

Living with the patient who has persistence vegetative state: a qualitative study

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Abstract

Aim: The purpose of this research is to discover the experiences of the families with Persistence Vegetative State (PVS) patients have during homecare after being discharged from Palliative Care Center. In this study, it has been tried to bring out the difficulties occurring during homecare and the reasons for these difficulties.

Material and Methods: The study is envisioned to be qualitative in regards with phenomenological approach, face to face and semi-structured interviews. The study carried out with the 17 family members of patients with PVS voluntarily at their houses. Interviews were analyzed according to qualitative content analysis.

Results: The age average of the family members in this study were 48.2±14.3 year, 12(70.6%) of them were woman. 7(41,2%) of the care providers were the spouse of the patient. The families gave homecare at a median value of 466(IQR =326) days. The study results brought out 4 main themes. The main themes were; Severe Burden, Concern/Fear, Limitations/Incompetencies, Hope/Acceptance/Rejection.

Conclusions: The study results indicate that it is very tough for families to have patients with PVS and they have to go through some strains as a result of the circumstances. With this study, it's set forth that in order to reintegrate these families into the society, support the ones with financial, physical and psychosocial problems, there has to be a social, health related and economic interference and policies have to be developed.

Keywords: Palliative Care; Persistent Vegetative State; Family Caregivers; Quality of Life; Psychosocial.

INTRODUCTION

Vegetative State (VS) is a state where the patient and patient's surrounding is oblivious to goings-on in their surroundings (1,2). Brain injuries are divided into two as traumatic and non-traumatic brain injuries. (3,4). Traumatic brain injuries (TBI) occur as a result of traffic accidents, gunshot injuries, falling, assaults and etc. (3,5). The causes of non-traumatic brain injuries (NTBI) are asphyxiation of the brain, cerebral hemorrhage and similar diseases (3,6). If the VS state still continues 3 months after NTBI and 12 months after TBI, the state can be identified as Persistence Vegetative State (PVS) (4,7,8). With whatever reason it is one of the worst case scenarios for patients who managed to stay alive after severe brain injuries is being with a VS (9).

There are strains to be dealt with in regards with homecare for patients with PVS after being discharged. Among all of them, dealing with emotional problems, difficulties of

giving care at home, and economic and social problems are the main issues (7,10). The need for long-term homecare for such patients are mostly fulfilled either by professionals in healthcare or social care (formal) or by family members, friends, people with no professional background (Informal) (11).

Homecare of patients with PVS can affect the quality of life of both the patient and the family of the patient negatively. Therefore, it is important for the families of PVS patients to be taught how to manage to live under such circumstances before being discharged. It is recommended for the palliative care to be taken at the earlier stages of the illness (12). Moreover, for patients with TBI, palliative care has important contributions both to the patient and to the patient's family (13). For one of the goals of palliative care is not only to increase the quality of life of the patients but also patient's families (12).

In this sense, Ankara Ulus State Hospital is the first hospital

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to give Palliative Care Center (PCC) in a civilized manner. There are trainings for families of the patients who are accepted to PCC in regards with how to give care at home, how to cope with difficulties during homecare and how to manage to live under such circumstances. In this study, the objective was to enable the integration of patients with PVS who were accepted to PCC after intensive care and discharged to homecare and to evaluate the difficulties that their families go through. And it is important that this study, being the first in this field in Turkey, will enlighten the way in developing supportive policies due to the increase in the quality of lives of such patients and their families.

MATERIAL and METHODS

The study is envisioned to be qualitative in regards with phenomenological approach. Purposeful Sampling Method was used during face to face and semi-structured interviews with the family members of patients with PVS who were discharged from PCC of Ankara Ulus Public Hospital. The interviews continued until data saturation was obtained (n = 17). Reporting was guided according to the consolidated criteria for reporting qualitative studies (COREQ) (14).

The information of the patients who attended the study was taken from hospital records. The interviews took place between 8th and 18th days of May, 2017, in the houses of the families who voluntarily attended the study and an audio record device was used during the interviews. The interviews were recorded with the attendees' permission as verbally. In interviewing family, question was asked to explain their experience during the care. The average time of the interviews was 50.25 minutes (from 20 to 98 min).

The research ethics committee approval was obtained from Ankara Numune Training and Research Hospital, registry number E17-1282 on February 22nd, 2017. All procedures were applied in accordance with the principles of the World Medical Association Declaration of Helsinki.

Data Analysis

The sufficiency of continuous variables (age, duration of illness, homecare period) to normal distribution was evaluated graphically by using Shapiro-Wilk test. It's observed that the age variable distributed normally when the duration of illness and homecare was not. When the descriptive statistics for age was viewed as average (±) Standard Deviation, the duration of illness and homecare was viewed with, median value [Inter Quartile Range (IQR)]. When projecting categorical variables (gender, degree of affinity, educational background, people who support care givers) numbers and percentages were used.

In data analysis content analysis method was used (15). The audio records were transferred into electronic environment. After following several reviews, meaningful units related to parts and sections of data were summarized and evaluations of the data received, possible codes were formed which can be brought out from each word and sentence. After the formation of the code, the obtained codes were compared based on their

similarities and differences. The codes were classified and adequate themes were extracted. Subsequently, the findings were interpreted and compiled into a report. Only some of the attendee's statements were covered since it was not possible to cover all statements in regards with theme description.

RESULTS

The attendees were at the age average of 48.2±14.3 years where 12 (70.6%) of them were woman and 7 (41.2%) of them were primary school graduate. Seven (41,2%) of the attendees were the spouse of the patient and 6 (35,3%) of them were the mother of the patient. Seven (41,2%) of the attendees were giving care with other children and 5 (29,4%) of them were giving care with their spouses for the median value of 466 (IQR =326.5) days (Table 1).

	n (%)	Mean±Sd	Min-Max (IOR)	Median
Degree of Affinity*	Mother		6 (35,3)	
	Father		2 (11,8)	
	Spouse		7 (41,2)	
	Son		2 (11,8)	
Gender of Family Member*	Woman		12 (70,6)	
	Man		5 (29,4)	
Age of Family Member**		48,2 ±14,3	(23-74)	
Educational Background of The Family Member*	illiterate		2 (11,8)	
	Primary school		7 (41,2)	
	High School		6 (35,3)	
Who does he/she give care with?*	Undergraduate		2 (11,8)	
	Spouse		5 (29,4)	
	Child		7 (41,2)	
	Sister/Brother		1 (5,9)	
What is the period of homecare? (days)***	Caretaker		4 (23,5)	
			466 (326.5)	(84-1288)
Gender of The Patient*	Women		2 (11,8)	
	Man		15 (88,2)	
Age of The Patient**		40,5 ±16,5	(18-67)	
Period of Illness (days)***		648 (IQR =688)	(285-1907)	
Diagnosis of The Illness*	Traffic accidents Inside vehicle		3 (17,6)	
	Traffic accidents Outside vehicle		2 (11,8)	
	Epidural haemorrhage		4 (23,5)	
	Anoxic brain		6 (35,3)	
	Falling		2 (11,8)	
	Trauma Type*	Traumatic		7 (41,2)
	Nontraumatic		10 (58,8)	

*n (%) **Mean ±Standart deviation ***Median (Interquartile range (IQR))

The age average of 15 (88,2%) male patients were 40,5±16,5 years. Ten (58,8%) of the PVS patients whose median value was 648 (IQR=688) days had NTBI (6 cases of anoxic brain, 4 cases of epidural haemorrhage), 7 (41,2%) of them had TBI (5 traffic accidents, 2 cases of falling). Also 15 (88,2%) of the patients were in PVS when 2 (11,8%) of them were in VS (Table 1).

Four themes were brought out from the interviews, and these themes were formed out of 11 categories (Table 2).

Table 2. Themes and categories

Themes	Categories
Severe Burden	Physical Burden
	Psychological Burden
	Formation of Pressure Sore
Concern/ Fear	Care at home
	An urgent medical condition regarding the patient to occur
	Economical
Limitations/Incompetencies	Public life
	Depending on the healthcare system
	To look for a remedy
Hope/Acceptance/Rejection	To hope
	Acceptance/rejection

Severe Burden

This theme focuses on psychological and physical burden. The attendees were stating that it was very hard to see their patients confined to bed, without any movement, and unconscious and not being able to do anything was making them feel desperate, helpless and exhausted.

"...His/her father is stressed out and very sad...Even though he had bypass surgery and quit smoking, he started again because of the circumstances...he forbid himself to be happy and stated that he can never be happy" (No: 1, Mother, 67 years of age)

"Spiritual Burden...It is pretty exhausting and sad to see a young person being in such a situation...we learned the meaning of desperation and how hard it is to handle." (No: 3, Father, 46 years of age)

"It is pretty tough to live in the same house with a patient who is confined to bed. My psychology is messed up. I'm exhausted and very tired and I want to cry constantly." (No: 6, Spouse, 55 years of age)

"I cannot even go into the room for I cry the moment I enter and get out right away" (No: 12, Spouse, 74 years of age)

"It was very tough to handle seeing him coming into the house in that situation. To be desperate, not being able to do anything. To see my son like that is very hard psychologically." (No: 14, Mother, 46 years of age)

Some attendees indicated that they were in need of psychological help regarding the experiences they had.

"Yes, there is an economic and social difficulty part to it but mostly we are in need of psychological treatment. I am

not some paper and my life is not consisted of the form you filled out. The people who will really understand what I'm going through are healthcare professionals." (No: 3, Father, 46 years of age)

"If you ask me, the government has to psychological support the whole family" (No: 16, Son, 28 years of age)

Moreover, the attendees indicated that the care they give is with love and passion however 24/7 homecare makes them feel tired, sleepless, also added that in order to prevent the patient to have pressure sore, they have to lift their patient and rotate them every two hours which is causing health problems of their own.

"I take care of my baby with love, but we are having a hard time getting him up for he gained weight and my knees are in a bad situation. We have been taking care of him for 5 years and just because we couldn't leave him, we weren't able to pay attention to our own health. (No: 1, Mother, 67 years of age)

"The muscle fiber of my arms was torn because of lifting and forcing. In this sense, I am having hard time while cleaning him up and rotating him. My other son injured his back and he has a slipped disc." (No: 8, Spouse, 50 years of age)

"I lost my health, developed a heart disease, and my varicose veins increased because of having to remain standing constantly." (No: 13, Spouse, 37 years of age)

"It is not tough to feel tired, I have forgotten myself so much that, I haven't been taking care of myself for 1, 5 years." (No: 14, Mother, 46 years of age)

"We cannot lift our patient or rotate him/her. We cannot sleep in a comfortable environment. We have to get up constantly at night like we are taking care of a baby. We are up hourly." (No: 17, Mother, 72 years of age)

Concern/ Fear

This theme focuses on the fear and concern of having an urgent medical condition regarding the patient to occur, formation of pressure soar, and being able to give care to the patient at home. The attendees indicated that they are concerned due to the fear of their patient forming pressure soar, of having an urgent medical condition to occur regarding their patient and if they can give the necessary care at home to their patients.

"We fear that the wound will open up, even if it is day or night, we get up and change his/her position. We've had enough of such wounds." (No: 5, Spouse, 48 years of age)

"I feel like, I've dedicated myself to her/him. I fear that something bad might happen when I go out." (No: 6, Spouse, 55 years of age)

"I'm worried that my patient's wound will open up." (No: 7, Spouse, 40 years of age)

"I panicked when they first told us that they were going to discharge our patient. I thought I was not going to be able to give care." (No: 9, Spouse, 58 years of age)

"We were worried mostly about what to do when he/she has sudden attacks. Is it possible to have professional

interference on time?" (No: 15, Father, 54 years of age).

In the meantime, the attendees also indicated that, even though they were scared to be discharged for they had to give the necessary care at home, they then pointed out that by the help of the trainings they have taken at the PCC, and they were able to take care of their patients at home comfortably. Moreover, they implied that, it is better to take care of their patients at home rather than the hospital.

"I do not have any problems during giving the necessary care; we were trained at the hospital regarding how to do it." (No: 4, Son, 23 years of age).

"..Palliative care has thought me a lot...It was like the end of the world for me when they told us that they were going to discharge our patient. Other families should never fear to be discharged." (No: 9, Spouse, 58 years of age)

"I'm glad we stayed in the hospital and took the necessary trainings. I do not have a hard time at all while giving care. I manage to handle everything." (No: 11, Mother, 50 years of age)

"They showed me what to do at the hospital. I was very scared at first however after being discharged; I figured out that there was nothing to worry about. On the contrary, it was easier for me to give care at home." (No: 13, Spouse, 37 years of age)

"We were sad at first when they told us to take our patient home; however after being discharged, it was more peaceful at home. (No: 17, Mother, 72 years of age)

Limitation/Incompetency

This theme is based on limitations due to economic, social life and incompetency of healthcare system. The attendees indicated that they were going through hard times to supply necessary material to give care at home, necessary medicine, and to take the rehabilitation treatment for they were not affordable. Additionally, it was pointed out by the families that the healthcare system was incompetent when it comes to transferring the patients, not having a healthcare unit for such patients to be able to reach directly in case of an emergency, and not having a home care system. Moreover, they indicated that with the fear of something bad is going to happen any minute, they couldn't go out and if they did, it was pretty limited so they did not have a social life at all.

" His/her father is asking me how I can go there with a smiling face and celebrate his/her birthday." (No: 1, Mother, 67 years of age)

"The biggest trouble is that no ambulance shows up when there is something urgent. Unavoidably, you are stuck in a room, I cannot go out. I cannot spare time for myself" (No: 2, Step Mother, 40 years of age)

"The period of prescribed formula of medical food has ended. They cannot come to the home care and prescribe a new one. " (No: 4, Son, 23 years of age)

"I am no longer free. You breath, eat, but your previous comfort and solitude or life no longer do exist." (No: 7, Spouse, 40 years of age)

"My husband has 2000TL of pension and it is impossible for me to afford all the medical care with that amount. The medicine, the physiotherapist who comes to the house, the cannula has to change twice a month and its unit price is 500 TL. How is it possible to afford them all?" (No: 9, Spouse, 58 years of age)

"He had diarrhea and I called home care, they told me that they only deal with blood, and to take him to our family practitioner. When I called the family practitioner, they told me that it was not in their range of work" (No: 10, Mother, 33 years of age)

"I am going through transfer problems. It is impossible to reach 112" (No: 15, Father, 54 years of age)

"We go through financial difficulties every once in a while. We couldn't go back to our normal life actually. No matter what, life goes on, when we are out; my mind is always at my father." (No: 16, Son, 28 years of age)

"We don't go out. We continuously stay in two people beside him to give care. I left the village to take care of my baby." (No: 17, Mother, 72 years of age)

Although most of the attendees indicated that they did not go out, have a limited social life and physically tired, they were not interested in hiring a professional caretaker even if they are financially capable of doing so.

" Somebody had to take care of him and there was no one and since they did not want a professional caretaker, I quit my job and start taking care of my father. For the caretakers give care with their eyes only." (No: 4, Child, 23 years of age)

"No, I can never leave my patient to anyone. The caretaker might give care but no one can give care the way we do." (No: 5, Spouse, 48 years of age)

"I need a helper to support me at home, not a professional caretaker for I would like to take care of my son on my own." (No: 10, Mother, 33 years of age)

"They told me if I wanted a caretaker to take care of my child for me to be able to have some time of my own, I said no. I did not accept. I cannot leave my kid to anyone." (No: 11, Mother, 50 years of age)

"I would like to take care of my patient on my own. I do not trust anyone regarding this issue. Of course, I would like to have someone to handle the work in the house, do the cleaning and etc." (No: 13, Spouse, 37 years of age)

Hope/ Acceptance / Rejection

This theme focuses on looking for a remedy for the patient, to hope for the patient to heal, acceptance and rejection regarding the patient's situation. The attendees indicated that they have taken their patients to various doctors for cure, they understand some of the reactions their patients give, and they still have hope for they believe in God. However according to their remarks, when some of them were accepting the situation of their patient, very few were not.

"I still cannot accept the situation and I still feel guilty and full of remorse. I've consulted with the doctors at Beijing. They told me to take my patient to them for stem cell

therapy. We had bioenergetics." (No: 3, Father, 46 years of age)

"We accepted the situation. We cannot lose hope for we believe in God. At first, they told us that he was not going to make it and can only live connected to a machine. But there is no need for a machine now." (No: 5, Spouse, 48years of age)

"My son searched through the internet. There is a doctor at.... Tomorrow we will take our patient to that doctor. Let's see what this doctor will say." (No: 8, Spouse, 50 years of age)

"When his/her uncle talks to him/her, tears come down from his/her eyes. This means he/she hears us!!" (No: 11, Mother, 50 years of age)

"What are you going to do if not accept the situation? How can you stand against God? He chews the gum given constantly. Feels like she/he is conscious." (No: 12, Spouse, 74 years of age)

"I keep telling myself that I hope he will wake up one day. We did not lose our hope. I pray to God. However you can accept! We call it faith." (No: 14, Mother, 46 years of age)

"We fought so hard for him/her to wake up. Thank God, we have come this far. We still haven't lost hope." (No: 15, Father, 54 years of age)

DISCUSSION

At the end of our study, it was observed that to have patients with PVS was a very difficult situation for the families and they had to live through these difficulties. These difficulties are similar to the ones which were specified in previous studies. The first difficulty is that during homecare, the care givers are neglecting their own health due to the 24/7 care giving. They injure their backs or arms as a result of lifting, rotating their patient, they are tired and sleepless for they have to stay awake most of the time. The family members who give one to one care have to face with physical injuries due to the continuous care they have to give and they indicate that they face with back and arm pain, in addition to feeling tired and getting sick for they are neglecting their own health (10,16). The families neglect their own health for they feel they are the only ones who can understand and provide the needs of their patient (17).

The second main difficulty that the families with PVS patients is psychological problems like deep sadness and depression, desperation and frustration they go through due to their loved ones losing their health all of a sudden and get into the situation of being with PVS. Moreover, they are socially isolated due to the fear of something bad is going to happen to their patient and not being able to leave them in addition to the psychological problems they have. In previous studies, it has been notified that the care givers of such patients have cognitive and mental problems and socially isolated based on stress (2,10).

At one of the studies, it has been notified that the psychological burden of the caretakers of PVS patients was gradually decreasing after 2,5 years due to finding out that there are physical and psychological burdens and

learning the strategies of how to cope with these burdens and stress while the economic burden was still affecting them negatively (11). In another study, the caretakers were going through high levels of long-term grief disorder and the coping strategies were being helpful (18). It is recommended by the studies that the families with PVS patients should get professional help in regards with their psychological situation (19-21). As a result of having to go through high levels of burden, difficulties in social life, changes in the quality of life for the families living with unconscious patients, in order to integrate them psychologically, socially and environmentally, a need for supportive interference occurs (19).

The first concern of the caretakers is to get social support on coping with difficulties. However, there are lots of deficiencies in the support system (22). Unfortunately in Turkey, there aren't support programs for caretakers to give them the necessary help during care giving and socializing.

Even though the families go through social isolation, get extremely tired, and exhausted, it is thought that feeling the need to give the necessary care to their father/ children/ spouse on their own, not trusting to others, and not accepting professional caretakers is because of the structure of the Turkish culture being male-dominated. No matter how much they would like to give the necessary care on their own, they indicated that they need a helper at home to help them with the house work. Although the municipality gives cleaning service for free once in 1-2 months, such support is found insufficient by the families.

The third difficulty is that in case of an urgent medical situation occurring related to the patient, the families couldn't interfere at home and fears for their patients to form pressure soar. It is notified that, families who were afraid to give care alone without professional help in the beginning were later rid of their fears after getting the necessary trainings in regards with how to give care at home from PCC before being discharged.

They even indicated that it was easier to give care at home when compared with hospital. There is a study which states that during the period of patients in PVS being discharged, the trainings on care giving at home by nurses help the families in enabling their own well-being (23).

Another difficulty that the families were going through was the financial problems that they had in providing the necessary material, handling rehabilitation expenses. It is also notified in other studies that the caretakers go through financial problems (2,11).

In this study, the families indicated that they pay contribution for the most needed materials whereas they do not pay contribution for the less needed ones. The Social Security Institution can make a review on which materials should have contribution margin in regards with supporting the families on mostly needed materials and economically. Also there has to be physical therapy services for patients who are confined to bed. It would be favorable for physical therapy services to be provided at home due to the economic difficulties that the families

are going through and the difficulties in transferring the patients. It is thought that these arrangements will be a great support for the families.

The difficulties that the families have to go through during homecare and the limitations and incompetence due to the healthcare system like transferring the patient and providing healthcare service at home, which is notified as the fifth difficulty that these families were going through. It is thought that such limitations and incompetence can be prevented by legislative arrangements and by getting necessary policy decisions in act. Programs have to be developed due to public health and economics and implementation of social and psychological support is recommended in regards with supporting and providing the needs of caretakers (24). It is thought that such models can also be used in Turkey.

It is observed that, the families carry hope in their patients recovery due to their beliefs in God, misinterpretations of involuntary movements of their patients and spontaneous respiratory of their patients when connected to the machine (6,25).

For the families with patients with PVS who are going through financial physical and psychosocial problems regarding homecare, it is necessary to determine social, economic and healthcare policies in regards with decreasing the burden of these families and enable ease for homecare by the public system. In this sense, this study would be a great guidance for international the researcher who interested in this area.

With this study, it is notified that after intensive care is completed, the trainings given to patient's families regarding how to give care at home will have some advantages. These advantages; By decreasing the fear and concern of the families, it's made possible for the period at home to pass more comfortably and unnecessary hospitalization of the patients and the unnecessary financial burden on public would be prevented.

This study is very important because it enlightens especially the problems of the families with PVS patients have to go through. In order to support families with such patients and to create a realization on how important these difficulties are. It also notifies that there have to be a new prevalence studies on PVS in Turkey.

REFERENCES

1. Shea N, Bayne T. The Vegetative State and the Science of Consciousness. *Br J Philos sci* 2010;61(3):459-84.
2. Chiambretto P, Moroni L, Guarnerio C, Bertolotti G, Prigerson HG. Prolonged grief and depression in caregivers of patients in vegetative state. *Brain inj* 2010;24(4):581-8.
3. Giustini A, Pistarini C, Pisoni C. Traumatic and nontraumatic brain injury. *Handb Clin Neurol* 2013;110:401-9.
4. Estraneo A, Moretta P, Loreto V, Lanzillo B, Santoro L, Trojano L. Late recovery after traumatic, anoxic, or hemorrhagic long-lasting vegetative state. *Neurology*. 2010;75(3):239-45.
5. Theadom A, Feigin V, Reith FCM, Maas AIR. Epidemiology of Traumatic Brain Injury. In: Winn HR, editor. *Youmans and Winn Neurological Surgery*. Seventh ed: Elsevier; 2017. p. 2748-54.
6. Monti MM, Laureys S, Owen AM. The vegetative state. *BMJ* 2010;341(c3765):292-6.
7. Bastianelli A, Gius E, Cipolletta S. Changes over time in the quality of life, prolonged grief and family strain of family caregivers of patients in vegetative state: A pilot study. *J Health Psychol* 2016;21(5):844-52.
8. Saout V, Ombredane MP, Mouillie JM, Marteau C, Mathe JF, Richard I. Patients in a permanent vegetative state or minimally conscious state in the Maine-et-Loire county of France: A cross-sectional, descriptive study. *Ann Phys Rehabil Med* 2010;53(2):96-104.
9. van Erp WS, Lavrijsen JC, van de Laar FA, Vos PE, Laureys S, Koopmans RT. The vegetative state/unresponsive wakefulness syndrome: a systematic review of prevalence studies. *Eur J Neurol* 2014;21(11):1361-8.
10. Goudarzi F, Abedi H, Zarea K, Ahmadi F. Multiple Victims: The Result of Caring Patients in Vegetative State. *Iran Red Crescent Med J* 2015;17(6):e23571.
11. Covelli V, Sattin D, Giovannetti AM, Scaratti C, Willems M, Leonardi M. Caregiver's burden in disorders of consciousness: a longitudinal study. *Acta Neurol Scand* 2016;134(5):352-9.
12. Connor ST, Bermedo MCS. *Global Atlas of Palliative Care at the End of Life: The World Health Organization, Worldwide Palliative Care Alliance*; 2014.
13. Kahveci K, Dincer M, Doger C, Yarici A. Traumatic brain injury and palliative care: a retrospective analysis of 49 patients receiving palliative care during 2013-2016 in Turkey. *Neural Regen Res* 2017;12(1):77-83.
14. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care* 2007;19(6):349-57.
15. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004;24(2):105-12.
16. Caicedo C. Health and Functioning of Families of Children With Special Health Care Needs Cared for in Home Care, Long-term Care, and Medical Day Care Settings. *J Dev Behav Pediatr* 2015;36(5):352-61.
17. Cipolletta S, Pasi M, Avesani R. Vita tua, mors mea: The experience of family caregivers of patients in a vegetative state. *J Health Psychol* 2016;21(7):1197-206.
18. Elvira de la Morena MJ, Cruzado JA. Caregivers of patients with disorders of consciousness: coping and prolonged grief. *Acta Neurol Scand* 2013;127(6):413-8.
19. Giovannetti AM, Covelli V, Sattin D, Leonardi M. Caregivers of patients with disorder of consciousness: burden, quality of life and social support. *Acta Neurol Scand* 2015;132(4):259-69.
20. Leonardi M, Giovannetti AM, Pagani M, Raggi A, Sattin D. Burden and needs of 487 caregivers of patients in vegetative state and in minimally conscious state: results from a national study. *Brain inj* 2012;26(10):1201-10.
21. Giovannetti AM, Cerniauskaite M, Leonardi M, Sattin D, Covelli V. Informal caregivers of patients with disorders of consciousness: experience of ambiguous loss. *Brain inj* 2015;29(4):473-80.
22. Noohi E, Peyrovi H, Imani Goghary Z, Kazemi M. Perception of social support among family caregivers of vegetative patients: A qualitative study. *Conscious cogn* 2016;41:150-8.
23. Imanigoghary ZP, Peyrovi HP, Nouhi EP, Kazemi MP. The Role of Nurses in Coping Process of Family Caregivers of Vegetative Patients: A Qualitative Study. *Int J community Based Nurs Midwifery* 2017;5(1):70-81.
24. Pagani M, Giovannetti AM, Covelli V, Sattin D, Leonardi M. Caregiving for patients in vegetative and minimally conscious states: perceived burden as a mediator in caregivers' expression of needs and symptoms of depression and anxiety. *J Clin Psychol Med Settings* 2014;21(3):214-22.
25. Jennett B. The vegetative state. *J Neurol Neurosurg Psychiatry* 2002;73(4):355-7.