Development and Validation of the Thirst Distress Scale for Patients with Autosomal Dominant Polycystic Kidney Disease

Seyda Gul Ozcan
Cerrahpasa Medical School: Istanbul Universitesi-Cerrahpasa Cerrahpasa Tip Fakultesi
Sibel Gokcay Bek
Kocaeli University School of Medicine: Kocaeli Universitesi Tip Fakultesi
Necmi Eren
Kocaeli University School of Medicine: Kocaeli Universitesi Tip Fakultesi
Zeynep Atli
Sinop University: Sinop Universitesi
Abdülmecit Yildiz
Uludag University Faculty of Medicine: Uludag Universitesi Tip Fakultesi
İsmail Kocyigit
Erciyes Universitesi Tip Fakultesi
Caner Cavdar
Dokuz Eylul Universitesi Tip Fakultesi
Sertac Tunc
Cerrahpasa Medical School: Istanbul Universitesi-Cerrahpasa Cerrahpasa Tip Fakultesi
Nana Waldréus
Karolinska Institutet
Tevfik Ecder
TC Demiroğlu Bilim Üniversitesi: TC Demiroglu Bilim Universitesi
Nurhan Seyahi (nseyahi@yahoo.com)
Istanbul University-Cerrahpasa, Cerrahpasa Medical Faculty https://orcid.org/0000-0001-7427-618X

Research article

Keywords: Polycystic Kidney Disease, Thirst distress scale, Reliability and validity, chronic kidney disease

Posted Date: July 15th, 2022

DOI: https://doi.org/10.21203/rs.3.rs-1725246/v1

Abstract

Background and Aims:

Thirst, is the main driver for fluid consumption. Abundant water intake is advised for patients with autosomal dominant polycystic kidney disease (ADPKD). However, daily routines may limit water intake. There is no established tool to quantify the drivers of water intake in ADPKD patients. The aim of this study was to modify and validate a thirst distress scale (TDS) to identify the factors that influence water intake in ADPKD patients.

Methods

The TDS-heart failure questionnaire was first modified to TDS-PKD to adapt to patients with ADPKD to assess (a) the intensity of thirst, (b) the consequences if the quench for thirst is not satisfied enough and (c) the disturbing effects of thirst on quality of life. Then, the TDS-PKD questionnaire was translated to Turkish using the guidelines of the World Health Organization. An electronic survey with the SurveyMonkey platform was used to collect data. Thirst intensity was evaluated using a visual analog scale (VAS).

Results

The questionnaire was filled in by 186 ADPKD patients, of which 126 were on tolvaptan therapy. The TDS-PKD questionnaire showed good internal consistency, with a Cronbach's alpha value of 0.859. According to the exploratory factor analysis, a three-factor structure was obtained. Three factors explained 60.7% of the total variance. There was a positive and statistically significant correlation between the total TDS and VAS scores ($r = 0.589$, $p < 0.001$). The average TDS-PDK score was 39.0 ± 1.4.

Conclusion

The TDS-PKD questionnaire is a valid and reliable tool for evaluating the thirst distress in ADPKD patients.

Introduction

Autosomal dominant polycystic kidney disease (ADPKD) is the most common hereditary kidney disease with a prevalence of 1 in every 400 to 1000 live births and is characterized by the development of renal cysts that eventually lead to end-stage renal disease (ESRD) in some of the affected individuals. (1) Abundant water intake is advised for patients with ADPKD, with the hope of slowing cystic progression. (2, 3)

Thirst, which can be defined as a sensation of dryness in the mouth and throat associated with a desire for liquids, is the main driver of fluid consumption. (4) Increased thirst can cause thirst distress, meaning ‘the degree to which a person is bothered by thirst’. (5) Thirst distress has been quantified with a Likert scale, whereas thirst intensity is measured using a visual analog scale (VAS). Previous studies have measured thirst distress in patients with kidney failure and heart failure, and established the validity of quantification methods. (6, 7) However, there is no established tool to quantify thirst in ADPKD patients. Additionally, in those patients, in contrast to the above-mentioned diseases, increased water consumption is desired.

Tolvaptan, is a vasopressin 2 (V2) receptor antagonist that preserves kidney function in patients with ADPKD. (8) The blockage of V2 receptors increases water diuresis and plasma osmolarity that triggers thirst.

The aim of this study was to modify and validate a thirst distress scale (TDS) to identify the factors that influence water intake in ADPKD patients.

Methods

Study Design, Settings and Participants

We conducted a cross-sectional study between December 2021 and February 2022 in five different nephrology centers located in different cities across Turkey. All participant centers were tertiary care university hospitals. Patients older than 18 years of age with a diagnosis of ultrasound-based ADPKD were included in the study. (9) Patients who were unable to fill out the questionnaire or were on dialysis treatment were excluded from the study. Demographic data, serum creatinine, serum sodium, estimated glomerular filtration rates, and data on tolvaptan treatment were collected. Stage of ADPKD was defined according to Mayo clinic classification using MRI data. (10)

Survey Development and Data Collection

Thirst distress scale-heart failure (TDS-HF) included items related to the desire for water intake in contrast to thirst distress scale-renal failure (TDS-RF) which quantifies only the effect of water deprivation. The previous TDS developed for patients with heart failure and renal failure were used to quantify thirst distress due to water deprivation in contrast to the distress in ADPKD patients who are advised to drink abundant water. However, despite increased water intake, patients with ADPKD might also be prone to thirst distress when they are on tolvaptan therapy. In addition, either prescribed or tolvaptan-induced water intake might be associated with frequent urination or nocturia that may disturb the daily routines and quality of life of the patients. Patients might tend to avoid water intake to avoid frequent urination; in that case, especially in patients on tolvaptan therapy, thirst distress might increase.

Based on these facts, the items in the original TDS were modified for ADPKD through literature review, interviews with ADPKD patients, and considering patients' experiences to develop a new questionnaire.

The new questionnaire was based on the TDS-HF developed by Waldréus et al. (6) The eight items of the original TDS-HF are rated on a five-point Likert scale, with a total score ranging between 8 and 40. A higher score indicates more thirst distress. The author of TDS-HF, Nana Waldréus, granted permission to modify the instrument for patients with ADPKD. (6)

The following changes were made:

a. We excluded one item since the study population are usually advised to drink water as much as they can.

'I am so thirsty I could drink water uncontrollably'.

b. We added five new items to assess the factors that promoted or limited water intake.

-Factors promoting water intake:

'If I don't drink enough water or liquid, I get headaches',

'When I am thirsty and I cannot get enough liquid, I get nervous', and

'When I am thirsty, I cannot work well and I lose my concentration'.

- Factors limiting water intake:

'I cannot get enough liquid to avoid frequent urination in the daytime',

'I have to wake up at night and cannot sleep well because of nocturia during nighttime'.

A total of 12 items regarding TDS-PKD were rated on a five-point Likert scale. Thus, the total score ranged between 12 and 60.

Following the modification of the scale, the English form was translated to Turkish separately by two bilingual medical experts; a nephrologist and an internist. Subsequently, the translated Turkish form was back-translated by a bilingual English translator, specialized in medical translations. Thereafter, all original, translated, and back-translated forms were evaluated by a panel of bilingual experts. The panel was composed of two participants who performed the first translation, one who performed the back translation, and two additional nephrologists who are specialized in the care of ADPKD patients. The final version in Turkish was constructed by the agreement of all participants. The translations were made according to the World Health Organization (WHO) guidelines on translation. (11)

Thirst intensity was measured using a visual analog scale (0: no thirst to 10: severe thirst). (6) The patients were requested to rate the severity of thirst from zero to 10 points. Zero refers to 'I don't feel thirsty' and 10 refers to 'the feeling of thirst is very severe'. The VAS score was classified as follows; mild (0-3), moderate (4-6), and severe (7-10). (6, 12)

We collected data using an electronic survey created by the SurveyMonkey© platform. The survey was filled out by the patients.

Data Analysis

The data are presented as mean values and standard deviations (SD) and median [minimum-maximum]. Sampling adequacy was measured with the Kaiser-Meyer-Olkin (KMO) test, while Barlett's test of sphericity was used to test the appropriateness of factor analysis. Exploratory factor analysis was conducted to reveal the validity and the factor structure of the questions in the questionnaire. Principal components were extracted using principal component analysis and varimax rotation method with Kaiser normalization. In factor analysis, the rule that eigenvalues greater than 1 was used to decide on the number of factors. Internal consistency of the TDS-PKD was evaluated with Cronbach's alpha coefficient and homogeneity of the questions with Hotelling's T-squared test. The correlation matrix was used to analyze inter-item correlations. The correlation between factor scores and the VAS scale was evaluated with Spearman's correlation analysis. All statistical analyses were performed using IBM SPSS version 21 (IBM Corp., Chicago, IL, USA) and R software (version 4.0.2).

Results

Participants' characteristics

The questionnaire was completely filled in by all of the 186 ADPKD patients, of which 126 were on tolvaptan therapy. The questionnaire was completely filled by all of the patients. The time taken to answer the questions was about four minutes. Demographic and laboratory data of the patients are shown in Table 1. The participants were generally middle-aged patients, with a slight dominance of males. The mean creatinine level was 1.33 ± 0.66 mg/dL and the median was 1.18 (min-max: 0.48–4.04) mg/dL. Nearly 60% of the patients had stage 1 or 2 chronic kidney disease (CKD). Regarding Mayo stages, 66.7% of the patients were classified as stage 1D or 1E.

Table 1
Demographic and clinical data of the patients.

	ADPKD patients (n = 186)
Age	40.23 ± 9.40
Gender, male n (%)	95 (51.1)
Stage according to Mayo classification, n (%)	n = 165
1A	5 (3.0)
1B	8 (4.8)
1C	42 (25.5)
1D	68 (41.2)
1E	42 (25.5)
Creatinine, mg/dL (n = 177)	1.33 ± 0.66
eGFR ml/min/1.73m2, n (%)	n = 177
Stage 1	59 (33.3)
Stage 2	46 (26.0)
Stage 3	51 (28.8)
Stage 4	18 (10.2)
Stage 5	3 (1.7)
Serum sodium, mg/dL	140.30 ± 2.75

Validity Analysis

Construct Validity and Factor Structure

According to the Kaiser-Meyer-Olkin (KMO) test, the sample adequacy value was 0.872, indicating that the sample size was sufficient to perform the exploratory factor analysis. Bartlett's test of sphericity results suggested the correlation among the data was sufficient for factor analysis (df:66, $p < 0.001$).

In Explanatory Factor Analysis, while evaluating the items to be included in the factors, we adopted the criterion of factor loads higher than 0.32. (13) In addition, if the item loaded on more than one factor, we included the item in the factor with the highest score.

After applying principal component analysis with Varimax rotation, a three-factor solution was obtained. The first factor consisted of the first 7 questions, the second factor questions 8–10, and the third factor questions 11–12. Three factors determined following varimax rotation method explained 60.76% of the total variance. When the sub-factors were examined, the first factor explained 41.34% of the total variance with the highest explanatory power. The second factor explained 10.39%, and the third factor explained 8.94% of the variance. Sub-dimensions and factor loads of the items are shown in Table 2.

Table 2
Sub-dimensions and factor loads of the 12 items.

Items	Factor 1	Factor 2	Factor 3
My thirst bothers me a lot	0.671		
My mouth feels like cotton when I am thirsty	0.796		
My mouth feels dry when I am thirsty	0.769		
My saliva is very thick when I am thirsty	0.685		
When I drink less water, my thirst gets worse	0.490		
My thirst feels difficult to overcome	0.505		
I am very uncomfortable when I am thirsty	0.613		
If I do not drink enough water or liquid, I get headaches		0.824	
When I am thirsty and cannot get enough liquid, I get nervous		0.752	
When I am thirsty, I cannot work well and I lose my concentration		0.702	
I cannot get enough liquid to avoid frequent urination in the daytime			0.845
I have to wake up at night and cannot sleep well because of nocturia during nighttime			0.740
Eigenvalues	4.972	1.246	1.073
Explained variance	41.344	10.385	8.938
Explained total variance	60.757		

Internal Consistency

Cronbach's alpha coefficient of the questionnaire was 0.859. Cronbach's alpha values for factors one, two, and three were 0.847, 0.776, and 0.492 respectively. According to Hotelling's T-squared test ($p < 0.001$), the scale consisted of homogeneous questions.

Inter-item correlations analysis showed that, the questions had a positive correlation with each other. Average inter-item correlation was 0.343 and varied between 0.057 and 0.711, indicating that the items fit together conceptually (Table 3). Item 10 (When I am thirsty, I cannot work well and I lose my concentration) had the strongest item-total correlation (r:0.679) whereas, the weakest correlation was found in item 11 (I cannot get enough liquid to avoid frequent urination in the daytime) (r:0.264). The strongest correlation was between item 1 (My thirst bothers me a lot) and item 7 (I am very uncomfortable when I am thirsty) (r: 0.711), whereas the weakest correlation was between item 8 (If I do not drink enough water or liquid, I get headaches) and item 12 (I have to wake up at night and cannot sleep well because of nocturia during nighttime) (r: 0.105) (Table 3).

Table 3
The item-total and inter-item correlations of the 12-item TDS-PKD scale.

Items	Item-total correlations	Inter-item correlations											
	12-item scale	1	2	3	4	5	6	7	8	9	10	11	12
1	0.664	1.00											
2	0.625	0.518	1.00										
3	0.569	0.430	0.597	1.00									
4	0.548	0.373	0.549	0.474	1.00								
5	0.519	0.448	0.355	0.377	0.327	1.00							
6	0.593	0.533	0.443	0.306	0.358	0.360	1.00						
7	0.660	0.711	0.445	0.427	0.369	0.444	0.550	1.00					
8	0.486	0.343	0.311	0.238	0.242	0.332	0.330	0.325	1.00				
9	0.580	0.388	0.342	0.320	0.376	0.311	0.323	0.455	0.515	1.00			
10	0.679	0.544	0.431	0.437	0.425	0.480	0.385	0.507	0.521	0.581	1.00		
11	0.264	0.057	0.153	0.137	0.161	0.085	0.290	0.145	0.154	0.184	0.115	1.00	
12	0.316	0.210	0.210	0.231	0.195	0.131	0.253	0.192	0.105	0.211	0.226	0.345	1.00

Concurrent Validity

The mean VAS score for thirst intensity was 8.0 ± 2.8 with a median value of 8 (range 0–10). One hundred and sixteen patients (62.3%) complained of severe thirst with a VAS score of 7 or greater.

There was a positive and statistically significant correlation between the total TDS and VAS scores ($r = 0.589$, $p < 0.001$). The correlation between each item and thirst intensity is shown in Table 4. There was no statistically significant correlation between item 11 and the VAS score ($r = 0.068$, p:0.359). The strongest correlation was with item 1 ($r = 0.588$, $p < 0.001$).

Table 4
The correlation between each item and thirst intensity

Items	VAS score (Spearman's correlation coefficient)
My thirst bothers me a lot	0.588, $p < 0.001$
My mouth feels like cotton when I am thirsty	0.484, $p < 0.001$
My mouth feels dry when I am thirsty	0.513, $p < 0.001$
My saliva is very thick when I am thirsty	0.260, $p < 0.001$
When I drink less water, my thirst gets worse	0.376, $p < 0.001$
My thirst feels difficult to overcome	0.425, $p < 0.001$
I am very uncomfortable when I am thirsty	0.543, $p < 0.001$
If I do not drink enough water or liquid, I get headaches	0.290, $p < 0.001$
When I am thirsty and cannot get enough liquid, I get nervous	0.293, $p < 0.001$
When I am thirsty, I cannot work well and I lose my concentration	0.417, $p < 0.001$
I cannot get enough liquid to avoid frequent urination in the daytime	0.068, $p = 0.359$
I have to wake up at night and cannot sleep well because of nocturia during night time	0.297, $p < 0.001$

Secondary analysis comparing the patients according to tolvaptan therapy status

We compared the total TDS, item-specific, and VAS scores between patients who were on tolvaptan therapy and those who were not (Table 5). The ROC analysis showed that the 12-item questionnaire was able to discriminate between patients who were on tolvaptan or not (AUC: 0.611).

Table 5
Thirst distress scale and thirst intensity according to tolvaptan therapy.

	Patients who are not on tolvaptan therapy n = 60	Patients who are on tolvaptan therapy n = 126	p
VAS score	5.0 (0.0–10.0)	8.0 (1.0–10.0)	< 0.001
Total TDS score	37.0 (12.0–60.0)	40.50 (17.0–60.0)	0.015
My thirst bothers me a lot	4.0 (1.0–5.0)	4.0 (1.0–5.0)	0.091
My mouth feels like cotton when I am thirsty	3.0 (1.0–5.0)	4.0 (1.0–5.0)	0.033
My mouth feels dry when I am thirsty	4.0 (1.0–5.0)	5.0 (1.0–5.0)	0.194
My saliva is very thick when I am thirsty	3.50 (1.0–5.0)	3.50 (1.0–5.0)	0.861
When I drink less water, my thirst gets worse	3.0 (1.0–5.0)	4.0 (1.0–5.0)	< 0.001
My thirst feels difficult to overcome	2.50 (1.0–5.0)	3.0 (1.0–5.0)	0.521
I am very uncomfortable when I am thirsty	4.0 (1.0–5.0)	4.0 (1.0–5.0)	0.004
If I do not drink enough water or liquid, I get headaches	4.0 (1.0–5.0)	4.0 (1.0–5.0)	0.419
When I am thirsty and cannot get enough liquid, I get nervous	2.0 (1.0–5.0)	3.0 (1.0–5.0)	0.285
When I am thirsty, I cannot work well and I lose my concentration	3.0 (1.0–5.0)	3.0 (1.0–5.0)	0.312
I cannot get enough liquid to avoid frequent urination in the daytime	1.0 (1.0–5.0)	1.0 (1.0–5.0)	0.380
I have to wake up at night and cannot sleep well because of nocturia during night time	2.0 (1.0–5.0)	3.50 (1.0–5.0)	0.006

TDS: thirst distress scale, VAS: visual analog scale.

Reduction of items

In the 12-item TDS-PKD, Cronbach's alpha was 0.859 for all items. We calculated Cronbach's alpha value for any item deleted and found that Cronbach's alpha values changed between 0.838 and 0.866 (Table 6). When the first 10 items were analyzed, we observed that Cronbach's alpha value decreased when any of these items were excluded from the analysis. When item 11 and item 12 were deleted, Cronbach's alpha value increased from 0.859 to 0.864 and 0.866 respectively, however it did not show a great change and the overall Cronbach's alpha coefficient for 12 item scale was over the suggested value of 0.70 (which shows the test is reliable).

Table 6
Reliability of the scale in case an item is deleted.

Item	Cronbach's alpha
My thirst bothers me a lot	0.841
My mouth feels like cotton when I am thirsty	0.842
My mouth feels dry when I am thirsty	0.847
My saliva is very thick when I am thirsty	0.847
When I drink less water, my thirst gets worse	0.850
My thirst feels difficult to overcome	0.844
I am very uncomfortable when I am thirsty	0.840
If I do not drink enough water or liquid, I get headaches	0.852
When I am thirsty and cannot get enough liquid, I get nervous	0.845
When I am thirsty, I cannot work well and I lose my concentration	0.838
I cannot get enough liquid to avoid frequent urination in the daytime	0.864
I have to wake up at night and cannot sleep well because of nocturia during night time	0.866

When item 11 and 12 were deleted, according to ROC analysis, the AUC for discriminating patients who were on tolvaptan or not decreased from 0.611 to 0.610 and 0.601 respectively. It can be said that the two items contributed to discrimination of patients who were on tolvaptan therapy significantly. In addition, the correlation between the total TDS and VAS scores decreased from 0.589 to 0.579 when items 11 and 12 were removed. Item 11 and 12 evaluates the factors that limit water intake because of disturbed daily routine and quality of life. However, each item evaluates different aspects of water consumption. Specifically, item 11 questions the cause of limiting water intake, whereas item 12 questions the consequence of increased water intake. Because of those reasons, we decided to keep item 11 and 12 in the final version of the questionnaire.

Discussion

We developed a 12-item scale to measure the thirst distress in ADPKD patients by modifying the TDS-HF. To the best of our knowledge, this is the first study to evaluate thirst distress in ADPKD patients. Quantification of thirst is important in ADPKD patients considering the fact that ADPKD patients usually have increased water intake either because of prescribed water intake or thirst-driven water intake due to tolvaptan use. In addition, tolvaptan therapy, which is currently the only approved disease-specific therapy, increases thirst, while daily routine activities of the patients might be a limiting factor for water intake. Because of those reasons, a reliable tool to quantify thirst in these patients will add to the personalized management of ADPKD.

The TDS-PKD was first developed by two medical experts. One of them (NW) was the developer of the TDS-HF questionnaire which formed the basis of the current questionnaire. The other one (SB) was a specialist of nephrology who has been managing ADPKD patients in routine clinical practice. We used the approach proposed by the WHO guidelines to perform the translation of the original form in English. Four external experts (NS, TE, NE, SGO) who performed the Turkish translation approved the validity of the questions. The patients did not have difficulty with answering or interpreting the questions, and the time taken to answer the questions was appropriate. There was no unanswered item. From these findings, we consider that face validity, content validity, and usability of the TDS-PKD have been confirmed.

We used the appropriate statistical approaches to test the statistical characteristics of TDS-PKD. A scree plot and factor analysis showed a three dimensionality for the scale. The first factor was composed of seven items. The items in the first factor had a high level of reliability in measuring thirst. In the second factor, there were three items. It can be said that the items in the factor were reliable in measuring thirst. The third factor consisted of two items; item 11 and 12. The reliability of these items in measuring thirst

was low. Those two items were constructed to assess factors that may limit water intake due to impaired quality of life rather than measuring thirst and discriminating the characteristics of patients who were on tolvaptan therapy.

There was a statistically significant relationship between the total score of the TDS-PKD and the value of thirst intensity, suggesting an adequately concurrent validity ($r = 0.589$, $p < 0.001$) The moderate correlation suggests that thirst intensity and thirst distress are different in nature and that these two concepts should be measured using different tools. Similar results were found in a previous study of Waldréus et al. where they developed the TDS-HF. (6)

The results provide support for the validity and reliability of the instrument. Quantifying thirst in ADPKD patients is important for two main reasons. First, patients' adherence to prescribed water intake is probably related to their thirst. Second, tolvaptan, which is the only approved disease-specific treatment for ADPKD, increases thirst and water intake.

Animal models of polycystic kidney disease show that the ingestion of large amounts of water promotes diuresis by suppressing plasma levels of arginine vasopressin (AVP) and renal levels of cyclic adenosine monophosphate (cAMP), resulting in slowing cyst progression. With voluntarily increased water drinking, plasma osmolality will decrease and therefore AVP secretion will decline, too. (3) However not all clinical studies support this concept; according to a randomized controlled clinical trial by Rangan et al., prescribed water intake compared with ad libitum water intake in people with ADPKD achieved target urine osmolality in half of the patients. Despite this fact, the patients' MRI-measured kidney volumes did not change significantly over three years. Therefore, the authors did not support the routine of prescribed increased water intake for people with ADPKD. (14)

Treatment with tolvaptan, a selective V2R antagonist, today is largely used for the management of patients with ADPKD. The drug therapy differs from prescribed water intake by the level of thirst and AVP. With voluntary increased drinking, plasma osmolality will decline and so will AVP secretion and thirst sensation. On the other hand, selective V2R antagonism will induce a loss of fluid that will stimulate AVP secretion and thirst. When V2R is blocked, AVP's effect on the V1a and V1b receptors increases; this pathway may provide greater benefit than voluntary water intake. (3)

There were some limitations to our study. First, we did not perform the test-retest reliability assessment. There might be information bias due to the nature of the study. Second, our study was conducted with Turkish patients, we do not have the validity study for the English or other language versions. However, previous works show that other TDSs might have language-independent reliability (for instance, Cronbach's alpha for TDS-RF in English is 0.78 and in Turkish is 0.81).(7, 15) Finally, we did not collect data regarding medication use, such as diuretics, which can affect thirst and the severity of thirst, and we did not measure the serum and urine osmolarity. However, all these points might be analyzed in further studies.

In conclusion, we developed and validated a reliable method to quantify thirst in patients with ADPKD. There might be many potential clinical applications of this tool in the daily care of ADPKD patients, including the individualization of tolvaptan treatment and prescribed water intake.

Declarations

Statement of Ethics

The study was approved by the local medical ethics committee (approval no: GOKAEK-2021/12.03) and conducted according to the Declaration of Helsinki. Informed consent was taken from all patients.

Conflict of Interest Statement

None declared

Funding Sources

This research received no specific grant from any funding agency.

Author Contributions

1. Conception or design, or analysis and interpretation of data, or both.

2. Drafting the article or revising it.
3. Providing intellectual content of critical importance to the work described.
4. Final approval of the version to be published.

Seyda Gul Ozcan 1, 2, 3, 4

Sibel Gokcay Bek 1,2, 3, 4

Necmi Eren 1, 4

Zeynep Atlı 1

Abdülmecit Yıldız 4

İsmail Kocyigit 4

Caner Cavdar 4

Nana Waldréus 1, 3, 4

Tevfik Ecder 3, 4

Nurhan Seyahi 1, 2, 3, 4

Data Availability Statement

The data that support the findings of this study are available from the corresponding author, [NS], upon reasonable request.

References

1. Levy M, Feingold J. Estimating prevalence in single-gene kidney diseases progressing to renal failure. Kidney Int. 2000;58(3):925–43.
2. Alekhya B, Varalakshmi B, Lakshmi BS, Manuel MB, Amarendra MR, Naveen K, et al. Water drinking practices in adpkd patients: A questionnaire based study. Indian J Nephrol. 2021;31(6):507.
3. Bankir L, Guerrot D, Bichet DG. Vaptans or voluntary increased hydration to protect the kidney: how do they compare? Nephrology Dialysis Transplantation. 2021.
4. Fitzsimons J, Thirst. Physiol Rev. 1972;52(2):468–561.
5. Waldréus N, Hahn RG, Engvall J, Skoog J, Ewerman L, Lindenberger M. Thirst response to acute hypovolaemia in healthy women and women prone to vasovagal syncope. Physiol Behav. 2013;120:34–9.
6. Waldreus N, Jaarsma T, van der Wal MH, Kato NP. Development and psychometric evaluation of the Thirst Distress Scale for patients with heart failure. Eur J Cardiovasc Nurs. 2018;17(3):226–34.
7. Welch JL, Molzahn AE. Development of the thirst distress scale/commentary and response. Nephrol Nurs J. 2002;29(4):337.
8. Gansevoort Ron T, Mustafa A, Thomas B, Henrik B, Giovambattista C, Adrian C, et al. Van Biesen Wim. Recommendations for the use of tolvaptan in autosomal dominant polycystic kidney disease: a position statement on behalf of the ERA-EDTA Working Groups on Inherited Kidney Disorders and European Renal Best Practice. Nephrol Dialysis Transplantation. 2016;31(3):337–48.
9. Pei Y, Hwang Y-H, Conklin J, Sundsbak JL, Heyer CM, Chan W, et al. Imaging-based diagnosis of autosomal dominant polycystic kidney disease. J Am Soc Nephrol. 2015;26(3):746–53.
10. Imaging classification of ADPKD. A simple model for selecting patients for clinical trials [Available from: https://www.mayo.edu/research/documents/pkd-center-adpkd-classification/doc-20094754.
11. World Health Organization. Process of translation and adaptation of instruments. http://www who int/substance_abuse/research_tools/translation/en/. 2009.

12. Yang L-Y, Yates P, Chin C-C, Kao T-K. Effect of acupressure on thirst in hemodialysis patients. Kidney and Blood Pressure Research. 2010;33(4):260–5.
13. Tabachnick BG, Fidell LS, Ullman JB. Using multivariate statistics: pearson Boston, MA; 2007.
14. Wong AT, Mannix C, Grantham JJ, Allman-Farinelli M, Badve SV, Boudville N, et al. Randomised controlled trial to determine the efficacy and safety of prescribed water intake to prevent kidney failure due to autosomal dominant polycystic kidney disease (PREVENT-ADPKD). BMJ open. 2018;8(1):e018794.
15. Kara B. Validity and reliability of the Turkish version of the thirst distress scale in patients on hemodialysis. Asian Nurs Res. 2013;7(4):212–8.

Figures

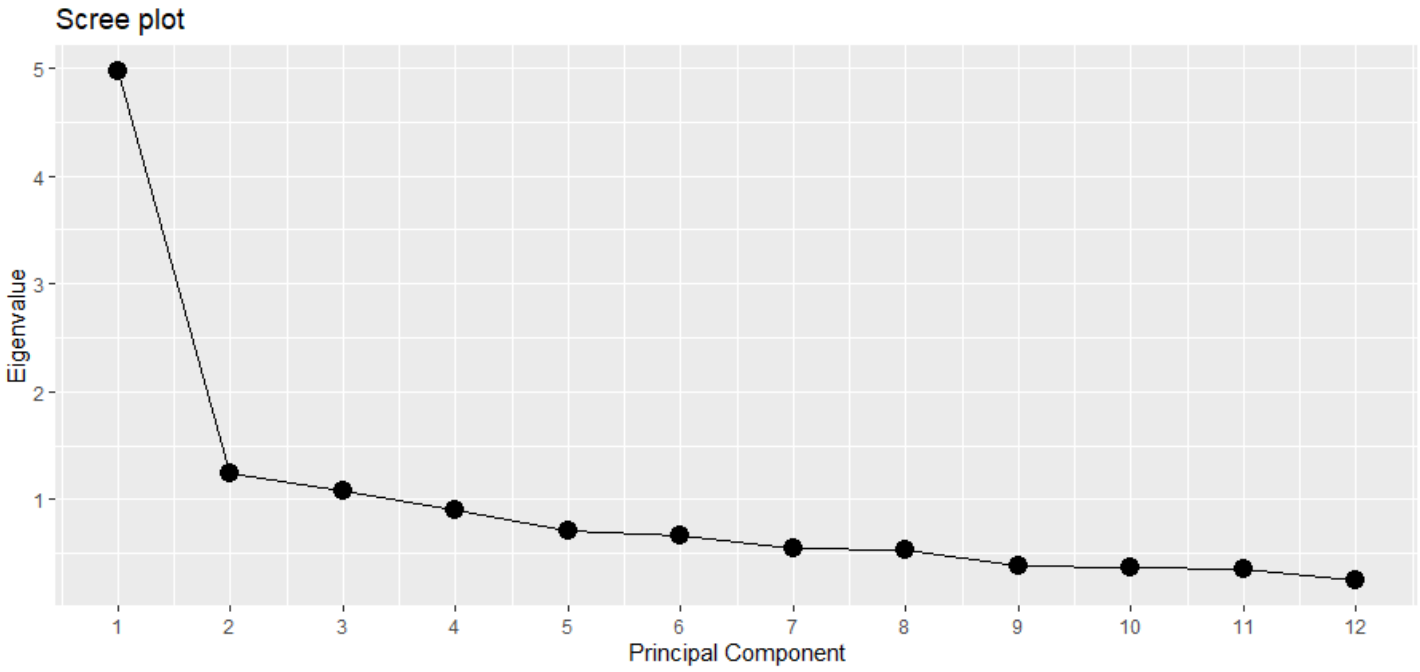

Figure 1

Components with eigenvalues greater than one were selected and the number of factors was determined as three.