Primary caregiver’s experiences in caring paranoid schizophrenia patients: A qualitative study

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\textbf{ABSTRACT}

\textbf{Background:} Mental disorders are accompanied by tremendous suffering for the patient and caregiver and can bring forth significant disability. A descriptive phenomenological study was conducted to explore primary caregiver’s experiences of caring for patients diagnosed with paranoid schizophrenia.

\textbf{Methods:} Caregivers were selected as study participants if they were the patient’s family members and the primary caregiver for the patient for the past six months. The participants were recruited through maximum variation sampling, and the researcher used a semi-structured interview guide to collect the data from the participants. Codes were identified, patterns analyzed, and themes were recorded using Braun and Clarke’s six phases of thematic analysis.

\textbf{Results:} The study found that the mean age of the participants was 47 years, and the duration of caregiving ranged from one to three years. Major themes identified from the study were: encountering gloom, challenges in caregiving, expectations, and coping strategies.

\textbf{Conclusion:} Caregivers of paranoid schizophrenic patients have significant challenges during their everyday lives. Whereas caregivers who receive adequate support from their family members and community better cope with their daily challenges.

1. Introduction

With increasing deinstitutionalization, most mentally ill patients reside with their family in the community rather than in mental health centres, causes an increase in the caregivers’ role.\textsuperscript{1} In Asia-Pacific countries, owing to close bonding among family members and scarcity of rehabilitation professionals, caregivers play a crucial role in the re-socialization, occupational and social skills grooming, well-being, functional independence, and quality-of-life (QOL) of a patient diagnosed with paranoid schizophrenia.\textsuperscript{2}

Debilitating symptoms (delusion and hallucination) blur the line between what is real and what isn’t, making it difficult for the patient to lead a typical life, which deteriorates the QOL of their caregivers. Caregivers spend hours caring for the patient and often suffer and end up with severe stress, making it difficult to cope with life situations.\textsuperscript{3} Understanding caregivers’ experiences would help the health-service providers to determine caregiver needs, plan effective interventions, reduce the burden of care, and enhance their well-being.

To this date, minimal studies have reported the in-depth experience of caring for a patient diagnosed with paranoid schizophrenia in India.\textsuperscript{5,6} Hence, the authors intended to explore the lived experiences among primary caregivers of patients diagnosed with paranoid schizophrenia using a descriptive phenomenological approach.

2. Material and methods

2.1. Sample

Primary caregivers of paranoid schizophrenic patients aged 18 years and above who speak Odia, the official language of Odisha, India, and giving care for the past six months in the in-patient psychiatric department of a tertiary hospital in Bhubaneswar, India, were recruited for the study. Non-family members, part-time, and institutional caregivers were excluded. Maximum variation sampling was adopted to ensure the richness of the data. Participants with the broadest range of perspectives, such as relationship to the patient, education qualification, and

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2.2. Methodology

A descriptive phenomenological approach was adopted for the study. The date and time for the interview were fixed with the participants at their convenience. The researchers conducted in-depth, face-to-face interviews from July 2020 to October 2020 in a room adjacent to the psychiatry ward using a semi-structured interview guide on the pre-decided date and time, with each interview lasting 75–90 min.

Participants were asked to describe their experiences of caring for the patients with a lead question, ‘Elaborate your experiences in caring for your family member diagnosed with paranoid schizophrenia?’. The interview guide also comprises supplementary questions on demographic information, personal life, caregiving challenges, expectations from others, managing treatment expenses, and coping strategies. After each interview, the authors listened to the participant’s verbal description, which was recorded using an encrypted audio recorder. Data collection continued until the data got saturated at the 20th interview with the emergence of all the themes. Anonymity was maintained throughout the study by sequentially assigning an alphabet to every participant. Participants were debriefed after the interview, and the concerns raised were later fed back to the clinical team. Audio recordings were transcribed and translated into English and then translated back to Odia to ensure the rigour and validity of translation within 48 h by language experts. The translated verbatim was given to two other language experts in Odia and English to ensure the translated data’s accuracy.

The study adopted Braun and Clarke’s six phases (familiarizing with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report) of thematic analysis.7 The translated data were simultaneously analyzed through inductive content analysis. After getting familiarized with the data (reading the data several times), initial codes were extracted relevant to answering the research question. Codes that were similar and dissimilar were categorized accordingly. Differences in the coding were discussed with the other authors and resolved. Finally, based on the objective of the interview, initial themes were generated, and themes were reviewed before defining and naming them. Narrative and data extracts were weaved and written. Lincoln and Guba’s five criteria were adopted to ensure rigour in the study.8

3. Results

3.1. Participant characteristics

Participants’ age ranged from 23 to 64 years (47.10 ± 12.30). The demographic characteristics of participants are depicted in Table 1.

3.2. Themes & subthemes

Primary caregivers reported their experiences with caring for a patient with PS, and these accounts constituted the primary data. Six themes emerged from the data. Themes and subthemes derived from the data are detailed below, and statements of the participants under each theme and subtheme are stated in Table 2.

3.3. Encountering gloom

Primary caregivers were stressed during their initial days of caring due to their lack of knowledge in caregiving and reluctance to accept the caregiver role. Over time, primary caregivers adjusted to the mentally ill’s behaviour, and the intensity of emotional pain that primary caregivers sustain from day-to-day events reduced. However, gloominess prevails in their everyday life.

3.3.1. Anguish

Primary caregivers reported that there isn’t anything more painful than seeing their patients suffer. Parents blamed themselves for their child’s suffering or bargained with God for their child’s healing.

3.3.2. Apprehension

This sub-theme describes the primary caregiver’s wariness about their mentally ill’s future. Most of the primary caregivers were parents to the patient and believed that no one else could look after their child as they did.

3.3.3. Stigma

Primary caregivers and the family feared that the whole family would be condemned if the diagnosis of their mentally ill family member was revealed, so they often chose to conceal the diagnosis.

3.3.4. Criticism

Primary caregivers were blamed and criticized for mental illness in the family or suffering. Criticizing was more evident among wives who were primary caregivers to their mentally ill husbands.

3.3.5. Taunt

People in society make fun of the mentally ill’s behaviour. There had been verbal spats and quarrels between the primary caregivers and community members regarding society’s inhumane behaviour.

3.4. Challenges

The primary caregivers encountered difficulties during caregiving. Episodes of aggressive behaviour exhibited by the mentally ill were common in most houses. Most primary caregivers perceived that most of these difficulties could be curtailed with adequate support from family members.

3.4.1. Hypervigilance

Most of the primary caregivers (12 out of 20) were worried about the
<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
<th>Participant Statements</th>
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<tr>
<td><strong>Themes, subtheme and Participant statements.</strong></td>
<td></td>
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<tr>
<td><strong>Encountering gloom</strong></td>
<td>Anguish</td>
<td>The only thing I wish is that no mother should have a child with mental illness ... It is not easy to see your child suffering, and you cannot do anything ...” (Pc, Husband)</td>
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<td></td>
<td>Apprehension</td>
<td>I am worried for his future ... Once I pass away, who would care for him as I do ...” (Pe, Mother)</td>
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<td></td>
<td>Stigma</td>
<td>“We don’t want anyone to know about her illness ... Her younger brother is unmarried ... Who would marry him if someone came to know about his sister’s mental illness ...”. (Pm, Mother)</td>
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<td></td>
<td>Criticism</td>
<td>“Some say that it’s my fault that my husband is mentally ill ... I didn’t give him proper care, because of which he has fallen ill ... After I do whatever is possible, people still blame me for all the misfortune is heartbreaking ...” (Pf, Wife)</td>
</tr>
<tr>
<td><strong>Challenges</strong></td>
<td>Hypervigilance</td>
<td>“I am very cautious with his behaviour so that he doesn’t harm himself or others ...”. (Pj, Wife)</td>
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<tr>
<td></td>
<td>Medicine and Food administration</td>
<td>“She refuses to take medicine and food ... She always screams that we are trying to kill her ...”. (Pg, Daughter)</td>
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<td></td>
<td>Physical and verbal abuse</td>
<td>“He becomes abusive and shouts at everyone if he is denied smoking and drinking alcohol!”. (Ph, Wife)</td>
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<td></td>
<td>Treatment expenditure</td>
<td>“We have spent a large amount of money on her treatment ... Still, she is not completely cured ...”. (Pj, Mother)</td>
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<tr>
<td><strong>Impacts</strong></td>
<td>Self-confidence</td>
<td>“It wasn’t easy in the beginning ... As years passed, I became confident and learned a lot in caring for my mother ...”. (Pd, Daughter)</td>
</tr>
<tr>
<td></td>
<td>Happiness</td>
<td>“I have been looking after my husband and daughters from the beginning ... Even now, it is continued ... I am happy that I can take care of them ...”. (Ps, Mother)</td>
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<tr>
<td></td>
<td>Resigned job</td>
<td>“I was working in a tailor shop before my mother got ill, and I stopped working after she was diagnosed with illness ...”. (Pd, Daughter)</td>
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<td></td>
<td>Discontinued education</td>
<td>“I couldn’t go to college after my mother fell ill ... I was responsible for taking care of her as my other family members are working and money is needed for her treatment expenses ...”. (Pg, Daughter)</td>
</tr>
<tr>
<td></td>
<td>Lack of time for children</td>
<td>“My elder daughter is staying with my sister and doing her schooling from there ... They are looking after her ...”. (Pj, Wife)</td>
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<td></td>
<td>Disrupted family relations</td>
<td>“Earlier, we all used to have some family time ... But after my mother fell ill, We hardly share good times ... Family interactions have reduced ...”. (Pg, Daughter)</td>
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<td></td>
<td>Desocialization</td>
<td>“I don’t get to spend time with friends, as I used to spend earlier ...”. (Pc, Husband)</td>
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<tr>
<td><strong>Managing treatment expenses</strong></td>
<td>Relative support</td>
<td>“My relatives provide financial support or sometimes bring necessary household items ...”. (Pe, Mother)</td>
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<td></td>
<td>Expectations</td>
<td>A portion of our land was sold out to meet the treatment expenses ... Though my husband’s brothers are giving us financial support, we ought to pay them back ...”. (Pf, Wife)</td>
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<td>Expectations from family members</td>
<td>“Though I expect many things, I haven’t received any. If they had helped, I would have found it easy to adjust ...”. (Pq, Wife)</td>
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<td>Expectations from society</td>
<td>“If they had looked after children, I wouldn’t have had to send them to my parent’s house ...”. (Pq, Wife)</td>
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<td>Expectations from health professionals</td>
<td>“Some of my family members come to our house to enjoy seeing my mother’s behaviour ... If I call them for help, they wouldn’t be there ... I wish their attitudes change ...”. (Pg, Daughter)</td>
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<td>“Since my son was diagnosed with the illness, society stopped talking with us ... His friends also rarely come to visit him ...”. (Pm, Mother)</td>
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<td>“While I go out with my husband, they laugh at my husband’s behaviour and make fun of him ... They tease my kids about their father’s behaviour ... Even if the society doesn’t offer any support is fine, but they shouldn’t make fun of others’ illness ...”. (Pj, Wife)</td>
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<td>Expectations from homemaker</td>
<td>“She is always refusing to take medicines ... If the nurses over here helped make her swallow the medicine, it would be highly helpful ...”. (Pg, Mother)</td>
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<td>Expectations from homemaker</td>
<td>“During initial hospitalization, they have taught us everything about my wife’s disease and how to care for her ... It has helped us a lot in caring for her”. (Pc, Husband)</td>
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Table 2 (continued)

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<td>Discernment</td>
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<td>Assistance</td>
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<td>Expectations from homemaker</td>
<td>Remedy</td>
<td>“You people are educated and know everything about mental illness ... I wish that you find out her problem ... I want her to be completely cured ...”. (Pj, Mother)</td>
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<tr>
<td>Expectations from homemaker</td>
<td>Coping strategies</td>
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<td>Mindfulness and self-adjustment</td>
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safety of the patients, themselves, and other family members. This wariness was attributed to the self-harm or other directed harm behaviour exhibited by the mentally ill.

3.4.2. Medicine and food administration
Primary caregivers perceived medicine and food administration as the most challenging tasks they encounter in their day-to-day lives. Owing to the suspicious nature of the mentally-ill about their family members, spitting the medicine given was an everyday occurrence.

3.4.3. Physical and verbal abuse
Verbal and physical abuse occur in conjunction. Primary caregivers perceived that the mentally ill became abusive when restricted from acting per their wishes. From their caregiving experience, participants believed abusive behaviour could be curtailed by permitting the patient to act per their wishes if the act doesn’t contradict the safety of the mentally ill or the other people around.

3.4.4. Treatment expenditure
Owing to the recurrent re-admission in the hospital and the numerous amounts of medicines the mentally ill consume, managing the treatment expenses was one of the complex tasks for the caregivers.

3.5. Impacts
This theme describes the consequences that have been felt by the primary caregiver in their day-to-day life, which resulted from caregiving for the mentally ill. The central theme is divided into two main sub-themes: positive and negative impacts.

3.5.1. Positive impacts
In India, there is a strong emotional attachment among the family members, and the family’s role in recovering the mentally ill is immense. As days pass with caregiving, caregivers tend to experience favourable changes.

3.5.1.1. Self-confidence. This sub-theme describes the confidence that the primary caregiver experiences in caring for and looking after the needs of the mentally ill. Primary caregivers perceived that autonomy could be attained with years of experience in caregiving for their family members.

3.5.1.2. Happiness. Primary caregivers experience satisfaction after being able to meet the needs of their patients. Most primary caregivers (13 out of 20) perceived they were fortunate enough to care for their family members in times of need.

3.5.2. Negative impacts
In the initial days of caregiving, most primary caregivers (14 out of 20) found it challenging to care for the mentally ill. In contrast, those primary caregivers with adequate family support had no difficulties coping.

3.5.2.1. Resigned job. Less earning members in the family were assigned the responsibility of caregiving so that there wasn’t a drastic reduction in the family’s income.

3.5.2.2. Discontinued education. Primary caregivers, the sole son/daughter of the mentally-ill, took a break from collegiate education so their parents weren’t left alone in the house. Primary caregivers perceive it as necessary as other family members are on the job, and an interruption in income can detrimentally affect their parent’s treatment.

3.5.2.3. Lack of time for children. Primary caregivers with mentally ill husbands (6 out of 20) found it difficult to give adequate attention to their children and their education.

3.5.2.4. Disrupted family relations. Primary caregivers (18 out of 20) perceive that mental illness has brought deviations in their family interactions.

3.5.2.5. Desocialization. Most primary caregivers don’t get time to interact with the people in society, as the mentally ill depend entirely on the primary caregiver for all their needs.

3.6. Managing treatment expenses
This theme describes how primary caregivers manage treatment expenses incurred in treating the mentally ill. The treatment costs were medicine, transportation, investigations, and hospital stay.

3.6.1. Relative support
Primary caregivers get monetary support from their relatives to meet the treatment expenses. At times, relatives buy medicines for the mentally ill or offer money so that the caregiver doesn’t have any financial difficulty fulfilling the needs of the mentally ill.

3.6.2. Land disposal
Primary caregivers opined that the expenses incurred in treating the mentally ill are high. The land they possess has been sold out to meet the treatment expenses or pay back the due money from treatment expenses.

3.7. Expectations

3.7.1. Expectations from family members
Owing to the complete dependency of the mentally ill on the primary caregiver and numerous responsibilities vested solely upon the primary caregiver, they expect support from their family members.

3.7.1.1. Homemaking. Looking after the household work and the mentally ill’s needs is arduous for the primary caregiver. Primary caregiver perceives that a helping hand in completing the household work would greatly help them.

3.7.1.2. Babysitting. Dependency on the primary caregiver, repeated admission, and a lengthy stay in the hospital are hindering primary caregivers from giving sufficient time for their children. Primary caregivers who were the spouses (6 out of 20) of their mentally-ill husbands were more worried about the children’s needs.

3.7.1.3. Concern and empathy. Primary caregivers expect family members to share their emotional states and have a rudimentary understanding of their emotions. There have been instances wherein family members have entirely neglected the primary caregiver (5 out of 20).

3.7.2. Expectations from society
Most of the primary caregivers (7 out of 20) were concerned about the inhumane and non-empathetic approaches they encountered daily.

3.7.2.1. Inclusiveness. Primary caregivers perceive discrimination in different ways. There have been instances where patients and their families have been isolated once they were diagnosed with mental illness. Primary caregivers urge that the village administrators give undue consideration to the mentally ill’s treatment expenses and the whereabouts of the mentally ill.

3.7.2.2. Discernment. Societal people find the behaviour of the mentally ill funny. They taunt the mentally ill and their family members. Most primary caregivers (6 out of 20) have isolated themselves from society,
with the pain of bullying about mental illness from people in their community.

3.7.3. Expectations from health professionals

Primary caregivers focused on the helplessness in caring for the mentally ill and themselves. They look to health professionals directly involved in treating their mentally ill family members.

3.7.3.1. Health education. Primary caregivers (13 out of 20) believed that they lack adequate knowledge about illness, ways to deal with the mentally ill, and measures to overcome the challenges and difficulties they encounter in caregiving. In contrast, those with more than three years of experience in caregiving expressed less concern about caring for their mentally ill family member.

3.7.3.2. Assistance. Most primary caregivers believed that the mentally ill would follow much of the instructions health professionals gave. Primary caregivers expect health professionals to help administer food and medicine for the mentally ill and spend time listening to caregiver concerns.

3.7.3.3. Remedy. Most mentally ill had received treatment from various hospitals before coming here. Primary caregivers strongly believe in their health professionals that they can cure illness.

3.8. Coping strategies

This theme describes primary caregiver’s strategies that helped them manage the toughness in caring for a mentally-ill family member.

3.8.1. Appeal to god

Primary caregivers hold on to the belief that God would hear their prayers and the patient would be completely healed. During worship, primary caregivers forget about their worries and get emotional relief while pouring their minds into God.

3.8.2. Catharsis

Primary caregivers with good family support, friends, or relative support disclosed their feelings about caregiving. They were comfortable confining their emotions only with those to whom they felt emotionally attached. The primary caregiver, who didn’t have good support, cries out alone or when no one is around. They feel emotionally ventilated while they cry.

3.8.3. Mindfulness and self-adjustment. Primary caregivers tend to avoid thinking or worrying about future events or happenings. They face and solve the problems as they arise, as they perceive that worrying wouldn’t help them.

3.8.4. Keeping oneself busy. Primary caregivers keep themselves involved in one or the other activities in the house. They don’t have time to sit and contemplate the mentally ill or their situation. Most of them keep themselves involved in household work and caring for other family members.

3.8.5. Acceptance. During their initial days of caregiving, primary caregivers were finding it difficult to accept the annoying behaviour of the mentally ill. Once they accepted that their family member was mentally-ill and annoying behaviour was exhibited due to his illness, they started to feel better adjusted to the situation.

3.8.6. Obligation. Primary caregivers felt their responsibility was to take care of sick family members. Primary caregivers who were parents thought they were bound to care for their ill child, whereas children who were primary caregivers felt that they weren’t doing much compared to what their parents had done for them.

3.8.7. Experiences of self and others. During interactions with fellow primary caregivers in the hospital, they inquire about their coping strategies and bring those experiences into their lives. As years passed in caregiving, primary caregivers have better coped with caregiving from their own experiences.

3.8.8. Hope. Primary caregivers live with the hope that the mentally ill will be completely healed. They hoped that the times of distress would wade off.

4. Discussion

Mothers assumed the primary caregiver role among the caregivers, ascribing their care to unconditional love and responsibility. In non-western countries, familial obligations have a substantial cultural value, and family is an invaluable resource in caring for sick family members. In the present study, wives who were the caregivers to their husbands reported a risk of rupture of spousal relationships and separation. Having children could be one of the critical factors in the continuation of marriage life.

Primary caregivers of patients diagnosed with schizophrenia worry more and have enormous nursing tasks than other caregivers. Most primary caregivers reported moderate to high levels of subjective burden and low levels of support from others in caregiving. Low- and middle-income countries have a considerable and neglected burden on primary caregivers. Significant neglect was reported in time, physical, psychological, social, and financial realms. Factors associated with heightened caregiver burden included duration of illness and care, criticism directed towards the caregiver, financial onus and patient disability, and medication non-adherence. Repeated admissions and regular medicine intake threaten the family member’s financial stability. Even with advancements in education, mentally-ill patients are bullied, and their family members are isolated from society.

To take up the arduous task of caregiving, compromises are made by the primary caregiver in their personal life. They find it challenging to spend time with them or a burden on retirement life. Though caregiving is arduous and negatively impacts a primary caregiver’s life, such as ruined relations and disruption in family relations, some primary caregivers were happy about the phase of caregiving. Positive impacts of caregiving reported by such caregiver’s included self-confidence and happiness in caregiving.

Most primary caregivers look upon healthcare professionals as they are ignorant about the psychopathology of mental illness and management and their coping strategies. To cope with the challenges experienced during caregiving, most participants adopted spiritual beliefs, lowered expectations, promoted communication, kept themselves busy, shared with relatives, adopted a positive attitude, accepted, and engaged in leisure activities. Psycho-educational interventions effectively reduce the subjective burden and depression associated with caregiving tasks. Although the effectiveness of such interventions is reported, they are neither widely used nor aptly incorporated into care plans. To ease the life of the primary caregiver, they need to be involved in the scheme of care of their patient, and sufficient education and support should be offered to the primary caregiver and their family members.

The study’s findings indicate that caregivers face several burdens during caregiving. Mental healthcare professionals should maximize the support system of the family members of the schizophrenic patient. Clinical interventions for caregivers experiencing distress must be implemented to improve their quality of life. The study findings reiterate the need to evaluate the ongoing health of the paranoid schizophrenic caregiver and provide them with adequate support and early
interventions for the challenges in caregiving.

The purposive sampling technique limits the generalizability of the study findings. Although maximum variation sampling was adopted to bring in a maximum difference in perspectives among the participants, most of the caregivers obtained during four months of data collection were mothers of the patient. However, the caregiving experiences didn’t vary much among the patient’s caregivers.

5. Conclusion

Caregivers of paranoid schizophrenia patients have significant challenges during their everyday lives. Whereas those caregivers who receive adequate support from their family members and community better cope with their daily challenges.

Ethical approval statement

The authors obtained the ethics committee approval (KMC&KH-IEC-97/2020), and the participants were given information sheets summarising the study’s purpose, methods, participant roles and responsibilities, confidentiality, and their right to withdraw. The consent for participation and audio recording was also obtained.

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Declaration of interests

None.

Authorship contribution

Conceptualization: AI, RY, LS; Data curation: AI; Visualization: AI; Writing-original draft: AI; Writing-review and editing: AI, RY, LS. All authors have read and agreed on the final version of the manuscript.

Declaration of competing interests

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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