

Experiences of Home Care Team Members and Family Caregivers in Addressing the Care Needs of Patients with Severe Traumatic Brain Injury During the Post-discharge Period

Abstract

Background: Providing care for unconscious patients with severe brain injuries at home can be challenging. One of the main difficulties is identifying and addressing their specific care needs. Therefore, the aim of this research is to extract the experiences of home care team members and family caregivers in addressing the care needs of patients with severe traumatic brain injury during the post-discharge period. **Materials and Methods:** This qualitative study was conducted on caregivers and healthcare providers of patients with severe traumatic brain injury in 2024-2025. Data were collected through semi-structured in-depth interviews with 22 patients' caregivers and health care providers in home. The recorded interviews were transcribed and then analyzed through inductive content analysis. **Results:** The care needs of patients with severe traumatic brain injury during the post-discharge period were categorized into 15 subcategories and four main categories: physical care needs (maintaining respiratory function, maintaining digestive function, maintaining urinary tract function, maintaining skin integrity, Enhancing physical mobility, Balancing Sleep and Rest, pain management, maintaining personal hygiene, and treatment coherence), mental care needs (managing emotions, improving self-efficacy), social care needs (patient Support, maintaining patient care environment, caregiver support), and spiritual care needs (promoting sense of meaning in life). **Conclusions:** The results of this study provide a clearer understanding of these needs, aiming to develop a holistic care program tailored to the patients' conditions at home, ultimately improving their quality of life and holistic care.

Keywords: Iran, Nursing, patient discharge, traumatic brain injury

Introduction

Trauma stands as a primary cause of mortality and a significant contributor to disability among the working-age population in developing nations. Despite its profound impact, this critical issue has not received sufficient attention and continues to escalate.^[1] Globally, the mortality rate attributed to trauma is notably high, with Iran experiencing an even more pronounced rate.^[2] Among patients admitted to hospital emergency and critical care units, the most frequent causes of trauma include motor vehicle accidents and falls from elevated surfaces.^[3] Additionally, brain injury is recognized as a major consequence of trauma and a leading cause of death and disability worldwide.^[4] In Iran, brain injury constitutes a substantial proportion of trauma-related fatalities, as indicated by available data.^[5] Traumatic brain injury (TBI), categorized by severity into mild, moderate, and severe

based on the Glasgow Coma Scale, is most commonly caused by falls, motor vehicle accidents, and physical altercations.^[6,7]

Risk factors associated with TBI include age ≥ 75 years, male gender,^[8] injury severity, comorbidity, length of hospital stay, and hospital mortality rate. Advancements in medical science and improvements in acute care services have led to increased survival rates among moderate to severe brain injury victims. However, most survivors experience varying degrees of long-term physical and cognitive disabilities, which impact their daily functioning, social interactions, and quality of life. They also suffer from neurological disorders such as seizures, sleep disturbances, and mental health issues, as well as non-neurological disorders like sexual dysfunction, urinary incontinence, gastrointestinal problems, respiratory difficulties, movement disorders, and

**Shahla
Mohamadirizi¹,
Alireza Irajpour¹,
Amir Mahaabadi²,
Bahram
Aminmansour²,
Nasrolah
Alimohammadi¹**

¹Department of Critical Care Nursing, School of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran,

²Department of Neurosurgery, School of Medicine, Isfahan University of Medical Sciences, Isfahan, Iran

Address for correspondence:
Dr. Nasrolah Alimohammadi,
Department of Critical Care
Nursing, School of Nursing and
Midwifery, Isfahan University of
Medical Sciences, Isfahan, Iran.
E-mail: alimohammadi@
nm.mui.ac.ir

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metabolic disorders.^[9,10] These complications significantly reduce the quality of life for these patients and present significant challenges in terms of care, including the need for re-hospitalization, long-term rehabilitation, and lifelong support.^[11]

In a study by Popernack *et al.* (2015), patients' impaired performance and motor skills were identified as the most significant problems they face.^[11] Vaezipour *et al.* (2019) also emphasized that brain trauma patients have unique needs due to the complexities of their condition, with the most common being the need for comprehensive support, continuous care, and achieving independence.^[12]

In many countries, individuals who sustain severe brain injuries are typically discharged from the hospital once their condition stabilizes and continue to receive care at home.^[13] In Iran's healthcare system, these patients are similarly discharged after stabilization and continue their care at home. Unfortunately, most of them face significant levels of dependence and encounter challenges due to the occurrence of secondary complications, which ultimately diminish their quality of life.^[14,15] One of the main challenges of caring for patients with severe brain damage at home is the difficulty in identifying and meeting their specific care needs. These patients may require regular medical and care services, physical therapy, speech therapy, specialized nutrition, emotional support, and assistance with daily activities. Failure to address and meet these needs can slow down the healing process and place a heavy burden on both families and the healthcare system. Studies conducted by Odgaard *et al.* (2019) and Brito *et al.*^[16,17] provide insight into this issue. Additionally, concussions can result in chronic conditions with ongoing and significant deterioration.^[18,19] these disabilities can hinder the return to a normal life.^[20,21]

Furthermore, caregivers of these patients often feel ill-equipped to care for them after discharge due to the severity of the accident and their lack of mental and emotional preparation. They also report that the patients' needs are not adequately met. In some cases, due to the patients' unawareness or reduced level of consciousness, they are unable to express their needs. This creates high levels of stress, anxiety, and mental disorders among caregivers.^[22,23] In essence, brain injuries not only affect the patients themselves, but also impact their entire families. As a result, families should be considered victims of trauma alongside the patients.

Another concern of caregivers is the utilization of advanced medical technologies, such as ventilators, various catheters, and assistive devices to improve mobility at home.^[24] Caregivers encounter significant challenges during the time of discharge, which contributes to an increase in their care burden and a decrease in the quality of care they can provide.^[25] although most patients with severe brain injury are discharged from the hospital in a dependent state, there is typically no written and specific care plan in place for

them at-home care. This lack of planning has negative consequences for patients.^[26] Therefore, the main issue is accurately identifying the care needs of patients with severe brain injury at home and providing solutions to meet these needs. By extracting and providing appropriate care, we can improve patients' quality of life, reduce the burden on families, and help patients lead more independent lives.

However, in Iran, despite an increasing number of patients with severe brain injuries^[27] due to accidents and work-related incidents and the crucial role of caregivers in managing these patients after discharge, the needs of patients have not been adequately addressed from a family perspective. Furthermore, the provision of healthcare based on Iranian-Islamic cultural conditions has not received sufficient attention.^[28,29] Studies related to other chronic diseases may not be applicable to this group of patients and their caregivers^[30,31] due to the significant differences in the treatment and care process, hospital admissions, and economic consequences. Therefore, considering the high prevalence and consequences of brain injuries on patients, families, and the healthcare system in the country, it is crucial to focus on post-discharge care, assess the needs of patients and caregivers, and design culturally appropriate programs. It is important to consider the existing context and the experiences of individuals involved in the care of these patients, including their families and the treatment team. The research aims to extract the care needs of patients with severe brain damage through this study.

Materials and Methods

This study is part of a doctoral thesis that used content analysis to investigate the care needs of patients with severe brain injury through semi-structured interviews in 2024-2025. The research included caregivers and healthcare providers, with an initial focus on 15 healthcare providers (15 individuals) and 7 caregivers of patients with severe brain damage. The interviews took place in various locations, including the faculty, patients' homes, and a hospital room. The data was analyzed using content analysis, with guide questions based on the literature review used during the interviews. The duration of the sessions varied from 45 to 90 minutes, and all interviews were recorded for further analysis. The researcher led the discussions, ensuring the interviewee's trust and avoiding bias. The participants of this research consist of health care providers (including neurosurgeons, nurses, physiotherapists, occupational therapists, and nutritionists) and caregivers. Inclusion in the study required informed consent, a willingness to participate, and experience in providing care for at least one trauma victim with severe brain damage in a home setting. Exclusion criteria encompassed any participant's unwillingness to continue cooperation throughout the duration of the study. Given the existence of previous studies on the needs of patients with severe brain injury and the aim of this study to gain a comprehensive understanding of the needs of severe brain injury victims in Iran, content

analysis was used. A systematic review was conducted using relevant keywords in reliable databases to identify the needs of the injured and create a classification matrix. Data analysis occurred simultaneously with data collection, with initial analysis guiding subsequent interviews. To ensure credibility, trustworthiness, transferability, and verifiability of the findings from the semi-structured interviews, participants were selected to maximize diversity in terms of age, work experience, education degree, and duration. The illness was also reviewed by the participants themselves, and the external observer method was used.

Ethical considerations

This study received approval from the Ethical Committee of Isfahan University of Medical Sciences (IR.MUI.NUREMA.REC.1401.160). Participants were informed of the study's objectives, assured confidentiality of their information, and provided written informed consent.

Results

A total of 22 interviews were conducted for this study. The participants included 15 healthcare providers, such as nurses, neurosurgeons, occupational therapists, physiotherapists, social workers, and speech therapists. Additionally, there were 7 family caregivers of patients with severe brain damage. The participants shared their insights on the care needs of patients in a home setting. Through an inductive analysis of the data, the study identified 1130 inferential codes, 73 sub-classes, 15 sub-classes, and 4 main categories. These categories, namely "physical care needs," "mental care needs," "social care needs," and "spiritual care needs," encapsulate the care requirements of patients with severe brain damage at home [Table 1].

Physical care needs

One of the main categories of study was physical care needs at home. This category includes maintaining respiratory function, maintaining digestive function, maintaining urinary tract function, maintaining skin integrity, enhancing physical mobility, and maintaining sleep and rest. Additionally, pain management, maintaining personal hygiene, and treatment coherence were also identified.

1.1 Maintaining respiratory function

Most participants reported respiratory complications, including airway aspiration, respiratory infections, and hypoxia due to secretion accumulation, all of which increased patient mortality at home. They emphasized the importance of tracheostomy care, preventive measures against airway aspiration and respiratory infections, continuous monitoring of respiratory status, patient respiratory rehabilitation, and regular evaluation of the respiratory status of ventilator-dependent patients. *"In many cases, patients experienced respiratory distress at home due to secretions accumulating and drying up in their closed airways... This led to oxygen deprivation, hospitalization,*

Table 1: Sub-subcategories, subcategories, and main categories of post-discharge care needs for patients with severe brain injury

Main Category	Subcategories	Sub-subcategories
Post-Discharge Care Needs	Physical Care Needs	Maintaining Respiratory Function
		Maintaining Digestive Function
		Maintaining Urinary Function
		Maintaining Skin Integrity
		Enhancing Physical Mobility
		Balancing Sleep and Rest
		Pain Management
		Maintaining Personal Hygiene
		treatment coherence
		Patient Support
	Socio-Economic Care Needs	Maintaining the Patient's Care Environment
		Caregiver Support
		Promoting Sense of Meaning in Life
		Improving Self-Efficacy
	Spiritual Care Needs	Managing Emotions

and, in severe cases, even cardiac arrest. The brain damage worsened as a result" (Participant No. 6).

1.2 Maintaining digestive system function

Another important physical care requirement for patients at home was maintaining digestive system function. Participants stressed the need for comprehensive care to ensure optimal digestive system functioning. This included nutrition assessment, providing appropriate nutritional interventions to prevent weight loss, maintaining electrolyte and fluid balance, and specialized nutrition counseling. Additionally, as many patients with severe brain damage couldn't consume sufficient nutrition orally, enteral nutrition support was mentioned as a crucial need. *"Nutrition is a critical discussion with these patients because their brain metabolism is almost doubled. Meeting their nutritional needs is crucial, and they require the guidance and advice of a nutritionist to follow a suitable diet"* (Participant No. 5).

Furthermore, it was noted in the present study that many patients with severe brain damage cannot consume enough nutrition orally. Therefore, enteral nutrition support was identified as another crucial need for these patients. *"as their brain metabolism is nearly doubled. It is essential to ensure that their nutritional requirements are properly met. Additionally, they require the guidance and advice of a nutritionist"* (Participant No. 7).

1.3 Maintenaning of urinary function

Another important aspect is the maintenance of urinary function. The participants in the qualitative interviews recognized the need to address urinary incontinence, prevent urinary tract infections, and provide proper care for urinary catheters. These factors play a crucial role in preserving urinary system function and preventing complications for

patients receiving care at home. *“Most of these patients have Foley or external urinary catheters, which can lead to urinary infections. If these catheters are properly cared for, the risk of infections can be greatly reduced”* (Participant No. 3).

1.4 Skin integrity

Individuals living with brain injuries are more susceptible to skin complications as a result of both immobility and cognitive impairment. This risk is particularly heightened for those who experience limited mobility. To maintain skin integrity, participants highlighted the importance of regularly changing the patient's position, using standardized skin assessment tools, preventing pressure ulcers, consulting with wound specialists for severe skin damage, providing skin care during episodes of excretory incontinence, and having dedicated skin care equipment. *“These people are highly susceptible to bedsores, and unfortunately, we observe that they often return to the hospital with severe wounds”* (Participant No. 2).

1.5 Enhancing physical mobility

Patients who have suffered from severe traumatic brain injuries (TBI) often experience a prolonged period of immobilization due to multiple injuries and loss of consciousness. As a result, it is crucial to prioritize early mobilization of the patient and utilize mobility aids when moving them. The participants highlighted the importance of consulting with physiotherapists and occupational therapists in order to minimize these complications. This recommendation ultimately gave rise to the subcategory of the need for physical mobility. *“In many cases, families neglect the changes in their loved one's hands, feet, and joints until they become problematic and seek a solution. However, by that time, it is often too late.”* (Participant No. 4)

1.6 Balancing sleep and rest

One of the primary requirements for patients in the physical dimension, when at home, is the maintenance of a proper balance between sleep and rest. Several participants expressed the need to adjust their sleep and rest patterns and provide appropriate care to address any sleep-related issues. The following quote from two participants effectively highlights this need: *“Many caregivers and families keep the lights on all night, fearing that their loved ones will experience sleep problems. This, in turn, can cause patients to feel drowsy during the day or, conversely, restless.”* (Participant No. 2)

1.7 Pain management

Pain is the most commonly reported issue by home care providers. Participants have identified pharmaceutical methods as the most powerful tools to control patients' pain at home. Additionally, the use of non-pharmacological pain control methods, standardized pain assessment tools, and consideration of cultural and social norms are other essential aspects of care that can contribute to better pain management and improved quality of patient care at home. *“The first few days after we brought him home, he was restless and kept pulling out his tubes multiple times. We*

didn't realize that he was in pain, so we had to call a nurse to come back and take care of him. The nurse then informed us that our patient needed painkillers” (Participant No. 2).

1.8 Maintaining personal hygiene

Maintaining personal hygiene is crucial for individuals with severe brain damage to ensure their holistic health. This includes activities such as bathing, changing clothes, managing excretory incontinence, oral and dental hygiene, and eye care. Due to their condition, these patients rely on others to assist them with these tasks. The level of dependence varies based on the severity and stage of the disease. During the acute stage, patients are completely reliant on others for these activities. A caregiver highlighted the significance of perineal hygiene and oral hygiene, including the use of mouthwash. *“It is unfortunate that many patients neglect these aspects and only seek medical attention when necessary”* (Participant No. 12).

1.9 Treatment coherence

Patients with severe brain damage require a comprehensive and sometimes lengthy treatment process. It is crucial to comply with all the recommendations and instructions provided by doctors, treatment and care staff. This includes accurately taking prescribed medications and avoiding any potential drug interactions. Additionally, patients must prioritize monitoring and managing any underlying conditions, such as multiple injuries or traumas. Attending rehabilitation sessions punctually and following through with regular referrals are also essential for ensuring a faster recovery and a better quality of life for patients. *“it is unfortunate that some patients still have a tracheostomy and are reliant on a ventilator, despite the possibility of being disconnected from these devices and having the trachea removed (Participant No. 18). Furthermore, there are cases where patients have undergone craniotomy and are eligible for cranioplasty, but their doctor has not taken any action yet, even after one or two years”* (Participant No. 16).

2. Social care needs

Based on the participants' experiences, patient social support can be categorized into three subcategories: “maintain the patient's care environment,” “patient support,” and “caregiver support.”

2.1 Patient support

Most participants emphasized the importance of supporting individuals with s-TBI who are receiving care at home. Examples of this support, as reported by the participants, include support from the patient's network of relatives, insurance coverage for home care services, and support from rehabilitation and welfare centers. *“The lack of patient follow-up by the hospital after discharge and the absence of a coherent care plan for home care lead to these patients being practically forgotten within the healthcare system”* (Participant No. 8).

2.2 Maintaining patient care environment

Nurses believe that it is crucial for patients to have a calm and safe care environment at home. They stress the need to evaluate the home environment in terms of the necessary conditions for patient care, ensuring the safety of medical equipment, and removing obstacles to the patient's movement at home. *"Before a patient is transferred home, a specialist, a home care provider, or an experienced ICU nurse must thoroughly assess the conditions of the house. For example, the patient's room should not have carpets due to the risk of contamination from patient secretions. It should be close to a toilet, well-lit, properly ventilated, with sufficient electricity and suitable electrical outlets. All these factors need to be checked when transferring the patient."* (Participant No. 1).

2.3 Caregiver support

Taking care of patients puts significant psychological pressure on family caregivers. They face the burden of care, anxiety from the inability to communicate effectively with the patient, and worries about the patient's future. Furthermore, providing continuous care leaves little time for caregivers to take care of themselves. Many participants also highlighted the issue of high costs related to acquiring medical equipment and hiring additional help. One participant stated: *"Caring for these patients is not a task that can be done by one person alone. There is a need for multiple caregivers to assist with feeding, bathing, and administering medication. Ideally, the patient should have friends or acquaintances who can help, or there should be an institution that can provide temporary care for the patient. Unfortunately, this is not currently possible in our country."* (Participant No. 7)

3. Mental health care needs

Psychological care is crucial for managing patients with severe brain damage. This patient group faces various emotional and psychological challenges, which must be comprehensively addressed by the treatment team. In this study, two important needs emerged: improving self-efficacy and emotion management/adaptation to changes.

3.1 Managing emotions

Participants reported experiencing mood emotions such as aggression, anger, difficulty adapting to limitations caused by the disease, and fear about the future. These emotional challenges highlighted the importance of managing emotions, adapting to changes, and improving self-efficacy. One participant shared their experience: *"Since my son regained consciousness and improved, he constantly fights, becomes angry very quickly. He wasn't like this before"* (participant no. 13).

3.2 Improving self-efficacy

Patients with severe brain damage may lose physical and cognitive abilities, sense of control over their lives, and independence in decision-making. Participants emphasized

the importance of regaining these abilities, returning to previous activities, and maintaining individual identity to enhance quality of life and self-confidence. *"Most patients with severe brain damage are young, active family members who have become highly dependent and lost their freedom to live and work due to their disabilities. It is crucial to reduce this dependency and increase their independence"* (participant no. 19).

4. Spiritual care needs

In this study, most participants believed that spiritual care is a neglected aspect of patient care needs at home. They expressed that while caregivers and home care providers focus more on the patients' physical needs, attention to their spiritual needs and providing spiritual care is equally important.

4.1 Promoting Sense of Meaning in Life

Strengthening the patient's sense of meaning and purpose in life, aligning religious and spiritual care with their needs, increasing access to spiritual resources, and promoting interdisciplinary cooperation for spiritual care were identified as significant needs. A participant shared: *"Ever since he regained consciousness, he has been blaspheming and questioning why God kept me alive. I wish I would die too"* (participant no. 21).

Discussion

The objective of this study was to determine the care needs of patients with severe Traumatic Brain Injury (TBI) after they are discharged, from the perspective of both family caregivers and the healthcare team. Recognizing and addressing these needs is crucial for enhancing the quality of care provided, and ultimately improving the health and quality of life of the patients as well as their family caregivers. In this study, the care needs of discharged patients were categorized into four main areas: physical, mental, spiritual, and social. To support these findings, Stålnacke *et al.* (2019) reported that respiratory problems are one of the leading causes of death among patients with severe brain damage in the first two years after the injury.^[32] Alimohammadi *et al.* identified maintaining physical health as a priority for these patients, with specific focus on preventing bedsores, muscle atrophy, deformities, and infections in various organs, as well as respiratory and urinary tract infections.^[33] Cognitive problems, respiratory difficulties, and swallowing disorders were found to be the most common issues after the acute phase of the disease, as observed in Diehl *et al.* 2012 study.^[34]

Apart from physical needs, patients with severe brain damage also have important psychological care needs. The study reveals that many patients experience psychological challenges, particularly after the acute phase of the disease, and require management of behavioral and cognitive changes.^[35] Dulhanty *et al.* (2020) found that patients commonly reported unmet needs related

to health problems, fatigue, mood fluctuations, and cognitive changes.^[36] Mental disorders following TBI are a significant concern during the recovery process, as they can hinder quality of life, return to work, and interpersonal relationships.^[37] Therefore, it is crucial to develop a comprehensive care plan that addresses the psychological needs of these patients in order to enhance the quality of care provided.

“Other category examined in this study were spiritual needs. Brain damage often presents with sudden, unexpected signs and symptoms, creating an unstable and unpredictable situation that evokes a sense of impending death among patients. As a result, these patients experience various negative emotions and face challenges in improving their health. This highlights the need for spiritual care.^[38] Jadidi *et al.* (2019) emphasized that addressing spiritual needs and implementing a coherent spiritual care program during illness is often underestimated.^[39] Supporting this, a study suggesting that spiritual well-being can serve as a coping strategy, offering protective effects against stress-induced illness and treatment-related complications.^[40] These findings underscore the importance of integrating spiritual care into the holistic management of patients with severe conditions, such as traumatic brain injury, to alleviate emotional distress and enhance overall well-being.

Another category that emerged from this study was the need for social care, which consisted of three subcategories: maintaining the patient's care environment, supporting the patient, and supporting the caregiver. Piccenna *et al.* (2017) conducted a similar study on the needs of patients with severe brain damage and identified six main categories: comprehensive risk assessment, having two caregivers, providing training, modifying the home environment, acquiring necessary equipment, and implementing policies.^[41] Mamman *et al.* (2024) also explored social support as a facilitator in improving the quality of life of patients with severe brain damage.^[42] This included receiving support from communities, participating in rehabilitation programs, and involving family and friends in the care of these patients, all of which contribute to guiding new and unexpected experiences following an injury.^[43,44]

There were a few limitations and recommendations in this project. The most significant limitation was the lack of participant cooperation and their inability to express their views on the needs of patients with severe brain damage due to their busy schedules. Overcoming this limitation required obtaining informed consent, ensuring confidentiality and ethical standards, and coordinating interview times with the participants.

Conclusion

To the authors' knowledge, no previous study has been conducted in Iran on the identification of care needs for patients with severe brain injury at home. The findings of this study shed light on the unique care needs of Iranian patients with severe traumatic brain injury in different dimensions. In addition to physical care needs, attention to

the psychological, spiritual, and social dimensions of these patients is crucial for their well-being. Following discharge, it is important to focus on these dimensions in the home care environment. The results of this study provide a clearer understanding of these needs, aiming to develop a holistic care program tailored to the patients' conditions at home, ultimately improving their quality of life and holistic care.

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Conflicts of interest

Nothing to declare.

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