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Research Paper

Caregiver Burden of Patients with Chronic Mental Illness - A Mixed Method Study

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ABSTRACT

Background: The rising prevalence of mental illness has a profound impact on caregivers, affecting them across multiple dimensions: physically, mentally, emotionally, socially, and financially. This study was aimed to assess the caregiver burden and to explore the facilitating factors and barriers in caregiving.

Objectives: Primary objective of the study were to assess the caregiver burden, secondary objective were to find the association between caregiver burden and selected socio-personal and clinical variables and to explore the facilitating factors and barriers in caregiving.

Methodology: A mixed-method approach with a sequential explanatory design were used with two phases:

Phase I used a quantitative descriptive design and recruited 150 caregivers through consecutive sampling. Zarit Burden Interview was used in assessing caregiver burden using Interview technique. Percentage, frequency and Chi square were used in analysing the data.

Phase II

From this pool of 150 caregivers, 12 caregivers who reported severe burden were recruited purposively in phase II. Data were collected with a semi structured interview guide using a face-to-face in depth interview technique. Braun and Clarks thematic analysis were used in data analysis.

Results: In Phase I, results showed that, 1.3% of caregivers had severe burden, 14.7% had moderate to severe burden, 33.3% had mild to moderate burden, and 50.7% had no or little burden. Statistically significant associations were found between caregiver burden and factors like age (p=0.024), educational status (p=0.035), marital status (p=0.035), economic status (p=0.039), physical morbidity in caregivers (p=0.013), clinical diagnosis of patients (p=0.005), duration of illness (p=0.007), frequency of recurrence of illness (p=0.001), and frequency of hospitalization (p=0.012).

In Phase II, exploration of facilitating factors and barriers revealed eight themes. Two facilitating factors were identified: Faith in God and Intake of timely medicine. Six barriers were identified: Caregiving prioritizes relationship, Secrecy surrounding illness, Accessibility of mental health services, Unstable financial situations, Fears and anxiety, and Family backing.

Conclusion: Among the caregivers, 1.3% had severe burden, 14.7% had moderate to severe burden and 33.3% had mild to moderate burden highlighting the significance of addressing the barriers uncovered in qualitative that helps in mitigating caregiver burden.

Keywords: Caregiver burden, chronic mental illness, caregivers, facilitating factors, barriers.

INTRODUCTION

Mental health is a pressing global concern, with India being no exception. Dr. Brock Chisholm, the first WHO Director-General, aptly stated in 1954 that "without mental health, there can be no true physical health."[1] Despite this, progress in mental health service delivery has been slow in low and middle income countries due to competing public health priorities influencing funding, challenges in delivering mental health care in primary care settings, a shortage of trained professionals, and a lack of mental health representation in public health leadership.

Chronic mental illnesses, such as schizophrenia, bipolar mood disorder, and major depressive disorders, have prolonged disease courses that can result in physical and social consequences, as well as significant family burden. Caregiving is influenced by various psychosocial factors, which can compromise caregivers' quality of life and adversely affect their physical and mental health. If left unsupported, caregivers can become "hidden patients." [2]. Moreover, mental health professionals often prioritize patient care, neglecting the needs of their family and caregivers. In hospital settings, caregivers rarely have opportunities to express their concerns and problems, further exacerbating their struggles.

The needs of the caregivers caring for individuals with chronic mental illness often go unaddressed which made the investigator evaluate the caregiver burden and explore the facilitating factors and barriers of caregiving. Understanding their burden helps to address and tackle the mental health problems and challenges faced by the caregivers within the resources and facilities available in our setting.

MATERIALS & METHODS

The study adopted a mixed methods approach with a sequential explanatory design was used with two phases: Phase I used a quantitative design and Phase II Qualitative design. Study was conducted at the Psychiatry department of Government Medical College Hospital, Thiruvananthapuram, Kerala. Caregivers of patients diagnosed with Chronic mental illness and seeking treatment from Psychiatry department of Government Medical College Hospital, Thiruvananthapuram.

Care givers of patients diagnosed with Chronic mental illness who were the immediate family members, staying with the patient and taking primary responsibility of care and supporting the patient, caring patients for a minimum of one year, willing to participate in the study and able to comprehend Malayalam were selected for the study.

Sample size calculation for Phase I was based on the following study, according to a cross-sectional study on the caregiver burden among caregivers of mentally ill individuals and their coping mechanisms, the prevalence of severe burden was 40.9% [3]. The formula used were single population proportion formula, n = 4pq/d2. Desired sample size of 144 caregivers was calculated. However, to account for potential dropout and to ensure more robust samples, sample size of 150 caregivers were selected. Sample size was limited to the point of data redundancy. The caregivers for phase II were the caregivers who particularly answered "extremely" for the 22nd question in Zarit Burden Interview, "overall how burdened you feel in caring for your relative"

Data collection Instrument and procedure

Phase I

The questionnaire consisted of 3 sections, Section A, consisting of socio-personal details such as age, gender, education, occupation, marital status, type of family, domicile, economic status, relationship to the patient, presence of physical morbidity of caregivers. Section B consisting of Clinical variables of patients containing clinical diagnosis, duration of illness, frequency of recurrence of illness in past 2 years, frequency of hospitalization in past 2 years. In Section C, Zarit Burden Interview scale to assess the burden among caregivers. Zarit Burden Interview (ZBI-22) consists of 22 items, where the caregiver burden is addressed through 5 domains, relationship burden (6 items), emotional and well-being (7 items), social and family life (4 items), finances (1 item) and loss of control over life (4 items). Total scores range from 0 to 88. Higher scores imply greater caregiver burden. Recommended cut off points for the ZBI-22 are as follows: 0-20(little or no burden), 21-40(mild to moderate burden), 41-60(moderate to severe burden) and 61-88(severe burden). Initially, pilot testing of the questionnaire was done to ensure the reliability and identify potential area for improvement. The process involved administering the questionnaire to 15 caregivers before administering to large group. The feedback received from the pilot testing helped in refining the questionnaire. The questionnaire had an overall good reliability, with a reliability co-efficient 0.84. Content validity analysis was conducted to ensure that the questionnaire accurately measures the intended construct. Content validity was assessed by 5 experts in the filed by reviewing the questions and provided their feedback on relevance and clarity of the questions.

Phase II

Semi structured interview guide was prepared to explore the facilitating factors and factors that burden the caregiving. Initially, pilot testing of the questionnaire was done to ensure the practicability and to identify potential areas for improvement. In phase II, the questionnaire was administered to 3 caregivers. The feedback received from the pilot testing helped in refining the questionnaire.

Data analysis

Phase I

The collected data were entered, coded and analysed using SPSS version 27, in accordance with the study objectives. The interpretation of data was done by descriptive and inferential statistics. Socio personal and clinical data were described in terms of frequency and percentage. Caregiver burden was described in terms of frequency and percentage. Chi square test was used to find out the association between the caregiver burden and selected socio personal variables of caregiver and clinical data of the patient. Results were discussed with the experts in department of Psychiatry, Psychiatric Nursing and Statistics.

Phase II

The data from the in-depth interviews were transcribed and analysed using thematic coding analysis, which includes identifying, categorizing, and interpreting themes that emerge from the data. Braun and Clarks method were used in the analysis. The steps in the analysis were,

1. Familiarization of data
2. Generating Initial codes
3. Generating themes
4. Validity and Reliability of themes
5. Defining and naming themes
6. Interpretation and Reporting

RESULT

Socio-personal characteristics of the caregivers (n=150)

The present study comprised 150 caregivers. Results in table 1, shows that, the majority of them belonged to the middle to older age group of 41-70 years. Female caregivers (63.7%) predominated over males (36.7%). Most caregivers (54 %) had completed high school education, while only a smaller proportion were graduates or postgraduates (14%), indicating a moderate educational background. A large proportion of caregivers (34%) were unskilled workers or unemployed, and the majority (74.7%) hailed from rural areas. Most caregivers were married (89.3%) and belonged to nuclear families (96.7). Socio-economic assessment revealed that a substantial majority of caregivers (66%) belonged to the below poverty line category, reflecting financial constraints among the study population. With regard to the relationship to the patient, parents (42%) constituted the largest group of caregivers, followed by spouses (31.3%) and children (18%), indicating that caregiving responsibilities were mainly undertaken by immediate family members. Most caregivers (86.7%) had been residing with the patient for more than five years, suggesting long-term involvement in caregiving. Although more than half of the caregivers (56.7%) were free from physical morbidity, a considerable proportion (24%) reported multiple chronic conditions such as diabetes, hypertension, hypothyroidism, and dyslipidemia, highlighting the physical health burden associated with prolonged caregiving.

Table 1: Distribution of caregivers based on socio-personal variables (n=150)

Variables		**Percentage (%)**
Age in years	20-30 years	10.0
	31-40 years	14.0
	41-50 years	22.7
	51-60 years	23.3
	61-70 years	24.7
	71-80 years	4.7
	81-90 years	0.6
Gender	Male	36.7
	Female	63.7
Educational status	No formal education	1.3
	Primary education	12.7
	High school education	54.0
	Higher secondary	10.7
	Graduate/post graduate	14.0
	Professional education/ Technical education	7.3
Occupation	Professional	3.3
	Semi professional	0.7
	Semi-skilled worker	9.3
	Unskilled worker	34.0
	Clerical/Shop/Farm owner	22.0
	Unemployed	26.0
	Retired	4.7
Domicile	Rural	74.7
	Urban	25.3
Marital Status	Married	89.3
	Unmarried	6.0
	Separated	0.7
	Widow/Widower	4.0
Type of Family	Nuclear family	96.7
	Joint family	3.3
	Extended family	0
Economic Status	APL	34.0
	BPL	66.0
Relationship to the Patient	Children	18.0
	Spouse	31.3
	Parents	42.0
	Siblings	7.3
	Other	1.3
Duration of stay with the Patient	1-2 years	9.3
	2-5 years	4.0
	More than 5 years	86.7
Presence of physical morbidity	No morbidity	56.7
	Diabetes Mellitus	4.7
	Hypertension	8.7
	Dyslipidemia	5.3
	Hypothyroidism	0.7
	Multiple morbidities	24.0

Clinical variable of Patients' (n=150)

Table 2 results reveals that, the study included caregivers of patients with schizophrenia, bipolar disorder, and major depressive disorder in equal proportion (33.3%), allowing a balanced representation of major psychiatric illnesses. Most caregivers (74%) had been providing care for more than five years, reflecting the chronic nature of mental disorders and the long-term responsibility assumed by family members. This prolonged caregiving period highlights the sustained emotional and practical demands placed on caregivers over time.

With regard to the clinical course of illness, the majority (48%) of patients had less than 2 recurrences of illness and did not require hospitalization (64%) in the last two years. Fewer hospital admissions suggest effective treatment adherence and outpatient management. However, the occurrence of recurrence and hospitalization in a subset of patients emphasizes the fluctuating course of psychiatric illnesses and the continued need for caregiver involvement and mental health support services.

Table 2: Distribution of caregivers based on clinical variables of patients (n=150)

Clinical Variables		Percentage
Clinical diagnosis	Bipolar Disorder	33.3
	Major Depressive Disorder	33.3
	Schizophrenia	33.3
Duration of illness	1-2 years	14.7
	2-5 years	11.3
	More than 5 years	74.0
Recurrence of illness in past 2 years	Nil	38.7
	Less than 2 times	48.0
	More than 2 times	13.3
Frequency of hospitalization in past 2 years	Nil	64.0
	Less than 2 times	28.0
	More than 2 times	10.0

Caregiver burden (n=150)

The findings of the present study in table 3 shows, that 1.3% had severe burden, 14.7% had moderate to severe burden, 33.3% mild to moderate burden and 50.7% had little or no burden. This indicates that although some caregivers adapt well to caregiving responsibilities, a significant number continue to face emotional, physical, and social challenges. The presence of moderate levels of burden highlights the need for regular assessment of caregiver stress and the provision of supportive interventions to prevent escalation of burden and to promote caregiver well-being

Table 3: Distribution of caregivers based on caregiver burden (n=150)

Variable		Percentage
Caregiver Burden	Little or no burden	50.7
	Mild to moderate burden	33.3
	Moderate to severe burden	14.7
	Severe burden	1.3

Association between caregiver burden and selected socio-personal variables (n=150)

The study revealed that, there was a statistically significant association using chi square analysis between caregiver burden with age ($\chi 2$=7.470,df=2,p =0.024), educational status ($\chi 2$ =10.331,df =4,p =0.035), marital status ($\chi 2$ =6.703,df =2, p=0.035), economic status ($\chi 2$=6.464, df=2, p=0.039) and presence of physical morbidity ($\chi 2$=8.712, df=2,p=0.013) of caregivers. The present study inferred that there was no statistically significant association between caregiver burden with other socio demographic variables such as gender ($\chi2$ =0.197, df=2,p=0.906) occupation ($\chi2$=0.097, df=2,p=0.953) domicile ($\chi2$=2.635, df=2,p=0.268), type of family ($\chi2$=0.417, df=2,p=0.812) caregiver's relation to patient ($\chi2$=5.095, df=4,p=0.278) duration of stay with the patient ($\chi2$=2.161,df=2,p=0.339).

Association between caregiver burden and selected clinical variables (n=150)

The study shows that, there was a statistically significant association between caregiver burden with clinical diagnosis of patients ($\chi2$=14.772, df=4,p=0.005), duration of illness of patient ($\chi2$=10.070, df=2,p=0.007), frequency of recurrence of illness in last 2 years ($\chi2$=14.478, df=2, p=0.001) and frequency of hospitalization in last 2 years ($\chi2$=12.927,df=4,p=0.012)

Phase II

The study explored the experiences of caregivers of individuals with mental illness, analysed using Braun and Clarke's thematic analysis. The following themes were identified, reflecting the challenges, responsibilities, and emotional burden faced by caregivers. The following themes emerged after data analysis.

1.Caregiving Prioritizes Relationship

Most caregivers considered caregiving more than just a duty; they considered it as an obligation to perform which showed emotional attachment, cultural obligations, and familial responsibility. These insights emphasize the necessity for support systems that acknowledge and address caregiver's emotional burden.

"I take care of him very well, I go for job, come back and takes care of him" (C8)
"Only my husband and I are there to take care of her" (C3)
"I will take care of him till I die, then I don't know what his future will be" (C11)
"I feel burdened when I can't fully invest on her" (C10)
"I gave birth and raised him; the crow thinks her own birds fairest" (C5)

2.Secrecy surrounding illness

Most caregivers highlighted a persistent stigma associated with mental illness, reinforcing caregivers' reluctance to seek external support. They verbalized their concern about the future of their child with mental illness. Awareness programs are necessary to break the cycle of secrecy and improve social acceptance.

"He doesn't talk about his illness to anyone, may be because he is humiliated" (C11)
"I didn't tell anyone about his illness; it may affect his future" (C12)
"Without disclosing her illness, we married her off, and it didn't last long" (C3)
"I married him without knowing about illness" (C8)

3.Timely intake of medicine

Majority of the caregivers reported that, strict adherence to medicine helped in relieving the symptoms, aggression and sleep problems patient had. They also stated that taking medicine helped in changing their behaviour to normal.

"Taking medicine helps a lot, she is good when taking medicine, she comes and hugs me, tells sorry" (C1)
"She is taking regular medicine, now she loves kids and takes care of them" (C4)
"His anger reduced" (C5)
"With medicine she is improving, so never skipped medicine" (C10)

4.Accessibility of mental health services

Many caregivers reported the lack in availability and accessibility of mental health care services nearby. Nearby hospitals were short in psychotropic drugs, psychiatrist and services. Caregiver were unaware about the service provided in nearby hospital.

"Nearby there is hospital, if there is no doctor then he may stop medicines" (C6)
"We have nearby hospitals, but there are no facilities for admission and medicine". (C10)

"The distance is too far but it doesn't matter if he gets better" (C9)
"Some doctors write medicine to outside pharmacy, last time wrote medicine for 900 rupees, I felt very sad" (C1)

5.Unstable financial situations

Caregivers expressed that they had other family members without any employment that had negative impact on the financial stability in their family. So they had to earn alone to meet the two ends.
"Her father doesn't take care of family, I work hard, work as home maid, coolie works, does farming I work that much for my daughters". (C1)
"Elder son doesn't have any job and younger ones are students. I get pension" (C6)
"There is no one to help financially, I go for job, roll from others" (C9)

"We both get pension" (C2)

6.Fear and Anxiety

Many caregivers highlighted that caring a relative with mental illness causes fear and anxiety in them which has a negative impact in caregiving. Caregivers expressed suicidal thoughts during caregiving.
"I get thought of committing suicide. When my younger daughter blamed me, I tried to commit suicide". (C1)
"I didn't get what I expected in my life, I didn't get a family life" (C6)
"He tries to harm me, even tried to kill me after few days he will repeat" (C8)

"She shows aggressiveness, pulls own hair and makes some horrifying face like ghost that frightens kids". (C4)

7.Family Backing

Majority of the caregivers reported that, they had no one to support or help them to take care of the relatives diagnosed with mental illness.
"Family cooperates but not that much because of her illness" (C1)
"There is no one to help, my other children also don't help, I have sisters but nobody helps" (C2)
"Me and husband take care of her" (C3)
"I don't have anyone to help; I have another son when I call, he would say he has to take care of his family". (C5)

Theme 8: Faith in God

Majority of the caregivers reported praying and having faith strengthens their hope and coping.
"I tried to kill myself and was at brick of death, I believe that god bought me back to take care of my child." (C1)
"I am a Hindu but I believe in all religion and God. Praying might have helped me to overcome my difficulties." (C2)
"I believe praying helps in reducing bad omen and illness and there is some changes" (C3)
"When he is aggressive, I pray to god and he turns calm" (C6)

DISCUSSION

Family members play a very important role in taking care of patients with psychiatric illness. They suffer a lot due to the behavioral changes and symptoms of the patient. The present study was aimed at estimating Caregiver Burden of patients with Schizophrenia, Bipolar Disorders and Major Depressive Disorder and also to explore facilitating factors and barriers in caregiving. In this study, it was identified that, caregivers had varying levels of caregiver burden.

Caregiver burden

The present study revealed that 1.3% of caregivers experienced severe burden, 14.7% had moderate to severe burden, 33.3% had mild to moderate burden, and 50.7% had little or no burden. A study conducted in Maharashtra in 2014 reported that 24% of caregivers had moderate burden, 61% had low burden, and 15% had no burden, which is not congruent with the findings of the present study [4].

Similarly, a study conducted in Nepal in 2024 showed that 9.4% of caregivers experienced severe burden, 31.3% had moderate burden, 18.8% had mild burden, and 40.6% had little or no burden. These findings are also not congruent with the present study [5].

Association Between Caregiver Burden and Socio-personal Variables

The present study demonstrated a statistically significant association between caregiver burden and age (p = 0.024) as well as educational status (p = 0.035). A cross-sectional study conducted in Bangladesh also reported a significant association between caregiver burden and age (p = 0.004) and educational status (p = 0.006), thereby supporting the findings of the present study [6].

In addition, a statistically significant association was observed between caregiver burden and marital status (p = 0.035) and economic status (p = 0.035). A similar study conducted in Assam reported a significant association between caregiver burden and marital status (p = 0.001) and family income (p < 0.001), mirroring the findings of the present study [7].

No statistically significant association was found between caregiver burden and other sociodemographic variables such as gender, domicile, caregiver's relationship to the patient, and duration of stay with the patient. A study conducted at Jimma University, Southwest Ethiopia, also found no significant association between caregiver burden and gender (p = 0.087) or place of residence (p = 0.162), which is consistent with the present study [8].

Furthermore, the present study revealed no significant association between caregiver burden and occupation (p > 0.05) or type of family (p > 0.05). Similar findings were reported in a study conducted in Telangana, India [9], and another study from Bangladesh also found no significant association between caregiver burden and type of family (p = 0.350) [6].

Additionally, no significant association was observed between caregiver burden and relationship to the patient. A study conducted in Amritsar also reported no significant association between caregiver burden and relation to the patient (p = 0.523), supporting the present findings [10].

Association Between Caregiver Burden and Clinical Variables of the Patient

The present study found a statistically significant association between caregiver burden and clinical diagnosis of the patient (p = 0.005), duration of illness (p = 0.007), frequency of recurrence in the last two years (p = 0.001), and frequency of hospitalization in the last two years (p = 0.012).

A study conducted at Jimma University Medical Centre, Southwest Ethiopia, similarly reported a significant association between caregiver burden and clinical diagnoses such as schizophrenia (p = 0.002), major depressive disorder (p < 0.001), and frequency of illness episodes (p < 0.001), which aligns with the present study [8].

A study conducted in South Africa found a significant association between caregiver burden and history of relapse after admission (p = 0.018) [11]. Likewise, a study from Tamil Nadu reported a significant association between caregiver burden and duration of illness (p = 0.004), further supporting the present findings [12].

Phase II: Facilitating Factors and Barriers in Caregiving

Phase II of the study explored the facilitating factors and barriers experienced by caregivers of patients diagnosed with mental illness.

Facilitating Factors

Facilitating factors refer to circumstances that positively influence caregivers while providing care. The present study identified timely medication as an important facilitating factor, as psychotropic drugs helped reduce symptoms such as aggression, violent behavior, and sleep disturbances, thereby easing the caregiving process. A qualitative study conducted in Temeke

Municipality, Dar es Salaam, Tanzania, also reported caregiver satisfaction with the therapeutic effects of psychotropic medications, which is congruent with the present findings [13].

Another facilitating factor identified was faith in God, which helped caregivers cope with the burden of caregiving. Caregivers reported finding comfort and emotional strength through prayer. A qualitative systematic review also identified religious practices as an effective coping mechanism under the theme of caregiving mindset, supporting the present findings [14].

Barriers in Caregiving

Caregivers experienced several barriers that hindered effective caregiving. One identified theme was caregiving as a prioritized relationship, where caregivers viewed caregiving as a moral and familial duty. Many caregivers expressed concern about the future of the patient, particularly after their own death. Similar findings were reported in a qualitative systematic review, where caregivers described a strong cultural and familial obligation to provide care [14].

A qualitative study conducted in Switzerland also identified caregiver concern regarding the future of individuals with schizophrenia, which is consistent with the present study [7].

Another barrier identified was secrecy surrounding mental illness, where caregivers were reluctant to disclose the illness due to fear of stigma and societal judgment. A qualitative study conducted in Saudi Arabia similarly identified a dilemma of disclosure, where caregivers struggled with whether to reveal the diagnosis due to concerns about privacy and social perception [15]

Accessibility to healthcare facilities was also identified as a major barrier. Caregivers reported a lack of nearby mental health services, limited availability of psychiatrists, psychotropic medications, and admission facilities, as well as financial difficulties related to travel and treatment costs. Additionally, unstable financial situations further compounded caregiving challenges, particularly when caregivers were the sole earners. These findings are consistent with a qualitative systematic review that highlighted economic burden, limited healthcare access, and ineffective collaboration with health workers as significant barriers to caregiving [14].

The present study also identified fear and anxiety among caregivers, often related to managing disruptive and violent behaviors of patients. Similar experiences were reported in a qualitative study conducted in South Africa, where caregivers described dealing with aggression, property damage, and physical assaults by patients [16].

Lastly, lack of family support emerged as a major barrier, with caregiving responsibilities often falling on a single individual. A qualitative systematic review similarly reported lack of support as a significant barrier, noting increased family conflict and caregiver isolation [14].

CONCLUSION

In conclusion, it is clear that the caregivers of patients with chronic mental illness experience burden in caregiving. Caregivers may be overwhelmed by caregiving and experience challenges affecting their emotional, physical and financial wellbeing. The burden of caregiving can be overwhelming, affecting not only the caregiver's quality of life but also their relationships, work, and overall health. Addressing caregiver burden requires a comprehensive and multifaceted approach that includes developing targeted support systems, increasing access to resources and services, and promoting awareness and understanding of the challenges faced by caregivers. By prioritizing the needs of caregivers and providing them with the necessary support and resources, we can improve caregiver well-being, enhance patient outcomes, and promote a more sustainable and compassionate healthcare system.

Declaration by Authors

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