

Spiritual Challenges of Family Caregivers of Patients in a Vegetative State: A Qualitative Content Analysis

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Abstract

Background: Spirituality helps family caregivers of vegetative state patients to overcome the stressful conditions of patient care. However, the illness and caregiver burden may also negatively affect the caregiver's spirituality. Accordingly, this study aimed to investigate the challenges of family caregivers of patients in a vegetative state.

Methods: The present qualitative study was conducted through conventional content analysis from August 2020 to September 2021 in two provinces of Iran (Sistan and Baluchestan and Khorasan Razavi). A total of 20 family caregivers of patients in a vegetative state were included in the study. Semi-structured interviews were employed to collect data. Data were analyzed using the method proposed by Graneheim and Lundman via MAXQDA2020 software. Data collection continued until data saturation and identification of main categories.

Results: Based on data analysis, *spiritual disintegration* and *spiritual coherence* were identified as the two main categories to describe the spiritual challenges of family caregivers of patients in a vegetative state. The experiences of family caregivers showed that spirituality is effective in accepting the conditions and adapting to the role of the patient caregiver. However, illness and caregiver burden lead to spiritual damage and the turning away of family caregivers from performing religious rites and rituals.

Conclusion: Considering the undeniable role of spirituality in dealing with the stressful situation of caring for a patient in a vegetative state, the spiritual needs of family caregivers and the implementation of nursing interventions to enhance the spiritual health of caregivers should be given more attention.

Keywords: Spirituality, Family caregivers, Vegetative state, Qualitative content analysis

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Introduction

Vegetative state is defined as wakefulness without consciousness due to diffuse brain injuries (1). The patients in a vegetative state do not show cognitive performance or targeted behavioral responses to external stimuli (1,2). Having a vegetative patient is an emotional paradox for family caregivers. Since the patient has not died, they cannot mourn, and social assistance is reduced compared to the time of hospitalization. An efficient solution to helping family caregivers adapt to these conditions is the

use of effective coping mechanisms (3,4).

The coping mechanism is an intellectual activity and behavioral attempt to manage extrinsic and intrinsic requirements, sometimes more important than the resources available to the person. People use two types of coping strategies including emotion-oriented coping strategies, which reduce negative emotions, and problem-oriented coping strategies, which emphasize controlling stressful situations. Spirituality increases people's motivation to use effective coping strategies (5). When



people are faced with stressful situations, spirituality protects them by highlighting the role and aid of God. This protection reduces their emotional distress and makes the situation bearable (6).

High levels of spirituality are associated with growth and excellence, a good understanding of the meaning and purpose of life, high levels of adjustment, and mental health (7-10). Spirituality also significantly improves overall life satisfaction and increases the level of well-being of patients and their family caregivers (11). A study by Rezaei et al indicated the spiritual health of family caregivers in Iran is at an intermediate level which leads to an increase in the caregiver burden (12). Besides, Shirinkam et al reported the spiritual attitude of Iranian family caregivers at an intermediate level (13). However, the study by Abasnejad Mousavi et al showed the spiritual health status and social support of Iranian family caregivers are favorable (14).

Furthermore, spirituality and religion overlap and depend on people's culture, beliefs, and social and family support. Spirituality and religion are essential resources to deal with the burden on family caregivers of patients in a vegetative state (5). After treatment, religiousness and spirituality impressed both survivors and caregivers. Spirituality can make life meaningful, providing support and guidance in complicated situations (15). To provide appropriate spiritual care, the family caregivers' spiritual and religious challenges need to be identified. Understanding the religious and spiritual challenges helps healthcare providers to deliver effective care plans based on the needs of caregivers. Despite its importance, the role of spirituality for family caregivers of patients in a vegetative state has not received enough attention in the literature. Therefore, the present study aimed to investigate the spiritual challenges of family caregivers of patients in a vegetative state.

Methods

A conventional qualitative content analysis approach was used for conducting the study. This approach allows researchers to interpret the authenticity and truth of the data subjectively and scientifically (3,16,17). With this method, the researcher can explain the phenomenon while avoiding using default texts but allowing the results to emerge from the data instead (18). Content analysis is an appropriate and valid research method that provides new insight, knowledge, and a coherent and comprehensive description of a phenomenon (3,18).

The present study was conducted after receiving the required permits from the Deputy of Research and Technology of Mashhad University of Medical Sciences and presenting them to the Zahedan University of Medical Sciences and hospitals affiliated with the two universities with intensive care wards from August 2020 to September 2021. The participants included 20 family

caregivers of patients in a vegetative state, selected through purposive sampling (Table 1). To reach the participants, the researcher attended the home care training centers of hospitals and nursing care centers. After investigating and identifying the patients in a vegetative state and obtaining the phone numbers of their caregivers, the researcher contacted the caregivers by phone to conduct the interviews. In case of consent to participate in the study, the necessary arrangements were made regarding the place and time of the interview. Maximum variation sampling was used to obtain rich data on the experiences of family caregivers. Thus, interviews were conducted with family caregivers with different ranges of age, education level, and experience in patient care.

The inclusion criteria were having a first-degree relationship with the patient, direct involvement in patient care, and consent to participate in the study. The exclusion criteria were rejecting the researcher's request for recording the interview and not permitting the researcher to use the collected information for the study.

The data were collected through in-depth, face-to-face, semi-structured interviews. At first, the researcher introduced himself and the research team; presented the necessary permits; explained the study objectives and the necessity of voice recording for data analysis; and assured the participants of the confidentiality of the collected data and that the data would be analyzed anonymously using coding. The researcher also reassured the caregivers that participating in the study would be voluntary. If the caregivers agreed to participate in the study, they were presented with informed consent forms to sign. Afterward, each interview started with a general open question: "Would you please introduce yourself and outline your family member's condition?" Then, based on the purpose of the study, the following main questions were asked: "What religious and spiritual experiences have you gained while taking care of the patient?" and "How do religion and spirituality affect patient care?" Exploratory questions included: "Can you explain more?", "Would you please explain this by mentioning one of your experiences?"

After each interview was recorded, the audio files were listened to several times. Then, the interviews, as well as the nonverbal field notes on the caregivers' tone, pauses, breaks, and emphases, were typed in Word files. The transcripts were reviewed multiple times and entered into MAXQDA 2020 software to analyze the data using Graneheim and Lundman's method. This analytical approach has several stages including: transcribing the conducted interviews and frequently reading them to obtain an acceptable understanding of the collected data, extracting meaningful essences and labeling them as condensed meaning units, categorizing them, selecting titles with a higher level of abstraction called codes, putting them into subcategories based on their semantic similarity, and assigning proper headings for the created

Table 1. The participants' demographic characteristics

Participants	Gender	Age	Education level	Occupation	Family relationship	Care duration
Caregiver-1	Male	44	Master's degree	Employee	Offspring	6 months
Caregiver-2	Female	33	Bachelor's degree	Housewife	Mother	1 year
Caregiver-3	Male	44	Master's degree	Employee	Offspring	8 years
Caregiver-4	Female	22	Diploma	Housewife	Offspring	18 months
Caregiver-5	Male	42	Diploma	Self-employed	Offspring	9 months
Caregiver-6	Female	52	Bachelor's degree	Employee	Spouse	25 days
Caregiver-7	Male	42	Bachelor's degree	Employee	Offspring	25 days
Caregiver-8	Female	40	Bachelor's degree	Employee	Offspring	35 days
Caregiver-9	Female	40	Bachelor's degree	Housewife	Offspring	10 days
Caregiver-10	Female	38	Bachelor's degree	Housewife	Offspring	15 days
Caregiver-11	Male	45	Bachelor's degree	Employee	Father	40 days
Caregiver-12	Female	30	Middle school	Housewife	Offspring	70 days
Caregiver-13	Male	38	Middle school		Offspring	25 days
Caregiver-14	Male	44	Associate's degree	Self-employed	Father	33 days
Caregiver-15	Female	24	Diploma	Housewife	Offspring	3 months
Caregiver-16	Female	34	Master's degree	Employee	Sister	25 days
Caregiver-17	Male	36	Middle school	Self-employed	Brother	10 months
Caregiver-18	Female	50	Middle school	Self-employed	Mother	14 days
Caregiver-19	Female	41	Bachelor's degree	Employee	Sister	21 days
Caregiver-20	Female	30	Bachelor's degree	Employee	Sister	3 days

categories as the main categories (19).

To evaluate the accuracy and robustness of the qualitative data, four criteria including credibility, dependability, transferability, and confirmability were used. The researcher devoted sufficient time to data collection to enhance credibility. The research team assessed the data to ensure the formed categories were consistent with the participants' statements. All the viewpoints were captured in cases where some inconsistencies in opinion were observed. The participants were also asked to review the data to ascertain the accuracy of the data and the extracted codes and rectify them, if necessary. The research team then scrutinized their views and made the necessary corrections. The researcher applied some methods, such as original data availability, clarified coding, and evidence-based writing (quotations), to enhance the dependability of the study. To ensure confirmability, some excerpts of the interviews, codes, and categories were singled out and handed out to two reviewers outside the research team familiar with qualitative research analysis. They were asked to examine the accuracy of the process of data coding. The required corrections were made until they confirmed the process (20).

Results

The participants included 20 family caregivers of vegetative state patients of whom 7 (35%) caregivers were male, and 13 (65%) were female. The mean age of the participants was 39.5 ± 3.5 years.

Based on data analysis, two main categories including *spiritual disintegration* and *spiritual coherence* were identified to describe the spiritual challenges of the family caregivers in taking care of vegetative state patients. These two categories included six subcategories (Table 2).

Spiritual disintegration

Spiritual disintegration involves mental crises, their confrontation with religious and spiritual beliefs in some family caregivers, and the deterioration of spirituality. This category shows that the occurrence of severe disease has destructive effects on the religious beliefs of the family caregivers and leads to the weakening of religious views and abandonment of many religious and spiritual rituals.

Spiritual crisis

Spiritual crisis occurs when the individual wonders why a religious person has been afflicted with the disease, is confronted with hurtful stigma, and attempts to adapt to identification, and also when the expected miracle to heal the patient does not take place. The participants' experiences showed when a family member is in a vegetative state, the family caregivers cannot understand the cause of the disease and are constantly faced with the mental challenge of what is the cause of this problem. They frequently ask if there has been a defect in performing the religious duties on their part or the patient, if they have committed an unforgivable sin, or if God did not accept their worship and has sent down this disease to punish them.

Table 2. Main categories and subcategories of the spiritual challenges of family caregivers

Main categories	Subcategories
Spiritual disintegration	Spiritual crisis Spiritual decay
Spiritual coherence	Surrender to God's will Caring as a religious duty Belief in God for care Reliance on spirituality

"My father was a very religious person. He always prayed on time, fasted, and had extreme beliefs. Even though he was not very old, this happened to him. I can't understand why my father should suffer from such a disease; which sin is he paying back?" (Participant 3).

This spiritual crisis was aggravated by the hurtful stigmas attributed to them by those around them. Some people tried to connect the occurrence of illness with committing great sins by the patients or their family members, which was very painful for the family caregivers.

"When this happened to my father, they talked behind us. They said that he must have violated the rights of someone or he's paying for his sins. While, my father did his best to provide his family only with halal and legitimate income. He always prayed on time and was a religious person" (Participant 4).

"Since my child got sick, everyone allowed themselves to talk behind us. They said it is unknown when they swore a false oath or what great sin they committed that God brought this disaster upon them" (Participant 2).

Therefore, to overcome these spiritual crises, the family caregivers sought to provide justifications so that accepting the family member's condition and illness could be spiritually justified for them. Moreover, by presenting these reasons to the people around them, they can escape the burden of annoying stigmas.

"When this terrible incident happened to us, I was constantly reviewing in my mind and talking to God, 'My God, where did I do something wrong? What sin did we do? Why did you consider us worthy of this punishment?' The acquaintances talking behind us put much pressure on us and made the situation unbearable. Until another one of our relatives, whom we knew was from a religious family, had an accident and had the same problem as my father. Then, it became easier for us to bear the situation. because we were comparing ourselves with them and we had something to say in front of the others" (Participant 8).

The unfulfilled expectations of the family caregivers regarding improving the patient's condition after the onset of the disease caused the spiritual crisis to be felt more strongly and led the family caregivers to spiritual decay. Many family caregivers stated that in the first stage, they were sad and could not understand the occurrence of the disease spiritually. However, they still did not despair of God's mercy and expected that they would receive God's favor by the patient being treated, considering that they were faithful servants and did not fail to perform religious

duties and rites. Nevertheless, the patient remained in a permanently vegetative state, and the family also suffered greatly seeing the patient's condition.

"When my father had an accident, I told myself it could happen to anyone; I tried not to be unfair so that God would not be angry. But he never forgot God; he always prayed on time; in Muharram [The first month of the Islamic calendar in which Imam Hussein was martyred], he was the head of the mosque committee and recited Imam Hussain prayer. So, I thought God would help him, and he would get better soon. Even when the anesthesiologist said this could not be cured, I said God would surely grant us a miracle. But when I saw him going towards death with this suffering, lots of questions were raised in my mind, I could no longer have those previous beliefs" (Participant 14).

Spiritual decay

Spiritual decay refers to the weakening of the family caregivers' spiritual and religious beliefs and the abandonment of religious rituals following the illness of a family member. The experiences of family caregivers showed at first, they intensified religious rituals so that their request for the patient's recovery would be accepted by God. When they did not receive the desired answer, their beliefs were significantly reduced, and they stopped performing religious rituals.

"My mother did not have a comfortable life but she never failed to worship God. Since my mother's brain tumor was diagnosed, I went to the shrine of Imam Reza for 40 days. I appealed to him and prayed for my mother to get better. But she didn't get better. Now, not only do I not pray, but I believe it is unlikely that there is anyone who will hear us" (Participant 1).

Another caregiver also commented in this regard:

"I used to believe in God a lot more. I always thought that God would hear my voice and help me. I was praying and asking God to help my patient recover. But you're stuck in an endless void when no one can hear you. There is no miracle. All beliefs and worships are futile works" (Participant 8).

Spiritual coherence

This category shows the positive effects of spirituality on overcoming mental tensions and accepting the stressful conditions of patient care on family caregivers. The caregivers' religious beliefs and trust in God made them believe that a supernatural power would help them care for the patient. These beliefs created a feeling of peace and confidence in them, and they believed that they would overcome all the challenges caused by patient care with the help of God. This category was subdivided into four subcategories including surrender to God's will, caring as a religious duty, belief in God for care, and reliance on spirituality.

Surrender to God's will

This subcategory indicated that some caregivers believed the power beyond their understanding guides the conditions and events related to the patient's health status and their role as patient caregivers. Therefore, with the help of these beliefs, they considered the recovery or death of the patient to be related to God's will, and this created a sense of peace in them.

"I said whatever is God's will. It is not God's will to give me this child. That's why I am calm. The nurses also tell me, you are calm; I say it may be because my faith has increased. I say to myself, the God who created us from nothing can surely bring back this patient" (Participant 2).

"I left my patient to God, and I saw a miracle. We gave up hope on the patient, but he survived. It is God who determines the life of a person, and if the patient is to survive, God will surely protect him" (Participant 16).

Caring as a religious duty

According to the experiences of some participants, taking care of the patient was a divine grace given to the caregivers. As there is a lot of emphasis on patient care in Islam, they considered caring for the patient their religious duty and stated that this would result in God satisfaction and an excellent afterlife reward for the caregivers.

"Our religious beliefs help us to bear the situation more easily. This difficult situation is considered a positive thing, a good deed for us. If we take care of our father today, we will see the reward in this world or the afterlife" (Participant 18).

"It is the religious duty of children to take care of their parents if necessary" (Participant 5).

Belief in God for care

Some caregivers believed God would help them in this challenging situation and give them the strength and ability to care for their patient, and their patient would recover with a miracle. This belief gave them the energy and power to undertake patient care. Some family caregivers also believed that the suffering experienced by their family members would result in sins being forgiven, and the patient going to heaven pure and without sin.

"It was only because of the hope in God and His help that I was able to overcome my fear. I gave my heart to God to control my stress" (Participant 6).

"I desperately hope that God will do something, my patient will come back to life, and a miracle will happen so that she will get better" (Participant 20).

Reliance on spirituality

According to the participants' experiences, praying, appealing to Imams, making vows, and reciting the Qur'an led to a sense of comfort in them. With these methods, they gained the necessary peace and energy to care for the patient, and felt they were not alone as an unseen force

would help them care for the patient.

"Whatever your religion is, God will protect you. I appealed to Imam Reza; I am sure he will heal the patient miraculously. Also, I calm down by reciting the Qur'an, and a smile comes to my face. For me, the Qur'an and saying prayers are very helpful and calming" (Participant 16).

Discussion

The present study aimed to investigate the spiritual challenges of family caregivers of patients in a vegetative state. The results showed that taking care of a patient in a vegetative state led to spiritual disintegration and spiritual coherence among the caregivers. Spiritual disintegration was associated with a sense of inconsistency between beliefs and the realities of life and the loss of meaning, purpose, and religious beliefs. Spiritual coherence showed the use of spirituality by family caregivers was an effective defense mechanism to accept the situation and take care of the patient.

Similar to the results of the present study, in the study by Nemati et al., the religious challenges of family caregivers of patients with cancer were classified into two categories including spiritual crisis and spiritual coherence. In spiritual crisis, family caregivers considered the cancer a result of punishing the patients for their past behaviors, which led to a conflict with their spirituality. They doubted God's justice, blamed God for their patient's cancer, and to compensate, refused to perform religious and spiritual rituals. Moreover, they were disappointed with the effect of religious and spiritual rituals in restoring the patient's health. However, after these critical ups and downs, harmony was established in the caregivers' beliefs. They believed that God would not harm His servants and that even cancer may be a divine providence. Therefore, they sought to get closer to God by trusting in Him, praying, and making vows in the shrines of the Imams. They believed that God is the source of goodness and that whatever happens, good or evil, is the divine providence (11).

Nevertheless, there were also some differences in the results. In the present study, the caregivers who suffered from spiritual decay did not even regret their thoughts over time and did not seek to repent of their past beliefs and behaviors. In some cases, they even questioned the existence of God. In contrast, some other caregivers considered all the events suitable for the patient and themselves and believed that God supports them in all situations. They believed that the patient would be cured if they sought refuge in God and the infallible Imams and asked for their help. In addition, they considered taking care of the patient as a gift from God.

Understanding the cause of disease is essential for perceiving the purpose and meaning of life. Finding answers to the questions in this regard might lead to

some consequences such as spiritual distress (21) or increase self-knowledge and spiritual growth (22). Misunderstanding the illness due to incorrect religious and spiritual beliefs leads to negative consequences such as psychological distress, hopelessness, and impairment of physical health (23,24). However, the successful search for meaning in life contributes to the psychological well-being of the individual (9,11). Religious beliefs, if misinterpreted, are a major source of tension and stress (25). During negative life events, people may experience disappointment or anger toward God (26). These feelings often appear in those with poor adaptability and coping skills (27). Nevertheless, those who can use spirituality and religion as suitable coping mechanisms are more likely to adapt to the situation and have fewer negative emotions (11,25). In Pashaei and colleagues' study, religious beliefs helped the family resist caregiving tensions and their consequences (28). The concept of God is different for different people but He is an eternal and endless power available to everyone. Believing that God is superior and beyond fear, suffering, and human defects, calmed people (29). Religious ceremonies such as praying, worshiping, attending holy places, and reciting religious prayers increase the tolerance of family members and make them cope more effectively with stress and tension (30).

Family plays an essential role in providing care for patients with chronic diseases, particularly in the Asian context where sociocultural rules, structures, and beliefs strongly lead to greater family cohesion (31). People often find relief through religious or spiritual practices in scary events, illness, and death. The basic premise in coping with such conditions is that religion is more than a defense mechanism. Religion inspires people and allows them to interpret negative events through a holy lens (32,33). Spiritual support is also a source of coping as people who have religious support also have higher social support (34). Imani-Goghary et al. also mentioned spirituality and religion as facilitators and coping strategies for the problems of caring for patients in a vegetative state. Family caregivers considered caring for the patient as worshipping and believed God could help the patient recover. Besides, prayer and worship increased their participation in religious ceremonies, and the formation of prayer groups enhanced the sense of hope and peace in family caregivers. They resorted to God and His infinite power to help them bear the hardships (5). Nemati et al. showed in the first stages, family caregivers face religious tensions. But in the end, they reach spiritual coherence and ensure that God will notice them and heal their patient (35).

One of the limitations of the present study was finding family caregivers with a long history of patient care since many patients in a vegetative state die shortly after being discharged from the hospital. Another important limitation of the study was the refusal of caregivers to talk

about religious and spiritual challenges. Due to the special religious conditions governing the Iranian society, talking about spiritual challenges has become a taboo making it very difficult for the researchers to manage the interviews.

Conclusion

Considering the positive and negative effects of spirituality and religion on the mental health of family caregivers and their compatibility with patient care, it is necessary to pay more attention to the spiritual needs of family caregivers. Accordingly, it seems that all family caregivers of patients in a vegetative state need to receive training on how to strengthen their spiritual beliefs and attitudes with the help of a religious clergy. It is recommended to investigate the reasons for not providing spiritual care to family caregivers by the healthcare system and religious centers in Iran in future studies.

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Competing Interests

The authors declare no conflict of interest in this study.

Ethical Approval

This study was approved by the ethical committee of Mashhad University of Medical Sciences with the ethics code IR.MUMS.NURSE.REC.1399.032.

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