Original Article

Taking care experiences of improved comatose patients with traumatic brain injury and their families

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Abstract

Introduction: The most prominent causes of coma are traumatic brain injuries (TBIs), which have high incidence. However, little research about the caring aspects of these patients has been done, and the notion of caring experiences is unknown. Therefore, this study was conducted to describe the care-taking experiences of coma patients and their families during and after treatment. **Methods:** This study is a qualitative content analysis. Participants in this study were improved TBI patients and their families. Participants were selected purposefully. The method of data collection was 16 interviews that were held with 14 of the participants. Data were analyzed using Elo and Kyngäs conventional content analysis guidelines with MAXQDA software, version 10. **Results:** The results showed four main themes and eight categories. Themes included "crisis," "comprehensive support," communication," and "unprofessional care." **Conclusion:** Patients and families experience a crisis during hospitalization and after discharge. Therefore, patients and families need psychological support. Informing families and communication decrease the conflicts between healthcare personnel and the family. Medical staff must be careful about their statements and behaviors during comatose patients' care because they understand the care process.

Keywords: Care experiences, comatose patients, traumatic brain injury

Introduction

Coma involves a lack of long-term consciousness following injury or illness.[1,2] The most prominent causes of coma are traumatic brain injuries (TBIs). The incidence of TBIs in the USA, Europe, and Australia is estimated to be 538.2, 235, and 322 per 100,000 people, respectively. Based on the data from Iranian Red Crescent, it is about 433 per 100,000 people in Iran.[3]

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After hospitalization, comatose patients with TBIs are exposed to more invasive and noninvasive measures than other coma patients because the type of care needed by these patients is different from other coma patients.[1] Improper care in comatose patients leads to worsening of the physical and mental conditions of these patients. Improper care causes moral distress in nurses and physicians.[4]

A primary care physician (PCP) plays an important role in monitoring progress and interventions of TBI patients.[5] In addition, patient-specific communication, monitoring medications, counseling, patient education, and secondary prevention are other roles of PCP for this patient.[6]

Coma patients who suffer from TBIs are able to understand the above-mentioned cares.[7] Therefore, exploring the care

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experience of these patients is very valuable as they may be neglected. In addition, the hospitalization and care process involve patients' families. However, what the family is feeling and experiencing is very important.

A qualitative study can reveal, describe, and explain an unknown phenomenon.[8] Therefore, this study was conducted based on the qualitative description method to describe care-taking experiences during and after coma in patients with head trauma and their families.

Methods

Design of the study and participants

We conducted a qualitative, conventional content analysis. Participants in this study were improved TBI patients and their families who were selected purposefully from educational hospitals of Tehran University of Medical Sciences, based on the following inclusion criteria:

a. The patient was exposed to a traumatic event
b. Their coma scores were <8 of the 15 GCS scores at coma time
c. The patient was fully conscious of time, place, and person at the time of their interview
d. The patient experienced a coma for at least 7 days
e. The patient remembered their care experiences during their coma.

We also selected five family members (FMs) of interviewed patients who had the highest involvement in patient care and were willing to participate in the study.

Data collection

The method of data collection was the interview. The duration of each interview was approximately 45–90 min. The interview began with several open-ended questions about the subject under investigation. However, participants were invited to expand on any issues. The general question in all interviews for patients was, "What do you remember about your care during your coma? Moreover, FMs were asked the following questions: How was your patient care? Interviews were held until data saturation was achieved, resulting in 16 interviews from 14 participants [Table 1].

Data analysis

Interviews were analyzed using Elo and Kyngäs's (2008) conventional content analysis guidelines.[9] In this study, at the end of each interview, the audio-recordings were typed in MAXQDA software, version 10 (VERBI, Berlin, Germany). After reading all data repeatedly and word-by-word, the unit of analysis and meaning was defined. Open coding and creating categories, grouping codes, and abstracting were the next steps. The last step was to analyze and deduce results and reports.

Trustworthiness

Trustworthiness of qualitative content analysis is often presented using the terms proposed by Goba and Lincoln,[10] such as credibility, dependability, conformability, transferability, and authenticity. To ensure the rigor of this study, several measures were taken, including member check; selecting the most suitable meaning unit; agreement among co-researchers for codes; clear descriptions of the context; and use of annotations.

Ethical considerations

Ethical considerations followed by researchers in the study contain the following: obtaining permission to conduct research from the Research Ethics Committee of the Tehran Medical Sciences University (code: IR.TUMS.FNM.REC.1397.152), obtaining written informed consent, and voice-recording permission from the participants. In addition, ensuring the freedom of participants to leave the study at any desired time was another consideration.

Results

The four main themes extracted from the interview data were classified as "crisis," "comprehensive support," "communication," and "unprofessional care" [Table 2].

Crisis

The crisis theme has two categories: inability and negative feelings.

Inability

One of the most important categories of the crisis theme is inability. Most participants say that they feel an inability to do some things, such as the following situations: A participant stated, *"We wanted to take our patient to a private hospital, but the nurse said don't take him and here has the best staff and facilities why do you want to take him, so we've been hesitant to take him." (FM. 2)*

Physical disability after a coma is the second condition that FMs mentioned. Codes of this category are the inability to walk, eat, or speak, and these physical disabilities are the causes of many other problems.

"I have bought the books for her and my daughter is currently studying at home and can't go to school. Besides, people like her may find it difficult to go out and are ashamed." (FM. 6)

Negative feelings

Another category of the crisis theme is negative feelings. This category has six subcategories.

Stress is the first that many participants emphasized. Many other psychological problems of their families are due to stress and have affected all aspects of family life.

A FM mentioned, *"We arrived at the hospital at 11 o'clock, but we knew that the patients' meeting time would start at 3 o'clock. To decrease our stress, we went sooner, hoping to visit at the earliest time." (FM. 4)*

Table 1: Characteristics of the participants

Participant number	Age	Sex	Days of hospitalization	Days in a coma	Level of education	Occupation
P1	22	Male	33	18	Associate degree	Student
P2	17	Female	45	32	Diploma	Student
P3	23	Male	77	56	Diploma	Restaurant worker
P4	48	Male	90	77	Bachelor	Pilot
P5	62	Male	106	16	Secondary school	Unemployed
P6	34	Male	41	24	Diploma	Employed
P7	41	Female	52	27	Associate degree	Employed
FM1	44	Female	33	18	Secondary school	Homemaker
FM2	48	Male	45	32	Diploma	Employed
FM3	42	Female	45	32	Secondary school	Homemaker
FM4	32	Male	77	56	Diploma	Chef
FM5	33	Female	106	64	Diploma	Homemaker
FM6	24	Male	41	24	Bachelor	Student
FM7	39	Female	52	27	Diploma	Employed

FM: Family members

Table 2: Extracted themes and categories from the interview data

Categories	Themes
Inability	Crisis
Negative feelings	
Empathy	Psychological support
Emotional support	
Religious communication	Communication
Incomplete communication	
Ineffective care	Unprofessional care
Deficient informing	

Agitation and shock comprise the second subcategory of the negative feelings category and are more often seen in parents, especially mothers. It begins during the early phase when they first hear about the accident.

One of the participants stated, "*After I went and saw that situation, I could no longer tolerate, so taken me immediately to the emergency ward and treated until my child was taken to the operating room." (FM. 1)*

Confusion is the third category of negative feelings. Many patients complain that confusion often occurred while they were in a coma and semiconscious because they were unable to communicate with others, and nurses did not communicate with them.

A patient mentioned, *"At one time in coma period, I was completely confused, and most of the time, I was alone and no one could talk to me." (P. 1)*

Fear is one of the most common problems among FMs and patients. Sometimes, patients felt fear, especially when they felt lonely and when caregivers did not talk to them. Families often became frightened when the patients had a sudden negative change.

A FM mentioned, *"I wouldn't go out of the hospital because I was afraid that the staff would make a decision that would not benefit my patient." (FM. 5)*

Disappointment is a subcategory that patients and FMs have experienced in various situations. A FM stated, *"Can't describe it during the 32 days that my daughter was in a coma. The hospital staff always said that your daughter wouldn't survive and die. Eventually, if we remove the ventilator for another week, she will die." (FM. 7)*

Prolonged waiting is the last subcategory and includes admission time, transportation to other wards, hospitalization, and discharge.

"We're really in trouble for 1 week, my daughter has a fractured leg that the doctor said should undergo a surgery, but they said you have to wait for the ankle specialist to come." (FM. 4)

Psychological support

The psychological support theme has three categories: empathy, emotional support, and support from religious subjects.

Empathy

Empathy with family and patients is the first subcategory of empathy seen in different situations in this study. As one participant stated, *"One of the security guards called me and said, "How's your brother? I told him he is conscious, but he might be vegetate, and everyone saw us there, they would come and talk to us and sympathize." (FM. 2)*

Empathy with other patients is the second subcategory of empathy that occurred at the time of admission to the ward and after discharge.

A patient stated, *"I said to some patients don't be scared. I encouraged them to try to calm down. For example, a woman had a baby who had a stroke. She was crying so badly. I talked for relaxing her." (P. 1)*

Emotional support

Emotional support helps individuals and communities to heal emotional wounds and rebuild social structures after an emergency or a critical event. Emotional support category has three subcategories, as follows:

Patient support from family and friends is one of the most common subcategories of emotional support. A FM stated, *"The heat, the cold, the pain, and the hunger didn't matter to me at all. I did not feel any of them. If it is possible, I wanted to give my heart, kidneys, liver whatever he wanted to be cured." (FM. 2)*

The modification of bad news is the second category of emotional support. People did modify bad news for FMs.

"We wouldn't let my mother visit our brother when he was not good, and we would try to let her meet our brother when he was better. Sometimes, I would take pictures of the level of consciousness from the documentation then searched the internet and I was telling my mom that his condition was getting better." (FM. 7)

Family participation in the care process is the third category of emotional support. As one participant asserted, *"My family was involved; my dad was going between hospital and home for 6 months. In addition, I was very involved every day. We would make food for her and take it there, and we would massage her back in the meeting time." (FM. 3)*

Communication

The communication theme has two categories: religious communication and incomplete communication.

Religious communication

Religious communication during a coma means talking to angels, God, and the prophets about problems. A patient mentioned, *"I was thinking of the prophets when I was in a coma, and I was dreaming of them and asking them to help me. I would say to them if someone asks you for help, you will certainly help and not reject it." (P. 2)*

Communicating with the environment during a coma is the next subcategory of religious communication. Based on the experiences of the participants, this kind of communication involves bilateral communication just with their children.

"When I was in a coma, my nephew had come to visit me. He was crying and I had never seen him in this situation in my life. I said, what are you doing, why are you crying? Whatever, I was saying to my nephew, he did understand." (P. 1)

Incomplete communication

In this study, incomplete communication happens either when the patient has not been able to convey their message or when the hospital personnel have not given a proper response to the patient's family.

Trying to communicate is the first situation related to incomplete communication. Based on the experiences of one participant, *"After I got out of the coma because I couldn't do anything and couldn't talk, I was ripping my bottom plastic mat. Because I wanted to call the nurses." (P. 6)*

Improper communication by personnel is another subcategory of incomplete communication. A FM stated, *"The staff treated the patient like a car, and the doctors didn't communicate well with the patient and didn't talk at the time of the physical examination. Doctors wouldn't answer questions, up to a point when I wanted to have a physical fight with them." (FM. 2)*

Unprofessional care

The unprofessional care theme has two categories: ineffective care and deficient informing.

Ineffective care

Annoying care to the patient is a subcategory of ineffective care that patients and families were worried about. This problem may be caused by the negligence of the medical staff or as a common complication of care. In this study, participants talked about the neglect of nurses and doctors.

A FM stated, *"Look at her right foot. The wound had been treated with the therapeutic ointment. The wound was because of the weight of the sinker that is for treating fractured bone which had pressed it. All this time, nurses dad not seen this wound and did not move the sinker." (FM. 4)*

Vain care from the viewpoint of staff is another subcategory of ineffective care. According to the family's experiences, some patients were seen as having no hope of surviving a severe TBI, and so, they were not well treated or cared for.

"For 45 days, it was always said that my daughter was not alive and the doctors wouldn't do surgery. If you saw how they behaved, it was just to close our mouths. They said it was useless to have the surgery." (FM. 3)

Poor quality of care is the next subcategory. Some participants complained of poor quality of care in various aspects of their treatment.

"In the ward, we were taught to suction, and when my brother needed to suction, I myself did it, besides, I would empty the urinary bag."(FM. 2)

Not paying attention to family beliefs is the fourth subcategory of improper care. The participants believed that the medical staff did not pay enough attention to their family's beliefs.

"I told the doctor if there is a miracle and God wants, my daughter will survive. The doctor said, "I haven't seen a miracle here in 20 years and I don't believe it." (FM. 7)

Lack of psychological support is the final subcategory. Psychosocial problems can be exacerbated by a lack of a support system. Our findings from the experiences of participants showed a lack of psychological support in this study.

A FM mentioned, *"Personnel cared for the patient but did nothing for the family, while the family was struggling with problems, sometimes staff pressured the family for many reasons." (FM. 2)*

Deficient informing

Not giving the family the right information is a major problem in the health system. Based on the statements of patients' families, in many situations, the medical staff did not give them sufficient information.

"Since they did not give us accurate information about our patient's condition, I secretly took picture of the information in the file of my brother and then searched the internet for it." (FM. 2)

Weakness in patient education is the second subcategory of the deficient informing category. In this study, several expressions indicate that patients, while in the hospital and while being discharged, received insufficient information about their illness and self-care.

"My son had a physical problem when he was discharged, and we didn't go to physiotherapy for a long time because we didn't know and we told no one about that until we went to a forensic and he told us." (FM. 1)

A lack of informing and informed consent forms another subcategory. Based on family members' experiences, in some cases, this right is not respected.

"Medical staff had not told us anything about tracheostomy. They had begun the operation before getting their consent, and we could not do anything or think because my son was in the operating room for tracheostomy and we had not enough knowledge." (FM. 1)

Discussion

The first theme in our research is crisis. Motaghi and Assadisharif conducted a study to determine the family experiences of trauma patient care. In the study by Motaghi and Assadisharif, analysis of experiences showed initial shock theme with "not believing the present situation" subcategory. This theme is partly in line with the crisis theme of our study. Generally, based on the results of this research and our research, families have high stress in the 1st days after discharge.[11] In addition, from the results of our research and of research conducted by Imam *et al.*, it has been emphasized that prolonged wait times can increase client dissatisfaction.[12]

Psychological support was another main theme extracted from the interview data. It involves empathy and emotional support. Oyesanya *et al.* conducted a cross-sectional, exploratory survey of 692 nurses. Concerns about providing support to patients with acute TBI and their families were the greatest concern of the nurses, which our study also strongly emphasizes.[13] Coco *et al.* stated that members of the nursing staff provide emotional support to family members by consoling them; this alleviates feelings of insecurity, anxiety, hopelessness, and depression.[14]

Another important theme of the research was communication. The findings of a study conducted by Shokati *et al.* showed that patient care requires effective communication.[7] In addition, bad communication – particularly when the doctor appears indifferent, unsympathetic, or short of time – makes most patients feel dissatisfied.[15] Based on the research of Lee *et al.*, communication around a comatose patient is an important subject. In the event of a breakdown in this interaction, there is a risk of a strained relationship being established between nurses, the patient, and their family, which is a source of conflicts or judgments.[16]

The last theme is unprofessional care. Unprofessional care in TBI is a new theme that, generally, has not been discussed in other studies, though it has been partially mentioned. In this study, unprofessional care consists of two categories: ineffective care and deficient informing. In a study conducted by Robertson and Schmitter-Edgecombe, impaired self-awareness in patients and their families following a TBI can reduce the effectiveness of rehabilitation and result in poorer outcomes.[15]

Limitations of the study

One major limitation of this study, like with other qualitative research, is related to the transferability of the findings. To increase transferability, we tried to provide as much detail as possible about the participants, including their status and context.

Conclusion

Patients and families experience a crisis during hospitalization and even after discharge. Therefore, patients need psychological support. The families of these patients need a comprehensive support and care plan, and nurses and medical staff should arrange family support meetings for this purpose. Informing families and communicating effectively also help families participate in the process of care and decrease conflict between healthcare personnel and the patient's family. Finally, medical staff must be careful with their statements and behaviors related to comatose patient care because these patients are aware of the care process.

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Conflicts of interest

There are no conflicts of interest.

References

1. Buchini S, Quattrin R, Zampieron A. Valuing dignity in patients in a vegetative state on an intensive rehabilitation ward: Improvement project. J Nurs Manag 2014;22:140-50.
2. Ahmadi Chenari H, Esmaili AA, Hasanzadeh F, Taheri NK. A review of the effective factors on physical rehabilitation of stroke patients. Iran J Rehabil Res Nurs 2016;2:68-77.
3. Azami-Aghdash S, Abolghasem Gorji H, Sadeghi-Bazargani H, Shabaninejad H. Epidemiology of road traffic injuries in Iran: Based on the Data from Disaster Management Information System (DMIS) of the Iranian Red Crescent. Iran Red Crescent Med J 2017;19:e38743.
4. Cain C. Trauma nursing: From resuscitation through rehabilitation, Fifth Edition. Crit Care Nurs 2020;40:89.
5. Hofman M, Andruszkow H, Kobbe P, Poeze M, Hildebrand F. Incidence of post-traumatic pneumonia in poly-traumatized patients: Identifying the role of traumatic brain injury and chest trauma. Eur J Trauma Emerg Surg 2020;46:11-9.
6. Schindler CR, Lustenberger T, Woschek M, Störmann P, Henrich D, Radermacher P, *et al.* Severe traumatic brain injury (TBI) modulates the kinetic profile of the inflammatory response of markers for neuronal damage. J Clin Med 2020;9:1667.
7. Abad MS, Hasani P, Manoochehri H. The lived experiences of nurses of comatose patients: A hermeneutic phenomenology approach. J Q Res Health Sci 2012;1:182-8.
8. Pashaeypoor S, Baumann SL, Sadat Hoseini A, Cheraghi MA, Chenari HA. Identifying and overcoming barriers for implementing Watson's Human Caring Science. Nurs Sci Q 2019;32:239-44.
9. Elo S, Kääriäinen M, Kanste O, Pölkki T, Utriainen K, Kyngäs H. Qualitative content analysis: A focus on trustworthiness. SAGE Open 2014;4:2158244014522633.
10. Guba EG, Lincoln YS. Competing paradigms in qualitative research. Handbook of qualitative research. Thousand Oaks, CA, US: Sage Publications, Inc; 1994. p. 105-17.
11. Motaghi M, Assadisharif F. Experiences of family from caring patient suffering from trauma: A qualitative study. J Clin Nurs Midwife 2017;5:90-100.
12. Imam SZ, Syed KS, Ali SA, Ali SU, Fatima K, Gill M, *et al.* Patients' satisfaction and opinions of their experiences during admission in a tertiary care hospital in Pakistan-A cross sectional study. BMC Health Serv Res 2007;7:161.
13. Oyesanya TO, Bowers BJ, Royer HR, Turkstra LS. Nurses' concerns about caring for patients with acute and chronic traumatic brain injury. J Clin Nurs 2018;27:1408-19.
14. Coco K, Tossavainen K, Jääskeläinen JE, Turunen H. The provision of emotional support to the families of traumatic brain injury patients: Perspectives of Finnish nurses. J Clin Nurs 2013;22:1467-76.
15. Robertson K, Schmitter-Edgecombe M. Self-awareness and traumatic brain injury outcome. Brain Inj 2015;29:848-58.
16. Lee HY, Park JH, Kim AR, Park M, Kim T-W. Neurobehavioral recovery in patients who emerged from prolonged disorder of consciousness: a retrospective study. BMC Neurology. 2020;20(1):198-204.