressed that sometimes they get angry on the patient as their daily routine got affected, had to managing everything alone, tolerate patient’s unusual and aggressive behaviour, being physically hurt by patient and minimal or no response from the patient when asked something.

“I get angry when she does not reply to us even after repeatedly asking something. Even though we talk in a soft and calm voice she will never reply. Sometimes I feel that she is not mentally ill but she is doing it intentionally to irritate us.”(C9)

“She did not allow anyone to touch the baby. Even if the baby cried, she will not let anyone to come near. She bathes the baby in cold water due to which the child suffered from fever. The baby was given formula feeding as she did not want to breastfeed. Her ignorance towards the child makes me angry.” (C13)

5.3 Fear

Caregivers reported that they were afraid as the patient threatened them verbally and tried to harm them physically. Due to illness, they exhibited symptoms which were fearful to the caregivers. Fear of being not accepted by the society was also expressed.

" …. She threatened to kill me with a knife and even tried to attack me. I was so afraid of her that one day I ran away from the house and returned back after five days. She was all alone at home." (C15)

"….I know that my son is mentally unstable. But I cannot disclose this fact to others. I am afraid that if people come to know about his condition than they may not accept him and make fun of him." (C16) 2847

DISCUSSION

Findings of the study reveals that the major burden of the caregivers included strain on their physical health due to caregiving process, economic burden due to treatment related expenses and affected work life, increased responsibilities as they had to manage everything alone, psychological impact as they are mentally exhausted and had to be on medications, had to manage unusual behaviour and face discrimination and criticism from relatives and society.

The study of Chen et al., (2019) revealed that that caregivers burden included financial and daily housework burdens, limited social communication, psychological stress, high cost of caring, prejudice and discrimination from others.[6]

The main needs of the caregivers in this study were subsidized rate of treatment and medicines and need for information regarding the patient's condition.

A qualitative study conducted by Jagannathan A et al., (2010) revealed that needs of education which included information and education on illness, medication, its side effects, emergency medicines and available concessions or benefits were some of the needs of caregivers.[7]

This study revealed that caregiving had affected the caregivers emotionally as they experienced sadness during caregiving process, got angry as they have to manage everything alone and were fearful as they were being verbally and physically abused by patient.

A study by McHugh DR, Brown CH, Lindo JLM (2016) revealed that the emotional burden experienced by caregivers included feelings of anger, sadness, fear and depression.[8]

CONCLUSION

The findings of the present study clearly confirms that the family caregivers face a lot of challenges while caring for the individual with schizophrenia. The family caregivers experiences burden in many areas and many of their needs were unmet. They had to undergo not only physical but psychological and emotional turmoil too. Therefore, it is the high time to apply holistic caregiving approach, to plan interventions for the caregivers, involving them in various recreational activities, conducting group sessions to share their thoughts and feelings and provision for counseling to ease their caregiving burden.

Declaration by Authors

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