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Original Article

# Development of the Chronic Kidney Disease Symptom Index – Sri Lanka; a symptom assessment instrument for Chronic Kidney Disease patients

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**Keywords: Chronic Kidney Disease, Symptom Index, Symptom Burden**

## Abstract

**Background & Objective**

An assessment of the symptom burden of chronic kidney disease (CKD) patients is very important in clinical management. A comprehensive validated questionnaire designed specifically for the assessment of symptoms in CKD patients is lacking in the local context. Such an instrument could be used for research purposes and as a tool to improve the care of patients. Thus, in the present study, a tool was developed to assess the presence and severity of symptoms experienced by CKD patients

**Method**

Development of the Chronic Kidney Disease Symptom Index – Sri Lanka (CKDSI – Sri Lanka) followed a step wise process. Identifying the items, identifying overlapping symptoms, reducing the items, identifying the appropriate time duration to inquire, reaching for a consensus on a method to quantify the symptom burden, translation, pre testing, assessment of discriminant and convergent validity and reliability assessment were the steps followed.

**Results**

Two hundred and fifty adults participated in the study. The mean age of the sample was 57.7 years (SD 10.6). A majority (71.6%) were in either category three or category four CKD. Compared to the study population without any long term comorbid conditions, presence of comorbidities was found to be statistically significantly associated with high median scores of symptom burden ($p<0.001$) Symptom burden scores significantly correlated with CKD stage ($r = 0.357$). These denote satisfactory discriminant validity of the instrument. Domains of KDQOL-SF correlated negatively with the symptom burden which confirmed convergent validity. The Spearman's r value was more than 0.9 which indicates perfect test re-test reliability.

**Conclusions**

The CKDSI-Sri Lanka showed good psychometric properties and is suitable to assess symptom burden in different CKD populations. Thus this instrument could be used for research purposes and as a tool to improve patient care.

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## Introduction

Over the years, chronic kidney disease (CKD) has emerged as a major public health problem, with adverse physical, psychological and economic outcomes. Troublesome physical and psychological symptoms are among the main manifestations of CKD and the symptom burden plays a central role in the patient's experience of the disease [1]. Common symptoms experienced by CKD patients are fatigue, pruritus, irritability,

anxiety and nausea [2]. International research have used symptom burden of CKD patients as a valid indicator of their health status.

An assessment of the symptom burden of CKD patients is very important in clinical management. But evidence shows that healthcare providers frequently under-recognize and under-treat physical symptoms, leading to immense physical and psychological trauma for the patients[3]. Many instruments currently used to assess the Health Related Quality of Life (HRQOL) of CKD patients have items pertaining to symptoms. But these instruments often do not capture the complete range of symptoms that may be relevant and bothersome to patients with different stages of CKD [4]. Most of the symptom assessment instruments that have been used in studies have not followed a proper validating process, possibly affecting the validity of these studies

A comprehensive validated questionnaire designed specifically for the assessment of symptoms in CKD patients is lacking in the local context. Such an objective method of assessing symptom in CKD patients may be important in many ways. Such an instrument could be used for research purposes and as a tool to improve care of the patients. When new interventions are implemented in the future it will be critically important to assess their effects on patients. Although biochemical parameters are considered valid indicators of the effectiveness of an intervention, obtaining the patient's perspective and patient's symptom status are considered equally important in evaluating an intervention. A validated symptom assessment index would be invaluable for this purpose.

The modified Delphi technique, an accepted method of consensus reaching around the world, has been used in several studies to develop indexes [5]. Thus in the present study a tool was developed to assess the presence and severity of symptoms experienced by CKD patients and the tool was named the Chronic Kidney Disease Symptom Index – Sri Lanka (CKDSI – Sri Lanka).

## Methods

Development of the CKDSI – Sri Lanka followed a step wise process.

### Step 1: Identifying the items to be included in the Chronic Kidney Disease Symptom Index

In the first step, a literature survey was conducted to identify the symptoms that are experienced by CKD patients at different stages of the disease. Studies conducted to assess the presence of symptoms among CKD patients and instruments used to assess HRQOL of CKD patients were reviewed. Symptoms which either directly or indirectly affected physical and psychological health were identified and listed.

Furthermore, detailed discussions were conducted with two nephrologists, two medical officers attached to a nephrology unit, two nursing officers and five CKD patients who were in different stages of the disease. The health staff was questioned on symptoms that CKD patients complain of and the patients were questioned about symptoms that

they experienced. The final list comprised of 71 symptoms. The words used to describe the symptoms were culturally appropriate and commonly used in the local context.

Each symptom was considered an item of the Chronic Kidney Disease Index being developed.

### Step 2: Identifying overlapping symptoms in the Chronic Kidney Disease Symptom Index

The possibility of overlapping symptoms, i.e. more than one item referring to the same symptom in different words, was apparent. Thus, a panel of experts to identify such items and determine the words that best represented the symptom in the context of the present study was convened. The expert panel consisted of two nephrologists, two general physicians and two medical officers attached to a nephrology unit and consensus was reached through a modified Delphi process. The lists of symptoms were circulated among the panelists via individually addressed electronic mail in order to secure anonymity and confidentiality of the responses and to minimize the possibility of the panelists being influenced by the responses of others. The identities of the panelists were not revealed until the end of the process. The panel was provided with an explanatory note indicating the purpose and details of the study Of the 71 symptoms in the initial list, 36 items were judged as overlapping with other symptoms by one or more experts (Table 1). Taking into account the inputs of all the experts, the principal investigator formulated a modified list of symptoms with 50 items.

### Step 3: Reducing the number of items to be included in the Chronic Kidney Disease Symptom Index being developed

The next step of the process aimed at reducing the number of items to be included in the Index based on the most common and most troublesome symptoms. This step of item reduction was performed by the same expert panel using a modified Delphi process.

The list of symptoms developed after the first iteration, was modified into an online questionnaire and the members of the panel were asked to score each symptom using a 5 point Likert scale, considering the troublesomeness and commonness of each symptom. Symptoms which were very common were to be marked as 5 and symptoms which were not common were to be marked as 1. Similarly, the symptoms which are highly troublesome were to be marked as 5 and symptoms which are not at all troublesome were to be marked as 1. The members of the panel were also informed that the two ratings for each item would be considered as scores and would be combined and averaged and that only the symptoms with a combined average of three or above would be selected for the Index. After this process 25 symptoms were selected to be retained (Table 2). Feedback was obtained and there was agreement among the expert panel regarding the selected items.

**Table 1: Grouping of the symptoms by the expert panel**

| | Symptoms judged to be overlapping | Combined into | Symptom |
|---|---|---|---|
| 1 | Chills | 1 | Cold intolerance |
| 2 | Cold intolerance | | |
| 3 | Easy bleeding | 2 | Easy bruising |
| 4 | Easy bruising | | |
| 5 | Bad taste in mouth | 3 | Bad taste in mouth |
| 6 | Change in taste | | |
| 7 | Loss of taste | | |
| 8 | Dry mouth | 4 | Excessive thirst |
| 9 | Excessive thirst | | |
| 10 | Loss of appetite | 5 | Loss of appetite |
| 11 | Lack of appetite | | |
| 12 | Mouth sores | 6 | Difficulty swallowing |
| 13 | Difficulty swallowing | | |
| 14 | Blurred vision | 7 | Trouble seeing |
| 15 | Trouble seeing | | |
| 16 | Feeling nervous | 8 | Feeling anxious |
| 17 | Feeling anxious | | |
| 18 | Lightheaded | 9 | Dizziness |
| 19 | Dizziness | | |
| 20 | Back pain | 10 | Bodily pain |
| 21 | Bodily pain | | |
| 22 | Pain | | |
| 23 | Swollen feet and ankles | 11 | Swelling of arms or legs |
| 24 | Swelling of arms or legs | | |
| 25 | Can't fall asleep | 12 | Difficulty sleeping |
| 26 | Can't stay asleep | | |
| 27 | Difficulty sleeping | | |
| 28 | Interest in sex | 13 | Loss of / decreased libido |
| 29 | Problems with sex | | |
| 30 | Loss of libido/decreased | | |
| 31 | Lack of energy | 14 | Lack of energy |
| 32 | Lack of strength | | |
| 33 | Washed out/drained | | |
| 34 | Weakness | | |
| 35 | Worrying | 15 | Feeling sad |
| 36 | Feeling sad | | |

**Table 2: Results of the scores obtained after the Delphi process to develop CKDSI**

| No | Symptom | Mean score |
|---|---|---|
| 1 | Difficulty keeping legs still | 4.9 |
| 2 | Lethargy | 4.7 |
| 3 | Loss of libido/decreased | 4.4 |
| 4 | Loss of appetite | 4.3 |
| 5 | Lack of energy | 4.3 |
| 6 | Nausea | 4.3 |
| 7 | Difficulty in breathing | 4.1 |
| 8 | Difficulty concentrating | 3.9 |
| 9 | Dry skin | 3.9 |
| 10 | Diarrhea | 3.7 |
| 11 | Feeling irritable | 3.7 |
| 12 | Difficulty sleeping | 3.6 |
| 13 | Impotence | 3.6 |
| 14 | Itching | 3.6 |
| 15 | Changes in skin color | 3.4 |
| 16 | Heartburn | 3.4 |
| 17 | Muscle cramps | 3.4 |
| 18 | Bone/joint pain | 3.3 |
| 19 | Numbness/tingling of hands and feet | 3.3 |
| 20 | Weight loss | 3.3 |
| 21 | Feeling sad | 3.1 |
| 22 | Hiccups | 3.1 |
| 23 | Swelling of arms or legs | 3.1 |
| 24 | Trouble with memory | 3.1 |
| 25 | Vomiting | 3.1 |

### Step 4: Identifying the appropriate time duration to inquire regarding presence of symptoms and the appropriate scale to be used to assess the severity of each symptom in the Chronic Kidney Disease Symptom Index being developed

The Index was planned to be designed so that if someone is not experiencing the symptom during a specified time duration prior to the time of inquiry it would be marked as 'No'. Similarly, if someone is experiencing the symptom during a specified time duration prior to the time of inquiry it would be marked as 'Yes'. During the same iterative process described in step two, the expert panel was inquired about the appropriate time duration to be specified. The panel was given the option of selecting one from the following, 'within one day', 'within one week', 'within two weeks' and 'within one month' or any other duration. Four out of five suggested 'within one week' and all four had stated the potential transient nature of many of the symptoms inquired in the index as the reason.

The expert panel was also inquired as to the appropriate scale to be used to assess the severity of each symptom. They were given the option of selecting between a 5 point Likert scale and a 10 point Likert scale or any other scale that they would suggest. All panelists suggested that the 5 point Likert scale is appropriate to assess the severity of

each symptom with the lowest score of one indicating very mild symptoms and the highest score five indicating very severe symptoms.

Consolidating the findings of the above steps, the draft symptom index titled Chronic Kidney Disease Symptom Index –Sri Lanka (CKDSI-Sri Lanka) was formulated in the form of an interviewer administered questionnaire.

### Step 5: Reaching for a consensus on a method to quantify the symptom burden in the Chronic Kidney Disease Symptom Index being developed

The opinion of the same experts was sought on designing a system to quantify the symptom burden in the present study. With consensus from the experts it was decided to assign a scoring system of equal weightage to each symptom. The severity rate of each symptom 1 to 5 was decided to be taken as the score. Those who did not experience the symptom were given a score of zero. Thus the symptom burden assessed using the Chronic Kidney Disease Symptom Index being developed could be a minimum of zero and a maximum of 125.

### Step 6: Translation of CKDSI-Sri Lanka

The forward and backward translation methodology was applied for the translation process. The draft English index was translated into the Sinhala language by an expert proficient in both Sinhala and English languages. Then the Sinhala symptom index was independently re-translated into English by another expert in both languages. The differences in the two English versions were discussed at a meeting with both translators and the draft Sinhala symptom index was adjusted based on consensus.

The appropriateness of the translated Sinhala words was assessed by an expert panel consisting of two Consultant Community Physicians, two Medical Officers of Health working in the Anuradhapura District and two Public Health Inspectors working in the Anuradhapura District. Both the Sinhala and the relevant English terms were communicated to them and they were requested to rate the appropriateness of the Sinhala terms, using a five point Likert scale. They were also informed that mean scores above four would be taken as agreement of the terms as appropriate translations. All mean scores obtained were above four which indicated agreement of the panel of experts regarding the appropriateness of the Sinhala terms used.

### Step 7: Pre testing

The translated instrument was pre-tested on 10 CKD patients coming to the renal clinic at the Maligawatta National Institute for Nephrology, Dialysis and Transplantation. Care was taken not to include patients residing in Anuradhapura. Administration of the instrument was followed by a structured interview conducted by the principal investigator. The interview focused on each item separately to determine difficulty in understanding, acceptability and the best way of asking each question. The practical difficulties arising during completion of the questionnaire were also assessed. The average time taken to fill the questionnaire was approximately 10 minutes.

### Step 8: Assessment of discriminant and convergent validity

Discriminative validity is the ability of an instrument to distinguish between groups that are expected to differ based on their clinical diagnosis or other characteristics [6]. Convergent validity refers to the degree to which scores on a measure associate with scores on other measures that are intended to assess similar constructs [7].

To assess the discriminant and convergent validity of the CKDSI, it was administered to 250 randomly selected CKD patients attending the five renal clinics of the District General Hospital, Polonnaruwa, Base Hospital, Medirigiriya and Divisional Hospital, Hingurakgoda. The required number of 250 study units was distributed equally and 50 eligible study units were selected from each clinic using a convenient sampling method. Patients over the age of 18 years, diagnosed as having CKD (irrespective of whether the aetiology was known or unknown) by a consultant nephrologist or by a consultant physician were included in the study, irrespective of the stage. Patients who had undergone a renal transplant and patients who were critically ill were excluded.
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Previous studies have shown that symptoms among CKD patients correlate with poor health-related quality of life (QOL) [8,9]. Therefore, we hypothesised that the symptom burden assessed by the CKDSI-Sri Lanka would negatively correlate with scores of a health-related quality of life assessment instrument. After informed written consent, the newly translated CKDSI-Sri Lanka and the Kidney Disease Quality of Life short form (KDQOL-36™) was administered. KDQOL-36™ has two components; a Kidney Disease Specific Component and the SF 36. Of the total 81 questions in 19 domains, 43 questions assess 11 kidney disease specific domains of QOL and the SF-36 questionnaire assesses the general health related QOL in eight domains. When scoring, each question is scored on a scale ranging from 0 (worst health) to 100 (best health). All items in a domain are summed up and averaged to give an average score for each domain which ranges from 0 (worst health) to 100 (best health). Two summary scores; physical component summary (PCS) and mental component summary (MCS) can be derived from the 08 domain scores of Sf-36 component.

Ethics approval for this component was obtained from the Ethics Committee, Faculty of Medicine, Colombo.

### Step 9: Reliability assessment of CKDSI-Sri Lanka

According to previous studies, reliability assessment of CKD symptom indexes have been done after four to seven days to account for the transient nature of the symptoms assessed [3]. Therefore, the test re-test reliability of the CKDSI- Sri Lanka was assessed by administering the same tool, after an interval of four days, to a sub sample of the above study units.

Thirty study units were randomly selected by the principal investigator and visited at their homes by the data collectors and the draft CKDSI-Sri Lanka was re-administered. An identification number which was known only to the principal investigator was used to link the two questionnaires of these study units, the test and the retest.

The respondents were re-educated on the period of inquiry regarding the symptoms i.e. one week prior to the initial round of data collection. An additional question was included to indicate whether they had developed any significant physical or psychological symptoms during the last four days which was not present during the initial data collection. Two study units who responded as having developed such symptoms were excluded from the analysis to avoid any possible mistake of reporting such symptoms as experienced during the week prior to the initial round of data collection.

A correlation coefficient (Spearman's r) of symptom burden between the initial and re-test groups was computed. A correlation coefficient (Spearman's r) of 0.70 or greater was considered satisfactory [10].

## Data analysis

Data entry was carried out by the Principal Investigator using the REDCap Version 6.6.0 software. Each item in the study tools was entered with a unique variable name. During data cleaning, the frequency distribution of categorical variables was examined and incomplete data entries were identified and corrected using the original questionnaire. Statistical analysis was done using SPSS version 20.0.

Socio-demographic and kidney-related information of the study population were described using frequency distributions. In assessing the symptom burden, the severity rate of each symptom, 1 to 5, was treated as a score. Those who did not experience the symptom were given a score of zero. Symptom burden score for each respondent was the sum the symptom severity scores of each of the symptoms inquired into in the Chronic Kidney Disease Symptom Index and the possible scores ranges from zero to 125.

## Results

### *Sample characteristics*

Two hundred and fifty adults with documented evidence of CKD participated in the study. The mean age of the sample was 57.7 years (SD 10.6). The majority of the study population were females (n=145; 58.0%). A majority of those who were currently employed in the study population were farmers (n=85; 73.3%). Details of the CKD conditions were obtained from the medical records, which showed that the mean number of years since the diagnosis of CKD was 6.3 years (SD = 3.7). The mean eGFR value was 29.3 ml/min/1.73m$^2$ (SD = 19.0). A majority (n=179; 71.6%) were in either category three or category four. Chronic Kidney Disease of unknown origin (CKDu) was the commonest etiology for CKD (n=52; 20.8%). Further details of the study population are given in the Table 3.

**Table 3: Distribution of the Study Population by Socio Demographic and Renal Related Characteristics**

| Socio demographic characteristics | | (N=250) n | % |
|---|---|---|---|
| **Age categories (Years)** | 18 – 40 | 17 | 6.8 |
| | 41 - 60 | 130 | 52.0 |
| | 61 - 80 | 103 | 41.2 |
| **Sex** | Male | 105 | 42.0 |
| | Female | 145 | 58.0 |
| **Highest level of education** | Never gone to school | 24 | 9.6 |
| | Grade 1 - 5 | 93 | 37.2 |
| | Grade 6 – 11 | 95 | 38.0 |
| | Passed G.C.E O/L* | 32 | 12.8 |
| | Passed G.C.E. A/L** | 05 | 2.0 |
| | Graduate | 01 | 0.4 |
| **GFR category** | Stage 1 | 48 | 19.2 |
| | Stage 2 | 11 | 4.4 |
| | Stage 3 | 71 | 28.4 |
| | Stage 4 | 108 | 43.2 |
| | Stage 5 (Non dialysis) | 09 | 3.6 |
| | Stage 5 (Dialysis) | 03 | 1.2 |

*General Certificate Examination Ordinary Level **General Certificate Examination Advanced Level

### *CKDSI-Sri Lanka psychometric results*

The median symptom burden score of CKD was 34.0 (IQR 20.0-50.0) while the mean score was 33.3 (SD 18.3).

### *Discriminative validity*

Discriminative validity is the ability of an instrument to distinguish between groups that are expected to differ based on their clinical diagnosis or other characteristics (6). Subgroups of the patients based on age and history of co-morbid conditions (e.g. hypertension & diabetes mellitus), was compared to see the ability of the instrument to discriminate between 2 subgroups or if differences occurred in the predicted directions (Table 4). Initial analysis revealed non- normal distribution of the scores of symptom burden of CKD, thus non-parametric tests were used for the analysis. Compared to the study population who did not have any long term comorbid conditions (29.5; IQR 16.0-46.0), presence of comorbidities (37.0; IQR 23.0-52.0) was found to be statistically significantly ($p<0.001$) associated with high median scores of symptom burden of CKD. Symptom burden scores of CKD significantly ($p<0.001$) correlated negatively with the eGFR value ($r = -0.201$) of the study participants, which denotes that advanced stages of the disease had higher symptom burden scores.

**Table 4: Comparison of the CKDSI-Sri Lanka symptom burden scores for some selected characteristics among the 250 CKD patients**

| Descriptive criteria | Symptom Burden | p value |
|---|---|---|
| **Age** | | |
| Less than or equal to 60 years | 34.0 (IQR 18.0-49.0) | 0.019* |
| More than 60 years | 36.0 (IQR 23.0-36.0) | |
| **Comorbid conditions** | | |
| Present | (37.0; IQR 23.0-52.0) | p<0.001* |
| Absent | (29.5; IQR 16.0-46.0) | |

* *Mann-Whitney U test*

### *Convergent validity*

Symptom/problem domain (r =-0.697), effects of kidney disease (r = -0.579) and burden of kidney disease (r = -0.512) scores significantly correlated negatively (p<0.001) with symptom burden score. The physical component summary score (PCS) and the mental component summary score (MCS) showed a significant (p<0.001) negative correlation with symptom burden (Table 5). These results confirmed the convergent validity of the CKDSI-Sri Lanka.

**Table 5: Relationship of Scores of KDQOL SFTM with Scores of Symptom Burden of CKD**

| Domains | Symptom Burden of CKD | |
|---|---|---|
| | Correlation coefficient | p values[+] |
| **Kidney Disease Specific Component** | | |
| Symptom/problem domain | -0.668 | **P<0.001**[*] |
| Effects of kidney disease | -0.565 | **P<0.001**[*] |
| Burden of kidney disease | -0.512 | **P<0.001**[*] |
| **Physical Component Summary Score** | -0.576 | **P<0.001**[*] |
| **Mental Component Summary Score** | -0.366 | **P<0.001**[*] |

[+] *Spearman Correlation coefficient*

### *Test re-test reliability*

The Spearman's r value was more than 0.9 which indicated perfect test re-test reliability.

## Discussion

In the absence of a validated instrument to assess the symptom burden of CKD in the local context, the Chronic Kidney Disease Symptom Index – Sri Lanka (CKDSI – Sri Lanka) was developed to assess the symptom burden of CKD patients. The development of the CKDSI – Sri Lanka was a stepwise process and the methodologies used in development of CKD symptom indexes in other countries were reviewed to ensure the quality of data obtained by the instrument [3,4]. Patient and provider centered approach was used in the stepwise process of developing the instrument, as this has been shown to facilitate use in clinical practice in the future [3].

A comprehensive literature review and detailed discussions held with patients at different stages of the disease and their care givers ensured that the initial list comprised an exhaustive list of symptoms experienced in all the stages of the disease.

The initial list included 71 symptoms and this number was comparable with the study done by Weisbord et al., (2004) who had initially identified 75 symptoms from literature review and discussions. In keeping with the methods used by other researchers, the Delphi technique was used to identify overlapping symptoms and to decide on the list of symptoms to be retained in the index based on the most troublesome and the commonest symptoms. The inclusion of experts in the field of nephrology for the iterative process of Delphi technique ensured acceptability of the developed index by the nephrology fraternity.

The CKDSI – Sri Lanka includes 25 symptoms, which is different to the indexes developed by Weisbord et al., (2004) (which has 30 symptoms ) and Agarwal (2010) (which has 37 symptoms). Considering the practical difficulty of applying a lengthy index, 25 symptoms can be consided appropriate. The transient nature of the symptoms experienced by CKD patients was captured by inquiring only for presence of symptoms over a period of one week. This was similar to the indexes developed by Weisbord et al. (2004) and Agarwal (2010).

The assessment of the symptom burden, taking into account both the number of symptoms reported and the perceived severity was considered as a meaningful measure of the symptom burden of CKD patients. However, it was noted that others who have developed similar tools have only considered the prevalence of symptoms when assessing the symptom burden. Though the method used in the present study can be considered as a better measure of the symptom burden, adopting this method hampers direct comparison of our results with other studies.

Test re-test reliability of CKDSI-Sri Lanka was assessed by administering the same tool to a sub sample following an interval of four days. According to previous studies, reliability assessment of CKD symptom indexes have been done after four to seven days to account for the transient nature of the symptoms assessed [3]. A correlation coefficient (Spearman's r) of the symptom burden between the initial and re-test a group was more than 0.9 which indicated perfect test re-test reliability. A similar high correlation value was found in the study done by Agarwal (2010).

Discriminant validity was demonstrated to be satisfactory, indicating that the CKDSI-Sri Lanka can discriminate between patients in different stages of the disease between patients with and without comorbidities. The time taken to complete the index was around 10 minutes which can be considered a reasonable time. Further evidence of construct validity was demonstrated by examining the relationships between the CKDSI-Sri Lanka and domains of KDQOL-36. These results are consistent with previous studies that have demonstrated that CKD symptoms are negatively correlated with HRQOL [11,12,13].

## Conclusions

The CKDSI-Sri Lanka showed good psychometric properties and it was demonstrated that it is suitable to assess symptom burden for different CKD populations. Thus this instrument could be used for research purposes and as a tool to improve patient care.

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