Original Article

Arabic Translation, Adaptation, and Validation of The Kidney Disease Quality of Life Short-Form 36

Sarra Elamin¹, Abdelbagi H. E. Elbasher², Shima E. E. Ali³, Hasan Abu-Aisha¹

¹Department of Internal Medicine, University of Khartoum, Khartoum, Sudan ²Doctor Salma Center, University of Khartoum, Khartoum, Sudan ³Sudan Peritoneal Dialysis Program, Khartoum, Sudan

ABSTRACT. The Kidney Disease Quality of Life Short Form 36 (KDQOL-36) is a self-reported measure of health for patients with chronic kidney disease. Our goal was to develop an Arabic version of KDQOL-36 that is linguistically and conceptually equivalent to the original English version. We translated KDQOL-36 into formal Arabic language using forward and backward translation. To assess conceptual equivalence, we administered the Arabic and English versions simultaneously to a group of 10 bilingual patients. To assess test–re-test reliability, we administered the instrument twice to a group of 10 hemodialysis (HD) patients. To assess internal reliability, convergent validity, and discriminate validity, we administered the instrument to 62 HD patients and 82 kidney transplant patients asking them to simultaneously fill the Depression, Anxiety and Stress Scale (DASS-21). The intraclass correlation coefficient (ICC) between the Arabic and English versions indicated excellent conceptual equivalence. The ICC between test and re-test scores revealed good reliability in the burden of kidney disease subscale and excellent reliability in the remaining four subscales. The translated version of KDQOL-36 had a Cronbach’s alpha of 0.81, indicating good internal reliability. We found significant negative correlations between the five subscales of the instrument and DASS-21, indicating good convergent validity. Kidney transplant recipients had significantly better scores than HD patients in the five subscales of the instrument, indicating excellent discriminate validity. The current Arabic version of KDQOL-36 has excellent conceptual equivalence with the original English version. It is a reliable and valid instrument for Arab kidney disease patients.

Introduction

Measuring health-related quality of life (HR-QOL) is an integral part of the clinical evaluation of chronic illnesses. It is also an invaluable tool in determining the impact of different therapeutic interventions. The Kidney Disease Quality of Life Short Form (KDQOL-SF) instrument is a self-reported measure of health that particularly concerns individuals with chronic kidney disease (CKD). The KDQOL-36 is a short version of KDQOL-SF
that includes only 36 questions. The survey can be administered in 3–5 min, which saves both time and resources in large-scale population surveys. Each subscale score ranges between 0 and 100, with increasing values equating to better health.

The first part of the KDQOL-36 (items 1–12) includes the medical outcomes study short form 12 health survey (SF-12) as a generic core. It includes questions about general health, activity limits, ability to accomplish desired tasks, depression and anxiety, energy level, and social activities. These 12 items make up the physical component summary (PCS) and mental component summary (MCS) scales. Some items contribute most to the PCS scale (items 1–5 and 8), whereas other items contribute most to the MCS scale (items 6, 7, and 9–12). The second part (items 13–16) constitutes burden of kidney disease subscale. It includes questions about how much kidney disease interferes with daily life, takes up time, causes frustration, or makes the respondent feel like a burden. The third part (items 17–28) covers symptoms and problem list subscale. It includes questions about how bothered a respondent feels by sore muscles, chest pain, cramps, itchy or dry skin, shortness of breath, faintness, lack of appetite, feeling washed out or drained, numbness in the hands or feet, nausea, or problems with dialysis access. The fourth part (items 29–36) covers the effect of kidney disease subscale. It includes questions about how bothered a respondent feels by fluid limits, dietary restrictions, ability to work around the house or travel, feeling dependent on doctors and other medical staff, stress or worries, sexual life, and personal appearance.

Our goal was to develop an Arabic version of KDQOL-36 that is linguistically and conceptually equivalent to the US English version. We used formal Arabic language in our translation because it is easily understood by the general public of different Arab nations. The translated version was then tested in the field and subjected to rigorous reliability analysis. In this report, we describe the translation steps in detail and present the results of reliability and validity testing.

**Methods**

**Translation steps**

Translation was performed according to the recommendations of the KDQOL working group. The instructions, items, and response choices of the US English version of the KDQOL-36 were independently translated by two bilingual translators who are native Arabic speakers. The translators then compared their translations and reconciled discrepancies. Two different translators independently rated the quality of the reconciled forward translation and rated each response scale for conceptual equivalence to the English version using a 0–100 scale, with 100 indicating exact equivalence; 12 items were given an average score of 100, 20 items were given average scores of 90–99, and three items were given average scores of 80–89 (items 2, 7, and 10).

The Thurstone and Chave method of equal-appearing intervals was employed to test the equivalence of response options. A group of twenty raters were asked to rate the position of intermediate response choices using a 10-cm line anchored by the extreme response choices. This resulted in changes to the response options of items 1–3 and 12. The most important change resulting from this evaluation affected item-1. During evaluation, 63% of raters considered the literal translation of “good” to indicate a better than intermediate response. Accordingly, we adopted a different word for the intermediate response that literally means “acceptable” in English language. Other response options for item-1 were changed in order to accommodate for this adaptation (Table 1).

Finally, the translation was reviewed by two nephrologists, a member of the Arabic Language Academy, and two bilingual CKD patients. The forward translation was then finalized based on their feedback. The final forward translation was back translated into English by two other translators and the reconciled back translation was then compared against the original English version and rated for equivalence on a 0–100 scale, with 100 indicating exact equivalence. All items and
response scales were rated 90–100 except for items 1–3, 6, and 7, which were rated 75%. The literal translation of these items was intentionally adjusted by the review panel during forward translation. A summary of changes and adaptations to the literal translation during the translation process is presented in Table 1.

Validation methods
To calculate scores, individual responses to the 36 items of KDQOL were entered into a Microsoft Excel 97 spreadsheet program that computed the subscale scores of the PCS, MCS, burden of kidney disease, symptom/problem list, and effect of kidney disease. Further analysis was performed using the IBM SPSS Statistics software version 19.0 (IBM Corp., Armonk, NY, USA).

To compare parallel scores during repeat testing, we calculated intraclass correlation coefficient (ICC) assuming a two-way mixed-effects model and using an absolute agreement definition. ICC values of 0.75–1.00 and 0.60–0.74 were considered to indicate excellent and good reliability, respectively.

During field testing, we administered the Arabic version of KDQOL-36 to 144 adult Sudanese CKD patients who were native Arabic speakers, including 62 hemodialysis (HD) patients and 82 kidney transplant recipients, asking them to simultaneously fill the Arabic version of Depression, Anxiety and Stress Scale 21 (DASS-21). To assess internal reliability, we calculated Cronbach’s alpha and ceiling and floor effects for each section of the translated instrument. The ceiling and floor effects were defined by the percentage of respondents who scored at the top and the bottom of a scale, respectively. Cronbach’s alpha values of 0.90–1.00, 0.80–0.89, 0.70–0.79, and 0.60–0.69 were considered to indicate excellent, good, acceptable, and questionable reliability, respectively. Ceiling and floor effects <20% were considered desirable.

To assess convergent validity, we correlated KDQOL-36 scores and DASS-21 scores using Pearson’s correlation coefficient. To assess discriminative validity, we compared the mean scores of HD patients and kidney transplant recipients using Student’s t-test. P <0.05 was considered statistically significant.

### Results
The final version of the Arabic translation is
presented in Appendix 1.

In order to assess conceptual equivalence, we asked a group of ten bilingual CKD patients to simultaneously fill the Arabic and English versions of the instrument and compared the five subscale scores. Conceptual equivalence was confirmed by demonstrating excellent reliability in the five subscales of KDQOL-36 (Table 2).

To assess test–re-test reliability, we asked another group of ten HD patients to fill the Arabic version of the instrument twice, one week apart. When we compared the five subscale scores, we found excellent reliability in the PCS, the MCS, symptoms/problem list, and effect of kidney disease subscales, while the burden of kidney disease subscale had good reliability (Table 3).

During field testing, the instrument had good internal reliability with a Cronbach’s alpha of 0.81. We observed statistically significant inter-item correlation between the five subscales of the instrument (Table 4). Regarding individual subscales, all subscales had acceptable to good reliability.
دراسة
نوعية حياة مرضى الفشل الكلوي

ما هو الغرض من هذه الدراسة؟
تجرى هذه الدراسة بالتعاون بين الأطباء ومريضي الفشل الكلوي لتقييم نوعية حياة المصابين بأمراض الفشل الكلوي.

ما المطلوب مني؟
من أجل هذه الدراسة، نريد أن تكمل خلال هذا اليوم استبياناً حول صحتك وشعورك وencingاتك العامة.

سرية المعلومات
لا تطلب معرفة اسمك. سوف تدلي إجاباتك مع إجابات المشتركين الآخرين عند تقديم نتائج الدراسة. أي معلومة تسمح بالتعرف عليك سوف تعتبر في غاية السرية، بالإضافة إلى ذلك فإن كل المعلومات التي تجمعها مستعملة لهذه الدراسة فقط، وت圬 كشفها أو الإفصاح عنها لآي غرض بدون موافقتك المسبقة.

بماذا نفذي المشارك؟
ستخزن المعلومات التي تقدمها عن شعورك تجاه الرعاية التي تتلقاها وتنمي فهماً لتأثير الرعاية الطبية على صحة المريض. سنتدو هذه المعلومات على تقييم الرعاية المقدمة.

هل ترغب في المشاركة؟
لست متزامناً بملء الاستبيان، لا يمكنك رفض الإجابة على أي سؤال. قرارك بالمشاركة لن يؤثر على فرصتك في الحصول على الرعاية الطبية.

اكتسابك
يعتبر هذا الاستبيان على أسئلة متنوعة عن صحتك وحياتك. لنحن مهتمون بمعرفة شعورك تجاه كل من المواضيع التالية:

1. بصورة عامية، يمكنك أن تقول أن صحتك: (ضع علامة X في المربع الذي يصف إجابتك بشكل أفضل)

|   |   |   |   |
|---|---|---|---|
|   |   |   |   |
|   |   |   |   |
|   |   |   |   |

الفقرات التالية تتعلق بالأنشطة التي يمكن أن تمارسها خلال يوم عادي. هل تمكنك صحتك الآن من ممارسة هذه الأنشطة؟ وإذا كانت تمكنك، فإني أرى Que? (ضع علامة X في مربع واحد من كل سطر).

|   |   |   |
|---|---|---|
|   |   |   |
|   |   |   |
|   |   |   |

2. الأنشطة المعتادة، مثل: تحرير الأنف، ومسح الغبار، والحركة داخل المنزل، إلخ.

|   |   |   |
|---|---|---|
|   |   |   |
|   |   |   |
|   |   |   |

3. الصعود على السلم تملي من الطوابق.

|   |   |   |
|---|---|---|
|   |   |   |
|   |   |   |
|   |   |   |
Continuation of Appendix 1.

 خلال الأسابيع الأربعة الماضية، هل واجهتك أي من المشاكل التالية عند أدائك لعملك أو أنشطتك اليوم؟

1. لا
2. نعم
3. لا
4. نعم
5. كنت مقيدة في نوع العمل أو النشاط الذي توديه
6. لم تتم بعملك أو نشاطاتك اليومية بالجودة المعتادة

خلال الأسابيع الأربعة الماضية، هل واجهتك أي من المشاكل التالية عند أدائك لعملك أو أنشطتك اليومية نتيجة لأي مشكلة نفسية (كالشعور بالاكتئاب أو الخوف)؟

1. لا
2. نعم
3. لا
4. نعم
5. أحسنت ما كنت تربذ
6. لم تتم بعملك أو نشاطاتك اليومية بالجودة المعتادة

خلال الأسابيع الأربعة الماضية، إلى أي مدى أثر الأزمات في أدائك لأعمالك العادية (بما يشمل العمل خارج المنزل والأعمال المنزلية)؟

1. لا
2. نعم
3. لا
4. نعم
5. تأثير كبير
6. تأثير متوسط
7. تأثير ضئيل
8. لا تؤثر

تدور الأسئلة التالية حول شعورك وكيف كانت أحوالك خلال الأسابيع الأربعة الماضية. لكل سؤال، من فضلك أعط الإجابة الأقرب إلى الطريقة التي كنت تشعر بها. كم من الزمن خلال الأسابيع الأربعة الماضية...

9. لم يحدث
10. حدث

خلال الأسابيع الأربعة الماضية. كم من الوقت أدرست صحتك الجسدية أو مشاكلك النفسية على انشطتك الاجتماعية (مثل زيارة الأصدقاء والأقارب...الخ)؟

11. لم يحدث
12. حدث

خلال الأسابيع الأربعة الماضية. كم من الأوقات...

13. لم يحدث
14. حدث

خلال الأسابيع الأربعة الماضية. كم من الأوقات...

15. لم يحدث
16. حدث
مرضاك الكلوي

ما مقدار صحة أو خطا كل من العبارة التالية بالنسبة لك؟

لا أقدر خاطئة
تماماً في الغالب
تماماً

أكثر من الألزام

أدنى الكثير جداً من وقتي

في التعامل مع مرضى الكلوي

يشعرني التعامل مع مرضى الكلوي بالإحباط

أشعر بأنني عيب

على أسرتي

خلال الأسابيع الأربعة الماضية، إلى أي درجة ضاقتك كل مما يلي؟

أصدق حقيقة
أصدق
كمية كبيرة جداً
كمية متوسطة
كمية قليلة

أقل تجربة
أقل

الم في الجلد؟
الم في الصدر؟
تشنج في العضلات؟
حكة في الجلد؟
جفاف في الجلد
مضيق التنفس
الدوار أو الدوخة
وقود النهبة
الارهاب أو القلق
خذ في الأيدي أو الأرجل؟
غراز أو اضطراب في المعدة؟

أخصب مرضى الارضي الاستبخاء الدموي "الفحيل الدموي"

أخصب مرضى الارضي الديليسية اللافتة "الفحيل البرونزي"
internal validity except for the MCS which had a Cronbach’s alpha value of 0.66, indicating questionable internal reliability. There were mild ceiling effects in the burden of kidney disease and effect of kidney disease subscales. This ceiling effect was caused by kidney transplant recipients, 36.6% of whom scored 100% in the burden of kidney disease subscale compared to 4.8% of HD patients and 39% of whom scored 100% in the effect of kidney disease subscale compared to 1.6% of HD patients (Table 5).

When we correlated the five subscales of the Arabic KDQOL-36 instrument to the depression, anxiety, and stress scores of DASS-21, we found a significant negative correlation between the two groups of scores. This confirmed the convergent validity of the Arabic DKQOL-36 instrument (Table 6). When we compared the scores of HD patients and kidney transplant recipients, we found significant differences in the mean scores of the five subscales of KDQOL-36, indicating excellent discriminate validity of the instrument (Table 7).
Table 2. Estimates of intraclass correlation coefficient after simultaneous administration of the Arabic and English versions of kidney Disease Quality of Life Short Form-36 (n=10).

| Domain                  | ICC  | Lower bound | Upper bound | P       |
|-------------------------|------|-------------|-------------|---------|
| PCS                     | 1.00 | 0.97        | 1.00        | ≤0.001  |
| MCS                     | 0.96 | 0.79        | 0.99        | ≤0.001  |
| Symptom/problem list    | 0.99 | 0.95        | 1.00        | ≤0.001  |
| Effect of kidney disease| 0.98 | 0.90        | 1.00        | ≤0.001  |
| Burden of kidney disease| 0.98 | 0.90        | 0.99        | ≤0.001  |

ICC: Intraclass correlation coefficient, PCS: Physical component summary, MCS: Mental component summary.

Table 3. Estimates of intraclass correlation coefficient after test–re-test administration of the Arabic versions of kidney Disease Quality of Life Short Form-36 (n=10).

| Domain                  | ICC  | Lower bound | Upper bound | P       |
|-------------------------|------|-------------|-------------|---------|
| PCS                     | 0.97 | 0.84        | 1.00        | ≤0.001  |
| MCS                     | 0.96 | 0.74        | 0.99        | ≤0.001  |
| Burden of kidney disease| 0.74 | -0.27       | 0.94        | 0.046   |
| Symptom/problem list    | 0.93 | 0.69        | 0.99        | ≤0.001  |
| Effect of kidney disease| 0.98 | 0.92        | 1.00        | ≤0.001  |

ICC: Intraclass correlation coefficient, PCS: Physical component summary, MCS: Mental component summary.

Table 4. Interitem correlation matrix between the five subscales of the Arabic Kidney Disease Quality of Life Short Form-36 (n=144).

| Subscale                  | PCS  | MCS  | Burden of kidney disease | Symptoms of kidney disease | Effect of kidney disease |
|---------------------------|------|------|--------------------------|----------------------------|--------------------------|
| PCS                       | -    | 0.26 | 0.59                     | 0.57                       | 0.61                     |
| MCS                       | 0.26 | -    | 0.43                     | 0.37                       | 0.52                     |
| Burden of kidney disease  | 0.59 | 0.43 | -                        | 0.62                       | 0.71                     |
| Symptom/problem list      | 0.57 | 0.37 | 0.62                     | -                          | 0.62                     |
| Effect of kidney disease  | 0.61 | 0.52 | 0.71                     | 0.62                       | -                        |

P<0.01 for all parameters. PCS: Physical component summary, MCS: Mental component summary.

Table 5. Internal reliability of the five subscales of the Arabic Kidney Disease Quality of Life Short Form-36 (n=144).

| Section                  | Items       | Ceiling (%) | Floor (%) | Cronbach’s Alpha |
|--------------------------|-------------|-------------|-----------|------------------|
| PCS                      | 1–5 and 8   | 0.0         | 0.0       | 0.85             |
| MCS                      | 6, 7, and 9–12 | 0.0          | 0.0       | 0.66             |
| Burden of kidney disease | 13–16       | 22.9        | 2.1       | 0.77             |
| Symptoms/problem list    | 17–28       | 14.6        | 0.0       | 0.86             |
| Effect of kidney disease | 29–36       | 22.9        | 0.7       | 0.83             |

PCS: Physical component summary, MCS: Mental component summary.
Discussion

To the best of our knowledge, this is the first translation of KDQOL-36 into formal Arabic language that underwent adequate reliability and validity testing. Some authors translated and used the KDQOL instruments into Arabic language without describing any validation procedure. Other authors performed reliability analysis to confirm the internal reliability of their translated instrument, but did not perform appropriate tests for conceptual equivalence and convergent or discriminate validity.

During the translation and adaptation process, we deviated from the literal translation of certain response options. However, we were able to confirm conceptual equivalence between the translated and original versions of KDQOL-36 by simultaneous administration to a group of bilingual CKD patients. The ICC was above 0.95 in all the subscales of KDQOL-36.

During repeat administration of the instrument, the burden of kidney disease subscale had acceptable test–re-test reliability, while the remaining four sections had excellent reproducibility. This difference may reflect the great variability of disease burden over short periods of time. During field testing, the instrument had good internal reliability with a Cronbach’s alpha of 0.81 and significant inter-item correlation between the five subscales of the instrument. The correlation coefficient was high between the PCS, burden of kidney disease, symptoms of kidney disease, and effect of kidney disease subscales. MCS had a relatively weak, albeit significant, correlation with the other subscales. The MCS subscale also had the lowest Cronbach’s alpha value among other subscales. This may be due to the cultural background of the participants who often consider it inappropriate to display “impatience” or “intolerance” to illness.

To further confirm the validity of the instrument, we compared KDQOL-36 scores with the depression, anxiety, and stress scores of the Arabic version of DASS-21 and found statistically significant negative correlation. According to the recommendations of the KDQOL working group, we compared HD patients with kidney transplant recipients to...
test the instrument’s ability to discriminate between the two groups. Kidney transplant recipients achieved significantly better scores in all the subscales. The difference between the two groups was half the standard deviation in MCS and approximately one standard deviation in the remaining four subscales.

In this translation, we have intentionally used formal rather than colloquial Arabic words. Although the translation was validated in a group of Sudanese patients, we believe that it is equally applicable to patients from other Arab countries. In addition, the first 12 items of KDQOL-36 represent the SF-12 instrument for generic health surveys. It can be used in isolation to measure HR-QOL that is not related to a particular disease.

**Conclusion**

The current Arabic translation of the KDQOL-36 instruments has excellent conceptual equivalence with the original U.S. English version. It has good internal reliability and reproducibility. It also showed good convergent validity with DASS-21 and excellent discriminate validity between HD and kidney transplant patients.

**Conflict of interest:** None declared.

**References**

1. Hays RD, Kallich JD, Mapes DL, Coons SJ, Carter WB. Development of the kidney disease quality of life (KDQOL) instrument. Qual Life Res 1994;3:329-38.
2. RAND Corporation. RAND Health. Kidney Disease Quality of Life Instrument (KDQOL). RAND Corporation; 2018. Available from: https://www.rand.org/health/surveys_tools/kdqol.html.
3. Ware J Jr., Kosinski M, Keller SD. A 12-item short-form health survey: Construction of scales and preliminary tests of reliability and validity. Med Care 1996;34:220-33.
4. Moussa MT, Lovibond PF, Laube R. Psychometric Properties of an Arabic Version of the Depression Anxiety Stress Scales (DASS21). Report for New South Wales Trans-cultural Mental Health Centre. Sydney: Cumberland Hospital; 2001. Available from: http://www2.psy.unsw.edu.au/dass/Arabic%20DASS-21.pdf.
5. Bayoumi M, Al Harbi A, Al Suwaida A, Al Ghonaim M, Al Wakeel J, Mishkiry A. Predictors of quality of life in hemodialysis patients. Saudi J Kidney Dis Transpl 2013;24:254-9.
6. Kamal NN, Kamel EG, Eldessouki KH, Ahmed MG. Health-related quality of life among hemodialysis patients at El-Minia university hospital, Egypt. J Public Health 2013;21:193-200.
7. AL-Jumaih A, Al-Onazi K, Binsalih S, Hejaili F, Al-Sayyari A. A study of quality of life and its determinants among hemodialysis patients using the KDQOL-SF instrument in one center in Saudi Arabia. Arab J Nephrol Transplant 2011;4:125-30.
8. Bouidida B, Rhou H, Ezaitouni F, et al. Translation, cultural adaptation and validation of the kidney disease quality of life-short form 1.3 in an African country. Transplant Proc 2014;46:1295-301.
9. Abd ElHafeez S, Sallam SA, Gad ZM, et al. Cultural adaptation and validation of the “kidney disease and quality of life-short form (KDQOL-SF™) version 1.3” questionnaire in Egypt. BMC Nephrol 2012;13:170.

Date of manuscript receipt: 8 August 2018.
Date of final acceptance: 16 September 2018