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Perception of social support among family caregivers of vegetative patients: A qualitative study

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ABSTRACT

A vegetative state (VS) is the probable result after brain damage. After VS patients are discharged from the hospital, the responsibility of caring of them is transferred to their families, which impacts a caregiver's physical and psychological health. Social support as a valuable resource reduces the negative effects of stressful events. This study aimed to explore the perception of social support among family caregivers of VS patients.

This study is a part of a larger qualitative study which used the descriptive and qualitative method. Purposeful and theoretical sampling was done, and data was gathered through face-to-face, in-depth interviews. The four categories of "Family, a supporter in all aspects," "Beautiful emanation of the nurse's role," "Revitalization via empathy and companionship," and "Defects in support," were extracted. The primary concern of participants was receiving social support which can facilitate caregiving and coping with difficulties, but there are many shortcomings in supporting these caregivers.

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1. Introduction

A vegetative state is the probable result after severe brain damage. It is the result of dissociation between two parts of consciousness: awareness and wakefulness (Laureys, 2005). A patient in a VS is apparently awake, but has no sign of awareness of his own body or the environment, no purposeful or voluntary behaviors in response to stimuli, and is unable to communicate (Bernat, 2009; Giacino, Fins, Laureys, & Schiff, 2014). The number of VS patients in the world is increasing as a result of improvements in medical science and cardiac pulmonary resuscitation techniques. According to studies, the incidence of VS cases is 0.6–10 in 100,000 people (Zampolini, 2003); however, there are no statistics on the exact number of these patients in Iran.

Advanced medical interventions have prolonged the life of VS patients; the life expectancy of these patients has been estimated at 2–5 years, but it has also been reported to be more than 25 years (Chiambretto, Ferrario, & Zotti, 2001). VS patients are discharged from the hospital after passing the acute stage and reaching a stabilized medical condition (Beis et al., 2009). Afterward, the responsibility of patient care is vested to the patient's family. Even though the VS patient's condition is stabilized, he still require continuous medical and nursing care (Healy, 2010).

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Having someone in a vegetative state in the family is a complex and stressful experience, and caring for these patients creates many ethical, psychological, physical, and financial complications for family caregivers (Zarit, 2006). The patient's family suffers more than others (Chiambretto & Vanoli, 2006). Some of these caregivers leave their jobs, and most of them leave their interests, friends, or relatives and feel socially alone (Boss & Couden, 2002). Furthermore, the cost of caring for such a patient and leaving work cause financial, personal, social, and organizational problems (Dumont, Dumont, & Mongeau, 2008). In many studies, the burden and stress have been reported as side effects of caregiving (Chiambretto, Moroni, Guarniero, & Bertolotti, 2010; Chiambretto & Vanoli, 2006) which affect the caregiver's physical and psychological health (Giovannetti, Leonardi, Pagani, Sattin, & Raggi, 2013) and, as a result, the quality of patient care (Zarit, 2006).

Social support is defined as a subjective feeling of belonging, acceptance, recognition, and assistance in the required situation (Pehlivan, Ovaryolu, Ovaryolu, Sevinc, & Camci, 2011; Uchino, 2006), which can be provided by family members, friends, colleagues, professional groups, or the community (Uchino, 2006). Several studies have reported social support as a valuable resource which lightens the burden experienced by caregivers (Amendola, Oliveira, & Alvarenga, 2011; van der Voort, Goossens, & van der Bijl, 2009) and an emotion-oriented coping mechanism which improves the family caregiver's quality of life (Amendola et al., 2011), health behaviors (Yu & Petrini, 2010), and ability to cope with life events, thereby reducing the negative effects of stressful events (Shankar & Muthuswamy, 2007). In contrast, people with weak social support are vulnerable (Yu & Petrini, 2010) and experience high levels of stress (Shankar & Muthuswamy, 2007).

Many studies have emphasized the important role of social support in reducing the burden and improving mental well-being and physical health. Leonardi, Giovannetti, Pagani, Raggi, and Sattin (2012) assessed the burden and needs of caregivers of patients in vegetative states and minimally conscious states. The results showed a heavy burden related to providing care to these patients. The authors suggested planning comprehensive support strategies for caregivers in order to reduce the level of burden (Leonardi et al., 2012).

Study results obtained by Grant et al. (2006) indicated that higher levels of social support are associated with lower levels of caregiver depression symptoms and higher levels of well-being and general health (Grant et al., 2006). For example, Ryff, Radler, and Friedman (2015) reported that intervention and educational programs designed for improving the well-being of adults were followed by better physical health. Relieving a caregiver's mental problems increases his ability to cope with stressful situations. Grant et al. (2006) further stated that interventions that provide social support assist caregivers in developing adaptive abilities toward problem solving and coping with difficulties in caring. These kinds of support should be provided throughout the care delivery period. In their study, Giovannetti et al. (2013) expressed that support to the caregiver should be guaranteed throughout the duration of the relative's disease, because care-giving is a long-term commitment.

It is obvious that providing care to patients in a VS is oppressive, and the role of social support is pivotal in reducing care difficulties. Family caregivers receive support from different sources, including family and friends, HCPs, and community care organizations (Cameron, Naglie, Silver, & Gignac, 2013; Lilly, Robinson, Holtzman, & Bottorff, 2012). To the best of the authors' knowledge, only a few studies have focused on caregivers of VS patients, and most of them are quantitative assessments. Accordingly, there is a need for a detailed description which can illustrate the family caregivers' perception of social support. Therefore, the present study aimed to explore the perceptions of social support among family caregivers of patients in a vegetative state. Clarifying family caregivers' perceptions of social support can help in promoting caregivers' health and facilitating their coping with its challenges.

2. Method

This study is part of a larger study entitled "Exploring the coping process in family caregivers of vegetative state patients," which was conducted in the Kerman province in 2014. Since the study dealt with an unexplored area, it was important to choose a descriptive and qualitative method to obtain knowledge from the caregivers' own frames of reference. The study investigated perception of participants about types of social support they wanted and received, and perception about types of support they felt lack.

2.1. Informants

Purposeful sampling was used to recruit participants (Corbin & Strauss, 2008). Those who could best describe and enhance one's understanding of the phenomenon under study were recruited. Inclusion criteria were direct involvement in providing care and being responsible for care for at least 6 months. The criteria for patients being cared for by potential participants were the diagnostic criteria of the Royal College of Physicians (2013).

Because of its qualitative nature, this study did not determine sample size before data was gathered. The number of participants was determined based on information gathered. When additional interviews did not add new information about the targeted concept, the end point, or data saturation, was reached. Analysis occurred concurrently with data gathering in an iterative process, meaning that when no new information was observed after 10 interviews, two additional interviews were conducted to ensure data saturation had been reached.

Participants included 10 family caregivers and 2 nurses who helped families deliver care. Demographic characteristics are presented in Table 1.

Table 1
Overview of participant demographics.

Participant code	Age (year)	Gender	Employment	Relationship with patient	Duration of caregiving (month)	Marital status	Educational status	Financial support
1	26	Male	Office worker	Brother	60	Single	Diploma	Welfare organization
2	54	Female	Housewife	Son	60	Married	Primary	Welfare organization
3	50	Female	Housewife	Mother	6	Married	Primary	Family members
4	44	Female	Office worker	Mother	6	Divorced	Diploma	Family members
5	32	Female	Teacher	Mother	12	Single	BS	Family members
6	20	Female	Pupil	Father	23	Single	BS student	Family members
7	42	Female	Nurse	Son	24	Married	BS	Welfare organization
8	23	Female	Pupil	Mother	18	Single	BS student	Family members
9	37	Male	Nurse	Professional caregiver		Married	BS	
10	35	Female	Housewife	Spouse	7	Married	Diploma	Family members
11	41	Female	Nurse	Professional caregiver		Married	BS	
12	32	Male	Tradesman	Father	26	Single	Diploma	Family members

2.2. Data collection

At first, participants were called and interview dates were set after the aim of the current study was explained to them. Then, data was gathered through face-to-face, in-depth interviews with semi-structured questions conducted in places preferred by the participants. Field notes and observations complemented the interviews. At the start of the interviews, the interviewer asked some introductory questions, followed by more specialized questions related to support. Interviews lasted 35–75 min. One of the authors (ZI) conducted the interviews, transcribed them verbatim, and reviewed the transcripts to ensure accuracy. The interviews explored participants' experiences and views on the sources and types of support received or provided and their satisfaction with it, its gaps, and its quality and quantity. The interviews were rich in content and created a pattern that the authors found adequate to serve as a basis for the findings.

2.3. Data analysis

Interviews took place at least 6 months after patient care had begun at home and were transcribed immediately afterward. MAXQDA 10 software was used to manage data. Each interview was read several times for a better understanding before analysis. The next interview was conducted after the previous one was analyzed using a constant comparative method of analysis. This method focused on comparing and contrasting similarities and differences in the data as well as questioning the data throughout the analysis (Corbin & Strauss, 2008). Codes were identified in the data and clustered together to create categories.

2.4. Ethical considerations

This study was approved by the Kerman University of Medical Sciences; its allocated ethic code is K/93/337. Prior to the interviews, the participants were informed of the purpose and method of the research, and they provided written informed consent to participate. They were assured their personal information would be kept private, and they were told that all data would be treated confidentially and used only for the discussed purpose. Participants were also informed that participation in the study was voluntary, that they could withdraw from the study at any time, and that they had the right to ask the researchers to return the audiotapes of their interviews to them. They were assured of the anonymity and confidentiality of the study.

2.5. Rigor

The methodological quality of the data was maximized in several ways using the criteria of Corbin and Strauss (2008). Fitness of the data collection was enhanced by interviewing the participants in their preferred locations as well as audio

recording and transcribing verbatim the interviews. The content of all transcripts was checked to ensure the transcript matched the recording. For member checking, the researcher's interpretations of data were presented to the participants and they were asked to react; all of them agreed with the interpretations. Triangulation of researchers was accomplished by sending the interview transcriptions to other researchers independently and discussing the results.

Concepts were organized based on their characteristics and the other researchers' opinions. All stages of data collection were carried out in the appropriate, best way; the authors tried to deepen the data using in-depth interviewing and triangulation. Variation in data was achieved by interviewing participants with different ages, genders, relationships with patients, and durations of caregiving.

3. Findings

Four categories were extracted from data analysis: "Family, a supporter in all aspects," "Beautiful emanation of the nurse's role," "Revitalization via empathy and companionship," and "Defects in support."

3.1. Family, a supporter in all aspects

In Iranian society, VS patients are cared for by family caregivers, and because of the complete dependence of a patient upon his/her caregiver, caregivers endure a heavy burden. According to participants' statements, families support caregivers not only by delivering physical care to the patient, but also in psychological and financial issues. From the category "Family, a supporter in all aspects," three sub-categories emerged: "Empathy of family members," "Companionship of family members," and "Family members as financial supporters."

3.1.1. Empathy of family members

According to the caregivers, family members' behaviors and speech improve their morale and help them cope with the difficulties of caregiving. One participant stated, "My sister always gives me hope and reassures me. Without my sister and brothers-in-law, I'd have broken down," (N 10). Another participant declared, "The fact that my brothers, even the little one, care about me is such a valuable thing for me . . . I don't feel alone when I see them," (N 8). Such statements indicate that empathy and kindness among family members, especially with the one who has the most responsibility of caring, play an important role in improving the caregiver's calmness and morale.

3.1.2. Companionship of family members

According to statements by the participants, providing care to a VS patient is something beyond a routine activity. The caregiver can postpone everything in his life, but caring activities must be done promptly and perfectly, which requires a great amount of energy. Caring would be frustrating without the cooperation of family members. "Taking care of these patients requires lots of energy, and man . . . at the beginning my brothers were helping Mom and me take care of Dad. Without them, we couldn't even move him. Even now they should help us with some things," said participant number 6.

3.1.3. Family members as financial supporters

Health care costs, including care equipment, drug preparation and the costs of losing one's main source of income and being forced to leave work daily for at least several hours to take care of the VS patient, impose a big financial load on the caregiver. Other family members give the caregiver a sense of financial safety by supporting him/her and resolving his/her financial needs. One participant was self-supporting and had a good monthly income (based on her declaration), saying: "We didn't have any financial problems, thank God; my sister was taking care of Mom so I could work freely, and since I couldn't cooperate directly in the caring, I accepted all the costs. Albeit, my brothers also helped and we never felt poverty," (N 4).

Another participant who was not financially independent and had insufficient income said, "Health care costs were too heavy. First, they said you have to buy a pressure relief mattress, suction, oxygen capsule, and the like, and then, provide food, detergent, diapers, and such. To summarize, costs were so heavy and my father's monthly income was only \$250 USD, so my brother was forced to work in his spare time," (N 8). Obviously, the cooperation of family members facilitates coping with financial issues.

3.2. Beautiful emanation of the nurse's role

Based on the interviews, helping caregivers take care of their patients, educating caregivers, consulting them as needed, and supervising them with nurses, are essential in delivering safe care for patients and calming caregivers. It is noteworthy that all of these tasks are inseparable parts of nursing. The subcategories "Nursing support as care facilitator," "Nursing support as caregiver's energizer," and "Nurse as a consultant and educator were formed in this category.

3.2.1. Nursing support as care facilitator

Participants expressed that receiving nursing support and cooperation, or benefitting from nursing knowledge, is essential in delivering safe and better care. One of the participating caregivers who was a nurse said, “I’m a nurse, and I can take care of my son by myself; I can change his tubes, prevent him from getting bed sores, and thank God that I’m a nurse and I have knowledge about caregiving,” (N 7). Another participant who had no nursing knowledge and was supported by a private nurse stated that, “His nurse helped us so much. We called him when necessary and he always came on time. We didn’t have any nursing knowledge; the nurse was doing everything for him until we gradually learned,” (N 6). Participant number 1 said, “In the first days after his discharge, we didn’t know anything, didn’t know anything about lung suctioning . . . so we hurt his lungs.”

3.2.2. Nursing support as caregiver’s energizer

According to the interviews, when the care of a VS patient is given to his/her family, anxiety and fear is their first reaction, because they are not familiar with this condition. Having a professional supporter who helps as needed is a huge energizer for the caregiver. Participant number 8 reported that, “As soon as Miss R (the nurse) said that I could call her if I needed any help, I had less stress about taking care of my mom at home.”

Another participant who is a nurse and delivers home care stated, “His family called me only on emergencies, and anyway, I would have helped them if they had called. I think being a nurse is encouraging,” (N 9).

3.2.3. Nurse as a consultant and educator

According to what was inferred from the interviews, continuing patient care training and educating is a duty for every nurse while the patient is alive. Educating and consulting are essential in the process of care giving. Participant number 10 declared, “During the 10-day period our patient was in post ICU, we learned a lot from nurses, such as how to suction, check for fever, fumigate and feed, but that wasn’t all. As soon we got into trouble and didn’t know what we should do, inevitably we called the nurse or the doctor to guide us.” Another participant said, “God bless Mr. B! When we wanted to discharge our patient, he taught me how to take care of her . . . every time I had problem with something I called ICU and the nurses guided me,” (N 8).

3.3. Revitalization through empathy and companionship

In addition to the supportive role of the family and nurses, the participants mentioned getting support from acquaintances (relatives and friends). The codes for these statements were put under the sub-categories “Empathetic friends” and “Companion relatives.”

3.3.1. Empathetic friends

Based on caregivers’ statements, friends who listen patiently to caregivers give them a feeling of inward tranquility and remind them that they are not alone. As participant number 7 said, “When I’m upset about something or somewhere, my friends give me lots of hope and calm me down, so I feel I’m not alone through difficult times.” Another participant also said, “A good friend is a relief in difficult times. I have a friend who lives in Turkey. Some time ago, memantine tablets were scarce in Iran. She bought some and sent them to me,” (N 5).

3.3.2. Companion relatives

According to participants, the companionship of relatives facilitates patient care. As maintained by one participant, “In the first days, my brothers and uncles did most of the caring work. We were a 20-member team; if they weren’t there, indeed, the caring would have been so difficult,” (N 6). Another participant said, “Since my father has been in this condition, we have been trying to care for him ourselves. But staying at home all day long was impossible, so my uncles and cousins helped us,” (N 12). As mentioned above, the companionship of relatives is an important factor in reducing the burden of care.

3.4. Defect in support

In addition to the above, revealed by the analysis of texts that caregivers searching for a needed support which is not available. The related codes were situated in three sub-categories: “Sense of rejection by medical team,” “Absence of government supportive centers,” and “Gradual downside in support.”

3.4.1. The sense of rejection by the medical team

Data analysis showed that, in most cases, the hospital staffs insisted on discharging patients regardless of the feelings and concerns of family caregivers. Therefore, family members inevitably transferred the patient to the home, and care was imposed upon the family. Participant number 3 who takes care of his mother said, “They wanted us to take our mother home. We continued to protest, but it was useless. . . finally we brought her home from the hospital.” Another participant who was very young and had insufficient experience said, “Sometimes her physical condition became worse, so we prepared her despite many difficulties and drove to the hospital, but the staff told us not to bring her to the hospital, not to do anything for her, and to let her stay home,” (N 8). Participants also had complaints about doctors who rejected them. Participant num-

ber 2 said, “We asked Dr. H. to visit our patient, but he said, “Even if you pay millions, I won’t visit these kinds of patients at home.”

3.4.2. Absence of government supportive centers

The absence of supportive centers for these patients and their families was mentioned in all interviews. Participant number 1 said, “Most patients have an association or a place where they can get some kind of services, but there isn’t any place for these patients. The Welfare Organization gives us only seven dollars, which is nothing.” They spoke about their need for governmental help. One participant said, “The government must help families in caring; for example, send someone to work at homes, because caring for these patients is so frustrating and expensive, especially in providing the equipment,” (N 7).

3.4.3. Gradual downside in support

Although support from family and relative was discussed, in some cases, participants mentioned that this type of support was absent or faded gradually. For example, despite the benefit of family and friends’ support, participant number 5 complained about the lack of support from relatives and said, “In the first days, our uncles called us sometimes, but now they ignore us. They are busy...” Another participant said, “In the first days, my uncle took care of Mom, and my dad helped too, but I think, maybe, they grew exhausted. After that, my grandma and uncles only came once a year, stayed an hour and went. Over the last year and a half, I think they only came two or three times,” (N 8).

4. Discussion

Having a family member in a vegetative state is a complex emotional experience, and facing this situation causes many problems for the family. Since caregivers can better cope with the burden of care by using social support, this study explored the perception of social support among family caregivers of vegetative patients. Four categories were extracted from data analysis: “Family, a supporter in all aspects,” “Beautiful emanation of the nurse’s role,” “Revitalization via empathy and companionship,” and “Defects in support.” The findings of the current study shows that a VS patient’s family needs help in providing care, financial and emotional support for coping with the difficulties involved with caregiving, and a firm base of support throughout the caring period. Having these needs met, will reduce their difficulties and stress and will calm them. [Liu, Zhu, Liu, and Guo \(2015\)](#) claimed that, because of the severity of the patient’s condition, the psychological pressure on their family caregivers is high ([Liu et al., 2015](#)); therefore, they need to gain support from family members, relatives, the government, nurses, and health professionals. Other studies stated that caregivers receive support from different sources to improve patient comfort and quality of life, and this is effective in reducing family stress and improving the caregiver’s physical and mental well-being too ([Given, Given, & Kozachik, 2001](#); [Romaniello et al., 2014](#)).

In the current study, participants mentioned family as a supporter in all aspects, which shows the commitment of family members and emphasizes the issue that family members support each other in all situations, whether financial, medical, or emotional. This result is similar to those of other studies ([Gaugler, Kane, Kane, & Newcomer, 2005](#)). From the viewpoint of [Staccini, Tomba, Grandi, and Keitner \(2015\)](#), family members are parts of an integrated system, and the sudden occurrence of an illness can change how a family functions. Family members of VS patients are affected by physical, mental, and economic issues ([Goudarzi, Abedi, Zarea, & Ahmadi, 2015a](#)). In this challenging situation, the family as the most important source of support, delivers support to family caregivers to reduce problems in caregiving and encourage them to cope with difficulties ([Asgari, Mohammadi, Khoshknab, & Tamadon, 2011](#)). Previous studies also showed that in difficult situations like caring for VS patients, only one or two members provide care directly; even so, the others do not stand aside ([Chiambretto & Vanoli, 2006](#)). Family members have strong relationships with each other ([Fallatah & EdgeDana, 2015](#)), and all of them are involved in providing care, supporting the main caregiver ([Gaugler et al., 2005](#)), and sharing their information and experiences with each other ([Magliano et al., 2005](#); [Ware & Raval, 2007](#)). Giving long-term care to VS patients imposes high costs on family caregivers ([Giovannetti et al., 2013](#)). Providing financial support to family caregivers could relieve the care burden ([Leonardi et al., 2012](#)). According to finding of recent study family members give this support because of the absence of any organization for providing appropriate financial assistance to these caregivers; thus, the family plays a vital role in providing support to its members.

As mentioned, VS patients are discharged after stabilizing, and family members are forced to deliver care which was previously administered by hospital personnel ([Goudarzi et al., 2015a](#)). They endure stresses associated with the VS patient’s uncertain outcome and the practical problems of the caregiving process ([Wade, 2014](#)). Therefore, family caregivers need support from health care professionals, especially nurses, to improve their ability to care for their loved ones ([Grant & Ferrell, 2012](#)). Participants of this study emphasized the supportive role of nurses in helping caregivers take care of patients, solving emotional issues, and training and consulting caregivers in unexpected situations. In fact, support is one of the fundamental roles of nurses, and as a bridge, they connect patients’ families with the health care system and fulfill their responsibility in supporting patients and caregivers ([Shankar & Muthuswamy, 2007](#)). The results of a study by [Kirk and Glendinning \(2002\)](#) indicated that nursing professionals support delivering care through emotional, practical, and informational assistance. These results are consistent with those of the current study. From the viewpoint of [Hutti \(2006\)](#), the professional care given caregivers by nursing professionals includes health and psychological care, training, consulting them in problem solving, and helping them play their roles. These findings also matched those of the current study. Other studies mentioned, a patient’s

family searches for information on how to care for their patient, the disease process, and its prognosis (Fallatah & EdgeDana, 2015), which indicates the need of families for nursing support at the training and informational levels. Grant et al. (2006) pointed out that family education in providing professional care, the psychological and emotional support given to caregivers, and the assistance given to caregivers in delivering care are the duties of the nursing profession. They went on to state that these kinds of support help families take care of their patient and cope with the difficulties associated with caregiving, and they play an important role in preventing and solving health problems (Grant et al., 2006). Mohammadi and Babaye (2011) maintained that support from nurses and professional groups enables caregivers to deal with problems, decrease the burden, improve their spiritual health, and confront the negative effects of care. Intervention and educational programs can improve family caregivers' health and well-being (Ryff et al., 2015), which are necessary in caring for an unconscious patient. Conversely, because a vegetative state is a chronic condition, long-term care and the changes in such care that a VS patient needs during these processes and maintaining and promoting the health of the caregivers depend on the continuation of educational and supportive programs for them (Mohammadi & Babaye, 2011). One participant in the current study emphasized the supportive role of nurses as a factor in improving the health of both patients and caregivers that must continue as long as the patient is alive.

In addition to the need of caregivers for support from nurses and family members, the findings of the present study also show that empathy from friends relieves caregivers' mental suffering, and support from relatives, acts as a facilitator in caring. VS caregivers endure intense emotional suffering because of the daily static condition and uncertain future of the patient (Giovannetti et al., 2013). Thus, they need to relax by getting support from their friends. In a study by Fallatah and EdgeDana (2015), such support was mentioned as a source of relaxation for family caregivers. In study of Chanari, Noroozi, and Tahmasbi (2012), the support of friends proved to have a direct effect on stress management (Chanari et al., 2012). In yet another study, Asgari et al. (2011) reported that support from friends improves social relations and, as a result, reduces caregivers' depression and anxiety and increases their self-confidence. Obviously, the role and supportive behavior of friends assures caregivers that they are not alone and they have friends who are worried about them. Relief is the result of this empathy.

Forasmuch as visiting a patient and expressing empathy for people with problems are rooted in Iranian and Islamic cultures, friends and relatives in Iran visit a patient's family and give them emotional and practical support. The participants of the current study referred to this kind of support and stated that relatives help them by taking care of the patient in some situations, which facilitates their caring and coping with dependence difficulties. The results of the study by Amendola et al. (2011) also confirm the claims of the current study. Esmaili, Ahmadi, Mohammadi, and Seraj (2012) indicated in their study that support from relatives helps caregivers overcome the caring burden.

According to the findings of this study, caregivers referred to the lack of medical staff support, lack of governmental supportive centers, and the gradual fading in support as instances of support defects. Participants of the current study also pointed to the lack of medical staff support, which is a requisite for taking care of a completely dependent patient, such as those in a VS state. Caregivers need health specialist support, but in Iran there is no organization responsible for supporting family caregivers in homecare. This kind of support is found in private form, but it is not sufficient and, because of its cost, caregivers sometimes ignore it (Shorofi, Jannati, & Moghaddam, 2014). This defect was also considered in some other studies. In the study by Pouladi, Anooosheh, Kazemnejad, and Zarejyan (2013), weakness in the infrastructure of the family health system and inadequate utilization of the existing potential to support families in caregiving were mentioned as reasons for creating individual problems for family members and weakening their social and familial conditions in providing care. Kirk and Glendinning (2002), pointed out the weakness in received support from health professionals, even in the emotional field. Imposing caring responsibilities and stress upon family caregivers causes adverse effects, such as feelings of inadequacy and disability, so family caregivers feel they have been left alone with the heavy responsibility of patient care (Liu et al., 2015). The family caregivers of VS patients want to gain the continuous support of health professionals, but in the community, such follow-up has been studied in only a limited number of diseases; VS patients and their family challenges have not been investigated, and there is no center to follow-up on such patients' conditions (Goudarzi, Abedi, Zarea, & Ahmadi, 2015b).

Furthermore, studies support the idea that the existence of services and trained staff prepares caregivers for coping with difficulties, empowers them, and reduces the burden of care (Amendola et al., 2011). These factors were mentioned by participants in the current study as a need, and these needs can be met by public organizations offering such services. Moreover, the lack of legislation, official and governmental support systems, and the lack of information on the existence of such facilities are considered as factors causing more difficulty during patient care. This finding is consistent with those of the study by Hsiao and Van Riper (2010).

The findings of this study signify that caregivers gradually encounter reductions in support from some of their relatives. This reduction diminishes the caregiver's morale, increases the caregiver's burdens, and can even change the caregiver's future. Several other studies pointed out the lack of support from some relatives, despite the caregivers' need for further support in delivering care (Magliano et al., 2005; Merrell, Kinsella, Murphy, Philpin, & Ali, 2004). Santana, Almeida, and Savoldi (2009) mentioned lack of support from relatives in delivering care as a reason for choosing emotion instead of problem-focused coping strategies to gain solace; in other words, caregivers tend to obviate problems with renunciation or use of religion rather than solve them using purposeful methods.

5. Conclusion

Caring for VS patients is a long-term process, and it may be accompanied by physical and psychological problems for caregivers and a decline in the quality of patient care. Thus, supporting caregivers can reduce the burden of care and increase a caregiver's well-being, which will lead to increased quality of care. This study explored the perception of social support among family caregivers of vegetative patients. The findings of this study indicate that delivering care, without receiving information, advice and education, counselling, and emotional, financial, and practical support is extremely painful for family caregivers. As seen in this study, receiving social support is the primary concern of our participants; however, there are many shortcomings in supporting caregivers. After publication, the findings of this study can encourage health professionals to actively and effectively cooperate in reducing care complications for caregivers. They can also be used by researchers, managers, and decision-makers to address caregivers' support needs based on evidence, and by the government to organize locations and staffs to support these caregivers.

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