



Palliative Medicine Original Article

Kannada Translation and Validation of the ESAS-r Renal for Symptom Burden Survey in Patients with End-Stage Kidney Disease

Bharathi Naik¹ , Shankar Prasad Nagaraju², Vasudeva Guddattu³, Naveen Salins⁴ , Ravindra Prabhu², Anuja Damani⁴, Prathvi Naik², Krithika S. Rao⁴, Indu Ramachandra Rao², Pankaj Singhai⁵

¹Department of Renal Replacement Therapy and Dialysis Technology, Manipal College of Health Professions, ²Department of Nephrology, Kasturba Medical College, ³Department of Data Science, Prasanna School of Public Health, ⁴Department of Palliative Medicine and Supportive Care, Kasturba Medical College, Manipal Academy of Higher Education, Manipal, Karnataka, ⁵Department of Palliative Medicine, Sri Aurobindo Medical College and PG Institute, Sri Aurobindo University, Indore, Madhya Pradesh, India.

ABSTRACT

Objectives: End-stage kidney disease (ESKD) is a life-limiting illness that leads to significant health-related suffering for the patients and their caregivers. Moreover, disease-directed options such as dialysis and renal transplant might not be universally accessible. Inadequate assessment and management of symptoms often lead to diminished quality of life. For evaluating symptoms and their associated distress, various tools have been identified. However, these are not available for the native Kannada-speaking population for assessing ESKD symptom burden. In this study, we determined the reliability and validity of the Edmonton Symptom Assessment System Revised Renal (ESAS-r: Renal) in Kannada-speaking ESKD patients.

Materials and Methods: ESAS-r: Renal English version was translated into Kannada using the forward and backward method. The translated version was endorsed by Nephrology, Palliative care, Dialysis technology and Nursing experts. As a pilot study, 12 ESKD patients evaluated the content of the questionnaires for appropriateness and relevance. The ESAS-r: Renal Kannada version was validated by administering this tool to 45 patients twice a fortnight.

Result: The translated ESAS-r: Renal Kannada version questionnaire had an acceptable face and content validity. Experts' opinion was assessed by content validity ratio (CVR), and the value of CVR of ESAS-r: Renal Kannada version was '1'. Internal consistency of the tool was assessed among Kannada-speaking ESKD patients; its Cronbach's α was 0.785, and test-retest validity was 0.896.

Conclusion: The validated Kannada version of ESAS-r: Renal was reliable and valid for assessing symptom burden in ESKD patients.

Keywords: Edmonton symptom assessment scale, End-stage kidney disease, Symptom burden, Validation, Translation

INTRODUCTION

According to the 2019 Global Kidney Health Atlas survey, the global average prevalence of new end-stage kidney disease (ESKD) is estimated at 144 per million.^[1,2] The chronic kidney disease (CKD) strategy has often focused on preventing and managing CKD risk factors such as diabetes mellitus, hypertension, obesity and cardiovascular disease.^[3-5] Besides, the increase in ESKD prevalence has led to costs associated with renal replacement therapy.^[2] In the Indian context, there are limited data on ESKD prevalence and incidence, and often patients find it challenging to access renal replacement

therapies.^[6,7] An Indian CKD study showed that only 32.1% of participants had health insurance. Moreover, most of the patients (83%) had to pay by pocket, and 10.6% could not afford any CKD treatment due to a lack of finances.^[8] Advanced renal failure patients have symptoms that might diminish their quality of life (QOL), functional state, health perceptions and emotional well-being.^[9-11] Distress associated with symptoms is known to negatively impact the QOL in patients with kidney disease.^[10,12,13] Renal teams often fail to recognise that this contributes to needless health-related suffering.^[14,15]

*Corresponding author: Pankaj Singhai, Department of Palliative Medicine, Sri Aurobindo Medical College and PG Institute, Sri Aurobindo University, Indore, Madhya Pradesh, India. doctorpsinghai@gmail.com

Received: 08 September 2022 Accepted: 23 March 2023 Published: 30 May 2023 DOI: 10.25259/IJPC_216_2022

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Symptom evaluation and healthcare outcomes in patients with ESKD could be standardised using validated tools like Edmonton Symptom Assessment System Revised (ESAS-r).^[16] However, such measures are unavailable for use in the native Kannada-speaking population with ESKD.

The ESAS-r: Renal is a simple and widely used tool for assessing physical and psychological symptom distress that has been validated in ESKD patients.^[17] The ESAS-r: Renal consists of eleven item visual analogue scales for pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, shortness of breath, itching and problems in sleeping with a superimposed 0–10 scale.^[18] The scale for each symptom is annotated by the words 'No' and 'Severe' at 0 and 10, respectively.^[18,19]

In Karnataka, most people speak Kannada, and ESKD patients from rural and remote areas find it challenging to comprehend a self-administered tool in English. Therefore, we did this study to assess the validity and reliability of the ESAS-r: Renal questionnaire of the Kannada version in the ESKD population.

MATERIAL AND METHODS

The study was conducted between September 2021 to February 2022 in the haemodialysis unit and the renal outpatients of an academic medical centre in Southern India. The study was approved by Kasturba Medical College and Kasturba Hospital's Institutional Ethics Committee (IEC-214/2021). The permission for use and translation of the ESAS-r: Renal tool was obtained from the authors of the original English version.^[18]

Translation of ESAS-r: Renal tool

Validation of an ESAS-r: Renal questionnaire had three steps:

Forward translation

The ESAS-r: Renal questionnaire (English version) was translated by two independent translators fluent in English and Kannada. The third independent person reconciled two translated versions. The ESAS-r: Renal questionnaire, translated into Kannada, was referred to an expert committee for evaluation. Based on the expert committee's advice, a reconciliation version of the ESAS-r: Renal questionnaire was created.

Backward translation

This step aimed to identify any inconsistencies or variations in the translated questionnaire version. Back-translation into English was performed on the initial version of the Kannada-translated questionnaire. The translated version was compared to the original ESAS-r: Renal questionnaire to see whether there was any deviation in the contents. If there were any deviations, the translation exercises were repeated until the translated questionnaire was developed in the correct format. Subsequently, the original questionnaire and the reconciled back translation were compared.

Content validation of ESAS-r: Renal questionnaire

Content validation of the ESAS-r: Renal Kannada version was determined based on panel experts' viewpoints. There were ten health professional experts- 5 Nephrologists, 1 Palliative medicine physician and 2 Dialysis technologists and 2 Nurses. Each panelist reviewed the ESAS-r: Renal Kannada version and asked them to score their level of agreement with the relevancy and accuracy. Based on experts' suggestions, grammatical changes were made to two questions. Lawshe content validity index (CVI) was used to measure the content validity of ESAS-r: Renal quantitatively using the content validity ratio (CVR) and the CVI using a formula.^[16,20] As Lawshe and Davis State, this formula CVR with items ranging from 0.75 to 1 was acceptable^[16,20,21]

$$\begin{aligned} \text{CVR} &= (\text{Ne}-\text{N}/2)/(\text{N}/2) \\ (\text{N} &= \text{No/of Experts}) \\ (\text{Ne} &= \text{No/of panelists given for items was essential}) \\ &= (10-10/2)/(10/2) \\ &= 5/5 \\ &= 1 \end{aligned}$$

Pilot-testing

To test the translated version's cultural compatibility and acceptability, pilot research was undertaken with 12 ESKD patients. Symptom distress scores were as follows 0-No symptom, 1–3 mild, 3–6 moderate and 7–10 severe.^[18,22]

Sampling method and psychometric evaluation of ESAS-r: Renal

Validated ESAS-r: Renal questionnaire was completed by 45 consenting adult participants receiving either haemodialysis/peritoneal dialysis or conservative management.

Reliability

Cronbach's- α coefficient and test-retest reliability were determined to assess the reliability of the questionnaire.

Statistical analysis

'Cronbach's- α coefficient was used to evaluate the internal consistency. Cronbach's α score of 0.70 or above was considered satisfactory internal consistency reliability.^[23,24] The intraclass correlation coefficient was used to identify the agreement between ESAS-r: Renal, first and second measurements. Two interviews were used to evaluate test-retest reliability in a sample of 45 ESKD patients. Interpretation of intraclass correlation coefficient values: <0.4 – weak agreement; 0.4–0.75 – good agreement; and ≥ 0.75 – excellent.^[25,26] The Statistical Package for the Social Sciences (version 15) was used for data analysis.

RESULTS

Translated ESAS-r: Renal Kannada version was found to be acceptable and correlated well with the English version. The CVR of ESAS-r: Renal questionnaires was 1, indicating that panelists perceived each question to be appropriate and relevant.

During the pilot phase, the participants did not report any significant challenges concerning the questionnaire's simplicity, readability and comprehension. The piloted ESAS-r: Renal Kannada version was administered to 45 ESKD patients from dialysis and nephrology outpatient clinics. The demographic details of ESKD patients are mentioned in [Table 1].

The ESKD patients reported a mean of 2.42 ± 1.59 symptoms. Tiredness, loss of well-being, pain and sleep disturbances were the commonly reported symptoms, as shown in [Table 2].

Table 1: Demographic details ESKD patients (n=45).

Gender	
Male	35 (78%)
Female	10 (22.7%)
Age in year	54.73±11.68
Causes of ESKD	
Hypertension	21 (46.7%)
Diabetics mellitus	16 (35.6%)
Renal diseases	8 (17.8%)
Dialysis vintage in months	67.13±44.74
ESKD: End-stage kidney disease	

The reliability of the Kannada version of the ESAS-r: Renal was good, with Cronbach's α of 0.785. The description of symptom burden Mean \pm Standard deviation (SD) and Cronbach's α values of ESAS-r Kannada version is shown in [Table 3].

Test-retest value of ESAS-r: Renal Kannada version intraclass correlation coefficient was 0.948, and the 95% confidence interval was 0.905–0.97, as summarised in [Table 4].

The final Kannada version of the ESAS-r: Renal, which was used among ESKD patients, is shown in [Figure 1].

DISCUSSION

Kannada version of ESAS-r Renal was found to be feasible and well accepted. Over the many years, ESAS has evolved as the most commonly used patient-reported outcome measure for distressing symptom documentation in chronic care.^[27] ESAS-r has been used in other Indian languages but mostly in cancer patients.^[28] This is the only study translating and validating the renal version of ESAS-r Renal in patients with ESKD in India. To the best of our knowledge, this is no other validated tools available in native Kannada to assess symptom burden in patients with ESKD. Like other studies,^[29] our

Table 2: ESAS-r: Renal symptom burden mean±SD values and score distribution.

ESAS-r: Renal symptoms	Mean±SD	No Symptom (0)	Mild (1–3)	Moderate (4–6)	Severe (7–10)	Total
Pain	3.18±3.0	10 (22.2%)	17 (37.7%)	9 (20%)	9 (20%)	35 (77.7%)
Tiredness	3.4±2.68	8 (17.7%)	18 (40%)	12 (26.6%)	7 (15.5%)	37 (82.2%)
Drowsiness	2.29±2.89	18 (40%)	17 (37.7%)	4 (8.8%)	6 (13.3%)	27 (60%)
Nausea	1.25±2.19	27 (60%)	12 (26.66%)	3 (6.66%)	3 (6.66%)	18 (40%)
Lack of appetite	2.85±2.69	16 (35.55%)	11 (24.44%)	12 (26.66%)	6 (13.33%)	29 (64.4%)
Shortness of breath	1.14±2.16	30 (66.6%)	8 (17.7%)	5 (11.1%)	2 (4.4%)	15 (33.3%)
Depression	1.78±2.46	23 (51.1%)	13 (28.8%)	5 (11.1%)	4 (8.8%)	22 (48.8%)
Anxiety	1.56±2.19	24 (53.33%)	14 (31.1%)	5 (11.1%)	2 (4.44%)	21 (46.6%)
Well-being	3.6±2.64	9 (20%)	13 (28.8%)	16 (35.55%)	7 (15.55%)	36 (80%)
Itching	1.4±2.11	26 (57.77%)	12 (26.66%)	5 (11.11%)	2 (4.4%)	19 (42.22%)
Problem sleeping	3.18±3.06	13 (28.8%)	9 (20%)	12 (26.66%)	11 (24.44%)	32 (71.11%)

ESAS-r: Edmonton symptom assessment system revised, SD: Standard deviation

Table 3: Kannada version of the ESAS-r: Renal tool Cronbach's α values among end-stage kidney disease patients.

ESAS-r: Renal domain	Scale mean if item deleted	Scale variance if item deleted	Corrected item-total correlation	Cronbach's α if item deleted
Pain	23.0222	226.340	0.314	0.786
Tiredness	22.8000	211.300	0.592	0.751
Drowsiness	23.9111	218.219	0.447	0.768
Nausea	24.9556	223.998	0.543	0.760
Lack of appetite	23.3556	233.825	0.284	0.786
Shortness of breath	25.0667	238.882	0.314	0.781
Depression	24.4222	225.840	0.442	0.769
Anxiety	24.6444	224.780	0.532	0.761
Well-being	22.6000	216.473	0.531	0.758
Itching	24.8000	225.345	0.550	0.760
Problem sleeping	22.4222	211.386	0.411	0.776

ESAS-r: Edmonton symptom assessment system revised

Table 4: The Kannada version of the ESAS-r: Renal tool test retest value among end-stage kidney disease patients.

Domain	No. of items	Intra-class correlation coefficient	95% confidential interval
Pain	1	0.731	0.511–0.852
Tiredness	1	0.528	0.14–0.740
Drowsiness	1	0.992	0.985–0.995
Nausea	1	0.996	0.994–0.998
Lack of appetite	1	0.989	0.980–0.994
Shortness of breath	1	0.569	0.215–0.763
Depression	1	0.623	0.313–0.793
Anxiety	1	0.651	0.365–0.808
Well-being	1	0.524	0.134–0.738
Itching	1	0.784	0.608–0.882
Problem sleeping	1	0.892	0.803–0.940
All items of ESAS-r: Renal	11	0.948	0.905–0.971

ESAS-r: Edmonton symptom assessment system revised

ಎಡ್ಮಂಟನ್ ಸಿಂಪ್ಟಮ್ ಅಸೆಸ್‌ಮೆಂಟ್ ಸಿಸ್ಟಮ್ ರಿವೈಸ್ಡ್ :
ರಿನಲ್ (ಇಎಸ್‌ಆರ್-ರೆ: ರಿನಲ್)

ನಿಮಗೆ ಈಗ ಹೇಗೆ ಭಾವಿಸುತ್ತೀವೆಂದು ಉತ್ತಮವಾಗಿ ವಿವರಿಸುವ ಸಂಖ್ಯೆಯನ್ನು ದಯವಿಟ್ಟು ವ್ಯಕ್ತಿಸಿ

ನೋವು ಇಲ್ಲ	0	1	2	3	4	5	6	7	8	9	10	ಕೆಟ್ಟದಾದ ನೋವು ಇದೆ
ಯಾವುದೇ ದಣವು ಇಲ್ಲ (ದಣವು: ಶಕ್ತಿಯ ಕೊರತೆ)	0	1	2	3	4	5	6	7	8	9	10	ಕೆಟ್ಟದಾದ ದಣವು ಇದೆ
ಆಲಸ್ಯ ಇಲ್ಲ (ಆಲಸ್ಯ: ನಿರೀಕ್ಷಿಸಿದ ಸಾಮಾನ್ಯ ಸಕ್ರಿಯತೆ)	0	1	2	3	4	5	6	7	8	9	10	ಕೆಟ್ಟದಾದ ಆಲಸ್ಯ ಇದೆ
ವಾಕರಿಕೆ ಇಲ್ಲ	0	1	2	3	4	5	6	7	8	9	10	ಕೆಟ್ಟದಾದ ವಾಕರಿಕೆ ಇದೆ
ಆಹಾರವು ಹಸಿವೆ	0	1	2	3	4	5	6	7	8	9	10	ಹಸಿವು ಇಲ್ಲ
ಉಸಿರಾಟದ ತೊಂದರೆ ಇಲ್ಲ	0	1	2	3	4	5	6	7	8	9	10	ಕೆಟ್ಟದಾದ ಉಸಿರಾಟದ ತೊಂದರೆ ಇದೆ
ಬಿನ್ನತೆ ಇಲ್ಲ (ಬಿನ್ನತೆ : ಉತ್ಸಾಹವಿಲ್ಲದಂತಹ ಮನಸ್)	0	1	2	3	4	5	6	7	8	9	10	ಬಿನ್ನತೆ ಇದೆ
ಆತಂಕವಿಲ್ಲ (ಆತಂಕ: ಹೆಚ್ಚಿನ ಭಾವನೆ)	0	1	2	3	4	5	6	7	8	9	10	ಕೆಟ್ಟದಾದ ಆತಂಕವಿದೆ
ಉತ್ಸಾಹ ಯೋಗಕ್ಷೇಮ	0	1	2	3	4	5	6	7	8	9	10	ಕೆಟ್ಟದಾದ ಯೋಗಕ್ಷೇಮ (ಯೋಗಕ್ಷೇಮ: ಸಾಮಾನ್ಯ ಸಕ್ರಿಯತೆ)
ತುರಿಕೆ ಇಲ್ಲ	0	1	2	3	4	5	6	7	8	9	10	ಕೆಟ್ಟದಾದ ತುರಿಕೆ ಇದೆ
ನಿದ್ರಾಹೀನತೆ ಇಲ್ಲ	0	1	2	3	4	5	6	7	8	9	10	ಕೆಟ್ಟದಾದ ನಿದ್ರಾಹೀನತೆ ಇದೆ
ಇತರೆ ಸಮಸ್ಯೆಗಳು ಇಲ್ಲ _____ (ಉದಾ: ಮಲಬದ್ಧತೆ.....)	0	1	2	3	4	5	6	7	8	9	10	ಕೆಟ್ಟದಾದ ತೊಂದರೆ ಇದೆ

ರೋಗಿಯ ಹೆಸರು : _____ (ಇವರ ಪೂರ್ವನಾಮ ಇದೆ)

ದಿನಾಂಕ _____ ಸಮಯ _____

ರೋಗಿ
 ಆರೈಕೆಗಾರ
 ವೈದ್ಯಕೀಯ ವ್ಯಕ್ತಿತ್ವದ ಸಹಾಯಕ
 ಆರೈಕೆಗಾರ ಸಹಾಯ

Figure 1: Kannada translation of Edmonton symptom assessment system revised renal.

patients found the translated tool simple to use, easy to understand and feasible to implement. This study reported that the Kannada version of the ESAS-r: Renal had good face validity, internal consistency and acceptability. The results were comparable to the

studies conducted on validity and reliability in other countries.^[19,22,30,31] On test-retest validity of ESAS-r Renal, the overall intraclass correlation coefficient showed good agreement for all items. However, a moderate agreement was seen for fatigue, dyspnoea and loss of well-being. Similar results were seen in other translation-related studies of ESAS-r.^[25,26,29] The symptom pattern and burden reported by patients in this study match patterns reported in other studies using other QOL tools in ESKD patients.^[13] Interestingly, similar symptom patterns were reported in other Indian studies where ESAS-r was used on advanced cancer patients.^[32] Patients’ reluctance to express their symptoms and clinicians’ inability to explore it is a significant barrier to patient management in an ESKD setting.^[14] Applying simple and validated symptom assessment tools in the local language in the clinic/dialysis waiting area can help the renal supportive care team provide better care.

Our study has a few limitations. The translated tool was not compared with a standard tool from India as no previously validated tool was available for comparison. However, we sought expert opinion from the palliative care and nephrology team to ensure that the translated tool is comprehensive and applicable. Another limitation was a long gap between test-retest evaluations, which could have led to variability in test-retest reliability.

CONCLUSION

ESAS-r: Renal Kannada version is reliable and valid for identifying the symptom burden in Kannada-speaking ESKD individuals. The Kannada version of the ESAS-r: Renal may be a useful clinical tool in integrated renal supportive care services for ESKD patients in our population.

Acknowledgment

We express our sincere thanks to the authors of ESAS-r an ESAS-r Renal for their permission to use this tool.^[18,33,34]

Declaration of patient consent

The Institutional Review Board (IRB) permission obtained for the study.

Financial support and sponsorship

Indian council of medical research.

Conflicts of interest

There are no conflicts of interest.

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How to cite this article: Naik B, Nagaraju S, Guddattu V, Salins N, Prabhu R, Damani A, *et al.* Kannada translation and validation of the ESAS-r renal for symptom burden survey in patients with end-stage kidney disease. *Indian J Palliat Care* 2023;29:195-9.