

# Informal carer's knowledge of traumatic brain injury questionnaire: Initial development and validation

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## Abstract

**Aim:** To develop and psychometrically test the instrument for measuring the knowledge of traumatic brain injury of informal carers.

**Design:** Instrument development.

**Method:** Focus group discussions were conducted among informal carers and health-care specialists in March 2017. The content validity was determined by the mean of the item content validity index. A reliability test was performed by the Kuder-Richardson 20 and Pearson's correlation coefficient among 40 informal carers of patients with a traumatic brain injury in the rehabilitation medicine department of a tertiary hospital from August–September 2017.

**Results:** The final 34-item questionnaire covers the nature of traumatic brain injury, the consequences of traumatic brain injury, the rehabilitation process, and the role of the caregiver. The item content means ranged from 0.8–1.00, and the difficulty of knowledge items ranged from 0.18–0.98. The internal consistency reliability and correlation coefficient were 0.70 and 0.84, respectively.

## KEYWORDS

carers, head injury, instrument development, psychometric properties

## 1 | INTRODUCTION

By the year 2020, the World Health Organization stated that traumatic brain injury (TBI) will surpass many diseases as the major cause of death and disabilities. In Malaysia, TBI is the third cause of admission to hospitals and the fifth cause of death (Ministry of Health Malaysia, 2013). TBI is a chronic disease process; therefore, it requires an informal carer's involvement for several years. With the increasing number of chronically ill individuals, the number of informal carers providing care is also expected to increase by 85% by the year 2050 (Family Caregiver Alliance, 2012).

Lack of knowledge of TBI has implications for the social environment of informal carers, awareness about TBI and access to resources about TBI; and plays a critical role in increasing stress, distress, burden (e.g. physical, emotional, and financial) and caregiver burnout (Block et al., 2014). On the contrary, informal carers of patients with long-term illness who possess knowledge and awareness about the illness have experienced better well-being compared with those with poor knowledge and awareness (Lua et al., 2014). Hence, it is important for informal carers to receive accurate knowledge about TBI. It has been shown that inaccurate knowledge about TBI has the potential to adversely affect the home environment and caregiver relationship

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(Block et al., 2014). Therefore, it is very important to have a valid and reliable instrument to measure informal carer's knowledge of TBI; subsequently, need-based education interventions should then be developed for informal carers of patients with TBI.

## 2 | BACKGROUND

Several researchers had assessed knowledge about TBI among informal carers using Gouvier's instrument (Common Misconceptions About Head Injury and Recovery) (Block et al., 2014; Maviş & Akyıldız, 2013; Polit & Beck, 2017; Yuhasz, 2013). Gouvier et al., (1988) developed a survey named Common Misconceptions About Head Injury and Recovery, which has been used for the past 30 years. The survey, consisting of 25 statements used to assess what the public knows about TBI, has become the standard instrument to measure knowledge about brain injury among the public. Numerous researchers have added, removed, rephrased individual items, adjusted the instructions and/or translated the items into different languages (Linden et al., 2013). Although there were numerous changes made to the questionnaire, up until recently, researchers have continued to use the instrument to assess knowledge of TBI.

It is very important to assess the level of information that the informal carers obtain during their care of the TBI patient. Providing informal carers with adequate information can alleviate psychological distress such as anxiety and strain and help them cope better with the changes that they are facing as they would feel more prepared (Samartkit et al., 2010). Therefore, there is an immediate need to develop a valid, reliable and psychometrically sound instrument to measure the informal carer's knowledge about TBI. Following which, a need-based education intervention can be developed for the informal carers of patients with TBI.

## 3 | THE STUDY

### 3.1 | Aim

The aim of this study was to develop and psychometrically test the instrument for measuring the knowledge of TBI of informal carers.

### 3.2 | Methodology

Qualitative and quantitative research designs were used to develop the statements in the questionnaire. For the qualitative research design, the authors described their efforts to create a set of items that reflect information and knowledge about TBI through two focus group discussions. For the quantitative research design, a cross-sectional survey was conducted among informal carers of patients with TBI. The authors tested the psychometric properties (validity and reliability tests) of those items on a broad sample

that is representative of informal carers for whom the instrument might be used.

### 3.2.1 | Qualitative research design: development of informal carer's knowledge of traumatic brain injury questionnaire (ICK-TBI)

#### *Participants*

In the current study, two focus group discussions were conducted in March 2017. The first focus group discussion consisted of six informal carers; while the second focus group discussion consisted of eight participants (two nurses from the rehabilitation ward, three therapists and three rehabilitation physicians). Both sessions took place in the interdisciplinary room (IDR) of the Rehabilitation Ward at the Department of Rehabilitation Medicine of a teaching hospital. Both sessions lasted about 45–60 min.

#### *Focus group discussion*

A focus group discussion was used in this study as the method to collect data from informal carers to reflect on their knowledge of TBI gained from educational programmes related to long-term consequences after TBI, held in the Department of Rehabilitation Medicine Centre, initiated when the patients are still in the sub-acute rehabilitation care and subsequently, conducted once or twice yearly.

The same five questions that were used to lead the discussion are as follows:

1. What information do you think the informal carer should know about the nature of traumatic brain injury?
2. What do you think are the consequences of traumatic brain injury?
3. Where can informal carers receive funding?
4. What do you think are the rehabilitation process that a traumatic brain injury patient should undergo?
5. In general, what important information should informal carers know for the role of caregiver of a traumatic brain injury patient?

Both focus group discussions were recorded and transcribed verbatim. Five steps were involved of which the first was typing the transcriptions and saving them in a Word document while listening to the audio recording repeatedly. It was initially transcribed in the Malay language. Then, the researchers translated them into English and had them checked by a registered translator in terms of the accuracy of translation and the quality of data. The second step was to read through all the data. The third step was the coding of the data, which was done by two experts in traumatic brain injury. The fourth step was to generate a description and to form themes and sub-themes. The final step was the interrelating and interpreting of themes, with each theme being identified and described.

Four themes emerged from the focus group discussions including "Nature of traumatic brain injury," "Consequences of traumatic brain

**TABLE 1** The themes and sub-themes of focus group discussion

Themes	Sub-themes	Questionnaire items	
1. Nature of TBI	General information of TBI	1. Brain injury is an injury to the brain caused by external force for example; car accident.	
		2. Brain injury is equally common in males and females.	
		3. The most common cause of brain injury in Malaysia is due to motor cycle accident.	
		4. Operation for brain injury is sometimes necessary to repair skull fracture, bleeding or remove large blood clots.	
		5. Acute or early treatment is to stabilize the patient's medical condition and prevent physical and emotional damage/disturbance.	
		6. The long-term treatment involves staying at nursing care facility where the patient will receive care for complications after brain injury.	
		7. <i>Kumpulan Wang Persaraan</i> (KWAP) is a place to get financial support for retired government servant with brain injury.	
	Coma period	8. Many people who had coma following brain injury, will wake up from coma within two weeks.	
		9. After several weeks in a coma, when the patient wakes up, they can recognize people and able to speak right away.	
		10. After brain injury, there is a period when the patient is partially or fully conscious but is confused and disorientated.	
		11. After brain injury, agitation can occur which is a state of hyper activity accompanied by increased tension and irritability.	
2. Consequences of TBI	Behavioural and mood impairment	12. Brain injury patient will have behavioural problems such as changes of mood even after 1 year of injury.	
		13. Many people with severe brain injury will suffer from loneliness and social isolation.	
	Cognitive impairment	14. The anger related to a brain injury may be due to physical changes and psychological adjustment.	
		15. Brain injury patient will suffer from memory loss for the rest of his/her life.	
		16. Sleeping problems are more common in brain injury patient.	
		17. Inability to concentrate can affect patient with brain injury to return to work.	
		18. Many patients will experience problems after brain injury such as language impairment and speech difficulties.	
		19. Seizures, headaches and imbalance are problems following brain injury.	
	Medical problems and Physical impairments	20. Individual with brain injury will experience vision problems related to the injury, but he/she is unaware of it.	
		21. Swallowing is common problem affecting brain injury patient.	
22. Individual who suffer from brain injury can also suffer from constipation or diarrhoea problems.			
23. The goal of rehabilitation after brain injury is to increase physical abilities such as walking.			
3. Rehabilitation process	Purpose of rehabilitation	24. Therapy or rehabilitation for brain injury patient may continue even after 5 years after injury.	
	The progress of recovery	25. Recovery from brain injury is most rapid in the first 3–6 months, but TBI may continue to recover for several years after the injury.	
		26. The more severe the injury, the more likely the person needs assistance	
4. Role of caregiver	Activity of daily living (ADL)	27. Home-based rehabilitation can be performed by the patient at home under the supervision of caregiver	
		28. Asking the brain injury patients to name pictures of familiar objects at home such as pets, will improve speech problems	
		29. There are many daily activities such as; making a bed, putting on cloths and bathing that can be done at home to help improve brain injury patient with attention problems	
		30. A safe and effective exercise programme at home for example; balance training can play an important role in reducing the risk of falls and fear of falling.	
		Medication	31. Sleepiness and memory impairment are common side effects of medication used to control aggressive behaviour
			32. Traditional herbs are not suitable for someone recovering from brain injury.
		Nutrition	33. Food intake will be affected due to memory loss
	34. A healthy diet such as: vegetables, fruits, fish and lots of water becomes more important after brain injury as the patient starts the recovery process		

injury," "Rehabilitation processes" and "Role of caregiver." Ten sub-themes were identified under each theme. Table 1 shows the themes and sub-themes of the focus group discussions.

### 3.2.2 | Quantitative research design: psychometric properties of the informal carer's knowledge of traumatic brain injury questionnaire

#### Participants

The study population included informal carers of patients with TBI ( $N = 40$ ) who accompanied the patients with TBI to the physiotherapy gym at the Department of Rehabilitation Medicine. The informal carers were invited to participate in this study from August–September 2017. The researchers approached the informal carers while they were waiting for the patients to complete therapy in the physiotherapy gym and explained to the informal carers the nature and purpose of the study. In this study, informal carers are anyone who is unpaid and cares for a friend or family member who suffers from brain injury. They could be spouses, siblings, parents, children or relatives (Shaji & Reddy, 2012).

#### Face validity

Face validity of the questionnaire was analysed by distributing the questionnaire to ten informal carers to read and thus to provide an evaluation of the content in terms of its comprehensiveness, relevance and clarity of expression, and to gauge the time taken to complete the questionnaire (LoBiondo-Wood & Haber, 2014).

#### Content validity index

The mean item content validity index (Mean I-CVI) was analysed using the number of experts, giving a rating of either 3 or 4 (relevant) divided by the total number of experts. Six experts (two rehabilitation consultants, two nurses from the rehabilitation ward, one senior lecturer from the nursing department and one physiotherapist) were invited to judge the relevance of the item content in the Informal Carer's Knowledge of Traumatic Brain Injury Questionnaire and the level of agreement. An index of the agreement for each rater was calculated to produce the content validity index (CVI). Each expert made an independent assessment by rating the content relevance of each item using a 4-point ordinal scale: 1 = not relevant, 2 = somewhat relevant, 3 = quite relevant and 4 = highly relevant (Polit & Beck, 2017). To check the content validity of the overall scale, the scale-level content validity index (S-CVI) was calculated.

#### Difficulty and discrimination index

Difficulty concerning the knowledge items was analysed by the proportion of correct answers by item. The optimal range is 20%–80%; a low index may mean that informal carers are attempting the item but are getting it wrong and an index that is too high may mean that regardless of whether the informal carers are poor or good, they are able to answer it correctly (Yusoff & Taib, 2014).

For the discrimination index for each item, the researchers calculated the item discrimination by subtracting the number of informal carers in the lower group who got the item correct from the number of informal carers in the upper group who got the item correct. This was then divided by the number of informal carers in one group. An item with the discrimination index of 0.40 or more is considered very good, 0.30–0.39 is reasonably good, 0.20–0.29 is subject to improvement, and 0.19 or less is poor (items to be rejected or improved by revision) (Yusoff & Taib, 2014). Both the difficulty index and discrimination index were calculated using IBM SPSS v23.0.

#### Reliability test

A reliability test for the Informal Carer's Knowledge of Traumatic Brain Injury Questionnaire was conducted. The test–retest reliability was done through a pilot test of 40 informal carers using the Pearson Product Moment Correlation Coefficient ( $r$ ), whereas the internal consistency of the Informal Carer's Knowledge of Traumatic Brain Injury Questionnaire was measured using the Kuder-Richardson-20 (KR-20).

#### Ethical considerations

This study was approved by the Medical Research Ethics Committee (MRECID.NO: 201610184379). Written consent was obtained from the informal carers prior to the study. The researchers also informed them that there would be a retest of the same questionnaire with a 2-week interval. The research procedure and instructions were explained to the participants before the survey. An information sheet was provided, addressing the details of the study: purposes, procedure, inclusive and exclusive criteria, and duration of the survey. The participants were informed that participation was voluntary, and they could withdraw at any time during the survey.

## 4 | RESULTS

### 4.1 | Findings of qualitative research design

According to the focus group discussion, the final instrument is a self-report questionnaire, with 34 items divided into four themes to ease administration of the questionnaire, that is "nature of traumatic brain injury" (two sub-themes)—*general information of traumatic brain injury* (seven items) and *coma period* (four items); "consequences of traumatic brain injury" (three sub-themes)—*behavioural and mood impairment* (two items), *cognitive impairment* (five items) and *medical problems and physical impairments* (four items); "rehabilitation process" (two sub-themes)—*purpose of rehabilitation* (one item) and *the progress of recovery* (two items); and "the role of caregiver" (three sub-themes)—*activity of daily living (ADL)* (five items), *medication* (two items) and *nutrition* (two items).

The researchers also decided to use a "yes/no/I don't know" response format rather than the multiple-choice format. Inclusion of the "I don't know" response could provide an index of genuine

knowledge that is not inflated by guesses when only “true” and “false” are the available response options (Pollux et al., 2016). In addition, the researchers chose the “yes/no/I don't know” format because of its relative ease for the respondents and ease in scoring. The items were also written in plain language to maximize readability.

Informal carer's knowledge-Traumatic brain injury scores range from 0–34 with each correct answer scoring 1 point. Any incorrect responses, unanswered items or “unsure” responses are scored 0. The cut-off point for the Informal Carer's Knowledge of Traumatic Brain Injury Questionnaire score is 22, which was obtained from the median score of the pilot study; a score below 22 is considered to be poor knowledge, while a score equal or above 22 is considered to be good knowledge. Appendix S1 and S2 below shows the 34 items of the Informal Carer's Knowledge of Traumatic Brain Injury Questionnaire.

#### 4.1.1 | Demographic and background information

The result showed that the mean age of the informal carers was 48.2 years ( $SD 10.3$ ), ranging from 27–67 years old, with nearly half of them ( $N = 18, 45\%$ ) aged above 50. Nearly two-thirds of the informal carers were female ( $N = 26, 65\%$ ), and 50% were Malay. Most informal carers were married ( $N = 33, 82.5\%$ ). A total of 17 were employees (42.5%) and more than half of them received secondary education ( $N = 23, 57.5\%$ ). More than half of the informal carers ( $N = 23, 57.5\%$ ) had a monthly income of less than RM3000 (USD 750). Most informal carers were caring for patients with severe TBI ( $N = 32, 80\%$ ), of which about two-thirds of the informal carers ( $N = 24, 60\%$ ) provided care for more than 8 hours per day. More than half of the informal carers ( $N = 21, 52.5\%$ ) were parents. Most informal carers ( $N = 33, 82.5\%$ ) were not caring for another disabled person. Table 2 shows ten of the demographic data related to the informal carers and one characteristic data related to the TBI patient.

## 4.2 | Psychometric properties of the 34-item questionnaire

### 4.2.1 | Face validity

The mean time required to answer all the questions was 23 min (range: 15–30 min). There were no issues that arose about the content of the questionnaire. The question items were easily understandable.

### 4.2.2 | Content validity index (CVI)

The results of the preliminary study to verify the validity test of the questionnaire found that none of the experts suggested removing any item from the questionnaire. The Mean Item-Content Validity

**TABLE 2** Informal carer's and patient's demographic and characteristics data ( $N = 40$ )

Informal carer's demographic data	N (%)
Age (mean), years $\pm$ SD	48.20 $\pm$ 10.28
<40	12 (30%)
41–50	10 (25%)
>50	18 (45%)
Gender	
Male	14 (35%)
Female	26 (65%)
Ethnicity	
Malay	20 (50%)
Chinese	17 (42%)
Indian	3 (7.5%)
Marital status	
Single	7 (17.5%)
Married	33 (82.5%)
Employment status	
Unemployed	4 (10%)
Employee	17 (42.5%)
Self-employee	10 (25%)
Retired	9 (22.5%)
Level of education	
Primary school	3 (7.5%)
Secondary school	23 (57.5%)
Tertiary	14 (35%)
Monthly income	
<RM 3,000	23 (57.5%)
$\geq$ RM 3,000	17 (42.5%)
Frequency of caregiver	
4–8 hr per day	95 (67.9%)
>8 hr per day	45 (32.1%)
Caring for another disabled person	
Yes	7 (17.5%)
No	33 (82.5%)
Relationship to the patient	
Spouses	9 (22.5%)
Siblings	2 (5%)
Parents	21 (52.5%)
Children	8 (20%)
Patient's severity of injury	
Mild	2 (5%)
Moderate	6 (15%)
Severe	32 (80%)

Index (I-CVI) of the questionnaire ranged from 0.8–1.00, and the scale-level content validity (S-CVI) was 0.93. Usage of I-CVI suggested high validity as CVI  $>0.9$  (Terwee et al., 2007). Table 3 shows the content validity index of the items.

TABLE 3 Content validity index

Item	Expert 1	Expert 2	Expert 3	Expert 4	Expert 5	Expert 6	Number in agreement	Item- CVI
1	√	√	√	√	√	√	6	1.00
2	√	√	√	√	√	√	6	1.00
3	√	√	√	√	√	√	6	1.00
4	√	√	√	√	√	√	6	1.00
5	√	√	√	√	√	√	6	1.00
6	√	√	√	√	√	√	6	1.00
7	√	√	√	×	√	√	5	0.8
8	√	√	×	√	√	√	5	0.8
9	√	√	×	√	√	√	5	0.8
10	√	√	×	√	√	√	5	0.8
11	√	√	√	√	√	√	6	1.00
12	√	√	√	√	√	√	6	1.00
13	√	√	√	√	√	√	6	1.00
14	√	√	×	√	√	√	5	0.8
15	√	√	√	√	√	√	6	1.00
16	√	√	√	√	√	√	6	1.00
17	√	√	√	√	√	√	6	1.00
18	√	√	×	√	√	√	5	0.8
19	√	√	×	√	√	√	5	0.8
20	√	√	×	√	√	√	5	0.8
21	×	√	√	√	√	√	5	0.8
22	√	√	√	√	√	√	6	1.00
23	√	√	√	√	√	√	6	1.00
24	√	√	×	√	√	√	5	0.8
25	√	√	×	√	√	√	5	0.8
26	√	√	√	√	√	√	6	1.00
27	√	√	×	√	√	√	5	0.8
28	√	√	√	√	√	√	6	1.00
29	√	√	√	√	√	√	6	1.00
30	√	√	√	√	√	√	6	1.00
31	√	√	√	√	√	√	6	1.00
32	√	√	√	√	√	√	6	1.00
33	√	√	√	√	√	√	6	1.00
34	√	√	√	√	√	√	6	1.00

Mean I-CV = 0.8–1.00  
S-CVI = 0.93

Note: I-CVI, item-level content validity index.

S-CVI, scale-level content validity index, the overall scale.

#### 4.2.3 | Individual item properties: item difficulty and discrimination index

The difficulty index of the Informal Carer's Knowledge of Traumatic Brain Injury Questionnaire ranged from 18%–98%, which is considered an optimal level of difficulty. For the discrimination index of the 34 items, the researchers identified high scorers (top 55%,  $N = 22$ )

and low scorers (bottom 45%,  $N = 18$ ). Five items were considered as very good items, one item as reasonably good, eight items as marginal and require improvement, and 20 items as poor items that need to be either rejected or improved by revision. Table 4 shows the difficulty and the discrimination index for each item. This index was used in tandem concert with the item difficulty index and coefficient alpha to determine which items to drop.

**TABLE 4** Item characteristics for the difficulty and discrimination index

Knowledge items	Discrimination index	Difficulty index
1. Brain injury is an injury to the brain caused by external force for example; car accident	0.27	88%
2. Brain injury is equally common in males and females	0.05	88%
3. The most common cause of brain injury in Malaysia is due to motor cycle accident	0.17	63%
4. Operation for brain injury is sometimes necessary to repair skull fracture, bleeding or remove large blood clots	0.05	88%
5. Many people who had coma following brain injury, wake up from coma within 2 weeks	0.28	38%
6. After several weeks in a coma, when the patient wakes up, they can recognize people and able to speak right away	0.44	45%
7. After brain injury, there is a period when the patient is partially or fully conscious but is confused and disorientated	0.05	78%
8. After brain injury, agitation can occur which is a state of hyper activity accompanied by increased tension and irritability	0.16	48%
9. Acute or early treatment is to stabilize the patient's medical condition and prevent physical and emotional damage/disturbance	0.22	95%
10. The long-term treatment involves staying at nursing care facility where the patient will receive care for complications after brain injury	0.11	70%
11. Brain injury patient will suffer from memory loss for the rest of his\her life	0.05	18%
12. Brain injury patient will have behavioural problems such as changes of mood even after 1 year of injury	0.11	65%
13. Seizures, headaches and imbalance are problems following brain injury	0.16	78%
14. Sleeping problems are more common in brain injury patient	0.05	58%
15. Many people with severe brain injury will suffer from loneliness and social isolation	0.5	28%
16. The anger related to a brain injury may be due to physical changes and psychological adjustment	0	60%
17. Individual with brain injury will experience vision problems related to the injury, but he/she is unaware of it	0.44	40%
18. Unable to concentrate can affect patient with brain injury to return to work	0.05	68%
20. Swallowing is common problem affecting brain injury patient	0.22	65%
21. Food intake will be affected due to memory loss	0.27	38%
21. Food intake will be affected due to memory loss	0.27	38%
22. Individual who suffer from brain injury can also suffer from constipation or diarrhoea problems	0.11	15%
23. A healthy diet such as: vegetables, fruits, fish and lots of water becomes more important after brain injury as the patient starts the recovery process	0	75%
24. sleepiness and memory loss are common side effects of medication used to control aggressive behaviour	0.55	50%
25. Traditional herbs are not suitable for someone recovering from brain injury	0.05	23%
26. The more severe the injury, the more likely the person needs assistance	0.22	95%
27. Kumpulan Wang Persaraan (KWAP) is a place to get financial support for retired government servant with brain injury	0.38	33%
28. The goal of rehabilitation after brain injury is to increase physical abilities such as: walking	0.16	98%
29. Therapy or rehabilitation for brain injury patient may continue even after 5 years after injury	0.27	58%
30. Recovery from brain injury is most rapid in the first 3–6 months, but TBI may continue to recover for several years after the injury	0.11	65%
31. Home rehabilitation can be performed by the patient at home under the supervision of caregiver	0	90%
32. Asking the brain injury patients to name given objects at home such as; animal pictures, will improve speech problems	0.22	80%
33. There are many daily activities such as; making a bed, putting on cloths and bathing can be done at home to help brain injury patient with attention problems	0.11	95%
34. A safe and effective exercise programme at home for example; balance training can play an important role in reducing the risk of falls and fear of falling	0.16	98%

**TABLE 5** Pearson product moment correlation coefficient (Test-retest) (N = 40)

Correlations		Total score test	Total score retest
Total score test	Pearson correlation	1	0.835**
	Sig. (2-tailed)		<0.001
Total score retest	Pearson correlation	0.835**	1
	Sig. (2-tailed)	<0.001	

#### 4.2.4 | Test-retest reliability

The researchers administered the 34-item questionnaire on two occasions to 40 informal carers with a time interval of 2 weeks. The mean total score of the first test was (*mean* = 21.30, *SD* 4.44), and the mean total score of the second test was (*mean* = 22.03, *SD* 4.28), which indicates that there is no significant difference between the test and retest with a test-retest coefficient of 0.84,  $p < .001$ , thereby suggesting adequate test-retest reliability. Table 5 shows the Pearson product-moment correlation coefficient among the 40 participants.

#### 4.2.5 | Internal consistency

The internal consistency reliability of the test of Informal Carer's Knowledge of Traumatic Brain Injury Questionnaire is  $KR-20 = 0.70$ . Higher values indicate a higher level of internal consistency. Scores above 0.70 are considered acceptable (Allen, 2017).

## 5 | DISCUSSION

The purpose of this paper was to develop and validate a questionnaire on the informal carer's knowledge of TBI. To achieve this aim, a series of steps were performed: focus group discussions (to help develop a set of questions to be asked in the subsequent questionnaire), expert review (to enable potential user input during test construction), investigation of item properties of the level of TBI knowledge in an informal carer's sample, and a readability analysis of the test. Overall, the outcome of the item selection and review process resulted in a 34-item version of the informal carer's knowledge of TBI with adequate readability, good coverage of relevant content and acceptable item properties. This multidimensional-constructed questionnaire was designed for the informal carers of patients with TBI that measured their knowledge in four dimensions: "the nature of TBI," "the consequences of TBI," "the rehabilitation process" and "the role of the caregiver." The face and content validity, feasibility, test-retest reliability and internal consistency of the questionnaires were investigated. When considering the difficulty of the knowledge

statements, the results also designated the optimal statements to use with the calculated difficulty ranging from 0.2–0.98. The knowledge statements were designed to respond to three categories of answers: yes, no, and I don't know. Consistent with Chamroonsawasdi et al., (2017), when the proportion of correct answers is between 0.2–0.8, the items are neither too difficult nor too easy and are considered appropriate.

In addition, the study showed that the questionnaire demonstrated acceptable reliability and validity results. The face validity indicated that the questions were clear and easy to understand by the informal carers. According to Sullivan and Dunton (2004), face validity is useful to assess the informal carers' understanding of the items. Based on the informal carers' comments in the current study, the wording of questions that caused ambiguity was improved without causing any major change to the questionnaire. The results demonstrated an extremely high value of mean I-CVI in each part of the questionnaire. Regarding feasibility, this study indicated that the instrument had good feasibility with no missing items, no floor and ceiling effects and acceptable skewness values. It also produced a high correlation of test-retest and good internal consistency reliability of the questionnaire; the Pearson product-moment correlation coefficient calculated the range as being from  $-1$ – $+1$  (Mukaka, 2012); with adequate internal consistency levels through the KR-20.

This instrument used qualitative data as a basis for generating quantitative tool items that were carefully tested afterwards. The instrument was developed from different views from informal carers and healthcare specialists, validated by a panel of experts and piloted among informal carers. It took the researchers 6 months to develop and validate the questionnaire prior to testing, as all areas, including language, were carefully checked during its development with the assistance of native speakers of both languages (English and Malay). The pilot testing was completed within 1 month, due to the cooperation of the healthcare providers in the rehabilitation department and the willingness of the staff.

## 6 | LIMITATIONS

However, there are limitations to this paper that should be noted. Despite acceptable correlation coefficient result of the instrument, Pearson's  $r$  is not ideal for test-retest reliability as  $r$  often overestimates actual reliability. Besides, confirmatory factor analysis (CFA) and exploratory factor analysis (EFA) were not performed in this study. We had run the data, revealing many variables to be not normally distributed and not correlated. And although there are 34 variables, our sample size is very low (this accounts for distribution and correlation observations—it does not bode well for factor analysis), this is almost a perfect storm against a good factor analysis outcome (Glen, 2014).

We ran the data and saw the problem right away (it was apparent even before running the data). Here is the general SPSS fault report outlining possible issues: "There are fewer than two cases, at least one of the variables has zero variance, there is only



one variable in the analysis, or correlation coefficients could not be computed for all pairs of variables. No further statistics will be computed."

## 7 | CLINICAL IMPLICATIONS

The researchers used ICK-TBI questionnaire to assess informal carer's knowledge of TBI. This study showed that the informal carers obtained adequate knowledge about TBI, implying that informal carers benefit from the educational and teaching programmes provided by the centre; either during the informal sessions during the acute period or the formal education programmes. As new knowledge is discovered, continuous educational programmes should be availed to informal carers for future reference. The current study suggests that to maintain this good level of knowledge of informal carers, educational programmes should be held not only once or twice in a year as practised, but it can be a monthly routine to educate the carers on long-term consequences after TBI when patients are still in sub-acute rehabilitation care.

## 8 | CONCLUSION

To conclude, this study demonstrates that the easy-to-use questionnaire developed here can measure informal carer's knowledge of TBI and provides good internal consistency. The development and validation of the questionnaire took 6 months prior to testing, as all areas, including language, were carefully checked during its development. The pilot questionnaire testing was completed within 1 month, due to the excellent communication of the healthcare system with their patients and the willingness of the informal carers. Further investigation is needed to improve the assessment of procedural knowledge and to test the validity of the questionnaire in other populations.

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### CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

### AUTHOR CONTRIBUTIONS

AAB, CMC and MM were responsible for the study design. AAB performed data collection and analysis. CMC and MM supervised the study process. AAB, CMC and MM were responsible for the manuscript write up. AAB, CMC, MM, CCC, RF and NN made critical revisions to the paper to refine important intellectual content.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author, on reasonable request. The data are not publicly available due to [restrictions, e.g. their containing information that could compromise the privacy of research participants].

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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