



Experiences of Family Caregivers in Caring for Patients with Schizophrenia: A Qualitative Study

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Abstract

Background: Family caregivers of individuals with schizophrenia in Iran face unique challenges due to the chronic nature of the illness and limited mental health infrastructure. Understanding their experiences within the sociocultural context of Iran, particularly in resource-constrained settings such as Guilan, is vital for developing culturally sensitive interventions.

Objectives: To explore the lived experiences of family caregivers of patients with schizophrenia in Guilan, Iran, with an emphasis on culturally specific challenges and strengths.

Methods: This qualitative study, conducted from March 2022 to January 2023 at a psychiatric hospital in Guilan, employed conventional content analysis. Fifteen family caregivers were purposively selected to maximize variation in socio-demographic characteristics until data saturation was achieved. Data were collected through in-depth, semi-structured interviews and analyzed using Graneheim and Lundman's approach.

Results: Three main themes emerged: "Culturally Shaped Caregiving Challenges", "Support Needs in a Resource-Limited Context", and "Positive Caregiving Outcomes", encompassing nine subthemes. Caregivers faced emotional, social, and financial burdens, which were intensified by regional stigma and Islamic cultural expectations. Positive outcomes included strengthened family bonds and personal resilience.

Conclusions: In Iran, particularly in Guilan, family caregivers require tailored interventions, including psychoeducation, financial subsidies, and stigma reduction programs, to address culturally specific challenges. Policymakers should prioritize family-centered interventions to enhance caregiver well-being and patient outcomes.

Keywords: Caregiving Burden, Family Caregivers, Guilan, Iran, Qualitative Study, Schizophrenia, Stigma

1. Background

Mental disorders represent a significant global health challenge, contributing to 13% of the global burden of disease, with approximately one in four individuals experiencing a mental health condition at some point in their lifetime (1). Among mental disorders, schizophrenia stands out as one of the most severe and debilitating, characterized by profound disruptions in thought, perception, emotions, language, sense of self, and behavior. Common symptoms include

hallucinations (e.g., auditory or visual experiences of phenomena that are not real) and delusions (fixed, false beliefs resistant to reason) (2). According to the World Health Organization, schizophrenia affects over 24 million people globally, with a prevalence of 0.6 - 1% in Iran (3). Low- and middle-income countries, including Iran, face disproportionate challenges due to limited access to mental health services, exacerbating the global and regional burden of the disease (1, 4).

The global shift toward deinstitutionalization, driven by policies aimed at reducing long-term psychiatric

hospitalizations, has significantly altered the landscape of care for individuals with schizophrenia. In many countries, including Iran, limited financial resources, shorter hospital stays, and restrictions on mandatory treatment have transferred the primary responsibility of care to families (5). This shift is particularly pronounced in Asian healthcare systems, where cultural norms, religious beliefs, and social structures emphasize family solidarity and collective responsibility (6). In Iran, Islamic values and traditional family structures, particularly in regions such as Guilan, further reinforce the expectation that families serve as primary caregivers for individuals with chronic conditions, including schizophrenia (7).

The chronic and unpredictable nature of schizophrenia imposes substantial challenges on family caregivers, who often experience significant emotional, social, and financial burdens. Caregivers frequently report high levels of stress, anxiety, and burnout due to the demanding nature of the illness, which requires constant vigilance and management of complex symptoms (8). Social isolation is a common consequence, as caregivers' social and leisure activities are often curtailed, leading to feelings of loneliness and disconnection from their communities (3). Additionally, societal stigma surrounding mental illness exacerbates these challenges, with 65% of caregivers in Iran, particularly in northern regions such as Guilan, reporting stigma-related barriers, such as social exclusion and employment difficulties (4). A study found that nearly 60% of family caregivers in Iran experienced stigma-related barriers, including negative societal perceptions that impacted their employment and social relationships (7).

Financially, schizophrenia places a heavy burden on both healthcare systems and families. The high costs of medication, therapy, and hospitalizations, combined with low family income and the occupational challenges faced by patients, create significant economic strain (9). In Iran, where public mental health funding is limited, families bear up to 80% of care costs, exacerbating economic strain, particularly in resource-scarce regions such as Guilan. Moreover, caregivers' needs are frequently overlooked by healthcare systems, which tend to focus primarily on the patient. Psychiatric nurses and other healthcare providers often exclude families from treatment planning and decision-making processes, leaving caregivers without adequate support or opportunities to voice their concerns (10). This lack of

engagement can exacerbate caregivers' sense of isolation and helplessness.

Despite these challenges, caregiving for individuals with schizophrenia can also yield positive outcomes. Research indicates that some caregivers experience personal growth, increased resilience, and enhanced self-esteem as they develop adaptive coping strategies and experiential knowledge of the illness (11). In the Iranian context, particularly in Guilan, where family ties are strong, caregivers may find meaning in their role, viewing it as a fulfillment of familial and cultural obligations. However, these positive outcomes are often overshadowed by the lack of formal support systems, such as psychoeducation programs, financial assistance, or community-based interventions, which are critical for sustaining caregivers' well-being (6).

The unique cultural, religious, and social context of Iran, particularly in Guilan, necessitates a tailored examination of caregivers' experiences. Islamic values emphasizing compassion and family duty, combined with traditional expectations of caregiving, create a distinct caregiving landscape compared to Western countries. Furthermore, societal attitudes toward mental illness in Iran, often influenced by misconceptions and stigma, add complexity to the caregiving experience (7). Qualitative research is particularly well-suited to capturing the nuanced, subjective realities of caregivers in this context, providing rich insights into their challenges, needs, and strengths.

2. Objectives

By exploring these experiences, this study aims to inform the development of family-centered interventions that address the specific needs of caregivers in Iran, ultimately improving outcomes for both caregivers and patients with schizophrenia.

3. Methods

3.1. Study Design

This qualitative descriptive study was conducted from March 2022 to January 2023 to explore the lived experiences of family caregivers of patients with schizophrenia in Guilan, Iran. A conventional content analysis approach was selected to identify culturally specific patterns in caregivers' experiences, tailored to the unique sociocultural context of the region (12).

3.2. Participants and Setting

The study was conducted at a referral psychiatric hospital in Guilan, Iran. Fifteen family caregivers were purposively selected based on a sampling matrix to ensure diversity in age (24 - 70 years), gender (60% female, 40% male), relationship to the patient (parents, siblings, spouses, children), and caregiving duration (5 - 14 years). Inclusion criteria included being over 18, fluent in Persian, and caring for a family member with a DSM-5-confirmed schizophrenia diagnosis who had completed at least one course of pharmacological treatment. Participants were identified through hospital records and contacted by the research team, with recruitment continuing until thematic saturation was achieved (13).

3.3. Data Collection

Data were collected through in-depth, semi-structured interviews conducted by the first author, a psychiatric nursing researcher with five years of experience in qualitative interviewing. An interview guide with 16 open-ended questions was developed based on a literature review and consultation with two psychiatric nursing experts and one clinical psychologist to ensure cultural and clinical relevance. Example questions included: "How has caring for your family member with schizophrenia shaped your daily life?" and "What resources or support have been most helpful or lacking in your caregiving role?" Probing questions (e.g., "Could you elaborate on that experience?") were used to elicit detailed responses. Interviews, lasting 45 - 75 minutes, were conducted in a private room at the hospital to ensure confidentiality and comfort. All interviews were audio-recorded with participants' consent and transcribed verbatim in Persian. Non-verbal behaviors, such as emotional tone and pauses, were documented in field notes to contextualize verbal data. Data collection continued until thematic saturation, defined as the point where no new themes or insights emerged after three consecutive interviews (13).

3.4. Data Analysis

Data analysis was conducted concurrently with data collection to refine the interview guide and focus on emerging themes. The process followed Graneheim and Lundman's conventional content analysis method. Transcripts were read multiple times by the first author

to immerse in the data, followed by identification of meaning units (text segments reflecting key ideas). These were condensed into codes, which were iteratively grouped into subcategories and categories based on similarities and differences. Themes emerged through constant comparison. The analysis was performed manually, with MAXQDA software used to organize codes and track thematic development. Weekly meetings with co-authors ensured analytical rigor, with discrepancies in coding resolved through consensus (14).

3.5. Trustworthiness

The study adhered to Lincoln and Guba's criteria for trustworthiness (14). Credibility was ensured through prolonged engagement during interviews (building rapport over multiple sessions when needed) and member checking, where five participants reviewed preliminary themes to confirm accuracy. Dependability was maintained through peer debriefing, with co-authors independently reviewing coding and thematic development. An audit trail, including detailed notes on recruitment, interview processes, and coding decisions, supported confirmability. Transferability was enhanced by providing detailed descriptions of the study context, participant characteristics, and direct quotations, allowing readers to assess applicability to other settings.

3.6. Ethical Considerations

Ethical approval was obtained from Guilan University's Ethics Committee ([IR.GUMS.REC.1400.141](#)). Participants provided written informed consent, with confidentiality ensured through anonymized data storage. Interviews were scheduled at participants' convenience, and access to a hospital-based counselor was offered to address potential emotional distress.

4. Results

Content analysis of interviews with 15 family caregivers of patients with schizophrenia yielded three main themes: Culturally shaped caregiving challenges, support needs in a resource-limited context, and positive caregiving outcomes, encompassing nine subthemes. Participants had a mean age of 45 years (range: 24 - 70), with 60% female and 40% single or divorced. They were parents, siblings, spouses, or children of patients, with caregiving experience ranging from 5 to 14 years ([Table 1](#)). The themes and subthemes, summarized in [Table 2](#), reflect the multifaceted

Table 1. Demographic Characteristics of Participants

Caregiver ID	Age	Gender	Marital Status	Education Level	Relationship to Patient	Occupation	Duration of Illness (y)	Duration of Caregiving (y)
1	52	Female	Married	Illiterate	Mother	Farmer	12	9
2	60	Female	Married	Bachelor's	Mother	Housewife	9	13
3	42	Female	Single	Master's	Sister	Social worker	15	10
4	55	Female	Single	Associate degree	Sister	Housewife	17	5
5	37	Male	Single	Bachelor's	Child	Freelancer	20	10
6	30	Male	Single	Bachelor's	Child	Cabinet maker	15	12
7	65	Female	Married	Bachelor's	Spouse	Housewife	18	12
8	42	Female	Married	Middle school	Spouse	Tailor	18	14
9	32	Female	Divorced	Bachelor's	Child	Freelancer	16	5
10	24	Female	Single	Student	Child	Housewife	8	8
11	38	Female	Divorced	High school	Sister	Housewife	9	11
12	45	Male	Married	Middle school	Father	Farmer	10	10
13	70	Male	Divorced	Bachelor's	Father	Retired teacher	8	8
14	36	Male	Married	Bachelor's	Spouse	Freelancer	7	6
15	47	Female	Married	Bachelor's	Mother	Housewife	10	10

Table 2. Themes and Subthemes

Themes	Subthemes
Culturally shaped caregiving challenges	Emotional distress, stigma-driven isolation, hopelessness, and family role conflicts
Support needs in a resource-limited context	Financial subsidies, psychoeducation, healthcare system engagement, and community awareness
Positive caregiving outcomes	Personal resilience, sense of duty, and family cohesion

challenges and benefits experienced in the Iranian sociocultural context, particularly in Guilan, where Islamic values and regional stigma shape caregiving. Each theme is detailed below with illustrative quotes.

4.1. Culturally Shaped Caregiving Challenges

This theme captures the emotional, social, and familial disruptions shaped by Guilan's cultural and religious context, with four subthemes: Emotional distress, stigma-driven isolation, hopelessness, and family role conflicts.

4.1.1. Emotional Distress

Caregivers reported significant psychological strain, including depression, anxiety, and exhaustion, due to the chronic and unpredictable nature of schizophrenia. A 38-year-old sister shared, "Some days, I feel so defeated I just want to sleep to escape. I'm more depressed than my mother" (Participant 4). A 34-year-old spouse added, "The constant worry about his episodes drains me emotionally." (Participant 13).

4.1.2. Stigma-Driven Isolation

In Guilan's stigmatizing environment, where mental illness is often attributed to spiritual causes, caregivers faced judgment and social exclusion. A 52-year-old mother stated, "I can't take her out; people stare and call her 'sick.' I feel trapped at home." (Participant 1). Another caregiver noted, "In our village, people think it's a curse, so we avoid social gatherings." (Participant 7, mother, 46 years).

4.1.3. Hopelessness

The chronicity of schizophrenia and lack of visible improvement fostered despair and loneliness. A 41-year-old wife said, "I've cared for him for years, but I'm helpless now. I've lost hope for us." (Participant 8). A 37-year-old sister reflected, "No matter how much I do, he stays the same. It's like I'm alone in this fight." (Participant 9).

4.1.4. Family Role Conflicts

Caregiving disrupted traditional family roles, particularly for women expected to fulfill multiple duties in Guilan's patriarchal culture. A 45-year-old father stated, "Our family life is in disarray. Nothing is normal anymore." (Participant 12). A 50-year-old mother added, "As a mother, I'm expected to care for everyone, but schizophrenia makes it impossible to balance." (Participant 3).

4.2. Support Needs in a Resource-Limited Context

Caregivers emphasized the necessity of external support to sustain their role, with four subthemes: Financial subsidies, psychoeducation, healthcare system engagement, and community awareness.

4.2.1. Financial Subsidies

High costs of treatment and hospitalizations, coupled with lost income, imposed significant burdens. Caregivers sought government-funded medication and hospitalization coverage. A 32-year-old sibling said, "My sister's hospitalizations are so costly. We need financial help." (Participant 9). A 29-year-old daughter noted, "We sold our farmland to cover costs. Subsidies would ease this burden." (Participant 10).

4.2.2. Psychoeducation

Limited knowledge about schizophrenia hindered effective caregiving. Participants desired structured educational programs. A 43-year-old daughter shared, "I was lost at first because I knew nothing about this illness. Information would've helped." (Participant 12). Lack of access to mental health education in Guilan intensified feelings of helplessness.

4.2.3. Healthcare System Engagement

Caregivers felt overlooked by healthcare providers, who rarely involved them in treatment plans or provided guidance. A 50-year-old father stated, "The staff don't explain anything. I feel alone in this." (Participant 13). A 37-year-old sister said, "Doctors focus on my brother but ignore our struggles. We need training." (Participant 9).

4.2.4. Community Awareness

Societal misconceptions, particularly in Guilan, where mental illness is often linked to spiritual causes, led to discrimination. Caregivers sought public education to reduce stigma. A 48-year-old mother said,

"People call my sister 'mad' and avoid us. Understanding would help." (Participant 6). A 35-year-old brother noted, "Some families here turn to traditional healers because of these beliefs." (Participant 11).

4.3. Positive Caregiving Outcomes

Despite challenges, caregivers identified benefits, with three subthemes: Personal resilience, sense of duty, and family cohesion.

4.3.1. Personal Resilience

Caregiving fostered resilience and self-reliance. A 47-year-old mother reflected, "Caring for my son has made me stronger. I handle challenges I never thought possible." (Participant 15). A 40-year-old brother noted, "I've learned to study the illness and manage crises on my own." (Participant 9).

4.3.2. Sense of Duty

Caregivers found meaning in their role, rooted in Iran's Islamic and collectivist culture. A 50-year-old mother said, "Caring for my daughter gives my life purpose. It's my duty." (Participant 6). This sense of religious and familial obligation alleviated some emotional burdens.

4.3.3. Family Cohesion

Caregiving strengthened family bonds for some, as members united to support the patient. A 36-year-old brother shared, "This illness brought our family closer. We work together for her." (Participant 10). These bonds provided emotional support in Guilan's tight-knit communities.

5. Discussion

The findings highlight the profound, culturally shaped challenges and strengths of family caregivers of individuals with schizophrenia in Guilan, Iran, reflecting unique regional and Islamic influences. The theme "Culturally Shaped Caregiving Challenges" underscores the emotional, social, and familial toll of caregiving, intensified by Guilan's patriarchal and religious context (4). Emotional distress, including depression and anxiety, aligns with global literature (8). However, in Guilan, this distress is compounded by cultural expectations of familial duty, particularly for women balancing multiple roles (7). Stigma-driven isolation, rooted in regional misconceptions linking

mental illness to spiritual causes, is particularly acute, with caregivers reporting social exclusion in Guilan's tight-knit communities (15). The subtheme of hopelessness reflects the chronicity of schizophrenia and the scarcity of mental health infrastructure in northern Iran, limiting access to supportive interventions. Family role conflicts, a novel finding in this context, highlight how traditional gender roles in Guilan exacerbate caregiving burdens, especially for female caregivers (10).

The "Support Needs in a Resource-Limited Context" theme emphasizes the critical need for systemic support in settings such as Guilan. Financial burdens, driven by high treatment costs and lost income, are a global issue but are particularly acute in Iran due to limited public funding for mental health (9). Caregivers in Guilan specifically requested government-funded subsidies for medications and hospitalizations to alleviate economic strain. Psychoeducation is a well-documented need, with studies indicating that informed caregivers are better equipped to manage schizophrenia's challenges (6). In this study, caregivers emphasized the need for structured programs, such as cognitive-behavioral workshops, to address knowledge gaps about symptom management (10).

The lack of engagement with healthcare systems reflects a gap in family-centered care, as noted in prior research (3). Caregivers in Guilan reported feeling excluded from treatment planning, underscoring the need for healthcare provider training to involve families. Community awareness is crucial to reducing stigma, which in Guilan is driven by cultural beliefs attributing mental illness to spiritual causes, prompting some families to seek traditional healers (15).

Positive caregiving outcomes, though less prominent, reveal the resilience and meaning caregivers derive from their role. Personal growth and a sense of duty align with findings that caregiving can foster adaptive coping and self-esteem (11). In Guilan, the sense of duty is deeply rooted in Islamic values of compassion and collectivist family structures, which provide emotional strength despite challenges (7). Family cohesion, a strength in Guilan's close-knit communities, underscores the role of cultural values in shaping caregiving experiences (4). These positive outcomes suggest that interventions should leverage caregivers' cultural strengths, such as peer support groups grounded in shared religious values, to enhance well-being.

5.1. Implications for Practice

The findings align with the identified themes and underscore the need for comprehensive, family-centered interventions tailored to Guilan's cultural context. The following interventions, supported by evidence, address caregivers' specific needs (6,10).

1. **Psychoeducation:** Weekly cognitive-behavioral workshops to teach symptom management, stress coping strategies, and communication skills, tailored to Guilan's caregivers (6).
2. **Financial Subsidies:** Government-funded programs to cover medication and hospitalization costs, reducing economic strain in resource-scarce regions such as Guilan (9).
3. **Healthcare inclusion:** Training programs for psychiatric nurses and clinicians to involve caregivers in treatment planning, enhancing their sense of agency (10).
4. **Community awareness:** Culturally sensitive campaigns led by religious leaders to reframe mental illness as a medical condition, reducing stigma in Guilan's communities (15).

5.2. Limitations

The study was conducted in a single psychiatric hospital in Guilan, Iran, which may limit the transferability of findings to other regions or settings. The qualitative nature of the study, while providing rich insights into Guilan's context, precludes generalization to larger populations. Future research should explore caregivers' experiences in diverse settings and consider longitudinal designs to capture changes over time.

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Footnotes

Authors' Contribution: M. A. designed the study, conducted interviews, and led analysis. M. A. and N. D. N. contributed to the study concept and manuscript. F. R. and N. D. N. supervised analysis and provided expertise. All authors approved the final manuscript.

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Data Availability: The data supporting the findings of this study, including audio-recorded interviews and field notes, are not publicly available due to ethical restrictions concerning participant confidentiality and privacy. Anonymized transcripts or additional details may be available from the corresponding author upon reasonable request.

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