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Educational challenges of family caregivers of vegetative state patients for home care preparedness: A qualitative content analysis

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Abstract:

BACKGROUND: Patients with a vegetative state (VS) are completely dependent on caregivers in all physical aspects of their lives. Caring for such patients comes with a great deal of difficulty for family caregivers. As a result, family caregivers must be fully trained and prepared for this role. The present qualitative study was conducted to investigate the educational challenges faced by family caregivers of VS patients for home care preparedness.

MATERIALS AND METHODS: The present qualitative study was conducted through the conventional content analysis method from August 2020 to September 2021 in two provinces of Iran (Sistan and Baluchestan Province; and Razavi Khorasan Province). Fourteen family caregivers of patients in a VS were included in the study. Semi-structured and in-depth interviews were employed to collect data. The Graneheim and Lundman method was utilized to conduct the data analysis using MAXQDA2020 software. Data collection continued until data saturation and the identification of main categories.

RESULTS: As indicated by the data analysis, three categories of “unmet educational needs,” “confused caregiver,” and “searching for practical knowledge” which included 19 sub-categories described the experiences of family caregivers of patients in a VS concerning challenges they went through in preparation for patient care at home. Participants’ experiences revealed that despite the inadequacy of educations provided by health-care providers on knowledge and skills required by family caregivers, they were committed to caring for the patient and trying to acquire the required knowledge.

CONCLUSION: Results indicated that inadequate education and the lack of family caregivers’ contribution to caring for the patient in the VS during their stay in the hospital impedes their acquisition of adequate knowledge and skill to care for patients at home. Therefore, healthcare system policymakers should be planning to eliminate the educational barriers faced by family caregivers and expand the educational activities of hospitals’ homecare centers to provide educational support of family caregivers after the patient’s discharge.

Keywords:

Content analysis, family caregivers, family caregivers’ preparedness, home care, qualitative research, vegetative state

Introduction

Vegetative state or unresponsive wakefulness syndrome (VS/UWS) is one of the worst conditions occurring due

to brain damage.^[1] This condition may occur suddenly (as a result of traumatic or nontraumatic brain injuries such as anoxia, hypoxia, infection, or bleeding) or gradually (as a result of neurodegenerative diseases such as Alzheimer’s disease).^[2]

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VS/UWS patients open their eyes spontaneously but are unable to perceive, speak, or engage in purposeful activities. They have normal thermoregulation, and their cardiovascular, respiratory, and gastrointestinal systems function normally, but they suffer from severe urinary and fecal incontinence. In the event that this condition persists, it refers to: A persistent VS, if it continues for a month after the brain injury, a permanent VS when it lasts more than 3 months after a nontraumatic brain injury or more than a year after a traumatic brain injury.^[1,3]

Care of high quality is vital for patients in a VS to avert preventable complications. The standard actions included: sufficient nutrition, often through gastrostomy tubes, good skincare, passive joint exercises to minimize muscle contraction and joint stiffness, tracheostomy suctioning, if needed, to prevent aspiration, careful management of the doubly incontinent bladder and bowel, given the patient's severe incontinence; and attention to oral and dental hygiene.^[4]

Most of the care provided for these patients must be delivered by professional caregivers. Therefore, when implemented by family members, these care measures can lead to complications for the patients and caregivers.^[5] In many developed countries, these patients are usually discharged from the hospital after reaching a stable state, given the long period of care required, and care services continue at long-term care facilities or nursing homes.^[5,6] However, as there are no long-term care facilities or home care services available for these patients in Iran, their families, with no prior relevant education who are incapable of catering to the patients' numerous caring needs, have to bear the responsibility of caring for them.^[7]

Caring for patients in a VS may come with many hassles for family caregivers since they require constant nursing and medical care even when they are obviously in a stable condition. Almost all of these patients have endotracheal tubes, nasogastric tubes (NG), or percutaneous endoscopic gastrostomy tubes, and their position must change every 2 h.^[8] Family caregivers of patients in a VS must be able to perform professional care such as suction, tracheostomy care, medical treatment, fluid therapy, nutrition care, wound care, and to change position.^[9] They must constantly care for the patient, make decisions, solve problems, ensure the patient's convenience and provide them with provide them emotional support, and control the drug schedule and medical equipment. They might need to adjust the patient's living environment to improve their immunity and function and access the required medical equipment. They also must learn how to monitor the patient and notice any new symptoms or responses to the treatment.^[10] Thus, the caregivers must be properly trained and prepared for their role.

Literature review

Previous studies have shown that patients' family caregivers are under a lot of stress due to a lack of information about their patient's diseases and the treatment process. Therefore, to reduce psychological reactions, they need to learn more about their family member's disease.^[11,12] In many countries, treatment and patient care is a family-centered process. Since this method increases the information of family caregivers and empowers them for patient care after discharge.^[13,14] However in Iran, the entry of family caregivers into the intensive care unit (ICU) is limited and sometimes prohibited.^[15-17] Therefore, nurses' scientific skills and attitudes play an important role in establishing proper communication and training of family caregivers.^[17] The qualitative study conducted by Goudarzi *et al.* revealed that training of VS family caregivers before the discharge is short and incomplete. Furthermore, any shortages in education negatively affect the caregivers' ability to deliver the required care.^[7] The above-mentioned studies show that the educational challenges of family caregivers are influenced by organizational culture, attitudes, and practices of nurses. Therefore, it needs to be examined in different contexts and cultures. Since the attitude and practice of nurses are influenced by managerial, cultural, and structural factors of organizations and communities.^[18]

Since the number of studies investigating the challenges that family caregivers face while caring for patients in the VS, particularly the challenges concerning learning how to care for these patients at home is limited and given that enlightening care service providers as to these challenges will help the caregivers to provide patients with better care, the present study aims to investigate the educational challenges of family caregivers of patients in the VS so that they are empowered to care for their patient at home.

Materials and Methods

Study design

Qualitative conventional content analysis approach was used for conducting the study. This approach is useful when an existing theory or research literature on a phenomenon is limited. This approach allows researchers to interpret the authenticity and truth of the data subjectively and scientifically.^[19,20]

Setting and participants

The present study was conducted after receiving the required permits from the Mashhad University of Medical Science and presenting them to Zahedan University of Medical Science and hospitals of the two universities with trauma intensive care and neurosurgery departments from August 2020 to September 2021. The

participants included 14 family caregivers of patients in the VS, selected through purposive sampling [Table 1]. The researcher became present at the home care training centers of the hospitals with prior arrangements to access the participants and made arrangements for interviews on the phone after evaluating the documents of the patients hospitalized and discharged in a VS. Furthermore, as all the intensive care departments had assigned the home care training to the home care training centers, the researcher got involved in the training process of new patients in the company of the head of the center. He obtained their phone number to schedule interviews after making their acquaintances. They then agreed to set a time to meet the caregivers at their home after 7–10 days of their discharge.

The inclusion criteria included: (1) Having the experience of at least 7 days’ care for the patient in the VS. (2) Consent for participation in the study, and (3). Being able to interact with the researcher verbally. In addition, the exclusion criteria included. (1) Rejecting the researcher’s request for recording the conversation. (2) Not permitting the researcher to use the collected information for the purposes of the study.

Data collection and analysis

The data were collected through in-depth face-to-face, semi-structured interviews. At first, considering their house’s space quality, the interviews were conducted at one part of the caregivers’ homes that produced the least amount of noise pollution for the patient. After that, the researcher introduced himself and the research team; presented the necessary authorizations; explained the study goals and the necessity of voice recording for data analysis to them; assured them of confidentiality of the collected data and that the data would be analyzed anonymously using coding. The researchers also reassured the caregivers that participating in the study would be voluntary but not obligatory. In the event

that the caregivers agreed to participate in the research, they were presented with informed consent forms to sign. After that, every interview started with a general open question: “Please introduce yourself and outline the condition of your family member.” Following these questions, the main questions on the purposes of the study were posed to them: “Would you please explain the types of education you found necessary to nursing your patient?,” “How did you acquired the skills for taking care of your patient?,” “What were the hassles you went through while learning how to care for your patient?.” The probing questions included: “Will you enlarge on that” or “Please, elaborate it by mentioning one of your personal experiences.”

To enrich the interview even further, the participants were allowed to raise any subjects they personally thought of as important. After every interview, the recorded voices were heard several times. Then, the interviews, the nonverbal field notes on the tone of the caregivers, pauses, and breaks in their speech, and their emphases were captured in word files. The transcripts were reviewed multiple times and copied into MAXQDA2020 software, through which the data were analyzed using Graneheim and Lundman methods (2020). In this method, the content analysis comprises the implementation of the conducted interviews and repeatedly reviewing them to gain an acceptable level of understanding of the collected data, extracting meaningful essences and labeling them as a condensed meaning unit, categorizing them and selecting a title with a higher level of abstraction called codes, sorting them into sub-categories based on their differences and similarities, and assigning a proper title for the created categories, regarded as the main category.^[21] That being said, first of all, the content units, including the transcripts of the interviews and the field notes were repeatedly reviewed to obtain a general understating of them; then, the meaning units

Table 1: Demographic characteristics of participations’ family caregivers

Participants	Sex	Age	Education level	Occupation	Relationship to the patient	Caring duration
Caregiver-1	Male	44	MA, MSc	Employee	Offspring	6 months
Caregiver-2	Female	33	BA, BSC	Housewife	Mother	1 year
Caregiver-3	Male	44	MA, MSc	Employee	Offspring	8 years
Caregiver-4	Female	22	Diploma	Housewife	Offspring	1.5 years
Caregiver-5	Male	42	Diploma	Self-employed	Offspring	15 days
Caregiver-6	Female	52	BA, BSC	Employee	Spouse	25 days
Caregiver-7	Male	42	BA, BSC	Employee	Offspring	25 days
Caregiver-8	Female	40	BA, BSC	Employee	Offspring	35 days
Caregiver-9	Female	40	BA, BSC	Housewife	Offspring	10 days
Caregiver-10	Female	38	BA, BSC	Housewife	Offspring	7 days
Caregiver-11	Male	45	BA, BSC	Employee	Father	40 days
Caregiver-12	Female	30	Middle School Education Degree	Housewife	Offspring	70 days
Caregiver-13	Male	38	Middle School Education Degree	Self-employed	Offspring	25 days
Caregiver-14	Male	44	Associate Degree	Self-employed	Father	33 days

relating to different parts and sections of the data were extracted. After that, the meaning units were labeled with various codes. The obtained codes were compared regarding the differences and similarities multiple times, and thereby similar codes were classified into one category. Moreover, finally, relationships between the sub-categories were determined, and the main themes surfaced as the main category. The interviews continued to the level of data saturation, once the main categories emerged.

Data rigor

The criteria proposed by Lincoln and Guba were employed to evaluate the accuracy and robustness of the qualitative data. The mentioned criteria consisted of credibility, dependability, transferability, and confirmability.^[22] To enhance credibility, the researcher devoted a sufficient amount of time to data collection in this study. Moreover, in-depth interviews with the caregivers of the patients in a VS were conducted. The research team assessed the data to ensure that the formed categories were consistent with the participants' statements. Concerning the cases in which some inconsistencies in opinion were observed, all the viewpoints were captured. The research team reviewed the codes, sub-categories, and categories. Another evaluation was carried out by a group of evaluators outside the research team. This procedure continued to the point of consensus. The participants were also asked to review the data to ascertain the accuracy of the data and the extracted codes and rectifying them, if necessary, after finalizing the codes, categories, and sub-categories. Thus, printed materials including the quotations, codes, sub-categories, and categories were put forward to the participants, and they were asked to announce their opinion on them. Their views were then scrutinized by the research team and the necessary corrections were made. 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 scrutinized and applied according to the findings of the external reviewers until they confirmed the process.

Ethical considerations

The present research plan was approved in the research ethics committee of the Mashhad University of Medical Sciences with the ethics code of IR.MUMS.NURSE.REC.1399.032. The nursing faculty of Mashhad University of Medical Sciences provided a letter of introduction which were given to the family caregivers

and hospitals. Moreover, the study permissions were given to the family caregivers to ensure them of the study process. Next, members of the research team, and study aims were explained and caregivers were ensured of the privacy of the information and they freely decided on participating in the study. Participants were given informed consent forms for signing. Moreover, a 3-h educational session was held after each interview and they could freely contact the main researcher to seek advice on caregiving at home.

Results

Participants of this study included 14 family caregivers of patients with VS, including 7 men (50%) and 7 women (50%). The mean age of participants was 39.5 ± 3.5 years [Table 1].

Data analysis revealed three main categories including "Unmet educational needs," "confused caregiver," and "searching for practical knowledge" described the educational challenges of family caregivers of patients with VS for taking care of their patients at home which included 19 subcategories [Table 2].

Unmet educational needs

Unmet educational needs consist of nonconsideration of the trainee's conditions and characteristics, improper educational method, and content, neglecting educational needs of the caregivers, defects in the education of technical care skills, defects in the supplying and handling caregiving equipment, improper education time for the desired skill, and nondetermination of the course of treatment after discharge and shows that the family caregivers are not sufficiently educated by the health care professionals for taking care of their patient at home.

Nonconsideration of the trainee's conditions and characteristics

For appropriate learning of Nursing educational plans should be adjusted based on the psychological state of caregivers and provided in proper times, and based on the educational level of the caregivers in simple words. Although, participants' experiences showed that they were shocked when they were informed that their patient is in the VS and should be discharged and taken care at home. Not considering the psychological state and learning ability of the caregivers, nurses proved some individual educations with no educational plan and in technical language which is not understood by many caregivers.

In this regard, family caregiver 8 stated that "then, I had a very bad feeling for the patient's condition and did not catch any of the points."

Table 2: Main categories and sub-categories of the educational challenges of family caregivers of patients in vegetative state on getting prepared for patient care at home

Main categories	Sub-categories
Unmet educational needs	Nonconsideration of the trainee's conditions and characteristics
	Improper educational method and content
	Neglecting educational needs of the caregivers
	Defects in the education of technical care skills
	Defects in the supplying and handling caregiving equipment
	Improper education time for the desired skill
	Nondetermination of the course of treatment after discharge
confused caregiver	Lack of caring knowledge
	Lack of skill
	Terrifying unawareness
	Contradiction between the provided caregiving information
	Uncertain caregiving
Searching for practical knowledge	Searching for opportunities for learning necessary caregiving knowledge
	Searching for practical information on working with caregiving equipment
	Trying to improve learning with practical training
	Commitment to participating in care
	Searching for caregiving information in reliable resources
	The obligation of the continuity of caregiving training
	Gradual gain of caregiving ability

Furthermore, family caregiver 13 stated "I don't have proper literacy, I entered the ward, they told me some points, I did not catch at all, as if they are talking to their peers. If they are gonna teach me something, it should be at the level of my understanding."

Improper educational method and content

Patient caregiving at home requires practical skills, while the participants' experience showed that they were mostly theoretically trained which is forgotten soon. Even, printed materials were not provided for the participants so that they can recall the information.

Family caregiver 7 explained that "all educations were theoretical, we are not computers to learn all of them, they should provide a leaflet and explain about the patients and their needs. It is surprising that they have sent such patients home, with no written protocol for family caregivers."

Neglecting educational needs of the caregivers

Participants of the study stated that the educations were provided without considering their educational needs for at-home caregiving. In this regard, family caregiver 9 stated that "we thought that we need to know about

some things, but nurses did not teach us. When we asked, instead of answering, they acted in a way that we were ashamed of our question."

Defects in the education of technical care skills

Family caregivers stated that their patients were discharged with brief education of some skills such as suctioning and gavage, and they realized that they are not sufficiently skilled when they started taking care of their patients at home.

In this regard, family caregiver 10 stated that "He has trouble passing stools after hospital discharge, but no one told us what to do for it." On the other hand, the educations have been insufficient in some cases. For example, family caregiver 14 stated that "they thought me how to suction, though they did not tell me how far I should enter the catheter-to the end, to the half-should I turn it or insert it directly?"

Defects in the supplying and handling caregiving equipment

Various pieces of equipment, including suction device, oxygen generator, pulse oximeter, and oxygen capsule and manometer are required for taking care of patients in the VS at home. Family caregivers should learn how to work with these devices. Based on the statements of the participants of this study, they were minimally trained for working with these devices; in some cases, only they were merely educated by the sellers of the devices. Moreover, these devices require accessories. For example, the suction device requires nelaton catheter and finger tube, for which the family caregivers should be trained. Some participants stated that they were given a list of devices before discharge, though they found some missing devices, when it was needed to use the devices at home.

In this regard, caregiver 10 stated that "I was given a list of devices, and I bought them. When, our patient needed to be suctioned, we found that nelaton catheter was not on the list; unfortunately, this indifference might have led to suffocation of our patient."

Improper education time for the desired skill

Family caregivers should be highly skilled for numerous needs of their patients in the VS. Thus, they need a proper educational course for learning these skills, while participants of this study stated that their educational course was very short and they could not learn the required skills for taking care of their patients at home. They said that they needed a longer and more specialized course.

Family caregiver 7 stated that "they only thought for 20 min. Complicated cares such as gavage, suction,

changing position, drugs, and oxygen therapy may not be learned in this short course.”

Nondetermination of the course of treatment after discharge

Determining the course of treatment after hospital discharge is an essential strategy which helps family caregivers on the prognosis of their patients, required duration for care, treatment, and the time of rehabilitative treatments. Although, all participants of this study stated that they were not informed of the treatment course after hospital discharge, and they did not know when to start rehabilitative treatments and how long should they continue the treatments.

In this regard, family caregiver 9 stated “they discharged my patient without telling me which treatments should I continue at home, when should I take my patient for physiotherapy for best outcomes.”

Confused caregiver

Confused caregiver includes lack of caring knowledge, unawareness of the outcome of the care, lack of clinical skill, contradiction between the provided caregiving information provided by different sources, and caregiver’s inability to distinguish between right and wrong cares. This category includes lack of caring knowledge, lack of skill, terrifying unawareness, contradiction between the provided caregiving information, and uncertain caregiving.

Lack of caring knowledge

Due to the extended needs of patients in the VS, caregivers are not able to learn adequate information in all aspects of patient care. Family caregiver 6 stated in this regard “Our problem was that we didn’t know what to do. We did not know what to do if he got fever, or if he had a problem passing stool, or how should his head be positioned? Upward? Downward? How should we evaluate him? Which catheter is suitable? Should we use urinary catheter or condom sheath? how should we take him to the bath or restroom? May he be taken to the bath or not?”

Lack of skill

Some advanced cares such as taking care of tracheostomy, suction, changing the urinary catheter, gavage, working with oxygen generator device and suction device were the responsibilities of the family caregivers. They stated that they are not sufficiently skilled in many cases. Family caregiver 4 stated that “they just told me how to turn the oxygen generator device on and off. Now, when I turn it on, it starts beeping and does not supply oxygen. I am not a technical person and I don’t how to deal with this problem.”

Terrifying unawareness

All family caregivers stated that they have experienced terrifying unawareness at least in one period of time when they were taking care of their patient, since they did not weather their care is beneficial or hazardous for the patients. Their biggest concerns belonged to dealing with urinary catheter and NG.

In this regard, family caregiver 9 stated “our biggest fear is that we may harm our patients when doing something. The 1st day, we could not even get close to the patient due to our fear of damaging something.”

Contradiction between the provided caregiving information

Family caregivers were afraid of taking care of patients due to a lack of knowledge and skill; thus, they tried to learn skills through asking nurses and physicians. Yet, contradiction between the provided information made them more confused. Variety of therapeutic methods and different ideas about the therapeutic method such as suctioning or bedsore care made the family caregivers doubtful when taking care of their patients.

Family caregiver 5 stated that “Only 50% of the educations of the nurses and physicians were similar. One person says something, the other one does not confirm it. For example, regarding suctioning, one nurse said that do not enter the nelaton catheter more than 10 cm, the other one said that you can continue up to two-thirds of the catheter. Regarding bedsore, one says that only apply ointment, the other one says that it should be dressed. I am surprised why they have different recommendations. Should not medical principles be trained the same?”

Uncertain caregiving

The complexities of patient care, providing different information by physicians and nurses to the family caregivers, and the inability of them in distinguishing right and wrong information led the family caregivers to think they are doing the care wrongly. Moreover, they considered the information and health services provided by the professional health-care providers outside the hospital was not reliable.

Searching for practical knowledge

Statements of all participants showed that they were looking for information and improving their skills during hospitalization and after discharge through various accessible methods since they felt the need of improving their knowledge and skills for taking care of their patients at home.

Searching for opportunities for learning necessary caregiving knowledge

Due to the limitations of the presence of patients’ companions in the ICUs in Iran, entering the ward

and effective learning occurs with difficulty. Thus, most participants announced that they tried different ways (influential relatives or insisting the nurses) to enter the ward and effectively learn some cares including suction, respiratory physiotherapy, gavage, bed sore prevention methods, diaper exchange, and urinary bag emptying. Yet, all of them considered limitation of the presence of patients' companions in the ICU as a big barrier for learning patient care.

In this regard, family caregiver 4 stated that "Hospital's charity has introduced me to nurses and physicians of the ICU. Thus, contrary to routine conditions, I was allowed to enter the ward 2-3 h a day for a week. In these hours, nurses trained me how to suction, how to use oxygen generator, how to work with the pulse oximeter."

Searching for practical information on working with caregiving equipment

One of the most important skills in taking care of patients in VS is learning how to work with medical devices, which are complex and even newcomer nurses have difficulty working with them. Family caregivers stated that working with medical devices was among the difficult steps of taking care of their patients and they asked device sellers and ICU nurses for effective educations.

Trying to improve learning with practical training and commitment to participating in care

Trying to improve learning with practical training and commitment to participating in care are two complementary subcategories. Family caregivers stated that when they realized that the long-term VS of their patient, they tried to participate in patient care; though, they were only theoretically educated in the ICU, due to the limitation of the presence of patients' companions, and they were rarely allowed to take part in patient care. In some cases, as they insisted to participate in patient care, they were allowed to perform some parts of patient care, including gavage and suctioning which improved their self-confidence and they could provide appropriate care after patient discharge. Moreover, practical training and participation in patient care improved in general wards of the hospital, where nurses better cooperated with them to take part in patient care.

Family caregiver 10 stated that "10 days before discharge, our patient was transferred from ICU to neurology ward 3 where nurses cooperated with us and let us set the serum, give medications, prepare and give patient gavage, and move the patient and they just observed and guided us. This helped us learn how to take care of the patient."

Searching for caregiving information in reliable resources

Some caregivers who had a physician or nurse among their relatives consulted nurses and physicians on their patient's problems and necessary measures. Lettered caregivers performed Internet search for their problems and acted accordingly. Moreover, family caregivers of patients who were directly discharged from ICU were not able to take care of their patients at home. Thus, they paid out-of-pocket and had a nurse teach them the patient care skills.

Family caregiver 1 stated in this regard that "our patient did not have defecation for some days. I asked a relative physician and he prescribed Lactulose syrup, then I searched on the internet and found out that apple juice gavage may be used for constipation. This helped our patient and he passed stool."

The obligation of the continuity of caregiving training

A considerable amount of the educations was forgotten in the course of time. To prevent it, some family caregivers recorded the nurses' education and reviewed it. Moreover, all family caregivers stated that they better felt the need for education when they took care of the patient at home, and they were more ready to learn the skills since their psychological mood was more stable. At the same time, they are supported by the Health care system and no education or supervision is available for family caregivers.

In this regard, family caregiver 4 stated that "the left us alone and there is no support, while it is not a difficult job, and even does not need in-person visits, only they need to have a nurse whom we can contact using video call, to evaluate the condition of our patient and help us how to take care of the patient."

Gradual gain of caregiving ability

In the course of time and by learning information from different sources, the majority of the family caregivers learned to control their fear and take appropriate care of the patient. Family caregiver 3 stated that "in the beginning, I was afraid doing invasive procedures such as suction, since I see that patient suffers and the color of his face changes. Then, I realized that it is necessary for his health and he might get suffocated if I don't do that. I studied and asked about the procedure, I read its benefits and complications, and realized that it is not that awful, I performed it a few times and learned how to do it easily and accurately."

Discussion

Data analysis in the present study revealed that "unmet educational needs," "confused caregiver,"

and “searching for practical knowledge” describe the educational challenges of the family caregivers at home. Results of the present study showed that the provided education by the health-care provider does not provide sufficient knowledge and skills for family caregivers due to improper time and method.

The following factors were considered as the major causes of failure of these educations by the participants: Not being allowed to enter wards and nonparticipation in patient care, limited time of nurses for caregiver education, inattention of nurses to the educational needs of the caregivers, limitation in assigning patient care to family caregivers in the hospital, providing mere theoretical education and not providing postdischarge educations. Lack of knowledge and skills needed to take care of the patient led to confusion of caregivers and cares are given in an aura of fear and uncertainty. To compensate for this educational deficit, caregivers tried to learn the required knowledge from different sources such as relative physicians and nurses and Internet searches. Eventually, some caregivers obtained enough skills and self-confidence for taking care of the patient by gaining experience over time.

Consistent with the results of this study, a study conducted by Goudarzi *et al.* showed that care education to family caregivers of patients in VS was provided in a very short time leading to the inability of family caregivers to perform the specialized care for their patients properly and had to seek education from various sources to improve their knowledge and skills.^[7] Consistent with the results of the present study, Hetland *et al.* also considered the impossibility of the presence of family caregivers during the patient’s stay in the ICU and their nonparticipation in patient care among the main reasons for the short training time of family caregivers.^[23] The use of the closed ICU approach in the medical system of the hospitals in Iran has made it impossible that nurses use the benefits of the presence and participation of family caregivers in taking care of their patients during their stay in the ward, to train the family caregivers and supervise their learning. Thus, they only have a limited time to teach the necessary care to the caregivers when the patient is discharged by the physician, due to the limited time, regardless of their educational needs and the condition of the patients.

Supporters of using closed ICU believe that using this method will prevent the increased risk of infections dissemination. While studies over the past decade have demonstrated that adopting an open ICU policy does not increase the risk of infection. On the other hand, applying this policy will reduce cardiovascular complications, delirium, anxiety, and stress levels of hormonal markers and improve the recovery of the

patients.^[24,25] On the other hand, caregivers of patients hospitalized in closed ICUs suffer from distance from the patient and show symptoms of anxiety, depression, and posttraumatic stress. These symptoms will also worsen if family caregivers are not involved in patient care.^[23,26] The present study also demonstrated that family caregivers cannot learn the provided education due to the psychological stress of hospitalization of their patient in the ICU. Although in cases where family caregivers were involved in patient care, the caregivers’ knowledge, skills, and self-confidence in taking care of the patient at home were enhanced. Results of this study and previous studies reveal that for improving learning, and the skills of family caregivers, and reducing the physical complications of family caregivers and patients, it is suggested to review the policy of closed ICUs in Iran. Since involving family caregivers in patient care during their hospitalization provides a great opportunity for caring skills training, and caregivers will also more close to the patient, which will reduce their anxiety since they have more time to accept the patient’s condition. Sadeghi *et al.*’s study demonstrated that engaging family members of ICU admitted patients in programs of patient care can effectively reduce the anxiety of family members and improve the process of patient care.^[27] Other studies have demonstrated that the participation of family caregivers in daily visits and patient care in the ICU improves information, provide opportunities for asking their questions, and improve their educational status, reduce their anxiety, improve the communication between family caregivers and treatment team, and increase caregiver trust in the treatment team; moreover, caregivers will feel more comfortable and familiar with the caring needs of the patient after discharge.^[28-30]

This study revealed that the family caregivers of patients in VS felt the need for more educational support after hospital discharge since new symptoms and problems have occurred to the patient that the caregivers had not encountered before and had not received training about. On the other hand, ambulances were required for transporting patients for visits by health care providers, which could not be provided frequently by free public emergency centers, and family caregivers could not afford private ambulances. Also, visiting a nurse and a doctor at home is expensive, and caregivers stated that they could not afford the high costs. In many cases, family caregivers stated that home care nursing centers sent nonspecialists to take care of the patient who did not have the academic literacy and ability to care for the patient. Therefore, it is necessary that the national health care system consider appropriate strategies for the educational support of family caregivers at home so that they can take care of their patients independently without paying high costs.

Consistent with the results of the present study, a systematic review by Mardom *et al.* on studies conducted in Iran, showed that family caregivers of patients with stroke also face many challenges, including lack of knowledge and skills for taking care of patients, and experienced a sense of hopelessness after discharge. Therefore, they needed to be supported from various emotional, informational, caring, educational and equipment aspects.^[31] Results of the present study and other studies confirmed the deficiency of education in discharge and the need to continue the training of family caregivers, it is necessary that the Ministry of Health and Medical Education of Iran design and implement an appropriate structure with the cooperation of legislative authorities to fill the gap between the treatment system and the care of patients at home by family caregivers.

For many years, the Ministry of Health and Medical Education has been training community health nurses at the master's level, but unfortunately these the expertise of these nurses is not used and these expert nurses are not employed. Thus, it is recommended to define their duties and employ these nurses in the home care centers of hospitals and use their expertise in providing continuous educational support to patients with chronic diseases, family caregivers as well as monitoring the health status of patients after discharge to improve their situation at home so that community health is improved and the cost of home care is reduced for family caregivers.

Limitation

One of the limitations of the present study was the fear of family caregivers about COVID-19 and the unwillingness to participate in interviews. As a result, a number of interviews were canceled after coordination. The second limitation of the study was the expectation of the participants to respond to the problems of the health-care system by the researcher, which sometimes disrupted the interview process. The third limitation of the study was the reluctance of participants to review the analyzed interview transcripts. Therefore, while a lot of effort has been taken, some concepts may not be in line with all participants' experiences.

Conclusion

Results of the present study showed that hospital policies and treatment plans of patients in VS in ICUs are not based on the educating and improving the skills of family caregivers for home-care. The provided educational plans are not sufficient for empowering the family caregivers for taking care of their patients at home. On the other hand, lack of long-term caring centers or home-visit or care by nurses for patients in VS by Iranian health care system, obligated family caregivers to take care of their patients with minimal information and skills.

Despite all the mentioned problems, due to cultural and religious background of Iranian families and society, family caregivers were committed to taking care of their patients and tried to learn the required information from any accessible source. Thus, proper planning and policy making by the Health care system for engaging family caregivers in patient care during hospitalization, and continuation of their educational support after patient discharge, not only improves the quality of home-care of patients and reduced family costs, but also reduces the care and treatment burden of the health care system due to reduced re-hospitalization of patients in VS.

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Conflicts of interest

There are no conflicts of interest.

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