Caregivers' Experiences of Aggressive Persons with Schizophrenia

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ABSTRACT

Background: Understanding the caregivers' experiences of aggressive persons with mental disorders is very important from the public health point of view. Only a few Indian studies have focused on this. No Indian studies could be found that explored the caregivers' experiences of aggressive persons with schizophrenia. This study was conducted to explore the same.

Methods: A qualitative phenomenological study was conducted in the outpatient and inpatient settings at a tertiary care mental health institute at Bengaluru, Karnataka. Ten participants meeting the eligibility criteria were selected using purposive sampling. Data collection was done by individual, in-depth, face-to-face, semi-structured interviews using topic guide along with subjective observation and field notes. Each interview was audio-recorded, transcribed, translated, and coded. A total of five master themes and 22 subthemes were derived from the codes by using the qualitative research software ATLAS-Ti.

Results: The themes derived based on the experiences of caregivers living with their aggressive persons with schizophrenia were the aggressive behaviors of the patients, reasons for the aggression of the patients, dealing with the aggression of the patients, the impact of aggression on the caregivers, and the coping methods of the caregivers.

Conclusion: This study explored the experiences of the caregivers living with the aggressive patients. The results show the need for care and support to the caregivers. The themes can guide mental health professionals while developing culture-specific tools and interventions for future research as well as suggest them standard operating procedures for prevention and management of aggressive patients in the psychiatric hospitals.

Keywords: experiences, caregiver, schizophrenia, aggression, violence

Key Messages: Caregivers of aggressive persons with schizophrenia experience negative impact because of the different types of aggression from the patients. The reasons for the aggression vary from patient to patient. The caregivers adopted different coping strategies to deal with their patients' aggression.

Schizophrenia is a mental disorder that affects millions around the world, both males and females.[1] It has a global prevalence of 0.3%–0.7%, with three million Indians suffering from it.[2] National Mental Health Survey of India (2015–2016) recorded the prevalence of schizophrenia and other psychoses as 0.64% and that it was 2–3 times more common in urban than rural areas.[3]

The World Health Organization estimates that 40%–90% of persons with schizophrenia live with their relatives.[2] Even though caring for a person with schizophrenia may be a positive experience for some, it is also frequently associated with a negative impact on the caregivers' life.[4]

In addition to the positive symptoms associated with schizophrenia, patients also present with other associated symptoms such as aggression, agitation, and anxiety.[5] According to a study, verbal aggression and violence were the behaviors that caused most difficulty to the caregivers.[6] Even though aggression among persons with schizophrenia is a major problem faced by the caregivers, limited qualitative studies have been done to explore the experiences of caregivers of aggressive patients with schizophrenia. A large majority of these studies were conducted in Western countries.[6–17] It is difficult to generalize the results to caregivers in India because of cultural differences. Therefore, this study was undertaken to describe the caregivers' experiences of aggression by their family member with

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HOW TO CITE THIS ARTICLE: Neha A, Gandhi S, Manjula M, Padmavathi N. Caregiver's experiences of aggressive persons with schizophrenia. *Indian J Psychol Med.* 2021;43(1):10–15.

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Submitted: 11 Feb. 2020
Accepted: 4 Jun. 2020
Published Online: 4 Aug. 2020

ACCESS THIS ARTICLE ONLINE
Website: journals.sagepub.com/home/szj
DOI: 10.1177/0253717620928728

schizophrenia. This study would provide a more holistic and rich description of the phenomenon of caring for the aggressive persons with schizophrenia. The results could provide insights to mental health professionals while developing need-based interventions to empower family caregivers in handling aggression in persons with mental illness.

Materials and Methods

This phenomenological study was conducted at a tertiary care mental health institute at Bengaluru from April 2017 to April 2018. The study was approved by the ethics committee of the institution.

Ten participants were selected from psychiatric wards (n = 5) and the outpatient department (n = 5) using purposive sampling technique. Primary caregivers, both male and female above 18 years of age, living with the patients with schizophrenia for the past six months, who had experienced aggressive behavior during the last one year were selected. Caregivers other than family members of persons with schizophrenia and caregivers suffering from any kind of sensory deficits or mental illness were excluded. The adequacy of the sample size was evaluated by the quality and completeness of information provided by the participants. Data collection continued till saturation occurred.

The caregivers who signed the informed consent were enrolled and then sociodemographic information was collected using a brief participant profile prepared by the researcher. A semi-structured interview using a topic guide, which was prepared by the researcher and validated by five experts, was done with each individual. The topic guide included the following questions:

1. What could be the reasons for the aggressive behavior of your patient?
2. How do you feel when your patient becomes aggressive?
3. How did you react when your patient became aggressive?
4. What do you do to reduce the aggressive behavior of your patient?
5. How do you manage the feelings evoked by the aggressive behavior of your patient?
6. What are the changes you experienced in your life due to the aggressive behavior of your patient?

Each participant was interviewed for approximately 30–45 minutes in one session. Interviews were audiotaped and field notes were written by the researcher to complement the audiotaped interviews. After clarification of the themes, the researcher (NA) gave psycho-education on homecare management that can be applied when the patient becomes aggressive.

Results

The sociodemographic details of the participants and the clinical details of the patients are given in **Table 1**.

One of the researchers (NA) interpreted the data initially by making filters about own concepts or ideas regarding the data without diminishing the quality or significance of the analysis.

Individual Case Analysis

Each interview was individually analyzed in depth. All audio recordings were translated from the languages Malayalam, Tamil, and Hindi to English and transcribed verbatim. The two researchers (NA, PN) read the lines of text by listening to the recording several times and corrected the text for any errors. After this, coding was done to identify topics, issues, similarities, and differences revealed through the participants' narratives and they were interpreted by the researchers with a hard copy of the transcript. The qualitative data management software, ATLAS-Ti was used to analyze the transcriptions and code the data. The credibility of the coding was maintained by involving three naive coders. It was also supervised by two research experts (**SG, MM). This helped in the revision of the codes and to clarify the results.[18]

Emergent Themes

Each code and transcript were thoroughly examined and brought together as the patterns emerged. These emerging patterns were stated as themes. Some of the themes clustered together and some emerged as master themes.

TABLE 1.

Sociodemographic Profile of Participants

Proxy name	Age	Gender	Marital status	Education	Occupation	Place	Family type	Religion	ES	Relationship with patient	Duration of care taking	Diagnosis of Patient on ICD 10	DOI/NAE
Ayna	38	Female	Married	Higher secondary	Home maker	Rural	Nuclear	Muslim	APL	Mother	7 years	F 20.0	7 years/7
Amala	51	Female	Married	Graduation	Home maker	Urban	Nuclear	Hindu	APL	Mother	8 years	F 20.0	8 years/30
Monika	52	Female	Married	Primary	Home maker	Urban	Nuclear	Christian	APL	Wife	30 years	F 20.3	30 years/60
Padma	55	Female	Married	Illiterate	Home maker	Rural	Nuclear	Hindu	APL	Mother	9 years	F 20.0	9 years/20
Mari	70	Male	Married	Illiterate	Agriculture	Rural	Nuclear	Hindu	BPL	Father	10 years	F 20.3	10 years/25
Sumi	42	Female	Married	Primary	Home maker	Urban	Nuclear	Muslim	APL	Mother	5 years	F 20.0	5 year/20
Sandhya	30	Female	Widow	Primary	Home maker	Rural	Joint	Christian	APL	Sister	1 year	F 20.0	1 year/6
Nadhu	56	Male	Married	Graduation	Pharmacist	Urban	Nuclear	Hindu	APL	Father	7 years	F 20.0	7 years/10
Kala	54	Female	Married	Graduation	Home maker	Urban	Nuclear	Hindu	APL	Mother	7 years	F 20.0	7 years/40
Selvan	66	Male	Married	Graduation	Doctor	Urban	Nuclear	Christian	APL	Father	18 years	F 20.0	18 years/30

ES: economic status, DOI: duration of illness of patient, NAE: number of aggressive episodes of patient, APL: Above Poverty Line, BPL: Below Poverty Line.

Cross Case Analysis

A list of the themes for all the ten interviews was drawn up and patterns were identified across the themes. These were then clustered into master themes and subthemes (**Table 2**).

Discussion

This qualitative study explored the lived-in experiences of caregivers of aggressive patients with schizophrenia. The caregivers reported one or the other kind of aggressive behavior from their patients. Most of them experienced multiple types of aggression (verbal aggression, physical aggression, and damage to property). Similar findings were shown by some studies which revealed that aggression could take the form of verbal threats, threats with knives, punches, wrestling, and damage to property.[6–8]

The reasons for aggression vary from patient to patient. Caregivers reported that their patient's aggression was mainly because of them denying the patient, their likes, saying no to their demands of wanting to do certain activities, and challenging their own way of thinking and perception. In other studies, the caregivers believed that the patients' delusions and hallucinations, along with their wish to fulfil their desires and needs, were leading to the patients' aggressive behavior.[6,7,9]

Dealing with the aggressive behavior of patients with schizophrenia was a difficult situation for the caregivers. They were confused about what to do when their patients with schizophrenia became aggressive. They were not aware whether what they did to their patients was right or wrong. Some showed a reaction similar to what the patient expressed to them, while the others became silent, moved

TABLE 2.
Themes Derived

Master theme	Subtheme	Verbatim (proxy names are used to narrate the verbatim)
The aggressive behaviors by the patients	Verbal aggression	"He (patient) likes to sit in his room 24 hours a day engaged in watching programs on TV or mobile phone. If my husband or I go inside his room for cleaning or to call him to have food, he gets angry and shouts at us and sometimes he uses abusive words. He also says he will harm us for entering his room without his permission." (Kala) "If I won't agree for unnecessary demands of my daughter (patient) such as going out and buying a costly dress, she gets angry and scolds my husband and me very badly." (Padma)
	Physical aggression	"Whenever she (patient) sees a boy with me, whom others or I can't see, she shouts and beats me hardly. There are redness and markings all over my body because of getting frequent beatings from my daughter." (Ayna) "My husband (patient) gets attracted to ladies easily. He gives money to widows as gifts, which we don't even know, and after some time when he needs money, he goes to their houses to get the money back. If I ask him why he gave them the money in the first place, he gets angry, locks me up in a room, asks me to kneel down with hands up, and beats on my face for questioning him." (Monika)
	Damage to properties	"He likes to have food from hotels every day. For this, money is needed. If his papa doesn't give him money, he breaks things in his room, including the TV, by throwing them to the floor." (Amala) "She (patient) shouts and throws things such as flower vases towards images that only she can see, to get away from them." (Sumi)
Reasons for the aggression by the patients	Hearing a "no" from the caregiver	"She (patient) gets angry and quarrels with me when I disagree with her or say no when she asks me to go out and buy costly dress and ornaments." (Padma) "He (patient) gets angry easily when we say no to any of his wishes." (Amala)
	Desire for patient's likes	"He (patient) demands money from me for buying cigarettes and visiting prostitutes. If I don't obey, he starts to beat me up till I give money." (Selvan) "He (patient) loves non-vegetarian food, especially chicken. He demands chicken curry for food every day. I do not have money to buy chicken daily. Even if I try to make him understand it, he won't listen. He will continuously ask for chicken until he gets it. Otherwise, he gets angry and beats me." (Mari)
	Being compelled to do activities of daily living	"He (patient) gets angry when we tell him to take bath in time or have food in time." (Kala) "He (patient) sleeps till 12 pm every day. After waking up, he will eat nicely and spend time with mobile phone and TV. If I ask him to wake up in the morning, brush, and take bath, he gets angry and shouts at me." (Nandhu)
	Odd way of thinking and perception	"He (patient) scolds and threatens whoever comes to our house because he thinks that they are coming to our house and speaking with us to make a plan to kill him. I don't know how to control his aggressive behavior towards others." (Nandhu) "My sister (patient) used to tell me that others are listening to whatever we speak with each other. Hence, she approaches those seen near our house, quarrels with them, and uses abusive words for hearing what we had spoken." (Sandhya)
Dealing with the aggression by the patients	Equal and opposite reaction towards patient	"I feel angry towards my daughter (patient) whenever she gets angry and beats me. I beat her back to generate fear in her so that she won't beat or hit me again. Then I lock her inside her room." (Ayna)

Master theme	Subtheme	Verbatim (proxy names are used to narrate the verbatim)
	Remaining away from the patient	"When he (patient) is angry and beats me hard, I used to run away from our house and hide somewhere away." (Mari)
	Keeping silent	"Whatever he (patient) does to me when he is angry, I should tolerate it and remain silent." (Monika)
	Accepting the patient's demands	"If we allow him (patient) to go out and have food from the hotel, he won't show his anger towards us and he won't break things in our home." (Amala)
	Providing medications	"I used to give medications to (patient's name) when she is angry by mixing it with milk or juice, which will help her to get out of her anger and behave normally." (Sandhya)
The impact of aggression on the caregivers	Emotional disturbances	"I feel angry towards my daughter (patient) when she gets angry and beats me. I have beaten her and locked her in a room to be safe from her aggressive behavior. But after that I feel really guilty for what I did. I know she is not getting angry intentionally and that it's because of her illness." (Ayna) "I am much disturbed by thinking about his (patient) condition. Even when I go to work, I always worry about my son as he may make problems with the villagers. When I see him after my return, then only my mind gets relaxed." (Mari) "By thinking about him (patient), I get tensed. I want him to lead a normal life with normal behavior. Till that, my mind will be in distress. I used to feel bad about our life as my son always shows anger." (Nandhu) "I can't predict what all he (patient) will do when he is angry. I am really afraid even to speak to him after an episode of his aggression." (Amala) "I felt really bad for my daughter (patient). I used to cry a lot by thinking about my daughter's illness and aggressive behavior. I used to think why it happens only to my daughter and our family. We didn't do anything bad to others, and we didn't hurt anyone. Then why we are suffering because of my daughter's aggressive behavior." (she started crying) (Sumi)
	Health issues	"Every time he (patient) gets angry, he will beat me hardly after locking me in a room. I lost my health. I am weak." (Monika) "Because of my daughter's (patient) anger, me and my husband's health got declined. We got admitted in a hospital for treatment of elevated blood pressure after worrying a lot about her. We always think about her fluctuating behavior and get tensed." (Padma)
	Financial burden	"I am spending a huge portion of my pension for fulfilling the demands of my son (patient) and to escape from his aggression." (Selvan) "She (patient) is the only regular employee from our family. If she does not come out of her illness and anger, she can't go back to the job. Now our family is suffering because of some financial issues due to her hospitalization and treatment. If this situation continues, we can't even get her a proper treatment." (Sandhya)
	Non-acceptance by society	"Relatives and neighbors don't understand our situation. They isolated us because of my daughter's (patient's) aggressive behavior. No one is there to support us." (Padma) "Everyone avoids my daughter (patient) and our family because of her aggressive behavior. We are alone now. Our relatives and neighbors say that some spirit is there inside my daughter's body; that's why she becomes aggressive frequently. They are there to blame us, not help us." (Sumi)
	Perceived stigma	"I don't want others to know about our son's (patient) illness and anger outbursts. I am afraid that they may think bad about my family, and my son won't be able to get married in the future. So, I won't share anything about my son to my relatives or neighbors." (Kala) "We can't take him (patient) to public places or any functions, because we don't know when he will get angry and make some problems. It will be really embarrassing for us." (Selvan)
	Disgraced because of patient's aggression	"Every time, we have to explain to others about his illness and aggressive behavior, to get out of situations created by him (patient). Because of him, our family's name is getting spoiled in the society." (Nandhu) "When he (patient) is angry, he will scold whoever comes in front of him. He doesn't even think about his parents when he makes problems with others. My husband and I need to go after each person to solve the problems that he makes with them, by telling them sorry. It is really a shameful situation for me and my husband who are living in the society with a good name." (Kala)
The coping methods of the caregivers	Pray to God	"I used to go to every temple and pray to God to make him (patient) good and get out of his illness and aggressive behavior." (Amala) "I used to ask God why only my daughter (patient) is always suffering from excessive anger. I pray together anger removed so that she can lead a normal life." (Padma)
	Support from others	"I share my feelings with my family members. They all know about my husband's (patient) illness and his aggressive behavior. So, they support me mentally and financially." (Monika) "My brothers support me and our sister (patient). Because of their mental support only I am standing here for my sister's treatment. We all want our sister back without any illness and anger." (Sandhya)

Master theme	Subtheme	Verbatim (proxy names are used to narrate the verbatim)
	Accepting the patient's aggression	"I know he (patient) is getting angry because of his illness. Whatever he does to me in anger is not really him; it is the illness within him. Now I accept the way he is, and I learned to tolerate his anger." (Monika) "Whenever he (patient) gets angry, not only my wife and I, even my brothers and the members of their families go to own rooms to escape his scolding. We all understand his illness, live according to his mood, and accept his aggressive behavior." (Nandhu)
	Engaging in own work	"To get relief from my feelings, I used to engage in my household work." (Ayna) "When I feel so sad after fighting with my daughter, I feel heaviness in my heart. To release that heaviness, I engage in household work such as cooking, washing, cleaning, etc. After that, I feel a relief from the heaviness in my heart." (Sumi)

away, or accepted the patient's demands. Others gave medications. Some previous studies too had revealed the practices caregivers adopt to deal with or prevent the aggressive behaviors of their patients, such as close observation, giving advice and reasoning, communication tactics, and taking help from others.[9–11]

The caregivers experienced emotional disturbances, health issues, financial burden, non-acceptance from society, perceived stigma, and disgrace because of their patient's aggression. Different studies had revealed similar findings—that the aggression had impact on the caregiver's emotional, financial, social, and family functioning, including having to manage disruptions by the patient during family gatherings, stress over decisions to commit the patient to hospitalization, non-acceptance by the society, prejudice, and stigma.[7, 12–14] Jose reported that the caregivers expressed off-putting personality elements like asociality or introversion, passive attitude, low frustration tolerance, and low self-esteem and also presented with troubling stressors like comorbidities and familial, financial, and legal issues due to their patient's aggression.[15]

To cope with the aggressive behavior of their patients, they were praying to God, accepting support from others, accepting patient's aggression, and engaging in their own work. Likewise, other studies had revealed that contacting family, friends, psychiatrists, and neighbors; compassionate feelings; faith in God; self-help approach; acceptance and finding a solution; supportive handling; hopefulness; and religious participation were helpful in coping with the aggression of the patients.[12, 16, 17]

This was a qualitative research study that resulted in rich data; however, perhaps, a greater depth would have been obtained by adding more exploratory questions. The study cannot claim to represent the full picture of the experiences of caregivers of aggressive patients with schizophrenia.

The study needs to be replicated using a mixed methodology and a bigger sample size, adding the perceptions of professionals, patients, and caregivers of patients with other mental illnesses, and taking into account the patient's duration of illness and number of episodes of aggression. There is also a scope for further studies with a focus on socioeconomic, demographic, and cultural variations; the difference in perceptions based on the caregivers' living arrangements; and planning and evaluating interventions to manage the aggressive behavior of patients with schizophrenia.

This study explored the experiences of the caregivers living with their aggressive patients. The results show the need for care and support to the caregivers.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

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