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ORIGINAL RESEARCH

Experiences, Knowledge and Perceptions of Family Caregivers of Individuals with Mental Illness: A Qualitative Thematic Analysis

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ABSTRACT

Background: Family caregivers are key players in the provision of support to mentally ill patients, especially in low-resource and community-based care facilities.
Objectives: The objective of the proposed study was to investigate the experiences of family caregivers concerning persons with mental illness and their knowledge and perceptions of the caregiving role.
Methodology: The qualitative descriptive design was adopted in the form of the six phases in the thematic analysis framework by Braun and Clarke. A total of 20 family caregivers of the outpatient psychiatric clinics of Azadi Teaching Hospital were recruited using purposive sampling. The data were gathered using semi-structured face-to-face interviews in Arabic, audio-taped, transcribed in their verbatim, and English translations. The collection of data was done until saturation was reached.
Results: There were six high-level themes, including caregiver duties and stress, emotional and psychological impact, role transformation and altered family relationships, coping strategies and lack of support, knowledge and misconceptions, and resiliency and new outlook. Caregivers reported they spent many hours a day supervising, the person didn't take medication, risked their safety, became emotionally exhausted, placed financial burdens on the family and felt stigmatized. Poor mental health literacy and cultural models of explanation were affecting behaviors of seeking help and management of crisis.
Conclusion: Mental illness family care is a multidimensional and transforming experience that may be associated with a high burden and considerable resilience. It is critical to enhance family-focused psychoeducation, diminish stigma, increase access to services and enhance culturally competent support systems.

Keywords: Experiences; Knowledge ; Perceptions; Family caregivers; Mental illness.

INTRODUCTION

Family caregivers are a key source of support for people with mental illness, especially when there is less access to mental health services and resources. Families have taken on a larger role in managing symptoms, providing emotional support, mediators in crisis situations and providing treatment coordination as more and more mental health services move into the community. These duties may lead to psychological, social, and financial burden on caregivers, such as stress, fatigue, and routine disruption, stigma, and reduced quality of life (Ntsayagae et al, 2019; Sharif et al, 2020).

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Knowledge and understanding of mental illness matters for caregivers' caregiving practices and help-seeking. Low mental health literacy can result in misunderstandings about causes and treatments of mental disorders, delayed access to professional services, and use of non-evidence-based methods. Higher mental health literacy, on the other hand, is linked to better interactions with health care providers, effective coping mechanisms, and psychiatric crisis management (Alyafei et al., 2021).

Although there is growing awareness of the contribution of caregivers, there are still significant gaps in knowledge about how caregivers understand mental illness, react to its stigma, access help and support, and adjust to the long-term demands of care provision in different sociocultural contexts. Most of the existing literature has been centered around caregiver burden and less on the meanings and experience of caregiving, which are likely as important as burden. Thematic analysis, as a method of qualitative research, is suitable for exploring these lived experiences and finding patterns that cannot be detected by quantitative methods (Abolfotouh et al., 2019). Such a better understanding of these experiences can inform culturally responsive psychoeducational interventions, family-focused services, and policies that serve to bolster caregiver resilience and enhance mental health outcomes (Davies, 2024).

The study aims through a qualitative thematic analysis to produce detailed perceptions, which can be used to inform culturally sensitive interventions, family-based support plans and policies to promote better caregiver wellbeing and greater continuity of mental health care.

AIMS OF THE STUDY

Objective of the study was to understand the day -to- day caregiving issues and challenges faced by family caregivers of mentally ill relatives. To investigate the emotional, psychological, social and financial effects of care giving on the family members.

METHODOLOGY

Study Design

This study employed a qualitative descriptive design using Braun and Clarke's thematic analysis approach to explore the experiences, knowledge, and perceptions of family caregivers of individuals with mental illness.

Study Setting

The study was conducted in outpatient psychiatric clinics, at Azadi Teaching Hospital , Caregivers were recruited from families caring for individuals diagnosed with mental illness and receiving treatment or follow-up in the selected setting.

Participants and Sampling

Inclusion Criteria

Family caregivers who:

1. Provided care for a relative diagnosed with a mental illness for at least 6 months.
2. We're aged 1 8 years or older.
3. Were directly involved in daily caregiving tasks (e.g., supervision, emotional support, medication monitoring).
4. Were able and willing to participate in an in-depth interview.

Exclusion Criteria

1. professional caregivers.
2. Caregivers of individuals with acute organic conditions, unless psychiatric comorbidity was present.

Sampling

A purposive sampling approach was used to ensure inclusion of caregivers with rich, diverse caregiving experience. Sampling continued until data saturation was achieved. A total of 20 caregivers participated in the study.

Data Collection

Instrument: Data were collected using a semi-structured interview guide developed based on literature review and expert consultation. The guide covered:

1. Daily caregiving responsibilities.
2. Emotional and psychological impact.
3. Knowledge and beliefs about mental illness.
4. Stigma, cultural perceptions, and family dynamics.
5. Coping strategies and support needs.

Interview Procedure

Face-to-face interviews were carried out in a convenient and private place. The duration of every interview was about 30- 45minutes.. The interviews were done in Arabic, and audio-taped with the consent of the participants and subsequently transcribed word-by-word. Transcripts were put into English to be analyzed. Transcripts were reviewed twice to guarantee accuracy on the part of the researcher, as well as preservation of meaning of local expressions.

Ethical Considerations

Informed consent obtained from Kirkuk health directors.- Ethical committee approval .And also informed written consent was obtained from all participants. Voluntary participation and the right to withdraw at any time were ensured. Anonymity was maintained through assigning participant codes instead of names. Audio recordings and transcripts were stored securely and accessed only by research.

Data Analysis

Data was analyzed using Braun and Clarke's (2006) six-phase thematic analysis framework to ensure a systematic and rigorous examination of caregivers' narratives. The analysis began with familiarization with the data, during which the researcher repeatedly read the Arabic transcripts and their English translations to gain a comprehensive understanding of the content and contextual meanings.

Next, initial codes were generated through manual inductive coding using Microsoft Word. Significant statements related to caregiving responsibilities, challenges, emotional experiences, knowledge, cultural beliefs, and coping strategies were identified and coded. These codes were then organized in the third phase, searching for themes, by grouping similar codes into preliminary subthemes and overarching themes that reflected caregivers' lived experiences and perceptions. During the reviewing themes step, the emerging themes were narrowed down by evaluating how they made sense of the coded excerpts and the dataset in general. Differing themes were combined, and the ones that were not supported enough were dropped to enhance analytic clarity. In the fifth step, defining and naming themes, conceptual refinement of the themes was done, and they were given clear narrative definition, and subthemes were clustered to represent the multidimensional nature of caregiving experiences. Lastly, during the producing of report stage, the themes were grouped into a logical analytical story and backed up with word-to-letter quotes of the participants. This method ensured originality of the voices of the caregivers and strength of credibility of the outcomes.

RESULTS (Qualitative Findings):

Theme 1: Caregiver Responsibilities and Challenges

Caregivers reported high-level daily care tasks such as help with activities of daily living, care over hygiene, and constant monitoring of symptoms, indicating a change in patient autonomy to dependency. The issue of medication supervision and non-adherence were also predominant because patients would often drop treatment once they felt better, resulting in a relapse and the added responsibility of caregiving on the part of the caregiver. Constant safety worries and hyper vigilance were reported with caregivers indicating that they feared they would self-harm or harm others and reorganized their daily lives around constant supervision. There was also a lot of emotional and physical tiredness such as stress, insomnia, burn out and exposure to aggressive behaviors. Lastly, there were significant financial costs including treatment, transport costs, and lost employment.

Theme 2: Emotional and Psychological Effects

The long-term illness and the intermittent symptoms were cumulatively reflected and manifested helplessness and hopelessness. Repeating relapses caused emotional depletion, sleeping problems, and lack of hope of recovery. Caregivers reported deep distress over the condition of their loved ones. Stigma and shame became a prominent social liability. Participants complained of negative community labeling, rejection and social exclusion. Stigmatization attitudes contributed to secrecy, withdrawal, isolation and aggravated caregiver strain. Frustration and guilt were usually voiced. Caregivers described self-blame over the development of illness and frustration about unpredictability of behaviors and conflicting family. Rejection of illness by other family members especially spouses also exacerbated emotional distress.

Theme 3: Role Changes and Changed Family Dynamics

The reallocation of roles in the family was manifested by disrupted family roles. Caregivers also took up a variety of roles at their own cost to the detriment of their needs which resulted in role strain and intrafamilial conflict. Lack of equal care giving roles created tension and other children were emotional and jealous because of perceived neglect. Social isolation was also on the spot. Participants noted decreased involvement in social activities in the community and withdrawal, voluntarily in some cases because of the stigma and involuntarily because of lack of access in the community. Reduced invitations, lack of interest in getting to know the neighbors and being marginalized only contributed to a feeling of isolation.

Theme 4: Support Needs and Coping Mechanisms

Failure to cope with the situation was also noted through dependence on denial, fear-based reactions or solely relying on traditional healing methods. Citing lapses in the knowledge and crisis management competence, some caregivers explained the symptoms by supernatural causes and indicated limited readiness to crises, like panic attacks or aggression. Lack of formal and informal support also added to burden. Participants also reported a lack of access to mental health services specializing in mental health, long journey times, and financial constraints. Lack of adequate guidance by health workers on the response and long-term management of crisis and the lack of adequate preparation and support of systemic shortcomings in caregiver preparations and support were also reported by the families.

Conversely, positive coping mechanisms were found in some caregivers because they actively sought professional assistance, support networks, and reframed mental illness as a treatable condition. The more knowledge, the less stigma, better treatment adherence, and acceptance.

Theme 5: Knowledge and Misconceptions

Insufficient mental health literacy was observed in the inadequate knowledge of the caregivers with regards to diagnosis, symptoms, triggers, and crisis management. The participants said that they had problems with differentiating between myths and true information, making them uncertain and fearful of reacting to unpredictable actions. Interpretations of illnesses and help-seeking behaviors were highly influenced by cultural beliefs. Most of the caregivers claimed mental illness to be caused by supernatural powers like the evil eye, black magic or possession by spirits. These beliefs tended to slow down medical consultation and were supported by the fear of social repercussions, such as stigmatization, marriage opportunities, and family reputation. Conversely, education influenced the outcomes through the experience, manifested in increased illness acceptance and decreased stigma, as well as increased treatment adherence. Better knowledge or prior experience in caregivers showed more confidence, resilience and more effective coping mechanisms.

Theme 6: Changed Perspectives and Resilience

The process of acceptance and advocacy proved to be very transformative where caregivers redefined mental illness through compassion and sympathy. Acceptance was linked with a better emotional stability and less internal conflict. Other caregivers even took up the role of advocacy where they gave advice and counsel to other caregivers with similar experiences. The sources of resilience were hope and spiritual strength. Spiritual faiths offered purpose, patience and emotional perseverance and sickness was often viewed as a challenge of God or fate. Religion strengthened long-term care-giving commitment and endured caregivers amidst life-long suffering.

DISCUSSION:

This study emphasizes that the process of family caregiving to family members with mental illness is multidimensional and transformative due to the significant burden of responsibilities, psychological distress, stigma, financial burden, disrupted family relationships, and unequal access to resources. Meanwhile, the adaptability, resilience and meaning-making of caregivers were also shown, usually based on spirituality and increasing health awareness.

As reported in the literature, caregivers detailed the growing daily care responsibilities and intense surveillance (i.e., symptoms, relapse, and safety) which further augment role strain and burnout. The most notable problem was medication non-adherence, which was common when patients felt well resulting in relapse issues and placing more responsibility on caregivers-patterns that are highly prevalent in severe mental illness (Laranjeira et al., 2023). Chronic and relapsing severe mental illnesses might also contribute to the growing caregiving burdens, as they often need on-going supervision and assessment of symptoms. Families often take on tasks that would be performed by health and mental health care providers in settings with insufficient or inadequate community mental health services, which increases the burden of the family caregiver. The fear of self-harm and hypervigilance reported by caregivers are indicators of how the safety concerns may limit autonomy and amplify caregiver anxiety and distress (Carswell et al., 2024).

There was a significant helplessness, hopeless and grief in emotional narratives especially when symptoms were exacerbated, behaviors were unpredictable or treatment appeared unproductive (Munie et al., 2024). Aggression/violence reports also highlight the susceptibility of caregivers to trauma and chronic stress. (Wildman et al., 2023).

Financial accounts were focused on direct and indirect expenses (treatment, travel, frequent consultations and lost jobs). This financial impact reported by participants could be especially heavy in the Iraqi context where mental health services are more likely to be found in urban areas and where out-of-pocket payments for health care are relatively high. These factors, combined, lead to economic stressors and caregiving stresses (Perlick et al., 2016). Notably, participants reported about a loop where financial stress, insufficient services, and emotional tax burden feed off each other, augmenting caregiver burnout risk (Cham et al., 2022).

Stigma was not only a social problem, but also also a mechanism that indirectly aggravated the burden of the caregiver. These worries about the risk of backlash from society can lead to secrecy and social isolation, reducing the potential for materials and services that could relieve caregiving stress. This process echoes the notion of ‘courtesy stigma', where the stigma endured by family members is a result of their relationship with someone with a mental illness. This can thus create a vicious cycle of isolation, emotional distress and decreased help-seeking behaviour, as reported by Wang et al. (2023). The families in the current study also reported experiencing internal conflict and family support that was limited, indicating that the impact of stigma may

not be limited to the community level, but also affect family systems (Evans et al., 2024).

Most caregivers had reported superstitions and beliefs that impacted help-seeking and even biomedical treatment (Goda et al., 2025). In contrast, caregivers who were educated, received professional advice, or had increased knowledge from experience seemed to be less stigmatizing, more confident and more supportive of adherence and crisis management (Kishore et al., 2011).

Although the burdens they had were considerable, the caregivers had also positive adaptation, such as acceptance, advocacy, and problem-focused coping (support groups, information-seeking). The coping particularly in the spiritual front was very relevant and served as a source of endurance as well as hope and assisted caregivers in maintaining long-term commitment to care (Simões et al., 2024). In general, these results highlight the need for family-focused mental health interventions, such as psychoeducational programs, stigma reduction programs, accessible support services and shared decision-making in the development of care plans to help reduce burden and build resilience (World Health Organization, 2024).

CONCLUSIONS:

1. Caregiving for people with mental illness is associated with significant multiple burdens, including high levels of supervision, emotional distress, financial strain and social isolation due to stigma. These burdens converge to increase the risk of burnout, and contribute to poor mental health.
2. Concerns about safety and low levels of mental health literacy play a major role in caregivers' experience, impacting medication regimes, crisis procedures and seeking help. Myths, cultural explanatory frameworks and a lack of professional support can lead to a delay in treatment and contribute to caregiver distress.
3. Despite the difficulties, caregivers have adjustment and coping strengths such as acceptance, advocacy, spiritual practices and problem solving. Such capacities suggest the possibility of interventions to bolster resilience and diminish stress through appropriate structural and educational supports.

RECOMMENDATIONS:

1. Implementing structured family psychoeducation in routine mental health care targeting illness awareness, adherence to treatment, relapse prevention and crisis management. Use culturally sensitive and differentiated education materials.
2. Implement community-based support services for caregivers, such as peer support groups, counseling, respite and stigma reduction services, to alleviate caregiver burden and enhance coping.
3. Improve mental health policies to better support family carers with subsidized treatment costs, better access to community and primary mental health services, and better engage family carers in care planning and decision making.
4. Do research and evaluation of caregiver support programs, using both intervention and longitudinal methods, to identify effective supports and viable means for enhancing caregiver and patient outcomes.

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TABLES:

Table (1): Caregiver Responsibilities and Challenges

Subtheme	Key Findings	Illustrative Quotes
Day-to-day caregiving responsibilities	• Caregiving occurs within the family and continues throughout illness stages.• Caregivers provide meals, assist with supervising hygiene, monitor symptoms and relapse signs.• Clear shift from patient independence to dependence.• Care tasks require constant reminders and replace the patient's own functioning.	"He used to take care of himself, but now you have to tell him to do everything. ""When he is well he eats too much, but other times… he throws food away."
Medication supervision and non-adherence	• Medication refusal is very common.• Patients often stop medication when feeling better → frequent relapse.• Caregivers	"Sometimes when he feels comfortable… he stops the medication. "Unless I personally

	must persuade or directly administer medication.• Non-adherence creates fear, frustration, and increased responsibility.	administer the medicine, she does not follow the same."
Safety concerns & hypervigilance	• Caregivers report always being afraid of self-harming or harming others.• Routines at home are reconstituted around patient safety.	"I am so scared when I am away and leave my mother alone. I think she can be able to hurt herself"
Emotional & physical exhaustion	• Caregivers experience emotional breakdown, sadness, constant fear, helplessness.• Exposure to aggression: hitting, throwing objects, destruction of property.• Physical exhaustion: insomnia, burnout, depression.	"She hit me ""I was burnt out with thinking… insomnia and depression."
Financial burden	• Medical bills, time and money spent on test-retesting. • Lost income because of caregiving needs. • Problems with covering medication costs or transportation to the doctor.	"The cost of transport to get free medicine is nearly the same as purchasing the drug. "" Due to repeated tests, I lost all my money."

Table (2): Emotional and Psychological Effects

Subtheme	Key Findings	Illustrative Quotes
Helplessness & hopelessness	• Long-term illness, fluctuating symptoms repeat cycles of fear and despair.• Caregivers describe mental exhaustion and losing hope for recovery.• Emotional pain from seeing loved ones deteriorate.	"My experience was very difficult and stressful… I could not sleep. ""We lost hope she would ever recover."
Shame & stigma	• Community labels mentally ill people as "crazy."• Caregivers experience rejection, insults, and social avoidance.• Stigma leads to shame, secrecy, and isolation.	"They think the mentally ill is crazy and incapable. ""We felt as if we were alone on an island."
Guilt & frustration	• Caregivers blame themselves for the illness or inability to prevent harm.• Frustration due to unpredictable behavior and family conflict.• Spousal denial increases caregiver distress.	"I blame myself sometimes—was it because my uncle had a similar condition? ""My husband will not believe she is really sick."

Table (3): Role Changes and Changed Family Dynamics

Subtheme	Key Findings	Illustrative Quotes
Disrupted family roles	• Caregivers take on additional roles at expense of own needs.• Conflict arises due to unequal distribution of responsibilities.• Children express jealousy and emotional strain.	"I feel like I failed my other children… all my attention goes to her."" My son cried: 'You love her more than us.'"
Social isolation	• Caregiving reduces social participation and contact.• Some caregivers avoid social situations due to stigma.• Neighbors stop visiting; families feel excluded.	"We were not invited to celebrations." "All the neighbors stayed away from us."

Table (4): Support Needs and Coping Mechanisms

Subtheme	Key Findings	Illustrative Quotes
Ineffective coping	• Caregivers rely on denial, fear, panic, or traditional healing alone.• Lack of preparedness for crises (panic attacks, aggression).• Some interpret symptoms as supernatural causes.	"Some relatives say she was struck by the evil eye." "We used ruqyah… but her condition got worse."
Formal and informal support gaps	• Lack of special mental health facilities.• Distance and financial constraints.• Families are not well-informed during times of crisis.• Medical staff may not adequately prepare families.	"Our fight is made more difficult because of the distance to the hospital and lack of centers."
Positive coping	• Some caregivers join support groups, search for information, seek professional help.• Reframing mental illness as treatable reduces shame.• Improved knowledge increases treatment adherence.	"I do not feel ashamed; it is an illness that requires care. ""I saw improvement after following medical recommendations."

Table (5): Knowledge and Misconceptions

Subtheme	Key Findings	Illustrative Quotes
Limited mental health literacy	• Caregivers lack understanding of diagnosis, symptoms, and triggers.• Difficulty distinguishing between myths and accurate information.• Uncertainty about how to respond to crises.	"I don't know what's going on in his mind when he turns on the gas stove."
Cultural beliefs	• Many attribute illness to evil eyes, black magic, jinn, curses.• Cultural interpretations influence help-seeking and delay medical care.• Fear of social consequences (marriage, reputation).	"She was possessed by an evil spirit." "People say she will never be married now."
Impact of education	• Education improves acceptance, decreases stigma, and increases adherence.• Experienced caregivers more confident and effective.• Knowledge reduces fear and promotes resilience.	"I realized her sickness is a health condition, not weakness."

Table (6): Changed Perspectives and Resilience

Subtheme	Key Findings	Illustrative Quotes
Acceptance and advocacy	• Caregivers reframe illness with empathy.• Some become advocates, support others.• Acceptance improves emotional stability.	"I started to look at my son as more than a patient; I saw him as a person with an inner struggle."
Hope and spiritual strength	• Spirituality offers purpose, resilience and stamina.• Illness as a test or will of God.• Faith supports caregiver commitment.	"God will reward me for my patience. ""Illness is a test from God."