

ORIGINAL ARTICLE

The Role of Nurses in Coping Process of Family Caregivers of Vegetative Patients: A Qualitative Study

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ABSTRACT

Background: Vegetative state (VS) occurs through return of the brain stem after coma state. After hospital discharge, responsibility of caring for VS patients is transferred to their families, which causes a high burden on them. Nurses have an important role in helping the family caregivers to meet their needs and cope with difficulties. To explore the role of nurses during coping process of family caregivers of VS patients.

Methods: This study is a part of a larger qualitative study which was performed in Kerman province, Iran during 2014 - 2015. Purposive and theoretical sampling was used. 14 caregivers participated in the study. Data were gathered using face-to-face in-depth interviews and managed by MAXQDA 10 software. Analysis was done through constant Comparative Method.

Results: Three themes of “nurse as a pursuer teacher”, “nurse as a compassionate caregiver”, and “nurse as a supporter” were derived from analysis that represent various roles of a nurse in the coping process of family caregivers of vegetative patients during the care process.

Conclusion: Nurses can play an effective role in improving the caregivers’ well-being by considering the importance of training at discharge time and during home care, helping families in providing care and support them during care process.

KEYWORDS: Family caregivers, Nurses role; Qualitative study; Vegetative state

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INTRODUCTION

The vegetative state (VS) is a condition which occurs through return of the brain stem after coma state.¹ These patients experience wakefulness without awareness with sleep-wake cycles; they probably use reflex and spontaneous behaviors, but not purposeful movement for responding to stimulation.² VS patients are not aware of themselves and the environment and are not able to communicate.^{1,2}

Advancements in medical science and critical care have increased the number of VS patients and prolonged their lives so their life expectancy is estimated more than ten years.³ The prognosis of VS with passing time becomes weak and improbable after a year.⁴ In Iran, after passing the acute phase, the patient care will continue at home by the family caregivers.⁵

VS patients need constant assistance and whole services from family caregivers, such as feeding, bathing, changing clothes and so on.⁶ The management of a VS patient creates medical, ethical and financial challenges for family caregivers.^{4,7} Therefore, family caregivers must be in center of notice, and health professionals especially nurses should consider their needs.⁸

Family caregivers need skills to provide care to these patients;⁶ several studies explored the informational needs of family caregivers,^{6,9,10} which is described as greedy search for information.⁶ Family caregivers require to learn about the disease, making difficult decisions regarding the care and how to continue it and cope with the consequences of the illness.⁹

Long-term caregiving is associated with changes in everyday life of the caregivers, such as failure to perform duties, do interests and social interactions.^{5,11} Following these limitations, signs of mental disorders like depression, prolonged grief disorder,^{10,12,13} post-traumatic stress disorder (PTSD),¹² anxiety,¹⁴ fatigue and caregivers' burnout⁴ arise among family caregivers.

Previous studies mentioned that family

caregivers encounter with a high level of strains; they are worried about the patients' future. They tend to experience helplessness and guilt that cause loss of vitality and interfere with their daily activities⁴. Health professionals should help the family caregivers to cope with caring problems and related emotional distress; however, it is not being done perfectly.¹⁵

In addition, long term costs of caring and providing necessary equipment have created concerns for family caregivers; most of them don't have enough information about supportive and insurance centers.⁵ Lack of information and lack of official and governmental support systems cause more difficulty for family caregivers during the care process¹⁶ whereas social support as a valuable resource reduces the burden of care.¹⁷

A recent study mentioned that family caregivers should receive support from nurses and health professionals throughout the duration of their relative's disease;⁴ this enables them to deal with care problems¹⁸ whereas most of the nursing care in Iran is allocated to the hospital, and nurses' activity is very limited in the community level.¹⁹

Since VS patients are being cared by their families in Iran, it seems essential to understand the role of nurses in coping process of family caregivers. Results of this study can help nursing professionals to develop effective programs for family caregivers. The nurses can promote family caregivers' capabilities and quality of life by running these programs in the community level.

This study aims to explore the role of nurses in coping process of family caregivers of vegetative patients as a part of the findings of a larger study "exploring coping process of family caregivers of VS patients".

MATERIALS AND METHODS

This study is a part of a grounded theory study entitled "Exploring the coping process of family caregivers of vegetative state patients" which was conducted in Kerman province, Iran in

January 2014- December 2015. The present study provided greater insight into the role of nurses in coping process of family caregivers of vegetative patients, how nurses can help them cope with caring difficulties and in which part there is an unmet need. It was important to choose a qualitative method to acquire knowledge from the caregivers' own view, because the study dealt with an unexplored area, and addressed the human's experiences and feelings.

Participants

Purposive and theoretical sampling was used to recruit the participants. The researchers tried to select the subjects who had an experience of caregiving for a family member in VS at home. We selected new samples according to data analysis and use of constant comparative method. During the study, the researchers tried to expand the concepts with selecting additional cases by theoretical sampling, so two nurses were interviewed in addition to 12 family caregivers. Sampling continued until reaching the data saturation point.

Inclusion criteria to select the subjects were direct involvement in providing care to a VS patient and being responsible for care for at least 6 months.

Participants who were in a fragile psychological state were not enrolled in the

study. If a participant was not willing to take part in the study or wanted to take back his interview data, we agreed with him/her.

Demographic characteristics are presented in Table 1.

Data Collection

At first, the participants were called, the aim of the study was explained to them, and the interview dates were set. Written and verbal consent forms were obtained; then, the data were gathered through face to face in-depth interviews with semi-structured questions. The researchers encouraged the participants to talk about their experiences by asking open-ended questions, for example: "please tell me about your experience in caring of a VS patient", "how nurses helped you cope with caring difficulties?" and "what gaps did you feel?"

Interviews were conducted at home, where care was provided. Field notes were created when the researcher observed activities of the participants and nurses. The interviews lasted 35-75 minutes. One of the researchers conducted the interviews, transcribed them verbatim, and reviewed the transcripts to ensure accuracy. The interviews explored the participants' experiences and views on the role of nurses, types of support received from them, their satisfaction with it, its gaps, and its quality and quantity. The interviews were

Table 1: Overview of participants' demographic characteristics

| Participant code | Age (year) | sex | Employment | Patient- caregiver family relationship | 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 | 36 | Married |
| 10 | 35 | Female | Housewife | Spouse | 7 | Married |
| 11 | 41 | Female | Nurse | Professional caregiver | 60 | Married |
| 12 | 32 | Male | Tradesman | Father | 26 | Single |
| 13 | 24 | Male | Office worker | Father | 2 | Single |
| 14 | 44 | Female | Housewife | Son | 57 | Married |

rich in content and created a pattern which the authors found adequate to serve as a basis for the findings.

Data Analysis

The interviews were done at least 6 months after the patients' care had begun at home and transcribed right after. MAXQDA 10 software was used to manage the data. Data analysis was done according to Strauss and Corbin (2008) methodology; each interview was read several times for a better understanding; then a conceptual label, a code, was given to events in the raw data. The next interview was conducted after analysis of the previous one; coding and analyzing were done at the same time by using constant comparative method of analysis, with comparing similarities and differences in the data and questioning the data during the analysis.²⁰ Identified cods were clustered together and created categories.

Ethical Consideration

Kerman University of Medical Sciences approved the study and allocated an ethics code "K/93/337". Prior to the interviews, the participants were informed of the purpose and method of the study and oral and written informed consent was obtained. They were assured that their personal information and all data would be saved secretly and would only be used for the mentioned purpose. Participation in the study was voluntary and they could withdraw from the study at any time and 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.

Trustworthiness of the Data

The methodological quality of the data was maximized in several ways. Credibility of the data collection was improved by interviewing the participants in their preferred places. The interviewer was trained in qualitative interview techniques and had 10 year experience in providing care in ICU for VS patients. In addition to audio

recording and verbatim transcribing of the interviews, we also enhanced the credibility. The content of all the transcripts was checked to ensure accuracy. For member checking, the researcher's interpretations of four randomly interviews were presented to the participants and they were asked to react; all of them agreed with the interpretations.

Concerning the conformability and dependability, team analysis was done to ensure the accuracy of data analysis. The team was comprised of nursing professionals with various levels of knowledge in the qualitative study. Concepts were formed based on their characteristics and using professionals' opinions. All phases of data collection were performed in the best way; the authors tried to deepen the data by using in-depth interviewees and also using observation and field notes as complements. Variation in data was obtained by interviewing the participants with various ages, genders, relationships with patients, and durations of caregiving.

Transferability of data was set by presenting a comprehensive description of the subject, participants, data gathering, data analysis process, and a detailed presentation of the findings.

RESULTS

Analysis of the interview texts indicated the fact that nurses are an integral part of the health system and act as mediators between the VS patients' families and the health system. Three themes of "nurse as a pursuer teacher", "nurse as a compassionate caregiver", and "nurse as a supporter" were derived from analysis of the interview texts that represent various roles of a nurse in the coping process of family caregivers of VS patients. Themes, categories and subcategories are presented in Table 2.

1- Nurse as a Pursuer Teacher

According to the analysis of the interview texts, two categories "teach to accept care" and "teach to provide safe care" were obtained which represent the needs of family caregivers

Table 2: Themes, categories and subcategories

| Themes | Categories | Subcategories |
|------------------------------------|--|--|
| Nurse as a pursuer teacher | Teach to accept care | Provide information about the disease Teach problem solving skill |
| | Teach to provide safe care | Care while maintaining patient safety Care while maintaining caregiver safety |
| Nurse as a compassionate caregiver | Taking care of a patient | Cooperating in providing care Consultation in providing care Continuous care |
| | Taking care of a caregiver | Physical care of a caregiver Mental care of a caregiver |
| Nurse as a supporter | Providing available services | Providing care facilities Access to skilled workforce |
| | Referral to other supportive organizations | Referral to a psychologist Referral to supportive organizations |

for training before undertaking this serious task and during providing care to prevent complication in patients and their caregivers.

1-1- Teach to Accept Care

According to the interview texts, in order to undertake the care responsibility, family caregivers need to be trained in the field of VS disease and its process; they also need to gain the ability to solve the unexpected problems during the care period. The following subcategories “provide information about the disease” and “teach problem solving skill” formed this category.

A participant (12) said:

“We had no medical knowledge; seeing our patient in this condition confused us whether he is alive or dead. Can he talk? Anything is gonna change? and many other questions. We needed a reliable and experienced person to get some information from, especially initial information”.

Another participant (1) said:

“My brother was in post ICU for a few days. I learned many things from the nurses. I saw what they did when he was coughing, vomiting or had lung secretions. It was so useful since I learned what to do in each condition and for any problem ...”

Training has a significant effect on the acceptance of a patient’s care. Family caregivers look for information about the disease, treatment process and its prognosis

before accepting the care responsibility. They need to learn how to do it and make appropriate decisions under unpredicted conditions.

1-2- Teach to Provide Safe Care

Analysis of the interviews showed that caregivers look for a care that has the lowest risk and complication for the patients, and additionally does not threaten the caregivers’ health. Subcategories of “care while maintaining patient safety” and “care while maintaining caregiver safety” formed the mentioned category.

One of the participants (2) said:

“For his lungs’ secretion, we were told to use suction. We always did it. But because we didn’t do it correctly, his lungs became infected, and we were in trouble”.

A participant (8) who is a frail girl said:

“I didn’t know how to move her. It was hard; my brothers were so young. We put her on a blanket and pulled her. It was really painful. I think one thing that caused bed sore was bad movements.... At the end, I became so weak like a bone in some clothes. I had no strength”.

This participants’ statements show that inadequate training has caused physical and psychological complications for family caregivers as well as physical complication for patients.

2- A Nurse as a Compassionate Caregiver

According to the participants' statements, the nurses' role in taking care of a VS patient is not limited only to the hospital; the patients' families need a compassionate nursing care during the whole life of the patients. They are calling for nurses' attention to the family as well as to the patient. According to the analysis of interviews data, categories of "taking care of a patient" and "taking care of a caregiver" were obtained as the mentioned theme components.

2-1- Taking Care of a Patient

According to data analysis, three subcategories "cooperating in providing care", "consultation in providing care" and "continuous care" were obtained, which formed the category. The participants stated that nurses should provide professional care to the patient; investigate the VS patients care process, needs and health condition; and consult family caregivers for making better care decisions at home.

Another participant (14) said:

"When his lungs were infected, the doctor prescribed 10 grand penicillin which had to be applied in the serum per day. We employed a nurse to do that. Also about gastric tube, I really didn't dare to change it myself".

A participant (8) said:

"After my mother was discharged, anytime I faced a problem, I called ICU and asked the nurses; although it was not their duty, they taught me well".

Field note NO (6):

"As I attended the interview session, a nurse was changing the patient's urinary catheter. Then, he mentioned some caring points to his caregiver such as controlling of intake and output (I&O) according to urine volume and color and the caregiver listened carefully"

By interviewing the family caregivers of VS patients, it is confirmed that nurses provide care and consult to these families only in private sector.

According to one of the participants (10):

"When we took him home, finding someone

who visits him at home was really difficult... Since we have took him home no one has asked about his status or us. No one cares if we can handle it or not."

2-2- Taking Care of a Caregiver

According to interview analysis, two subcategories "physical care of a caregiver" and "mental care of a caregiver" were derived which formed the mentioned category and showed the family caregivers

Participants (6) said:

"We were crying when we saw my dad in this condition; we were all shocked. We invited Mr. M (a nurse) to guide us. The nurse talked to us ..., he tried to calm us that we felt we were not alone so we could go back to normal state".

A participant (2) said:

"Seeing the child in this condition, everybody considered me healthy. I was forgotten; no one would care if I'm alive or not. But God knows what I ever experienced. When I do things, I easily get exhausted; it is not clear what my disease is."

According to the above statements, daily exposure of family caregivers to care related stress and burden caused them to experience physical and mental problems, so family caregivers need attention and care, and community nurses should consider their health, but unfortunately this need isn't met, based on the participants' statements

3- A nurse as a Supporter

Another role of a nurse that was derived from the analysis of the interviews was "a nurse as a supporter". This consists of two categories "providing available services" and "referral to other supportive organizations".

3-1- Providing Available Services

The family caregivers stated the need for round-the-clock nursing centers which assist caregivers in providing necessary facilities and experienced workforces who help family caregivers under critical conditions. Two subcategories "providing care facilities" and

“access to skilled workforce” were derived from the analysis of interviews that formed the mentioned category.

One of them (13) said:

“Costs of providing medicines and equipment are too high, which makes taking care of the patient difficult. If insurance organizations pay the costs, or an organization provides facilities and equipment with a proper or insured price, it really helps us”.

Another patient (10) said:

“There is no reliable organization to follow the patient at home. On the first days, when his tracheostomy had a problem, we called his nurse, but he didn't answer at nights... One night at three o'clock, we got out of oxygen, we took the capsule to a hospital to change it; they didn't do that, and until we found someone to get oxygen, he was nearly dead.”

3-2- Referral to Other Supportive Organizations

According to the participants' statements, VS caregivers endure great mental and physical suffering, they need supportive organizations. Nurses as a mediator between the family and supportive organizations should take the responsibility for referring. According to the analyses, subcategories “referral to a psychologist” and “referral to supportive organizations” were derived that formed the category.

A participant (8) who provides care with the aid of her 2 teenage brothers said:

“My brother was depressed gradually. We didn't have any knowledge to realize and nobody had warned us.... We saw the complications. My brother fell from the top of a 4-floor building and his legs and jaw were broken. Then, his doctor and nurses advised us to take him to a psychologist; if they had said it before, it would not have happened.”

Another participant (9) who is a private nurse said:

“The family members' mood is changing gradually; a nurse should really consider the facts and refer them to a psychologist”.

One of the patients (7) said about supportive organizations:

“Welfare Organization provided some limited services for us, such as bed or some other stuff; I heard it from one of my colleagues in the hospital informally.”

According to the participants' statements, supportive role of nurses in the health system of the country has been forgotten while the family needs it.

DISCUSSION

Nurses have different roles based on the patient and his family needs; they may perform several roles simultaneously. As nurses have started to provide home care during recent years, their roles have been varied.²¹ According to interviews' analysis, the following themes were derived: “a nurse as a pursuer teacher”, “a nurse as a compassionate caregiver” and “a nurse as a supporter”. The themes indicate educational, caregiving and supportive roles of nurses in coping process of family caregivers of VS patients.

The first theme indicates that, as families realize the necessity of continuing VS patients' care at home, nursing educational role will be felt more. Training should be done by nursing team to empower the family to accept care and provide it safely. Other studies also emphasize the educational needs of family caregivers which are consistent with the results of the present study.^{15,22} A study stated that in order to get prepared for providing care, the families should look for information related to the nature of the disease, its prognosis and how to provide care;²³ such information is necessary for future life and participation of family caregivers in patients' care.²⁴ This has also been considered effective on the increase in the level of self-efficacy²³ and improvement of the caregivers' mental health.²⁴ By providing information about the disease and its process, complication of the care will be reduced and family caregivers can perform their care duties in the best way.⁶ The participants of the study strongly emphasized receiving information as a prerequisite need for taking the responsibility of care. Educating the family caregivers is considered as one of

nurses' key roles in the provision of health services,²⁵ especially in chronic and dependent patients such as VS patients.

Moreover, the findings of this study showed that family caregivers should be able to make decisions as to problems related to the patients' condition. By recognizing the problem and investigating the needs and available resources, family caregivers can make the best decision and cope with stressful situations,²¹ so caregivers need problem solving skill in order to achieve this ability.²⁶ The ability to handle the patients' problems reduces the caregivers' stress, promotes their physical and mental health level,²¹ and helps the family caregivers to reduce high-risk behaviors.²⁶ Most of the caregivers cannot provide successful care; they have difficulty making decision in different situations, so they endure too much stress for taking care of a patient.²⁷ Education about how to provide care, and how to deal with different situations is one of the nurses' duties that can greatly help family caregivers during the care period;²⁷ this was emphasized by the participants of this study.

Assessing training needs, providing information and involving families in discharge programs and decisions related to patients improve the sense of self-esteem and readiness for accepting care in family caregivers.²⁸ Another objective of training is to transfer care skill to a trainee to make changes in caregiver activities' trend.²⁹ In Ira, there is no place to provide care to VS patients; it is the families' responsibility to do caring activities at home, while the patient has no collaboration with caregivers.⁶ At the beginning of care, they experience too much stress and anxiety and attempt to reject this task, because they know that taking care of a dependent patient requires a lot of skills;⁷ otherwise, they may unwittingly hurt their beloved.²¹ Thus, they should be trained well by medical staff, especially nurses.³⁰

Lifting and moving a patient increases the risk of physical injury for caregivers.²⁶ Studies show that herniation of Inter-vertebral disc and

limbs' pain are the most common physical complication of taking care of a dependent patient.^{4,6,12} In addition, fatigue and mental problems such as depression, PTSD and prolonged grief disorder have been stated as long term complications of care provision.^{12,14} Taking the responsibility of care and doing nursing procedures are challenging for novice nurses, but family caregivers should routinely provide these kind of cares, which imposes great stress on them,²⁸ and leads to distress and fatigue of caregivers.¹⁵ Adequate training helps the family caregivers do their role perfectly, so they can reduce care adverse effects²⁸ and resolve the caregivers' stress and depression.³¹ These trainings are about choosing appropriate method and position, getting help of suitable workforce, and using equipment to move and take care of the patient.²⁶ Training causes a sense of self-esteem and readiness in caregivers, so they experience less difficulty and feel more confident.¹⁵

Nurses should provide understandable information by different methods to the family caregivers, and should not expect the family caregivers themselves to seek information.³² But studies showed that the family caregivers face many problems in getting information from the nurses and health care professionals.^{6,22}

Nursing has been known as a caring profession and nurses should take care of patients and their families according to their needs. Nursing care includes cooperation in taking care, consultation with family caregivers and provision of continues care,²¹ which was also mentioned in the present study participants. Nurses have a significant role in resolving the family needs and providing home care along with the family caregivers.³³ As our participants mentioned and similar to the results of previous studies, the role of nurses in providing home care has been ignored,³⁴ which is related to high financial burden imposed on families and lack of insurance support,³⁵ so despite the caregivers' willingness, after a short period the nurses' role has changed from taking care of a

patient to providing care consultation, and care responsibility is completely imposed on the family caregivers.⁵ Unfortunately, lack of consultant nurses and nursing consultation centers has limited this only to informal and relational consultations, and access to these group of nurses is difficult too⁶, so family caregivers feel they are left alone with heavy responsibility of caring.³⁶

Results of various studies in line with findings of present study mentioned to the need for continuous communication between caregivers and nurses to investigate their needs and problems and help caregivers to maintain, improve and promote the patient health.^{9,22,36,37} Also, the results of assessing the effects of continuous care model showed an improvement in the patients' physical condition,³⁸ while providing continuous care to patients at the community level has been only investigated on a limited number of diseases and only at research level that VS patients are exceptional. It is worth mentioning that in Iran there is no center to follow the VS patients' state after discharge and at home.⁶

Taking care of a VS patient at home is a big source of stress for families and can cause a lot of mental and physical problems.²⁶ Caregivers of VS patients, due to the patient's need for 24hr care services, do not have enough time for relaxing, doing personal activities and even forget prescribed care for their chronic disease. Thus, their overall health is endangered.¹⁰ Half of the caregivers have one chronic disease at least,⁴ and have been introduced as hidden patients.¹⁵ It has been mentioned that consultation sessions are effective in reducing the family caregivers' mental problems.¹⁵ Home visit and support to family caregivers by nurses have been known effective in reducing the caregivers' depression and help them manage specific problems.²¹ Nurses encourage family caregivers to have rest periods, choose healthy diet, do exercise, use preventive care, etc.; this can improve their health.^{5,39} This study showed that nurses should consider the family caregivers' health in addition to the patient health.

According to the findings of this study, another role of nurses in the coping process of family caregivers of VS patient is the supportive role. With the development of nursing services outside the hospitals, nurses can provide the family caregivers with required services and guide them with necessary guidance. But in this regard, many care plans are still not designed in the country or they are few and the cost of achieving to them is high, so even wealthy families cannot receive the required services.¹⁹ In addition, home care services provided by Welfare Organization and the private and charitable sectors have quantitative and qualitative deficits.¹⁹ Family caregivers should receive support from nurses in home care activities, but the result of this study in line with a previous study shows that most of the nurses in Iran provide nursing care at the second level of prevention, hospital, and their activity is very limited to the community level.⁴⁰ Lack of rules, governmental support systems and access to efficient and equipped centers and expert personnel in the field of home care lead family caregivers to experience greater difficulty during the care period.²² Facilities, like the needed equipment for moving the patient or providing specialized care, are only provided to a very limited extent by Welfare Organization. Other home care programs such as providing workforce to help the family caregivers only address a limited number of patients, too. Unfortunately, there are a limited number of supportive organizations in Iran and their activities are not done comprehensively and based on standards.¹⁹ As participants of the current study mentioned only at the request of the families, the services are provided at basic care level by private nursing centers the cost of which is problematic for the family.

The current study show that the family caregivers of VS patients suffer from mental and emotional problems, which has also been mentioned in other studies.⁴ Lack of emotional support for family caregivers is an obstacle for providing appropriate care to

VS patients.¹⁴ Close relationship between the nurses and families is effective in choosing the best solution for families' health.²¹ Thus, nurses who work in the community should refer the family caregivers of these patients to available psychology centers.

Many family caregivers of VS patients have no sufficient information about available supportive services; even some caregivers do not know when they need social services and how to find and use them.⁶ This was also mentioned by the participants of the current study, too. Nurses should have sufficient knowledge about psychologists or other supportive organizations and refer the caregivers if needed.⁸

Although valuable information was obtained from the current qualitative study about the role of nurses in coping process of family caregivers of VS patients, the generalizability of the results is limited because the results reflect the experience of a limited portion of the caregivers and sampling method was purposive. However, we feel confident that the categories were saturated.

This study specially explores the role of nurses during coping process of family caregivers of VS patients. Additional research conducted with VS family caregivers by different methods will deepen our knowledge in this regard. Also, it is recommended that the study should be repeated for different diseases, too.

CONCLUSION

Family caregivers are the main participants in caring of VS patients. They face with mental stress and high workload. Nurses have the most caring relationship with family caregivers, so they should consider issues related to the patients and the family caregivers' safety. According to the findings of the study, this is achieved by considering the importance of training at discharge time and during home care and taking care of the patient and his family during the entire care period. According to the findings, the following measures are recommended: emphasis

on providing information about the disease on discharge; providing training on problem solving and safe care skill, assistance and consultation during the care period; continuous follow up of the patient and the family caregivers condition; building and equipping special clinics and supportive centers; changing service provision model from hospitals to the community; and delivering psychological and supportive services for the families of VS patients.

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