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Psychological Well-Being of Caregivers of Parents with Mental Illness: An Exploratory Study

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Abstract

The current study was conducted to explore the psychological well-being of caregivers having a parent with mental illness. The purposive sampling technique was used to conduct the study. A sample of 12 (8 women and 4 men) adults aged 18-40 years having parents with mental illness, such as schizophrenia, depression, and compulsive disorders were selected from the psychiatry ward of one of the government hospitals in Faisalabad, Pakistan. A focus group discussion was conducted through the trained facilitator. Thematic analysis was used to examine the data. Five major themes, namely significant impact on life, responsibilities, societal pressure, attention towards religion, personal, social and family dynamics, and nine sub themes, namely psychological impact, overall health affected, influence on academic performance, balancing caregiving and personal roles, social integration, religious strength, social life circumstances, family situation, emotions and feelings were extracted. The findings highlight the impact of parents' mental illness on the well-being of adult caregivers in Pakistani context. Furthermore, findings may also help clinicians in tailoring the interventions accordingly to the context of the current study in order to enhance and improve caregivers' well-being.

Keywords: academic performance, focus group, mental illness, psychological well-being

Introduction

Mental illness, such as depression, anxiety, and bipolar disorder, not only affect an individual, however, such illness also affects their loved ones including adult children who often assume caregiving roles. Caregiving may be defined as the process of helping another person who is unable to do so for themselves in a "holistic" (physically, mentally, emotionally, and socially) manner (Hermanns & Mastel-Smith, [2012](#)). According to the

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study conducted by Cejalvo et al. (2022), caregivers get affected the most and may experience a decline in their mental well-being as well as stress-related disorders. Researches have shown that caregiving for a family member with a mental illness may have significant emotional, social, and financial consequences for caregivers (Cuijpers & Smit, 2002; Schulz & Sherwood, 2008). Adult children, in particular, may experience unique challenges as they navigate their own lives. The challenges faced by caregivers include abrupt shifts in their daily routine, increased time commitment to the patient, financial burdens, and other factors (Vu et al., 2022). Research suggests that informal caregivers may stress out which may possibly lead towards certain negative individual outcomes. Additionally, caregivers have to suffer the effects of depression which may cause deterioration in their subjective health (Gérain & Zechariah, 2021). Many other researches have concluded that caregivers are more likely to suffer from the symptoms of stress, depression, anxiety, and poor life quality. Moreover, they also encounter higher levels of burden and are emotionally traumatized due to the lack of proper psychological care provided to them (Adejumo et al., 2019).

Cejalvo et al. (2022) reported that adult children with at least one parent suffering from mental illness face trouble in adapting and connecting with their peers. Thus, caregivers may be subjected to secondary stressors in various spheres of their lives including professional surroundings, private, and social contacts (Petrini et al., 2019).

Recent studies have highlighted the complexities of caregiving for a parent with a mental illness. The study explains that adult child caregivers experienced higher levels of depression and anxiety than non-caregivers, emphasizing the need for targeted support (Wang et al., 2020). Another study published in 2019 revealed that caregivers' mental health was significantly impacted by the severity of their parent's symptoms, underscoring the importance of symptom management (Liu et al., 2019). Furthermore, research has shown that caregiving may affect adult children's relationships, careers, and the overall well-being (Huang et al., 2022).

The current study investigated the impact of a parent's mental illness on the psychological well-being of adult caregivers including their experiences, coping mechanisms, and support needs. The exploration of this critical issue would contribute to the development of effective interventions and support systems for this vulnerable population.

Literature Review

The family caregivers encounter specific challenges and demands which have not been mentioned in the existing literature (Bangerter et al., [2019](#)). Evidence-based literature shows that delivering the care for a dementia patient may have negative consequences on the health of caregivers, such as psychological distress, social challenges, as well as medical problems (Lethin et al., [2020](#)). The more advanced the disease is, the more pronounced it becomes to an extent that the patient's physical and mental capabilities start diminishing. It not only impacts the patient's health, however, also caregivers' health and quality of life (Moura & Hamadan, [2020](#)). In their experimentation, Truglio-Londrigan and Slyer ([2019](#)) adopted systematic focus group interviews, developed by Kreuger and Casey ([2009](#)). Participants' data was collected through the transcription of a 90 minute taped session. The results of the survey made it evident that caregivers easily transferred the role of caregiving to themselves and realized the need of support in order to confront diverse hardships. Afterwards, the survey provided the evidence that the family caregivers are burdened with excessive work pertaining to responsibility management. Additionally, the lack of sufficient time away from caring has a negative impact on the well-being, stress levels, and capacity of family caregivers to provide care for the individual (Rayment et al., [2019](#)). Research has indicated that the difficulties faced by family caregivers and their ensuing requirements are exceedingly challenging, since they must adjust to their circumstances and acquire new skills in a highly stressful environment. The caregivers who bear the full-time responsibility of patients with dementia often find themselves lacking the energy to cater to their own needs, which, in turn, has consequences for their own health and well-being (Steenfeldt et al., [2021](#)).

A study documented that caregivers are motivated by several factors and incentives when caring for the patients of Alzheimer's disease, with love and financial concerns being the main drivers. Due to the extensive allocation of resources required for patient care, caregivers are increasingly expected to assume a greater role in patients' everyday lives. Consequently, they have less time available for personal pursuits, family commitments, and professional responsibilities, leading towards heightened stress levels which may have a negative impact on the individuals' physical, mental, and social well-being (Vu et al., [2022](#)).

Cejalvo et al. (2022) sought to evaluate the influence of caregiving on those who require assistance while examining specific attributes, such as self-esteem and resilience. Findings indicated that caregiving imposed a significant workload with detrimental effects on the physical well-being as well as the psychological and mental state of caregivers. Family Systems Theory proposed by Wright and Leahey (2013) primarily focuses on the interaction among family members and between the family and other systems. A system may be described as a collection of interconnected components. Family is regarded as a collection of interconnected individuals, functioning as a system. Any alteration in one family member, such as a severe illness, would have an impact on all other family members (Anderson & Bury, 2024).

Another study reported that parents' illness disrupts the daily schedule of all family members and modify their roles within the family. The current study aimed to uncover trends, dynamics, and potential sources of support or pressure within the family unit. This information may be utilized to develop treatments in order to improve the well-being of caregivers. Caring for a family member suffering from a significant mental illness becomes more difficult due to the additional hardship caused by the stigma associated with mental illness (Siddiqui & Khalid, 2019).

In Pakistan, the responsibility of caregiving primarily rests solely on family members. Nevertheless, the reduction in family size, the process of industrialization, poverty, and the high occurrence of chronic illness in older persons may impose considerable pressure and burden on family caregivers (Noreen et al., 2022). Individuals afflicted with severe mental illness exhibit a profound reliance on caregivers mostly due to the substantial debilitation linked with their condition (Siddiqui & Khalid, 2019). The current study sought to investigate the influence of caregiving on the psychological well-being of caregivers. By the identification of characteristics linked with psychological well-being, insights may be gained into the appropriate preventive actions and early interventions required to mitigate the negative impact of caregiving on caregivers.

Research Questions

The current study attempted to answer the following research questions:

1. What are the major psychological concerns of caregivers of parents with mental illness?

2. To what extent are cultural and societal factors important in the psychological health of adult caregivers of parents with mental illness?
3. How do adult caregivers manage their own caregiving needs and responsibilities towards other family members while attending to a parent with a mental illness?
4. How do adult caregivers manage stress that arises from caring for a parent with a mental illness?

Method

Research Design

The current qualitative study utilized an in-depth exploratory approach (Focus group technique) to examine the lived experiences and perspectives of adult caregivers, gaining insights into the understanding and interpretation of their parents' mental illness.

Participants

Focus group discussions is a widely used qualitative research method to gather the data, involving a moderated conversation among a small, diverse group of individuals, typically ranging from 5-12 participants (Kreuger & Casey, [2009](#)). This technique facilitates the exploration of collective perspectives, experiences, and opinions on a specific topic, allowing for rich, in-depth, and nuanced insights (Morgan, [1997](#)). Twelve (12) participants participated in focus group discussion in the current study. Recruitment was conducted at outpatient ward. Flyers and informational brochures were distributed and announcements were made during group meetings to inform potential participants about the study. Additionally, healthcare providers at the hospital referred eligible caregivers to the study. All participants provided informed consent prior to their inclusion in the study. The study protocol ensured the maintenance of ethical standards throughout the recruitment and data collection process. Participants were divided into smaller groups and each group consisted of 4 participants. Eight females and four males were included in the study. All participants were caregivers of psychiatric patients' outdoor ward from Faisalabad, Pakistan.

Focus group discussion is often used as an experimental technique and a source of data collection. Twelve-fifteen (12-15) participants are deemed

adequate to achieve thematic saturation in focus group discussion led by a moderator (Sivakanthan et al., [2023](#)).

Inclusion Criteria

Adults, who were the primary caregivers for their parents with mental illness, were selected as participants. Furthermore, caregivers with at least 18 years of age and above could participate in the study with an experience of six months to determine the effect caregiving had on their psychological state.

Exclusion Criteria

The participants who were caregivers of other illness were excluded from the study. Those who have been caregiving for less than six months were not included into the study. This is because their understanding of caregiving was not profound enough to provide the necessary information. Following are the details of participants included in the study:

Table 1
Characteristics of the Participants

	Age	Gender	Education	Employment	Duration of Care-Taking Parents
P1	22	Female	Graduation	Part-Time	2 Years
P2	30	Male	Graduation	Full Time	>5 Years
P3	35	Female	Intermediate	Part-Time	11 Months
P4	18	Male	Matriculation	Part-Time	2 Years
P5	28	Female	Graduation	Unemployed	>2 Years
P6	40	Male	Graduation	Full-Time	>5 Years
P7	32	Female	Graduation	Full-Time	4 Years
P8	20	Female	Intermediate	Part-Time	2 Years
P9	18	Female	Matriculation	Unemployed	8 months
P10	29	Male	Graduation	Full-Time	>4 Years
P11	34	Female	Graduation	Unemployed	5 Years
P12	23	Female	Graduation	Part-Time	3 Years

Assessment Measures

To extract information from participants, an interview guide was developed consisting of 10 open-ended questions pertaining to adults' daily lives, future, spiritual strength, social life, mental state, and behavioral

change which was used while conducting interviews. The interview guide was developed with reference to the previous data on caregiving and psychological well-being (Alyafei et al., [2021](#); Tamizi et al., [2020](#)). All the participants were fluent speakers of Urdu. Therefore, the interview guide was prepared in Urdu to minimize confusion or discomfort while responding. Other techniques used during the interviews included asking probing questions to obtain a clearer response from participants (for instance, “Can you elaborate on that?” or “I did not quite understand, please explain?”).

Following research questions were asked from interviewees.

1. What was a typical day in your life as an adult which emphasizes the daily routines and activities you engage in?
2. What are your achievements and aspirations for future? Where do you see yourself in the next two years fulfilling your ambitions?
3. How do you define spiritual strength in your life and how does it influence your daily decisions?
4. Can you describe your social life contributions to your health overall? What do friendships and general relationships mean to you?
5. Could you describe your mental state as of now and factors influencing your emotional well-being?
6. Have you noticed any shifts in your actions or what you do? Or what you might think is causing these changes?
7. What are some of the significant daily struggles as an adult caregiver? What are some of your usual ways to work through these kinds of challenges?
8. Think of the most recent experience that changed your life, or made you think differently about what is important to you?
9. How do you include self-care into your daily schedule? What helps you maintain your well-being?
10. What are the things that you believe contribute most to an adult to live a satisfying and thriving life?

Procedure

Participants were contacted via the hospital psychiatry department and sessions were conducted at timings that best suited the participants. Participants arrived for focus group sessions via their means of traveling. No logistics were privately arranged for participants to reach the hospital for focus group sessions. Sessions were conducted in one of the private conference rooms within the hospital so that confidentiality and comfort could be assured.

These focus group sessions were facilitated by a senior research assistant who was skilled at qualitative research methods and experienced in leading focus groups. Each session lasted for approximately 60-90 minutes which was enough time for detailed discussions as well as participant interactions. Focus group sessions were conducted till data saturation was reached (Braun & Clarke, [2021](#)). In total, 3 focus group sessions were conducted as it enabled a richer and more detailed assessment of the caregivers' experiences and ensured that the conclusions were thorough and replicated in various groups' interactions. Conducting multiple focus group sessions helps to achieve data saturation, where no new information emerges, and themes become repetitive (Glaser & Strauss, [1967](#)). Multiple focus groups allow for validation of findings, increasing the credibility and reliability of the data (Kreuger & Casey, [2009](#)). By conducting three focus group sessions, researchers may verify that the emerging themes and patterns are consistent across different groups. Three focus groups may accommodate a diverse range of participants, reducing the risk of a single group dominating the discussion (Morgan, [1997](#)). This helps in ensuring that a broader range of experiences and opinions are represented. Multiple focus groups provide a richer and a more nuanced understanding of the research topic, allowing for a deeper exploration of themes and sub-themes (Fern, [2001](#)). Therefore, three focus groups may help reach saturation, ensuring that a wide range of perspectives are captured. Studies have reported that after three focus group sessions, there would be a saturation point (Carlsen & Glenton, [2011](#)). The study protocol ensured adherence to ethical issues were taken into account. All consent forms were signed; this guaranteed privacy concerns amongst other things. Participants were informed of their right to withdraw from the study at any point, without penalty or consequence, if they felt uncomfortable or wished to discontinue their involvement. Participants were made aware that they

can stop participating in the study at any time if they didn't feel comfortable doing so.

Data Analysis

Verbatim statements from the audiotapes and debriefing notes were coded to identify common themes. Braun and Clarke's (2006) deductive thematic analysis was used to analyze the data. Six steps, that is, familiarization, coding, generating themes, reviewing themes, defining, and naming themes, were used while analyzing the data. Themes were continually developed and explored during data analysis.

Results

Initial codes and sub-themes were extracted through thematic analysis and were converted into main themes. The researcher extracted five main themes, nine connecting themes, and many emerging themes. Key findings may be summarized in tables, figures, and narration.

Table 2

Master Table of Themes

Main Themes	Sub Themes	Initial Codes
Significant Impact on Life	Psychological Impact	Inferiority complex
		Anxiety
		Stress
	Impact on Health	frustration
		Anger
		Depression
	Influence on Academic Performance	Feelings of Hopelessness, and Negative Thinking
		Dizziness
		Vomiting
		Headache
		Lack of Concentration on Studies
		Dropping out from School/College
		Adverse Impact on Education

Main Themes	Sub Themes	Initial Codes
Responsibilities	Balancing Caregiving and Personal Roles	Caretaker Responsibilities Domestic Responsibilities
Societal Pressure	Social Integration	Struggle/Hardworking Criticism by People Social Burden Relationship with Spouse affected
Inclination towards Religion	Religious Coping	Visiting Shrines Spiritual Resilience Attentiveness towards Allah Prayer Hope Faith Peer Pressure to Visit Faith Healers
Personal, Social and Family Dynamics	Social Life Circumstances	Difficulty in Social Mobility No Social Support Lack of Social Attention Disturbances at Home Not spending Time at Home
	Family Situation Emotions and feelings	Economic Burden Negative Relationship with Siblings Indecision Prevails Separation from Spouse Hopelessness and Helplessness Jealous from others Self-hatred Unhappy

Significant Impact on Life

Three sub-themes were identified under this main theme. The details these sub-themes are discussed below.

Psychological Impact

Psychological stress was observed in all adult caregivers. Many of them reported being anxious and stressed all the time. This emotional pressure reduced self-esteem and hope among caregivers, especially where they saw themselves as having no way out of the roles they perform. For instance, P6 stated, “every day it feels like fighting... fighting with those feelings of anxiety and stress, and I don’t see things changing... I want to quit”. Such feelings were coupled with frustration and anger considering the fact that they lacked the necessary support as caregivers.

Impact on Health

Participants claimed to have experienced physical health problems manifested almost in each one of them as dizziness, vomiting, headaches, and so on. All these physical complications were attributed to stress arising due to caregiving. P12 said, “The constant worry just gave me headaches all the time, dizziness that almost paralyses me”. These complications show a considerable impact of caregiving on the physical health of participants.

Impact on Academic Performance

Caregiving affected the academic performance of participants, especially the young participants. Some of them were unable to focus on their studies which resulted in poor performance or complete school dropout. For instance, as P4 argued: “It was difficult to attend my classes, when I was constantly worried about my father; in fact, I had to drop out of school because I could not cope”. This disruption of education contributes to various negative effects of caregiving on one’s development and potential for the future.

Responsibilities

Balancing between Caregiving and Personal Roles

The stress of basic caregiving tasks, combined with additional duties unrelated to providing care, may weigh heavily upon caregivers. These changes could affect the personal lives of students and could be quite stressful in addition to school. Family caregivers often balance their

caregiving roles with other personal commitments. P6 reported “It is a constant struggle to maintain a balance. I need to take care of my parent, manage the house, and life on top of all — not an easy task!”.

Societal Pressure

Social Integration

Caregivers often face social challenges which add more stress to their roles. Participants described being judged and criticized by society, which further increased their feelings of loneliness and burden. P8 said, “People don’t understand what I’m going through. They just see the spectacle and think I’m not doing enough”. Such expectations of society also strain the personal relationships of caregivers, that is, their relationships with spouses.

Inclination towards Religion

Religious Coping

Many people responded to daunting challenges by relying on religion for comfort and strength. Caregivers frequently visited shrines, prayed, and remained faithful to seek comfort and resilience from their religious beliefs. "Namaaz (prayer) was a vital key to help me get on with my day, I always think that Allah is looking after us", shared P11. Participants who did not engage in religion also faced pressure by peers or family members to visit spiritual healers, illustrating a cultural fixation on religion as a tool to manage mental health issues.

Personal, Social, and Family Dynamics

Social Life Circumstances

Caregivers have a limited social life due to the nature of their work. They face difficulty in maintaining their friendships and participating in social events, as most of them feel abandoned by their communities. P12 reported, “. . .this evoked a sense of being unseen. Unfortunately, they've all stopped inviting me to things anyway because I'm such a homebody”.

Family Situation

Caregiving roles impact family dynamics and are a cause of tension among household members. Additionally, taking care of dependent parents puts economic pressure on caregiver children and may lead towards conflicts with siblings who do not support their efforts. As P4 reported, “We

argue all the time. My siblings think I am always in a state of stress, but they don't aid either". It frequently causes disharmony within families and, in instances, may lead towards estrangement from spouses.

Emotions and Feelings

Caregiving has a significant emotional impact on caregivers. Many of them experience feelings of hopelessness and helplessness which leads towards self-contempt and dissatisfaction. As one caregiver stated, "I hate feeling this way, but at the same time, I wouldn't feel any other way. I see my friends getting to do what I cannot do, and I am stuck here, doing this". These emotional layers speak to the need for psychological support for caregivers.

Discussion

The findings offered a nuanced and contextualized understanding of the experiences of caregiving adults living with mentally ill parents, shedding light on their complex experiences and perspectives. Through the voices and stories of participants, insights were gained into how caregiving shape the lives, experiences, and perceptions of caregivers.

The first major theme discussed in the study was "significant impact on life" of adults living with mentally-ill parents. It includes several emerging themes, for instance parental behavior involving various psychological problems which have multiple negative implications for adults. In Middle Eastern cultures, the act of providing care is considered as a culturally appreciated practice, and also a cultural obligation (Ar & Karanci, [2019](#)). Despite the importance of family and its duty in Muslim Middle Eastern communities, emerging research shows that family caregivers may sacrifice their own needs for the benefit of their relatives (Daher-Nashif et al., [2021](#)). Islamic faith encourages family members to ensure well-being of their relatives' well-being (Khalaila, [2020](#)).

The current study pointed out that adult children residing with parents having mental illness in Pakistan face psychological, health issues along with sacrificing their education to perform their duties. Due to the lack of formal care services in Pakistan, caregivers mainly consist of family members (Qadir et al., [2013](#)). Family caregivers are under immense pressure, as they often sacrifice their own health and well-being to care for their family member (Balouch et al., [2020](#)). The anxiety of caring often goes hand-in-hand with behavioral problems, such as increased aggression

and poor quality of life (Imran et al., [2010](#)). Ehsan et al. ([2018](#)) found that caregiving negatively impacts the mental health and psychological well-being of informal caregivers. Informal caregiving imposes a significant strain on caregivers.

Participants also described that higher education aspirations of caregivers are routinely thwarted by their need to juggle caregiving with school. This not only makes them sadder, however, this kind of stress also pushes some to the brink where they consider quitting school altogether. Khalid et al. ([2016](#)) reported that young caregivers are home bound as there are no alternate alarms or reporting systems and their work commitments and studies are profoundly affected.

The current study proved that caregivers experience fear, a finding consistent with the literature. However, in the Pakistani context, this fear is further fed by cultural norms where a stigma is attached to mental health and family members are expected to bear caregiving alone. The stress inflicted by caregiving is both chronic and overwhelming, particularly in places where there are cultural norms against getting help from beyond the family circle (Helgeson et al., [2018](#)).

The next theme discussed by the current study was "responsibilities". Adults living with mentally ill parents have more responsibilities. Despite the importance of family and its duty in Muslim Middle Eastern communities, emerging research shows that family caregivers may sacrifice their own needs for the benefit of their relatives (Daher-Nashif et al., [2021](#)) Our results reported that informal, caregiver have not to take care of themselves, also having to take care of their parents and give proper time to their parents because they need intense care. They will also have to perform the household chores if their mothers face psychological problems. Research has indicated that care givers may have additional responsibilities in addition to their caregiving duties, which can have a greater impact on them (Saleem et al., [2024](#)).

The study highlighted the third theme, that is, "inclination towards religion". People gravitate towards religious activities as they believe that it would give them peace. Furthermore, caregivers in Pakistan strongly believe in spiritual healing, especially when it comes to deal with mental illness. Pakistan, being a traditional country, considers spirituality as central to health and healing in Muslim philosophy of care (Lalani & Ali, [2021](#)).

Rashid et al. (2023) reported that religion plays a significant role as a coping strategy and being members of a religiously oriented society, people are more inclined towards the confirmation of positive religious coping.

Psychological issues are stigmatized in Pakistani society (Balouch et al., 2020). Adults whose parents are not mentally healthy have to face a lot of "societal pressure," in our society, if anyone is going through any mental illness, it becomes a stigma for their family. People avoid them, and they have to struggle for a better position in the society. A study reported that caregivers usually receive negative stigmatized reactions from society (Balouch et al., 2020). Another study determined that stigma and informal caregiving significantly impact health and well-being which, in turn, may result in unfavorable health and social outcomes (Zwar et al., 2020).

The last major theme discussed by study was "social, emotional, and family life". Caregivers face several problems which may profoundly effect their functioning and quality of life (Jabeen et al., 2024). Additionally, children also undergo an inferiority complex as they do not have a normal life. Study reported that caregivers of impaired family members may experience many problems which, in turn, may affect their own health. Furthermore, they also face financial problems due to giving care to their older family members (Ahmad, 2012).

Research has indicated that caregivers require emotional, social, educational, and physical assistance when providing care for a patient. In addition, they are likely to necessitate financial guidance and assistance with their professional trajectory. Caregivers in low socioeconomic circumstances are prone to experiencing the most significant economic repercussions. The financial burden arises from the loss of employment and the expenses associated with care which may last for a significant period even after the patient's death (Bradley, 2019).

Conclusion

The current study aimed to investigate the psychological well-being of adults taking care of a parent with a mental illness. These patients were observed to exhibit considerable emotional distress and social pressure which impacts the quality of life and efficiency of adult caregivers. The study demonstrated that adult caregivers need to be recognized for their sacrifices. Moreover, they also require specialized support structures to help them overcoming the psychological and social problems that come with

their caregiving positions. This study aimed to enrich the knowledge pertaining to the effects of caregiving on mental health which may be viewed as a plea to increase research and interventions in the respective area. According to Ehsan et al. (2018), regular caregiver well-being checks are urgently needed, especially in informal cultures where caregiving is not a formal or supported role.

Limitations

The current study has some limitations. The results may not be generalized to the rural population. These considerations may cause limitations in the generalization of results gathered from this geographical area. Due to time limitation and participants, the study employed purposive sampling method. While this approach was consistent with the nature of study due to its exploratory focus, this may limit the generalization of the degree of outcomes. Furthermore, there are no quantitative measures that would give a differential score to some of the domain facets of caregiver burden, namely stress, fatigue, and costs. Nevertheless, the absence of such quantitative data could have excluded the range of the views concerning the possible impact of caring entirely. All interviews were conducted in hospital, which was slightly challenging given the need to control for other factors that might have influenced the participants' responses.

Recommendations

Here, the following recommendations for future research are suggested. Regarding the geographical limitation, the study recommended that future researches, include rural caregivers in order to identify whether factors are different. However, purposive sampling was relevant to this qualitative study; nevertheless, subsequent researches may further enhance sample diversification for a diverse range of views. Furthermore, the researchers should consider incorporating quantitative measures combined with qualitative interviews to improve the understanding of the overall concept of burden including stress, financial costs, and fatigue for caregivers. Besides, it was also suggested that subsequent studies should be conducted in lesser interference settings, likely outside the hospitals to eliminate anything that could possibly hinder the patients' response.

Conflict of Interest

The authors of the manuscript have no financial or non-financial conflict of interest in the subject matter or materials discussed in this manuscript.

Data Availability Statement

The data associated with this study will be provided by the corresponding author upon request.

References

- Adejumo, O. A., Iyawe, I. O., Akinbodewa, A. A., Abolarin, O. S., & Alli, E. O. (2019). Burden, psychological well-being and quality of life of caregivers of end stage renal disease patients. *Ghana Medical Journal*, 53(3), 190–196. <https://doi.org/10.4314/gmj.v53i3.2>
- Ahmad, K. (2012). Informal caregiving to chronically III older family members: Caregivers' experiences and problems. *South Asian Studies*, 27(1), 101–120.
- Alyafei, A. H., Alqunaibet, T., Mansour, H., Tamizi Ali, A., & Billings, J. (2021). The experiences of family caregivers of people with severe mental illness in the Middle East: A systematic review and meta-synthesis of qualitative data. *PLOS ONE*, 16(7), Article e0254351 <https://doi.org/10.1371/journal.pone.0254351>
- Anderson, R., & Bury, M. (2024). *Living with chronic illness: The experience of patients and their families*. Routledge.
- Ar, Y., & Karanci, A. N. (2019). Turkish adult children as caregivers of parents with Alzheimer's disease: Perceptions and caregiving experiences. *Dementia*, 18(3), 882–902. <https://doi.org/10.1177/1471301217693400>
- Balouch, S., Zaidi, A., Farina, N., & Willis, R. (2020). Dementia awareness, beliefs and barriers among family caregivers in Pakistan. *Dementia*, 20(3), 899–918. <https://doi.org/10.1177/1471301220915066>
- Bangerter, L. R., Griffin, J. M., & Dunlay, S. M. (2019). Positive experiences and self-gain among family caregivers of persons with heart failure. *The Gerontologist*, 59(5), E433–E440. <https://doi.org/10.1093/geront/gny162>
- Bradley, C. J. (2019). Economic burden associated with cancer caregiving. *Seminars in Oncology Nursing*, 35(4), 333–336. <https://doi.org/10.1016/j.soncn.2019.06.003>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>

- Braun, V., & Clarke, V. (2021). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health*, 13(2), 201–216. <https://doi.org/10.1080/2159676X.2019.1704846>
- Carlsen, B., & Glenton, C. (2011). What about N? A methodological study of sample-size reporting in focus group studies. *BMC Medical Research Methodology*, 11, 1–10. <https://doi.org/10.1186/1471-2288-11-26>
- Cejalvo, E., Martí-Vilar, M., Merino-Soto, C., & Aguirre-Morales, M. T. (2021). Caregiving role and psychosocial and individual factors: A systematic review. *Healthcare*, 9(12), Article e1690. <https://doi.org/10.3390/healthcare9121690>
- Cuijpers, P., & Smit, F. (2002). Excess mortality in depression: A meta-analytic review. *Journal of Affective Disorders*, 68(2–3), 227–236. [https://doi.org/10.1016/s0165-0327\(01\)00413-x](https://doi.org/10.1016/s0165-0327(01)00413-x)
- Daher-Nashif, S., Hammad, S. H., Kane, T., & Al-Wattary, N. (2021). Islam and mental disorders of the older adults: Religious text, belief system and caregiving practices. *Journal of Religion and Health*, 60(3), 2051–2065. <https://doi.org/10.1007/s10943-020-01094-5>
- Ehsan, N., Johar, N., Saleem, T., Khan, M. A., & Ghauri, S. (2018). Negative repercussions of caregiving burden: Poor psychological well-being and depression. *Pakistan Journal of Medical Sciences*, 34(6), 1452–1456. <https://doi.org/10.12669%2Fpjms.346.15915>
- Fern, E. F. (2001). *Advanced focus group research*. Sage Publications.
- Gérain, P., & Zech, E. (2021). A harmful care: The association of informal caregiver burnout with depression, subjective health, and violence. *Journal of Interpersonal Violence*, 37(11-12), NP9738–NP9762. <https://doi.org/10.1177/0886260520983259>
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Aldine.
- Helgeson, V. S., Jakubiak, B., Van Vleet, M., & Zajdel, M. (2018). Communal coping and adjustment to chronic illness: Theory update and evidence. *Personality and Social Psychology Review*, 22(2), 170–195. <https://doi.org/10.1177/1088868317735767>
- Hermanns, M., & Mastel-Smith, B. (2012). Caregiving: A qualitative concept analysis. *Qualitative Report*, 17, 1–18. <https://doi.org/10.46743/2160-3715/2012.1727>

- Huang, G., Guo, F., & Chen, G. (2022). The role and wellbeing of female family caregivers in the provision of aged care in China. *Social Indicators Research*, 159(2), 707–731. <https://doi.org/10.1007/s11205-021-02769-6>
- Imran, N., Bhatti, M. R., Haider, I. I., Azhar, L., Omar, A., & Sattar, A. (2010). Caring for the caregivers: Mental health, family burden and quality of life of caregivers of patients with mental illness. *Journal of Pakistan Psychiatric Society*, 7(1), 23–28.
- Jabeen, S., Zakar, R., Zakar, M. Z., & Fischer, F. (2024). Experiences of family caregivers in dealing with cases of advanced breast cancer: A qualitative study of the sociocultural context in Punjab, Pakistan. *BMC Public Health*, 24(1), Article e1030. <https://doi.org/10.1186/s12889-024-18404-1>
- Khalaila, R. (2020). Caregiver burden and compassion fatigue among Arab family caregivers of older relatives. *Journal of Applied Gerontology*, 40(7), 722–730. <https://doi.org/10.1177/0733464820920100>
- Khalid, W., Rozi, S., Ali, T. S., Azam, I., Mullen, M. T., Illyas, S., & Kamal, A. K. (2016). Quality of life after stroke in Pakistan. *BMC Neurology*, 16(1), Article e250. <https://doi.org/10.1186/s12883-016-0774-1>
- Kreuger, R. A., & Casey, M. A. (2009). *Focus groups: A practical guide for applied research*. Sage Publications.
- Lalani, N., & Ali, G. (2021). Global APN case study in spirituality: Stories of hope from Pakistan. In M. Roger (Ed.), *Spiritual dimensions of advanced practice nursing: Stories of hope* (pp. 181–194). Springer
- Lethin, C., Leino-Kilpi, H., Bleijlevens, M. H., Stephan, A., Martin, M. S., Nilsson, K., Nilsson, C., Zabalegui, A., & Karlsson, S. (2019). Predicting caregiver burden in informal caregivers caring for persons with dementia living at home—a follow-up cohort study. *Dementia*, 19(3), 640–660. <https://doi.org/10.1177/1471301218782502>
- Liu, H., Fang, B., Chan, J., & Chen, G. (2019). The relationship between comorbidities in dementia patients and burden on adult–child primary caregivers: Does having a secondary caregiver matter? *International Journal of Mental Health Nursing*, 28(6), 1306–1317. <https://doi.org/10.1111/inm.12640>

- Morgan, D. L. (1997). *Focus groups as qualitative research*. Sage Publications.
- Moura, F. P., & Hamdan, A. C. (2020). Relations between subjective well-being and Alzheimer's disease: A systematic review. *Dementia & Neuropsychologia*, *14*, 153–158. <https://doi.org/10.1590/1980-57642020dn14-020008>
- Noreen, N., Abdullah, M., & Lalani, N. (2022). Geriatric care in Pakistan: Current realities and way forward. *Pakistan Journal of Public Health*, *11*(4), 214–219. <https://doi.org/10.32413/pjph.v11i4.872>
- Petrini, M., Cirulli, F., D'Amore, A., Masella, R., Venerosi, A., & Venerosi, A. (2019). Health issues and informal caregiving in Europe and Italy. *Annali Dell'Istituto Superiore Di Sanita*, *55*(1), 41–50.
- Qadir, F., Gulzar W., Haqqani S., & Khalid A. (2013). A pilot study examining the awareness, attitude, and burden of informal caregivers of patients with dementia. *Care Management Journals: Journal of Case Management; The Journal of Long Term Home Health Care*, *14*(4), 230–240. <http://dx.doi.org/10.1891/1521-0987.14.4.230>
- Rashid, M. A. U., Muneeb, S. A., Manzoor, M. M., & Fischer, F. (2023). Religious coping, care burden and psychological distress among informal caregivers of COVID-19 patients: Results of a cross-sectional survey in Pakistan. *International Journal of Social Psychiatry*, *69*(6), 1369–1376. <https://doi.org/10.1177/00207640231162277>
- Rayment, G., Swainston, K., & Wilson, G. (2019). Using photo-elicitation to explore the lived experience of informal caregivers of individuals living with dementia. *British Journal of Health Psychology*, *24*, 102–122. <https://doi.org/10.1111/bjhp.12342>
- Saleem, T., Saleem, S., & Tahan, M. (2024). Assessing caregiving burden in family caregivers of depression & schizophrenia in Pakistan. *Neuropsychopharmacologia Hungarica*, *26*(2), 86–93.
- Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing*, *108*(9), 23–27. <https://doi.org/10.5175/JSWE.2008.773247702>
- Siddiqui, S. P., & Khalid, J. (2019). Determining the caregivers' burden in caregivers of patients with mental illness. *Pakistan Journal of Medical Sciences*, *35*(5), 1329–1333. <https://doi.org/10.12669/pjms.35.5.720>

- Sivakanthan, S., Cooper, R., Lopes, C., Kulich, H., Deepak, N., Lee, C. D., Wang, H., Candiotti, J. L., Dicianno, B. E., Koontz, A., & Cooper, R. A. (2024). Accessible autonomous transportation and services: A focus group study. *Disability and Rehabilitation: Assistive Technology*, 19(5), 1992–1999. <https://doi.org/10.1080/17483107.2023.2242898>
- Steenfeldt, V. O., Aagerup, L. C., Jacobsen, A. H., & Skjødt, U. (2021). Becoming a family caregiver to a person with dementia: A literature review on the needs of family caregivers. *SAGE Open Nursing*, 7, 1–14. <https://doi.org/10.1177/23779608211029073>
- Tamizi, Z., Fallahi-Khoshknab, M., Dalvandi, A., Mohammadi-Shahboulaghi, F., Mohammadi, E., & Bakhshi, E. (2020). Caregiving burden in family caregivers of patients with schizophrenia: A qualitative study. *Journal of Education and Health Promotion*, 9(1), Article e12. https://doi.org/10.4103/jehp.jehp_356_19
- Truglio-Londrigan, M., & Slyer, J. T. (2019). Caregiver decisions along the Alzheimer's disease trajectory. *Geriatric Nursing*, 40(3), 257–263. <https://doi.org/10.1016/j.gerinurse.2018.10.015>
- Vu, M., Mangal, R., Stead, T., Lopez-Ortiz, C., & Ganti, L. (2022). Impact of Alzheimer's disease on caregivers in the United States. *Health Psychology Research*, 10(3), Article e37454. <https://doi.org/10.52965%2F001c.37454>
- Wang, S., Cheung, D. S. K., Leung, A. Y. M., & Davidson, P. M. (2020). Factors associated with caregiving appraisal of informal caregivers: A systematic review. *Journal of Clinical Nursing*, 29(17–18), 3201–3221. <https://doi.org/10.1111/jocn.15394>
- Wright, L. M., & Leahey, M. (2013). *Nurses and families: A guide to family assessment and intervention*. FA Davis.
- Zwar, L., Angermeyer, M. C., Matschinger, H., Riedel-Heller, S. G., König, H.-H., & Hajek, A. (2021). Are informal family caregivers stigmatized differently based on their gender or employment status? A German study on public stigma towards informal long-term caregivers of older individuals. *BMC Public Health*, 21(1), 1–14. <https://doi.org/10.1186/s12889-021-11955-7>