



Validity and reliability of a questionnaire assessing the knowledge, attitude, and awareness in the informal caregivers of comatose patients: An observational study

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Keywords

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Abstract

Background: Comatose is a state of deep unconsciousness in an individual being unresponsive which has an impact on the informal caregivers providing care to their kinships. The validity and reliability of the domains of the Knowledge, Attitude, Awareness-Comatose Caregiver Questionnaire (KAA-CCQ) and has been taken into consideration as an outcome measure to assess the level of knowledge, attitude, and awareness among the caregivers of comatose patients.

Methods: 68 informal caregivers above the age of 18 years related to comatose patients were included in the study. The self-developed KAA-CCQ was administered on the informal caregivers of comatose

patients to assess the level of knowledge, attitude, and awareness regarding coma. Validity and reliability of the questionnaire were calculated by Spearman's rank correlation and Cronbach's alpha, respectively.

Results: The reliability of all the three domains and the questionnaire was found to be 0.8 and the item correlation with respect to the domain was above 0.6 for the knowledge whereas it was above 0.6 for the attitude and awareness domains that justified the validity of the questionnaire, and also the questionnaire had an excellent reliability.

Conclusion: The KAA-CCQ will be a suitable questionnaire to assess the knowledge, attitude, and awareness in the informal caregivers of comatose patients.

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Introduction

Coma is a state of profound unawareness from which patients cannot be aroused, a normal sleep wake cycle is absent, and eyes are closed. An individual with coma is an unarousable state represented by a collapse of the arousal and alerting system of the brain, i.e., ascending reticular activating system (ARAS), as the ARAS functions as a regulator in maintaining consciousness.^{1,2} An informal caregiver is an individual taking responsibility voluntarily and without any payment, providing care along with support to the family member or social network with physical and mental aspects in addition to psychiatric disabilities.³ The caregivers experience stress, anxiety, and helplessness.⁴ The extent of impact is in a way the caregiver feels a sense of disconnection from the environment and their time is completely dedicated to the patient (individual).⁵ Considering the above factors, the caregivers are unable to focus on other aspects of life. Due to this, there is a burden among the patient caregivers. The families may express their emotions experiencing the feelings of shock, disbelief, fear, sadness, and hopelessness. The emotional requirements of the family members must be addressed and recognized as it is necessary for fostering overall well-being. Family members may struggle to grasp the complex medical concepts; breaking down the information into manageable pieces and checking for understanding can help ensure that families have a clear understanding of the prognosis and potential implications. Prognostic uncertainty can create significant emotional distress for family members as they navigate end of life decisions and cope with uncertainty about future. The aim of the present study was to test the validity and reliability of a questionnaire assessing the level of awareness, knowledge, and attitude in informal caregivers of patients suffering from coma.

Materials and Methods

The present study has been approved by the Institutional Board of the Institute of Physiotherapy with a duration of 1 year. The study assesses the validity and the reliability of Knowledge, Attitude, Awareness-Comatose Caregiver Questionnaire (KAA-CCQ).⁶ 68 informal caregivers (above 18 years of age) of the comatose patients were included in the study and anyone except the primary caregivers were excluded.

The KAA-CCQ was developed in phase I

consisting of defining the items referred as item generation and modification as the stage 1 in the 1st phase of the development process and the draft of the questionnaire was constructed with 3 domains, i.e., knowledge, attitude, and awareness.⁶⁻¹¹ The items were included based on the review of literature indicating a scarcity of knowledge and awareness along with distress regarding coma. Following the drafting of the domains and items, the questionnaire was considered for an expert review, experts from the field of neurophysiotherapy were considered comprising the stage 2 of phase 1 in the process of development.¹² A total of 16 experts were involved for questionnaire evaluation and the responses provided by the experts were calculated using content validity index (CVI).¹² The content validity score was 0.91 indicating that the items were relevant to the questionnaire. The questionnaire was ready to be applied on patients for pilot study. The response format for the questionnaire was based on the Likert scale.

The final version of the questionnaire was taken for validity and reliability.^{12,13} In the second phase, the study consisted of 68 subjects as per the sample size calculated. An explanation of the study was given to the participants in a detailed manner and their consent was taken prior to introducing the questionnaire and assessing for their levels of knowledge, attitude, and awareness. The informal caregivers of the comatose patients were recruited from the intensive care units (ICUs) of the tertiary care hospitals of Belagavi City, India. The scores of the domains were calculated and converted into frequency and percentage. The intrinsic validation was performed for the items of each domain. The validity and reliability of the items of the questionnaire were assessed using Spearman's rank correlation and Cronbach's alpha, respectively.¹³⁻¹⁵

Data were analysed by using the SPSS software (version 19, SPSS Inc., Chicago, IL, USA). The data collected involving the demographic details of the patients [age, gender, cause of coma, Glasgow Coma Scale (GCS) score] and their caregivers (age, gender, relation to the patient) were summarized using the method of descriptive statistics [frequency, percentage, mean, and standard deviation (SD)]. For analysing the reliability, Cronbach's alpha was used for each domain of the questionnaire and also for the overall questionnaire (KAA-CCQ).¹⁶ For validity, Spearman's ratio was used to find the relation between the items of each domain of the questionnaire and the relation

between the domains of KAA-CCQ.¹⁷ The validity and reliability were also verified by the item-total correlation. For analysing the frequency and percentage of each response, the chi-square test was used to find the response of each domain. This was analysed for all the items in all the 3 domains. The exploratory factor analysis (EFA) was done by the Kaiser-Meyer-Olkin (KMO) Measure of Sampling Adequacy and Bartlett's Test of Sphericity.

Results

The study comprised a total of 68 informal caregivers of comatose patients. Among the informal caregivers, the majority of the participants were men (54.4%). The age of the caregivers ranged between 21 and 73 years (Table 1).

Table 1. Baseline characteristics of the participants

Characteristics	Total (n = 68)
Patient age (year) (mean ± SD)	18.57 ± 54.40
Duration of coma (day) (mean ± SD)	4.85 ± 4.99
GCS score (3-6) (mean ± SD)	17.00 ± 14.37
Gender [n (%)]	
Men	51 (51.0)
Women	17 (25.0)
Causes of coma [n (%)]	
Ischemic stroke	19 (27.9)
Haemorrhagic stroke	13 (19.1)
Traumatic brain injury	12 (17.7)
Status epilepticus	9 (13.2)
Brain tumor	4 (5.9)
Encephalopathy	3 (4.4)
Sepsis	2 (2.9)
Chronic kidney disease	2 (2.9)
Nasal bone fracture	1 (2.9)
Pneumonia	1 (1.5)
Patient caregiver	
Age (year) (mean ± SD)	40.00 ± 12.50
Gender [n (%)]	
Men	37 (54.4)
Women	31 (45.6)
Relation of the patient [n (%)]	
Son	22 (32.4)
Daughter	13 (19.1)
Brother	10 (14.7)
Wife	7 (10.3)
Mother	6 (8.8)
Sister	3 (4.4)
Father	2 (2.9)
Husband	2 (2.9)
Caretaker	1 (1.5)

GCS: Glasgow Coma Scale; SD: Standard deviation

The knowledge domain had a score ranged between 0 and 27 out of the total score 40 and this showed that the score for the knowledge was low and the participants had low knowledge. The

attitude domain of the questionnaire had a score ranged between 0 and 18. The awareness domain had a score ranged between 0 and 20 out of 40 showing that the score was low and participants had a low awareness (Table 2).

Table 2. Descriptive statistics for Knowledge, Attitude, Awareness-Comatose Caregiver Questionnaire (KAA-CCQ)

Component	Range	Mean ± SD
Knowledge	0-27	7.00 ± 5.33
Attitude	0-18	8.68 ± 3.54
Awareness	0-20	5.66 ± 4.26

SD: Standard deviation

The obtained coefficients for the items of the knowledge, attitude, and awareness domains was 0.883, 0.808, and 0.877, respectively, and as the scores were > 0.700, the items were acceptable and reliable for all the domains of the questionnaire. This indicates that the items in the questionnaire assessed are reliable and consistent (Table 3).

Table 3. Item reliability of each component of Knowledge, Attitude, Awareness-Comatose Caregiver Questionnaire (KAA-CCQ)

Component	Cronbach's alpha	No. of items
Knowledge	0.883	10
Attitude	0.808	7
Awareness	0.877	7

The Spearman's ratio was used to find the relationship between the items of knowledge domain of KAA-CCQ. For all the 3 domains, there were correlations between some of the items (knowledge domain: Table 4, attitude domain: Table 5, awareness domain: Table 6).

The Spearman's ratio was used to find the relations between the domains of the KAA-CCQ questionnaire. The correlation coefficient (r) between the knowledge and attitude domains was statistically non-significant and had a non-linear association. This indicates that both the variables (knowledge and attitude) were moving in opposite directions as there was an indirect relationship between the two variables, and the knowledge domain was negatively correlated with the attitude domain. The correlation coefficient between the attitude and awareness domains was statistically non-significant and had a non-linear association. This indicates that both the variables (attitude and awareness) moved in an opposite direction as there was an indirect relationship between the two variables and the attitude domain was negatively correlated with the awareness domain (P > 0.050).

Table 4. Relation between the items of knowledge component

		Correlations										
Item		1	2	3	4	5	6	7	8	9	10	
Spearman's rho	Item 1	Correlation coefficient	1.000	0.547**	0.413**	0.466**	0.297*	0.225	0.301*	0.503**	0.352**	0.206
		P (2-tailed)	.	< 0.001	< 0.001	< 0.001	0.014	0.065	0.013	< 0.001	0.003	0.092
		N	68	68	68	68	68	68	68	68	68	68
	Item 2	Correlation coefficient	0.547**	1.000	0.443**	0.342**	0.256*	0.063	0.147	0.291*	0.293*	0.191
		P (2-tailed)	< 0.001	.	< 0.001	0.004	0.035	0.607	0.231	0.016	0.015	0.119
		N	68	68	68	68	68	68	68	68	68	68
	Item 3	Correlation coefficient	0.413**	0.443**	1.000	0.467**	0.590**	0.346**	0.354**	0.299*	0.427**	0.116
		P (2-tailed)	< 0.001	< 0.001	.	< 0.001	< 0.001	0.004	0.003	0.013	< 0.001	0.344
		N	68	68	68	68	68	68	68	68	68	68
	Item 4	Correlation coefficient	0.466**	0.342**	0.467**	1.000	0.506**	0.132	0.129	0.391**	0.336**	0.080
		P (2-tailed)	< 0.001	0.004	< 0.001	.	< 0.001	0.283	0.296	0.001	0.005	0.516
		N	68	68	68	68	68	68	68	68	68	68
	Item 5	Correlation coefficient	0.297*	0.256*	0.590**	0.506**	1.000	0.306*	0.353**	0.307*	0.278*	0.063
		P (2-tailed)	0.014	0.035	< 0.001	< 0.001	.	0.011	0.003	0.011	0.022	0.611
		N	68	68	68	68	68	68	68	68	68	68
	Item 6	Correlation coefficient	0.225	0.063	0.346**	0.132	0.306*	1.000	0.747**	0.254*	0.326**	0.264*
		P (2-tailed)	0.065	0.607	0.004	0.283	0.011	.	< 0.001	0.037	0.007	0.029
		N	68	68	68	68	68	68	68	68	68	68
	Item 7	Correlation coefficient	0.301*	0.147	0.354**	0.129	0.353**	0.747**	1.000	0.179	0.259*	0.382**
		P (2-tailed)	0.013	0.231	0.003	0.296	0.003	< 0.001	.	0.145	0.033	0.001
		N	68	68	68	68	68	68	68	68	68	68
	Item 8	Correlation coefficient	0.503**	0.291*	0.299*	0.391**	0.307*	0.254*	0.179	1.000	0.453**	0.228
		P (2-tailed)	< 0.001	0.016	0.013	0.001	0.011	0.037	0.145	.	< 0.001	0.061
		N	68	68	68	68	68	68	68	68	68	68
	Item 9	Correlation coefficient	0.352**	0.293*	0.427**	0.336**	0.278*	0.326**	0.259*	0.453**	1.000	0.339**
		P (2-tailed)	0.003	0.015	< 0.001	0.005	0.022	0.007	0.033	< 0.001	.	0.005
		N	68	68	68	68	68	68	68	68	68	68
	Item 10	Correlation coefficient	0.206	0.191	0.116	0.080	0.063	0.264*	0.382**	0.228	0.339**	1.000
		P (2-tailed)	0.092	0.119	0.344	0.516	0.611	0.029	0.001	0.061	0.005	.
		N	68	68	68	68	68	68	68	68	68	68

*Correlation is significant at the 0.05 level (2-tailed); **Correlation is significant at the 0.01 level (2-tailed)

Table 5. Relation between the items of attitude domain

			Correlations						
Item			1	2	3	4	5	6	7
Spearman's rho	Item 1	Correlation coefficient	1.000	0.439**	0.486**	0.615**	0.531**	0.156	0.453**
		P (2-tailed)	.	< 0.001	< 0.001	< 0.001	< 0.001	0.205	< 0.001
		N	68	68	68	68	68	68	68
Item 2	Correlation coefficient	0.439**	1.000	0.295*	0.412**	0.413**	0.186	0.405**	
	P (2-tailed)	< 0.001	.	0.015	< 0.001	< 0.001	0.130	0.001	
	N	68	68	68	68	68	68	68	
Item 3	Correlation coefficient	0.486**	0.295*	1.000	0.632**	0.456**	0.274*	0.136	
	P (2-tailed)	< 0.001	0.015	.	< 0.001	< 0.001	0.024	0.268	
	N	68	68	68	68	68	68	68	
Item 4	Correlation coefficient	0.615**	0.412**	0.632**	1.000	0.727**	0.091	0.317**	
	P (2-tailed)	< 0.001	< 0.001	< 0.001	.	< 0.001	0.458	0.008	
	N	68	68	68	68	68	68	68	
Item 5	Correlation coefficient	0.531**	0.413**	0.456**	0.727**	1.000	0.192	0.249*	
	P (2-tailed)	< 0.001	< 0.001	< 0.001	< 0.001	.	0.117	0.040	
	N	68	68	68	68	68	68	68	
Item 6	Correlation coefficient	0.156	0.186	0.274*	0.091	0.192	1.000	0.269*	
	P (2-tailed)	0.205	0.130	0.024	0.458	0.117	.	0.027	
	N	68	68	68	68	68	68	68	
Item 7	Correlation coefficient	0.453**	0.405**	0.136	0.317**	0.249*	0.269*	1.000	
	P (2-tailed)	< 0.001	0.001	0.268	0.008	0.040	0.027	.	
	N	68	68	68	68	68	68	68	

*Correlation is significant at the 0.05 level (2-tailed); **Correlation is significant at the 0.01 level (2-tailed)

The correlation coefficient between the knowledge and awareness domains was statistically significant and there was a linear association. This indicates that both the variables moved in the same direction as there was a direct relationship between the two variables and the

knowledge domain was positively correlated with the awareness domain ($P < 0.050$) (Table 7). The reliability and validity were verified with item total correlation for all the domains individually. The values were above 0.3 for all the three domains; hence, it validated the instrument.

Table 6. Relation between the items of awareness domain

			Correlations						
Item			1	2	3	4	5	6	7
Spearman's rho	Item 1	Correlation coefficient	1.000	0.425**	0.463**	0.331**	0.506**	0.326**	0.417**
		P (2-tailed)	.	< 0.001	< 0.001	0.006	< 0.001	0.007	< 0.001
		N	68	68	68	68	68	68	68
Item 2	Correlation coefficient	0.425**	1.000	0.549**	0.595**	0.415**	0.580**	0.232	
	P (2-tailed)	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001	< 0.001	0.057	
	N	68	68	68	68	68	68	68	
Item 3	Correlation coefficient	0.463**	0.549**	1.000	0.463**	0.503**	0.404**	0.313**	
	P (2-tailed)	< 0.001	< 0.001	.	< 0.001	< 0.001	0.001	0.009	
	N	68	68	68	68	68	68	68	
Item 4	Correlation coefficient	0.331**	0.595**	0.463**	1.000	0.553**	0.890**	0.308*	
	P (2-tailed)	0.006	< 0.001	< 0.001	.	< 0.001	< 0.001	0.011	
	N	68	68	68	68	68	68	68	
Item 5	Correlation coefficient	0.506**	0.415**	0.503**	0.553**	1.000	0.459**	0.196	
	P (2-tailed)	< 0.001	< 0.001	< 0.001	< 0.001	.	< 0.001	0.110	
	N	68	68	68	68	68	68	68	
Item 6	Correlation coefficient	0.326**	0.580**	0.404**	0.890**	0.459**	1.000	0.284*	
	P (2-tailed)	0.007	< 0.001	0.001	< 0.001	< 0.001	.	0.019	
	N	68	68	68	68	68	68	68	
Item 7	Correlation coefficient	0.417**	0.232	0.313**	0.308*	0.196	0.284*	1.000	
	P (2-tailed)	< 0.001	0.057	0.009	0.011	0.110	0.019	.	
	N	68	68	68	68	68	68	68	

*Correlation is significant at the 0.05 level (2-tailed); **Correlation is significant at the 0.01 level (2-tailed)

Table 7. Correlation coefficient between the domains of Knowledge, Attitude, Awareness-Comatose Caregiver Questionnaire (KAA-CCQ)

Questionnaire	r	P
Knowledge and attitude	-0.128	0.299
Attitude and awareness	-0.191	0.120
Knowledge and awareness	0.536	0.001

P < 0.05 is significant

The correlation value for knowledge was 0.6 and for the attitude as well as awareness domain was 0.5. The KMO Measure of Sampling Adequacy was 0.802 and Bartlett's Test of Sphericity with approximate chi-square value was 347.578. These results were statistically significant at 5% level (P < 0.001). All the above statements in the knowledge domain were distributed normally and were suitable for further data collection as valid responses were provided by the sample units. The KMO Measure of Sampling Adequacy was 0.744 and Bartlett's Test of Sphericity with approximate chi-square value was 159.846. These results were statistically significant at 5% level (P < 0.001). Hence, all the above statements in the attitude domain were distributed normally and were suitable for further data collection as valid responses were provided by the sample units. The KMO Measure of Sampling Adequacy was 0.795 and Bartlett's Test of Sphericity with approximate chi-square value was 273.081. These results were statistically significant at 5% level (P < 0.001). Hence, all the above statements in the awareness domain were distributed normally and were suitable for further data collection as valid responses were provided by the sample units.

Discussion

The present study focused on determining the validity and reliability of a self-constructed questionnaire KAA -CCQ. The purpose of developing this questionnaire was to assess the different factors, i.e., knowledge, attitude, and awareness of the informal caregivers of comatose patients. The questionnaire was constructed following scrupulous literature regarding the concerns witnessed by the informal caregivers of patients in a state of coma either in the ICU or at home. The facts and details regarding coma by reviewing the studies reflected a deficiency in the clarity among the informal caregivers of comatose patients. After reviewing these factors, 3 domains were drafted, i.e., knowledge with 10 items, whereas attitude and awareness domains

consisted of 7 items each. The responses were recorded on the basis of a 5-point Likert scale for the knowledge and awareness domains and 4-point Likert scale for the attitude domain.

These informal caregivers are categorized as the primary caregivers of the comatose patients and these caregivers are considered as a probable aspect in taking care of the patients by committing to the patient care and also due to the involvement of emotional aspect. In a meta-analysis done on the mental health as well as physical health of the caregivers compared with the non-caregivers, elevated levels of stress and depression were observed in the caregivers.³ Moreover, there were reduced levels of well-being, confidence, and self-assurance in the caregivers. Families undergo several changes mentally and physically, and their family members are in a state of uncertainty regarding the patients condition and the recovery of their family members suffering from a coma.⁴

The caregivers experience multiple emotional issues, anxiety, and other psychological effects indirectly hampering their daily routine, and also due to the provision of care to their loved ones, there is a difficulty in focusing on other aspects of life. Coma is a condition that impacts the family members in a debilitating manner especially the caregiver and their prolonged illness becomes a factor that impedes the attitude of caregivers in an emotional aspect. As discussed initially, studies focused on the negative impact on the informal caregivers due to the uncertainty or deteriorating condition of the patient with coma. In addition, the literature highlights that the caregivers have deficient information regarding coma. Though the literature has emphasized these issues, there have been several methods considered previously in providing information to the caregiver regarding disorders of consciousness (DOC). Sattin et al. administered the Social and Family Evaluation (SAFE) tool into the participants allowing the caregiver to assess the level of consciousness. This tool was described as an information tool by the author but this is partially a self-diagnostic tool designed for informal caregivers. Before administering the tool, there should be adequate information or knowledge among the participants and a basic assessment of knowledge must be done and then the SAFE tool should be incorporated.¹⁸

Other methods have been considered in the previous studies regarding the medical professionals providing information to the caregivers regarding coma based on neuro-

investigatory aspects. Once the information was delivered, the participants were evaluated for feedback regarding their response or satisfaction with the provision of information through semi-structured interviews. The caregivers responded to the interviews and the majority of the participants raised concerns related to the experience with the professionals as there was a lack of clarity in comprehension due to the complicated information provided by them to the caregivers. There have been other studies of caregivers raising concerns; especially when the patients are in ICU or a state of unresponsiveness, the medical professionals provide vague or fragmented information to the caregiver related to the condition whether improving or deteriorating.¹⁹

Some studies mentioned the issue that families face economic burdens either due to low income or ongoing treatment expenses leading to distress, uncertainty of the situation, and management of monetary aspects. This occurs as there is lack of information provided to them or it has been provided in a vague manner. There must be an effective communication between the informal caregiver as it is an important aspect in cases of critical or prolonged illness. This is required between the family members and professionals, and thus continuous interaction ensures that the caregiver gets clear information regarding the condition.²⁰

Inadequate communication between the caregiver and the professionals results in distress among the caregivers leading to unsatisfactory responses.²¹ Effective communication is an important aspect in cases of critical illness and this is a requirement between families and the professionals. This inadequate communication creates a distress among the family members and as a result, the caregivers experience an unsatisfactory response. The information received by the caregiver is delivered in a complex manner by the professional and there is reduced awareness and knowledge among the family members. Considering the above factors, the knowledge and awareness components are evaluated in the present study based on the facts focused on the prior studies.^{20,21} However, according to the results, there was a negative correlation to be found between the attitude and knowledge as well as attitude and awareness domains.

Previously, studies have also emphasized that these conditions have a major effect on the quality of life of family members of patients with consciousness disorders, in addition to witnessing

difficulties in communication as well as behaviour leading to psychological distress.²² The impact of coma on family caregivers leads to various emotional, physical, and financial burdens due to the prolonged state of the patient with a poor prognosis, resulting in anxiety and restlessness, and because of a prolonged hospital stay, the expenses for medical ailments and the hospital charges cause an economic burden on the caregivers.²³ Pagani et al. assessed depression and anxiety symptoms of caregivers of patients with consciousness disorders by using several outcome measures.⁴ The study reported the symptoms of depression, anxiety, or stress levels. Leonardi et al. study also focused on the burden and needs of the caregivers.²⁴ Though the symptoms are reported by the evaluation tools, how often the caregivers experience the emotions is not evaluated whereas the attitude domain in this study reports the level of attitude towards comatose patients by the informal caregivers.

The degree to which the results of one item correspond with the results of another item within the same domain measured in a similar period is intrinsic validity. In this study, we measured the correlation between the items within each domain, i.e., 10 items in the knowledge domain, were correlated with each other, and the same was performed for the items of attitude and awareness domains where 7 items were correlated with each other. This was done to demonstrate whether the items correlate well with each other to be suitable for their respective domain, and correlation between items and existing domains was acceptable. There was a positive correlation between the knowledge and awareness domains whereas there was a negative correlation between the knowledge and attitude as well as between the attitude and awareness domains. The reliability was calculated and all the domains of KAA-CCQ had excellent reliability. The overall questionnaire had an excellent and acceptable reliability of 0.8. Hence, the KAA-CCQ can be used to assess the informal caregivers of patients with coma. Based on the results, the study suggests that the KAA-CCQ will be an appropriate method in the assessment of knowledge, attitude, and awareness in the informal caregivers, those providing care for their family member as a primary caregiver to the patient. This questionnaire would assess their levels of knowledge, attitude, and awareness and information will be available for the assessor regarding the facts and information of coma

known to the caregivers and also their attitude towards their patient's condition.

The limitation of the study was that the KAA-CCQ had an acceptable validity rather than the excellent validity as there was no correlation between very few items from all the domains. The items might have shown an acceptable score due to the number of questions varying in each domain although the items were verified by experts' opinion. The future scope questionnaire can be translated into other languages and on the basis of results, there can be educational programs or awareness program for the population lacking or having deficient information regarding coma emphasizing the prevention, hygiene, possible causes, and complications.

Conclusion

KAA-CCQ is a well validated and a reliable

instrument and it is a good outcome measure in assessing the level of knowledge, attitude, and awareness in the informal caregivers. The KAA-CCQ is easy to administer and requires very less time to administer. This outcome measure will provide information to the assessor regarding the level of knowledge and awareness the caregiver has and the attitude towards the condition of the family member.

Conflict of Interests

The authors declare no conflict of interest in this study.

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References

- Young GB. Coma. *Ann N Y Acad Sci* 2009; 1157: 32-47.
- Mehta R, Chinthapalli K. Glasgow coma scale explained. *BMJ* 2019; 365: 11296.
- D'Ippolit M, Aloisi M, Azicnuda E, Silvestro D, Giustini M, Verni F, et al. Changes in caregivers lifestyle after severe acquired brain injury: a preliminary investigation. *Biomed Res Int* 2018; 2018: 2824081.
- Pagani M, Giovannetti AM, Covelli V, Sattin D, Raggi A, Leonardi M. Physical and mental health, anxiety and depressive symptoms in caregivers of patients in vegetative state and minimally conscious state. *Clin Psychol Psychother* 2014; 21(5): 420-6.
- Chiambretto P, Moroni L, Guarnerio C, Bertolotti G, Prigerson HG. Prolonged grief and depression in caregivers of patients in vegetative state. *Brain Inj* 2010; 24(4): 581-8.
- Kumar S, Swaminathan A. Questionnaire to assess the knowledge, attitude, and awareness regarding coma among the informal caregivers of comatose patients: An observational study. *J Sci Soc* 2024; 51(3): 356-9.
- Tsang S, Royse CF, Terkawi AS. Guidelines for developing, translating, and validating a questionnaire in perioperative and pain medicine. *Saudi J Anaesth* 2017; 11(Suppl 1): S80-9.
- Bai Y, Li J, Bai Y, Ma W, Yang X, Ma F. Development and validation of a questionnaire to evaluate the factors influencing training transfer among nursing professionals. *BMC Health Serv Res* 2018; 18(1): 107.
- Ozair M, Baharuddin KA, Mohamed S, Esa W, Yusoff MSB. Development and validation of the knowledge and clinical reasoning of acute asthma management in emergency department (K-CRAMED). *Educ Med J* 2017; 9(2): 1-17.
- Mohamad Marzuki MF, Yaacob NA, Yaacob NM. Translation, cross-cultural adaptation, and validation of the Malay version of the system usability scale questionnaire for the assessment of mobile apps. *JMIR Hum Factors* 2018; 5(2): e10308.
- Lau ASY, Yusoff MSB, Lee YY, Choi SB, Xiao JZ, Liong MT. Development and validation of a Chinese translated questionnaire: A single simultaneous tool for assessing gastrointestinal and upper respiratory tract related illnesses in pre-school children. *J Taibah Univ Med Sci* 2018; 13(2): 135-41.
- Yusoff MSB. ABC of content validation and content validity index calculation. *Educ. Med. J* 2019; 11(2): 49-54.
- Boateng GO, Neilands TB, Frongillo EA, Melgar-Quinonez HR, Young SL. Best practices for developing and validating scales for health, social, and behavioral research: A primer. *Front Public Health* 2018; 6: 149.
- Schober P, Boer C, Schwarte LA. Correlation coefficients: appropriate use and interpretation. *Anesth Analg* 2018; 126(5): 1763-8.
- Bujang MA, Omar ED, Baharum NA. A review on sample size determination for cronbach's alpha test: a simple guide for researchers. *Malays J Med Sci* 2018; 25(6): 85-99.
- Edlow BL, Takahashi E, Wu O, Benner T, Dai G, Bu L, et al. Neuroanatomic connectivity of the human ascending arousal system critical to consciousness and its disorders. *J Neuropathol Exp Neurol* 2012; 71(6): 531-46.
- Moulton R. Head injury. In: Young GB, Ropper AH, Bolton CF, editors. *Coma and impaired consciousness*. New York, NY: McGraw-Hill; 1998:149-81.
- Sattin D, Magnani FG, Cacciatore M, Leonardi M. Towards a New Assessment Tool for Caregivers of Patients with Disorders of Consciousness: The Social and Family Evaluation Scale (SAFE). *Brain Sci* 2022; 12(3).
- Boegle K, Bassi M, Comanducci A, Kuehlmeier K, Oehl P, Raiser T, et al. Informal caregivers of patients with disorders of consciousness: a qualitative study of communication experiences and information needs with physicians. *Neuroethics* 2022; 15(3): 24.
- Emanuel EJ, Fairclough DL, Slutsman J, Emanuel LL. Understanding economic and other burdens of terminal illness: The experience of patients and their caregivers. *Ann Intern Med* 2000; 132(6): 451-9.
- Amanda J, Stephens E, Joy V. Family caregiver communication in the ICU: Toward a relational view of health literacy. *J Fam Commun* 2017; 17(2): 137-52.
- Alfheim HB, Smastuen MC, Hofso K, Toien K, Rosseland LA, Rustoen T. Quality of life in family caregivers of patients in the intensive care unit: A longitudinal study. *Aust Crit Care* 2019; 32(6): 479-85.
- Chinner A, Pauli R, Cruse D. The impact of prolonged disorders of consciousness on family caregivers' quality of life - A scoping review. *Neuropsychol Rehabil* 2022; 32(7): 1643-66.
- Leonardi M, Giovannetti AM, Pagani M, Raggi A, Sattin D. Burden and needs of 487 caregivers of patients in vegetative state and in minimally conscious state: results from a national study. *Brain Inj* 2012; 26(10): 1201-10.