

## Information Seeking Experiences of Family Caregivers of Patients with Persistent Vegetative State: A Qualitative Study

### Abstract

**Background:** Providing care for patients in Persistent Vegetative State (PVS) by family caregivers without enough training and knowledge may be problematic both for the patients and for the caregivers. Therefore, the present study tries to explain the experiences of family caregivers of patients with PVS of seeking information needed to provide adequate care. **Materials and Methods:** Twenty two participants, including 17 family caregivers and 5 professional caregivers were enrolled by purposive sampling into this qualitative content analysis study, carried out between 2013 and 2015. Unstructured interviews and field notes were used to gather the data. Data collection was stopped when data saturation was achieved. Data analysis was performed by content analysis based on Graneheim and Lundman's approach. **Results:** As a result of the analysis of the collected data a main theme emerged labeled as "Seeking constructive education" with three categories including "Neglected requisite education," "Greedy search for useful education" and "Dynamic independence in care." **Conclusions:** In this study, information seeking by family caregivers of patients with PVS was constructive. Family caregivers insistently sought needed information from various sources. Ultimately, they found these insistent efforts beneficial and fruitful, because their efforts made them independent in providing care for their patients.

**Keywords:** Caregivers, family, home nursing, information seeking behavior, nursing, persistent vegetative state

### Introduction

Having achieved stabilized conditions, patients with disorders of consciousness are transferred to post-acute care units, if their level of consciousness improves. But, if they progress to persistent vegetative states (PVS), the decision about where to provide care for them depends on the available resources. They will usually be transferred to residential care facilities, if available. But in many countries, care of patients continues at home.<sup>[1]</sup> In Iranian families, the special importance of members of the household and family commitment to members are the factors that cause families to consider themselves obliged to offer the best care to sick family members.<sup>[2]</sup> The patients with PVS need continuous and extensive care,<sup>[3,4]</sup> including ensuring the airways are open, maintaining body fluid balance, feeding, skin health and corneal care, urinary and fecal elimination, and providing sensory stimulations.<sup>[4]</sup> Many of the mentioned services require professional

knowledge and skills, such that if family caregivers provide them, problems may arise both for the patients and caregivers. Moreover, families and professionals have differing attitudes and expectations about the recovery of these patients that can lead to conflicts among them.<sup>[5]</sup> These issues might seriously impact the families, which may put them in need of various kinds of support, particularly educational support.<sup>[6]</sup>

Nowadays, homecare has received increasing attention and emphasis. The reason for this emphasis is the high prevalence rates of chronic diseases, such as vegetative states.<sup>[7]</sup> There are striking differences in the prevalence of patients with PVS in different geographical areas, such that, the prevalence of patients with PVS has been reported as 3.36 in Australia and 0.2 in the Netherlands per 100,000. Nevertheless, there are no data about patients with PVS in Iran. The variations in the statistical data can be attributed to cultural

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and legal factors, especially those related to end-of-life issues. Furthermore, medical advances have increased the survival rates of patients with PVS, such that after the first year, the life expectancy of them is 10.5 years on average, and after 4 years, it is 12.2 years.<sup>[8]</sup> In fact, the increased survival rates of these patients duplicates the importance of providing homecare to them because they need long-term care that cannot possibly be offered by hospitals because of the various kinds of limitations hospitals facilities. Naturally, family caregivers of patients with PVS have to face some challenges and barriers. One of these barriers is the complexity of providing care to patients that originates from the specific needs and functional limitations of each individual patient.<sup>[9]</sup> Inadequate knowledge about how to monitor and provide care to patients is another important obstacle.<sup>[7]</sup> Therefore, the implementation of a discharge program emphasizing the provision of proper education and training to patients' families is of great importance. Access to an educationally appropriate discharge program ensure that continuing care can be provided at home.<sup>[10]</sup> Indeed, an educational discharge program can resolve many of the post-discharge problems in the care of such patients.<sup>[11]</sup> On the one hand, a suitable educational program can reduce the number of re-hospitalizations and the frequency of transfers of patients with PVS between home and hospital.<sup>[12]</sup> On the other hand, a satisfactory educational program can improve the readiness of family caregivers to provide care, and subsequently reduce the patient's re-admissions. Finally, it will promote the quality of life and satisfaction of patients and their families<sup>[11,12]</sup> by making them autonomous in the long-term care of the patient.<sup>[13]</sup>

It's worthwhile to mention that the most serious need of family caregivers at home is receiving education and information related to the care of their patients.<sup>[14-17]</sup> Different studies on family caregivers' needs have also revealed that the most important expectation family caregivers have is receiving educational support from professional resources.<sup>[18,19]</sup> However, other studies have shown that their educational needs are not usually met by professional sources.<sup>[19,20]</sup> Although the accuracy and validity of information sought by family caregivers and patients with chronic diseases forms the basis of making proper decisions for providing care, information seeking behaviors are an effective and crucial factor in this regard.<sup>[21]</sup> In studying the information seeking behaviors of family caregivers and patients with chronic diseases, it has been determined that these behaviors are performed either passively or actively to acquire information about the diet, exercise, complications, and medications from healthcare professionals or the Internet as the main sources.<sup>[22]</sup> However it should be mentioned that these behaviors are also affected by factors like the duration of affliction, lifestyle, and socioeconomic determinants.<sup>[23]</sup>

By taking into account the fact that it is crucial for family caregivers of patients with PVS to have access to the required

information, this study aimed to "explain the experiences of family caregivers of patients with PVS of information seeking" using content analysis as a qualitative approach for a couple of reasons. On the one hand, socioeconomic factors have significant effects on information seeking behaviors and qualitative studies are valuable instruments in discovering and exploring complex phenomena in natural settings.<sup>[24,25]</sup> On the other hand, in the literature review, it was revealed that the majority of studies on family caregivers of patients with PVS were related to issues like their experiences of providing care for these patients,<sup>[26]</sup> their perceptions of social supports,<sup>[27]</sup> making decision about their patients<sup>[28]</sup> and their psychiatric health under the circumstances.<sup>[29]</sup> Additionally, authors could not find any studies about the phenomenon of information seeking by family caregivers of patients with PVS. Therefore, since qualitative studies attempt at the discovery, description and exploration of unknown phenomena,<sup>[24,25]</sup> this study was conducted using content analysis as a qualitative approach.

## Materials and Methods

This qualitative content analysis study (as part of a larger project) was conducted between 2013 and 2015. In this study, in-depth interviews was used for data collection. Furthermore, data analyzing was carried out by content analysis method. The participants were enrolled into the study by purposive sampling from among the caregivers of patients with PVS who had at least 1-month experience of providing care for their patients at home. Due to lack of care or support centers for these patients and also because their diagnoses had not been recorded in their medical records, they were found by inquiries from hospital staff, especially those providing homecare services to these patients. The sampling was carried out in Khuzestan, Lorestan, and Tehran Provinces of Iran. The participants were 22 caregivers of patients with PVS, including 17 family caregivers and 5 professional caregivers. At first, family caregivers were enrolled into the study. However, as the study progressed, it was revealed that some types of care were provided by professional caregivers, so some of them were interviewed at their workplaces after obtaining their consent. Characteristics of the participants are shown in Table 1.

In this study, unstructured face-to-face interviews and field notes were used to collect the data. The duration of the interviews was between 41 and 122 min (with an average of 69 min). It is worth noting that there was a complimentary 15 min interview. In interviewing the caregivers, the open-ended question which was asked from the participants was "Would you please explain to me your experiences with providing care for Mr/Ms ...". As the interviews went on and as they mentioned their attempts to learn about the provision of care, the focus of the interviews shifted to this issue. In addition, during interviews, some probing questions like "Is there any instance in this regard? What did you feel when that happened? What do you do when you feel

so?” were asked based on the participants’ statements to deepen the interviews. The interviews were recorded with the permission of the participants. Simultaneously, some field notes about the care that family caregivers provided during interviews and their interactions with their patients were taken. Since care for patients with PVS is provided in a family-focused way at home, interviews with their family caregivers were carried out at home. This made the observation of the patients and also some of the cares they received possible in a real field investigation. Moreover, interviews with professional caregivers were carried out at their workplaces for their convenience. Data collection and analysis were performed during the same period. Data gathering continued until no new data were collected.

Data analysis was performed in accordance with the stages of Graneheim and Lundman’s approach. The analysis units included 22 interviews and 22 filed notes. The transcription of interviews and field notes were read repeatedly in order to understand the gist. Then, meaning units related to data components and sections were summarized. Next, meaning units were condensed, abstracted, and labeled using suitable codes. Codes derived from constant comparisons were further compared to find similarities and differences, so that similar codes could be placed in subcategories and then categories to finally extract the themes. In this study, in order to ensure the accuracy and reliability of qualitative data and the scientific precision of the study, the four evaluative criteria of Lincoln and Guba including credibility, dependability, conformability, and transferability were taken into account.<sup>[30]</sup> In order to increase the data reliability, the researchers were engaged with the data for more than a year and half. Colleagues experienced in qualitative research were asked to review the interview transcriptions and the extracted codes and categories. In case of disagreements, discussions and clarifications were held to reach full consensus. The texts of encoded interviews were also sent to some of the participants to assess and confirm the codes. Finally, to ensure the possibility of verification and auditability, the research process was carefully recorded and reported. Long-term engagement with the data, triangulating in data collection, constant comparative analysis and the reassessment of the encoded texts by three participants were the methods used to increase the credibility of the study. Peer review and evidence-based writing (by quoting the participants) were used to ensure dependability. To increase the conformability of the study bracketing, member checks and experts’ panels were put to use. Maximum variation in the selection of the participants and the clear and transparent reporting of the data and results which make auditability possible can guarantee the transferability of the study results.

**Ethical considerations**

This study was approved by The Research Council of the Ahvaz Jundishapour University of Medical Sciences (NO.

AJUMS. REC. 1392, 202). Prior to enrollment in the study, enough explanations were provided to the participants about the purpose and method of the study and written informed consents were taken from them. The participants were also assured about the confidentiality of the data and that they could leave the study whenever they wished.

**Results**

The analysis of the collected data eventuated in a main theme labeled as “Seeking constructive education” with three categories and eight subcategories as presented in Table 2.

**Neglected requisite education**

This category with two subcategories of “frightening unawareness” and “Military hospital training “ showed that the fear caused by unawareness and inadequacy of the discharge training provided to family caregivers made them intensely perceive the need for further education and information.

**Table 1: Characteristics of participants**

Variables	Values
Family caregivers	
Age* (year)	33.29 (10.38) (Range: 21-58)
Gender**	
Female	11 (64.71)
Male	6 (35.29)
Relational situation	
Father	1
Mother	2
Sister	3
Brother	3
Spouse	3
Offspring	5
Caring duration*(month)	20.91 (26.99) (Range: 1.5-108)
Professional caregivers	
Age* (year)	33.4 (8.81)
Gender	
Female	2 (40)
Male	3 (60)
Working experiences* (year)	10.4 (9.53) (Range: 1-22)

\*Mean (SD). \*\*N(%)

**Table 2: The Formation of Subcategories, Categories and Theme**

Theme	Categories	Subcategories
Seeking constructive education	Neglected requisite education	Frightening unawareness
		Military hospital training
	Greedy search for useful education	Effort for learning
		Getting education from various sources
		Effective education
	Dynamic independence in care	Initial multiple-sources-dependent care
		Gradual independent care
		Constant dependent care

### **Frightening unawareness**

The family caregivers did not have adequate knowledge about the methods of providing care to patients in PVS in the early days after the discharge, and this made them worried and stressed. One of the participants stated in this regard: *"Suctioning was a very unusual thing to us, feeding by gavage was so hard. At first, we were very scared about everything, especially suctioning. Removing the tracheal tube was very difficult for us. We did not know how to do it ourselves, we were scared something might happen."* (Participant5 (P5), Family Caregiver (FC)).

According to a professional caregiver, the fear caused by lack of unawareness even led some families to refuse to take the patients home from the hospital. He said: *"The patient had been discharged more than a month ago, but his family caregiver said: 'I will not take the patient home because I'm afraid of suctioning, I do not know how to do it.' They do not take the patients home because they are scared of them."* (P18, Professional Caregiver (PC)).

### **Military hospital training**

The special condition of patients with PVS in terms of multiple care needs and also the lack of awareness of family caregivers about the types of care such patients need necessitate that them receive comprehensive training from healthcare professionals at hospital. Contrary to this, they claimed that they had received very brief trainings. One of the respondents commented in this respect: *"They did not teach me much things in the hospital. They just taught me how to feed by gavage, and when the patient was to be discharged, they taught me how to perform suctioning only once...."* (P12, FC).

Another caregiver confirmed this by talking about lack of sufficient training despite its crucial role and necessity. One of the participants noted in this regard: *"The family did not have any medical information, whenever the patient underwent some changes, the whole family got nervous. The hospital staff should provide enough explanations about the patient's condition at discharge, and clearly explain what needs to be done."* (P4, FC).

### **Greedy search for useful education**

This category was derived from three subcategories including the "effort for learning," "getting education from various sources," and "effective education". In other words, family caregivers started to search for information from diverse resources in order to learn the care process.

#### **Effort for learning**

Family caregivers made extensive attempts to learn the types of care as a result of their need for education. A family caregiver described his efforts this way: *"I ask questions from everyone at the hospital and gather information to use them for my patient at home."* (P6, FC).

One of the professional caregivers also claimed: *"Most family caregivers prefer to provide care to their patients themselves, so they try to learn what they can do."* (P11, PC).

#### **Getting education from various sources**

Family caregivers took advantage of various available sources including healthcare workers and other families in the same circumstances when they were trying to increase their knowledge.

Healthcare workers as an education sources: Family caregivers learned providing care from different healthcare workers such as hospital nurses, professional home caregivers, nurses among family members and relatives, or others. But based on participants' statements, they received the most education from professional home caregivers.

One of the participants stated in this respect: *"The nurse who came for homecare taught me everything. He taught me how to change the wound dressing, how to change his position, how to make his food and how to feed him. In general, he taught me what to do and how to do it."* (P4, FC).

A professional home caregiver also stated: *"I taught him whatever he needed. Bathing, feeding by gavage, suctioning, changing position, dressing the wound, preventing bedsores and, in general, all necessary things"* (P13, PC).

Peer families as education sources: In a limited number of cases, family caregivers consulted their peers to get the needed information. One of the respondents commented in this respect: *"At the hospital, the mother of the patient in the near to us helped me a lot. She taught me how to change the diapers, how to bath my patient, and how to feed him."* (P8, FC).

#### **Effective education**

On the one hand, family caregivers stated that their fears and anxieties decreased as a result of receiving education from the mentioned sources. One of the participants mentioned in this regard: *"The first days were very stressful, and I used to call the homecare nurse to come and provide the care. He taught me a lot of things, then my fear and stress were gone."* (P12, FC).

On the other hand, they asserted the educations they received could be used in practice and considered applicable and beneficial. In this regard, one of the respondents stated: *"Every other day, we took him for occupational therapy. The occupational therapist taught me the exercises and he emphasized that the exercises should be performed more than once a day. I always made the patient do the exercises. Their training was very helpful to me."* (P8, FC).

In addition, family caregivers were satisfied with the training they received from professional caregivers. In this respect, one of the participants said: *"The nurse we hired for the patient was really fair, he taught me everything."*

*I owe what I know to the nurse. God bless him.” (P4, FC).* Indeed, they found the educations they had received effective in care process of their patients.

### Dynamic independence in care

This category was extracted from three subcategories of “initial multiple-sources-dependent care,” “gradual independent care,” and “constant dependent care.” In other words, family caregivers were initially dependent on professional caregivers, but they gradually became more independent in providing care by receiving instructions and learning all types of care.

#### Initial multiple-sources-dependent care

At the beginning of care patients at home, most family caregivers were dependent on professional healthcare workers to provide different types of care, such as inserting urinary and gastric catheters, dressing wounds, suctioning secretions, and administering drugs. Most of them were supported by paid home nurses at first. One of the participants mentioned in this regard: *“He needs to use Foley catheter for urination. At the beginning, the nurse used to come and change it. He also had a feeding tube and the nurse used to change it too.” (P15, FC).*

Some families also received help from nurses or physicians from among their relatives and acquaintances. Two participants stated in this regard: *“My sister is a nurse. At the beginning, she did the suctioning and performed the venipuncture for serum infusion.” (P1, FC).*

*“Our cousin is an operating room technician, three days ago, he came to inject his drugs and serum... We also sometimes call a physician to come and change his nasal gastric tube, but now we carry out most of the other care types ourselves.” (P2, FC).*

#### Gradual independent care

Over time, family caregivers gradually learned more about patients' cares and provided the care more independently. Two family caregivers commented in this respect: *“In the first year, the nurse used to come home. He taught me how to perform care, but I have been carrying out all types of care by myself for three years.” (P17, FC).*

*“Nurses who came to our house for inserting his urinary catheter or gastric tube, or injecting his drugs, taught us how to do these, so I learned and performed them myself.” (P16, FC).*

A homecare nurse said: *“It's about two months that I've not gone their home. In fact, they have learned how to insert the urinary catheter or the gastric tube for their patient.” (P19, PC).*

#### Constant dependent care

In a few cases, despite the passage of a long period of time from the beginning of the homecare, family caregivers continued to ask for help from professional caregivers for

some types of care, especially for dressing bedsores. One of the participants mentioned in this regard *“In the last days, he had a bedsore. Every day we used to call the nurse to come and change his dressing. The nurse taught us, but I was afraid because I had heard that the bedsores might be very deep.” (P14, FC).*

## Discussion

In the present study, under the category of “Neglected requisite education,” the findings indicated that worrisome unawareness about the provision of care, on the one hand, and inadequate hospital training at discharge, on the other hand, led family caregivers of patients with PVS to perceive the need for education and to focus on it. Since caregivers who take care of patients with chronic illnesses have many educational needs, lack of training worries and stresses them, thus increasing the risks of physical and mental health problems.<sup>[31]</sup>

In the care process of patients with various chronic diseases at home, acquiring information and knowledge is one of the main needs of family caregivers and patients. In some studies like those of Abdoli *et al.* (2011) and Pashae *et al.* (2010), patients and their families mentioned that acquiring adequate information was essential for managing the conditions.<sup>[32,33]</sup> They also acknowledged that lack of awareness about the conditions led to fear, stress, and inability to cope with the situation adequately.<sup>[32]</sup> However, receiving education and training reduced their stress levels.<sup>[33]</sup> It should be mentioned that among the essential needs perceived by patients' families in the Intensive Care Unit (ICU) whose patients mostly suffer from LOC disorders, the need to acquire information is of great importance.<sup>[4]</sup> The need to get information is even more important for caregivers of patients with PVS, because even professional caregivers consider PVS a special condition, the management of which requires training.<sup>[34]</sup> In this regard, in a study by Fedorka *et al.* (2014), nurses stated that they felt like novitiates without any knowledge when they were providing care for women with PVS who had given birth to live children. In addition, this lack of adequate knowledge made them anxious and angry and they acutely felt the need for training.<sup>[35]</sup> Various studies on unresponsiveness patients and patients with PVS have shown that their caregivers considered training as their most important need because of the fear and anxiety originating from unawareness.<sup>[36,37]</sup>

In the present study, another reason which was mentioned by participants for their need for education was that they did not consider the hospital training as adequate. In line with the present study, a study by Shabani *et al.* (2018), showed that participants perceived the discharge training to be inadequate in different dimensions such as incomprehensiveness of the content, the inadequate time allotted to it, inappropriate timing, unfavorable space and ineffective teaching methods.<sup>[38]</sup> Often, patients and their

families expect healthcare workers to support them in all aspects like providing information at discharge, but often do not consider the support provided by professional caregivers to be adequate and suitable.<sup>[39]</sup> As a matter of fact, inadequate training of caregivers of patients with PVS not only puts patients' lives at risk, but is also a major risk factor for the physical and psychological health of family caregivers.

Under the category of "greedy search for useful education," family caregivers of patients with PVS craved to receive information and acquire the skills needed to take care of their patients. Therefore, they searched for and got information from various sources. The findings of a study by Verhaeghe *et al.* (2007) indicated the willingness of caregivers to get information about all aspects of the condition, particularly regarding the prognosis, treatment, and nursing care of the patients. They also expected to receive the needed information from professionals, such as physicians and nurses.<sup>[17]</sup> In line with our study, Verhaeghe *et al.* (2005) found that family members of patients with traumatic coma sought different information about the patients at different stages and they obtained them in various ways, including observing, listening, and asking question from different sources. Moreover, failure to receive enough information would make them stressed and worried.<sup>[40]</sup> Therefore, it can be understood that caregivers of patients, especially patients with LOC disorders, are greedy to constantly ask for information at all stages and expect to receive accurate information from the healthcare staff.

In this study, family caregivers received information from various professional sources and unprofessional ones. Consistent with the present study, in the study by Verhaeghe *et al.* (2005), the caregivers also used different sources, including professionals, acquaintances, and friends who were familiar with the medical world, or the experiences of people in the same circumstances in order to meet their need for information.<sup>[40]</sup> Participants in a study by Abdoli *et al.* (2011) also received their information mostly from their peers such as other diabetic patients.<sup>[32]</sup> Therefore, it can be understood that the greedy information searching from various sources is an effective solution to reduce the fear caused by unawareness. In addition, in line with the present study, in which the participants acknowledged this fact, in a study by Korkmaz *et al.* (2019) conducted on women with cancer who were to undergo mammoplasty, it was revealed that getting information from web-based sources reduced patients' anxiety and fear.<sup>[41]</sup> Nevertheless, it would be more useful if the information required by caregivers is provided by professional sources.

Under the two categories of "dynamic independence in care" and "effective education", the findings showed that using the information seeking strategy helped family caregivers to provide care to their patients independently

by gradually learning them. The gradual independence of the caregivers reduced their stress, and also made them consider received education as applicable and effective. Consistent with this study, Ferré-Grau *et al.* (2014) found that receiving education reduced the anxiety, depression, and emotional distress of family caregivers.<sup>[42]</sup> Rivera *et al.* (2008) reported that training family caregivers of patients with traumatic brain injury decreased their distress, burden, depression, and health complaints and led to their independence in providing care.<sup>[43]</sup>

Family caregivers acknowledged that they received both psychological support and educational support from professional caregivers. Providing support is among the main roles of a nurse. Nurses consider the support they offer as part of their professional and ethical roles, and perform this duty through various actions and activities.<sup>[39]</sup> Therefore, the presence of professional caregivers in the care process of patients with chronic illness gives the patients and their families a sense of safety, which is one of the factors contributing to the improvement of the quality of care.

The main limitation of this study like other qualitative studies is related to the generalizability of findings to other environments. In the present study, it was attempted to make the findings more generalizable by ensuring maximum variation in selecting the participants.

## Conclusion

Based on the findings, lack of awareness of family caregivers of patients with PVS and insufficient and unfavorable hospital training they had received made them feel need for receiving education and information seriously. Therefore, they tried to seek and get information from professional healthcare workers and their peers. Their information seeking efforts resulted in their independence in the care process, which they finally perceived as beneficial. The important point is that, to be more effective, to prevent wasting the time of caregivers and also to prevent the likely damages resulting from lack of awareness, the education needed by caregivers should be provided at the right time. Actually, facilitating the process of getting information by family caregivers as a key part of holistic nursing is so important that it should be performed by considering some approaches that can be taken. Formulating comprehensive discharge plan based on standard criteria in terms of time, place and educational content is a valuable method of achieving this goal. Indeed, because of their job descriptions, nurses play a significant role in training family caregivers of patients with PVS. Moreover, given the ever increasing prevalence rates of chronic diseases, incorporating a homecare component into the health system is another essential and valuable method of improving the conditions of such patients. Finally, by establishing specific care centers for these patients, their families would be able to take

advantage of their peers' experiences in providing care to the patients.

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### Conflicts of interest

Nothing to declare.

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