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Nursing Section

Unveiling the Unseen: Exploring the Lived Experiences of Family Caregivers of Young Adults with Chronic Mental Disorders: A Qualitative Phenomenological Study

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ABSTRACT

Introduction: One of India's most valuable resources is its young people, and this generation needs to be nurtured for the bright future of the nation. However, when the young generation is affected by chronic mental disorders, families find it difficult to take care of them and are burdened with the responsibility for several years.

Aim: To explore the lived experiences of Family Caregivers (FCGs) of young adults with chronic mental disorders.

Materials and Methods: This qualitative study was conducted at the selected mental inpatient and outpatient Department of a selected mental health facility in Urban Bangaluru, Karnataka, India from April 2021 to December 2021. The authors used a phenomenological qualitative study to explore the lived experiences of family caregivers of young adults with chronic mental disorders {mania, depression, Bipolar Affective Disorder (BPAD), schizophrenia} aged between 18-40 years. The Family Caregivers of young adults undergoing treatment were approached for written informed consent and recruited through purposive sampling. Data were collected using face-to-face, in-depth, semi-structured interviews. Each interview lasted around 45 minutes to one hour, and data saturation was achieved with 15 samples. Interviews were conducted over a period of nine months. The audio-recorded interviews were transcribed, interpreted, and investigated using Colaizzi's data analysis framework. Baseline variables were analysed using descriptive statistics.

Results: In the present, the family caregivers' ages ranged from 28 to 60 years, with the majority (67%) being females and employed. One of the family members was affected by a mental disorder. A rehabilitation facility was unavailable to the majority (67%) of them near their residence. Regarding the young adults with chronic mental disorders, the majority (74%) were unemployed and diagnosed with affective disorders. The maximum duration of illness was 20 years, with onset typically at the age of 17-21 years. From the analysis, six main themes and 36 subthemes emerged. The main themes were as follows: family caregivers experience difficulty in identifying the responsible person and support system, providing physical care, tackling emergencies, problems with medication and early identification of relapse, problems with indecent behaviour, and knowledge deficit related to mental disorders and their management.

Conclusion: The study concludes that family caregivers of young adults with chronic mental disorders experience various psychosocial and economic issues and problems while caring for a young adult with chronic mental disorders. The knowledge generated from the present study can be utilised by mental health professionals to plan home-based care strategies to improve the quality of life and reduce the burden of care for FCGs.

Keywords: Bipolar affective disorder, Psychosocial and economic issues, Rehabilitation

INTRODUCTION

Our world is home to 1.8 billion young people aged 10-24 years, contributing about one-fourth of the total world population. Nine out of 10 of them live in less developed countries. India has the world's highest number of this age group with 356 million, despite having a smaller population than China [1]. Of all the population groups, the young population is growing fastest, especially in the poorest nations.

The young age is one of the most important phases of life, being the formative period with major impacts on the future. The phase carries special significance for mental health, since most Mental and Substance Use Disorders (MSUDs) have onset in young age or adolescence, and many tend to run a chronic or relapsing course [1]. According to the World Health Organisation (WHO), mental health disorders are one of the leading causes of disability worldwide. One in every eight people, or 970 million people around the world, was living with a mental disorder [2]. Three of the ten leading causes of disability in people between the ages of 15 and 44 are mental disorders. Schizophrenia affects approximately 24 million people or 1 in 300 people worldwide. In 2019, 40 million people experienced bipolar disorder [3].

One of India's most valuable resources is the young people of its country, and this generation needs to be nurtured for a bright future of the nation [4]. However, when the young generation is affected by chronic mental illness from a young age, the family finds it difficult to take care of them, and the family is burdened to look after them for several years. Thus, the family gets shattered. The family constitutes a major support system in the continuing care of the mentally ill in the community. Although many families show strong resilience in caring for an ill relative, their share of physical and emotional distress cannot be ignored. The family plays a very vital role in the care of mentally ill patients [4].

A caregiver has been defined as a family member who has been staying with the patient and has been closely related to the patient's activities of daily living [5]. The family caregiver also has to bear with the behavioural disturbance of the patient, supervise the treatment, and provide emotional support to the patient.

Family members are the primary caregivers of persons with mental illnesses in most of the non Western world. In India, more than 90% of patients with chronic mental illness live with their families [5]. The family caregiver plays multiple roles in the care of persons with mental illness, including taking day-to-day care, supervising medications, taking the patient to the hospital, and looking after the financial needs. The family caregiver also has to deal with the behavioural disturbances in the patient. Thus, the family caregiver experiences considerable stress and burden and needs help in coping with it. The caregivers develop different kinds of coping strategies to deal with the burden. An unhealthy coping style is likely to adversely affect the caregiving function. Hence, it is important to take care of the needs of the family caregivers. The family caregiver has remained a neglected lot, often ignored by mental health professionals. This key support system can't be taken for granted and ignored by mental health professionals [6]. The family caregiver plays multiple roles in the care of persons with mental disorders, including day-to-day care, supervising medications, monitoring the mental state, identifying the early signs of illness, relapse, and deterioration, taking the patient to the hospital, and looking after the financial needs.

Though deinstitutionalisation has mostly brought about positive outcomes, it is not without shortcomings, wherein family caregivers may be unprepared to manage unpredictable behaviours, such as violence and verbal or physical aggression, which have all been found to be contributing factors toward caregiver burden [7]. It is important to focus on family caregivers' experiences in order to explore their needs and preparedness to care for their relatives who are suffering from chronic mental disorders. Overall, the mental burden of care for a patient with mental disorders is very high, and it reduces the quality of life of caregivers. Thus, if caregivers are left without adequate social support, they may also be considered as hidden patients [5].

There have been only a handful of studies conducted on the lived experiences of family caregivers of young adults with chronic mental disorders. There is a limited holistic understanding about the different issues faced by the family caregivers. It is important to empower the caregivers with information regarding the home care of their relatives with chronic mental disorders to prevent relapse of illness and recurrent hospitalisation.

The close relatives of a mentally ill person experience considerable levels of enduring strain. To assist the families caring for a mentally ill member, it is important to understand their roles and experiences as caregivers. To this end, the current study explores the lived experiences of family caregivers of mentally ill individuals. The present investigation differs from other qualitative studies because it aims to explore the lived experiences of family caregivers of mentally ill patients below the age of 40 years. These patients need to be managed by their family caregivers over several years. The themes emerged through this phenomenological approach will enable the investigator to prepare home-based care for the mentally ill so that the family caregivers can manage their patient in their own familiar settings. This phenomenological qualitative research study explored the lived experiences of family caregivers of young adults with chronic mental disorders.

MATERIALS AND METHODS

The study used a phenomenological qualitative research design to conduct in-depth face-to-face interviews. The study was conducted At the selected mental inpatient and outpatient Department of a selected mental health facility in Urban Bangaluru from April 2021 to December 2021. Interviews were conducted over a period of nine months. The study was approved by the Institutional Ethical Committee, A J Institute of Medical Sciences and Research Centre, Mangaluru, Karnataka, India (Ref. No. AJEC/REV/35/2019). The researcher adhered to the four ethical principles: autonomy, non maleficence, beneficence, and justice. Written informed consent was obtained before attending the face-to-face interview, and the family caregivers were informed that the interview would be audio-recorded and would only be used for research purposes.

Family caregivers were recruited using a purposive sampling technique from inpatient and outpatient care units of the mental health facility. Recruitment ended after 15 face-to-face interviews, as the ongoing analysis indicated saturation of the data.

Inclusion criteria:

- Caregivers of clients who have looked after at any time in the past or stayed with the client for the last six months;
- Have a family member diagnosed with major mental disorders between 20 to 40 years;
- Caregivers willing to participate in the study;
- Caregivers of the clients who can understand and speak English, Kannada, Tamil, or Malayalam and residing in and around Bengaluru.

Exclusion criteria:

- FCG diagnosed with mental illness.
- FCG who have hearing and speech problems.

Study Procedure

Research tools: The data collection tools had three sections.

Section-1: Socio-demographic characteristics of family caregivers, which included the following:

1. Gender
2. Relationship with the Client
3. Marital status
4. Education
5. Employment status
6. Monthly income [8]
7. Residence-Urban/Rural Bengaluru/Migrants
8. How many family members are affected by mental illness?
9. How many family members are involved in caring for the mentally ill?
10. Years spent in caring for the ill relative
11. Any financial help for caring for the mentally ill
12. Availability of rehabilitation facility near to the home

Section-II: Socio-demographic characteristics of the client which included the following

1. Age
2. Gender
3. Marital status
4. Education
5. Employment status
6. Monthly income
7. Diagnosis
8. Duration of illness
9. Age of onset
10. Number of times admitted to the hospital during the last two years.

Section-III: Semi-structured interview schedule to assess the lived experiences of the family caregivers of young adults with chronic mental disorders, consisting of 12 open-ended questions with probes to explore the lived experiences in terms of difficulties faced while caring for the young adult with a mental disorder.

1. Can you please narrate your experiences in caring for your family member suffering from mental illness?
2. What difficulties have you faced while caring for your family member? In which areas of care do you find the maximum difficulties, and why? Could you share these experiences in detail?
3. Activities of daily living are required to be performed every day. Can you detail how you manage to perform the activities of daily living for your family member?

4 Your patient is advised to continue medications after discharge for a longer duration. Can you narrate the process of your family member taking medication?
   - Is giving medication an easy task?
   - If the patient does not take it themselves, do you continue to give medications to the patient? If no, why?
   - What makes the patient to stop taking the medications (reasons)?
   - What difficulties do you face in giving medications to the patient at home every day?
5. Forgetting to give medications is a common issue in adherence to medications. What methods do you adopt to remember to give medications?
6. In your experience, what are the common triggering factors for anger? How does the patient show his/her anger?
   - Does he/she become angry when their demands are denied?
   - When instructed to perform daily activities?
   - When instructed to take medication?
   - When meeting new people?
   - When sitting and muttering to oneself?
   - Without any provocation?
   - Does he/she show anger by:
   - Using abusive language?
   - Shouting?
   - Breaking household items?
   - Throwing items at others?
   - Injuring oneself?
   - Injuring others?
   - Locking the door?
   - Leaving the home without informing anyone?
   - Not talking to family members?
7. As a family member, can you shed some light on the early signs you try to recognise to avoid violent behaviour?
8. Over the years, you have witnessed violent behaviour. How do you try to handle the anger and protect the patient, family, and others?
9. How have you been able to manage emergency situations? Can you narrate your experiences?
   - Who helps you to get hospital admission?
   - Are you helped by your neighbours, relatives, religious groups, voluntary organisations, self-help groups, community leaders, etc.?
   - How do you manage transportation?
   - Will you restrain your relative?
   - Will you lock him in a room, beat him, scold him, or shout at him?
10. From your experience in taking care of the family member, what early signs are you able to recognise and prevent a future attack of illness?
11. In your experience, what indecent behaviour was shown towards you or others by the patient? Express your thoughts and concerns. Have other family members reported the indecent behaviour?
    - Sexually flavoured talks
    - Inappropriate dressing/being naked in public
    - Unaccepted body gestures like flashing
12. Have you experienced any discrepancies as your family member is a mentally ill?
    - Isolated in the community
    - Not invited for functions like marriages, festivals, etc.
    - Marriage proposals for your mentally normal relatives are rejected.
    - Neighbours and relatives are not communicating with your family
    - Considering you and your family as cursed by God
13. I would be really happy if you could share any other experiences, you had while caring for your relative.

The data collection tools were submitted to experts in the field of qualitative and mixed research, mental health nursing, and psychiatry for relevance, clarity, and appropriateness. The suggestions and corrections by the experts were incorporated into the final tool. To ensure validity (or 'trustworthiness') of the findings of the qualitative data, the researcher's prolonged engagement, triangulation, and member checking were employed. The authors read the transcripts multiple times, compared the coding system results which led to the emergence of themes and subthemes as a measure of ensuring trustworthiness of the data. The researcher's prolonged engagements ensure constant interaction with the data until data saturation was reached. In the course of writing the manuscript, the emergent themes were compared with the transcript individually and as a whole. Findings from the observation were used to validate that of the in-depth interview.

The study recruited caregivers of clients who have looked after, at any time in the past or stayed with the client for the last six months, and have a family member diagnosed with major mental disorders between 20 to 40 years. They should be willing to participate in the study, understand and speak English, Kannada, Tamil, or Malayalam, and reside in and around Bengaluru. The interviews were conducted in Kannada, English, Tamil, or Malayalam, depending on the proficiency and the choice of the participant. The interviews were conducted with open-ended questions as per the interview guide. The researcher did not know any participants before the study. The duration of the interview ranged from 45 to 60 minutes.

STATISTICAL ANALYSIS

The researcher audio recorded the interview with the consent of the family caregiver, which then transcribed to verbatim. The interviews recorded in the Vernacular languages were translated into English. The data analysis was done using Colaizzi's data analysis framework [9]. This framework is a rigorous approach to qualitative data analysis that aims to uncover the deep meaning and structure of human experiences. The narratives were read and re-read, line by line, and codes were written. A codebook was also developed based on both the initial study objectives and interview guide content. Two researchers independently reviewed the interview materials, summarised and extracted meaningful statements, and formulated the themes. Data were analysed in three levels:

Level 1 coding: Examined the data line by line and made codes, which were taken from the language of the subjects.

Level 2 coding: This involved comparing coded data and the creation of categories.

Level 3 coding: The researcher compared the various codes based on differences and similarities and sorted them into categories. Then final themes and subthemes were generated by grouping similar categories.

RESULTS

The family caregivers' ages ranged from 28 to 60 years. Ten were females. Only one was unemployed. The majority of them were graduates, and only one family member was affected with a mental disorder. Rehabilitation facilities were unavailable to the majority of them near their residence [Table/Fig-1].

Proxy name	Age in years	Gender	Relationship with the client	Marital status	Education	Employment status	Monthly income (in rupees)	Residence	No. of member affected with mental disorders	No. of members involved in caring the mentally ill client	Years spent in caring (years)	Financial help in caring for the clients	Availability of rehabilitation service near to home
L1	51	F	Mother	Widow	TTC	Unemployed	10,000	Rural	1	2	6	Yes	No
L2	36	F	Sister	Married	MA. B. Ed	Teacher	24,000	Urban	1	1	8	No	Yes
L3	54	F	Son	Married	10th	Farmer	8,000	Rural	1	2	8	No	No
L4	38	M	Brother	Unmarried	12th	Driver	15,000	Urban	2	3	18	No	No
L5	40	F	Sister	Married	11th	Business	18,000	Rural	1	3	10	No	No
L6	40	F	Sister	Married	MSc	Web designer	60,000	Rural	1	4	15	No	Yes
L7	36	M	Husband	Married	Diploma (Eng)	Engineer	45,000	Urban	1	4	7	No	Yes
L8	34	M	Wife	Married	BA	Housewife	12.000	Urban	1	1	14	Yes	No
L9	60	M	Father	Married	8th	Farmer	5,000	Rural	1	4	11	No	No
L10	28	F	Husband	Married	10th	Shopkeeper	8,000	Migrant	1	2	10	No	No
L11	31	F	Husband	Married	BA	Sales girl	15,000	Urban	1	1	11	No	No
L12	40	M	Brother	Married	MBA	Manager	60,000	Urban	1	1	8	No	No
L13	54	F	Son	Widow	BA	Housewife	30,000	Urban	1	1	12	No	No
L14	49	F	Sister	Married	BSc	Manager	25,000	Urban	1	1	11	No	Yes
L15	34	F	Husband	Married	B.com	Businessman	35,000	Urban	1	1	12	No	Yes

[Table/Fig-1]: Socio-demographic profile of the caregivers (N=15).

Regarding the relatives with mental disorders: Ten of them were males, the majority of them were unemployed and suffering from affective disorders. The maximum duration of illness was 20 years, with onset at the age of 17 to 21 years [Table/Fig-2].

[Table/Fig-3]: Thematic analysis of the interviews- Themes and sub themes.

The family caregivers reported various psycho-socio-economic problems faced while caring for young adults with chronic mental disorders. From the analysis, the following themes were generated.

Theme 1: Challenges in determining accountability and support network

The FCGs expressed concern about the care of their mentally ill relatives in the future. Lack of support from relatives and stigma regarding mental disorders further isolates the family members and the individuals with mental disorders in society. For example, "When it comes to mental illness, no one likes to help the patient and his family; even close relatives try to avoid us. No one likes to have a neighbour with this kind of illness. No religion, no relatives, no one helped him" (Caregiver 15, father caring for a 30-year-old son with Schizophrenia).

Many caregivers were getting older, and the future care of their young relatives was a source of worry. One caregiver expressed, "As I am aging, I worry about his future. What I can do is that I can keep him in some care home after me... do you know any facility like that? I too must try" (Caregiver 13, caring for a 23-year-old son with BPAD).

The lack of support from relatives and stigma regarding mental disorders further isolates the family members and the individuals with mental disorders in society. Another caregiver mentioned, "When it comes to mental illness, no one likes to help the patient and family; even close relatives try to avoid us. No relative, no religion, no relatives, no one helped us" (Caregiver 2, caring for a 36-year-old brother with bipolar disorders).

The lack of help and understanding from relatives and neighbours is a common issue in caregiving shared by almost all the participants. One caregiver expressed, "We are like outcasted people in our

Proxy name	Age (in years)	Gender	Marital status	Educational status	Employment status	Monthly income	Diagnosis	Duration of illness (years)	Age of onset (years)	Number of times admitted during last two years
L1	23	F	Single	PUC	Unemployed	-	BPAD	6	17	Twice
L2	34	M	Married	10th	Unemployed	-	BPAD	12	22	Once
L3	27	M	Single	B. Tech	Art teacher	2,000	Schizophrenia	9	18	Once
L4	40	M	Single	10th	Unemployed	-	Schizophrenia	18	22	Nil
L5	38	F	Single	10th	Unemployed	-	Schizophrenia	20	18	Thrice
L6	37	M	Single	B. Pharm	Shop owner	5,000	Schizophrenia	18	19	Nil
L7	27	F	Married	10th	Housewife	-	Depression	7	20	Nil
L8	38	M	Married	10	Unemployed	-	BPAD	19	19	Thrice
L9	30	F	Separated	12	Unemployed	-	Mania	12	18	Once
L10	39	M	Married	10th	Unemployed	-	BPAD	19	20	Twice
L11	34	M	Married	10th	Unemployed	-	Mania	16	18	Four times
L12	29	M	Separated	12th	Unemployed	-	BPAD	12	17	Twice
L13	30	M	Single	10th	Unemployed	-	Paranoid Schizophrenia	12	18	Thrice
L14	40	M	Married	12th	Unemployed	-	BPAD	20	20	Once
L15	30	F	Married	10th	Housewife	-	Depression	12	18	Nil

[Table/Fig-2]: Socio-demographic characteristics of the client.
N=15

Themes	Subthemes
1. Challenges in determining accountability and support network	• Lack of support • Stigma • Physical assault • Verbal abuse
2. The struggles and strategies in nurturing and supporting the young adult with mental disorder	• Problems in physical care • Lack of motivation and interest in living chores • Nutritional, safety and sleep needs • Financial difficulties • Poor geographical accessibility to mental healthcare unit • Lack of public transportation facility
3. Awareness gaps and challenges in responding to psychiatric emergencies	• Suicidal attempt, • Anger, aggression and violent behaviour risk taking behaviour, • Damage to property • Poor knowledge related to management of emergency • Absence of mental health facility near to home
4. Navigating medication management and relapse prevention	• Refusing medications • Spitting medications • Too many medications • Not recovering in spite of regular medication • Problems with the taste of medication
5. Addressing inappropriate behaviour in young adults	• Exhibitionism • Use of vulgar language • Being friendly with unknown opposite gender people • Sexually flavoured talk
6. Bridging the knowledge gap in mental disorder awareness and management	• Need of information regarding mental disorders and management • Mental healthcare and rehabilitation • Wanted to be included in the treatment planning session

[Table/Fig-3]: Themes and subthemes from the lived experiences of family caregivers of young adults with chronic mental disorders identified from the data are presented in the table.

family circle; no one communicates with us. When our own people are not helping us, how can I expect others? My relatives blame me for caring for him and keeping my brother; they ask why I have to waste money and energy on this man because whether I care for him or not, the illness still persists" (Caregiver 12, caring for a 28-year-old brother with bipolar disorders).

Physical assault and verbal abuse towards the mentally ill and the family were shared by the FCGs. One caregiver recounted, "One time he (a relative with a mental disorder) came out of our home and one of the neighbours slapped him. I felt very bad about it..." (Caregiver 4, caring for a 38-year-old brother with schizophrenia).

Theme 2: The struggles and strategies in nurturing and supporting the young adult with mental disorder

Caregiving is associated with significant challenges that hinder caregivers' ability to care for their relatives effectively. One of the main challenges for family caregivers is that the young adults are not meeting their needs. The majority of family caregivers faced problems in physical care. For example, "We need to bathe, wash, and do all the activities every day, for my son, it is once in a week/once in a month affair. He will not maintain any cleanliness. Never listen to us. We are scared to compel him. He will harm us" (Caregiver 8, caring for a 38-year-old son with Schizophrenia).

Lack of motivation and interest in daily living chores further deepens the problem. Family caregivers further faced difficulty in meeting the nutritional, safety, and sleep needs of their relatives. "Midnight she will be eating food, washing vessels, not sleeping at all, talk rubbish, talk in offensive language" (Caregiver 5, caring for a 34-year-old sister with Schizophrenia).

Financial difficulties were one of the major challenges faced by the family caregivers. One participant reported that their economic status is so bad that they are unable to cover their children's education. "We are financially too very poor. Our income from daily work is too disturbed with hospitalisations, frequent consultations, traveling, etc. We have no earning with us. Even the needs of other children are not met due to the treatment of this child" (Caregiver 9). The Coronavirus Disease-2019 (COVID-19) pandemic further increased the economic burden of the caregivers. "Every day expenditure and medicines too are very costly. Because of COVID-19, my school also not paying the full salary. I get only half salary. I need to manage everything with that house rent, groceries, medicine, everything. I too took alms from my friends, which I need to repay at the earliest. Of course, now the maximum difficulty is related to money only" (Caregiver 1, caring for a 23-year-old daughter with bipolar disorder).

Geographical accessibility to mental healthcare units is a major problem for many family caregivers. The public transport system is not available in the wee hours, especially when there is an emergency. "I too find it too difficult to get transportation at times. Last time when he was sick and I had to get him admitted to the hospital, transportation was a big problem" (Caregiver 2, caring for a 36-year-old brother with bipolar disorder).

3. Awareness gaps and challenges in responding to psychiatric emergencies

Suicidal attempts, anger, aggression, violent behaviour towards others, risk-taking behaviour, and damage to property, including tearing clothes, were some of the emergencies faced by the FCGs.

"Years back, I feel bad to keep him locked inside the house when he became angry. That time he used to leave the house and try to run away. I had a very tough time searching for him and getting him back home. Now his anger spells are less, if anything is noted, I will lock the doors so he cannot go out. I still feel bad about it, but what else can I do… It is for his safety and ours too."

"At times, when he tries to run away, we used to lock him in his room until he calms down and agrees to visit the doctor… If it is not done, it will be difficult for all of us" (Caregiver 4, caring for a 38-year-old brother with Schizophrenia).

Lack of knowledge regarding the management of emergency conditions forces the FCGs to keep their relatives under lock. Lack of mental health facilities near home and poor transport facilities worsen the situation.

4. Navigating medication management and relapse prevention

Drug adherence is an essential activity for the control and management of mental disorders. Refusing medications and spitting out medications were common among the mentally ill. The reasons for refusal were too many medications and problems with the taste of medications. Some of the FCGs felt that the patient is not recovering despite regular medication. Many of them expressed that discontinuing medication leads to decreased sleep, poor food intake, indecent behaviour, self-talk, smiling to oneself, and restlessness among the mentally ill clients.

"Nothing to talk about medicine: If only he continues to take medicine… he could have been much better now… However much I say, he will not continue the medication, as though he never wants to recover from this madness… he takes some days, then refuses, throws away all medicine…. Again, he will become sicker… then I bring him here; sometimes he gets admitted, sometimes we take medicine and go… that is how it is… always… he will never take medicine for more than two months… it's always the same" (Caregiver 12, caring for a 28-year-old brother with bipolar disorder).

"She is not taking it continuously as per the doctor's instruction, she takes it for some time, then stops, later she develops sleeplessness, fatigue. At that time I take her to the doctor."

"She has been admitted many times in the past due to increased problems" (Caregiver 15, caring for a 36-year-old wife with Schizophrenia).

Slow improvement in the patient's condition, despite prolonged regular intake, is a reason for non adherence to medication. "Even with medications, suddenly he becomes very delusional and aggressive, sometimes smiling and talking to himself. I am just wondering why is it like this… If he engages in some useful work, he feels better, that is what I think. For that, he must make up his mind; suddenly he will get some great ideas, which are practically not possible" (Caregiver 4, caring for a 27-year-old son with Schizophrenia).

Theme 5: Addressing inappropriate behaviour in young adults

Exhibitionism, use of vulgar language, being friendly with unknown people of the opposite gender, and sexually flavoured talk over the phone were reported by FCGs. The indecent behaviour further causes social isolation and stigma regarding mental disorders among the public.

"Yes, there is indecent behaviour from his side, there are 3 to 4 incidents of flashing, and the ladies who are doing the fieldwork in the land complained about this to me... They all know he was a decent boy, this all due to this illness he does this at home... Not going to public places. The girl in the neighbourhood also told me once that she saw him naked and once, he did exhibitionism to her... She thought he may pass urine, but that was not the situation. I asked for pardon and told her that this is due to his illness. Now that girl is married and not there. This incident caused a lot of embarrassment to us... Even I say young girls, our relatives also not to come home when I am not there. I am really scared if anything goes wrong, what will we do?" (Caregiver 4, caring for a 27-year-old son with Schizophrenia).

"Improper dressing, being naked in public, and being overly friendly with unknown people of the opposite gender cause embarrassment and shame for FCG. Nothing like that. But last time when she was sick, she was talking too friendly to the auto driver. She said that she wants to go around the city with the auto driver" (Caregiver 1, caring for a 23-year-old daughter with bipolar disorder).

Theme-6: Bridging the knowledge gap in mental disorder awareness and management

Many of the FCGs interviewed believed that because they were the primary caregivers to their mentally ill relative, they needed information about mental disorders and their management, mental healthcare, and rehabilitation facilities available. Furthermore, they wanted to be included in the treatment planning sessions so that they can provide better care. "I want to ask you, whether this illness can be cured? Will he be like before? At times he looks normal as though he has no illness. People seeing him for the first time, he appears very normal. He likes to teach drawing, helps me with household chores, and folds clothes just like how they fold and keep in a textile shop. Other times he is so angry and suspicious towards me. Even in the hospital, they are not giving much information about his illness or progress. How nice if we get some counselling services… I could tell all my difficulties to them. How long does he have to take these medicines? If we get some counselling service, it could have been a great help for us. I have not slept properly for so long" (Caregiver 3, caring for a 28-year-old son with depression).

The FCGs are expected to provide complex care at home with little information and support. The lack of counselling services increases the caregiving burden among FCGs.

DISCUSSION

The identified themes and subthemes in the present were derived from direct interviews with family caregivers. The present study explored the lived experience of family caregivers of young adults with chronic mental disorders using a phenomenological qualitative method. The findings of the study are summarised into six themes focusing on challenges in determining accountability and support network, the struggles and strategies in nurturing and supporting the young adult with mental disorders, awareness gaps, and challenges in responding to psychiatric emergencies, navigating medication management, and relapse prevention, addressing inappropriate behaviour in young adults, and bridging the knowledge gap in mental disorder awareness and management [10].

The findings of the present study are consistent with a qualitative study on the lived experience of caring for someone with bipolar disorder. The study identified five themes: Separation of the person and the disorder, carer health and coping strategies, unpredictability and variability of symptoms, carer disillusionment and silencing, and story sharing and support needs.

In another study conducted in Tasmania, Australia, on barriers and facilitators to supporting the psychosocial wellbeing of young people with mental illness, 14 subthemes were identified, including eight barriers and six facilitators in the care of the mentally ill, namely: 1) the complexity of young people's psychosocial needs, and 2) lack of awareness/knowledge of services available; at the interpersonal level; 3) negative experiences with adults, and 4) fragmented communication between services and family; and at the systemic level; 5) lack of services, 6) long waiting periods, 7) limited service accessibility, and 8) the missing middle, which are consistent with the present study's findings. The terminology used for the themes is different, but the underlying concept is the same as in the present study [11].

A qualitative phenomenological study conducted in Maharashtra on the lived experiences of caregivers of chronically schizophrenic patients identified a total of nine themes, such as the burden of patients' hospitalisation, concerns related to the treatment of patients, physical impact, psychological impact, social impact, financial impact, altered responsibilities, the need for information, and coping strategies. These themes correspond to the findings of the present study [12].

The study findings would help family caregivers manage the unpredictability and variability of symptoms, especially during violence, irritability, anger, and increased stress related to sexual indiscretions and out-of-character sexual behaviours of their young relatives. The findings demonstrate that there is a need for social support for families affected by mental disorders. Family caregivers were in need of greater practical support, including information about medication, management of emergencies, and the types of mental disorders. A combination of pharmacological and psychosocial interventions is effective for reintegrating patients with mental illness into the family [13,14]. Lack of awareness of supports, low mental health literacy among caregivers, the burden of accessing supports for their relatives, and difficulties in accessing services due to the location, distance, and amount of travel required were some of the findings of a study.

The findings of the study suggest that family-based psychoeducation regarding the disease condition, management of psychiatric emergencies, techniques to promote medication adherence, and homecare management of mentally ill family caregivers seem to be desirable. The present study would empower every member involved in the caregiving process on the homecare of their mentally ill young relatives. Family caregivers could come together and share their challenges and experiences with others who are in similar situations. Support groups are known to instill hope and create universality in group settings as they make individuals feel that they are not alone in their suffering and also get empowered in the process. Future research can focus on the experiences of a specific care group, for example, sibling caregivers, parent caregivers, or spousal caregivers, to highlight the needs specific to that group.

Limitation(s)

The experiences of the family caregivers from a single setting may not be representative of all the family caregivers in the region or country. The small purposive sample was too small to allow generalisability.

CONCLUSION(S)

Mental disorders place a huge burden not only on the individuals affected but also on the family members who live and interact with ill relatives in their daily life activities. Relatives of the patients have to face the multidimensional needs and problems of their chronic patients for a long period of time. The identified themes include family caregiver experiences of difficulty in identifying the responsible person and support system, providing physical care, tackling emergencies, problems with medication, and early identification of relapse. Additionally, they face problems of indecent behaviour and a knowledge deficit related to mental disorders and its management. Support from mental health professionals, such as mental health education, training for family caregivers on homecare of mentally ill individuals, home visits by mental health nurses, and family support groups, will empower the caregivers and boost their confidence in caring for their mentally ill relatives at their own home.

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