



JAT

Journal of
Applied Therapeutics

Advancing Evidence, Practice, & Policy



Volume 1 | Issue 1 | July 2026

Institute of Applied Therapeutics (IAT), Chennai

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Understanding Disability and Rehabilitation Barriers Faced by Individuals with Head Injury

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ABSTRACT

Background: Disability following head injury reflects a complex interaction between physical, cognitive, emotional, and social impairments that significantly affect an individual's ability to carry out daily activities. Individuals with acquired disabilities often experience greater psychosocial challenges compared to those with congenital conditions, particularly in adapting to altered roles and societal expectations.

Aim: The present study aimed to explore the nature and impact of disability, as well as the barriers to rehabilitation, among individuals with head injury from the perspective of caregivers.

Methods: A qualitative research design using a phenomenological approach was employed to understand lived experiences. A total of 15 caregivers were recruited through convenience sampling, and data were collected using semi-structured interviews. The data were analysed using thematic analysis, including horizontalization and clustering of meaning units into core themes.

Results: Four major themes emerged: self, reflecting loss of independence and emotional distress; family, indicating disruption, caregiver burden, and emotional strain; occupation, highlighting loss of vocational roles and cognitive challenges; and barriers to rehabilitation, including transportation difficulties, limited accessibility, and lack of awareness about available services. The findings suggest that head injury has a multidimensional impact extending beyond the individual to the family system, while structural and informational barriers continue to limit effective rehabilitation. The study underscores the need for improved rehabilitation accessibility, increased awareness, and family-inclusive intervention strategies.

Keywords: Head injury, Rehabilitation barriers, Phenomenology, Caregiver perspectives

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Submitted: 20.04.2026

Accepted: 04.05.2026

INTRODUCTION

Disability is an umbrella term covering impairments, activity limitations, and participation restrictions. An *impairment* refers to a condition of the body or mind; an *activity limitation* is a difficulty encountered by an individual in doing certain tasks or actions; while a *participation restriction* is a problem experienced by the individual in interacting with the world around them ². A *head injury* is any sort of injury to the brain, skull, or scalp, ranging from a mild bump or bruise to a traumatic brain injury. Common head injuries include concussions, skull fractures, and scalp wounds. Traditionally, classification of head injuries has been divided into two types: *open* and *closed injuries*. A closed head injury is produced by rapid acceleration followed by deceleration of the head, resulting in rapid linear or rotational movement of the brain against the hard, bony inner surface of the skull. The presence of coup and contrecoup injuries is typically found in closed head trauma. In cases of open head injury, the scalp is lacerated, and the skull is penetrated by an intruding object such as a bullet or projectile.

Acquired brain injury (ABI) is defined as damage to the brain occurring after birth. It can be *traumatic*, resulting from external forces such as motor vehicle crashes, sports injuries, or violence, or *non-traumatic*, arising from illness, infection, brain tumours, or stroke. ABI is considered a *catastrophic condition*, often resulting in a variety of challenges, including cognitive, physical, occupational, familial, social, and psychological difficulties. These resulting difficulties can create challenges that persist throughout a person's lifetime.

According to the World Health Organization (WHO), "*Rehabilitation* is the interventions needed when a person is experiencing limitations in everyday physical, mental and social functioning due to ageing or a health condition, including noncommunicable diseases or disorders, injuries or trauma." Disability is thus not just a health problem; it is a complex phenomenon that reflects the interaction between a person's bodily features and the society in which they live. Overcoming difficulties faced by people with disabilities requires interventions that remove

environmental and social barriers. Disability is an important public health concern, especially in developing countries. Recent evidence suggests that specific cognitive deficits, such as impaired divided attention and persistent forgetfulness, may persist for years even after injury. In India, where the majority of individuals with disabilities reside in rural areas, a recent rural appraisal identified key barriers to effective rehabilitation service delivery, including limited awareness, inadequate workforce and infrastructure, poor accessibility and availability of assistive aids, low utilization of services, and concerns regarding their cost-effectiveness.⁹

In India, access to neurorehabilitation services is limited by several systemic barriers, particularly in rural areas where most persons with disabilities reside. Challenges include long travel distances, inadequate transportation, limited public awareness of available services, and a significant financial burden on families. A shortage of trained rehabilitation professionals, insufficient government funding, and weak policy integration further hinder the delivery and accessibility of neurorehabilitation within the national health system.¹² Although previous studies have examined disability following head injury and barriers to rehabilitation, most research has focused on quantitative outcomes, functional recovery, or service utilization. Limited research has explored how caregivers perceive the multidimensional impact of disability and rehabilitation barriers in the Indian context, particularly using a phenomenological approach. Understanding these lived experiences may provide insights for developing patient-centred rehabilitation services.

METHODOLOGY

Aim

The present study aims to understand the nature and impact of disability, as well as barriers to rehabilitation among individuals with head injury.

Objective of the Study

- To explore the nature of disability and its impact on various aspects of individuals' lives, including personal identity, daily functioning, and occupational roles.

- To understand the different obstacles encountered by individuals in the process of rehabilitation.

Research Design

A qualitative research design was employed, using a *phenomenological approach* (realistic phenomenology) to gain in-depth insight into participants lived experiences.

Sample Selection

The total sample for the present study comprised 15 caregivers of individuals who had sustained a head injury. Recruitment continued until thematic saturation was achieved, at which point no substantially new themes emerged from subsequent interviews.

Sampling Technique

Participants were selected using a convenience sampling method.

Statistical Analysis

Data were analysed using thematic analysis within a phenomenological framework.

Inclusion criteria

- Caregivers of individuals who had undergone a head injury.
- Both male and female with head injury.
- Individuals between the age group 22-60 years.
- Individuals hailing from both rural and urban areas.

Exclusion criteria

- Caregivers of individuals with other mental disorders or intellectual disabilities.
- Individuals with a head injury who were previously unemployed.
- Individuals below 22 years of age and above 60 years of age.

Procedure

Participants who met the inclusion and exclusion criteria were selected for the study. Informed consent was obtained from the participants. A semi-structured interview was conducted by the researcher, which lasted between 30 - 60 minutes and was conducted in Tamil and English in the following areas:

- Changes in family dynamics following a head injury,
- Changes in self-perception following a head injury,

- Changes in occupational roles or employment following a head injury.
- Reasons for discontinuation or non-utilization of rehabilitation services.

After data collection, *horizontalization* was used to extract significant statements. These statements were then organized into clusters of meaning, resulting in emergent themes in four domains: *family, self, occupation, and barriers to rehabilitation*. These themes are then reduced to an essential structure that explains the behaviour (how it was experienced), a structured description. The phenomenological research ends with the reader understanding better the essential, invariant structure (or essence) of the experience, recognizing that a single unifying meaning of the experience exists.

Ethical considerations

Ethical guidelines for qualitative research were strictly adhered to throughout the study. Participants were provided with detailed information about the research and gave informed consent before participation. They were assured of confidentiality, voluntary participation, the right to withdraw at any stage without consequences, and protection from any physical or psychological harm. Issues related to deception and debriefing were also addressed in accordance with established ethical research standards.

RESULTS AND DISCUSSION

The present study was informed by the International Classification of Functioning, Disability and Health (ICF), which conceptualizes disability as an interaction between health conditions, personal factors, and environmental barriers. The respondents' narratives are analysed in this chapter to acquire a feeling for their ideas in order to understand them fully; for each of the significant statements, the meanings are formulated. This process is repeated across participants' stories, and recurrent meaningful themes are clustered. The resulting themes are integrated into a textual description of the phenomenon studied. These themes are then reduced to an essential structure that explains the behaviour, a structured description (how it was experienced).

Table 1.1 Themes and Sub-themes

Major Theme	Subthemes	Description
Theme 1: Self- Loss of Independence and Emotional Impact	Loss of Independence	Dependence on others for activities of daily living and mobility after injury.
	Altered Self-Identity	Changes in self-perception due to reduced functioning and inability to perform previous roles.
	Emotional Distress	Feelings of sadness, frustration, helplessness, and emotional suffering resulting from disability.
Theme 2: Family- Disruption, Burden, and Emotional Strain		Increased physical, emotional, and
	Caregiver Burden	caregiving responsibilities placed on family members.
	Financial Strain	Economic challenges arising from treatment costs, unemployment, and reduced family income.
Theme 3: Occupation- Loss of Role and Cognitive Challenges	Changes in Family Dynamics	Altered relationships, role shifts, conflicts, and disruptions within the family system.
	Loss of Employment and Vocational Roles	Reduced ability to return to previous employment or perform occupational duties effectively.
	Cognitive Difficulties at Work	Memory problems, attention deficits, and slowed processing affecting job performance.
Theme 4: Barriers to Rehabilitation- Lack of Access, Awareness, and Support	Reduced Self-Worth and Productivity	Feelings of inadequacy and diminished confidence associated with occupational limitations.
	Transportation and Accessibility Barriers	Difficulties travelling to rehabilitation centres, especially among rural families.
	Lack of Awareness of Rehabilitation Services	Limited knowledge regarding available rehabilitation resources and treatment options.
	Financial and Resource Constraints	Costs of treatment, limited service availability, and inadequate support systems affect rehabilitation utilization.
	Family Motivation Despite Barriers	Strong willingness of caregivers to seek rehabilitation and support recovery despite practical difficulties.

Theme 1: Self – Loss of Independence and Emotional Impact

The self is an integral part of oneself. From interviewing the samples, it was found that one fourth of the individuals who were independent with respect to the activities of their daily living, following head injury, had become either completely or partially dependent with respect to the activities of their daily living. Existing literature also identifies that aggression and apathy are significant contributors to work-related disability in individuals with severe traumatic brain injury (TBI); these personality changes can be temporary or permanent.

Excerpts from participants' interviews are given below:

My brother, a bold, confident, and outgoing person who worked in NLC mines earlier, was the sole breadwinner of the family. Following RTA, he has become dependent on his wife for his ADL; he needs assistance to go anywhere and often cries when he sees how much we are struggling.

Theme 2: Family – Disruption, Burden, and Emotional Strain

Family is the single most important influence in an individual's life. They are a group of people who are directly linked through blood relations or institutions of marriage. It was evident that following a head injury, many families experienced chaos, conflict, and financial crisis. Many also found difficulties in handling responsibilities. They described the injured person as having a *short fuse*, *flying off the handle* easily, being irritable or having a quick temper. He/she might also use abusive language, throw objects, slam fists into things, slam doors, or threaten or hurt family members or others. All these factors also create stress on the family members, as well as it takes a toll on them both physically and emotionally.

Excerpts from participants' interviews are given below:

My son used to live in Chennai with his wife and two kids, while my wife and I stayed in our native village. After his accident, he lost his job, and we moved in to take care of him. Now we support his family with my pension. He is restless, lacks motivation, speaks in short sentences, and cannot travel anywhere alone...

He seems to be restless with a lack of interest or motivation to do any work... He doesn't get along with his children like he used to, responds in short sentences when questioned, and is unable to travel alone anywhere.

Theme 3: Occupation – Loss of Role and Cognitive Challenges

Work provides individuals with meaning, self-respect, happiness, and the opportunity to build confidence, self-esteem, and a sense of contribution. It serves as the primary mode of living for most people around the world. Unemployment, therefore, can be deeply detrimental, depriving individuals of these essential elements. Interviews revealed that the majority of individuals with head injury were male, and among them, three-fourths had been the sole breadwinners of their families. In several cases, the injury had a significant impact on their occupational functioning. Despite their previous qualifications or professional roles, the chances of returning to work or securing new employment were markedly reduced. This often resulted in diminished self-confidence, lowered self-esteem, and feelings of inferiority. Additionally, many struggled to balance work and family life due to cognitive decline and newly assigned roles post-injury. A particularly prominent issue was difficulty sustaining attention at work, further impairing their occupational functioning.

Excerpts from participants' interviews are given below

My son, who had met with a road traffic accident last month, had completed his bachelor's in engineering, worked as a software engineer in an NLC for the past 2 years... but now he has difficulty in remembering things, which makes it difficult for him to take up any job ranging from small household chores to a job in any organization.

Another participant added:

My son works as an MTC bus conductor. Following his accident, he experiences slowness of movement because of which he is unable to make changes quickly and drops coins frequently at work...this has caused significant difficulty with regard to his occupation.

Cognitive impairments are a significant sequela of mTBI that can persist for an extended period of time

and impact the quality of life of individuals. Previous studies suggested that cognitive deficits may be due to structural damage to specific brain regions, and cognitive rehabilitation programs may be effective in improving cognitive outcomes⁸.

Theme 4: Barriers in Rehabilitation - Lack of Access, Low Awareness, and Transportation

According to the World Health Organization (WHO), “Rehabilitation is the interventions needed when a person is experiencing limitations in everyday physical, mental and social functioning due to ageing or a health condition, including noncommunicable diseases or disorders, injuries or trauma.” The goal of rehabilitation is to help the individual progress to the most independent level of functioning possible. The majority of the individual’s caregivers were willing to spend to bring him/her back to his /her premorbid personality, irrespective of their socio-economic status. However, their main concern was transportation, because following the accident, individuals were in need of more assistance to travel from one place to another place, especially of those hailing from rural areas. Lack of awareness regarding the aids available is found to be predominant. However, on the brighter side, caretakers do not hesitate to involve people with head injuries in making important decisions. Excerpts from participants' interviews are given below

My son has difficulties in remembering the names of objects and experiences, and slowness of movement. We have sent him for physiotherapy and yoga classes; however, we have stopped it because it was difficult for us to take him to the classes since it was distant from our house, and also, I’m 70 years old. But we do try our best to involve him in our family activities by taking him along with us for all, despite his not showing any interest in it.

Another participant added:

My son is only 24 years old we have come here to get few tests done so that we can claim insurance..a doctor here said that she can help my son to get back to adequate functioning level ..(When questioned whether she was aware about the rehabilitation processes earlier)..she replied saying that she wasn’t aware of any such thing,..since she comes from a distant place it was enquired whether she will be able

to bring her son from that far and despite hailing from distant place and low socio-economic status she was willing to come, just considering the betterment and future of her son.

The findings were consistent with previous literature. Research states that the main barrier to the utilization of services was distance from rehabilitation units and lack of financial coverage/assistance for rehabilitation by healthcare insurance providers¹³. Most studies indicate that the greatest recovery from head injury occurs within the first year following the injury. However, measurable recovery also has been shown to continue well beyond the one-year marker. In addition to actual brain recovery, improvements in functioning may result from rehabilitation and learned coping and compensatory strategies.

CONCLUSION

The present study concluded that there was a significant impact on the various aspects of the lives of individuals with head injury, ranging from mild impairment to severe impairment. Especially significant impacts were found to be greater on the area of self and almost equal on the areas of family and occupation. However, the notable positive finding was that family members were willing to provide support to help them return to their adequate level of functioning, irrespective of socioeconomic background or geographical location. The findings highlight disability following head injury as a multidimensional phenomenon affecting identity, family functioning, occupational participation, and access to rehabilitation. Environmental barriers, particularly transportation challenges and limited awareness of services, continue to impede rehabilitation participation despite strong caregiver motivation.

Recommendations

Based on the findings of this study, the following recommendations are proposed:

- Provide Psychoeducation to the individual as well as the family members.
- Implement intensive therapy including Speech-Language Pathologists, Physical Therapists,

Occupational Therapists, Psychologists and Neuropsychologists.

- Introduce structured cognitive retraining programs.
- Promote home-based rehabilitation.
- Facilitate environmental modifications to support recovery and independence.
- Encourage inclusion of individuals in family activities.
- Offer a vocational skills program tailored to the individual's current abilities.

Limitations

The study was conducted with a limited number of participants; this restricts the generalizability of the findings to wider populations.

Future implications

For future practice and research, the following considerations are suggested:

- Individuals expressing willingness to engage in therapy can be encouraged to participate in cognitive retraining, group therapy, and home-based rehabilitation interventions.
- Pre- and post-intervention assessments should be conducted to evaluate the effectiveness of therapeutic programs.
- Family members should receive psychoeducation regarding the nature of the condition, the availability of rehabilitation resources, the benefits of psychotherapy, and their rights under the Rights of Persons with Disabilities (RPWD) Act.

Suggestions for Future Research

- Incorporate Longitudinal Design:

A longitudinal study could track individuals with head injury over time to better understand how rehabilitation barriers and perceived disability evolve during different stages of recovery.

- Mixed Methods Approach:

Combining qualitative data with quantitative measures could enrich the findings and offer a more comprehensive view of the challenges faced.

DECLARATIONS

Conflict of Interest

The authors declare no conflict of interest related to this manuscript.

Funding

No external funding was received.

Ethical Statement

No patient-identifiable information is included.

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Volume 1 | Issue 1 | June 2026

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Journal of Applied Therapeutics (JAT)

Volume 1, Issue 1 (2026)

Published by: Institute of Applied Therapeutics (IAT), Chennai



Advancing Applied Therapeutics Through Evidence, Practice, and Policy

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The **Journal of Applied Therapeutics (JAT)** is an interdisciplinary, practice-oriented journal that focuses on translating scientific knowledge into meaningful, real-world healthcare applications. The inaugural issue reflects this philosophy through articles exploring the multidimensional impact of head injury and barriers to rehabilitation, an integrated neurobehavioral outpatient model aimed at improving treatment acceptance, the complexity of suicide and its legal, social, and clinical determinants, the importance of multidisciplinary pain management as a core component of modern medicine, and a case report highlighting atypical Alzheimer-spectrum disease presenting with language impairment, depression, and suicidal behaviour. Collectively, these articles emphasize that effective healthcare requires the integration of biological, psychological, social, ethical, and practical factors to address complex human problems in real-world settings.