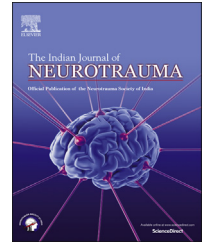


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Original Article

Quality of life and perception of illness in patients with traumatic brain injury

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ABSTRACT

Objective: To examine QoL and perception of illness in adult patients with a mild to moderate traumatic brain injury (TBI).

Methods and procedure: Thirty patients gave consent for participation in the study. Questionnaires included Rivermead Post Concussion Symptoms Questionnaire (RPQ), Depression Anxiety Stress Scales (DASS), WHO Quality of Life – BREF Version and Brief Illness Perception Questionnaire (IPQ).

Results: Cognitive and emotional complaints were reported by most of the patients. Higher percentages of patients fall in the medium range on all the four domains QoL. However on social and physical domain of QoL, the percentage is to some extent higher on the low range. On IPQ higher percentages fall within low and medium range. However on the coherence and emotional subscales of the IPQ, a higher percentage of patients fall in the higher range. Physical, psychological, environmental domains of QoL were found significantly correlated with overall subscale of IPQ at 0.01 and 0.05 level of significance. And a significant difference was also noted between mild and moderate TBI on IPQ but not on QoL.

Conclusions: The research findings highlight the need to emphasis not on physical but on psychosocial dimensions of individual as well, which may lead to better recovery and outcome.

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1. Introduction

TBI is a major burden worldwide on social, economic and health resources.¹ Globally the incidence of TBI is rising sharply, World Health Organization has projected that TBI would occupy third position by 2020 in terms of global burden.

In India 30,000 people die and 1, 25,000 become disabled due to TBI every year.² Symptomatic relief is usually the focus of management, ignoring the other psychosocial aspects of an individual.

Psychosocial aspects especially quality of life have gained importance and have become a primary objective of health care system interventions.³ The concept goes beyond the

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resources of living conditions available to individuals. World Health Organization⁴ defines quality of life as an individuals' perception of their position in life in the context of their cultural and value systems in which they live and in relation to their goals, expectations, standards and concerns. As QoL has both subjective as well as objective dimension same is true for perception of illness. A study estimated that 70–90% patients with head injuries receive treatment are mild.⁵ Many patients may recovery with treatment over time but usually how the patient perceives his illness and wellbeing, affect recovery process. It may effects patient's adherence to treatment, outcome and overall wellbeing.^{6,7} How a layperson perceives his illness is comparatively new area of research, but there is now an influential body of literature describing its importance and role in management especially in few medical illnesses.⁶ Both QoL and perception of illness are highly loaded with subjectivity and vary from individual to individual. The present study has tried to understand these variables and their relationship with each other.

2. Material and methods

2.1. Participants

Patients were recruited from outpatient department of neurosurgery and neuropsychology, NIMHANS, Bangalore. A sample of 30 male TBI patients comprising of 18 mild and 12 moderate GCS score at the time of trauma were included. The mean age was 38.13 (SD = 8.82). All the participants were educated, with a mean educational qualification of 10.67 (SD = 3.47). Data was collected 3 months after injury. Other neurological, neurosurgical and psychiatric conditions were excluded.

2.2. Materials

All the questionnaires were translated into regional language (Kannada) using Brislin's back-translation method.⁸ Questionnaires included:

2.3. Clinical interview and demographic record sheet

The clinical record sheet included demographic details, presenting complaints, brief history including pre-morbid history, medical history, psychiatric history, imagining test findings, Glasgow coma score and diagnosis.

2.4. Rivermead Post Concussion Symptoms Questionnaire (RPQ)⁹

Is a symptom checklist scored in two groups. The first group (RPQ-3) consists of the first three items (headaches, feeling of dizziness, and nausea) and the second group (RPQ-13) comprises of the next 13 items. A higher score reflects greater severity of post-concussive symptoms.

2.5. Depression Anxiety Stress Scales (DASS-21)¹⁰

This test consists of a set of three self-report scales, designed to measure the negative emotional states of Depression, anxiety and Stress. Subjects are asked to rate the extent to which they have experienced each on a 4-point severity or frequency scale. Internal consistency of the DASS subscales was high (Cronbach's alphas) 0.94, 0.88, and 0.93 for depression, anxiety, and stress respectively.

2.6. WHO Quality of Life – BREF Version¹¹

WHOQOL – BREF is a 26-item abbreviated version of the WHOQOL-100, is based on a four-domain structure: physical (seven items), psychological (six items), social (three items) and environmental (eight items). It is a Likert-type five-point scale to grade the patient's response to the QoL items. The scale gives continuous scores ranging from 4 to 20 for each domain. A higher score signifies better QoL. It is applicable cross-culturally. WHOQOL – BREF has been shown to correlate at 0.9 with the WHOQOL-100 with good discriminant validity, content validity and test–retest reliability.

2.7. Brief Illness Perception Questionnaire (IPQ)¹²

Measures patient's cognitive and emotional representations of their illness including consequences, timeline, personal control, treatment, control, identity, coherence, concern, emotional response and causes. Higher scores reflect threatening view of the illness. The test demonstrated good Pearson's test–retest correlation coefficient.

2.8. Procedure

This study was approved by National Institute of Mental Health and Neurosciences (NIMHANS) ethics committee. Patients were recruited from outpatient department of neurosurgery and neuropsychology, NIMHANS, Bangalore. A written consent was taken from each individual, who met inclusion and exclusion criteria. And the criteria were mostly determined by the scales. After recruitment, tests were administered individually and assistance was provided in terms of understanding the content, if needed.

3. Results

Patients in the current study were symptomatic with prominent cognitive and emotional complaints.

WHOQOL – BREF gives the score in continuum. So we divided the score into three groups. It is evident from Table 1 that higher percentage of patients falls in the medium range on all the four domains especially psychological domain of QoL. However on social and physical domain of QoL the percentage is to some extent higher on the low range.

Here again in Table 2 we divided the score into three groups. It is evident from Table 2 that a higher percentage of patients fall in lower range on timeline, treatment control and personal control subscales of IPQ. On the consequence, concern, personal control, emotional control, and the

Table 1 – Quality of Life (QoL) in patients with TBI.

Sub scales of QoL	N	Category	Percentage	Mean	SD
QoL-physical	30	High	23.3	58.23	19.392
		Medium	43.3		
		Low	33.3		
QoL-psychological	30	High	20	53.17	15.691
		Medium	66.7		
		Low	13.3		
QoL-social	30	High	13.3	56.23	22.117
		Medium	43.3		
		Low	43.3		
QoL-environmental	30	High	43.3	55.03	17.876
		Medium	33.3		
		Low	23.3		

coherence subscales of the IPQ, a higher percentage of patients fall in the medium range. However, on the coherence and emotional response subscales of the IPQ, a higher percentage of patients fall in the higher range. And overall, a majority of the cases fall in the low and medium range of IPQ.

Table 3 shows an overview of correlation between subscales of IPQ and subscales of QoL. As it is evident from the table that physical domain of QoL is significantly correlated with most of the subscales of IPQ at 0.01 and 0.05 level of significance. Psychological domain of QoL is found correlated with overall subscale of IPQ and timeline subscales of IPQ at 0.01 and 0.05 level of significance. Environmental domain of QoL is found correlated with overall subscale of IPQ at 0.05 level of significance. And the overall QoL is found correlated with overall subscale of IPQ and emotional subscale of IPQ at 0.05 level of significance.

Table 4 results show an overview of t-value of overall perception illness and domains of QoL between mild and moderate TBI subjects. The results show that there is a significant difference in perception of illness in mild and moderate TBI subjects at 0.05 level of significance. However such significant difference was not seen in different domains of QoL.

4. Discussion

Cognitive and emotional complaints were mostly reported by the patients on RPQ. Few patients met the criteria for mild to moderate depression and anxiety on DASS-21, which appeared secondary to TBI while interviewing.

Table 2 – Percentage of patients who scored low, medium and high on subscales of IPQ.

Subscale	Low	Medium	High	Overall mean and SD		
	%Age	%Age	%Age	N	Mean	SD
Consequence	30	53.3	16.7	30	4.83	1.967
Timeline	80	16.7	3.3	30	2.60	1.476
Personal control	43.3	50	6.7	30	3.97	1.903
Treatment control	76.7	20	3.3	30	2.63	1.974
Identity	50	36.7	13.3	30	3.80	2.107
Concern	36.7	53.3	10	30	4.20	1.864
Coherence	10	43.3	46.7	30	6.03	1.938
Emotional response	26.7	50	23.3	30	5.03	2.092
Total/Overall	36.7	60	3.3	30	33.10	9.091

With the increased number of researches emphasizing the importance of QoL in overall recovery process and outcome in different physical and mental illnesses.¹³ A significant impact on the different domains of QoL on individuals with TBI has also been reported in different studies. However variation is seen on different domains of QoL across cultures with usually physical domain being an exception.¹⁴⁻¹⁶ In our current study we found that overall most of the patients fall within low to medium range on different domains of QoL except psychological domain. However it was found that patients score on physical and social domain of QoL was more in the lower range.^{14,17,18} Physical and social domains include questions related to ability to do activities of daily living, personal relationship, working capacity, dependency on medical treatment, energy, sexual life, mobility, pain, and social support which are usually found compromised in TBI patients depending upon the region of brain involved and nature of trauma.

Clinicians and researchers usually ignore the patient's perception of illness, which usually play a significant role in recovery process.¹⁹ In the present study, overall majority of the cases fall in the low and medium range of IPQ. However significantly higher percentage of patients reported poor understanding of illness and high on emotional response in comparison to other domains on IPQ, which could lead to psychological reactions and negative emotional reactions to the trauma. Understanding of illness directly or indirectly generates different emotions with varying intensity and may provide the patients with a framework for coping.^{20,21} It is important to note that emotional reactions may not always lead to self-protective health behaviours and is one of the important factors in deciding about health behaviours. The relationship between worry and behaviours is determined by the intensity of emotionality, with either low or very high levels of worry impeding outcome of medical and psychosocial care.^{21,22} Patients are motivated by their subjective representations of what is happening in their body and what management does to it. So it is important to include individual factors in the plan of management for better outcome.^{23,24}

Correlation analysis was carried out to understand the relationship between domains of QoL and IPQ. A significant positive correlation was found between overall perception of illness and different domains like physical, psychological, and environmental of QoL. Most subscales of IPQ shares significant relationship with physical domain of QoL at different

Table 3 – Correlation between subscales of QoL with subscales of IPQ (N = 30).

		QoL-physical	QoL-psychological	QoL-environmental	Total-QoL
Total/Overall IPQ	Pearson correlation	0.511 ^a	0.471 ^a	0.396 ^b	0.369 ^b
	Sig. (2-tailed)	0.004	0.009	0.031	0.045
Consequence	Pearson correlation	0.384 ^a	0.356	0.273	0.318
	Sig. (2-tailed)	0.036	0.054	0.145	0.087
Timeline	Pearson correlation	0.270	0.372 ^b	0.331	0.221
	Sig. (2-tailed)	0.149	0.043	0.074	0.240
Personal control	Pearson correlation	0.435 ^b	0.170	0.156	0.182
	Sig. (2-tailed)	0.016	0.370	0.410	0.336
Concern	Pearson correlation	0.431 ^b	0.350	0.286	0.243
	Sig. (2-tailed)	0.017	0.058	0.126	0.195
Emotional response	Pearson Correlation	0.472 ^a	0.298	0.358	0.375 ^b
	Sig. (2-tailed)	0.008	0.109	0.052	0.041

^a Correlation is significant at the 0.01 level (2-tailed).

^b Correlation is significant at the 0.05 level (2-tailed).

levels of significance than other domains of QoL. Subscales of IPQ include consequence, timeline, personal control, concern and emotional response which directly or indirectly reflect patients understanding of his illness. There is dearth of studies on perception of illness and QoL in TBI. In other medical illness, better understanding of illness lead to better QoL and perception of illness is amenable to change over time.⁷ When we further divided our sample into mild and moderate categories, to compare the mean scores, we found significant difference in perception of illness at 0.05 level of significance. However there was no significant difference found on QoL between the two groups. It has been reported that schemas or representation about illness do lead to strong emotional reactions to the illness which effects overall QoL.²⁴

5. Limitations

The current study is, to the authors' knowledge, the first to explore the relationship between QoL and perception of illness following mild to moderate TBI. Every study has its merits and demerits. This study has highlighted some of the psychosocial aspects of traumatic brain injury and their relationship with each other. The study could not include female subjects because of inclusion and exclusion criteria especially education, duration of illness and GCS score. The frequency of TBI is also observed higher in males than

females. Out of 100 screened male patients only 30 patients met the inclusion and exclusion criteria. And due to the small sample size, it may be difficult to generalize these findings. However this study highlights the need for emphasis on psychosocial aspects, which plays important role in overall recovery process and rehabilitation. Due to time constraint, comparison group could not be included, which would have helped to understand whether these psychosocial issues are specific to the given population.

6. Implications

Although this is a preliminary study, several important findings were found. This warrants research in a larger group of patients in order to validate and generalize these findings. Furthermore, it is clinically very relevant to know how patient's perception of their illness influence recovery and adjustment. Patient's perception of his illness is not always in line with their physician. It is important to address these differences in order to build a good relationship and provide best possible care, which is only possible when patients and professionals share their understanding of what they are dealing with, which would improve overall wellbeing.

Conflicts of interest

All authors have none to declare.

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Table 4 – Comparison of mean scores of mild and moderate TBI in terms perception of illness and QoL.

Domains	TBI	N	Mean	SD	t-Value
Total/Overall IPQ	Mild	18	33.06	8.755	-0.032 ^a
	Moderate	12	33.17	9.971	-0.031 ^a
QoL-physical	Mild	18	59.78	19.341	0.528
	Moderate	12	55.92	20.088	0.523
QoL-psychological	Mild	18	53.56	17.051	0.163
	Moderate	12	52.58	14.113	0.170
QoL-social	Mild	18	58.67	21.382	0.732
	Moderate	12	52.58	23.639	0.717
QoL-environmental	Mild	18	55.61	16.089	0.213
	Moderate	12	54.17	21.001	0.202

^a Correlation is significant at the 0.05 level.

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