

Original Research Article

Unseen battles: exploring the psychosocial challenges, coping mechanisms and resilience among caregivers of individuals with traumatic brain injury

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ABSTRACT

Background: Traumatic brain injury (TBI) affects not only patients, but also primary caregivers and family members, impairing their psychological well-being, social roles, and health. Caregivers frequently experience interpersonal conflict, role obstacles, and stress-related health issues.

Method: The study utilized a qualitative research approach, incorporating in-depth, semi-structured interviews to capture caregiver's lived experiences. The study included eight caregivers of individuals with moderate to severe traumatic brain injury, selected using criterion-based purposive sampling. Caregivers were aged 18 years or above and had been providing care for a minimum of three months.

Results: The findings of the study revealed that caregivers of individuals with traumatic brain injury faced substantial emotional, social, and financial difficulties. Caregivers reported fear, anxiety, emotional exhaustion, identity disruption, and career strain during critical caregiving phase. Despite these difficulties, they demonstrated resilience through spirituality, family support, emotional commitment and motivation from recovery milestones.

Conclusion: Caregiving in traumatic brain injury involves substantial psychosocial burden alongside adaptive resilience. The findings emphasize the need for structured psychosocial, emotional, and financial support systems to reduce caregiver stress and enhance long-term well-being and sustainability.

Keywords: Traumatic brain injury, Caregiver burden, Coping strategies, Resilience, Psychosocial impact

INTRODUCTION

TBI is one of the largest cause of mortality and disability in young adults, and it is expected to be the top cause of impairment for all neurological diseases worldwide by 2030, at 2-3 times higher the rate than that of Alzheimer's disease.^{1,2} Every year around 2.8 million people in the United States suffer from traumatic brain injury, and up to 5.3 million people live with long-term physical, cognitive, and psychosocial problems.^{1,3,4} One of the major cause of traumatic brain injury is traffic accidents, and many survivors are young, making the transition all the more frightening for caretakers.⁵ Many people with

traumatic brain injury experience cognitive impairments as well as poor physical health in the first year after the accident, which affects their social integration and capacity to work.^{6,7}

Previous studies have shown that a caregiver's psychological well-being has a major impact on a patient's recovery path also individuals with chronic diseases who practice yoga may benefit from better cognitive functioning, self-awareness, balance, coordination, disability adjustment, and stress reduction.⁸⁻¹¹ Traumatic brain injury affects not only patients, but also primary caregivers and family members, impairing

their psychological well-being, social roles, and health. Caregivers frequently experience interpersonal conflict, role obstacles, and stress-related health issues.¹² The American Medical Association defines an informal caregiver as anyone who has a substantial relationship with the care receiver, such as a friend, parent, spouse, or other relative.¹³ The experience of caretakers following traumatic brain injury has previously been classified into three major categories: caregiver burden, caregiver requirements, and caregiver quality of life. These three categories are linked with increasing needs also associated with increased burden and depressed symptoms in caregivers.¹⁴

Furthermore, they face a wide range of distress, including depression symptoms, physical and financial strain, and social issues as the explanations given by healthcare providers are frequently insufficient for comprehending the injuries, their aftereffects, and implications.^{15,16} Caregivers may experience weight fluctuations, changes in sleep patterns, increased irritability, exhaustion, frequent headaches, mood swings, substance usage, and feelings of overwhelm.¹³ Thus leading to health issues such as coronary artery heart disease, obesity, sleep deprivation, and physical and mental discomfort.^{17,18}

To deal with these responsibilities, family members develop coping mechanisms that benefit both their own well-being and the patient's recovery. Previous studies worked the association between various coping strategies and caregiver burden and discovered that using the coping strategy escape-avoidance was associated with burden.¹⁹ Spiritual coping improves the caregiver's well-being, particularly psychological discomfort. Caregivers who adopt coping mechanisms based on their religious or spiritual beliefs experience mild depression, whereas another finding show that caregiver resilience is positively connected with meeting family requirements for emotional support.^{20,21}

Rationale of the study

Traumatic brain injury is frequently described as a “silent epidemic,” with nearly 70 million new cases reported globally each year. Due to the sudden onset of Traumatic Brain Injury, caregivers are often required to rapidly adapt to shifting roles and responsibilities as individuals with traumatic brain injury transition through different levels of medical care and rehabilitation. Caregivers play a crucial role in supporting recovery and long-term functioning; however, their needs are frequently overlooked, which may lead to increased psychosocial strain.

To the authors' knowledge, although existing literature has documented the psychological burden, stress, and reduced quality of life experienced by caregivers of individuals with traumatic brain injury, much of this research has relied on quantitative approaches that primarily focus on measurable outcomes such as

caregiver burden and mental health symptoms. While these studies provide valuable insights, they often overlook the nuanced and subjective experiences of caregivers navigating the long-term consequences of traumatic brain injury.

In particular, there remains limited understanding of how caregivers interpret their caregiving roles, the challenges they encounter in their daily lives, and the strategies they employ to cope with these demands. Addressing this gap, the present study aims to explore the lived experiences of caregivers of individuals with traumatic brain injury through qualitative interviews. Specifically, the study seeks to understand the emotional, social, and practical challenges faced by caregivers, as well as the coping mechanisms and sources of resilience that support them in their caregiving journey.

Aim of the study

To understand the lived experiences of caregivers of individuals with traumatic brain injury, focusing on the psychosocial and emotional challenges they face (if any), their coping mechanisms, resilience, and the support system that influence their caregiving journey.

Objectives

To explore the emotional and psychosocial challenges (if any) faced by caregivers of individuals with traumatic brain injury. To understand and identify the coping strategies and resilience factors adopted by caregivers to deal with the challenges they experience.

METHODS

Participants

The research involved eight primary caregivers of individuals with moderate to severe traumatic brain injury. Criterion based purposive sampling was utilized to select participants who fulfilled the established inclusion criteria. Eligible caregivers were required to be at least 18 years of age and to have been continuously involved in the caregiving process since the time of injury. This included caregivers who were present during the hospitalization period and who had continued providing care to the individual at home for a minimum duration of three months prior to data collection.

The severity of traumatic brain injury (moderate to severe) was confirmed by the treating neurosurgeon at the time of hospital admission, based on the patient's clinical presentation and medical evaluation. In this study, a caregiver is defined as any individual who has a substantial relationship with the care recipient, such as a child, parent, spouse, or any other relative. Participants were located and recruited from a clinical setting specializing in neurosurgery, under the guidance of a

neurosurgeon. Each caregiver played an active role in the ongoing care of the person with traumatic brain injury.

Exclusion criteria

Caregivers below 18 years of age, those who had not been continuously involved in caregiving since the time of injury. Also the caregivers who had not participated in the individual's hospitalization or provided home-based care for a minimum of three months prior to data collection were excluded. Caregivers of individuals with mild traumatic brain injury or conditions other than moderate-to-severe traumatic brain injury were also excluded. Additionally, individuals who were not substantially involved in the ongoing care of the person with traumatic brain injury or who were unable or unwilling to provide informed consent and participate in the interview were excluded.

Procedure

The study utilized a qualitative research approach, incorporating in-depth, semi-structured interviews to capture caregiver's lived experiences. Prior to the initiation of the study, ethical approval was obtained from the Institutional Ethics Committee. Written informed consent was secured from all participating caregivers. Before commencing the interviews, participants were asked brief introductory questions, including whom they were caring for and the duration of their caregiving role, to establish context and rapport. The severity of traumatic brain injury in the care recipients was confirmed by a qualified neurosurgeon based on clinical records. Caregivers were fully informed about the purpose of the study, and their right to withdraw at any stage.

Data collection and analysis

Data was gathered through comprehensive, semi-structured interviews aimed at obtaining detailed narratives of caregiver's experiences in caring for individuals with traumatic brain injury. The interviews were conducted in either English or Hindi, based on the preferences of the participants. With the consent of the participants, all interviews were audio-recorded for the analysis. The acquired data underwent thematic analysis, utilizing Braun and Clarke's six-phase framework, which included becoming familiar with the data, creating initial codes, identifying themes, reviewing themes, defining and naming themes, and generating the final report.

RESULTS

A thematic analysis was conducted on interviews with eight caregivers of individuals with moderate to severe traumatic brain injury to explore the emotional and psychosocial challenges they face, as well as to identify the coping strategies and resilience factors they employ.

Table 1 summarizes the characteristics of the caregivers included in the study. The participants comprised eight family caregivers providing care to individuals with traumatic brain injury. The caregiving relationships included mothers, fathers, spouses, siblings, and extended family members such as a grandson assisting in caregiving. The duration of caregiving ranged from three months to five years, reflecting both relatively recent caregiving experiences as well as long-term caregiving roles.

Theme 1: Caregiving roles, routines, and medical understanding

When caregivers were asked about their roles and routines, the majority described responsibilities such as assisting with personal hygiene, managing medications, providing mobility assistance and physiotherapy support, and ensuring round the clock supervision; additionally, all caregivers reported having full awareness of the care recipients' conditions, including brain injuries, fractures, and vision-related complications.

"I help him with gargling, bathing, giving medications, I also massage him daily."

"I have a clear understanding of his illness... temporal bone fracture, internal bleeding, vision problems."

Theme 2: Impacts on daily life and personal growth

Most caregivers reported profound disruptions to daily routines through caregiving, including restructured schedules around caregiving tasks, reduced social and leisure time, career compromises, alongside these challenges, several caregivers also described personal growth in terms of increased stamina and mental fortitude.

"My daily routine has revolved around my mother; I stay at home and work online to keep an eye on her."

"Work often has to be set aside... I had to take leave from work to take care of him."

Theme 3: Discovered strengths and challenges

During the caregiving process all caregivers discovered strengths such as enhanced patience, inner resilience, and willpower, but also faced challenges including emotional exhaustion, physical demands, and frustration from repetitive behaviors of care recipients.

"I became mentally stronger and physically capable... I found strength within myself."

"He cannot be reasoned with and becomes very adamant... my patience is wearing thin."

Theme 4: Emotional experiences and challenging situations

The caregivers mentioned that they regularly experience intense negative emotions including fear and anxiety, emotional exhaustion, guilt and self-blame, irritability and frustration, with the most challenging situations being ICU stays and persistent non-recovery fears.

“When my son was in surgical ICU, tension was much higher. There was constant fear about what complications might arise.”

“There was constant fear that he might fall or get injured... it felt like caring for a newborn.”

Theme 5: Emotional management, rewards, and resilience

The caregivers mentioned that they managed stressful moments and difficult behaviors from the care recipient through faith in God and prayer, meditation, and positive reframing of thoughts; most rewarding experiences included survival milestones and first communications, fostering emergent resilience.

“When he spoke for the first time after three months of being unable to speak, it felt incredibly good.”

“I meditate, read books, visit the temple, exercise... and have faith in God, believing that everything would eventually become normal.”

“We consciously speak positively to him and encourage hope... sometimes we change the situation by dancing or watching movies.”

Theme 6: Relational impacts and support dynamics

When questioned about changes in social life, all caregivers reported relationship changes, including reduced friendships, marital strain or, in some cases, strengthening, and increased family cohesion.

Helpful support was primarily characterized by practical assistance from family members and encouragement from friends, whereas unhelpful experiences included

judgment from relatives and emotional distance from others.

“My marital relationship has been deeply affected... we became emotionally distant and are no longer living together.”

“Family members came home, cooked food, managed household responsibilities... their presence felt comforting.”

Theme 7: Financial, career, and identity impacts

All caregivers faced disruptions in their careers, which included taking leaves or losing their jobs and experiencing career stagnation. They also incurred financial strain due to medical costs and experienced a loss of personal identity, as caregiving responsibilities overtook their personal lives. However, a small number reported being somewhat protected by previous financial savings.

“I lost my job and have not been working for the past year... I am financially disturbed.”

“We feel that we have forgotten our own identity... everything revolves around caregiving now.”

Theme 8: Motivation, future outlook, and advice

When questioned about daily motivation to provide care, caregivers reported being driven primarily by feelings of love and duty and by observing signs of recovery and progress. Their principal concerns about the future centered on the possibility of incomplete recovery, while their hopes focused on achieving long term stability.

Reflecting on their caregiving journey, caregivers emphasized the importance of being emotionally present for the care recipient, practicing patience, and offering care rooted in empathy and sincerity.

“Seeing my brother after such a serious incident motivates me deeply; his recovery gives me strength.”

“Caregiving must come from the heart... one should provide care with positive energy and simply be there for the person.”

Table 1: Characteristics of caregivers participating in the study.

Caregivers	Relation to recipient	Duration
C1	Sister to brother	1 years
C2	Mother to son	6 months
C3	Daughter to mother	5 years
C4	Grandson (with uncle) to grand father	2 years
C5	Wife to husband	3 months
C6	Husband to wife	3 months
C7	Wife to husband	10 months
C8	Father (with wife) to son	1.5 years

Table 2: Summary of key findings across themes.

Themes	Key findings, N (%)
Caregiving roles and medical understanding	Personal hygiene 8 (100%)
	Medication management 7 (88%)
	Mobility/physiotherapy 6 (75%)
	Continuous supervision 8 (100%)
	Medical awareness 8 (100%)
Daily life and personal growth	Restructured routines 8 (100%)
	Reduced social/leisure time 7 (88%)
	Career compromises 6 (75%)
	Increased stamina/mental fortitude 5 (63%)
Strengths and challenges	Patience 7 (88%)
	Resilience 6 (75%)
	Willpower 5 (63%)
	Emotional exhaustion 6 (75%)
	Physical demands 5 (63%)
	Frustration 4 (50%)
Emotional experiences	Fear/anxiety 8 (100%)
	Emotional exhaustion 6 (75%)
	Guilt/self-blame 4 (50%)
	Irritability/frustration 5 (63%)
	ICU stays 6 (75%)
Emotional management and resilience	Non-recovery fears 5 (63%)
	Faith/prayer 7 (88%)
	Meditation 4 (50%)
	Positive reframing 6 (75%)
	Recovery milestones 7 (88%)
	First communication 3 (38%)
Relational impacts and support	Relationship change 8 (100%)
	Reduced friendships 7 (88%)
	Marital changes 6 (75%)
	Family cohesion 5 (63%)
	Family assistance 7 (88%)
	Friend encouragement 5 (63%)
Financial, career and Identity impacts	Career disruption 8 (100%)
	Leave/job loss 5 (63%)
	Career stagnation 6 (75%)
	Financial strain 5 (63%)
	Identity loss 6 (75%)
Motivation and future outlook	Love/duty 8 (100%)
	Recovery/progress 6 (75%)
	Incomplete recovery concerns 5 (63%)
	Long-term stability 7 (88%)
	Emotional presence 7 (88%)
	Patience 7 (88%)
	Empathy/sincerity 5 (63%)

N represents the number of caregivers who reported or described each finding during the interviews. Percentages are based on the total sample of eight caregivers.

DISCUSSION

The research highlights the complex personal, relational, and systematic influences that impact caregiver well-being in the situation of caregiving. This study explored the demands of caregiving for individuals with traumatic

brain injury, its impact on caregivers' daily lives, their coping strategies, and resilience factors to gain an understanding of the emotional and psychosocial challenges faced by caregivers. Phenomenological research approach was used to explore and understand caregivers lived experiences of providing care to individuals with traumatic brain injury. Data was

collected through criterion based purposive sampling. Information was gathered through semi-structured interviews with eight caregivers, providing important insights into their experiences in caregiving.

The majority of the caregivers outlined care immediately after sudden accidents of care recipients (usually someone from immediate family) and described their roles and routines such as assisting with personal hygiene, managing medications, providing mobility assistance, ensuring round the clock supervision. Previous findings also indicate that caregivers require a large amount of energy daily to look after the care recipient.²³ In contrast to a previous study where caregivers complained lack of information regarding the care receiver's condition and treatment, this study found that caregivers reported having full awareness of the care recipients' conditions.¹⁶

During the caregiving process all caregivers discovered strengths such as enhanced patience, inner resilience, and willpower, but also faced challenges including emotional exhaustion, guilt, physical demands and frustration from repetitive behaviors of care recipients all while experiencing intense negative emotions including fear and anxiety. Caregivers have reported that the degree of the neurobehavioral consequences of a brain injury, make their lives more difficult which increases stress wherein emotional and psychological challenges faced by caregivers in this research is also supported.^{24,25}

Previous findings has shown that caregivers of individuals with traumatic brain injury frequently experience negative feelings such as sadness, frustration, guilt and helplessness, with many showing considerable symptoms of anxiety.²⁶ Additionally, findings from a study suggest that persistent feelings of guilt may hinder caregivers from seeking or maintaining social support, even when it is essential.²⁷ Caregivers in this study reported the most challenging situations being ICU stays and persistent non-recovery fears and most rewarding being survival milestones and first communications.

Significant relational changes around the caregivers were widely noticed, including reduced friendships, marital strain while in some cases, strengthening and increased family cohesion. Some research has shown that caregivers also suffered a personal loss of relationship with their spouses due to spending too much time with the family member with the TBI.²³ Also researches have shown that social support potentially decreases the burden and stress associated with the caregiving role.²⁷⁻²⁹

Additionally, caregivers also incurred disruptions in their careers and financial stress due to persistent requirement of the care recipient medical costs. However, a small number reported being somewhat protected by previous financial savings. As supported by the previous findings, financial pressure has been reported amongst caregivers of traumatic brain injury survivors as an enormous challenge in the caregiving role.^{26,27,30} Many a times

caregivers even have to choose between following a career and providing care for a family member who sustained a TBI.²³ With caregiving duties becoming more central to everyday life, numerous caregivers felt a reduced sense of individual identity. However, caregivers utilized various coping methods, including faith-oriented practices, meditation, and constructive cognitive reframing, which helped foster resilience and psychological strength over time. Researchers have found that caregivers of individuals with chronic conditions who practice yoga may experience improved cognitive functioning, self-awareness, balance, coordination, adjustment to disability, and reduced stress whereas escape avoidance coping strategies have been found to increase distress in TBI caregivers, the caregivers who use a religious or spiritual belief's coping strategies experience lower levels of depression.³¹⁻³³

The findings indicate that caregivers' daily motivation to provide care was largely sustained by feelings of love and duty and by observing signs of recovery and progress. At the same time, caregivers' predominant concerns about the future were marked by uncertainty regarding the possibility of incomplete recovery. As pointed out in most of the studies caregivers often worry about the future of their family member and can feel like they are not in control of the situation.²⁸ Despite these concerns, caregivers expressed their hopes focused on achieving long term stability.

Reflecting on their caregiving journey, caregivers emphasized the importance of being emotionally present for the care recipient, practicing patience, and offering care rooted in empathy and sincerity. The effects of traumatic brain injury significantly influence family caregivers. Those providing care encounter a variety of daunting obstacles in their roles. The complexities of caregivers need evolve over time. These insights highlight the urgent necessity for interventions that can lessen caregiver strain and enhance their quality of life, including programs for psychoeducation, support groups, and policy initiatives.

CONCLUSION

This research enhances our comprehension of caregiving in the context of TBI, emphasizing the interplay between unexpected challenges, established patterns, and emotional strains alongside protective factors like spirituality and social support. Despite recognizing considerable sacrifices, caregivers persist by utilizing their innate strengths and adaptive coping strategies.

These findings lay the groundwork for specialized interventions, such as resilience training and financial assistance programs, designed to alleviate caregiver burdens and promote sustainability within this vulnerable demographic. They indicate that support initiatives for caregivers should not only tackle stress and burden but also recognize their emotional commitments, cultivate a

sense of hope rooted in stability, and affirm the relational and empathetic aspects of caregiving.

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