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Explaining the multifaceted experiences of family caregivers of stroke survivors: a qualitative study in Iran

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ABSTRACT

Objectives As the family caregivers of stroke survivors are typically subjected to care burden, spirituality has been advocated to protect them from its negative effects. The purpose of this study was to describe the caregiving experiences of family caregivers of stroke survivors.

Design This qualitative study was conducted from December 2023 to June 2024 in Iran. Data were analysed using the conventional content analysis method.

Setting The study was conducted in the neurology wards of two referral hospitals affiliated with Shahid Beheshti University of Medical Sciences in Tehran, Iran.

Participants After meeting the inclusion criteria, a total of 17 family caregivers of stroke survivors were recruited using the purposive sampling technique with maximum variation. Data were then collected through 17 in-depth semistructured interviews, each lasting 30–60 min.

Results Four themes emerged from the study participants' statements: (1) 'challenges and struggles', (2) 'religious coping strategies', (3) 'psychological coping strategies' and (4) 'social and relational dynamics'. The core concept of 'balancing hope and hardship' was then introduced.

Conclusion The study findings highlight the need to develop comprehensive support programmes for family caregivers of stroke survivors to minimise their caregiving burden. Healthcare planners and providers are encouraged to use these findings to improve the health outcomes of these families and reduce the burden of caregiving.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The study provides a comprehensive exploration of the multifaceted experiences of family caregivers, integrating emotional, physical, spiritual and social dynamics to highlight their challenges and coping strategies.
- ⇒ The use of qualitative content analysis with techniques such as maximum variation sampling and systematic coding enhances the depth and reliability of the findings.
- ⇒ The small number of male participants limits the generalisability of findings across gender perspectives.
- ⇒ The focus of the study on a predominantly Muslim context limits the applicability of the findings to different cultural and religious backgrounds.

INTRODUCTION

Stroke has been documented to be among the leading causes of long-term disability[1] and the second cause of motor disability or mortality.[2] Thanks to medical advances, about 90% of stroke survivors survive the first event, but about 50% of cases struggle with multiple stroke-related disorders that disrupt their independence to perform activities of daily living.[3] As stroke is associated with many acute perceptual, cognitive and movement disorders, most stroke survivors have problems in resuming their social, family or recreational activities, and they are generally in dire need of long-term rehabilitation and full family support.[4] Accordingly, providing stroke survivors with essential care significantly contributes to their recovery, prevents recurrent strokes among them and promotes their overall health and well-being.[5]

Considering the insufficient number of governmental rehabilitation centres, post-discharge care services for elderly stroke survivors and the high cost of private centres and home care services in Iran, family caregivers (FCGs) usually assume caregiving responsibilities,[6] get involved and care for stroke survivors at home.[7] Of note, FCGs refer to the family members of stroke survivors who regularly provide long-term support during their rehabilitation and recovery.[8] Likewise, FCGs are family members such as spouses, children, siblings, friends or even those around such as neighbours who care for someone who suffers from a chronic illness and needs help with activities of daily living such as bathing, dressing and taking medications.[9] Such individuals provide vital support to stroke survivors and give a positive response to this role immediately following the stroke event.[10]

In most cases, FCGs of stroke survivors bear a heavy care burden (CB) caused by the unpredictable onset of disability, the chronic nature of the disease and the volatility of rehabilitation and recovery.[7] Such

FCGs always experience negative psychosocial aftereffects, such as anxiety, depression, social problems and isolation, and even many lifestyle changes and reduced quality of life. In fact, stroke can be a great challenge with significant impact on family communication, relationships, flexibility and functioning.[10] In view of that, drastic changes are likely to occur in the life of stroke survivors and their families and they might not return to normal life before this event. For this reason, stroke is considered a family disease.[6] In this context, burden represents objective and subjective negative consequences caused by caregiving, including physical, psychological and socio-economic problems.[11] Thus, CB can be defined as the stress experienced by those who care for chronically ill, disabled or elderly family members. It is also used to describe the side effects of caregiving, which are then very challenging for patients and their families.[5] Specifically, CB can be divided into objective and subjective forms, the former meaning the physical assistance provided by FCGs and the latter representing the psychological, social and emotional impact on FCGs following objective CB.[12]

Moreover, CB leads to emotional exhaustion in FCGs and makes them lose their enthusiasm, so the quality of care provided is further affected.[13] With regard to CB and stress faced by FCGs of stroke survivors in caring for elderly patients, family-oriented care must be maintained and subsequently the effective factors and needs in such FCGs must be met.[6] Despite much support for such care throughout rehabilitation in the last two decades, some conditions such as sense of loss, unhappiness and psychosocial-emotional needs in FCGs have been ignored by healthcare systems so far. Although FCGs strive to manage CB and related challenges after stroke survivors are discharged home, inadequate resources and support make them highly susceptible to burnout, thereby threatening their health and well-being.[14]

In Iranian culture, both nuclear and extended families are considered the primary support systems for patients who had a stroke. Due to strong emotional bonds and traditional values, these family structures naturally assume the responsibility of caregiving.[15] Among them, women, in particular, bear the main responsibility of caregiving while managing other roles such as wife, mother or employee, which leads to significant emotional and physical burden.[6] Cultural expectations rooted in traditional norms often force women to perceive caregiving as their duty, which further contributes to their physical and emotional exhaustion.[5]

The lack of formal support systems, professional care services and post-discharge training centres, especially in underserved areas, exacerbates the challenges of caregiving. The high cost of private centres and home care services has made family caregiving the most common solution, with families assuming full responsibility without external support.[6 16] These problems are exacerbated by limited resources, weak referral systems, a shortage of rehabilitation specialists and a lack of integration of rehabilitation services into primary healthcare, which puts additional burden on FCGs.[17]

In such a context, many FCGs, especially spouses and daughters, must juggle their caregiving duties with other life responsibilities. This multitasking, combined with economic and social constraints and lack of formal support, makes the caregiving experience in Iran uniquely challenging. In addition, individual differences such as health literacy, socio-economic status and emotional well-being significantly affect how FCGs perceive and cope with their caregiving roles and influence their overall burden.[18] It highlights the importance of understanding CB within a distinct cultural and structural framework.[19]

Literature review

Numerous qualitative studies have reported that FCGs of stroke survivors try to cope with multiple challenges and emotional burden at different stages of care. For example, Lin *et al*[20] had described the transition from hospital to home care as a critical period in which both stroke survivors and FCGs may experience uncertainty and stress and then require caregiver support. In a systematic review and meta-ethnography, Pindus *et al*[21] had also found that FCGs could often feel void of primary care and community health services. Comer *et al*[1] had further highlighted that caregiving could be a heavy burden for FCGs and significantly affect their physical and mental health. In addition, Wagachchige Muthucumarana *et al*[22] had pointed out that many cultural factors, especially in Sri Lanka, could contribute in this regard and some family obligations could promote CB. In this line, Qiu *et al*[23] had examined cultural stimuli in China and confirmed that traditional family values could create more emotional-social expectations from FCGs. Taken together, such studies demonstrated the complex nature of stroke survivor care and its reinforcement by cultural and emotional factors.

Given the psychological and physical burden associated with caring for stroke survivors, it is important to identify and implement effective strategies to reduce caregiver burden. Recent studies have highlighted the importance of formal support mechanisms–such as access to community-based health services, respite care and caregiver education programmes–that can help reduce stress and improve the overall well-being of stroke FCGs.[24] However, in many low-income and middle-income countries, such as Iran, the lack of structured support systems places FCGs of stroke survivors at greater risk of burnout. Therefore, a deeper understanding of their lived experiences and coping needs is crucial for designing targeted interventions and supportive health policies tailored to this group.

Considering the utmost importance of explaining the experiences of FCGs in caring for stroke survivors and the limited studies in this regard in Iran, this qualitative study was designed to shed light on the experiences regarding CB management among FCGs of stroke survivors. Specifically, the study aimed to answer the following research question: what are the lived experiences of FCGs in Iran regarding the management of care for stroke survivors?

Of note, the qualitative research design adopted here was the best for exploring human phenomena, especially CB, and evaluating different perspectives, because quantitative approaches could not explore human, socio-cultural and relational dimensions and values.[25] In addition, qualitative research could help identify health behaviour patterns, illustrate illness experiences, design and develop health interventions, and expand theories in healthcare.[26] In addition, qualitative research could help identify health behaviour patterns, illustrate illness experiences, design and develop health interventions, and expand theories in healthcare.

METHODS

Design and settings

This qualitative study was conducted from December 2023 to June 2024 using content analysis to interpret the data and its underlying meanings. Content analysis provided a systematic and objective approach to describe and measure phenomena,[27] specifically in this case CB. The study was guided by the interpretivist paradigm, which not only analyses individual experiences but also explores a deeper understanding of the caregiving process by considering the meanings that FCGs attach to their actions, as well as the social and cultural structures that shape these experiences.[26 28]

The study participants were the FCGS of stroke survivors admitted to the neurology wards of two referral hospitals affiliated to Shahid Beheshti University of Medical Sciences, Tehran, Iran. Iran has a population of more than 80 million, the majority of whom live in urban areas and are increasingly affected by non-communicable diseases. More than 99% of the population is Muslim, while followers of other religions—such as Zoroastrians, Jews and Christians—are a minority.[29]

Participants

A total of 17 eligible FCGs of stroke survivors were recruited through purposive sampling techniques in this study. The inclusion criteria were being the primary FCG of stroke survivors, having first-degree relatives (namely, spouses, children or siblings) with stroke survivors, being over 18 years of age and having sufficient ability to answer the interview questions. To maximise variation in the sample, different age groups, genders, kinship groups, educational levels and employment types were considered. Of note, five participants were FCGs of stroke survivors who had suffered recurrent strokes for the second and third time and were hospitalised. Sampling continued until data saturation was reached.

Data saturation was considered achieved when no new concepts, subcategories or themes emerged from the final interviews. This was determined through concurrent data analysis, in which the researchers coded and reviewed each interview before conducting the next. The criteria for determining saturation included the observation that the last two interviews produced repetitive data with no new insights or variations. In addition, no new themes or concepts emerged from these interviews, and further analysis indicated that additional data would not add significant new information to the existing themes. When these criteria were consistently met, the research team concluded that saturation had been reached.[30]

Data collection

The data were collected by the first researcher, as a senior expert in community health nursing, through in-depth semistructured interviews. She was trained to interview the participants. The first researcher conducted in-depth, face-to-face, semistructured interviews to collect data. As a senior expert in community health nursing, she has received extensive training in qualitative research methods, including interviewing, data analysis and ethical considerations. She has attended several workshops focusing on qualitative methods and has previously led several research projects involving interviews with participants in clinical settings. This extensive experience has provided her with the skills necessary to effectively engage with participants, adapt interview questions as needed and ensure a flexible approach that supports in-depth exploration of the research topics. The researcher's background in community health nursing may have influenced her interpretation of the caregiving experience. This potential influence was acknowledged through the use of reflexive journaling during data collection and analysis. In addition, the researcher's reflexivity was considered throughout the data collection process, acknowledging how her background and experiences might influence her interaction with participants and interpretation of the data.

After obtaining written informed consent, interviews were conducted with open-ended questions about the study objectives. No prior relationship was established between the interviewer and the participants prior to the interviews. The location and time of the interviews were chosen by the participants. Thus, the interviews were conducted in a quiet room in the neurology wards of the referral hospitals. A total of 17 semistructured interviews were conducted, each lasting 30–60 min. No participant withdrew from the study.

The first three interviews were conducted as pilot interviews to assess the clarity and relevance of the interview questions. As the questions were found to be appropriate and effective in eliciting rich and meaningful responses, no changes were made and the same questions were used in the remaining interviews. The interviews began with an open-ended question about experiences with CB management in the FCGs of stroke survivors. According to the participants' answers, the interviews were directed towards the main objectives of the study. In addition, some exploratory questions were asked to gain a deeper understanding. The questions in the interview guide were "Tell me about your experiences and feelings during patient care", "How did patient care affect you?" and "How do you cope with the negative effects of patient care?" The researcher further explored the participants' responses to each question. By restating the key points or summarising the participants' responses, an attempt was made to confirm the accuracy of the data and increase the credibility of the results. At the end of each interview, some questions such as "Is there anything else you would like to add?" and "Is there any other question I should have asked?" were used to help participants share any experiences or additional information. When necessary, the interview guide was flexibly adapted based on participants' initial responses to ensure relevance and depth of data collection. Interviews were also recorded using a voice recorder.

Before the interviews, socio-demographic information was collected by the first researcher. This was done by asking relevant socio-demographic questions and taking notes on a paper form. The notes were kept confidential and secure. This process took place at the beginning of the study, before the formal interviews, to ensure that the participants' background information was available for contextual understanding during the interviews.

Data analysis

Data analysis was conducted using conventional content analysis as the most common method of analysis in studies describing text properties. It could also provide an integrated view of the text and its related features so that the researcher could understand social phenomena subjectively but scientifically. The main stages of analysing the data were (1) transcribing the interviews, (2) reading the transcripts repeatedly to achieve immersion and get a sense of the whole, (3) taking notes on the manuscripts by mentioning different types of information, (4) defining the unit of analysis using some themes, (5) developing a coding system to organise the data in an understandable way, (6) coding the entire text and categorising the codes based on their meanings, (7) extracting the final themes and (8) describing and interpreting the findings.[31] Data analysis was supported using the MAXQDA (V.10) software.

Rigour

In this study, the main criteria of credibility, dependability, transferability and confirmability, and authenticity were used to determine the scientific accuracy and validity of the data. In all interviews, the relationship between the study objectives, the interview questions and the participants' answers was checked and validated by the researchers. In addition, to strengthen the data, the researchers immersed themselves in the data for a long period of time and started the interviews based on the required data. Coding and analysis of data through peer review by two researchers simultaneously and review of interview transcripts and initial codes by three participants (member checking) were other measures to ensure rigour. To ensure the accuracy of coding, data analysis was conducted by different researchers and in case of disagreement, group discussions were held to reach consensus. Although field notes were not taken specifically for environmental observations, all interviews were recorded and more detailed analysis was conducted through transcription and systematic coding. In addition, a reflective journal was used to clarify the researchers' personal influences and biases during the data collection and analysis process.

To increase transferability, relevant and accurate quotes from participants were included in the report to help transfer the study findings to similar contexts. Providing a detailed report of the study methods, including the characteristics of the participants, the sampling technique, the data collection method, the study setting and the results, along with the quotes from the participants, were other measures to strengthen the study and confirm the validity and reliability of the data. In addition, to increase credibility, the process of reviewing and confirming the data was conducted regularly with the research team, and continuous feedback was received from team members throughout the data analysis. The Standards for Reporting Qualitative Research were used to report the research findings.[32]

Patient and public Involvement

Patients and the public were not involved in the design, conduct, reporting or dissemination plans of this research.

RESULTS

There were a total of 15 female participants and 2 male cases, with an average age of 48 years. Approximately 30% of the participants were spouses of stroke survivors and 50% were their children. Other demographic characteristics are shown in table 1.

Analysing the statements by the participants led to the formation of four themes, labelled as (1) 'challenges and struggles', with four subthemes, including 'physical burden', 'emotional burden and insufficient sleep', 'financial burden' and 'inflated life responsibilities'; (2) 'religious coping strategies', containing three subthemes of 'faith in God and His help', 'worship and pilgrimage' and 'thankfulness to God'; (3) 'psychological coping strategies', comprised of five subthemes, namely, 'acceptance and care', 'positive thinking and strengthened inner energy', 'energising others', 'hope in the midst of despair' and 'happiness upon improvement in patient condition'; and (4) 'social and relational dynamics', consisting of three subthemes of 'patient attachment', 'emotional–financial support by those around' and 'negligence by those around'. As well, the core concept developed based on these themes was named 'balancing hope and hardship' (table 2). Each theme and its subthemes, as well as the core concept, are explained below.

Table 1 Participants' demographic characteristics

Participant no.	Age range	Sex	Relationship with stroke survivors
1	55–60	Female	Sister
2	45–50	Female	Child
3	35–40	Female	Child
4	35–50	Female	Spouse
5	40–45	Female	Child
6	40–45	Male	Child
7	65–70	Female	Spouse
8	35–40	Female	Child
9	35–40	Female	Child
10	50–55	Female	Child
11	50–55	Female	Spouse
12	60–65	Female	Spouse
13	65–70	Female	Mother
14	45–50	Female	Spouse
15	40–45	Female	Spouse
16	20–25	Males	Child
17	35–40	Female	Child

Table 2 Main theme, categories and subcategories developed from the experiences of family caregivers of stroke survivors about managing the care burden

Core concept	Themes	Subthemes
Balancing hope and hardship	Challenges and struggles	Physical burden
		Emotional burden and insufficient sleep
		Financial burden
		Inflated life responsibilities
	Religious coping strategies	Faith in God and His help
		Worship and pilgrimage
		Thankfulness to God
	Psychological coping strategies	Acceptance and care
		Positive thinking and strengthened inner energy
		Energising others
		Hope in the midst of despair
		Happiness upon improvement in patient condition
	Social and relational dynamics	Patient attachment
		Emotional–financial support by those around
		Negligence by those around

Theme 1: challenges and struggles

The first theme, 'challenges and struggles', represented the physical, emotional, socio-economic and practical problems faced by FCGs of stroke survivors. It consisted of five subthemes, including 'physical burden', 'emotional burden and insufficient sleep', 'financial burden' and 'inflated life responsibilities', elucidated as follows.

Physical burden

As the study participants explained, the FCGs of stroke survivors could often experience adverse conditions such as fatigue, pain and physical ailments due to CB, including lifting or transferring patients. On the subject of physical burden, one participant said:

> It's really hard for me to take good care of a sick person because I'm getting older, and it takes a lot of effort to look after him properly. (Participant 12)

Emotional burden and insufficient sleep

According to the study participants, it was distressing to see their patients in poor health when they had a sense of independence and self-worth prior to the stroke event. They also pointed out that the futile efforts to improve the patients' conditions had caused them emotional distress, resulting in insufficient sleep, hopelessness, depression and even isolation. In this regard, one of the participants stated:

> His poor health has influenced my entire life. I have turned into an agitated person, crammed with stress and anxiety. I have no time to take a rest and, I cannot sleep well. I feel that I have become a bit more aggressive toward my children or their studies and work. I even think I am now more isolated. I have a sense of despair for some time. (Participant 4)

Financial burden

Participants felt that healthcare costs could put a lot of pressure on FCGs. As one participant acknowledged:

> My father does not have a good income. These days, about three million Iranian tomans out of his unemployment insurance salary is spent on oxygen, capsule rentals, and other treatments. We only spend a great deal on his oxygen. Our state of affairs is not good even if my sister helps. I have to work hard these days. The disease has had many negative effects on our household economy and much pressure on the family. (Participant 9)

Inflated life responsibilities

Participants explained that patients' conditions could force them to take on many more responsibilities, including household chores, providing financial resources and caring for other family members, especially children. Ultimately, this could put a great deal of pressure on FCGs. In this regard, one participant stated:

> All these pressures are mostly on me. I have many responsibilities to tackle, such as working at home, taking care of children, taking them out, meeting everything in life, and practicing treatment. It is very easier said than done. I always pray and ask God to help me continue and endure. I think I will do it. (Participant 4)

In summary, the physical, emotional and financial challenges that FCGs of patients who had a stroke face significantly impact their quality of life and require effective coping strategies. In response to these challenges, many FCGs turn to spiritual and religious resources to alleviate psychological and physical burden, which will be discussed further.

Theme 2: religious coping strategies

Religious coping strategies, as the second theme, specified the main mechanisms related to religion that could play a supportive and coping role in reducing suffering and CB. This was derived from three subthemes of 'faith in God and His help', 'worship and pilgrimage' and 'thankfulness to God'.

Faith in God and His help

According to the participants, they had faith in God as an important source of guidance and support, and trusted that divine intervention would help them triumph over their problems. For example, one participant affirmed:

> I strongly rely on God. The moment I think that God exists and helps me raise my spirit. I become much more hopeful. Sometimes, I convince myself that my father is old, he may not be well, and his speech may not return fully, but we leave it up to God to help. (Participant 5)

Worship and pilgrimage

Participants said that praying and visiting holy places could help them connect with God, find peace, express gratitude and ask for help. Regarding prayer, one of the participants said:

> When my father is not in a good mood, the only thing that soothes us is to summon God. We can now have a ray of hope only by trusting in God, saying prayers, making vows, or reading the Holy Qur'an. (Participant 9)

Thankfulness to God

Many participants repeatedly thanked God and believed that He had helped them so far because the situation could have been worse. As one of the participants put it:

> My father's condition could have been much worse than this. Once more, we should be grateful. Thank God that he is in this condition as it can be controlled and resolved. (Participant 6)

Regarding the second theme, religious coping strategies have been a source of peace and hope for FCGs. These strategies, ranging from belief in God to prayer and pilgrimage, have helped FCGs cope with physical and emotional stress. In addition to religious coping strategies, FCGs also turn to psychological strategies to cope with the emotional and psychological challenges they face. These strategies help them to cope more effectively with their circumstances on a spiritual and emotional level, which will be discussed below.

Theme 3: psychological coping strategies

The third theme, psychological coping strategies, was based on the mental and emotional practices of FCGs of stroke survivors to deal with challenges and CB by placing much emphasis on building mental flexibility, making emotional investments and having positivity. This theme consisted of five subthemes, named 'acceptance and care', 'positive thinking and strengthened inner energy', 'energising others', 'hope in the midst of despair' and 'happiness upon improvement in patient condition'.

Acceptance and care

The core of psychological coping strategies was 'acceptance and care'. The participants explained that they had made great efforts to increase their adaptability by accepting and caring for the patients' condition. In this regard, one of the participants acknowledged:

> These days, my mother is not in a good condition. I am not in a good mood, too, but then again I have to accept everything. I am trying to be strong enough to care for my mother. I need to shoulder everything and have high spirits. (Participant 8)

Positive thinking and strengthened inner energy

Positive thinking and increased inner energy implied maintaining optimism and having inner strength to face many challenges and struggles as the FCGs of stroke survivors. Accordingly, participants stated that they had tried to cope with many situations through positive thinking. As quoted by one participant:

> I make an effort to be more positive. I do not think about why something like this happened. Well, it happened, God wanted it to happen like this. It may be a good thing. We do not know about good and bad. (Participant 12)

Energising others

As the participants expressed, they had tried to keep their family members and those around them out of distress, and then found peace by spreading positive energy and hope. One of the participants said:

> Despite the fact I am confused and feel worried about my husband, I try to give positive energy to others, above all my children. I do not want to make them involved in the existing problems. In the face of everything, they have their own studies and work. I endeavor to help them and give them positive energy that things finally get better. I feel better, too. (Participant 15)

Hope in the midst of despair

Participants noted that they sometimes felt exhausted and hopeless, but tried to light the way in the dark times for a better future for patients and their recovery. As one participant noted:

> I sometimes feel very enervated and disappointed, but I think about the past, and I feel comforted by the patient recovery in these few months. I hope that it will get better step by step, and my husband and I feel better. (Participant 4)

Happiness upon improvement in patient condition

Some participants emphasised that their mental state depended on the physical and mental state of their patients. In other words, they could feel happy and refreshed when the patient's condition improved. According to one participant:

> All through this time, I worked with him to improve the physical movements. Fortunately, his hand movements have bettered. His speech has also developed. I feel happy about this. As he is getting better, I am also feeling well again. (Participant 15)

Finally, regarding the third theme, psychological coping strategies helped FCGs manage their emotional and psychological challenges through positive thinking, acceptance of the situation and strengthening of inner energy. These strategies enabled them to be more resilient to pressure and to cope with the circumstances with hope for improvement. In addition to these strategies, social dynamics and supportive relationships also play a critical role in alleviating CB. The fourth theme explores the social dynamics and relationships among FCGs, patients and those around them.

Theme 4: social and relational dynamics

The fourth theme, 'social and relational dynamics', put emphasis on the role of relationships and social interactions in dealing with difficulties based on three subthemes of 'patient attachment', 'emotional–financial support by those around' and 'negligence by those around'.

Patient attachment

According to the participants, one of the psychological coping strategies was to feel more connected to their patients than before the stroke event. Some explained that the post-stroke conditions made them spend a lot of time with their patients and feel more dependent. In this case, one of the participants confirmed this:

> It was very difficult during this time when my husband had a stroke, because he was a real support in any case. After all, couples want to be together and they need each other. Now, he feels I love him more. I want to help him as soon as possible. God willing, we can soon live together. (Participant 12)

Emotional–financial support by those around

Emotional–financial support, as one of the subthemes of social and relational dynamics, highlighted the importance of receiving love and empathy from those around them, as well as financial support, to minimise CB in FCGs. In this regard, one participant said:

> It is vital that you feel that you are not alone in this situation. I had a good feeling and was encouraged when my wife's family wanted to stay with her and help. However, it is better to take care of her as my wife is at ease with me.

Negligence by those around

In contrast to the previous subtheme, some FCGs complained about the negligence of those around them and their lack of support for CB. Over time, the conditions had become routine and they had not supported them. In this regard, one participant stated:

> The relationships with those around have dwindled all this time, and it is bothering. I feel as if something has happened, but others think that is not something important, which means we always face this problem. (Participant 1)

Summarising the fourth theme, supportive and social relationships play a key role in coping with the challenges of caregiving. Emotional and financial support from those around the caregiver helps to reduce physical and emotional burden, while attachment to the patient promotes greater motivation and solidarity.

Core concept: balancing hope and hardship

The core concept of 'balancing hope and hardship' captures the duality of the experience of FCGs of stroke survivors, who simultaneously face numerous challenges while striving to maintain hope and resilience. This tension is first evident in the physical toll they endure. Fatigue, pain and physical ailments are common among FCGs, especially as they age. As one participant noted:

> It's really hard for me to take good care of a sick person because I'm getting older, and it takes a lot of effort to look after him properly. (Participant 12)

In addition to the physical burden, FCGs experience significant emotional challenges. Witnessing the decline of a once-independent loved one can lead to despair, depression and feelings of isolation. This emotional toll can disrupt sleep and personal well-being:

> His poor health has influenced my entire life. I have turned into an agitated person, crammed with stress and anxiety. I have no time to take a rest and, I cannot sleep well. I feel that I have become a bit more aggressive toward my children or their studies and work. I even think I am now more isolated. I have a sense of despair for some time. (Participant 4)

In response to this burden, many FCGs turn to religious coping strategies, finding strength in their faith. Belief in divine support serves as an essential resource for coping with their responsibilities:

> I strongly rely on God. The moment I think that God exists and helps me raise my spirit. I become much more hopeful. Sometimes, I convince myself that my father is old, he may not be well, and his speech may not return fully, but we leave it up to God to help. (Participant 5)

In addition to spiritual coping, psychological strategies—such as positive thinking and acceptance—enable FCGs to persevere. Some try to reframe their situation optimistically and embrace their role with inner strength:

> I make an effort to be more positive. I do not think about why something like this happened. Well, it happened, God wanted it to happen like this. It may be a good thing. We do not know about good and bad. (Participant 12)

Social and relational support further eases the CB. Emotional and financial support from others provides comfort and reassurance that FCGs are not alone:

> It is vital that you feel that you are not alone in this situation. I had a good feeling and was encouraged when my wife's family wanted to stay with her and help. However, it is better to take care of her as my wife is at ease with me. (Participant 9)

DISCUSSION

The analysis of participants' statements led to the identification of four key themes. These were 'challenges and struggles', 'religious coping strategies', 'psychological coping strategies' and 'social and relational dynamics'. All of these themes were linked to the core concept of 'balancing hope and hardship'. Given the limited number of qualitative researches on the experiences of FCGs of stroke survivors regarding CB management in Iran, the study findings here provided valuable insights that such FCGs had multifaceted caregiving responsibilities for their patients by balancing hope and hardship.

The first theme, 'challenges and struggles', highlighted the multiple physical and emotional difficulties faced by stroke survivors' FCGs. These challenges, which have a significant impact on FCGs' physical and emotional well-being, include physical strain, financial hardship and increased workload. These issues not only affect the health of FCGs, but also the quality of care they provide. Therefore, it is essential to provide FCGs with comprehensive support that includes psychological and emotional resources in addition to physical support.

These findings are consistent with other studies in this area. For example, Kokorelias *et al*[33] identified four key categories of life changes for FCGs of stroke survivors, such as reconstructed life, changes in relationships, physical challenges and psychosocial issues. In a study conducted in Sri Lanka, FCGs of stroke survivors reported major challenges such as physical strain, financial problems and increased workload as their main concerns.[22] Furthermore, a phenomenological study by Sidek *et al*[3] highlighted the significant impact of caregiving on FCGs' physical, mental and emotional health, as well as their professional and social lives in Malaysia.

The second theme, 'religious coping strategies,' emerged as a key mechanism employed by FCGs of stroke survivors. These FCGs often turn to religious and spiritual practices to cope with the emotional and psychological burdens of caregiving. This theme has been echoed in several studies that emphasise how faith can provide FCGs with emotional strength, resilience and a sense of purpose during difficult times. For example, Benites *et al*[34] explored the spiritual experiences of FCGs of patients with advanced cancer in Brazil and found that a personal connection to God was an essential coping strategy that provided emotional strength and confidence during caregiving. Similarly, Keykha *et al*[35] found that spirituality plays a leading role in helping FCGs accept their caregiving conditions and adapt to challenges, providing them with emotional resilience. In addition, Casaleiro *et al*,[36] in a systematic review of 26 qualitative studies, reported that FCGs of adults with severe mental illness often resorted to spiritual and religious practices as coping strategies.

This finding is consistent with the results of the current study, indicating that religious coping strategies are critical in helping FCGs of stroke survivors cope with caregiving stress and emotional struggles. Specifically, the role of faith is not only important for emotional adjustment, but also serves as a valuable tool for coping with the physical and psychological burdens of caregiving. Integrating religious support into caregiving interventions could enhance FCGs' emotional well-being, reduce stress and improve the quality of care provided to patients.

The third theme, 'psychological coping strategies', focused on the emotional and psychological mechanisms used by FCGs to cope with the stress of caregiving. The ability to draw on internal strengths and external resources plays a key role in coping with the pressures of caregiving. This finding is consistent with several studies that show the importance of psychological coping mechanisms for FCGs. For example, a study conducted in Sri Lanka identified personal strengths as a central coping strategy for FCGs, highlighting the importance of internal flexibility in coping with caregiving responsibilities.[21] Similarly, FCGs of stroke survivors in China relied on both family resources and their own inner strengths to cope with caregiving challenges, with emotional and psychological support from family members playing a crucial role.[22] Furthermore, a study conducted in Uganda found that support for FCGs is crucial for them to continue their work and caregiving responsibilities.[37]

These findings suggest that both internal and external psychological resources are critical in helping FCGs of stroke survivors cope with the challenges of caregiving. The study highlights the need for structured psychological support interventions that could improve FCGs' emotional well-being, reduce stress and increase caregiving effectiveness. The development of such interventions should be a priority to help FCGs cope with the emotional burden of caregiving and to ensure that they are able to provide quality care to stroke survivors.

The fourth theme, 'social and relational dynamics', revealed the complex emotional and social challenges that FCGs of stroke survivors face. These challenges affect the FCGs' emotional well-being and the quality of care they provide. Studies show that providing compassion and support through positive coping strategies is essential for FCGs. For example, a qualitative study in Sri Lanka found that compassionate care was a key coping strategy for FCGs of stroke survivors.[22] A systematic review also identified that FCGs of stroke survivors often experience emotional challenges but can overcome these difficulties through compassionate caregiving.[38] Similarly, Sidek *et al*[3] highlighted the importance of family and social support for FCGs of stroke survivors in Malaysia.

In conclusion, this study highlights the significant physical, emotional and financial challenges that FCGs of stroke survivors face that affect their health and quality of caregiving. FCGs rely on religious and psychological coping strategies to cope with these challenges, increasing their resilience and hope. In addition, emotional and financial support from family members, as well as the caregiver's dependency on the patient, plays a critical role in caregiving dynamics. The findings highlight the complex balance between stress and resilience in caregiving and underscore the need for comprehensive support to alleviate caregiver burden and improve caregiver well-being.

Implications for research and practice

The results of this study highlight the need for structured and culturally sensitive support programmes for FCGs of stroke survivors. Policymakers and healthcare providers should incorporate both religious and psychological coping strategies into their interventions. For example, empowerment programmes can include structured group sessions that teach stress-reduction techniques rooted in spirituality and mindfulness. These can be complemented by access to religious materials (eg, the Holy Qur'an, prayer books) and the availability of spiritual counsellors to address religious concerns.

Given the Islamic cultural context of Iran, providing opportunities for worship during caregiving, such as quiet prayer spaces and religious guidance, may improve FCGs' emotional well-being. To broaden applicability, future research should explore how such interventions could be adapted to non-Islamic or more secular contexts to ensure broader generalisability of the findings.

In light of these findings, it is critical for health policymakers to recognise the central role of FCGs in stroke rehabilitation. Developing policies that formally recognise and support the integration of FCGs into the healthcare system through financial support, caregiver education and culturally tailored mental health services can help reduce caregiver burden and improve patient outcomes.

In summary, the results of this study indicate that FCGs of stroke survivors face numerous physical, emotional and financial challenges that negatively affect their health and the quality of care they provide. These challenges include physical burdens, financial problems and increased workloads that occur in their daily lives. However, FCGs use religious and psychological coping strategies to manage these difficulties, which help them cope with emotional and psychological struggles and increase their resilience and hope. In addition, emotional and financial support from family members, as well as the caregiver's dependency on the patient, has a significant impact on caregiving dynamics. This study emphasises that the caregiving experience of stroke survivors is a complex interaction of stress and resilience, strongly influenced by personal beliefs and external support systems, and highlights the need for comprehensive support to reduce CB and improve FCGs' quality of life.

Limitations

A limitation of this study was the limited sample of male participants. The number of male participants in this study was lower than the number of female participants due to the smaller number of male FCGs in hospitals and the greater willingness of female FCGs to participate in research. This gender imbalance may affect the generalisability of the study's findings to different gender groups. In addition, due to the qualitative nature of the study and the limited research sample, the findings in this context are only applicable to a specific group of FCGs and stroke survivors. It is recommended that future studies consider larger and more diverse samples in terms of gender and culture to gain a better understanding of the experiences of different FCGs.

Conclusion

The results of this study identified four key themes: challenges and struggles, religious coping strategies, psychological coping strategies and social and relational dynamics. The findings highlight that FCGs face significant physical, emotional and financial burdens, often compounded by daily responsibilities. To cope with these challenges, FCGs rely on both religious and psychological coping strategies. In addition, emotional and financial support from family members, as well as the caregiver's dependence on the patient, plays a critical role in shaping caregiving dynamics.

This study highlights that caregiving for stroke survivors is a complex balance of stress and resilience, deeply influenced by personal beliefs and external support systems, ultimately resulting in a balance of hope and hardship. These findings may inform the development of culturally sensitive interventions. In addition, the findings provide valuable guidance for health policymakers and practitioners seeking to support FCGs, improve caregiver well-being and improve the quality of care for stroke survivors.

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Ethics approval All the measures taken in this study were approved by the Ethics Committee of Shahid Beheshti University of Medical Sciences, Tehran, Iran (code no. IR.SBMU.PHARMACY.REC.1402.189) in agreement with the ethical standards of the 1964 Declaration of Helsinki and its later amendments. The researcher introduced oneself to the participants and explained the study objectives. If the participants were willing to be included in the study, while obtaining written informed consent and permission to record the interviews, they were ensured about the confidentiality and anonymity of their information, no damage or loss, their voluntary participation and even the possibility of withdrawal from cooperation at any stage of the study.

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