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Exploring the Role of Spirituality in Coping Process of Family Caregivers of Patients in Vegetative State

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Authors' contributions

This work was carried out in collaboration between all authors. Author ZIG designed the study, wrote the protocol and wrote the first draft of the manuscript with advice of authors EN and HP. Author ZIG did the interviews, transcript them, all authors did analyses of the study. Author ZIG did all revises with the direct supervision of author HP. All authors read and approved the final manuscript.

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ABSTRACT

Introduction: The vegetative state (VS) is a condition which can occur after a severe brain injury. After hospital discharging responsibility of caring of patients in VS is transferred to their families, which cause high burden for them. Religion and spirituality help people to reinterpret uncontrollable events and cope with difficulties.

Aims and Objectives: This study was carried out to explore the role of spirituality during coping process of family caregivers of patients in VS with caregiving burden.

Place and Duration of Study: The present study was carried out in Kerman province, Iran during 2014- 2015.

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Methods: This study is a part of a larger qualitative study with using grounded theory method. Sampling was done by using purposeful sampling and then theoretical sampling according to data analysis and constant comparative method for expanding concepts. 11 family members and 2 nurses participated in the study. Data was gathered using face to face in-depth interviews and were analysed through constant comparison method.

Results: From the analysis of the interview texts two themes were extracted, first: "finding meaning in care" which indicates that there is meaning and purpose in delivering care. The categories "care is something spiritual", "looking toward the horizon" and "a sense of excellence in care" formed this theme. Second: "Internal solace provided by religious beliefs" that shows religious beliefs can be effective in bringing relief to the caregivers' life. The categories "reliance" and "invocation" formed this theme.

Conclusion: Spirituality and religion help family caregivers to accept care and strongly affected the ability of family caregivers to cope with the hardships of caregiving for patients in vegetative state. In light of spirituality, they maintained hope for a better future and experience inner peace by remembrance and supplicating to God.

Keywords: Family caregivers; spirituality; coping process; vegetative state; qualitative study.

1. INTRODUCTION

A vegetative state is a condition which can occur after a severe brain injury [1]. Patients in a vegetative state experience wakefulness without awareness of sleep-wake cycles, cannot communicate with others, and may respond to stimulation with spontaneous reflexes [2]. The number of patients in vegetative states is increasing because of recent advancements in medical technology and ICU care [3]. Saout mentioned that there are 56 to 140 individuals per million in vegetative states [4], but there are no reliable statistics on the exact number of these patients in Iran.

Advances in medical intervention have prolonged the life expectancy of patients in a vegetative state [4]. These patients can be discharged from the hospital when their condition stabilizes, but they are completely dependent and must receive continuous care from their families [5]. Having a family member in a vegetative state is a complex experience and places a heavy burden on family caregivers [6]. Some caregivers must leave their jobs, interests and friends to provide care [7], which causes financial, personal, social, and organizational problems for their families [8], negatively effects their physical and psychological health, and makes them feel a lack of meaning in their lives [9,10].

Religion and spirituality are cultural factors that give meaning to human values, behaviors, and structure [11]. Spirituality is the essence of a human that provides a framework through which to strive toward transcendental values and finding meaning in life [12]. It allows a person to

reinterpret uncontrollable events in a less stressful and more meaningful manner [13]. Studies show that spirituality and religion help people to control stress and cope with unexpected and difficult events [14-16]. It promotes a sense of control over feelings of helplessness [17] and reduces anxiety and depressive symptoms [18]. An increase in happiness improves physical and mental health and well-being and the ability to cope with life situations and enjoy of life, even in difficult situations [19-21]. This improves the quality of life for both patients and caregivers [22].

Spirituality can motivate people to use effective coping strategies [23]. Lazarus and Folkman [24] define coping as a cognitive and behavioral effort for managing external and internal demands when they are greater than the resources of the individual. They recommended two types of coping strategies; emotion-focused which reduce negative emotions and problem-focused that deal with stressful situations. Hefti [25] argued that, when people are faced with a stressful situation, spirituality empowers them with a sense of being protected by God, which reduces their emotional distress and makes the situation more tolerable.

Many researchers have found a strong relation between spirituality and coping with the difficulties faced by caregivers [26,27]. It has been shown that caregivers of the terminally and chronically ill rely on spirituality as a resource for coping with the hardship of caring [28]. Malhotra [27] found that religion is often used as an effective method of coping by caregivers and that caregivers who make greater use of religious

copied strategies experience lower levels of psychological distress. Daaleman stated that receiving spiritual care when providing long-term care is crucial for families when coping with the illness and death of loved ones [29].

The qualities of spirituality and religion overlap and depend on culture and beliefs. In the religious underpinnings of Iranian society, spirituality and religion are important sources of coping with the burden experienced by family caregivers of patients in vegetative states. The present study explored spirituality as experienced by family caregivers of patients in vegetative states when coping with their role as a caregiver in Iran society.

2. PARTICIPANTS AND METHODS

This study is part of a larger qualitative study “exploring coping process of family caregivers of patients in vegetative states” which conducted in Kerman province, Iran during 2014- 2015. As the study dealt with an unexplored area, it was important to choose a descriptive and qualitative method to obtain knowledge from the caregivers’ own frames of reference. The study investigated the role of spirituality in coping by family caregivers of patients in vegetative states.

2.1 Participants

Purposeful sampling was used in this study and it continued with theoretical sampling. For purposeful sampling, researchers first selected participants with experience in caregiving for a

family member in a vegetative state at home. Next, during analysis to expand the concepts, researchers selected new participants using the constant comparative method during data analysis to select additional cases as guided by participant statements. Two nurses were interviewed in addition to 11 family caregivers. Sampling continued until saturation was reached. The inclusion criteria for subjects were being over 18 years of age, direct involvement in providing care and being responsible for the care of a family member in a vegetative state for at least six months. The participants were 11 family caregivers and the two nurses who helped deliver care. The demographic characteristics are presented in Table 1.

2.2 Data Collection

Interviews were conducted in the participant’s or patient’s home where the care was provided. Field notes complemented the interviews. The field notes were recorded as the researcher observed the activities of the participants and nurses. The participants were contacted by telephone, the aim of the study was described to them and an interview date was arranged. Data was gathered using face-to-face in-depth interviews with semi-structured questions asked at an appropriate point when participants were comfortable. Field notes and observation complemented the tapes. Introductory questions were followed by more specialized questions in relation to spirituality. The interviews lasted 35 to 75 minutes.

Table 1. Overview of participant demographics

Participant code	Age (year)	Sex	Employment	Patient relationship with caregiver	Length of caregiving (month)	Marital status
1	26	Male	Office worker	Brother	60	Single
2	54	Female	Housewife	Son	60	Married
3	50	Female	Housewife	Mother	6	Married
4	44	Female	Office worker	Mother	6	Divorced
5	32	Female	Teacher	Mother	12	Single
6	20	Female	Pupil	Father	23	Single
7	42	Female	Nurse	Son	24	Married
8	23	Female	Pupil	Mother	18	Single
9	37	Male	Nurse	Professional caregiver		Married
10	35	Female	Housewife	Spouse	7	Married
11	41	Female	Nurse	Professional caregiver		Married
12	32	Male	Tradesman	Father	26	Single
13	24	Male	Office worker	Father	2	Single

One author (ZI) conducted the interviews, transcribed them verbatim, and reviewed the transcripts to ensure accuracy. The interviews explored participant experiences and opinions of family caregivers on the role of spirituality in coping with caregiving. The interviews were rich in content and created a pattern that the authors found adequate to serve as a basis for the findings.

2.3 Data Analysis

Data analysis was done according to Strauss and Corbin [30] methodology, by using of constant comparison. The interviews were taped, transcribed and analyzed immediately after transcription. MAXQDA 10 software was used to manage the data. Each interview was read multiple times for better understanding before analysis. The next interview was conducted after analysis of the previous interview. A constant comparative method of analysis was used. Coding and analysis were done at the same time. This method focused on comparing and contrasting the similarities and differences in the data as well as questioning it throughout analysis [30]. Codes in the data were identified and clustered to create subcategories. Related subcategories formed a category. During analysis using the inductive method, the theme of spirituality formed as a useful strategy for coping.

2.4 Ethical Considerations

The study was approved by Kerman University of Medical Sciences and allocated the ethics code of K/93/337. Prior to the study, the participants the purpose and method of research was described and a written informed consent was obtained. Participants were assured of privacy of their personal information and were told that all data would be treated confidentially and used only for the discussed purpose. The participants were informed that participation in the study was voluntary, they could withdraw from the study at any time, and they had the right to ask the researchers to return the audiotapes of their interviews. They were assured of the anonymity and confidentiality of the study.

2.5 Trustworthiness of Data

The methodological quality of the data was maximized in several ways. The interviewer had 10 years of experience in providing care in the ICU ward and for patients in vegetative states. She was trained in qualitative interview

techniques before the study began. By interviewing the participants in their preferred places, making audio recordings and verbatim transcriptions of the interviews improved the credibility of the data collection. After transcription of the interviews, the content of all transcripts were checked to ensure that they matched the recording. For member checking, the researcher's interpretations of four random interviews were presented to the participants and they were asked to provide feedback; all of them agreed with the interpretations. Team analysis was done to ensure the accuracy of data analysis.

Nursing professionals with different levels of experience in a qualitative study comprised the team. Concepts were formed based on their characteristics and professional opinion. Data collection out by the authors using in-depth interviews to deepen the data and field notes complemented the tapes. Participants of various ages, genders, relationships with patients, and duration of caregiving were used to provide variation in the data. Transferability of data was assured by providing a comprehensive description of the subjects, data gathering, data analysis, and through detailed presentation of the findings.

3. RESULTS

In the course of caring for a dependent patient in a vegetative state, caregivers apply strategies to assist them in navigating this difficult path. Spirituality and religion were mentioned by caregivers of patients in vegetative states as a factor that leveled the tortuous path of caregiving and facilitating coping with problems. Analysis of the interview texts extracted the themes of "finding meaning in care" and "Internal solace provided by religious beliefs" about the role of spirituality while coping with difficulties while caring for patients in vegetative states (Table 2).

3.1 Finding Meaning in Care

Caregivers stated that providing accurate and sincere boarding care required care providers to pursue an objective that considered the action as meaningful and enabled them to provide quality care and overcome the burden of a totally dependent patient in a vegetative state. Analysis of the transcripts of the interviews indicated that there was meaning and purpose to delivering care. The interview texts categories of "care is something spiritual", "looking toward the horizon" and "a sense of excellence in care" formed the theme.

Table 2. Derived themes, categories and sub categories

Themes	Categories	Sub categories
Finding meaning in care	Care is something spiritual	Care is a divine test Care is a human duty
	Looking toward the horizon	Continuity of care with hope for the future Moving toward dreams of the future
	A sense of excellence in care	Self-esteem Attaining peace
Internal solace provided by religious beliefs	Reliance	Submission to the will of God Gratitude to God in all circumstances
	Invocation	Knowing the will of God is supreme Supplication for patience Supplication for health

3.1.1 Care is something spiritual

Care of patients can be seen as futile depending on the condition of the patient and the likelihood that there will be no response to treatment [31]. Spirituality from the perspective of the participants made care of vegetative state patients a purposeful act and allowed them to continue providing care. Statements made by participants fell into the subcategories of “care is a divine test” and “care is a humane duty”.

- Participant 1 was responsible for the care of his ailing brother and stated: “We must set aside crying. It has happened and we cannot fight God. This situation is a test sent by God to us; God wants to test us and I know it’s my duty as a human to take care of him.”
- Participant 6 stated: “It’s kind of my duty to take care of my dad..... Another reason is humanity; if I desert my dad, it is something inhuman.”

These caregivers of patients perceive themselves as passing a test from God and as a performing a humane act by caring for their patients; thus, they take responsibility for patient care.

3.1.2 Looking toward the horizon

The subcategories of “continuity of care with hope for the future” and “moving toward dreams of the future” fall into the category of “looking toward the horizon”. Hope for the future was one of the most important needs of family caregivers. They stated being able to carry on with their lives and actions depended on hope for the future.

According to the caregivers, maintaining hope in the face of the current reality motivated a person to try to create a better future.

- Participant 3 said: “We only hope that he will get better, no matter how much the suffering and trouble. We hope he will get better, or at least not get worse than this--not get bedsores.”
- Participant 7 stated: “I am not willing to transfer his care to another place. I think this child still has time to recover, so I hope he will get better.”

Caregivers felt that, in addition to hope, dreams linking man to God and refusing to assume that something is impossible for the mighty hand of God motivates them to continue along the road of life and helps them to better care for the vegetative state patient.

- Participant number 10, who was caring for her young husband stated: “My only wish is that one morning I will see him stand up. I’d like to see him walk and talk like before. When I think about these things, I know I can still go on.”

3.1.3 A sense of excellence in care

This category resulted from merging the subcategories “self-esteem” and “attaining peace” from data analysis. Participants stated that spirituality removed anxiety and insecurity from their hearts and sowed the seeds of confidence. A person who believed in his/her own abilities tried with hard work, determination and perseverance to provide care. Providing proper care instilled a sense of excellence in caregiver.

- Participant 8 stated: "At first I didn't think I could take care of her, I just said, "God, help me." I now know God gave me the ability to care for her well. Now I feel that if I again decide to care for such a patient, I could do it."

Another care outcome that was expressed by these participants was achieving internal peace.

- Participant 3 stated: "When I take care of my mother, I feel a sense of peace in my heart and I know I'm doing the best thing. If I didn't feel this way, I would really have pangs of conscience."

3.2 Internal Solace Provided by Religious Beliefs

In the culture of Muslim Iranians, as noted in the caregivers words, it is certain that religious beliefs can bring relief. Analysis of the transcripts extracted the categories of "reliance" and "invocation".

3.2.1 Reliance

"Submission to the will of God", "gratitude to God in all circumstances", and "knowing the will of God is supreme" are the subcategories that form this category. The caregivers stated that they trusted in God and submitted to the will of God during all aspects of life. This includes accepting the duty of caring for a loving member of the family who is completely immobile, who cannot communicate and is dependent on them. This has allowed them to build peace in their own lives.

- One participant said: "We must rely on God, He knows everything better. We put our trust in Him so He comforts us and I am able to continue care; whatever God wills will come about."
- Participant 12 who, was responsible for the care of his father for two years, said: "We are a religious family. When dad was hospitalized they said his body infections were critical and he would not survive under these circumstances, but we said, 'Whatever God wills'. You are not God to determine when and how long a man survives. They even remove the devices for half a day but he survives, I told them, 'If God wills, he will survive'. I now say, 'Whatever God desires'".

The participants stated that they relied on God and prayed to God at all times to cope with difficulties.

- Participant 13 stated: "I put my trust in God and I thank God that we did not lose our father and that God gave us ability to take care of him."
- Participant 5, who took care of her mother, said: "My sisters and I learned to do our work ourselves. We always supported each other. I thank God for this blessing."

Family caregivers considered the will of God above all things and believed that events occur according to destiny and divine will.

- Participant 12 said: "Doctors are tools and should carry out their work properly, but God makes the final decision. Everything is as God wills."

3.2.2 Invocation

Prayer, worship, offerings, increased participation in religious ceremonies and organizing prayer groups were mentioned in the statements of many caregivers. They often expressed that such acts increased their sense of hope and tranquility. They resorted to the sacred and invoked the power of God for the strength to endure difficulties and the health of their patients. Analysis of interview transcripts developed the subcategories of "supplication for patience" and "supplication for health" in this category.

Participants believed that when taking care of a patient in a vegetative state, they will experience problems that could only be overcome with the patience that they sought from God.

- Participant 5 stated: "It's hard to take care of such patients. If you can just ask one thing of God, I think you should ask God to give you patience."
- Participant 9, who is a nurse involved in home care, said: "It is so difficult to handle an adult invalid. Their family should move him and change his clothes. God give them patience."

In addition to asking for patience, caregivers prayed for their patients and asked for restoration of their health.

- Participant 11, a nurse who has observed caregiver behavior in the hospital, said: "When they see their patients in this situation, they pray, donate in charity and usually hold prayer ceremonies in their homes. They are turning to God and sometimes tie a green cloth on a patient or his bed as a form of consecration."

4. DISCUSSION

Caring for patients in a vegetative state is the duty of family caregivers. These caregivers experience a heavy burden and workloads that challenge them mentally. They use different ways to facilitate caregiving and level the rocky path ahead. Caregivers stated that religion and spirituality sustain this process.

Analysis of the data extracted the themes "finding meaning in care" and "Internal solace provided by religious beliefs" that help family caregivers of patients in vegetative states accept the condition of the patients and provide care. They first must find a goal and meaning for caring. To provide daily care and deal with daily problems, these family caregivers must cultivate the inner peace that allows them to relax in the shelter of their religious beliefs.

Despite the crisis, individuals with a spiritual direction are able to find meaning and purpose in life and cope with suffering caused by the disease. They pass through crises more successfully [32]. Participants mentioned care as a spiritual affair and viewing care as a test from God and as a humanitarian task helped them to accept the burden. Several studies have found that acceptance of the disease as a divine test and providence contributed to their ability to cope with the disease and its related problems [33,34]. One benefit was the ability to move toward a normal life despite the disease, [35] which thus improved their quality of life [17]. Rasool [36] also stated that Muslims believe that illness, suffering and death are part of life and all are divine tests [36], so they accept the terms and become responsible for the care in accordance with their beliefs. Abandoning a patient or helping him to die are sins because death and life are in God's hand and helping a person to die is contrary to the principles of Islam [37].

In addition, participants believed that if someone in the family becomes ill, the family members have a humanitarian duty to care for and support him. Asgari et al. [38] also found that the family is

the primary source of support and that family members feel commitment for each other. This sense of duty is a factor in minimizing problems, encouraging family members and coping with problems [38]. Under tough conditions such as caring for a patient in a vegetative state at home, family members do not shirk the responsibility of care and consider it a duty [39].

God as the source of hope and dreams for the future was mentioned by family caregivers as effective for the continuity of care and moving toward the future [40]. Hope is a psychological source which helped caregivers deal with caregiving problems and concentrate on the transition from the present difficulty to a better future [41]. It portrays positive expectations of the future and is a known strategy for coping with difficulty [40]. The hope of God's assistance under difficult conditions encouraged family caregivers look to the future and hope for improvement in the patient's condition and an end to suffering and allowed them to continue caregiving. Feelings of happiness, lightening of stress in facing traumatic events and preserving mental health are all known effects of hope for the future [42]. The findings of the present study demonstrated the creation of a spiritual relationship with the infinite power that ensured individuals of a powerful source of support, making the future more hopeful and optimistic.

It is important to note that mankind has always carried hopes and dreams within themselves; hopes and desires have spurred them toward growth and excellence and move toward the future [43]. Participants acknowledged that desires and dreams for the future moved them forward despite the hardships of caregiving for a patient in a vegetative state. Participants stated that communicating with God and trusting in his eternal power provided a sense of confidence to family caregivers and helped them have confidence in their abilities. It allowed them to care for the patient and cope with difficulty with self-confidence. The role of spirituality and religious belief in strengthening self-confidence has been mentioned in previous studies [44,45]. Krause and Hayward found that people who have a close relationship with God (such as prayer) feel more confident and believe in their abilities [46].

Closeness to God and attention to spirituality eases the mind and improves mental health [47]. Spirituality is a positive and soothing structure and an emphasis on spirituality improves mental

health [42,48]. Participants referred to the teachings of Islam that mention spirituality as a factor to achieve peace. Family caregivers also mentioned that care in the light of spirituality is a factor for achieving peace and freedom from guilt. Inner peace and self-esteem followed by spirituality increased feelings of excellence in family caregivers. Religious beliefs and spirituality increase the ability to deal with problems related to chronic disease [44].

By providing spiritual care, caregivers look toward the future, anticipate changes in their and the patient's condition, achieve spiritual transcendence and find meaning and purpose to caregiving for a patient in a vegetative state, which helps them tolerate the hardships and difficulties of care. Family caregivers said that trust in God and seeking his help allowed them to achieve peace. Because all participants in this study were Muslim, these beliefs could be clearly recognized in the context of the interviews. In the Islamic teachings, trust means faith in God in all matters and reliance on Him [23]. Trust in God reduced anxiety in caregivers [49], helped them cope with stressful situations [34,50] and created a sense of calm. This concurs with the findings of previous studies [34,49,51]. Caregivers in the present study stated that because they relied on God and considered God above all and they believed that there is ease after every difficulty and God is all-knowing. Caregivers also said that they were grateful to God at all times for His blessings. Thinking about the greatness of God, the philosophy of creation, and giving praise and thanksgiving for His blessings eased the soul and relieved the heart [36].

Prayer is a beautiful manifestation of worship that is a direct relationship with God. Prayer and invocation allow a person to communicate directly with God and ask for help, feel God presence [52] and believe that he/she is being heard by a higher power [53]. Prayer controls a seemingly uncontrollable situation and is highly relevant in serious situations [54]. Taleghani [55] found that patients who make vows, go on pilgrimage, pray and appeal to the Imams find significant mental relief and reduce the fear of disease. Family caregivers who seek healing for their patients through prayer believe that the patient's healing is in God's hand.

In addition to asking for healing for the patient, caregivers seek patience from God in coping with problems. Family caregivers said that asking for

patience created a positive attitude for them that helped them tolerate difficulty, increased adaptive behavior and consolidated peace in their lives. These qualities have also been mentioned in previous studies [52,55].

Although valuable information was obtained from this study about role of spirituality in coping by family caregivers of patients in vegetative states, the results cannot be generalized because the sampling method was purposive and the findings reflect the experiences of a limited number of family caregivers. The authors feel confident about category saturation.

5. CONCLUSION

The findings of the present study showed that spirituality and religion strongly affected the ability of family caregivers to cope with the hardships of caregiving for patients in vegetative states. In light of spirituality, despite the difficulties and tensions, family caregivers accepted the role of caregiver and maintained hope for a better future. They provided optimal care and experienced positive feelings and peace. The difficulties of care were smoothed by invocations to and trust in God. Caregiver inner peace increased by supplicating to God and asking for patience and embracing the future.

Delivering care to vegetative state patients in the home increased the awareness of nurses about coping strategies of family caregivers. These strategies strengthened the caregivers, increased the quality of care and improved the condition of the caregivers. The challenge of caring for a family member in a vegetative state could end without leaving a negative effect on the family, and upon completion provided caregivers with enhanced mental abilities.

It is obvious that, clarification of this subject will facilitate family caregivers coping with the challenges of taking care of a VS patient, so the quality of care and family caregivers' wellbeing will improve.

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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