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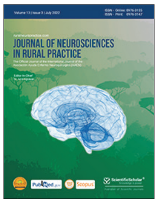

Original Article

Psychosocial needs of persons living with traumatic brain injury and their non-injured spouses: An exploratory study from a tertiary care center

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ABSTRACT

Objectives: Traumatic brain injury (TBI) has an immense impact on the family; particularly spouses, who face significant challenges such as changes in roles and responsibilities, relational dynamics, and financial instability. The study aims to explore the psychosocial needs of couples where one spouse is living with TBI.

Materials and Methods: The current study adopted the exploratory research design. Male or female patients receiving treatment and their spouses constituted the study population, selected through convenience sampling. Data were collected using a validated in-depth interview guide. In-depth Interviews were conducted with 24 couples, and the interviews were audio recorded with the participants' consent.

Results: A total of six themes have been identified from the study: educational needs, sexual issues, behavioral issues, diminished well-being, suicidal thoughts, and disturbance in Life.

Conclusion: The psycho-social needs are common among persons living with traumatic brain injury (PLwTBI) and non-injured spouses, which are atypical, and inimitable in nature. Neuroprofessionals should assess the psycho-social needs of individuals during admission and post-discharge to facilitate better psychosocial outcomes for non-injured spouses and support the recovery of PLwTBI. This research highlights the necessity of developing tailored psycho-social interventions to address the unique challenges faced by both, PLwTBI and their non-injured spouses.

Keywords: Couples, Person living with TBI, Psychosocial needs and India, Traumatic brain injury

INTRODUCTION

Traumatic brain injury (TBI) is a major cause of mortality and disability; making it a universal health concern.[1] It can be categorized as mild, moderate, or severe based on symptoms such as loss of consciousness, post-traumatic amnesia, and memory and motor impairments.[2,3] All age groups are affected by TBI in terms of fatalities, injuries, and impairments, but young, productive people are more likely to suffer than women. The financial burden on families is substantial due to hospitalization and rehabilitation costs.[1,2]

It has a catastrophic impact on the non-injured spouse, leading to shifts in roles and responsibilities, relationship strains, financial difficulties, and cognitive and behavioral challenges in the injured spouse. The quality and stability of the relationship as well as the partner's psychological health may suffer if they are unable to handle those difficulties.[4,5] Spouses typically report poorer levels of positive well-being, quality of life, and life satisfaction, as well as higher levels of anxiety, stress, and depression, when compared to the general population. Recognizing and addressing the psychosocial needs of both, persons living with traumatic brain injury (PLwTBI) and their spouses, are crucial for developing effective interventions.

Relationship dynamics may change due to altered communication, personality shifts, and cognitive impairments. In contrast to the general population, there is no conclusive evidence that TBI raises the rate of marital dissolution.[6] To improve the well-being of patients and caregivers, there should be proper educational programs and psychosocial interventions to identify and address their psycho-social needs.[7] Research findings on the psychosocial needs of non-injured spouses and PLwTBI from Western countries may not be directly applicable to the Indian context.

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Given India's distinct socio-cultural context, research on this topic is limited, necessitating this exploratory study.

MATERIALS AND METHODS

Study design

The study used a qualitative approach to explore the study variables. This approach has been used to identify the psychosocial needs and experiences of couples where one spouse has sustained TBIs and this area has not been studied in an Indian setting so far, therefore current study adopted the exploratory research design with a qualitative approach.

Study setting and participants

The data were collected from May 2023 to July 2023. The study was conducted in the neurosurgery outpatient department (OPD), at the tertiary care hospital. Male or female patients who were availing treatment at the OPD and their spouses were considered as the population of the current study. Researchers adopted convenient sampling to recruit participants and a total of 24 couples (both injured spouse and their non-injured spouse) were recruited for the study. Participants were recruited based on the inclusion criteria such as TBI survivors who have completed the 6 months of surgery process and accessing follow-up services, between the age group of 21–50 years, and the non-injured spouse living with the survivor. Those who had severe impairment with language, memory loss, and significant behavioral problems and those who did not want to participate in the study were excluded from the study.

Data collection process

Interview guide

The in-depth interview guide was developed by the researcher based on the existing review of literature and clinical experience. The guide was validated through expert consultations, including neuropsychologists (02), psychiatric social workers (02), neuro-rehabilitation specialists (01), and psychiatrists (01). All the differences raised by the experts were discussed and modified in consultation with the guide.

Semi-structured questionnaire

The semi-structured questionnaire was developed to capture the sociodemographic details such as age, gender, religion, socioeconomic status, domicile, employment status, and clinical profiles of the patients.

Face-to-face interview

Interviews were conducted in a private OPD room. Participants were briefed on the study's purpose, and informed consent was obtained before the in-depth interview. The interviews were audio recorded with the participant's consent. Later on, recordings were transcribed and then translated from Kannada to English. The average duration of the interview was 45 min–1 h.

Data analysis

The collected data were summarized soon after each interview and then transcribed into Word and translated from Kannada to English. The data were analyzed through the thematic analysis using the inductive approach.[8] Data were reviewed multiple times for consistency. Initial codes were generated and refined, with final codes grouped hierarchically. Peer scholars not involved in the study reviewed and validated the themes to ensure consistency and reliability.

Ethical consideration

This study is a part of PhD first Phase entitled "Development of Couple Well-being Program for Persons with TBI: A Feasibility Study." Ethical approval was obtained from the Institutional Ethics Committee at the National Institute of Mental Health and Neurosciences (NIMHANS), Bengaluru, Karnataka (NIMHANS), No. NIMH/DO/BEH.Sc.Div./2021–22.

RESULTS

Table 1 describes the socio-demographic profile of both dyads. The mean age of the patients is 37.79 ± 4.57 years. The majority were males 75% (18 individuals), 37.5% (9 individuals) had completed secondary education, and 25% (6 individuals) were drivers and farmers. The mean age of spouses is 36.42 ± 5.93, (29.2%), 29.2% of them had education up to secondary level education, and 12 of them (33.3%) were engaged in other occupations.

Table 2 revealed the other sociodemographic profiles of the dyads. The mean duration of a couple's marriage is 13.67 ± 4.86. 54.2% of the couples belonged to rural domicile, 62.5% of the couples were hailing from low socio-economic status (LSES), and the majority of the couples were living in nuclear families (79.2%).

The clinical information of the injured spouses is discussed in Table 3. The diagnosis of the injured spouses shows that, out of 24, 41. 7% (10) of them had been diagnosed with subdural hematoma, the majority of the injured spouses fall into the category of 6 months–1 year, accidents accounted for 79.2% of the cases (19 out of 24), accounting for the reason for injury.

DISCUSSION

TBI is increasing worldwide day by day and causing either permanent or temporary disability among injured persons. The impact of injury is not limited to a person alone, and it leads to psycho-social issues among the family members due

Table 1: Sociodemographic profile of the dyads.

Target population	Variable	Frequency (*n*=24)	Percentage
Injured spouse	Age (Mean±SD)		
	37.79±4.57		
	Gender		
	Male	18	75
	Female	6	25
	Education		
	No Education	2	8.3
	Primary	8	33.3
	Secondary	9	37.5
	PUC and above	5	20.8
	Occupation		
	Driver	6	25
	Farmer	6	25
	Homemaker	4	16.7
	Other	8	33.3
Non-injured spouse	Age (Mean±SD)		
	36.42±5.93		
	Education		
	No Education	2	8.3
	Primary	7	29.2
	Secondary	7	29.2
	PUC and Above	8	33.3
	Occupation		
	Homemaker	8	33.3
	Self-Employment	4	16.7
	Others	12	50

SD: Standard deviation, PUC: Pre-university course.

Table 2: Sociodemographic profile of the dyads.

Sl. No	Variable	Frequency (*n*=24)	Percentage
1.	Duration of Marriage		
	Mean score: 13.67±4.86		
2.	Religion		
	Hindu	23	95.8
	Muslim	1	4.2
3.	Domicile		
	Rural	13	54.2
	Urban	7	29.2
	Semi-Urban	4	16.7
4.	Socioeconomic status		
	LSES	15	62.5
	Middle Socioeconomic status	9	37.5
5.	Family type		
	Nuclear	19	79.2
	Joint	5	20.8

LSES: Lower socioeconomic status

Table 3: Injured spouses' clinical details.

Sl. No	Variable	Frequency (*n*=24)	Percentage
1.	Diagnosis		
	Contusion	6	25
	Extradural hematoma	8	33.3
	Subdural hematoma	10	41.7
2.	Duration of illness		
	6 months–1 year	17	70.8
	1 year–2 year	3	12.5
	2 years and above	4	16.7
3.	Reason for injury		
	Accident	19	79.2
	Fall	5	20.8

to a higher rate of dependency by the patient. Therefore, it is essential to explore the psychosocial needs of couples where one spouse has sustained a TBI. Thematic analysis of data has drawn 21 subthemes and 6 major themes [Table 4]. A detailed description of all the themes and subthemes, along with verbatim accounts from the participants, is provided in a Supplementary File. The majority of the participants expressed that they were not having adequate information about brain injury, its causes, effects, recovery and prognosis, follow-up, and long-term effects. Similarly, this specific need was observed in the Ottonello *et al*. study (2024),[9] in which caregivers of persons with neurological illnesses expressed an educational need. Furthermore, another study by Manskow *et al*., 2018[10] found that roughly half of the family members were dissatisfied with the style in which they were given information such as who to contact during an emergency if it occurs after discharge and information about the long-term effects of TBI. It determines the existence of an educational need among couples in which one spouse has experienced a TBI, and it is important to educate the dyads on TBI and its implications before discharge.

Another concern that couples have expressed is sexual issues; few patients reported increased sexual desire, few reported decreased desire and non-injured spouses reported consummation issues. The current study is supported by Sander *et al*., 2012,[11] 20% of spouses of people with TBI reported sexual dysfunction, and 44% reported dissatisfaction with sexual functioning. 62% of spouses reported a decrease in sexual activity during the year following the injury, 34% reported a decrease in sexual

Table 4: Psychosocial needs of PLwTBI and their non-injured spouses.

Main themes	Sub-themes
Educational Need	1.1 Poor knowledge
	1.2. Recovery process
	1.3. Medication and follow-up
Sexual Issues	2.1. Decreased sexual desire
	2.2. Increased sexual desire
	2.3. Consummation issue
Behavioral Issues	3.1. Unable to control anger
	3.2. Anger outburst
	3.3. Physical violence
Suicidal Ideations	4.1. Feeling of parting from family
	4.2. Sense of unworthiness
	4.3. Decided to end life
Diminished Well-Being	5.1. Future uncertainty
	5.2. Disturbance in sleep
	5.3. Alterations in eating pattern
Disturbance in Life	6.1. Decreased productivity
	6.2. No peace at home
	6.3. Less social participation
	6.4. Absence of social support
	6.5. Communication difficulties
	6.6. Increased roles and responsibility

PLwTBI: Persons living with traumatic brain injury.

desire, and 34% said that sexuality was less important than it was before the injury.

Impatience and aggressiveness are common behavioral difficulties that bother patients with TBI. These are the most difficult consequences of TBI which affects their social support networks. Anger was observed in 5–8% of military males examined within the first 6 months following TBI.[12] In the present study, 22 of the couples reported an increase in patients' anger. According to the study, anger is one of the most common emotional repercussions and found that injuries lasted between 6 months and 3 years, however, practically, all categories reported anger issues. However, there are no fresh studies to substantiate the findings of why non-injured spouses get angry; therefore it was observed in the interview that non-injured spouses would express their anger as a result of burden and stress or secondary to patients' injury. On the other hand, patients would have anger issues because of the injury itself.

Another theme that they have described is persistent suicidal ideations, such as wanting to terminate their lives and parting away from home. Hostetter *et al.*, 2019; Madsen *et al.*, 2018[13,14] discovered that patients with severe TBI are 2–4 times more likely to commit suicide than those without TBI. Bethune *et al.*, 2017[15] discovered that 6.3% of persons with TBI had suicidal thoughts at 3 months and 8.2% at 6 months. The current study also supports Bethune's findings, as 17 of them had been having 6 months to a year of illness duration. The study observation noted that the possible reasons for having suicidal ideations are poor coping, low resilience, burden, and lack of time for themselves and their spouse's health.

Most couples reported changes in their roles and responsibilities at home, which have emerged as one of the most common themes among couples. Spouses of people with TBI claimed that they have taken on all of the responsibilities and roles that their injured spouses previously performed, such as getting groceries, paying house rent, financial management, children care, and additionally patient care. This specific need is substantiated by Doser and Norup*et al.*'s 2016[16] study, which revealed that all of the responsibilities, roles, and household tasks that they had previous to the TBI, suddenly fell on the spouse, and they now have to take on many more roles as part of the home. The current study's findings are validated by the aforementioned studies. The injured person may require assistance with a variety of daily tasks, including self-care and mobility. In addition to his or her other responsibilities as a non-injured spouse, he or she is expected to care for the patient, which adds to the already existing tasks. The study also found that non-injured spouses were the major caretakers for the patients, regardless of gender.

Another theme that has emerged is impaired well-being, which includes sleep problems, daytime tiredness, and sleeping during the day. Both spouses experienced a decrease in sleep following one's brain injury. Ponsford *et al.*, (2013)[17] stated that individuals with TBI report significantly lower sleep quality, increased daytime drowsiness, reduced sleep efficiency, prolonged sleep duration, and more frequent daytime napping. However, the underlying causes of sleep disturbances in non-injured spouses remain inadequately explored, though emotional factors are likely contributors. Ikiugu *et al.*, (2021)[18] and Stefanacci and Riddle (2019)[19] suggest that the psychological, social, and emotional burdens associated with caregiving for an injured individual may negatively impact overall well-being. Family caregivers may experience disrupted sleep patterns, heightened irritability, fatigue, recurrent headaches, mood instability, increased substance use, and a pervasive sense of overwhelm.[20] Furthermore, caregivers frequently feel unprepared to care for their loved ones, raising the risk of depression and/or sleep disorders.[21,22] However, it has been perceived that decreasing sleep is causing additional problems for both couples, with non-injured spouses becoming more concerned about their injured partners.

As observed by the researcher during the interviews, most couples were more concerned about the injured spouse's physical health issues. They had been consulting neurosurgeons, physiotherapists, and neurologists for medical conditions but had not sought any psychosocial support for their problems, despite these issues causing difficulties for them. This indicates a lack of understanding of the overall challenges faced by the patients and their impact on family life. A need-based intervention is required in this area to address these problems before they lead to significant changes in the entire family system.

Strengths and limitations of the study

The researcher's findings indicate that this is the first study in India to explore the psycho-social needs of Indian PLwTBI and their non-injured spouses using only in-person interviews. However, limitations include a small sample size and convenience sampling, restricting generalizability.

Implications

The current study highlights the psycho-social needs of the PLwTBI and non-injured spouses post-hospitalization. These insights will help us to provide suitable and comprehensive psychosocial interventions for couples where one spouse has sustained TBI.

Recommendations

The perspectives and experiences of the PLwTBI and non-injured spouses of PLwTBI would be considered while creating tailor-made psychosocial interventions and testing them in controlled environments based on the psycho-social needs of the couples. The multidisciplinary team would incorporate the study's most recent findings into its management strategy to provide couples with a promising course for intervention. Future studies can combine quantitative and qualitative methods with a sizable sample to support their conclusions. Certain policy-level actions would be started to address some of the demands of the PLwTBI and non-injured spouses from their own perspectives.

CONCLUSION

Most of the PLwTBI were male, diagnosed with subdural hematoma, with accidents being the primary cause of brain injury. They primarily belonged to LSES and came from nuclear families. A total of six themes were reported by PLwTBI and their non-injured spouses as their psychosocial needs: Educational needs, sexual issues, behavioral issues, suicidal ideations, diminished well-being, and disturbances in life. These needs are common among PLwTBI and non-injured spouses, which are atypical, and inimitable in nature. Addressing these needs through psychosocial interventions is crucial for improving outcomes for both PLwTBI and their spouses.

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