Original Article

Erosive Costs as Experiences of Caregivers of Patients with Persistent Vegetative States: A Qualitative Study

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Abstract

Background: The treatment and care of patients with vegetative states (VS) is very complex and specialized. Prolonged care and obtaining the necessary equipment for the care of these patients at home imposes erosive costs on families. The present study was conducted to explore the experiences of caregivers of patients with VS.

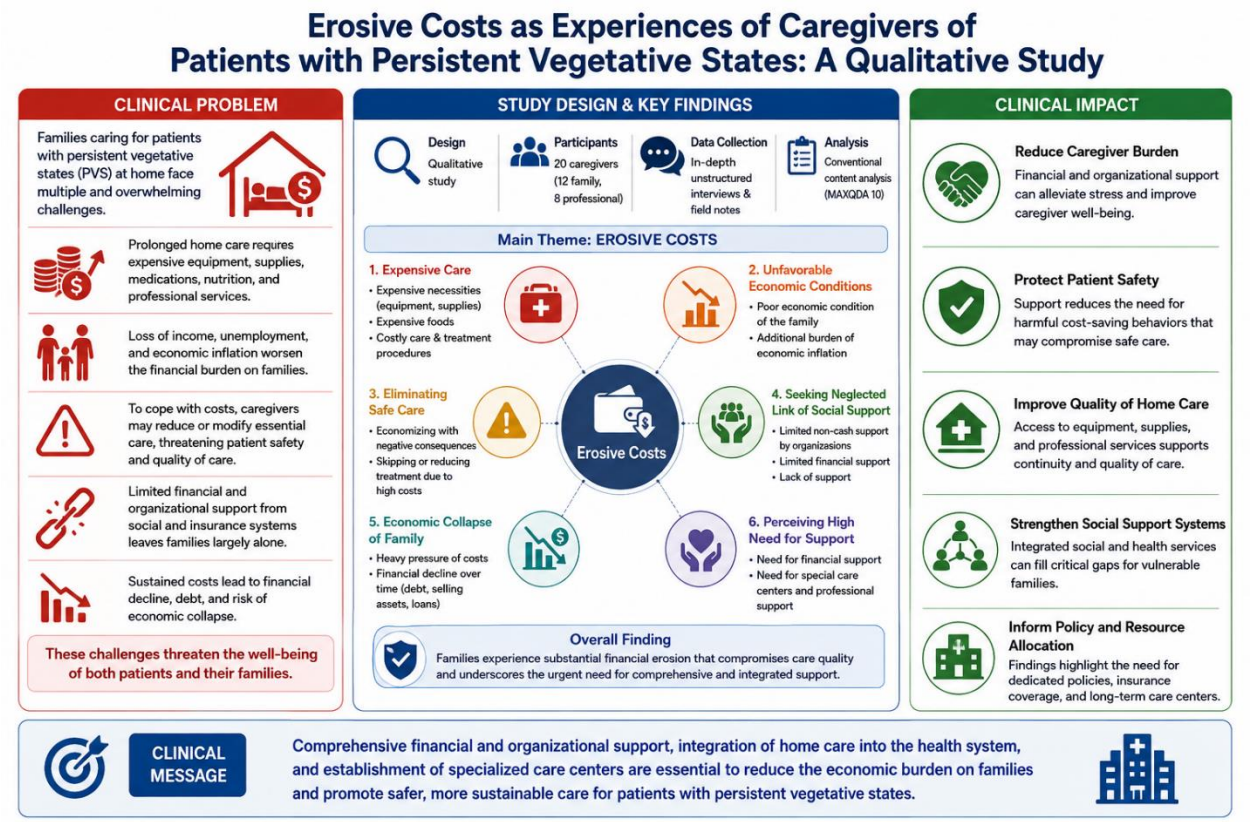
Methods: In the present qualitative study, 20 participants (12 family caregivers and 8 professional caregivers) were selected via the purposive sampling method. Data were collected through unstructured interviews and field notes. All interviews were recorded and transcribed and then analyzed by the qualitative content analysis method. The MAXQDA 10 software was used to facilitate the process of data analysis.

Findings: The main theme of the data analysis was "erosive costs", which included the six categories of "expensive care", "unfavorable economic conditions", "eliminating safe care", "seeking neglected link of social support", "economic collapse of family", and "perceiving high need for support".

Conclusions: Based on the results of the study, the authorities and planners of the health system should pave the way for comprehensive support, especially financial support, to such families in their policymaking and planning.

Implications for Patient Care: The findings highlight the substantial financial and caregiving burden experienced by families caring for patients with persistent vegetative states at home. Inadequate financial and social support may lead caregivers to reduce or modify necessary care, potentially compromising care quality and patient safety. Integrating homecare services into the healthcare system, improving access to essential equipment and supplies, and providing targeted financial and professional support may help reduce these burdens and facilitate safer long-term care.

Keywords: Cost; Family caregivers; Patients; Persistent Vegetative States; Qualitative research



Graphical Abstract. Erosive Costs as Experiences of Caregivers of Patients with Persistent Vegetative States: A Qualitative Study. Families caring for patients with persistent vegetative states experience substantial financial and caregiving burdens, including high costs of equipment, supplies, nutrition, and professional care, limited social support, and loss of household income. These pressures may lead to reduced or modified care and potentially compromise patient safety. Strengthening financial and social support, integrating homecare into the healthcare system, and establishing specialized long-term care services may help reduce caregiver burden and support safer, more sustainable care.

Introduction

Healthcare costs account for a significant portion of the national budgets worldwide (1, 2). Intensive care costs being estimated at more than $ 80 billion annually in the United States (3). In the meantime, the cost of caring for people with severe brain damage that progresses to chronic vegetative states is considerable, the average care costs for each of these patients being about $4 million. In 2000, the direct and indirect medical costs for these patients in the United States were estimated at $ 76.5 billion (4). Recent studies in the United States have shown that one in five families experiences the financial pressures of healthcare costs, which are even more tangible in chronic diseases (5, 6). In the case of chronic diseases, the findings of a study by Amiresmaeeli et al. (2014) show that the costs are very high in cardiovascular and neurological diseases and in cancer due mainly to the high amount that specialists charge and the high costs of equipment (7). Additionally, the overwhelming costs of treating patients with multiple sclerosis (MS), which in some cases lead to the disintegration of families were among the experiences of participants in a study by Masoudi et al. (2013) (8). Therefore, in addition to physical and mental problems, chronic diseases also cause financial problems for caregivers (9).

According to a meta-analytic study, among patients with severe brain injury, including traumatic and non-traumatic injuries, the

condition of 2.77 percent (with a range of 0.52 - 7.33 percent) of those with a traumatic brain injury progresses to a vegetative state over a six-month period from the onset of injury. Technological advances on the one hand and the end-of-life policies of different countries on the other have led to a higher prevalence of vegetative states as reported in Asian societies (10). Patients in vegetative states are often discharged from the hospital after medical treatment due to the uncertainty regarding their life expectancies and are cared for at home by family caregivers (11). However, these patients experience severe neurological, cognitive, and functional disorders and are not able to take care of themselves in any way (12). Caring for patients with VS at home is a complicated process (11). because they require a wide variety of cares such as enteral feeding, bathing, changing clothes, oral hygiene, and specialized care including suctioning and tracheostomy, administration of medications, bed sore prevention, vital signs control, and catheterization, mainly performed by family members (13). Therefore, caring for such patients imposes considerable costs on patients' families.

There are many post-discharge challenges associated with providing homecare to patients with VS. Dealing with emotional, economic, and social issues are especially important in this regard (14), among which the financial problems that caregivers face is one of the most important issues mentioned as a marginal finding in some studies (15, 16). In a study in Turkey, financial problems related to meeting the patient's basic needs and providing rehabilitation were important concerns for families of patients with VS (17). Pagani in Italy showed that having a family member with a long-term disability, such as disorders of consciousness, has negative financial consequences in terms of direct and indirect costs (18). In Iran, Goudarzi et al. (2015) have also shown that all family members of patients with VS experienced some degree of physical, mental, social, and economic damage and pressure due to their responsibilities (19). Thus, chronic neurological diseases, including VS, are considered crises for patients and their families due to the associated disabilities and the high costs of medical services (20). Since the financial problems of the families of patients with VS have been presented as only a marginal finding of more extensive studies and also due to the uncertainty surrounding the dimensions and characteristics of these problems, the present study was conducted to explore the experiences of caregivers of patients with VS with the costs of providing homecare to these patients. It should be noted that qualitative studies seek to discover and understand the inner world of individuals and contribute to achieving an in-depth understanding of phenomena by exploring the perceptions and experiences of individuals who have relevant knowledge and experiences (21).

Materials and Methods

This qualitative study was conducted in the Khuzestan and Lorestan provinces of Iran in 2020-2021 as part of a larger study with a qualitative approach using the conventional content analysis method. Qualitative approaches, including content analysis, are methods of explaining and describing complex phenomena based on textual reports of people's "lifeworlds" that can also act as the voice of vulnerable populations such as patients (22).

Ethical Considerations

This research was carried out after obtaining the approval of the Ethics Committee of the Lorestan

University of Medical Sciences (IR.LUMS.REC.1399.019). In order to obtain informed consent from the participants, they were given full explanations about the objectives and methods of research, the confidentiality of their information, and the right to withdraw at any stage of the research. Voice recordings were made during the interviews with the permission of the participants.

Participants

In this study, the key participants were family caregivers of patients with VS who were primarily responsible for patient care at home. However, as the study progressed, the findings revealed that family caregivers received support and services from professional caregivers, too. Therefore, some professional caregivers were also enrolled into the study as informed participants. In this study, due to lack of care or support centers for patients with VS and also lack of registration of their diagnoses in hospital medical records, the participants were found through inquiries from professional caregivers who provided homecare to such patients. Therefore, phone calls were made to family caregivers and after explaining the objectives and methods of the study, initial implicit consent of the participants were obtained before enrolling them in the study. In addition to willingness to participate in the study, the inclusion criteria for entering the study were having at least one month of experience with the provision of homecare to patients with VS for family caregivers or having the experience of providing homecare to patients with VS for professional caregivers. The exclusion criteria were having speech and hearing problems or lack of interest in continuing to participate in the study. Finally, 20 participants whose demographic characteristics are presented in Table 1 were enrolled into the study, including 12 family caregivers and 8 professional caregivers.

Family caregivers		**Professional caregivers**	
Variables	Values	Variables	Values
Age (years)	43.75 (33-70)	Age (years)	35.5 (26-62)
Sex		Sex	
Female	10 (83.34)	Female	5 (62.5)
Male	2 (16.66)	Male	3 (37.5)
Duration of care (months)	63.58	Work experience (years)	7.75

Table 1. Demographic characteristics of the participants.

Data Collection

In this study, in-depth unstructured face-to-face interviews (conducted by FM) as well as field notes were used to collect the data. The average duration of the twenty interviews was 42 minutes (with a range of 35 to 110). In interviews with family caregivers, an open-ended question was asked: “Please tell me what care you perform during the day and how you perform them for ...?” As the interview progressed and passed the warm-up stage and as the focus was shifted to costs, the participants were asked: “Can you explain your experiences with the expenses of providing care for your patient?” In most interviews, family caregivers shifted their discussions to the costs of care from the outset, at which time the researcher focused on the costs. Professional caregivers were also asked, “What experiences do you have with caring for these patients at home?” During the interview, probing questions were asked, such as “How did you deal with this situation?”, and “Can you give an example in this regard?” Simultaneously with the interviews, field notes were taken about the patient's care environment and how the caregivers interacted with the patient. The room where the patients were kept was observed for physical conditions, hygiene, and required equipment, and relevant information was recorded.The time and

place of the interviews were often selected at the convenience and request of the participants, often being conducted at their homes for family caregivers and at their workplaces for professional caregivers. In addition, purposive sampling continued until data saturation was achieved.

Statistical Analysis

Data were collected and analyzed concurrently. Immediately after the interviews, the recorded interviews were transcribed verbatim. Data analysis using the conventional content analysis method based on the approach proposed by Graneheim and Lundman was conducted in five stages including getting a general sense of the units of analysis, finding and determining the semantic units in the text and summarizing them, abstracting and labeling, categorization of the codes based on similarities and differences, and finally the extraction of the patterns by comparing and contrasting the categories and determining their interrelationships (23). The data were coded independently by two researchers (FM and FG). Differences in coding were discussed with an expert panel, and consensus was reached on the final codes and labels. MAXQDA 10 software was used to facilitate data management and analysis. To ensure the accuracy and reliability of the qualitative data, the four criteria proposed by Guba and Lincoln were taken into account including credibility, reliability, transferability, and confirmability (24). To increase data credibility, several methods were used, including long-term engagement with the data (more than one and a half years), expert panel in order to receive the opinions of experienced individuals with the objective of achieving consensus on the findings, and member check (approval of the codes by the participants). It was attempted to increase data reliability by long-term engagement with the data, triangulation in data collection, and checking the codes with the participants. To ensure the confirmability of the findings, methods, such as bracketing, member checks, and an expert panel, were used. Maximum variation in participant sampling (in terms of age, sex, relationship with the patient, duration of illness, duration of care, and the disease type), transparent and step-by-step reporting of the stages of data collection, data analysis, and the presentation of findings, along with quotations from the participants were among the methods used to increase the transferability of the findings of the present study.

Results

Data analysis led to the emergence of the main theme of "erosive costs" with 6 categories and 14 subcategories, the details of which are presented in Table 2.

1. Expensive care: This category with three subcategories of "expensive necessities", "expensive foods", and "expensive care and treatment procedures" showed that the families of these patients pay heavy expenses to meet the basic needs and care of their patients.

1.1. Expensive necessities: Patients with VS need many durable and non-durable products, the obtainment of which necessitates that families spend large amounts of money.

1.1.1. Variety and large amounts of non-durable products needed by patients: Patients with VS need different types of non-durable products including gastric, and Foley catheters, sterile gauze, serum, drugs, medical tapes, and

other health necessities and, on the other hand, they needed large numbers of these items, the obtainment of which imposed high costs on families. To compare the prices mentioned below with the monthly income, it should be noted that the average income in Iran is about 50000000 Iranian Rials (about US$1200) per month.

“There are so many things we need to buy. Mats, handkerchiefs, medical tapes for dressings, gastric tubes, and suction tubes. There are a lot of things to buy and they are expensive.” (Participant (P)17, Family Caregiver (FC))

The high costs of patients' medications were also emphasized by caregivers:

“Under the circumstances, each pill costs 500000 Rials (US$1.2), each vial costs 500-600 thousand Rials (US$12-14). It’s a difficult situation.” (P15, FC)

The statements of professional caregivers also confirmed this:

“I see them and they have to buy a lot of equipments that are used up quickly, e.g., diapers, hypoallergenic tapes, catheters, serums, and many other things.” (P9, Professional Caregiver (PC))

1.1.2. Large number and high prices of required devices: Alternating pressure mattresses, oxygen tanks, pulse oximeters, suction machines, and wheelchairs were among the durable devices required for the care of patients with VS.

“Before he was discharged, we were told that the devices and instruments for his room should be ready. I think they cost about 60 million Iranian Rials (about US$1500). The equipment we got was all second-hand: wheelchair for 10 million Iranian Rials (≈US$240), a bed for 20 million Iranian Rials (≈US$480), an alternating pressure mattress for 5 million Iranian Rials (≈US$120). But all the prices were high. The prices are very high.” (P12, FC)

1.2. Expensive foods: Family caregivers were committed to providing a varied and rich diet for patients. However, they regarded the provision of such nutritional support as a source of financial pressure:

“He needs a lot of food. He can't be given ordinary food. We have to give him nutritious foods, for example, we give him natural honey, which is expensive. In general, the costs of feeding him is very high.” (P16, FC)

Professional caregivers also verified the high costs of food for patients with VS:

“For the gavage solution, the nutritionist draws up a nutritional plan on which they should spend 500000 (≈US$12) to 600000 (≈US$14) Iranian Rials a day ...” (P13, PC)

1.3. Expensive care and treatment procedures: These patients need various treatment and care measures that require healthcare professionals to make visits to their houses, e.g., doctors, homecare nurses, physiotherapists, and sometimes occupational therapists, and this imposes additional costs on families:

“The doctor would visit our patient for a fee. When he had a fever or something like that, we would have to pay 2,500,000 Iranian Rials (≈US$60) to the doctor to visit the patient at home. Every time the nurse came to perform suctioning or to dress his wounds, it would cost 350,000 Iranian Rials (≈US$9).

2. Unfavorable economic conditions: This category with the two subcategories of “poor economic condition of family” and “additional burden of economic inflation” showed that the financial circumstances of the families and the society affected the pressure imposed on families.

2.1. Poor economic condition of family: The majority of families of patients with VS had poor economic conditions because most of the patients were the breadwinners of families, who had lost their sources of income and jobs due to disability. Sometimes the low salary of the breadwinner of the family or residing in a rented house was the cause of even more economic pressure.

"The costs of looking after him are high. He has a pension. It's about 15,000,000 Iranian Rials per moths (≈US$360), which is not enough." (P7, FC)

Professional caregivers also acknowledged this in their statements:

"There are some very poor families, you know. For example, one family has eight members with an old man who has a monthly salary of about 10,000,000 Iranian Rials (≈US$238) and they are tenants. They are in a very bad financial situation." (P13, PC)

2.2. Additional burden of economic inflation: Family caregivers of patients with VS pointed to the increase in prices and the burden of economic inflation, which put even more pressure on them:

"It used to be much simpler because the costs were much lower. For example, I used to buy a catheter for 10,000 Iranian Rials, but now I buy the same catheter for 20,000 Iranian Rials. I used to buy sterile gauze packages for 350,000 thousand Rials, but now they are 700,000 Rials." (P1, FC).

3. Eliminating safe care: This category, consisting of the two subcategories of "economizing with negative consequences" and "failure to follow up treatment measures due to high costs", showed that some steps taken by family caregivers to reduce costs made the care unsafe.

3.1. Economizing with negative consequences: One of the measures that family caregivers took to reduce costs was the repeated use of non-durable products such as Nelaton catheters:

"In the hospital, I was told to throw away Nelaton catheters every time I used them, but I use them for two or three days, both to wash his mouth and tracheostomy" (P12, FC)

Even one of the family caregiver prepared serums herself to save money:

"You see the water in the suction cup, it's boiled. I put a spoonful and a half of salt into it and boil it. I make my own rinsing serum because if we were to buy serum, it would cost us a lot." (P2, FC)

3.2. Failure to follow up treatment measures due to high costs: High costs caused the caregivers not to follow up with some treatment measures. Physiotherapy was one of the most expensive procedures for families, such that they skipped some of the sessions or bought the physiotherapy instruments themselves and performed it for the patients:

"At first, a physiotherapist came for three or four sessions. Because of the financial problems that we had, on the one hand we had to pay the fees of the nurse and on the other hand, we had to pay for the physiotherapist's services, and there were also instruments that we had to buy which were very expensive. So, we bought the physiotherapy instrument ourselves and now I administer the treatment for him at home twice a day." (P12, FC)

4. Seeking neglected link of social support: This category consists of three subcategories of "limited non-cash support by social organizations", "lack of support by social organizations" and "limited financial support by social organizations" showed limited support

offered by organizations that some families forwent.

4.1. Limited non-cash support by social organizations: In response to the assistance some families sought from social support organizations such as the Iranian Welfare Organization, the support they were offered was mostly non-cash assistance, including some non-durable goods that they needed. In some cases, some durable items such as alternating pressure mattresses, beds, or wheelchairs were provided to these families:

"They don't offer assistance continuously. There's no news for a few months. Then they say come and get your share. Sometimes they give healthcare items like diapers, catheters, gloves, tissue paper, and what they provide is not much." (Participant 16, family caregiver)

According to family caregivers, the non-durable goods provided by social organizations were inexpensive items:

"We saw that we couldn't purchase the equipment at all, so we went and said we couldn't buy them. They referred us to the Deaf Individuals' Center. They gave us catheters, bandage, tissue paper, serums, talcum powder, and betadine. They didn't give the expensive items and we had to buy them ourselves "(P14, FC)

4.2. Limited financial support by social organizations: According to family caregivers, the financial support provided by social organizations was very limited:

"Some people from the Welfare Organization came to see and investigate whether we needed money, and they saw that our breadwinner was sick, finally they decided to pay us very little, 1,500,000 Iranian Rials (about US$35) a month" (P14, FC)

The limited financial support provided by social organizations to families made them forgo pursuing such support:

"Some people from the Welfare Organization came to look at him and said, "We would pay you 3,000,000 Iranian Rials (about US$70) a month". We spend more than 1,000,000 Rials (about US$25) for him a day." The financial assistance was not worth the trouble and we did not pursue it." (P17, FC)

4.3. Lack of support by social organizations: In many cases, the families requested support from social organizations, but did not receive any support. Some caregivers even spoke of lack of support from insurance companies:

"The Social Security Insurance Corporation reduced his salary by 1,000,000 to 2,000,000 Rials (US$24-US$48) a month. Instead of adding to the salary, because he is sick and needs treatment, they reduced from it. They don't want to help at all." (P7, FC)

"We also referred to the Welfare Organization, too. They told us that the assistance does not apply to us. I went to a few charity organizations, and they said that the regulations do not allow them to help us." (P5, FC)

5. Economic collapse of family: This category, consisting of the two subcategories of "heavy pressure of costs" and "financial decline of family" showed that these families faced financial decline over time and were in very poor economic conditions.

5.1. Heavy pressure of costs: Various and costly needs of patients with VS under unfavorable economic circumstances caused the families to undergo heavy financial pressure and in describing this pressure admitted that:

"What put a lot of pressure on us was the financial costs. There was too much pressure" (P1, FC)
"We were tenants, we were under a lot of financial pressure" (P3, FC)

5.2. Financial decline of family: Families took various steps to obtain the money needed for the care of their patients, such as selling real estate, borrowing from others and even getting bank loans, which caused financial collapse and decline over time. Describing this situation, professional caregiver mentioned:
"One of them said, 'I've sold my house to buy instruments and items for him.' Most of their problems are financial." (P18, PC)
The financial decline of families was sometimes so great that made it difficult to meet the needs of other members, but the needs of patients were still a priority:
"For the past three years, I've been locked up in a room. I work in the room. It's been very damaging to me, to the whole family. Formerly, he was an employee but now he is disabled. We can't even pay the rent." (P1, FC)
"Sometimes we don't have any food to eat." (P5, FC).

6. Perceiving high need for support: This category with the two subcategories of "need for financial support" and "need for special care centers for patients with VS" showed that the families need support under such difficult circumstances, whether financial support or access to support centers.

6.1. Need for financial support: Some family caregivers mentioned that they and their families need financial support:
"Under these conditions, financial support is needed more. Every family could help a certain amount per month, it can be helpful for us. We could, for example, buy a catheter with this money." (P1, FC)
Even a family caregiver from a well-off family admitted:
"With the high costs and inflation, buying the medications and equipment that these patients need is difficult for us who are rather well-to-do. Now think about the situation of those who are not well-off. They are in a really difficult condition. I wish the government would do something for them" (P15, FC).

6.2. Need for special care centers for patients with VS: Due to the difficulty of taking care of patients with VS, some family caregivers expressed the need for availability of support centers to provide services to or even keep and them there:
"Many families either cannot provide the care these patients require or cannot afford the associated costs. They should be supported. There have to be some institutions to support them, to give them some care items or to support them financially" (P15, FC)
A professional caregiver also admitted:
"The Welfare Organization should be made responsible for these patients or a special organization should be set up to care for them, or specialists and experts should visit homes and monitor the care provided by family members for these patients" (P11, PC)
Another participant stated:
"If it were possible to set aside a special award for such patients in hospitals, because families do not have medical experience, if there were a place to keep such patients, the pressure on families would be reduced. Families could be sure their patients are cared for. That way, the patients and families would have access to better services and

facilities, and if the patient's condition becomes worse, the facilities and personnel are available to take care of the patient." (P4, FC).

Discussion

In this study, the theme of "erosive costs" consisted of the six categories of "expensive care", "unfavorable economic conditions", "eliminating safe care", "seeking neglected link of social support", "economic collapse of family" and "perceiving high need for support" indicating the exhaustion and financial erosion of families caring for patients with VS. The category of "expensive care" indicated that families of patients with VS were under financial pressure due to the costs of durable and non-durable necessities, foods, and care and treatment of their patients. In line with the present study, Dinser et al. found that families of patients with VS spend a significant portion of their monthly incomes to meet the basic needs of their patients (17).

The high cost of caring for patients with chronic diseases has been suggested in other studies, as well. In this regard, in a study by Izadi et al. (2014), the theme of "economic problems as a source of suffering" emerged, which pointed to the financial pressure caused by the high costs of drugs and treatment measures for the victims of chemical warfare (25). Families taking care of patients with multiple sclerosis also faced financial problems (26). Therefore, it can be concluded that the long-term process of meeting the needs of patients with chronic diseases is a factor contributing to the financial decline of families.

The category of "unfavorable economic circumstances" is indicative of the impact of poor financial family conditions and the additional burden of inflation on the financial pressure experienced by families. When it comes to the impact of chronic diseases on the global and national economy, in general, both direct and indirect costs should be considered.

Direct costs include all costs related to the diagnosis and treatment of the disease, while indirect costs include the loss of productivity and efficiency due to the disease (27). In the present study too, in addition to the direct costs of providing for the patient's needs, the participants pointed out the undesirable financial conditions of families due to the indirect costs of losing the patient as a bread-winning member of the family and the subsequent unemployment of family caregivers, who had to take care of the disabled member full time. It is worth noting that the economic inflation caused by the conditions of the country in recent years has also increased their financial pressure and has finally placed them in unfavorable economic conditions. Consistent with the present study, Bastianli's study on the challenges facing caregivers of patients with VS in Italy also showed an increase in the financial concerns of families due to economic crises and the impact of these crises on the national healthcare system (14).

The "eliminating of safe care" category showed that families stopped some of the cares or performed them themselves instead of seeking help from specialists to reduce the financial pressures, which affected the patient's safety, which could even be considered a form of unconscious noncompliance. In line with the present study, the findings of a study by Gupta et al. showed that patients with various disabilities were more likely to stop taking their medications due to income and employment barriers and the additional costs of healthcare (28).

Main theme	Categories	Subcategories	Secondary subcategories
Erosive costs	Expensive care	Expensive necessities	Variety and large amounts of non-durable products needed by patients
			Large number and high prices of needed devices and items
		Expensive foods	
		Expensive care and treatment procedures	
	Unfavorable financial conditions	Poor financial conditions of family	
		Additional burden of economic inflation	
	Eliminating safe care	Economizing with negative consequences	
		Failure to continue medical procedures due to high costs	
	Seeking neglected link of social support	Limited non-cash support by social organizations	
		Limited financial support by social organizations	
		Lack of support by social organizations	
	Economic collapse of family	Heavy burden of costs	
		Financial decline of family	
	Perceiving high need for support	Need for financial support	
		Need for special care centers for patients with VS	

Table 2. Themes, Categories, and Subcategories Emerging from the Qualitative Data. The table presents the main theme of "erosive costs" and its six categories and 14 subcategories identified through conventional content analysis of caregivers' experiences.

Therefore, the financial burden of healthcare costs poses a considerable risk to patients and society, especially when patients adopt harmful strategies to cope with these pressures (6).

The category of "seeking neglected link of social support" showed that seeking help of support organizations was another method of reducing the financial pressures, which families resorted to, but ultimately found to be ineffective. In a study by Ebrahimi et al. (2017), patients with MS sought support from some organizations, such as charities, the MS Association, and insurance companies, due to the high costs of their medications and the financial problems caused by unemployment and low incomes and considered the support useful and valuable (29). This difference in findings could be attributed to the fact that the MS Patients' Association is an association specific to these patients offering specialized services. Therefore, it may be deduced that the existence of a dedicated support center for patients in vegetative states could also play a more prominent role in supporting these patients.

The category of "financial collapse of family" showed that these families had to sell some real estate, borrow from others, or receive loans in order to care for the patients and provide for their needs, ultimately resulting in financial collapse. In the study by Ebrahimi et al., patients borrowed money from friends and relatives to cope with their financial difficulties (29). Similarly, in a study by Cowley et al. (2014), women who cared for patients in vegetative states under the theme of "pragmatic changes in daily life" stated that, on the one hand, caregivers were forced to temporarily or permanently suspend their jobs to take care of the patients and therefore their incomes had been reduced, and, on the other hand, the costs of caring for their patients had led to a deterioration of their financial conditions. They stated that they spent on average about $1,000 a month for the patients (15).

The category of "perceiving high need for support" suggests that these families perceived the need for financial support or the establishment of centers to care for their patients as a serious need in times of financial distress. Consistent with these findings, family caregivers of patients requiring ventilators in a study by Evans et al. (2012) believed that they did not receive enough support to care for their patients and expressed a great need for support, despite receiving support and not paying direct costs (30). Additionally, the caregivers of comatose and non-responsive patients in a qualitative study by McGuire (2009) also complained of not receiving enough support in the initial stages (31). Chronic neurological diseases, including vegetative conditions, are considered critical for patients and their families due to the concomitant disabilities and the high costs of medical services, and the psychological stress caused by these problems threatens the health of caregivers. Therefore, the availability of supportive resources is crucial in improving the health of families and caregivers (20). Of course, homecare services should be considered as an integral part of the healthcare and treatment services provision chain, and not as separate, especially in societies like the Iranian society that do not have previous experiences with such services. In Iran, where the care of patients with VS is entrusted to families and family caregivers without any support, the complaints about the financial burdens and pressures and the economic decline of the families due to providing care to patients must have a different meaning and be a very serious problem. In this context, limitations such as the absence of government tariffs to cover part of the home care costs, the lack of insurance support, as well as the lack of needed infrastructure and hospice support for this group of patients make

the situation so hard for the families with these patients.

In the present study, caregivers perceived need for support due to the enormous pressures they underwent in all dimensions (25).

On the one hand, receiving financial support was at the center of their attention due to financial pressures, and on the other hand, the social isolation of family caregivers because of full-time care was a factor in emphasizing the need for care centers or the availability of professionals to support families, so that they would be able to benefit from the support of these centers or professional caregivers, in case the family caregiver was not able to take care of the patient. Therefore, they sought the support of some social support organizations in Iran, such as insurance companies, the Iranian Welfare Organization, the Red Crescent Organization, and the Imam Khomeini Relief Committee (Quds). However, the support offered by these organizations is negligible and mostly limited to some inexpensive non-durable items in most cases, and even in some cases, the complexities of the process of obtaining the provided support caused patients' families to forgo them. In general, the families of patients with VS somehow faced a neglected link of support from social organizations. Therefore, the performance of existing support institutions and organizations and the expansion of the services provided by these institutions is one of the important issues that should receive attention from policymakers and planners. This study has some limitations. As a qualitative study conducted in two provinces of Iran with a small purposive sample, the findings may not be directly transferable to other populations or healthcare settings. Participants were identified through professional homecare providers, which may have introduced selection bias. In addition, the study explored caregivers perceived financial experiences and did not objectively measure healthcare expenditures or clinical outcomes. Future multicenter studies using mixed-methods approaches are warranted to further evaluate the economic and clinical implications of these findings.

Conclusion

The findings of the present study made it clear that families with patients in vegetative states were under extreme financial pressure due to the need to obtain non-durable and durable necessities, foods, and care and treatment procedures for their patients, which pressure was made even more unbearable by the unfavorable economic conditions of today's Iranian society. One of the solutions that families applied to reduce the financial pressure was to stop some of the cares, which would ultimately threaten the patients' health and safety. Another solution for families was to seek the support of social organizations, which was either negligible or non-existent. Because of the difficulties of funding the care and due to their obligation to provide care in the best possible way, families had to receive loans from banks and even borrow money from friends and acquaintances, which eventually led to the family's financial collapse. The final result of all this was that they expressed the need for financial support or even requested the establishment of care centers. Therefore, it is suggested that based on the conditions of families with patients in vegetative states at home, one strategy to help them is for the health system to offer families with disabled patients at home financial support for which policies and guidelines should be drawn up and adopted. Another strategy is to include homecare as part of the health system, such that some of the cares

provided at home is offered to families free of charge. Finally, the establishment of care and support centers or special wards or even the allocation of beds for the long-term care of such patients at hospitals can be very effective in reducing the financial, psychological, and physical costs imposed on these families. Such models may have the potential to improve the continuity and safety of care, but their clinical and economic effects should be evaluated in future studies.

Implications for Patient Care

The findings have important implications for the organization and delivery of long-term care for patients with persistent vegetative states living at home. The reported financial burden, loss of family income, high costs of equipment and care, and limited access to social support indicate that caregiving needs extend beyond the provision of medical treatment and require coordinated health and social care. Of particular clinical relevance, caregivers described reducing or modifying aspects of care because of financial constraints, including limiting professional services and reusing or substituting care supplies. Although these experiences cannot establish a causal relationship between financial hardship and adverse clinical outcomes, they identify a plausible patient-safety concern that warrants attention from healthcare professionals and policymakers. Incorporating structured homecare services into the continuum of healthcare, together with improved access to essential equipment, supplies, rehabilitation, and professional follow-up, may reduce caregiver burden and support continuity and quality of care. Multidisciplinary programs involving physicians, nurses, rehabilitation professionals, social workers, and community-based services may also help identify families at greatest risk of financial and caregiving distress and facilitate timely support. Future research should evaluate the clinical and economic effects of structured homecare and targeted financial-support interventions. Overall, strengthening integrated home-based and social support systems may promote safer, more sustainable, and more equitable long-term care for patients with persistent vegetative states and their families.

Author Contributions

All authors contributed to the conception and design of the study, literature search, data interpretation, drafting of the manuscript, and critical revision of the article. All authors approved the final version of the manuscript and agree to be accountable for all aspects of the work.

Conflict of Interest

The authors declare that they have no conflicts of interest related to this study.

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Ethics Statement

The authors confirm that all ethical principles of research and scientific publication, including plagiarism prevention, data integrity, and avoidance of duplicate publication, were fully observed.

Data Availability Statement

The datasets generated and/or analyzed during the current study are available from the corresponding author upon reasonable request.

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