

Living with a Mentally-Ill Patient: A Qualitative Study Exploring the Experiences and Problems of Caregivers of Patients with Schizophrenia in a Selected Hospital of New Delhi

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Abstract

Purpose: To present a detailed account of the subjective feelings and experiences of care-givers of patients with schizophrenia and the consequences of care-giving both on the quality of life of care-givers and the impact of it on the delivery of care. *Design:* Phenomenological methodology. *Method:* Open-ended, audio-recorded in-depth interviews were conducted in Dr. RML Hospital, New Delhi, with 6 care-givers (parents) of patients with schizophrenia, 61-66 years old (mean 64). The recordings were transcribed and translated into English and analyzed to identify themes pertinent to the care-giving experiences. *Results:* The major themes emerged were varying perceptions and misconceptions, institutionalization, a new experience, stigmatization of the mentally-ill, traumatic experiences of bizarre behavior, challenges of care-giving, apprehensions about marital relationships, abandonment by significant others, disrupted family functioning and family dynamics, failure to derive personal satisfaction, disordered personal life, imbalanced social life, disrupted occupational life, expensive treatment, consternation of future expenses, only God can help, reaffirming hope and meditation is the best coping resource. *Conclusion:* The care-givers attributed the occurrence of the symptoms to mythical ideations and considered mental-illness a paranormal phenomenon. Scarcity of knowledge was a big concern for the care-givers, which made them unskilled and untrained for the trials associated with the task of providing care for the family member with schizophrenia.

Keywords: Schizophrenia; Care-Givers; Qualitative Methodology.

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Introduction

Caring is a fundamental issue in the treatment for Persons with Severe Mental Disorder (PWSMD). The onset of a mental illness in any family is often, and understandably, a time of turmoil. Most families are ill-prepared to deal with the initial onset of severe mental disorder in their family member. Families generally have little knowledge of mental illness, and find that they not only have to deal with the ups and downs of the illness but also need to deal with the stigma and attitudes towards the mentally-ill family member in the community [1,2]. Caregiver burden has been described as the overall physical, emotional, and financial costs of caring for a relative suffering from the mental condition. Caregivers' experiences encompass distress, stigma, worry, shame, and guilt, but with positive aspects such as caregiver reward³. The substantial and growing public health burden arising from mental disorders (MDs) across the world has been well documented. The burden of MDs is estimated as 14% globally, with the highest burden in developing countries leading to continued economic burden and sub-optimal productivity at the individual and national levels. The interplay of care-giving consequences: poverty, discrimination and stigma, lack of support from others, diminished social relationships; depression, emotional trauma, and poor or interrupted sleep are associated with caregiver burden [4,5]. The substantial and growing public health burden arising from mental disorders (MDs) across the world has been well documented. Carer burden is exacerbated by issues of poverty and illiteracy. Such burden manifests in reduced caregiver well-being, which admittedly depends in part on caregiver factors such as care-giving style [6]. Another one of the problems that makes the care-giving experience exhausting is tending to the activities of daily living, as schizophrenia results in impaired cognition and social behaviour. Dangdomyouth et al

(2008) [7], Seloilwe (2006) [8], Shibre et al (2003) [9] described that the persons with serious mental health problems sometimes experience difficulties in performing the activities of daily living and depend largely on family members for assistance with simple tasks ranging from dressing and personal hygiene to more complex responsibilities, such as managing psychiatric symptoms, medication administration, and social relationships. It was also noted that the caregivers' lack of knowledge, support, and guidance from mental health services to manage ill relatives at home results in them being unable to provide the required care. The experience of caring for relatives or friends with mental health problems affects the physical, psychological, and socioeconomic well-being of the caregiver, as well as their capacity to cope with and adjust to those circumstances, often compromising their own health and well-being [10].

This study was also undertaken due to the reason that there is a need to understand representation of caregiver burden from caregivers themselves. Although previous research has highlighted the impact of caring for a person with schizophrenia on all aspects of a caregiver's life, no studies have thus far developed a conceptual model, which defines the concepts of interest, outlining the subjective experiences of caring for a person with schizophrenia. In recent years, studies about the burdens faced by family caregivers have become the focus due to the rising number of family caregivers of the mentally ill. This kind of study may enhance understanding of the families' lived experiences and the obstacles that those families deal with and the challenges they face on account of their relatives suffering from schizophrenia on a daily basis.

Methodology

The research approach was qualitative and the study employed the use of phenomenological research design as phenomenological studies examine human experiences through the descriptions provided by the people involved. The sample included the six parents of the patients with schizophrenia who were undergoing treatment in a selected hospital in New Delhi. The patients had been diagnosed as a case of schizophrenia according to ICD-10 criteria, for at least two to five years; married; in the age range of 18-45 years. Unmarried patients were not included in the study as the problems and challenges of caring for a married mentally-ill family member may be different from an unmarried mentally-ill family member. The sample size was considered to be six based on the

availability of the care-givers of patients who met the criteria, in the selected hospital.

Based on the purpose of this study, which was to understand in-depth, lived experiences of caregivers of patients with schizophrenia and the problems faced by them as well, in-depth interviews were employed in the study for data collection. Prior to data collection ethical permission and clearance was obtained and formal administrative permission for conducting the research was taken from the selected hospital.

The six broad research questions were: What are the experiences of family caregivers living with a family member who has the diagnosis of schizophrenia, through different stages of the mental illness, that is, before the onset of symptoms, during the onset of symptoms, after diagnosis and during the treatment process? What are the problems faced by the care-givers in caring for the family member? How has life been for care-givers, while living with, and caring for a family member with schizophrenia? How has the burden (physical and psychological) associated with caring for the family member with schizophrenia interfered with the care-givers' personal, social and occupational life? How has the care-giving affected the care-givers' financial aspects? What coping resources have the care-givers relied upon to cope with the problems and challenges associated with caring for mentally-ill family member?

A pilot study was done on two care-givers of patients with schizophrenia admitted and undergoing treatment at a selected hospital in New Delhi. In-depth individual interviews were done with each caregiver of patients with schizophrenia. An in-depth semi-structured interview schedule was prepared. The in-depth interview guide was developed under three sections: Subject data-sheet, in-depth interview guide and record of interviews. The in-depth interviews were also guided by trigger questions, conducted in Hindi, recorded using an audio-recorder and later translated into English and transcribed.

Semi-structured interview guide that was tentatively developed along with the trigger questions aided the researcher to maintain continuity in the conversation with the participants. Additional questions arising from the same were asked as well. Thereby, in-depth personal interview technique was considered and justified as the most appropriate method. Each interview was approximately of 30-45 minutes. The interviews were concluded with the question "Do you want to share anything else related to your experience?" The participants were allowed to withdraw their consent any time during the course

of the study, if any discomfort arose. The data was analyzed using thematic analysis.

Results

Out of the six care-givers interviewed, four were females and two were males with a mean age of 64.

Only 1 out of the six care-givers was a graduate. Four of them were home-makers and one was retired and remaining one was working. Out of the six care-givers one was diabetic, two were having hypertension, one had undergone a cardiac surgery and remaining two were health. Three of them belonged to lower socio-economic background and all of the six care-givers were having family members as their source of social support.

Table 1: Themes, sub-themes and categories

	Theme	Sub-theme	Category
1.	Varying perceptions and misconceptions Institution-alization: A new experience	Attribution to mythical ideations Scarcity of knowledge: a big concern	Unskilled and untrained for the trials
2.	Stigmatization of the mentally -ill Traumatic experiences of bizarre behavior Challenges of care-giving	Getting accustomed to discriminatory behaviors Behavioral challenges Challenges of therapy	Defying stereo-typing
3.	Apprehensions about marital relationships Abandonment by significant others Disrupted family functioning and family dynamics Failure to derive personal satisfaction	Non-responsiveness to call for help Pessimistic view of the future Care-giving: A responsibility and obligation	
4.	Disordered personal life Imbalanced social life Disrupted occupational life	Physical Exhaustion due to burden Detrimental effects on psychological health	
5.	Expensive treatment Consternation of future expenses	Compromised grand-children's education	
6.	Only God can help Reaffirming hope Meditation is the best coping resource	Social support is helpful	

The themes and subthemes identified are presented in Table 1.

Theme 1.1: Varyi NG perceptions of mental illness

Initial encounter with schizophrenia led to different perception of the mental illness that varied from one caregiver to another; for some it was a paranormal phenomenon, in which they thought that mental illness was a result of being possessed by evil spirits and as a result of someone's black magic, however others attributed the mental illness to myths such as curse of ancestors, karma of past life and still for others, the mental-illness was a result of exposure to bad air or some defect from birth. However, majority of the caregivers were under the impression that mental-illness had no cure.

Four out of the six agreed to have taken their family member to a faith healer to ward off the spirit-possession, in search of a cure and hospital was just the last resort.

Mental Illness: A Paranormal Phenomenon

Superstitions associated with mental-illness ruled most of the in-depth interviews with many believing that a mentally-ill person's state was due to possession by evil spirits and due to which they were taken to faith healers to ward it off.

I had heard about people being possessed by evil spirits, in my town and about how they used to behave and were uncontrollable. Once the spirits take control over your body it is very difficult to ward it off. But I seldom thought that something like this would happen to us. However, I also felt that someone had done black-magic on her. Because there was no way this would happen to her. (Code 4)

Difficulty in Finding Cure: First Resort is Faith Healers

The in-depth interviews revealed that many caregivers initially confided in faith healers to ward-off their beliefs of paranormal infestations. However, they could not find a cure. The parents also took their

family member to soothsayers to find out the faults with their stars, but could not find the reason for the occurrence here as well.

As I had witnessed my neighbour's daughter with the similar symptoms being treated by a 'baba', I too took her to a faith healer. But he could not do anything. We also took her to a local ayurvedic doctor but the medicines didn't work. (Code 4)

Hospital: the last resort

After many failed attempts to cure their schizophrenic family members, the care-givers considered taking them to hospital only as a last resort and anticipated stigma and embarrassment.

After no success with the faith healers, we were in a dilemma and that's when one of our relative who lives in Delhi gave us information about this hospital. (Code 1)

Theme 1.2: Institutionalization: A new experience

For many caregivers the very first time they had to stay at a hospital was a new and different experience altogether. Lack of adequate space, crowding of the unit, sharing space with other patients and caregivers, problems of getting access to food was some of the major concerns shared by most of the caregivers.

Scarcity of knowledge: a big concern

Four of the six caregivers of the in-depth interviews were home-makers. Being exposed to a new environment, blood tests and other tests being advised were not readily understood by them. Mental-illness in itself was something different to them and on top of that the scarcity of adequate knowledge added to their burden of care-giving.

Deficiency of knowledge related to the treatment is what sometimes perturbs me. However when the nurses are considerably free from their work, I try to update myself with the progress of my daughter.

As I am the one who is with her in the hospital, when my family members call up to enquire about her status, I have to be equipped so that I can provide them with the necessary details. (Code 1)

Unskilled and untrained for the trials

Many of the care-givers had a first-time exposure to mental illness. Due to inadequacy of knowledge related to the mental-illnesses and their treatment, many of the caregivers expressed being unskilled and untrained to face the challenges.

Although initially I felt that I was not equipped enough to take care of my daughter, but eventually I tried to gather all the information I could about the availability of the treatments. (Code 2)

Theme 2.1: Stigmatization of the mentally -ill

Having a family member at home with a mental-illness is a problematic event. Adjustments have to be made in several aspects of the lives of family members in order to provide care for the member with schizophrenia. It is never an easy task to handle the symptoms. And in top of that the stigma associated with mental-illness was also a major concern.

Getting accustomed to discriminatory behaviours

For the care-givers, experience of public exposure of the strange behaviours and symptoms associated with schizophrenia was unexpected. The caregivers verbalized that though initially they felt bad about these behaviours, gradually they became accustomed to it, as they had no choice.

Neighbours and our acquaintances gradually discontinued visiting our home, because they were scared of the violent behaviours of my son and also they didn't want to associate themselves with a family who had a mentally-ill family member. (Code 3)

Defying stereotyping

Mentally-ill persons are often subjected to stereotyping as being violent, abnormal, not having any emotions and not safe to be around. So it is evident that the caregivers of such persons get a portion of this stereotypical thinking in terms of not getting associated with them. However, certain caregivers have tried to break the stereotyping by explaining their family members' condition and being oblivious to the same while others were in the process of achieving it.

At first I was grieved by all the remarks I had to face on account of my daughter's behaviour. Some women in my neighbourhood used to say that it's some sort of curse and that her in-laws would never accept her back. Though it hurt me but I used to fight those remarks because I knew that if I joined in that conversation instead of my daughter getting better her condition would deteriorate. Moreover, I am her mother; I am responsible for her throughout my lifetime. (Code 1)

Theme 2.2: Traumatic experiences of bizarre behaviours

Some negative symptoms like apathy and anhedonia were of major concern. Middle-of-the night

delusional attacks were perceived as being scary, by one caregiver, while for other breaking of house-hold items were a concern as well as the violent streaks every now and then. While for some caregivers suspiciousness regarding preparation of meals and paranoia continue to be a traumatic experience as well.

Now also like before she has insomnia. She would say something or the other and would keep quiet. She disturbs the others also due to her this behaviour. Now it has decreased as they have prescribed some sleep-inducing medication for her. (Code 2).

Theme 2.3.: Challenges of care-giving

The parents reached a crisis point when the family member's personality, behaviour, and relationships with family and friends became so disruptive, bizarre, or dangerous that the changes could no longer be disregarded. Their family member became excessively angry, isolated, or preoccupied, and family relationships suffered.

Behavioural challenges

The biggest challenge with patients suffering from schizophrenia is the symptoms associated with it. The mentally ill family member behaved in ways that created challenges to the families.

Challenges of therapy

Getting the family member with schizophrenia to consume medications was one of the biggest challenges that the care-givers had to face.

The very first time, she had been prescribed medications; she was consuming it on a regular basis, though we had some difficulty making her do the same. She missed doses frequently and every time the symptoms resurfaced we had to make a visit to the hospital. (Code 1)

Theme 2.4: Apprehensions about marital relationships

The patients with schizophrenia whose care-givers were a part of the study expressed having apprehensions about the future of the relationship of their mentally-ill family members with their respective spouses.

Theme 3.1: Abandonment by significant others

In the light of a mentally-ill family member and the stigma associated with it, relatives of many caregivers

were non-supportive and did not extend any help. Though they were not judgemental about it, but were not willing to do anything about it as well.

Non-responsiveness to call for help

Many caregivers sought help from their relatives, while some were provided, others did not. Some caregivers expressed that their relatives were unresponsive to their plea.

Theme 3.2: Disrupted family functioning and family dynamics

Families living with a member with a chronic illness, such as severe mental illness, constantly adjust and adapt as the illness or the family situation changes. Adjustment and adaptation to a chronic illness may result in an increase in family emotional and physical well being.

I used to make food for my family, but being in the hospital now I cannot pack lunch and give to my husband or son. I do not have time to have a lengthy talk with my other children on phone, because her care-giving has taken most of my time. (Code 5)

Theme 3.3: Failure to derive personal satisfaction

Care-giving is a tedious work. Those involved in it feel as if they are trapped in the situation they are in, as they have to sacrifice their comfort to meet the demands of the person who requires their care.

Care-giving: A responsibility and obligation

With no assistance from their other relatives, the whole burden fell on the shoulders of the immediate family members. Some viewed care-giving as a responsibility where they were supposed to take care because in times of difficulty, it is the family who help each other out and others viewed it as an obligation, where they felt that 'if it is not me, then who else'.

Theme 4.1.: Disordered personal life

Constantly burdened with the tasks of either tending to the hygiene needs of the mentally-ill family member or collecting reports or taking the member for physical therapies or fetching medications as well as miscellaneous tasks drain the care-givers, in which their age serves as a catalyst. Many care-givers were patients of health adversities such as

hypertension, arthritis, diabetes-mellitus and even cardiac problems. In the light of non-availability of sustained assistance, they were compelled to consider their family-member's health as a priority over their own health.

Physical Exhaustion due to burden

Due to the ever-rising demands on the part of the mentally-ill family member, including repeated visits to the health professionals prior to admittance to hospitals; the care-givers have been forced to ignore their own health.

From past few days I am having severe headache. It is due to the noise and the chaos here. I try to take a nap or rest for a while but space is an issue and constantly some one or the other wakes you up. Her symptoms also are sometimes difficult to manage. (Code 6)

Detrimental effects on psychological health

As families have assumed the role of care-giver for members with severe mental illness, high levels of psychological distress among caregivers have been documented. The most common negative consequences were the primary caregiver's emotional problems, the disturbance in the caregiver's performance of work, and the disruption in the lives of other adults in the household.

Theme 4.2: Imbalanced social life

The in-depth interviews revealed that for the care-givers, life was just a normal routine prior to the occurrence of symptoms of schizophrenia in their family member. However once the symptoms started to appear, confusion started to set in and led to disruptions in all aspects of the life.

Theme 4.3: Disordered occupational life

Disruptions in the occupational life of the patients was there and the care-givers' as well. Four of the care-givers were home makers, out of whom three of the care-givers' husbands were retired and one's was still working, about to retire. Remaining two of the care-givers were males, out of whom one was retired. Overtiming was one aspect that they outlined as they had to meet the expenses of the ill family member. One caregiver had to take leave time and again to alternate care-giving with his wife for his son, however he also verbalized that his colleagues were understanding, which helped.

Theme 5.1: Expensive treatment

Many patients were admitted to the hospital more than two times and the expenses associated with it were hard to be met for three care-givers, who belonged to low socio-economic background, out of whom one had taken debt to pay for the expenses and others had to borrow money from relatives. One of the care-giver expressed that his pension was enough to meet the expenses, while other had apprehensions about meeting the same as his retirement was near.

Theme 5.2: Consternation of future expenses

Care-givers considered meeting the treatment expenses a challenge and were anxious awaiting future expenses. For many care-givers especially their grand-children's education were also compromised on account of the expenses.

Compromised grand-children's education

Since all the care-givers were grand-parents, their education was also a concern for them. Three of the care-givers were parents of male patients with schizophrenia. With their patient being unemployed and the family income being spent on the treatments, the education of the children was at stake and compromised.

Theme 6.1: Only God can help

By adopting problem-solving strategies and coping behaviours, the care-givers were able to function more effectively as a family unit. The most frequently used strategy by these families was seeking spiritual support. In times of trouble one turns to God and hope for the impending tribulations to get resolved and to be overcome.

Sometimes I get overburdened, with his repetitive hospitalizations, looking after him, the rest of the family, tending to all the requirements associated with care-giving etc. When I get overwhelmed I just pray to God and just wish all the problems would end. (Code 5)

Theme 6.2: Reaffirming hope

Providing care for a mentally-ill family member not only takes a toll on the physical health of the care-giver but on the psychological health as well. Pessimism, hopelessness, perceiving the future as bleak are some of the emotions that the care-givers go through. At such instances being hopeful is the only way one can overcome the burden to some extent.

Social support is helpful

Social support has been considered as a significant factor in buffering caregiver stress in severe mental illness and is a recognized and crucial need for caregivers of persons with a severe mental illness. Aspects of caregiver social support that were correlated with reduced re-hospitalization of family members with severe mental illness, were: a large number of the support network, a larger number of good advisers, and a smaller proportion of conflicted support.

Theme 6.3: Meditation is the best coping resource

After coming here I got acquainted with yoga and meditation. Along with her I go out in the morning for the same. I feel peaceful doing that and I found it helpful in easing out all the tensions. (Code 1)

Discussion

In the study it was established that the initial encounter with schizophrenia varied from one caregiver to another; for some it was a paranormal phenomenon as being possessed by evil spirits and as a result of someone's black magic, due to which they had to seek the help of faith-healers to ward off the paranormal infestation. They attributed the causes of mental-illness to past life's events that have been manifested in the present. This led them to consider faith healers and soothsayers as their first resort and hospital as only the last. It is consistent with studies by Singh et al (1992) [11] who reported stressful conditions as a cause for development of mental illness similar to the observations in the present study.

The results of the study also revealed that due to lack of adequate knowledge about the mental-illness, its progress and its treatment regimen, the care-givers expressed being not equipped with skills enough to take care of their family member with schizophrenia, being untrained for the same was of a much greater concern for them. Novel exposure to mental-illness and decreased popularity and visibility of mental health services contributed to their lack of awareness.

Care givers of patients with schizophrenia experience significant burden. This not only impacts their own health by causing anxiety and depression in them but also can indirectly lead to worsening of the patient's condition, as the role of the care-givers is crucial in the overall prognosis of such patients. Care-giver awareness and support must therefore also be given a priority in the management of patients with schizophrenia [13].

This supports the work of Rolland (1994) [13] in her work according to who, in a chronic disorder such as severe mental illness, there is an increasing strain on family caregivers as a result of exhaustion and the continual addition of new care-giving tasks over time. The family is always "on-call" to cope with the day-to-day crises of severe mental illness. The increased satisfaction with social support networks served to decrease subjective and objective burden.

Living with the mentally ill family member devastated family revenue. The family income, proceeds, earnings, and profits are used to pay for the expenses associated with caring for the mentally ill family member, which is in consistency with the findings of Leticia de Oliveria et al (2008) that mental illness imposed a large financial burden to the families with mentally ill patients.

Reaffirming hope was one of the adapting coping strategies used by the care-givers to ease the burden associated with care-giving process which is in consistency with the study by Bland and Darlingto (2002) [14], who conducted in-depth interviews with family members of persons with serious mental-illnesses in Australia to explore the meaning and importance of hope and found that hopefulness was an integral part of the coping process used by the family members.

Conclusion

Scarcity of knowledge is a big concern for the care-givers, which make them unskilled and untrained for the trials associated with the task of providing care for the family member with schizophrenia. One of the major problems faced by the care-givers are the stigmatization on account of mental-illness and the indifferent and discriminatory behaviours of the on-lookers, significant others and neighbours. New challenges come in the form of dealing with bizarre behaviours associated with schizophrenia, with suspicion leading to violence being one of the most traumatic experiences, leading to emotions of fear and anxiety and the challenges related to pharmacological and physical therapy.

Confronting the challenges led to better resilience among the care-givers leading to discovery of dormant strengths and anticipation of better days. There is a failure to derive personal satisfaction on account of care-giving and pessimistic view of the future is prominent and the same is considered an obligation to some and responsibility for others. Providing care evokes disorder in the personal life causing ignorance to self-health and physical exhaustion leading to burn-

out among the care-givers; detrimental effects on the psychological health with apprehensions about the possibility of recovery; imbalanced social life and disordered occupational life. Adaptive coping resources like seeking spiritual solace, getting access to social support, reaffirming hope and meditation is considered as key to prevent stress and cope with the many daily challenges and burden associated with schizophrenia.

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