

# Exploring the Lived Experiences of Family Members Caring for Persons with Mental Illness - an Interpretative Phenomenological Analysis

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## ABSTRACT

**Background:** Families caring for individuals with mental illness often encounter significant challenges that impact their daily lives, including work, relationships, and social well-being. These responsibilities can result in high levels of stress and emotional strain. In Nepal, there is limited qualitative research on how family members perceive mental illness, manage caregiving duties, and cope with related stress. This study aims to explore the lived experiences of primary family caregivers, focusing on their challenges, coping strategies, and overall understanding of mental illness.

**Methods:** The study involved ten family caregivers from the Mental Hospital in Lagankhel and Chiryau Polyclinic in Kathmandu, collected through semi-structured interviews. Data was analyzed using thematic analysis and coded in NVivo, identifying shared patterns and meanings.

**Results:** Ten caregivers aged 30 to 64 (mean age 47.8) described their roles as deeply demanding and painful. They faced challenging behaviors and often sacrificed their own needs, resulting in emotional distress and exhaustion. The caregivers reported experiencing anxiety, burnout, guilt, anger, and social stigma. To cope, they relied on strategies such as crying, distraction, adaptation, inner resilience, and support from family or social networks. Many also found personal growth, emotional strength, and a clearer understanding of mental illness and its treatment. Finally, participants emphasized the critical need for education, professional and family support, systemic services, government-facilitated healthcare access, and financial assistance to sustain effective caregiving.

**Conclusions:** This study highlights the intense challenges faced by family caregivers of individuals with mental illness and underscores the need for strong support systems. Understanding their experiences and coping strategies can help guide targeted interventions, ultimately improving support for both caregivers and those they care for.

**Keywords:** Caregivers; family; mental disorders; mental health; qualitative research.

## INTRODUCTION

Mental illness affects everyday functioning, including mood, thinking, and relationships.<sup>1</sup> Family members play a crucial role in caring for and treating individuals with mental illness.<sup>2,3</sup> The presence of a family member with mental illness significantly decreases overall quality of life.<sup>4-7</sup> Families face challenges like stigma, discrimination, and caregiving difficulties, which are well-documented globally. In developing countries, many individuals with mental illness live with family members who serve as primary caregivers and often experience psychological suffering without adequate social support.<sup>8,9</sup> A study in rural Nepal found that most caregivers were females (56.3%) and under the age of 45.<sup>10</sup>

There is limited qualitative research on the experiences of caregivers in Nepal, their knowledge of mental illness, caregiving abilities, and strategies for managing caregiving stress. This study aims to explore these lived experiences.

## METHODS

A person's lived experience of an event, the meaning they ascribe to it and their attempts to make sense of it may all be thoroughly examined using Interpretative Phenomenological Analysis.<sup>11</sup> A qualitative study design, particularly IPA, was used to explore the lived experiences of individuals who are caring for their loved ones with mental illness. IPA allows researchers to delve deeply into the subjective experiences and meanings

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that caregivers attribute to their roles, relationships, and challenges.

The study was carried out in Nepal's capital, the metropolitan area of Kathmandu. Family carers of patients with mental illness who are referred to the psychiatric clinic and/or admitted to a mental hospital from November 7<sup>th</sup>, 2023, to March 2024 make up the study population. In addition, the purposive sampling method was used to collect qualitative data based on the saturation principle. Data saturation was achieved after interviewing 10 participants. The duration of the interview sessions varied, with interviews typically lasting between 30 and 90 minutes on average.

Semi-structured face-to-face interviews were conducted using an interview guide. The past literature on the topic was reviewed to create a rough interview guide. It was initially written in English and later translated into Nepali. Before the data collection, a pilot interview was conducted with two family caregivers taking care of a loved one with mental illness. The pilot interview confirmed the suitability of the interview guide, requiring no changes.

Prior to the commencement of the study, the Research Committee of the Padma Kanya Multiple Campus, Department of Psychology at Tribhuvan University in Kathmandu gave its clearance.

The fieldwork started after ethical approval from the Nepal Health Research Council (NHRC). Informed consent was obtained from all the participants who agreed to participate in the study. This was done both verbally and in writing, ensuring that they had a detailed understanding of the study's purpose, procedures, potential risks, and benefits. Also, approval was received from the outpatient psychiatric clinic as well as mental hospital for data collection.

Furthermore, since it was a self-funded study, participants did not get any monetary compensation. The following were the inclusion and exclusion criteria.

The study required participants to be first-degree relatives of individuals currently receiving treatment for mental illness, residing in the same household, and at least 18 years old. Both male and female participants were eligible.

The study's exclusion criteria included family members with a chronic physical illness, individuals who had difficulty communicating or faced language barriers, and participants younger than 18 years of age.

## RESULTS

**Table 1. Demographic details of participants and relatives for whom they care.**

Participant's ID	Age	Gender	Marital Status	Duration of caregiving	Relation with the patient	Diagnosis
P1	54	M	Married	4 years	Daughter	Schizophrenia/ Psychosis
P2	46	M	Married	10 years	Wife	Bipolar
P3	60	M	Married	6 months	Son	Depression
P4	46	F	Married	5 years	Son	Substance-induced psychosis
P5	40	F	Widow	5 years	Son	Substance-induced psychosis
P6	30	F	Unmarried	5 years	Brother	Schizophrenia/Psychosis
P7	57	F	Married	30 years	Husband	Schizophrenia/Psychosis
P8	36	F	Married	5 years	Daughter	Personality Disorder
P9	45	M	Married	10 years	Wife	Schizophrenia/Psychosis
P10	64	F	Married	40 years	Husband	Schizophrenia/Psychosis

Ten family caregivers were recruited for the study, comprising six females and four male participants. The age of the sample ranged from 30 to 64 years, with a mean age of 47.8. Participant demographic and relationship with the

patient are summarized in Table 1

Five major superordinate themes and twenty five subthemes emerged from each superordinate theme (Table 2)

**Table 2. Superordinate themes and subthemes.**

Superordinate themes	Subthemes
1. Family members experienced the caregiving role as highly demanding and difficult, causing a lot of pain.	<ul style="list-style-type: none"> <li>• Difficult and demanding caregiving experience</li> <li>• Navigating the emotional and physical threat of behavioral volatility.</li> <li>• Caregivers often sacrificed their own needs and well-being to prioritize the care of their ill family members, leading to emotional distress and physical exhaustion.</li> <li>• Compounded burden of psychotic reality and community isolation.</li> <li>• A sense of loss and frustration over unfulfilled personal aspirations and missed opportunities.</li> </ul>
2. Family members experienced overwhelming emotional and psychological challenges as a result of their responsibilities.	<ul style="list-style-type: none"> <li>• Constant feeling of anxiety and stress.</li> <li>• Feelings of burnout and desire to escape.</li> <li>• Feelings of confusion and helplessness.</li> <li>• Feelings of embarrassment and guilt.</li> <li>• Feelings of hurt, anger, and resentment.</li> <li>• Feelings of isolation.</li> <li>• Facing negative societal attitudes and social discrimination.</li> </ul>
3. Coping strategies caregivers employ to manage their stress.	<ul style="list-style-type: none"> <li>• Crying as a coping mechanism</li> <li>• Distraction as a coping mechanism.</li> <li>• Embracing change as a coping mechanism.</li> <li>• Internal Resources for Resilience.</li> <li>• Seeking support from family and social networks</li> </ul>
4. Caregivers 'forward looking perspectives to enhance the understanding of mental illness among family members, thereby fostering greater acceptance and promoting personal growth.	<ul style="list-style-type: none"> <li>• Navigating the Depths of Emotional Resilience</li> <li>• Personal growth and awareness as a positive aspect of caregiving</li> <li>• Understanding the importance of medical attention for proper treatment</li> </ul>
5. Recognizing the importance of education, and need for family, and systemic support to overcome significant financial and practical hardship.	<ul style="list-style-type: none"> <li>• Education and awareness on mental health and mental illness</li> <li>• Professional support for caregivers</li> <li>• The government plays a crucial role in providing improved and easy access to health care facilities for its citizens.</li> <li>• Financial assistance</li> <li>• Family and community support</li> </ul>

Thematic analysis revealed the emotional and psychological strain family members faced while caring for individuals with mental illness. The participants' experiences can be categorized into five major themes and twenty five sub themes that emerged from the data analysis.

Family caregivers described sacrificing their own needs, dreams, and personal well-being to meet the demands of caregiving, leading to feelings of helplessness, isolation, and resentment. The role consumed their lives, leaving little room for personal growth, fulfilment, or self-care.

*"Ah, sometimes it irritates me greatly. I also have a job, and there are moments when I am quite stressed at work. I become angry and disappointed when she doesn't seem to understand my circumstances. She has been complaining about nightmares and trouble sleeping lately. She sleeps all day and doesn't go to sleep at night. I must thus arrange to work from home and adjust my office hours. Handling everything at work and taking care of her at the same time*

*is really challenging.” (P8)*

Navigating the emotional and physical threat of behavioral volatility.

The caregiving experience was characterized by intense emotional and psychological strain, as caregivers navigated through unpredictable behaviours, violence, and constant worry for the safety of their ill relatives and themselves

*“The difficult times were when he became aggressive and violent towards me. If he didn't like something and became stressed because of it, he would instantly try to hit me. During those times, I would try to protect myself, either by hiding in my son's room or locking myself in my room.”(P7)*

Caregivers often sacrificed their own needs and well-being to prioritize the care of their ill family members, leading to emotional distress and physical exhaustion.

*“I'd say I went through a lot of pain. I am the only one who can take care of her here. Back at home, my mother is also sick. My own health isn't in great shape either. I have been operated on a few times for kidney stone.” (P1)*

*“I cannot eat or sleep whenever I want. I don't get to rest well. Despite my personal health issues. I can't hear well out of my left ear but I've always put her needs first.” (P2)*

Caregivers face immense strain from their loved ones inability to distinguish between realities from illusion. Community pressure and constant vigilance to prevent harm intensify their distress, deepening feeling of isolation, inadequacy, and emotional pain.

*“She couldn't tell what was real and what wasn't and would go about the village shouting hurtful things at everyone. People in my village put a lot of pressure on me as well. She would often threaten to kill herself, and as a result, I became extremely worried.” (P1)*

A sense of loss and frustration over unfulfilled personal aspirations and missed opportunities.

Caregivers expressed longing for normalcy and opportunities lost due to mental illness in their families. This reflection on a paused life highlights the emotional complexity and a deep sense of loss they experienced while caring for their loved ones.

*“Two years into my marriage, my husband fell sick. Since then, I've felt like my life has been on hold. We never got the opportunity to enjoy our time together as newlyweds, and even now, we hardly go out. I find myself either working at my office or taking care of him. It feels as though my life is on pause.” (P10)*

Caregivers experienced emotional strain, often feeling helpless, discouraged, and frustrated. Constant care leaves them overwhelmed and exhausted, limiting their leisure and social life.

All the caregivers expressed a range of distressing emotions, such as sadness, anxiety, fear, frustration, disappointment, constant worry, and others.

*“I didn't go for a doctor's consultation, but I think I had symptoms of anxiety as I had a racing heartbeat, sweating, nervousness, and difficulty breathing.” (P7)*

Many feel burned out and wish to escape their caregiving roles, expressing a strong desire for relief, at times even having thoughts of death.

*“I've also wished I were dead in the past so that I wouldn't have to cope with anything, especially the responsibilities that I've been drowning under my entire life.” (P10)*

The relentless demands of caregiving leave caregivers exhausted, emotionally drained, and lacking the energy or motivation to continue fulfilling their caregiving role.

*“I mostly feel very helpless (cries), and I try to console myself saying this is my fate.” (P1)*

Feelings of embarrassment and guilt.

Caregivers also feel embarrassed and ashamed due to the unpredictable behaviors and symptoms that their ill relatives exhibit in social situations.

*“She would undress herself and walk around when we had guests at home. That's embarrassing.” (P2)*

Caregivers often felt hurt, anger, and due to the challenges they faced, including violence, abuse, and rejection from their ill relatives.

*“I wonder if I did anything wrong to him and that's why he behaves so rudely with me. He was always upset and angry. There was not even a day when he was quiet and calm. I see the improvement in him after he started*

taking his medicines but his attitude towards me hasn't, and that hurts very much." (P6)

*"Many people are ignorant about this issue and don't support you. The patient screams and shouts at you, the community also shames you and badmouths you, so yes, and I do feel alone." (P2)*

Caregivers shared how their relatives' erratic behaviours are often misunderstood, leading to stigma and judgement. Most hid their family member's mental illness out of fear of gossip, discrimination, and societal disrespect.

*"People at my hometown call my son insane and they say that no one should allow him to enter their homes. They talk very badly behind our backs." (P5)*

Participants frequently mention crying as a way to cope with the stress and emotional burden of caring for a relative with mental illness.

*"For me, crying really helped me manage and cope with stress. I feel much lighter and relieved after a good cry, so that's all I did." (P7)*

Distraction techniques, such as watching television shows, browsing social media, listening to music, and engaging in hobbies, serve as effective coping mechanisms for participants

*"When I feel exhausted, I divert my mind by watching YouTube and TikTok. I find it a very easy medium to distract my mind and forget about my worries." (P10)*

Some caregivers cope by embracing change and adapting to new circumstances.

*"Acceptance is my main coping mechanism. I have accepted that he is not well, and I have to get him the treatment he needs to recover." (P7)*

Internal resources, such as resilience, faith, positive self-talk, and introspection, play a crucial role in helping participants navigate the complexities of caregiving.

*"I prayed a lot. I have always had faith in God, so praying helped." (P4)*

Seeking support from family members, friends, and other caregivers emerges as a vital coping strategy.

*"Well... to comfort myself, I share my issues and*

*frustrations with other family caregivers who are going through similar situations like mine. This is how I unload my tensions and find comfort." (P3)*

This theme highlights caregivers' journey of acceptance, growth, and resilience emphasizing the importance of emotional strength, proper treatment, and self-care.

Despite experiencing emotional breakdowns and moments of despair, participants in the study developed strong emotional resilience over time as they faced ongoing challenges in caring for individuals with mental illness.

*"Occasionally, I do feel sad, but again, I feel that it will work out somehow. I have hope." (P8)*

Caregivers noted that caregiving role enhanced their own personal growth and awareness.

*"I believe I am more aware of mental health issues now that it has occurred in my family. Just like we can get sick physically, we can also get sick emotionally and mentally. I have learned that we shouldn't hide our mental health issues and most importantly mental health shouldn't be stigmatized." (P8)*

Caregivers emphasized that medication is crucial in improving their loved ones' wellbeing and for understanding the progression mental illness.

*"Medicines are important to manage this kind of illness. Over the last 40 years or more, I know I couldn't have done this without the support of his psychiatrist. Also, one must be resilient to live with someone with mental illness because it is not easy, especially emotionally." (P10)*

Recognizing the importance of education, and need for family, and systemic support to overcome significant financial and practical hardship.

The final theme shows that caregivers stress the need for mental health education and awareness, calling for programs that reduce stigma, promote community understanding, and support families facing financial and practical hardship.

Caregivers highlighted the importance of raising awareness on mental health and mental illness to combat misconceptions and mistreatment of mentally ill individuals.

*“My key suggestion is to educate and raise people’s awareness of this illness. There won’t be any stigma if individuals are aware of this illness.” (P2)*

Some of the caregivers highlighted the necessity of tailored professional support and safe spaces where they can openly discuss their challenges.

*“Being able to talk honestly about the issue without hiding it would greatly help family carers. Financial support for medication, hospital costs, or hiring a nurse would also be valuable. With a professional carer, family members like me could continue our lives without sacrificing time, interests, education, or career opportunities.” (P10)*

Caregivers emphasized the need for better and more accessible healthcare facilities, particularly in rural areas, to ease financial burden and keep support networks close.

*“Maybe have this health facility at my village so that I didn’t have to come all the way to Kathmandu for his treatment. It would have saved me a lot of money and I would have had my close ones around me.” (P3)*

They also stressed the importance of financial support to ensure families can seek timely and appropriate treatment.

*“Most importantly, I believe financial support from any organization or even the local government is a must. Many families don’t have access to financial support and because of that they never seek treatment.” (P6)*

Caregivers highlighted the pivotal role of familial and community support networks in strengthening the resilience and improving the quality of care.

*“My family has supported me. In fact, I am not alone here, my daughter is also with me. Having her here has helped me a lot.” (P3)*

*“I have a sister and she has helped me a lot. If it wasn’t for her, I wouldn’t be here even now.” (P1)*

## DISCUSSION

This study investigates the experiences of family members who provide care for individuals with mental illness, emphasizing the emotional, physical, and financial challenges encountered by these caregivers. The findings reveal a substantial psychological burden

among caregivers, characterized by feelings of sadness, helplessness, exhaustion, and distress. These results are consistent with prior research that underscores the emotional toll experienced by family caregivers. For instance, Lubman et al.<sup>12</sup> and Chang and Horrocks<sup>13</sup> reported that caregivers endure significant mental and physical stress, frequently resulting in burnout and adverse health outcomes.

Compounding these difficulties is the inadequate provision of mental health treatments and support systems in Nepal. Caregivers often feel overwhelmed by the responsibility of addressing gaps left by the healthcare infrastructure. Upadhaya et al.<sup>14</sup> and Luitel et al.<sup>15</sup> have documented the acute shortage of mental health professionals and facilities in Nepal, further exacerbating the challenges faced by family members. The study indicates that caring for a relative with mental illness disrupts caregivers’ lives, resulting in emotional distress, strained relationships, and declining health, particularly due to behaviors exhibited by the affected individuals, such as aggression and paranoia. The illness significantly alters family dynamics and imposes additional burdens on caregivers’ roles. Financial difficulties underscore the necessity for support systems, highlighting the critical need for financial assistance and community support in caregiving contexts.<sup>16</sup> Moreover, the breakdown of social interactions and feeling of loneliness experienced by caregivers in this study align with the experiences described by Khanal<sup>17</sup> and Shimange et al.<sup>9</sup>, indicating this is a prevalent issue across various cultural contexts.

The study advocates for the development of tailored support programs that offer emotional, financial, and educational resources to family caregivers, promotes increased public awareness and stigma reduction, and emphasizes the imperative for systemic improvements in healthcare access and financial support to mitigate caregiver burden. Caregivers navigate a complex journey of acceptance, personal growth, and resilience, gradually reconciling with their loved ones’ mental illness and discovering the strength to persevere.

Interpretative phenomenological studies involve the researcher analysing and interpreting narratives of the participants. This analysis introduces the possibility of subjectivity and bias. The researcher acknowledges that this study is specific to Kathmandu, Nepal, and its findings may not be applicable in other regions of the country or the continent. Furthermore, the sample size of ten is a major limitation. Given the qualitative and interpretative nature of the study, it is important to

note that the findings may not be generalizable.

## CONCLUSIONS

In conclusion, this study reveals the significant emotional, psychological, and practical challenges that family caregivers of individuals with mental illness encounter. It emphasizes the urgent need for comprehensive support systems catering to the diverse needs of caregivers and care recipients. In the Nepali context, caregiving responsibilities are largely influenced by gender norms, with women typically expected to care for children, the elderly, and ill family members. Consequently, women often take on this demanding role with minimal support, experiencing considerable strain while also navigating societal pressures to maintain family honor and manage domestic responsibilities. The findings highlight the need for culturally sensitive interventions to alleviate this burden and enhance caregiver well-being.

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## REFERENCES

1. National Alliance on Mental Illness. About mental illness [Internet]. 2023 [cited 2023 Oct 13]. Available from: <https://www.nami.org/about-mental-illness/>
2. Chadda R. Caring for the family caregivers of persons with mental illness. *Indian J Psychiatry*. 2014;56(3):221.
3. Kusumawaty I, Surahmat R, Martini S, Muliyadi N. Family support for members in taking care of mental disordered patients. *Adv Soc Sci Educ Humanit Res*. 2021. <https://doi.org/10.2991/assehr.k.210415.026>
4. Behere AP, Basnet P, Campbell P. Effects of family structure on mental health of children: a preliminary study. *Indian J Psychol Med*. 2017;39(4):457-63.
5. Phillips R, Durkin M, Engward H, Cable G, Iancu M. The impact of caring for family members with mental illnesses on the caregiver: a scoping review. *Health Promot Int*. 2022;38(3). <https://doi.org/10.1093/heapro/daac049>
6. Robinson E, Rodgers B, Butterworth P. Family relationships and mental illness: impacts and service responses [Internet]. 2008 Nov 10 [cited 2023 Oct 13]. Available from: <http://apo.org.au/node/1782/cite>
7. Subu MA, Wati DF, Netrida N, Priscilla V, Dias JM, Abraham MS, et al. Types of stigma experienced by patients with mental illness and mental health nurses in Indonesia: a qualitative content analysis. *Int J Ment Health Syst*. 2021;15(1). <https://doi.org/10.1186/s13033-021-00502-x>
8. World Health Organization. World mental health report: Transforming mental health for all. Geneva: WHO; 2022.
9. Shimange M, Poggenpoel M, Myburgh CPH, Ntshingila N. Lived experiences of family members caring for a relative with mental illness. *Int J Afr Nurs Sci*. 2022;16:100408. <https://doi.org/10.1016/j.ijnans.2022.100408>
10. Kunwar D, Lamichhane S, Pradhan N, Shrestha B, Khadka S, Gautam K, Risal A. The study of burden of family caregivers of patients living with psychiatric disorders in remote area of Nepal. *Kathmandu Univ Med J*. 2020;18(2):41-45. <https://doi.org/10.3126/kumj.v18i2.33224>
11. Smith JA, Osborn M. Interpretative phenomenological analysis. In: *The British Psychological Society and Blackwell Publishing Ltd eBooks*. 2008. p. 229-54. <https://doi.org/10.1002/9780470776278.ch10>
12. Lubman DI, Bamberg J, McCann F. Family carers' experience of caring for an older parent with severe and persistent mental illness. *Int J Ment Health Nurs*. 2015;24(3):203-12. <https://doi.org/10.1111/inm.12135>
13. Chang KH, Horrocks S. Lived experiences of family caregivers of mentally ill relatives. *J Adv Nurs*. 2006;53(4):435-43. <https://doi.org/10.1111/j.1365-2648.2006.03732.x>
14. Upadhaya N, Jordans MJD, Pokhrel R, Gurung D, Adhikari RP, Petersen I, et al. Current situations

- and future directions for mental health system governance in Nepal: findings from a qualitative study. *Int J Ment Health Syst.* 2017;11(1). <https://doi.org/10.1186/s13033-017-0145-3>
15. Luitel NP, Jordans MJ, Adhikari A, Upadhaya N, Hanlon C, Lund C, et al. Mental health care in Nepal: current situation and challenges for development of a district mental health care plan. *Confl Health.* 2015;9(1). <https://doi.org/10.1186/s13031-014-0030-5>
  16. Sharif L, Basri S, Alsahafi F, Altaylouni M, Albugumi S, Banakhar M, et al. An exploration of family caregiver experiences of burden and coping while caring for people with mental disorders in Saudi Arabia - a qualitative study. *Int J Environ Res Public Health.* 2020;17(17):6405. <https://doi.org/10.3390/ijerph17176405>
  17. Khanal P. Perceived stigma among caregivers of mentally ill patients: a descriptive cross-sectional study. *J Kathmandu Med Coll.* 2021;10(1):43-46. <https://doi.org/10.3126/jkmc.v10i1.38971>