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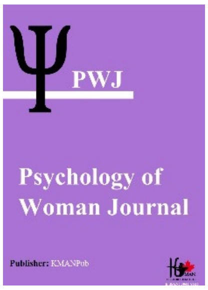

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Exploring the Lived Experience of Families with a Cancer Patient in the Face of COVID-19: A Phenomenological Study with an Emphasis on the Role of Women

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ABSTRACT

Objective: The objective of the present study was to explore the lived experience of families with a cancer patient in the context of COVID-19, with an emphasis on the role of women.

Methods and Materials: This qualitative study was conducted using a thematic analysis approach. The participants included 13 family members who were selected through purposive theoretical sampling. Data collection was carried out through semi-structured interviews with participants at Imam Hospital in Bojnord. The data were analyzed using the Corbin and Strauss method.

Findings: Stress resulting from the illness of a family member and the concerns of the family emerged as the contextual factors influencing the study. The primary concern of participants was the stress associated with the illness of their loved one. The main coping strategies adopted by the families to manage the stress included confronting problems, dealing with unpleasant emotions, addressing unresolved needs, seeking hope, battling the challenges of the illness, spiritual engagement, striving for support, normalization, optimal caregiving, and managing the illness. Stress reduction aimed at returning to a normal life emerged as the central category of the study, connecting all other categories.

Conclusion: Families of cancer patients during the COVID-19 pandemic faced significant psychological, social, and economic challenges. Nevertheless, they employed strategies such as maintaining morale, self-reliance, and enhancing spirituality to cope with the crisis. Therefore, the provision of social, financial, and psychological support by the government and relevant institutions—particularly during times of crisis—can help improve these families' quality of life and reduce their psychological burden.

Keywords: *Cancer, COVID-19, Lived Experience, Family, Social Support, Mental Health*

1. Introduction

Caregiving for cancer patients during the pandemic involved a paradoxical war on two fronts: combating the progression of a chronic and often terminal illness while simultaneously navigating the limitations imposed by a rapidly evolving infectious disease crisis (Mirlashari et al., 2021). The experience of cancer itself is deeply entangled with psychological distress, decision-making under uncertainty, and long-term emotional labor. When layered with pandemic-related challenges such as isolation, disrupted healthcare services, economic hardship, and fear of infection, the role of the caregiver became increasingly fraught with mental and emotional strain (Weiss et al., 2023). Studies across diverse contexts emphasize that caregivers frequently reported feelings of helplessness, burnout, and profound anxiety as they attempted to safeguard their ill loved ones from dual vulnerabilities (Pourmoradian et al., 2025; Rodriguez et al., 2023).

The heightened risks of COVID-19 for immunocompromised individuals created profound tensions around caregiving logistics. Protective health measures and visitation restrictions not only complicated access to care but also forced caregivers into emotionally distressing decisions—often needing to choose between physical proximity and the risk of viral transmission (Taylor et al., 2022). The emotional burden intensified for women caregivers, who traditionally carry a disproportionate share of caregiving responsibilities, especially in cultures with entrenched gender roles. Female caregivers, such as mothers, wives, and daughters, were often the primary coordinators of care and the emotional anchor of the family, a dynamic widely observed in both Western and non-Western societies (Fahed et al., 2023; Ma et al., 2023; Sharbafchi et al., 2025).

The qualitative literature has underscored the psychological and spiritual strategies caregivers employed to cope with ongoing uncertainty. Common coping mechanisms included emotional suppression, reliance on spirituality, and seeking meaning through the caregiving experience (Ferrara et al., 2023; Gilbert et al., 2023). Many caregivers leaned on religious faith and community-based forms of resilience to manage the mental toll of their responsibilities (Alharthi et al., 2023; Gautama et al., 2023). Others adopted normalization strategies, striving to maintain a sense of routine amid chaos, or practiced self-reliance to foster a sense of control (Cardoso et al., 2023). Notably, hope functioned as a central theme—a psychological lifeline that sustained caregivers through repeated cycles of fear, disappointment, and resolve (King-Dowling et al., 2023).

However, caregivers were also significantly constrained by structural and systemic shortcomings. The closure of outpatient clinics, delayed chemotherapy sessions, and reduced hospital capacities led to gaps in treatment continuity (Wang et al., 2022). Many caregivers reported that lack of professional support and clear communication from healthcare providers exacerbated their stress, as they often bore the burden of interpreting medical information and making decisions without adequate guidance (Dikobe et al., 2023; Robinson et al., 2022). Emotional exhaustion was further compounded by social stigma and isolation, particularly in communities where COVID-19 infection was associated with fear and social rejection (Lebni et al., 2022).

Importantly, digital transformation and the rise of telehealth were met with ambivalence among caregivers. While remote communication tools were essential to reduce exposure risk and maintain continuity of care, they often failed to meet the emotional and relational needs of caregivers and patients alike (Cardoso et al., 2023). The absence of in-person interaction with clinicians and support networks left many caregivers feeling abandoned and overwhelmed, especially during moments of acute crisis or end-of-life care scenarios (Burton et al., 2024).

Despite these immense challenges, resilience emerged as a salient feature in many caregiving narratives. Some caregivers discovered renewed strength in their familial roles and developed innovative coping strategies that helped them navigate resource shortages, policy ambiguities, and personal fears (Jiu et al., 2023; Rahimi et al., 2021). Others fostered communal bonds through informal support networks, emphasizing collective care and mutual aid in the face of institutional absences (Mwiinga-Kalusopa et al., 2022). These narratives not only reveal the multidimensional nature of caregiving during the pandemic but also underscore the importance of intersectional understanding—where gender, cultural values, economic status, and social infrastructure converge to shape caregiving realities (Hyeon & Moon, 2024).

The Iranian context provides a distinct cultural backdrop to investigate these dynamics further. Research shows that in Iran, caregiving is deeply embedded in family structures and is often considered a moral obligation, especially for women (Sharbafchi et al., 2025). During the COVID-19 crisis, traditional caregiving expectations were both a source of strength and a burden, as women negotiated their roles under conditions of extreme uncertainty and limited institutional support (Pourmoradian et al., 2025). Furthermore, the stigmatization associated with both cancer and COVID-19 added psychological strain, limiting caregivers' access to social support and heightening their sense of isolation (Fahed et al., 2023; Lebni et al., 2022).

The present study aims to fill a critical gap in the literature by delving into the lived experiences of female caregivers of cancer patients in Iran during the COVID-19 pandemic.

2. Methods and Materials

2.1. *Study design and Participant*

The present research employed a qualitative methodology using thematic analysis approach. Given the qualitative nature of the study, the research setting was Imam Ali Hospital in Bojnord during the outbreak of COVID-19. At that time, this hospital specifically admitted cancer patients and their families. The study population consisted of female caregivers within the families of cancer patients, particularly mothers and spouses. Sampling continued until data saturation was reached. Interviews and note-taking were carried out until no new information emerged from the data, indicating the point of data saturation. Data saturation refers to the stage at which further data collection yields no additional insights into the studied phenomenon and the analysis becomes sufficiently rich and flexible.

In this study, participants were selected through purposive theoretical sampling. Initially, the researcher sought participants with adequate experience related to the core subject (the experience of facing the COVID-19 pandemic alongside cancer care). This selection was made consciously by the researcher. Following that, theoretical sampling was employed as part of the data collection and analysis process with the goal of saturating theoretical categories and developing the theory. Sampling and data collection continued until no new data were obtained, signifying theoretical saturation.

Inclusion and Exclusion Criteria

Inclusion criteria:

1. Family members: Preferably first-degree relatives of the patient, including spouse, child, sister, or mother, who are the primary caregivers and have been in this role for at least six months.
2. A minimum of six months must have passed since the confirmed diagnosis of cancer in the patient.
3. Family members must be able to communicate and endure the interview process.
4. Participants must express willingness and consent to participate in the study.

Exclusion criteria:

1. If the participant loses physical ability to continue participation in the study.
2. If the participant expresses unwillingness to continue participation during the interview process.

2.2. *Measures*

2.2.1. *Semi-Structured Interview*

To collect data, semi-structured interviews and observation with field notes were utilized. Initially, general questions were asked to build rapport with the participants and establish a relaxed, stress-free atmosphere. This was followed by more specific questions aligned with the research objectives, focusing on the lived experiences of families, especially women, in facing the COVID-19 pandemic and cancer.

Interview questions for family members of patients included:

- What did you do when the cancer diagnosis of your family member was confirmed? Can you give me an example?
- Can you describe a typical day living with your ill family member?
- What experiences did you have after learning about the cancer diagnosis?
- What events occurred during the COVID-19 pandemic that affected the cancer treatment process of your family member?
- Please explain your personal condition and the limitations you experienced during that time.
- Can you describe your thoughts and feelings towards the patient, particularly in light of the treatment or hospitalization restrictions during the pandemic?
- What actions did you take to solve the problems caused by the illness during the COVID-19 pandemic?
- How did you adapt to the restrictions imposed by the COVID-19 crisis?
- During this period, how did you try to cope with the difficulties and limitations brought about by your family member’s cancer?

- Based on your caregiving experience, what factors helped you cope with your family member's illness?
- Based on your caregiving experience, what factors made it difficult for you to cope with your family member's illness?

After each set of interview questions, follow-up and probing questions such as "Can you elaborate on that?" were asked to extract richer and more detailed data. Each interview lasted approximately one hour. At the end of each session, participants were asked if there was anything they experienced that the interviewer had not asked about. Additionally, consent for follow-up contact was requested in case further clarification was needed.

2.3. Data Analysis

Data were analyzed using Corbin and Strauss's (2008) method, which involves four stages: 1) analyzing data for concepts, 2) analyzing data for context and process, 3) linking process with context, and 4) integrating categories. Initially, data were analyzed line-by-line and paragraph-by-paragraph to extract preliminary codes. These codes were then grouped based on similarities and contradictions into subcategories. In the open coding stage, words, lines, and paragraphs were labeled to identify main concepts. This process continued using constant comparative methods until the open codes were developed into core categories.

Following open coding, selective coding was applied to more accurately identify the key and relevant codes and eliminate irrelevant data. In the sorting phase, theoretical memos were conceptually arranged to form a conceptual framework for thematic network. Finally, in the theoretical coding stage, the relationships between categories were conceptualized, and connections between concepts were established. This analytical process resulted in the development of a contextual model explaining how families of cancer patients adapted to the restrictions imposed by the COVID-19 pandemic.

3. Findings and Results

The participants in this study were selected using purposive sampling aimed at achieving maximum variation, aligned with the trajectory of theoretical sampling. In total, 13 family members of cancer patients—particularly women serving as primary caregivers—participated in this research.

Table 1

Categories, Subcategories, and Concepts Explaining the Adaptation Process of Families with Cancer Patients to COVID-19-Related Restrictions

Categories	Subcategories	Concepts
Stress arising from the illness of a family member under COVID-19 restrictions	Coping with problems	Limited disease awareness; treatment challenges; lack of support from others; caregiving difficulties; caregiver burnout; financial problems; physical and psychological issues of the patient; family conflicts; communication problems
	Negative emotions	Despair and hopelessness; anxiety; depression
Family concerns	Unresolved needs	Financial support needs; social support needs; medical support needs
	Seeking hope	Optimism
Efforts to relieve stress caused by the illness under COVID-19 restrictions	Fighting the illness	Boosting morale; self-reliance; patience and endurance; acceptance of the disease
	Spirituality	Trust in God; sincere worship; faith in God
	Seeking support	Financial support; social support; emotional support; psychological support
	Normalization	Positive self-suggestion
	Optimal caregiving	Adequate care; caregiving experience
	Disease management	Accepting caregiving role; accepting COVID-related restrictions; coping with the patient's condition; lifestyle changes
Facilitating factors	Treatment efficacy	Partial recovery, renewed hope for life
	Receiving support	Financial, social, emotional, informational support
	Strengthening faith and willpower	Achieving psychological calm
Hindering factors	Hopelessness	Hopelessness about recovery
	Surrender to illness	Patient becoming bedridden
	Lack of support	Disappointment with support; social isolation
	Indifference	Neglecting treatment; abandoning the patient

In this study, participants shared various experiences related to facing cancer and the restrictions imposed by the COVID-19 pandemic. Women, especially in their roles as primary caregivers, encountered multiple challenges that were intensified by the crisis. These included insufficient knowledge about the disease, treatment and financial burdens, caregiver burnout, and psychological pressure. Additionally, lack of support from others and limited access to medical services exacerbated these difficulties. Such circumstances led to negative emotions in caregivers, such as anxiety, depression, and hopelessness.

One interviewee, a mother, stated: “Since I’m the mother, I’m with my child almost all day and night and witness their condition. Most of the time is spent on treatments and taking medications, or resting, with little time left for anything else. Sometimes, I suddenly see them in severe pain, which distresses me deeply.” This account illustrates that caregiving during the COVID-19 pandemic presented not only physical but also emotional challenges for mothers. The emotional toll of witnessing a child’s pain, particularly during disease exacerbation, triggered anxiety and feelings of inadequacy in many of the women.

Medical challenges during the pandemic, such as medication shortages and high prices, placed additional strain on caregivers. One mother shared: “Honestly, since the treatment costs were so high, we couldn’t buy the medications our child needed. We had to purchase cheaper alternatives that weren’t very effective. This financial burden constantly worried me.” During COVID-19, when many jobs were lost and family incomes declined, economic hardship intensified, further amplifying anxiety among caregivers.

Beyond economic and medical struggles, a lack of support from others and insufficient social backing were also highlighted by participants. One caregiver stated: “After our patient caught COVID-19, one of the neighbors called emergency services to remove us from the area, saying our family was infected and always sick and was contaminating the environment.” This reflects not only the absence of social support but also social rejection fueled by fear of infection, leading to isolation and heightened psychological stress for women caregivers.

In this study, families of cancer patients—especially caregiving women—faced numerous challenges that were exacerbated during the COVID-19 pandemic. The financial burden of high treatment costs, inability to secure medications, and a lack of social support imposed significant psychological pressure. One mother described: “During the days of radiotherapy, we’d wake up in the morning, have breakfast, and go to the hospital. Financial and medical conditions were extremely difficult.”

Financial and social support were among the families’ most urgent concerns. High treatment costs and job loss-related economic difficulties intensified their struggles. One participant said: “The terrifying costs of cancer treatment broke us. I wish there were an organization to financially support us.” Moreover, access to rare medications and treatment services became more limited during COVID-19, further complicating care. One caregiver noted: “The cost of medicine and transportation to treatment centers was very high. We even had to travel far to find the drugs.”

These challenges highlight the serious difficulties caregivers faced during the COVID-19 crisis and the urgent need for comprehensive financial, social, and medical support to assist such families.

The families of cancer patients—particularly women caregivers—faced significant psychological and social challenges, which stemmed from both the chronic nature of the illness and the broader crisis conditions of the pandemic. Participants emphasized that maintaining hope and uplifting the patient’s morale were key coping strategies. They attempted to foster an atmosphere of optimism and hope to endure the hardships and emotionally support the patient. One mother stated: “I tried to hide my sadness as much as I could so my father’s morale wouldn’t worsen.” These efforts helped reduce psychological tension within the family.

Additionally, families strived to fight the illness and overcome COVID-related restrictions. Relying on inner strength and maintaining morale, they spared no effort in caring for the patient and worked to improve the patient’s quality of life under challenging conditions. One participant said: “As I mentioned, not having money for treatment and my patient’s low morale made things worse. But with effort and hope, we moved forward with the treatment.” This pattern of increased self-reliance and persistence in caregiving ultimately contributed to stress reduction and acceptance of the situation.

Finally, lifestyle changes and adapting to COVID-19-related restrictions were among the primary strategies employed by families. By accepting changes and adjusting to the new reality, they were able to confront difficulties and improve their circumstances. One female caregiver remarked: “With help from others, charity support, and hope that a drug would eventually be found, we had to adapt and carry on.” This problem-focused approach illustrated families' resilience and determination to improve their situation amid crisis.

4. Discussion and Conclusion

The findings of this study underscore the multi-dimensional stress experienced by family caregivers of cancer patients during the COVID-19 pandemic, with a specific focus on women who primarily assumed caregiving responsibilities. Participants expressed intense psychological distress rooted in the simultaneous burden of caring for a chronically ill family member and navigating the socio-health complexities introduced by the pandemic. These findings confirm and expand existing literature that positions family caregiving, especially by women, as emotionally taxing and logistically demanding in crisis contexts such as pandemics (Ma et al., 2023; Sharbafchi et al., 2025).

One of the most prominent themes in this study was the emotional toll of caregiving under pandemic-related constraints. Participants reported feelings of despair, anxiety, and depression—often exacerbated by witnessing the physical deterioration of their loved ones and the persistent threat of COVID-19 exposure. These emotions align closely with the findings of Weiss et al., who identified heightened caregiver stress and emotional exhaustion among families supporting older cancer patients during the pandemic (Weiss et al., 2023). Similarly, Fahed et al. emphasized that caregivers, in the absence of adequate social and psychological support, frequently relied on internal coping mechanisms, which were insufficient under prolonged distress (Fahed et al., 2023).

Participants also cited a marked decline in access to medical services and treatment resources. Limited hospital capacities, medication shortages, and inflated treatment costs created a scenario where families had to make emotionally and financially difficult decisions. These barriers were particularly acute for caregivers from economically vulnerable backgrounds. Such challenges were widely documented by Ferrara et al., who noted that interruptions in treatment plans and communication gaps between providers and families severely impacted the quality of cancer care during COVID-19 (Ferrara et al., 2023). Wang et al. similarly found that palliative care practices suffered due to the pandemic, forcing caregivers to assume greater medical responsibilities without the requisite training or emotional preparation (Wang et al., 2022).

The role of social stigma and community rejection further intensified the psychological distress of caregivers in our study. Participants described experiences of being ostracized due to fears surrounding COVID-19 contagion, leading to isolation and a breakdown of traditional support networks. These experiences mirror the findings of Lebni et al., who observed similar stigmatizing behaviors among communities toward families affected by COVID-19, particularly in cultural contexts where infectious diseases carry a heavy social burden (Lebni et al., 2022). In our study, women were especially vulnerable to these dynamics, given their culturally ascribed roles as caregivers and moral stewards of family health.

Despite these adversities, our findings revealed a range of adaptive strategies employed by caregivers to manage psychological stress and caregiving demands. Many participants turned to spirituality, describing trust in God, prayer, and religious rituals as key mechanisms for coping with uncertainty and despair. These findings are supported by the research of Alharthi et al., who identified spiritual resilience as a common theme among ICU nurses during the pandemic (Alharthi et al., 2023), and by Gautama et al., who noted that cancer patients and their families often derive psychological comfort from religious and cultural practices in times of crisis (Gautama et al., 2023).

Hope and optimism emerged as central emotional resources in the caregivers' narratives. Participants reported that maintaining a hopeful outlook and fostering positivity in the patient helped reduce their own stress and improve the emotional well-being of the entire household. This aligns with the work of King-Dowling et al., who found that hope acted as a critical psychological buffer for both adolescent cancer survivors and their families during COVID-19 (King-Dowling et al., 2023). Furthermore, Gilbert et al. highlighted that families exhibiting resilience, defined by emotional regulation and positive reframing, were more likely to navigate the pandemic without long-term psychological harm (Gilbert et al., 2023).

Another salient theme was the pursuit of support—financial, emotional, and informational—from both formal institutions and informal networks. While formal avenues were often insufficient or inaccessible, caregivers actively sought aid from charities, religious groups, and community networks. Jiu et al. reported a similar phenomenon in post-stroke caregiving during the pandemic, where families developed decentralized support strategies to compensate for institutional deficits (Jiu et al., 2023). Our participants' efforts to maintain caregiving routines through such mechanisms echo the findings of Pourmoradian et al., who demonstrated that Iranian adults coped with the pandemic by building community ties and using faith-based resilience frameworks (Pourmoradian et al., 2025).

Moreover, the theme of lifestyle adaptation and disease management underscores the caregivers' capacity for behavioral flexibility in response to environmental stressors. Women caregivers described accepting their roles more completely, restructuring daily routines, and modifying expectations to accommodate pandemic restrictions. These behaviors align with the concept of adaptive caregiving proposed by Mirlashari et al., who observed similar patterns among Iranian families with pediatric cancer patients during the pandemic (Mirlashari et al., 2021). The commitment to adapting one's life to prioritize caregiving duties—even under extreme conditions—demonstrates not only resilience but also the cultural and gendered expectations surrounding care work.

Interestingly, some caregivers reported emotional numbness or indifference as a form of coping. Though seemingly maladaptive, this strategy has been interpreted in previous studies as a protective mechanism to prevent emotional burnout when prolonged stress becomes overwhelming. Burton et al. referred to this as "compassion fatigue," which commonly appeared among bereaved caregivers during end-of-life cancer care in the pandemic era (Burton et al., 2024). Similarly, Robinson et al. found that frontline nurses adopted emotional detachment to survive repeated exposure to trauma and death (Robinson et al., 2022).

A unique contribution of this study is its emphasis on gender-specific dynamics, particularly the experience of women as central figures in the caregiving process. The findings confirm that caregiving during COVID-19 not only reinforced but also intensified existing gender roles within Iranian families, echoing similar conclusions drawn in broader international contexts. For example, Dikobe et al. and Hyeon et al. both reported that women were disproportionately burdened in healthcare and familial settings, with their caregiving roles expanding in scope and complexity under pandemic pressure (Dikobe et al., 2023; Hyeon & Moon, 2024). In our study, the intersection of gender, illness, and crisis revealed how caregiving was not merely a logistical task but a deeply embodied experience shaped by cultural, emotional, and moral expectations.

5. Limitations and Suggestions

Despite the strengths of qualitative inquiry and theoretical depth, this study is not without limitations. First, the sample size was limited to 13 participants from a single hospital in Iran, which may constrain the generalizability of findings to broader populations or different cultural contexts. Second, because all participants were women, the gendered analysis does not account for the experiences of male caregivers, whose coping mechanisms and challenges may differ. Additionally, reliance on self-reported experiences introduces potential recall bias or emotional filtering, especially given the sensitive nature of caregiving and illness narratives.

Future studies should consider a more diverse and larger sample across multiple regions and care settings to enhance the transferability of findings. Comparative studies between male and female caregivers could provide richer insights into gender differences in caregiving burdens and resilience strategies. Longitudinal designs would also help track psychological and social outcomes over time, offering a dynamic view of adaptation and coping. Furthermore, incorporating mixed methods—such as integrating quantitative assessments of caregiver burden—could enhance the robustness of interpretations and policy implications.

Healthcare providers and policymakers should prioritize caregiver support systems, especially during public health emergencies. Initiatives such as caregiver counseling, emergency financial aid, and caregiver training programs can significantly ease the burden on families. Medical institutions should also develop communication strategies that facilitate timely and compassionate engagement with caregivers. Culturally sensitive frameworks—acknowledging the role of spirituality, community, and gender—must be embedded in support models to ensure that interventions are relevant and sustainable. Lastly, empowering caregivers through digital health literacy and remote care technologies can enhance continuity of care while safeguarding emotional well-being during future crises.

Authors' Contributions

Authors contributed equally to this article.

Declaration

In order to correct and improve the academic writing of our paper, we have used the language model ChatGPT.

Transparency Statement

Data are available for research purposes upon reasonable request to the corresponding author.

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Declaration of Interest

The authors report no conflict of interest.

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Ethical Considerations

The study protocol adhered to the principles outlined in the Helsinki Declaration, which provides guidelines for ethical research involving human participants.

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