Palliative Care Needs Among Jordanian Women Living with Stroke: A Descriptive Phenomenological Study

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Abstract

Background: Stroke is a common neurological disease. Women with stroke suffer many physical, psychosocial, and spiritual needs. Consequently, women living with stroke may have many marginalized palliative care needs as perceived by health care providers. However, the experience of women living with stroke and palliative care needs is understudied in Jordan.

Aim: This study aimed to explore the palliative care needs among women living with stroke in Jordan.

Methods: A qualitative descriptive phenomenological approach was employed with a purposive sample recruited from twelve women living with stroke. Data were collected using face-to-face semi-structured interviews. The Colaizzi (1978) method was used for data analysis.

Results: The study revealed three main emerging themes that reflected the palliative care needs of women living with stroke, which are: living with bothersome symptoms, receiving bad news, and spiritual practices, beliefs, and needs.

Discussion: This study sheds light on the aspects of Jordanian women with a comprehensive view of all aspects of life after suffering a stroke. The findings suggest that the burden of stroke has far-reaching consequences for women's lives. They have many unmet palliative needs that must be considered in the treatment plan.

Conclusion: This study provides insight into the palliative care needs of women. Women's health care needs included physical, psychosocial, and spiritual aspects. In line with these needs, integrating the palliative care approach with the rehabilitation program should be considered to improve the quality of life and alleviate the pain and further complications after stroke.

Introduction

Palliative care is “an approach to care that improves the quality of life for patients and their families facing life-threatening illness, through the prevention and relief of suffering, utilizing early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual”[1]. Initially, palliative care was developed to care for cancer patients at the end of their lives, but it has developed to include care for different illnesses and can be applied early in the courses of a chronic illness [2]. Early referral of patients to palliative care facilities will help to improve the Quality of Life (QoL) for patients and their families, symptom management, decrease re-hospitalization frequencies, and reduce the costs of healthcare services [2, 3]. Many research studies investigated the palliative care needs of stroke patients as they mostly focus on the physical, psychosocial, and spiritual symptoms that develop after a stroke. Patients with stroke show debilitating physical symptoms include fatigue, constipation, dry mouth, nausea, vomiting, numbness, tingling, seizures, bladder or bowel incontinence, and seizures. In contrast, psychological and spiritual symptoms include confusion, depression, anxiety, hopelessness, and loss of meaning [4–6]. Furthermore, patients with stroke face social and cultural
difficulties, due to dependence on others due to movement disorders, decreased senses, and reduced activity levels, which affect their daily lives, especially living activities such as showering, getting dressed, and going to the toilet. One of the biggest challenges for patients suffering from stroke is the feeling of pain and the inability to control and relieve it, which in turn leads to sleep disturbances and feelings of depression and anxiety [7]. Many healthcare providers are unaware of the necessity of palliative care services in caring for patients holistically from the aspect of social, emotional, and spiritual requirements, which is a significant clinical constraint [8]. The focus of clinical care has been in the traditional care of physical needs. The literature has shown a vital gap in recognizing the importance of palliative care initiated at the beginning of medical care provided to patients with stroke. It is increasingly being recognized that palliative care services should initiate at diagnosis [6].

Integrating palliative care needs routine care is limited to the rehabilitation services and other secondary prevention programs that [6]. Rehabilitation programs have a crucial role in reducing physical disabilities and reducing dependence on others, while the role of palliative care arises in improving the poor and reducing the physical, psychological, and spiritual effects of stroke [9]. In addition, palliative care can provide additional resources in ensuring the management of physical symptoms, psycho-social support, and spiritual care, and helps in decision-making for patients suffering from stroke and their families [10]. Accordingly, Burton, Forster [11] emphasized the need to assess the palliative care needs of patients with stroke and respond appropriately to meet these needs. Thus, the purpose of the current study is to explore the palliative care needs among women who suffer from stroke in Jordan.

**Methods**

**Study design**

A descriptive phenomenological design utilized in this study.

**Setting**

The participant women were recruited from outpatient clinic and visited the rehabilitation centers in two main governmental, and educational hospitals in Jordan operated by the Ministry of Health (MOH).

**Participants**

A purposive sampling approach was used to recruit participants according to the needs of the study and their knowledge of the phenomenon. In this study, the sample size was 12 participant women, which was sufficient to reach the saturation rate.

The following inclusion and exclusion criteria were followed in selecting the participants from the assigned rehabilitation centers. All participants were: 1) Women who suffer from a mild to moderate stroke between 18 and 50 years of this age range (study; 2) Women who suffer from a stroke within the
last 6 months. And 3) Women who are capable of comprehending and participating in a detailed interview (no major mental or linguistic disorders). Women suffering from other major conditions that may overshadow the experience of strokes, such as cancer, multiple sclerosis, or renal failure, were excluded from this study.

**Data Collection**

Semi-structured interviews were used to allow participants to freely tell their stories based on their experiences, providing richer information. In general, the data were collected by the researchers conducting 12 individual face-to-face interviews with the participating women without anyone present. The interview period ranged from 60 to 90 minutes. Interview guides were used to guide the semi-structured interview to ensure that all subject areas were addressed. The interviews were conducted in Arabic with the interviewee in an informal, conversational style to allow the participant speak comfortably in an open dialogue manner. Each interview began with the first research question: "What are the perceived palliative care needs during suffering from a stroke?". Followed by another probes question: Do you think that stroke affected the way you see yourself?; b. How do you relieve your suffering?; c. What special care do you need for physical care?; d. What special care do you need for emotional support?; e. What special care do you need for spiritual support?; f. What other care would be useful to you and your family? g. What are your hopes for the future?

**Data analysis**

Each interview was recorded, and the transcript was transcribed verbatim. This step further immersed researchers in the data. The written data was checked by listening to the recorded data and comparing it with the text for accuracy. The audio recordings have been kept safe and confidential. Each participant was issued an identification number, for example, “Participating woman (1), Participating woman (2), Participating Woman (3), Participating Woman (12).” the researchers used Colaizzi [12] method of descriptive phenomenological data analysis. See Fig. 1

[Please insert Fig. 1 here]

**Trustworthiness**

Trustworthiness is considered a gold standard for qualitative research and includes the following items, namely, credibility, dependability, conformability, and transferability; To confirm the trustworthiness, these principles were applied throughout this research study, starting by choosing the research questions and ending with the research findings. First, the researchers ensured credibility by choosing the participants from women who lived the experience and had rich data about the phenomena under study and matched eligibility criteria to capture variable perspectives regarding the specific research questions. Other strategies for improving credibility were prolonged engagement and member checking. Second, the
researchers used peer debriefing and interview guidelines during each interview to ensure dependability. Third, confirmability was ensured by separating the researcher's preconceptions, experiences, and beliefs from the descriptive raw data during all phases of the study to reduce preconceived notions and potential bias. Finally, the researchers provided a rich and thick description of the data in detail to enhance transferability.

**Ethical Considerations**

The ethical approval to implement the study was gained from the ethical research committee of the Ministry of Health (MOH) in Jordan.

**Results**

A total of 230 significant statements were extracted. Then, the researchers arranged the formulated meanings into clusters, and the data from transcript analysis of interviews spotlighted three emergent themes that reflected the palliative care needs of women living with stroke: (1) living with bothersome symptoms; (2) receiving bad news; and (3) spiritual practices, beliefs, and needs. Table 1.

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[Please insert Table 1 here]

**Theme 1: Living With Bothersome Symptoms**

All participants experienced various physical, psychological, social, and spiritual challenges

**Experiencing physical impairment**
When participant women were asked to describe their life experiences with the illness, all participant women mentioned various types of physical impairments, such as weakness or paralysis on one side of the body, imbalance; constipation or diarrhea; difficulty chewing solid food or swallowing food; bladder or bowel incontinence. Some participants described that had very weak hands and legs to the point that they could not walk or move their bodies. In addition, to the continual discomfort and numbness. This was mentioned by the participant woman (7), “My leg and hand were affected, and I was nearly paralyzed. I can't walk or move without help.”

Fatigue was a prominent and bothersome experience. All participants mentioned that they felt fatigued most of the time. Participants described fatigue as decreased physical endurance, often leading to less energy, and feeling unable to do routine work at home. Many women had an impact on women’s everyday lives, and they had no power to serve themselves. Participant women (8) said: “Most of the time I can't do anything; I don't have the energy to move my body. Fatigue affects my life and always makes it depressed and boring.”

**Experiencing intolerable pain**

Pain after stroke is a prominent shared experience among women. Most women described their experience with pain; there was some variation among the study participants regarding pain descriptions. Some participants described the pain as annoying, while others described it as terrifying. Participant woman (7) said: “I've been in pain until now. The pain is very annoying and terrible, accompanied by a feeling of fatigue”. While another woman said (9): “I still feel pain after the stroke, but it is just an unpleasant feeling”.

Most of the women reported having limitations in their lives caused by pain, as the presence of pain affected their daily activities and social interaction. This was clear in many women’s stories, and among the examples of this, participant woman (3) said: “Sometimes I have to stop doing anything because the pain increases when I try to move my hand. It hurts so badly. The pain prevents me from doing many things.” Some of the women participants who had little independence in their daily lives said that it took longer because of the pain. Participant woman (4) said: “I can do some special personal care, such as eating and brushing my teeth, but it takes longer because of my arm pain”.

About half of the women expressed emotional reactions because of the pain. Participant woman (5) was pitiful about herself when pain aroused, she said: “When my leg starts aching, I start crying without stopping”. Some participants indicated that the pain affected their mood and socialization with others. Participant woman (11) said: “I quickly became angry because of the pain, when the pain and numbness started on the left side of my body, I lost control of my mood, and I don’t want to deal with anyone.”

Pain control is one of the most important needs expressed by women. Half of the participants suffer from intolerable pain, which has not received sufficient consideration and attention from the healthcare providers. Participating women (6) said:
The pain was not observed by anybody, and no attempt was made to alleviate it. While the physicians wished for me to improve, they did not alleviate the agony produced by exercise. I often wonder why I get hurt and my suffering worsens; I hope the staff will assess the pain because it has a significant impact on my life.

The participants described how the pain had greatly affected their QoL, such as mood, bodily functions, sleep disorders, and physical activity. In support of that, the participant woman added (7): “Until today, I’ve been in excruciating discomfort. And this is what irritates me. I suffered from severe pain until now. And this is the thing that bothers me.”

**Experiencing psychological and emotional distress**

The sudden and unexpected nature of stroke made the women either fully or partially dependent on others, without an opportunity to be prepared physically or psychologically for the onset of stroke.

Therefore, participant women expressed many disturbances such as disability, embarrassment, depression, feeling of becoming burdened, boredom, fear, and uncertainty. In this context, Participant woman (6) highlighted how she felt disabled and helpless after a stroke because she lost their independence and needed continuous help from others in all daily life activities, she stated: “Because of the stroke, I am no longer able to do the parts that I enjoyed, and that makes me feel helpless. Now I am unable to engage in any of the activities that I enjoy. I’m not used to relying on others. A stroke makes me feel powerless. How difficult, terrible, and unpleasant this feeling is.”

Another participant woman (7) expressed her concern about what will happen in the future in the following words: “My experience has been described as a weary, hazy trip in which we have no idea how long it will endure or what the future holds for us. Uncertainty is constant in my life”.

Another feeling associated with the women's post-stroke experiences, as reported by the women, is depression. Nine women reported feeling depressed as a result of their inability to accept physical and psychological changes caused by the stroke. They were unable to perform self-care activities independently, resulting in a sense of weakness as their role in all aspects of life had changed. One of the participating women (4) said: I’m tired, exhausted, and depressed all the time. Furthermore, the effects of the stroke crushed my spirit and held me back. I’m no longer optimistic, and I’ve stopped being content with anything.

**Theme 2: Receiving Bad News**

**The challenge when receiving stoke diagnosis (Shock stage)**

The diagnosis of stroke is often a great shock to participant women and families, and their knowledge of the disease and its consequences may be lacking. Therefore, the way this unpredicted news and details
are presented, how healthcare providers communicate with women with stroke, and how much time was devoted to speaking with them, are what were highlighted by the women participating in the study.

Woman (3) provided an example of the sudden and bad way of conveying bad news to her that harmed her health: "My doctor arrived on the second day of my hospitalization. When she entered the room, he inquired, “Who is (W. S)? She informed me, “You had a stroke; I am sorry for you since you are still to have a stroke.” I was shocked. “I replied: Really! What are you talking about? I had a stroke. Unfortunately, he informed me that I had a major stroke. He did not attempt to assist or alleviate my fears. On the same day, I experienced another round of sorrow. The news saddened and irritated me, and I had a second stroke later that night."

A group of women expressed their need to discuss with the healthcare provider their needs after receiving the diagnosis of stroke, but the amount of time devoted to this was insufficient, and they considered this as an important element in such circumstances, especially with this type of bad news. A participant woman (7) said: “When I learned that I had a stroke, I wanted a lot of explanations, but nothing was clarified to me, and whenever I ask a doctor or a nurse to discuss, they don't have time.”

The need for clarification and empathically response from health care providers

All of the participating women had a wide range of emotional reactions when knowing about their stroke diagnosis and realizing their disabilities and complications that would accompany them for a long time. Some of them responded to the bad news with a state of silence or crying, and others with dramatic crying and entering a state of shock. The women needed to respond to these feelings through appropriate empathetic communication and find effective ways to process the emotions that are experienced by patients when a patient hears bad news.

Participant (5) said: “The problem was that the doctor's way of conveying the news shocked me. he gave me the news suddenly and grieved me. I did not find sympathy or support. It was very overwhelming.”

Theme 3: Spiritual practices, beliefs, and needs.

Almost all participating women were optimistic about restoring their normal lives and striving to maintain any glimmer of hope to hold on to life. In addition, they expressed their hope that they would recover completely and regain themselves. These methods had a positive effect on their adaptation to the disease

Participant woman (10) stated: “A person with this experience can come up with a positive attitude if she continues to maintain hope and trust in God and believes in herself. I tell myself every day that I will stay well. I believe in myself that I will return to my health if I maintain a positive outlook. I will not remain using the wheelchair forever.”
Another participant woman (6) indicated that the ability to maintain spiritual well-being and an optimum hope level comes from the health care provider, she said: “Because the nurse was very supportive, I chose to commit to occupational therapy sessions rather than physical one. She would come and talk with me while I was in agony and sobbing, trying to soothe my anguish and support me. She remained with me to talk and offer me an advice, hope, and support.”

Find Meaning In Their Illness And Suffering “why Me?”

The findings of this study revealed women's perceptions and attitudes toward finding meaning in illness and suffering in their lives. Some participating women refer to some positive meanings of their illness and suffering, and that their stroke is a time for reflection and enables individuals to count their blessings in life, in addition to the affliction that relieves sins and human mistakes. One of the participating women (2) said in this regard: “Illness is a test from Allah. I believe that the greater the suffering and pain, the fewer sins will inevitably be”.

Participant woman (10) expressed her gratitude for being lucky enough to have a stroke to learn to be better and closer to Allah. She said: “After surviving the stroke, I thanked Allah for giving me another chance to live. I realized that health is very important in my life. Allah gave me a chance to repent my many sins”.

On the contrary, five participants saw that their stroke had negative meanings in their lives; they found that their illness may be Allah's punishment for them, or that they are not righteous, and Allah is angry with them. One of the women participants (6) said: “I’m not sure why I acquired this sickness in particular; did I ever do something wrong in the past for which I’m now paying the price?” Along the same lines, another woman (8) said: “I am a human being, and no matter how strong my faith is, I occasionally question Allah, “Why me? Why did you put me through such a severe test? What did I do?”

Seeking spiritual support

The majority of participant women believed that their illness and wellness were in the hands of Allah. Hence, they accepted their illness and God's decree. Accordingly, they maintain a close connection with God through prayers, reading the Holy Quran, and asking God (Doa’a) for recovery. Participant woman (2) expressed: “In my prayers, I constantly asked God to help me regain my health. I pray to God for the patience I need to get through this hardship because I think that only God can help me solve my difficulties. Prayer has always been a source of comfort and a means for me to cope with illness.”

According to some women, this acceptance made coping with stroke events easier for them and helped decrease suffering from unwanted consequences related to stroke. According to one of the participating women (9): The initial source of my adaptation to the new environment was my faith in God, devotion to prayers, and reading the Qur’an.”
Many women have realized that getting closer to God and spirituality provides a sense of peace and comfort, as this has a direct impact on increasing motivation and improving their quality of life. Nine of the participating women revealed a need for spiritual support, and a desire to remain connected with others who are seen as sources of spiritual support for them, whether from a religious person, family, friends, or relatives. Participant woman (3) stated that: “My husband and children have always been supportive of me and have prayed passionately for my recovery. They have always been there to assist me and to help me come closer to God”.

Despite the high degree of faith among Jordanian participants and the close connection with God, few participating women thought that the cause of the stroke was envy (Al-Hassad) or demonic acts, and for this, they resorted to religious men for healing and to help them adapt to the new situation. A participating woman (5) said: “Envy is the cause of my stroke. I got it after my daughter's marriage. Someone envied me. I think that medicine is not my treatment. For this reason, we asked my husband's friend to treat me by non-medical methods and expel evil spirits from my body." Some women indicated that they resort to some traditional practices to treat the effects of stroke, such as using herbs and oils. For example, one of the participants women (2) said: “Olive oil and (Zamzam) water were the items that helped me feel better; they come from a blessed tree and have beneficial properties, and I read the Qur'an every day. I apply oil to my hands and feet and sip (Zamzam) water, which I highly suggest to everyone.”

**Discussion**

This study sheds the light on the aspects of Jordanian women with a comprehensive view of all aspects of life after suffering from a stroke. The findings indicate that stroke's burden has far-reaching consequences on women's lives. Therefore, the Jordanian women suffered from several bothersome symptoms and needs related to physical, psychosocial, and spiritual issues. Such as; physical impairment, fatigue, pain, dizziness, impaired memory, imbalance, insomnia, urine incontinence, and impaired mobility, which limited the women performing basic Activities of Daily Living (ADLs), and self-care. Therefore, the women became dependent on others. These findings were consistent with the previous study's findings [5, 13, 14].

Another prominent bothersome symptom that women reported was uncontrolled fatigue. These were significant symptoms that interfered with the QoL for Jordanian women and restricted them from performing many daily tasks. These results are consistent with previous studies [15–18]. Interestingly, a meta-analysis study that was conducted by Cumming, Yeo [19], revealed a significant relationship between post-stroke fatigue and gender. The fatigue reported by women was more frequent than in males; fatigue was one of the most prominent physical symptoms after stroke.

Furthermore, this study found that pain affects a woman's QoL; women experienced anxiety, lack of sleep, fatigue, inability to move, and lack of energy because of chronic pain. Previous studies [20–22] have indicated that about a quarter of patients with stroke have long-term pain. Pain occurs soon after a stroke.
Although post-stroke pain was a common clinical problem and affected women's QoL, it is still undiagnosed, neglected, and marginalized by health care providers as they did not receive adequate training in pain management. An integrative review conducted by Payton and Soundy [23] recommended that pain should be diagnosed and evaluated in a detailed and documented manner as soon as a patient begins to complain of pain, emphasizing the importance of effective communication between patients and caregivers to understand the patient's experiences of pain and pain-related problems, as pain treatment is often associated with poor evaluation and understanding of pain management. While Nesbitt, Moxham [24] confirmed that post-stroke pain is recurrent and multifactorial, there is still a significant number of patients complaining of ineffective pain management. This may be related to the difficulty of assessing pain in stroke patients due to communication disorders and cognitive problems.

Psychological and emotional distress is a common complication after stroke and impacts all aspects of recovery [25, 26]. This study explored many psychological symptoms experienced by Jordanian women, such as anxiety, loss of self-control, grief over life before the stroke, boredom, and social isolation. The causes of psychological distress were closely related because the participating women were still at a age; they believed that they had many responsibilities and obligations that could not be accomplished with their current physical impairments. These findings were consistent with the findings of previous studies [17, 27]. Based on the shared views from all the study participants, this research identified experiences mostly focused on their emotional disturbances. Most of these feelings harmed women's emotional and psychological health while experiencing the effects of stroke. One of the most critical issues revealed by this study is what the participants reported about their feeling of burden on their family and their sense of burden caused as a result of their total or partial dependence on their families to help in accomplishing daily tasks, in addition to increasing the financial burden on them. This is consistent with the results of previous studies where participants reported similar concerns [28, 29].

The prevalence of depression among women was common in this study. This finding is congruent with previous studies by Bourin [30], Dong, Mezuk [26] who reported that stroke patients are at risk of developing depression, explaining that more than half of patients with stroke develop what is known as "post-stroke depression" in the first year of their illness. In addition, this risk increases especially for women, the elderly, and people who lack social support in their lives, as well as those who suffer from psychological or cognitive disorders before, such as problems with perception or the ability to remember.

In the same line, a prospective cohort study was conducted in Jordan by Al Qawasmeh, Aldabbour [25], the authors reported that one in four Jordanian patients with stroke experienced Post-Stroke Depression (PSD) after one month of being stroked. In this study, depression has been identified through women's stories when asking about their moods, where women are experiencing the feeling of sad, mood change, losing interest in everyday activities, feeling worthless, insomnia, and loss of self-confidence.

The findings of the study showed that the majority of Jordanian women faced a problem in giving and receiving information related to their illness from health care providers, which was a particularly poignant topic in their life. The stroke events were shocking and unexpected, and most of the news about their
condition was bad and changed their expectations and hopes for the future. The findings are consistent with what was reported in previous studies, whereby stroke patients suffered from negative affect and emotional disturbances due to ineffective communication when bad news is communicated to them by the health care providers [31–33]. Research in the field of stroke indicates that health care providers must use effective skills in Breaking Bad News (BBN) in terms of clear style, realism, and hope, to avoid the occurrence of unwanted psychological and emotional symptoms such as shock, anger, and annoyance [34, 35]. In this study, not using a therapeutic method when telling bad news left the women in a state of confusion and shock. In the same context, a systematic review of 30 studies from eight countries indicated that to ensure emotional recovery and improve the experiences of stroke patients and their families, health staff should adopt an approach based on breaking bad news compassionately, and preparing the staff to meet the information needs of patients and their families [11].

Most Jordanian women strongly desire professional communication from healthcare providers; they describe the communication they need as caring, empathetic, compassionate, and respectful. The women's stories about their contact with the healthcare provider reveal how words convey significant meaning, women who often look to the healthcare provider for reassurance, understanding, and support; according to Denham, Wynne [36], the professional, smooth, empathetic way in communication process consider crucial aspects in better communication between health care providers and patients living with. Previous studies found that communication between women and professionals was found to be an essential element in building a trust and confidence relationship in the care process [37–39]. Furthermore, appropriate communication has great importance in meeting the healthcare needs of women and their caregivers [40].

The women in the current study expressed the necessity of communicating bad news in an empathetic manner, in respectful, clear, and understandable language, in order not to add an additional burden to their health condition. This finding was consistent with a study conducted by Read, Heslop [41] who emphasized the importance of preventing bad behaviors during communication with stroke patients that will be reinforced their feelings of shame and unfairness.

The Jordanian women reported in this study negative behaviors and attitudes about health care providers during communication, which was unsatisfactory and ineffective. The women expressed that they believe that the health care providers are the most prominent supporters and the most important pillars that help in the recovery process post-stroke. However, the expectations of the majority of women were not fulfilled due to the way of conveying bad news to them, receiving a minimum of time and sympathy from them. The women believed that their health outcomes and mental status would have improved if the health care providers had better skills in communicating bad news and had more emotional support.

The current study findings indicated that healthcare providers need to be well experienced in proper strategies for communicating effectively with women. For example, if they were using the SPIKES protocol (SPIKES: Setting; Perception; Invitation; Knowledge; Empathy; Summarizing), which was effective in communicating bad news with different populations and different cases [42, 43]. Allowing
more time for discussion with women to express feelings and answer their inquiries was recommended by Jordanian women.

Although Jordanian women were exposed to chronic diseases that left many disabilities and imbalances, many of the participating women stated that most of the disabilities they were exposed, should be accepted. Furthermore, life does not have to stop there. This study revealed different mechanisms of resilience and adaptation to their new situation. Spiritual and religious beliefs were among the most important mechanisms that helped women adapt with their illnesses. Previous researchers have found similar findings [44, 45], where attachment to God, prayer, and faith may confer hope, optimism, energy, security, and dignity.

The current study showed that Jordanian women need hope for recovery, regardless of their medical condition. In the same context, previous studies confirmed that all patients, their situation, age, need, and hope, mainly derived from health professionals. Communication with hope helps to accept their diagnosis and improve their well-being and quality of life [45, 46].

The findings of the study revealed that the women who did not accept stroke were they are still at an age and they link disability and stroke related to the elderly. Accordingly, they always wonder “Why me”; by this sentence, they mean, why they suffer from this disease specifically.

Interestingly, many women reported other aspects related to spirituality such as finding meaning in disease and suffering. For Jordanian women, Islamic religious beliefs were a source of adaptation and acceptance of illness. It made them look at life in new ways. They felt that they were closer to God and acknowledged a blessing in life. Jordanian women explained that disease and fatalism “accepted God's will” because God’s plan and illness are destiny.

Previous studies have found similar statements by Muslims [47–49]; these studies reported that Muslims view illness as an affliction from God Almighty and atone for their sins. So that created a new meaning for their purpose in life. Thus, their spirituality was strengthened through their faith and religious practices. This wasn't always positive, as two women failed to change due to different interpretations of fatalism. These participants explained the disease and fatalism; they believed the illness was connected with God's punishment. Kouwenhoven, Kirkevold [50] reported that stroke is a disruptive life event that can include a person's failure to return to normal, requiring self-redefinition and understanding of the meanings of suffering and disease.

Limitations

There are some limitations to be addressed in this study, the first limitation of this study is that all participants’ women were recruited from governmental hospitals. The second limitation, this study was women-based and did not include assessing the need for palliative care for all stroke patients of both sex
at the community level. Men's experience and their palliative care needs might be different from those of women.

Despite these limitations, the study findings contribute to nursing practice, education, policy, and research related to caring for women patients suffering from stroke. The significant contributions of the present research are providing several recommendations to improve the understanding of health care providers to the experiences of women suffering from stroke and giving insight into the palliative care needs from the Jordanian women's perspective. According to the study findings, there is a need for evidence-based research to determine the palliative care needs of stroke patients with stroke and caregivers. And to investigate the impact of integrating principles of rehabilitation and palliative care on a large sample scale.

**Conclusions**

This study described the palliative care needs of patients with stroke from their perspective. The most common symptoms among participant women that needed palliative care were: Fatigue or lack of energy, pain, reduced physical function, dizziness, impaired memory, depending on others, psychological disturbances, and the need for spiritual and psychological support. In this study, a decrease in the QoL and well-being of the woman was revealed due to the dramatic change in their roles in life after stroke. Moreover, The use of appropriate techniques to deliver bad news by health care providers is crucial for participant women. Accordingly, early integration of the palliative care approach besides stroke care within Jordanian health services, will prevent exacerbation of bothersome symptoms, meet psychosocial and spiritual needs, reduce hospitalization, and thereby reduced the health cost burden. Moreover, palliative care will reduce suffering, increase the quality of life for patients and families, and allow patients to remain and possibly die at home under the care of their loved ones.

**Declarations**

**Ethics approval and consent to participate:**

The Institutional Review Board at the Ministry of Health in Jordan approved the study, on June 20, 2021(Ref no. 4479). Informed consent was obtained from all participants. All methods were carried out following relevant guidelines and regulations or the Declaration of Helsinki.

**Consent for publication**

Not applicable.

**Availability of data and materials**

All data generated or analyzed during this study are included in this published article.

**Competing interests**
The authors have no conflicts of interest to disclose.

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None.

**Authors’ contributions**

MNA: Conceptualization. MNA, IAK, RSZ, HAB, ASM, AJN: Research design, Data collection, Analysis, Literature search, Manuscript preparation. All authors have accepted responsibility for the entire content of this manuscript and approved its submission.

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**References**


12. Colaizzi, P.F., Psychological research as the phenomenologist views it. 1978.


43. Milton, A.C. and B. Mullan, *Views and experience of communication when receiving a serious mental health diagnosis: satisfaction levels, communication preferences, and acceptability of the SPIKES*


Figures
Figure 1

Illustrates the process of data analysis created by Colaizzi (1978)