



## Original Article

# The Resilient Care of Patients with Vegetative State at Home: a Grounded Theory

Fateme Goudarzi<sup>1,2\*</sup>, Heidarali Abedi<sup>3</sup>, Kourosh Zarea<sup>4</sup>, Fazlollah Ahmadi<sup>5</sup>, Seyede Zahra Hosseini golafshani<sup>6</sup><sup>1</sup>Social Determinants of Health Research Center, Lorestan University of Medical Sciences, Khorramabad, Iran<sup>2</sup>Department of Nursing, Nursing and Midwifery Faculty, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, Iran<sup>3</sup>Department of Nursing, Nursing and Midwifery Faculty, Isfahan (Khorasgan) Branch, Islamic Azad University, Isfahan, Iran<sup>4</sup>Nursing Care Research Center in Chronic Diseases, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, Iran<sup>5</sup>Department of Nursing, Faculty of Medical Sciences, Tarbiat Modares University, Tehran, Iran<sup>6</sup>Department of Nursing, Nursing and Midwifery Faculty, Qazvin University of Medical Sciences, Qazvin, Iran**ARTICLE INFO**

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## \*Corresponding Author:

PhD in Nursung. Email:  
Goudarzi.f@lums.ac.ir**ABSTRACT****Introduction:** The care of patients in vegetative state at home is difficult because they need continuous medical interventions and extensive care. The present study aims to explain the process of home care of patients in vegetative state at home.**Methods:** This study was a qualitative research with a grounded theory approach. The participants were 22 people (included 17 family caregivers and 5 professional caregivers) who were enrolled in a purposive sampling. Data was gathered through unstructured interviews, observations and field notes. Data collection was continued to saturation. Data analysis was performed through the Strauss and Corbin 1998 approach. The MAXQDA10 software was used to facilitate data analysis.**Results:** The data analysis led to emerge four main concepts included "erosive care", "erosive expenditures", "seeking solver education" and "lasting hope" as the axes of the study. Participants' experiences showed that the main concern of family caregivers of vegetative patients was "playing an inevitable role in care", in which they did not hesitate to make any effort, and they tolerated all the problems and issues. Therefore, "resilient care" was extracted as the underlying idea of this study.**Conclusion:** The process of resilient care of vegetative patients at home showed planning by policy makers in health system is very important and underscored the necessity for supporting families and family caregivers of these patients. So some changes in the health system for this goal might include considering home care and supporting them in various aspects, especially information, financial and emotional dimensions.**Citation:** Goudarzi F, Abedi H, Zarea K, Ahmadi F, Hosseinigolafshani SZ. The resilient care of patients with vegetative state at home: a grounded theory. J Caring Sci, 2018, 7 (3), 163-55. doi:10.15171/jcs.2018.026**Introduction**

As a result of recent advances in medical technologies in saving the life of patients with severe brain damage, life expectancy of such patients, as well as their number have increased.<sup>1,2</sup> Previously, such patients did not survive for long; however, they have been surviving more and more nowadays, with their condition subsequently moving toward vegetative state or the minimal consciousness state.<sup>2</sup> The mean survival rate for these patients is about 2 to 5 years.<sup>3,4</sup> There have also been reports of survival of 10 years or more.<sup>4</sup>

What is important is that taking care of such patients is very difficult, so increasing their longevity and survival for several decades adds to the difficulty. The difficulty in the care of vegetative patients lies in their particular conditions, because they require continuous medical interventions and extensive care<sup>2,5,6</sup> such as maintaining airway, maintaining fluid balance, meeting nutrition needs, providing oral care, preserving skin health and integrity, maintaining corneal integrity, maintaining body temperature, urinating, improving bowel function and providing sensory stimuli.<sup>2</sup>

Most of the care required for the vegetative patients should be carried out professionally, and when such care has to be provided by family members, it can be quite

problematic for patients as well as the caregivers themselves. In many developing countries, due to the length of the care period of patients in a vegetative state, these patients are usually discharged from the hospital after their condition is stable and the care continues at home.<sup>7</sup> Therefore, the families play a major role in the lives of these patients and they constitute the main area of the patient's life.<sup>6,7</sup> In such situations, home care could yield many benefits for the patients and their families, as well as for the health system and society if it is conducted under the supervision of the health system. Because it also provides effective management of limited resources<sup>8</sup> as well as the possibility for family members to provide care.<sup>9</sup> Although, the implementation of home care is important and valuable,<sup>10</sup> it is one of the basic principles of primary health care in Iran that is poorly or rarely implemented.

When the care responsibility of vegetative patients is to be entrusted to the families, paying attention to the health of family caregivers is an issue that can simply not be neglected. Because studies have shown that long-term and uncertain care of vegetative patients without the support and training can cause problems not only for the patients themselves, but also for the family caregiver; problems such as physical and psychological erosions,<sup>11,12</sup>

anxiety,<sup>5</sup> unemployment and financial problems,<sup>11,13</sup> as well as isolation.<sup>13</sup> In the long run, it will interfere with providing proper care to these patients.<sup>11</sup> In addition, having a patient with these conditions will be a significant stressful situation for the family.<sup>14</sup>

Limited studies have been carried out on the family caregivers of vegetative patients. Most of these studies have evaluated the attitudes and views of formal and informal caregivers about the vegetative state along with the continuation of treatment and care for patients.<sup>15-17</sup>

Irrespective of the results of these studies in Iran's cultural and religious context, the evaluation of these views and attitudes with an emphasis on the continuation or discontinuation of treatment and care is not necessary. Because on the one hand, these patients are alive in the cultural and religious context of Iran, and according to Sharia law, euthanasia is not even an option. This is the theme of the 32<sup>nd</sup> verse of Al-Maidah Surah of Quran in which God says: "... whoever slays a soul, unless it be for manslaughter or for mischief in the land, it is as though he slew all men; and whoever keeps it alive, it is as though he kept alive all men;...". On the other hand, these attitudes must be studied with respect to their influence on the care process as provided by the family caregivers. Of course, such studies are notoriously absent from the conducted research.

The results of a few studies on the problems of family caregivers in the care of vegetative patients seem to point to certain psychological,<sup>3,18,19</sup> physical and economic<sup>19</sup> problems in the families of these patients. These studies have been conducted outside of Iran and the patients were either in the care centers or had professional care at home. In the Iranian care sector, however, the lack of specific care for these patients as well as the lack of home care make it even more pressing to assess the issues and problems of family caregivers of these patients and their effects on the care process. This is while studying about the care process of vegetative patients in Iran was not found. Only a limited number of studies have been done on patients in vegetative state in Iran, with their focus being on the coping process of their families.<sup>20,21</sup>

Therefore, their care process and its related factors remain largely unknown, which underscores the need for qualitative studies which might be very helpful in identifying unknown and less known phenomena. In this regard, the present qualitative study aims to "explain the process of taking care of patients in vegetative condition at home".

## Materials and methods

In the present qualitative study, a grounded theory approach was chosen to study the patient care process in a vegetative state at home.

This study was conducted between 2013 and 2015. The population of this study was people with the experience of taking care of vegetative patients. They were mostly family caregivers and in a few cases, they included professional caregivers with an experience in care of vegetative patients. In the present study, the participants

were selected through purposive sampling method and then by the method of theoretical sampling. Obviously in a qualitative study, the purpose is not so much the generalization of the findings to the research population, as it is gaining a deep understanding of the phenomenon<sup>22</sup> and in other words, discovering and identifying the meanings of the multiple realities.<sup>23</sup>

Therefore, the best way is to select the people who have the most information about the experience or event under study.<sup>22</sup> Therefore, the inclusion criteria for family caregivers was having at least one month's care experience of a vegetative patient at home and for professional caregivers having care experience of these patients at home. The desire to participate in the research and to express their experiences and the ability to communicate properly were other requirements for the participation of participants in the study.

The participants were 22 caregivers of vegetative patients including 17 family caregivers and 5 professional caregivers. Initially 2 family caregivers, introduced and addressed by a professional caregiver that cared the patients at home, were entered into the study, but as the study progressed it was known that some care had been provided by professional caregivers, so some of them and other participants were also included as theoretical examples. It is worth noting, in qualitative research to evaluate a complex phenomenon or the development of a theory, the use of maximum variation samples is necessary.<sup>22</sup> In order to have samples with maximum variation, family caregivers included in the study had at least one month of care experience at home, could belong to either gender, could have different relations with the patient, and different marital status, or different degrees and jobs. Professional caregivers were also of different gender, experience and age. Other details of the participants are shown in Table 1.

**Table 1. Characteristics of participations**

Variables	Values
Family caregivers	
Age* (year)	33.29 (10.38)
Gender	
Female	11 (64.71)
Male	6 (35.29)
Caring duration* (month)	20.91 (26.99)
Professional caregivers	
Age* (year)	33.4 (8.81)
Gender	
Female	2 (40)
Male	3 (60)
Working experiences* (year)	10.4 (9.53)

\*Mean (SD)

The first author used unstructured and face-to-face interviews in order to gather the data. The main method of collecting data in this study was deep and unstructured interviews with open questions. For this purpose, at the beginning of each interview, the researcher introduced herself and explained the aims of the research and provided explanations on the method of interviewing and voice recording. The right of individuals as to or not to participate in the study was explained to them and their informed written consent

was obtained. The official interview was started with an original question. The interview with family caregivers was started with this request "Would you please tell me about your experiences during the time when you were taking care of Mr/Ms ...". In the cases of caregivers' ambiguity, the interview was started with this request "Would you please explain to me about your experience in taking care of Mr/Ms ... in a day". The request in the interview with professional caregivers was "Explain to me the experience of taking care of vegetative patients." In order to guide the interview, and in line with the participants' statements, other questions such as; "Is there another example in this regard? What did you think when that happened? What do you do when you feel so?" were asked. At the request of the participants, the interviews with family caregivers were conducted at their home and the interviews with professional caregivers were done at their workplace or in the first author's office at university. The mean length of the interviews was 57.1 minutes (with the range of 15 to 122 minutes). According to Burns & Grove's recommendation, the texts of the interviews were immediately transcribed after they were listened to several times and the typed file was entered into MAXQDA10 software. In addition, data analysis was carried out simultaneously with data collection.<sup>22</sup> The interviews were stopped following theme identification and data saturation. Because of the family caregivers have been talked about receiving educational information regarding the care, two cases of providing educational information by professional caregivers for the family caregivers were observed in observer as participant method. Field notes regarding the care and interaction of family caregivers with their patients were also analyzed. The MAXQDA10 software was used to facilitate data analysis.

For data analysis, the version 1998 of Strauss and Corbin method was used in this study. Strauss and Corbin consider the data analysis in grounded theory as having three steps of open coding, axial coding, and selective coding.<sup>24,25</sup> In the present study, before beginning the encoding, each interview was listened to several times, and the transcript was repeatedly reviewed to get an overview of it. For open coding, the data was reviewed line-by-line and word-by-word, and basic sentences and concepts on each line or paragraph were identified and tagged or coded according to the event, incident, subject, action and reaction they were indicating. In the following, the primary codes were compared based on their similarities and differences and as a result of these constant comparisons, the similar activities, events, incidents, topics, actions and interactions were placed in categories with abstract codes or concepts.

In all stages of coding and creating categories, the researcher constantly pondered these questions in mind: "What is happening in the data? What is the main concern of the participants? What strategies do the participants use to address this concern?"

In addition, a constant comparison was made to ensure category variation.<sup>26</sup> Following the open coding, the researcher focused on identifying and developing the characteristics and dimensions of the categories.

In axial coding, the similar subcategories were placed around an axis, using the paradigm model in order to explain the phenomenon that was happening. In forming the axes and identifying the main phenomenon in each axis, the focus was on identifying the causes, conditions, and phenomena controlling strategies and outcomes in order to determine the relations between categories and subcategories. Four axes emerged as a result of this stage.

Selective coding is the process of integrating and refining the findings in which the purpose is to find the main category or the core variable as well as to communicate between categories in order to determine the basic framework of the theory.<sup>26</sup> At this stage, through continuous comparisons and constant sweeps between codes and categories and also writing the main line of the story, it was tried to determine the main concerns of the participants and their most important strategy in response to this concern which was the core variable. Finally, after theoretical saturation in the categories and with the strategies used, the core variable of the research and the fundamental concept of theory were identified and the grounded theory was written which is discussed in the research findings section.

In this study, to ensure the accuracy and robustness of the qualitative data, the Lincoln and Guba's criteria including credibility, dependability, confirm ability, and transferability were considered.<sup>27</sup> Regarding the credibility of the study, the researchers were engaged with the data for two years, as well as triangulation in data collection (interview, observation, field notes and memoing) and constant comparative analysis were used.

Additionally, through the process of checking by participants, the encoded texts of the interviews were returned to three of the participants and the unclear issues were resolved and the codes were approved. For dependability of the study some methods such as external reviewers, original data availability and evidence based writing (quotations) were used. The conformability of the study was guaranteed through bracketing, member checks and panel of experts. Finally for promoting the transferability of the study results, the participants were selected with maximum variation; and also the stages of the study have been clearly reported for increasing the auditability of study.

## Results

From the analysis of the collected data, the central category of "resilient care" and the four main categories including "erosive care", "erosive expenditure", "seeking solve reeducation" and "lasting hope" were achieved which described the experiences of family caregivers of vegetative patients at home. The main categories also had 15 sub-categories that give a more detailed description of the experiences of the participants (Table 2).

**Axis 1: Erosive care**

The “erosive care” axis consisted of six sub-categories, including “obligation to take care”, “comprehensive care responsibilities”, “and collaborative care spectrum”, “multiple damages to family caregivers”, “affected families” and “perceiving the care as a difficult whole”. This category showed that the families of vegetative patients in the situation of “obligation to take care” used “comprehensive care responsibilities” and “collaborative care spectrum” strategies in order to provide care. But as a result of such a comprehensive care and without the cooperation of other institutions, they encountered certain negative complications including “perceiving the care as a difficult whole”, “multiple damages to family caregivers” and “affected families”. So they experienced the “erosive care” phenomenon.

**Obligation to take care:** This subcategory implied that the need and dependence of the vegetative patients, their importance in the family and the family members’ commitment were some of the factors that obliged the participants to take care of the vegetative patients. Some participants’ statements in this regard included:

“I cannot ignore him. He’s my dearest. I cannot let him die. Even if the doctor says that there is no hope, I do not hear it. I should take care of him to the end of his life or my power.” (Participant (P) 14, Family Caregiver (FC)).

“I’ll do these things because he’s my father and that’s my responsibility.” (P7, FC).

**Comprehensive care responsibilities:** Participants’ statements indicated that in the lack of social and the health system support, and also the complete dependence of the vegetative patient on others, the family is responsible for the comprehensive care of the vegetative patient. As one of the family caregivers pointed out he takes care of the vegetative patient just as a mother would take care of her child. “We just do not give him milk, we change his diapers, we clean him, we give him a bath, we give him the food, we satisfy his needs, we feel as if he’s my child, I talk to him like a baby” (P12, FC).

As part of this comprehensive care, family caregivers provided various cares to these patients. Health care (such as changing bed sheet and clothes, bathing, oral hygiene, physical environment care) and supportive care (such as paying attention to under-pressure points and stimulation of the senses), which did not require much expertise, were parts of the care that the caregivers provided for their own patients. “We care about his health, we brush his teeth once a day, we give him a bath once or twice a week, and we clean his armpits and private part before the bath to make bathing shorter. We give him a haircut and trim his eyebrows with the scissors. We change his diaper after defecation every other day, once a day, and sometimes twice or three times a day; and we change his diaper 6 to 7 times after urination” (P15,FC).

It is worth noting that these patients, due to their special conditions, require specialized care such as wound care, intravenous insertion, suction, feeding through the tube, inserting and replacing the urinary tract, medication and fluid therapy, and so on. According to family caregivers, they learned these specialized care services after a while and they did it for their patients. Some of the participants’ statements on different specialized care is as follows:

“We have a pulse oximeter, whenever we see he gets oxygen saturation or sniffs, we give him suction” (P6, FC).

“I had learned to change her NG tube every other 10 days” (P3, FC).

“I change his Thoracic dressing and gavage once a day” (P17, FC).

**Collaborative care spectrum:** According to the participants’ statements, in the care process of vegetative patients at home, one family member often took the primary responsibility for care of the patient and did the major volume of care as the main caregiver. Nevertheless, in most cases, due to the high amount of needed care of vegetative patients, another member of the family cooperated in the direct patient care. There were also

**Table 2.** Core variable, categories and Sub-categories Related to Caring process of Patients in a Vegetative State

Core variable	Categories	Sub-categories
Resilient care	Erosive care	Obligation to take care
		Comprehensive care responsibilities
		Collaborative care spectrum
		Numerous family caregivers injuries
		Affected family
		Perceiving the care as a difficult whole
		Erosive expenditures
	Erosive expenditures	Expensive care
		Searching for the neglected social supports
		Economic collapse of the family
	Seeking solver education	Necessity of teaching
		Greedy search for education
		Dynamic independence in care
	Lasting hope	Conditions of hope threat
		Positive thinking about patient recovery
		Hopeful care

some cases in which none of the family members participated in the direct patient care. So participatory care spectrum was used. "I give him water and food, my son does the cleaning and bathing and all the hard work, he goes whole hog now, he even brushes and flosses his teeth" (P15, FC).

**Numerous family caregivers injuries:** According to the participants' statements, a lot of time was required due to the high amount of needed care for the vegetative patient; and it caused a great deal of physical and psychological harms to the main caregiver. Some of the damages that most of the participants referred to were:

Physical damages such as back pain and lumbar herniated discs, as well as foot and knee pain were the most common problems that the main family caregivers experienced. "Because she was pretty heavy and she could not move on her own, it was very difficult to move her around so we did it together. Two of my sisters got lumbar herniated discs" (P22, FC).

Disruption in daily activities was also a concern that was acknowledged by all main caregivers. "I cannot handle my personal affairs because I do not have time anymore. I haven't been able to go anywhere for five years" (P17, FC).

Caregiver's isolation, career and educational stagnation were also among the consequences of this care for most family caregivers. "They had forsaken their entire life, for instance, they had a factory but the fact that they were taking care of a patient was acting as a barrier in their job fulfillment, even causing recession" (P19, Professional caregiver (PC)).

Ultimately, all of these injuries caused mental health problems for family caregivers. "I was not in a good mood; I did not want to see him getting suction. I was stressed out; I began to lose my hair, my hair went grey" (P20, FC).

**Affected family:** Home care of vegetative patients also did similar, but less intense, damages to the caregiver. "My mother made food for him and, in her own words, she mixed the food, she satisfied his needs, we exercised him, my mother got neck arthritis" (P20, FC). In addition, the damage to the entire family structure, especially in the psychological dimension was another effect of home care of vegetative patients. "My mom and sister became depressed and isolated" (P16, FC).

**Perceiving the care as a difficult whole:** the statements of all participants indicated that they perceived the care as a difficult whole because of all the injuries sustained.

"I cannot do all this work alone. I cannot do the chores because most of the time I'm with him. I'm having trouble doing his work" (P8, FC).

"His care is too much. I'm busy with him from morning till night. I do not have time for my own work, it's very difficult to take care of him" (P7, FC).

#### **Axis 2: Erosive expenditures**

The category of "erosive expenditures" with three subcategories included "expensive care", "searching for the neglected social supports" and "family economic collapse" illustrates the erosive nature of vegetative patients care at home. This category indicated that caregivers, patients, and families were placed in difficult

financial conditions because of expensive care. Therefore, these families started "searching for the neglected social supports" but eventually the "family economic collapse" was the outcome of this condition. Therefore, the total of these subcategories indicated that they experienced the "erosive expenditures" phenomenon.

**Expensive care:** Participants' statements indicated that various factors led to excessive costs for the families of vegetative patients. Some of these factors that were mentioned by most of the participants included:

The need for a variety of consumable supplies including all types of nasogastric catheters, foley catheter, stomach catheter, sterile gas, serum, medications, band-aids, nappies and extensive hygiene needs were among the causes of expensive care of vegetative patients. "I see that they have to buy many things that run out pretty soon. Things like diapers, anti-sensory band-aids, Nalton Suction, serum, and so many other things..." (P9, PC).

The plurality and cost of non-consumable supplies such as beds, suction machine, air-mattress, and oxygen capsules should also be prepared before the patient is discharged and transferred home. Having to purchase these items would impose other expenses on the family. "Before discharging our patient, they told us to prepare his room's stuff. We bought the bed, suction, wheelchair, and air-mattress, etc ... Prices are too high" (P12, FC).

In addition, these patients need various and nourishing nutrition's which cost a lot; and caregivers had frequently referred to this issue. "The cost of feeding is high. We cannot feed him everything. He needs nutritious foods like meat, chicken, fish, fruits, the sort of foods that are expensive" (P7, FC).

Doing care procedures by professional caregivers who came home from private centers imposed even additional costs on them. "The doctor who came to our house charged \$15. The nurse who came home charged \$5, and charged another \$5 for suction and dressing" (P14, FC).

**Searching for the neglected social supports:** According to the participants' statements, seeking social support was a step that was taken by the families of vegetative patients because of facing heavy costs of taking care of vegetative patients. But families received no or little support after going to these centers such as welfare or insurance agencies.

"They came from welfare agency once, looked at the situation and told us they give \$25 per month. It costs more than \$25 per week. We concluded it is not worth pursuing" (P17, FC).

**Economic collapse of the family:** Finally, the families of the vegetative patients started to sell their real estate, borrow from relatives and even receive bank loans, which caused more financial pressure and economic collapse of the family. "He's the breadwinner of the family and his absence is financially difficult. We had some savings. We got some loans, and borrowed from others" (P16, FC).

But the family caregivers and families of vegetative patients did not give up taking care of the patients and tolerated these conditions through "seeking a solver education", and "keeping their hope".

### Axis 3: Seeking solver education

The category of "seeking solver education" consists of three subcategories: "the necessity of teaching", "greedy search for education," "dynamic independence in care". This category indicated that family caregivers in the field of "necessity of teaching" benefited the strategy of "greedy search for education" from various sources and, they reached the outcome of "dynamic independence in care" because of receiving these trainings. Therefore, family caregivers experienced "dynamic independence in care" in caring of vegetative patients.

**Necessity of teaching:** In their statements, participants emphasized on the need for adequate and desirable education. Two factors that caused the participants to understand the need for education included the following.

The fear of ignorance was one of the factors. The family caregivers of vegetative patients were not quite aware of the changes in the patient's symptoms, and the way of providing care for this condition in the early days after the patient was discharged caused fear and stress in them. "I had not seen such anything like that in my life, I was afraid, I thought such people would not need water and food, it was the first time I saw this situation. For the first 8 months, I was completely in the dark as what to do and it was very hard" (P16, FC).

Another factor was the lack of enough training at the discharge time. The participants acknowledged that the training given to them at the time of discharge was incomplete and limited. "I received little teaching in the hospital. They taught us how to do gavage and suctioning. Of course, the suction is not easy and they taught it only once. They did not tell us about his diet when he was discharged. They did not tell us that he needed a diet counselor. We gave him whatever we cooked" (P12, FC).

**Greedy search for education:** In their statements, the participants acknowledged that they did not have the knowledge and skills to take care of the patient. And so they began to learn from different sources. "I asked everyone at the hospital to get information to be used at home. I asked questions of each of the residents who went to the rotation office at the hospital" (P6, FC). The participants acknowledged that they mostly used professional sources in the search for information. "Nurses who came home taught me a lot of things such as changing his position, feeding, adjusting oxygen, changing his dressing, changing his urine catheter and diaper, and the way of giving him bath" (P12, FC).

It is worth noting that caregivers also searched for information from nonprofessional sources. "I read much on the Internet" (P1, FC).

**Dynamic independence in care:** All family caregivers have stated that they were initially ignorant and fearful of the condition and they were dependent on professional caregivers, but gradually they became independent through searching information and receiving education. "The nurses who came to the house for changing urinary and stomach catheter or his injections, taught me how to do these things, then I learned and did it myself" (P16, FC).

### Axis 4: Lasting hope

The "lasting hope" category consisted of three subcategories: "conditions of hope threat", "Positive thinking about patient recovery" and "hopeful care". "This category represented the fact that family caregivers of vegetative patients were exposed to conflicting opinions and views related to the vegetative patients' situation and because of its consequences that they were placed in "conditions of hope threat". In such a situation, they used the strategy of "Positive thinking about patient recovery" in order to keep hope. Therefore, because of using this strategy, they continued their "hopeful care" and kept their hopes dynamic. Finally, these family caregivers experienced "lasting hope".

**Conditions of hope threat:** the participants acknowledged in their statements that they sometimes were in conditions that could threaten their hope. The factors that put them in such a situation were as follows:

The controversial views of the surrounding people about the vegetative condition and the outcome of the care of vegetative patients was one of the factors that could interfere with the caregivers' hope. According to the participants, there were some negative attitudes towards the vegetative situation. On the contrary, others suggested positive views.

"Many say your youth is ruined, it's no longer useful. They disappoint us. It has a very bad effect on how I feel" (P7, FC).

"Those who were knowledgeable said, "You'll get the reward from God." My father said that every problem has a bright side to it. He said, "Don't lose your hope and keep taking care of him as long as you can" (P3, FC).

It is worth noting that, according to family caregivers, one-way and unanswered communication with a vegetative patient was another factor that sometimes threatened their hope. "I talk to him, but since I do not get an answer from the patient, it becomes a bit repetitive, and sometimes I become discouraged" (P1, FC).

**Positive thinking about patient recovery:** Despite the fact that family caregivers were in a hope threatening condition, they kept their hope by being optimistic. In this regard, they used the following measures:

One of the strategies of positivism for family caregivers was the desire for the patient improvement. "His breath gives warmth to our home. I like this warmth to remain longer. I wish its warmth in our home remained like the first day ... I say, Oh God, will there ever be day when my father will stand up and breathe as before" (P2, FC).

The reliance on spirituality was another way to keep hope that family caregivers often acknowledged. "I have to be hopeful to the end. I am trying to keep the family hopeful. I try to live with the hope so that I can take good care of him. Nobody knows the result of this world's affairs so it is better to be hopeful. Hope makes me do my best" (P17, FC). Family caregivers also benefited from the trust in God and remained optimistic about the patient's improvement. "Nine years is too long, it's so hard, every time I pray, I say O God, give me strength so that I can keep taking care of her. I always had trust in God" (P3, FC).

**Hopeful care:** According to the statements of family caregivers, intellectual positivity and focus on maintaining hope for the patient's improvement caused family caregivers to do their care task hopefully. "Every time I tell myself I'm saving my brother. I want my brother to be alive again; I want him to walk on his feet again. I like to do more for him. Hope is important, I am hopeful and I do my best for him" (P12, FC).

From the data analysis, four main categories were achieved including "erosive care", "erosive expenditures", "seeking for solver education", and "lasting hope". The categories indicated that family caregivers in the process of taking care of a vegetative patient had experienced erosive care in different physical and mental dimensions. The erosive nature of this care was due to the fact that these patients had multiple care needs and they also needed full-time and long-term care. Families of the vegetative patients had to cope with the erosive expenditures as well. The large needs of the patients for the care and treatment imposed heavy costs upon families.

Challenges of erosive care and erosive costs could be important factors in disrupting the patient care process. Despite these obstacles and difficulties, family caregivers and families of the vegetative patients considered taking care of the patient as their own duty and they tried to do

their duty in any way. Therefore, the main concern of family caregivers was "playing inevitable role of care".

Family caregivers did not spare any attempt to address this concern. On the one hand, they tried to reduce the patient's costs by becoming autonomous in taking care of the patient. Therefore, they strengthened their power by finding new information and strategies. It is worth mentioning that there were some conditions in which family caregivers had lost their hope.

Confronting family caregivers with conflicting views about the vegetative status and its outcome on the one hand and the unilateral communication without response, on the other, were the hope threatening factors. Even in this situation, family caregivers kept their hope alive by focusing on the patient's recovery and trust in God in order to play their role in the care process. Hence, "lasting hope" was another way to help caregivers be resilient, facing the challenges of providing home care.

Therefore, in the whole process of nursing the vegetative patients, tolerance was the response of family caregivers to their concern about 'playing an inevitable role in care'. In other words, family caregivers of vegetative patients tried to do their best throughout the care process.

Eventually it turned out that the four axes were under the central axis of the "resilient care" (Figure 1).

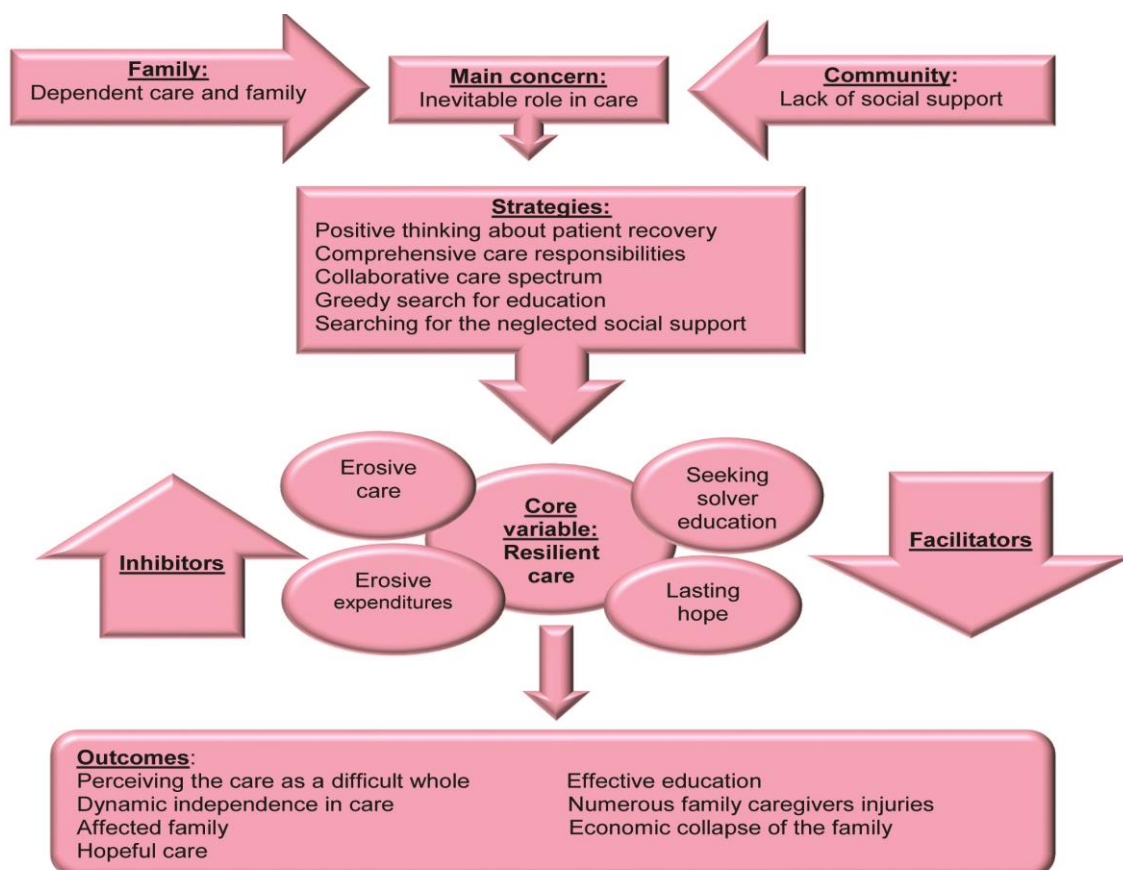


Figure 1. Basic psychosocial process of "Resilient care"

## Discussion

The concept of “**erosive care**” with six subcategories of “comprehensive care responsibility,” “multiple family caregiver damages” and “perception of care as a difficult whole” indicated that the comprehensive care of the vegetative patient provided by the family and family caregivers had erosive consequences.

Long-term care results in caregiver’s burnout. Several studies have shown that nurses suffer from burnout because of care.<sup>28,29</sup> Also family caregivers who care for the family member patients are potentially at risk of distress, burden and reduction of physical and mental health;<sup>30</sup> Because care for a sick person is a kind of job that forces family caregivers to quit their full-time job in order to take care of the patient while they are not paid for this job.

In line with this study, studies of family caregivers of patients with chronic diseases such as neurological disorders,<sup>31</sup> coronary artery surgery,<sup>32</sup> cancer,<sup>33</sup> and vegetative patients<sup>34</sup> have also been shown to impose pressure and distress. Nevertheless, several factors such as the degree of independence of the patient in self-care, duration of care, hours of patient care per day, and the demographic characteristics of caregivers can be effective on the burnout of family caregivers. As the findings of the study by Bugge *et al.*, showed there was a significant relationship between caregivers’ fatigue and distress and the duration of care of the patients with stroke.<sup>35</sup>

Meanwhile, patients with stroke, depending on their degree of inability, have a degree of autonomy and self-control; they are able to communicate and express their needs. This affects the motivation of their family caregivers and facilitates the identification of the patient’s needs; whereas the inability of the vegetative patient for in self-care and communication puts double pressure on the caregiver. In the same vein, McGuire’s study showed that the patient’s disability in expressing wishes and needs is a major contributor to the stress and concern of caregivers.<sup>19</sup>

As it was shown in the present study, the high amount of care, the repeatability and time consuming nature of care, the severity of procedures, and the duration of care are other causes that made nursing of these patients difficult for the caregivers. In the studies of Saout *et al.*,<sup>12</sup> and Leonardi,<sup>36</sup> the daily care time required has been reported to be between 3 to 7 hours that puts pressure on caregivers. In these two studies, the patients were taken care of in health centers by professional caregivers; while in the present study, the patients were taken care by family caregivers at home.

The axis of “**erosive care**” suggests that providing care for vegetative patients at home the families without support and follow-up at home has eroded the families in various dimensions; nevertheless, they tolerated all the problems and difficulties so as to play their inevitable role of care.

The concept of “**seeking solver education**” with three subcategories “necessity of education” , “greedy search for education” , “dynamic independence in care” showed

that family caregivers sought information from various professional and non-professional resources in order to play their inevitable role of care.

Rapid discharge from the hospital, relying more on outpatient care and increasing the outbreak of chronic diseases have increased the demand of family caregivers for care at home. But family caregivers need information and education to make sure they meet their patient’s needs.<sup>37</sup> So, the information need for patients with a critical condition is very important.<sup>38</sup> The findings of this study showed that family caregivers of vegetative patients also needed information and education for home care. In line with this study, the results of studies on the care of patients with other chronic diseases, including diabetic patients,<sup>39</sup> and patients with consciousness disorders<sup>19,40-42</sup> revealed that receiving information and awareness was one of the main needs of family caregivers and patients.

In this study, the need for education had some reasons. The stressful unawareness of family caregivers about care and issues related to vegetative patient was one of these causes. In accordance with the present research, the study by Evans *et al.*, also showed that the participants talked about the fear of the first days due to unawareness.<sup>43</sup> But in the present study, another reason that caregivers stated for the necessity of education was the poor education at the discharge time. Implementing a discharge plan is one of the key nursing care that could yield many benefits for the person, family and community; however, this program is not being well implemented for a variety of reasons.<sup>44</sup>

In addition, various studies consistent with the present study showed that the family caregivers were craving to obtain information.<sup>38</sup> Therefore, in response to this craving, family caregivers of vegetative patients in this study greedily sought information and education from various professional and non-professional sources. In line with this study, in the study of Verhaeghe *et al.*,<sup>45</sup> caregivers of comatose patients also used different sources, including professional or nonprofessional people with similar statuses. Other studies have also confirmed this issue.<sup>39</sup> Therefore, it can be understood that the greedy search for information has been a way of reducing fear of unawareness by the caregivers. In addition, in line with the current study, Taleghani *et al.*, in their study on cancer patients also found that getting knowledge from various sources helped them reduce their fear and anxiety,<sup>46</sup> but it would be better and more useful if the necessary information is provided by professional sources. In the present study, family caregivers have received most of the information and training they needed from the nurses who came home.

The result of this effort was receiving gradual learning and autonomy in care that reduced family caregivers’ stress and pressure. In line with the current study, several studies have shown that this issue has decreased the anxiety, depression and emotional distress in family caregivers.<sup>47,48</sup> Therefore, it seems that in case of family caregivers’ burnout as it was obvious in the present study, they turn to a greedy search for information to



address their care concerns and be able to tolerate erosive care.

The concept of “**erosive expenditures**” with three subcategories including “expensive care”, “search for the neglected social support” and “family economic collapse” represented the economic collapse of families with vegetative patients.

In line with the current study, numerous internal studies on other chronic diseases with common grounds, such as multiple sclerosis,<sup>49</sup> and patients with acute leukemia<sup>50</sup> also showed high levels of care costs for chronic patients. In the McGuire’s quality Study, caregivers of comatose patients indicated their complicated financial situations despite being sponsored by insurance companies or the state.<sup>19</sup> Participants in the study by Covelli et al., also acknowledged that on the one hand, the caregivers’ obligation to leave their job permanently or temporarily in order to care for the patient reduced their income and, on the other hand, the costs of the needed care for their patient worsened their economic conditions.<sup>51</sup> In a nutshell, Crispi and Crisci indicated that the high cost of vegetative patients’s care imposes the major problem for their families.<sup>52</sup> Although, in the studies conducted in other countries, families and family caregivers of patients had health system support, they were still grumbling about the financial burden.

Therefore, in our country where the nursing of vegetative patients is done without any support being provided to the families and family caregivers, the financial burden and family economic recession is a more serious problem.

The concept of a “**lasting hope**” with three subcategories including “the conditions of hope threat”, “intellectual positivism for patient recovery”, and “hopeful care” illustrated the efforts of family caregivers of the vegetative patients throughout the care period despite numerous problems. In the present study, encountering family caregivers with controversial perspectives on the nature of the vegetative situation placed them in a position that could affect their situation of hope or frustration, because some felt that patients in this condition lack perception and feelings, but others as well as the caregivers themselves did not believe so. In addition, the fear of the future and the uncertain outcome of the patient’s condition was another threatening factor for the caregivers’ hope. In line with this study, Covelli et al., also found that caregivers of vegetative patients fear thinking about the future.<sup>51</sup>

Difficulty in the caretaking of vegetative patients was another contributing factor to the hesitation regarding the nature of the disease and the outcome of care. In this light, Romaniello et al., attributed the high level of disappointment in family caregivers of vegetative patients to the nature of the chronic disease. Of course, this issue did not disappoint them completely and the caregivers often experienced a fluctuation of hope.<sup>53</sup>

Similarly, in the present study, caregivers stated that they always kept their hopes, but when the patient was getting worse, they felt disappointed. In line with the findings of this study, the results of Farsi et al., also

showed that fear and hope in people with acute leukemia were changing in the stages of diagnosis and treatment, and patients oscillated between them in different stages.<sup>50</sup> Therefore, the chronic nature of the disease and the outcomes of care and treatment leave patients and caregivers in a fluctuating hope and disappointment.

In case of hope threat, family caregivers created a positive inclination toward recovery of their patient, focusing on positive thoughts and beliefs and thereby maintained the hope for the patient’s recovery, the consequence of which is to cope better with the problems of the vegetative patient’s care. This strategy of positive thinking and induction is not unique to the caregivers of the patients in the present study and it has been seen in other chronic diseases.<sup>54</sup>

In addition, in this study, family caregivers used religious strategies with great emphasis on maintaining their hope. In different cultures, illnesses and disabilities have different meanings that have been construed as rewards, punishments or divine tests.<sup>55</sup> In the present study, it was considered as a divine test. This positive view certainly kept their hope alive. In line with the present study, in numerous studies on chronic diseases such as cancer,<sup>54</sup> and diabetes,<sup>39</sup> patients had similar views and considered the disease as a divine gift, examination, or providence, and submitted themselves to God’s satisfaction. In several other studies, trust in God was a strategy that kept family caregivers’ hope so that they could carry out their care responsibilities in the best possible way.<sup>54,56,57</sup> Thune-Boyle et al., also believes that religious beliefs contribute to disease tolerance.<sup>55</sup>

Based on the concept of “**resilient care**”, it became clear that family caregivers of vegetative patients, despite the existence of several problems, have resorted to various approaches to handle their duties in the best possible way and tried to tolerate the hardship to the best of their abilities.

Studies conducted on the care process in Iran have often covered professional care in hospital wards. Molazam et al., in the study of the care process in the surgical ward, found the concept of dealing with unfavorable contextual conditions.<sup>58</sup> Mahmoudi et al., achieved the concept of position fixation in the emergency care.<sup>59</sup> These concepts indicate that in acute wards, the focus of care is on fixing and taking control of the situation.

In contrast, Masoudi et al., achieved the concept of “**dynamic effort for sustainability and standing**” in the study of the process of caretaking for multiple sclerosis patients as a chronic disease.<sup>60</sup> This concept was the strategy for caregivers of Multiple Sclerosis patients in response to their main concern to “preserving the situation and preventing the deterioration of the situation”. The concept of “dynamic effort for stability and sustainability” in Masoudi’s study is similar to the concept of “**resilient care**” of vegetative patients in the present study.

Because both of them somehow show resistance to difficult situations as well as tolerating of long-term care of chronic illness. The exposure of patients and caregivers

to ups and downs of chronic conditions during long-term care period has caused them not try to control or fix the situation rather, by keeping hope, they look for a dynamic effort to tolerate the difficult conditions of vegetative state and multiple sclerosis case.

Montgomery and Kosloski who have done many studies on long-term care experiences presented a marker framework. Based on this model, the seven indicators of providing care are: I. carrying out the primary care task II. Presenting the definition of care III. Providing personalized care IV. Searching and using assistance services. V Attempting to be admitted to a hospital or a nursing home. VI. Delivering to the nursing home. 7. Terminating the care role. In addition, they believed that the order and timing of the mentioned indicators are based on the relation of caregivers to the patient, type of care and the existing culture will be different.<sup>61</sup> If the resilient care of vegetative patients done by family caregivers in the present study is regarded based on these markers, it seems that in the cultural context of Iranian society, care for the patients is done up to the fourth step only. Because on the one hand, there are no such centers available in the country, and on the other hand, families are obliged to provide care because of their cultural conditions despite all the difficulties.

Of course, it should be noted that along with the fourth indicator of this model, namely, the search for support centers, the families of the vegetative patients in our country were faced up with defective support links. This is while they understand the need for support and In addition, helping them ensure more effective and less complicated care for their family and family caregivers. In the same vein, findings of Mitchell and Chaboyer's study on the experiences of families on the provision of care to patients in the ICU showed that using one family-based care model has provided a lot of satisfaction in the family.<sup>62</sup>

Therefore, despite the lack of centers for caring of vegetative patients in the health system of our country, providing the minimal support by the health system through family-based care can reduce the pressure on the family. Therefore, the family-based care process of the patients in the health system of our community suggests the tolerability of this care for family caregivers and families of vegetative patients. The families and caregivers of vegetative patients should be financially, physically and mentally supported throughout the care period.

## Conclusion

The findings of this study showed that because of the health system's weakness in the establishment of caring centers or providing home visits for vegetative patients, their family caregivers are forced to undertake compulsory care of their patients. Affective affiliation of the family caused family caregivers to see their patient care as an inevitable duty.

Nevertheless, in the direction of playing this role, they experienced physical and psychological burnouts as well

as financial dissipation. On the other hand, the special nature and uncertainty of its outcome could interfere with the hope of the caregiver during the care path. Despite all the aforementioned difficulties, family caregivers tried to tolerate the mentioned problems through searching information and keeping their hopes in order to do their role as long as necessary.

Therefore, planning and policymaking of the health system for the appropriate care of vegetative patients in the form of designing specific care units for vegetative patients, determining the component of visit and care at home, determining a specific support organization for these patients, and the provision of financial or educational support for the families of these patients can be very effective in preventing the damages to their family and caregivers. And also, because of the varied problems of the families with patients in vegetative state, including heavy costs and burnout in the family caregivers and psychiatric damages in other family members, there is a pressing need for further studies in these domains, which might be useful in preventing such problems or identifying the best possible ways of handling them.

A limitation in this study was finding the patients in vegetative state and their family caregivers. The reason for this limitation was the weakness in recording the information of the patients. So recording the characteristics of the patients carefully in hospitals and clinics should be emphasized. Also establishing a supportive institute for these patients and their families can be helpful in this matter.

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## Ethical issues

None to be declared.

## Conflict of interest

The authors declare no conflict of interest in this study.

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