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## ORIGINAL ARTICLE

## Cultural adaptation and validation of the Kidney Disease Quality of Life-Short Form (KDQOL-SF<sup>™</sup>) version 1.3 questionnaire in Uganda

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#### ABSTRACT

**Background:** Chronic kidney disease is on the rise in sub-Saharan African countries such as Uganda, and patients often present with advanced disease requiring kidney replacement therapies. Health-related quality of life is a key outcome in chronic kidney disease management but, in Uganda, no tools have been validated to measure this. The aim of this study was to culturally adapt and validate the Kidney Disease Quality of Life-Short Form version 1.3 (KDQOL-SF<sup>™</sup>) questionnaire for use in the Ugandan setting.

**Methods:** We conducted a four-phase, mixed-methods study which included translation, cultural adaptation, optimisation of face validity and field testing. Our participants included healthcare workers, and patients aged >18 years with an estimated glomerular filtration rate <15 mL/min/1.73 m<sup>2</sup>.

**Results:** The tool was culturally adapted and translated into one of the Ugandan languages, Luganda, which, with an English version of the tool, was validated and field tested. Over 80% of the subdomains had less than 10% floor and ceiling effects. For reliability, Cronbach's **a** coefficient scores ranged from 0.96 to 0.41, with 10 out of 18 subdomains scoring >0.70, indicating acceptable internal consistency. The tool demonstrated discriminant validity, with patients with comorbidities reporting lower quality of life scores, as postulated.

**Conclusions:** The Luganda and English versions of the KDQOL-SF questionnaire have sufficient face and content validity, reliability and acceptability to assess the quality of life of patients with kidney failure in Uganda.

Keywords: quality of life; kidney failure; dialysis; developing countries; KDQOL-SF; Uganda.

#### INTRODUCTION

Non-communicable diseases are on the rise globally and in 2016 contributed to 40 million (71%) of the 56 million deaths reported [1]. Uganda, like most countries in sub-Saharan Africa, faces a dual burden of communicable and non-communicable disease, with 33% of the annual mortality in the country in 2016 attributable to non-communicable diseases, including kidney disease [2]. Chronic kidney disease (CKD) plays a major role as a cause and a consequence of other communicable and non-communicable diseases [3,4]. The true burden of CKD is not well documented in low and middle-income countries (LMICs), although estimates suggest these countries contribute close to 70% of the global burden of 700 million people living with CKD [5,6].

In LMICs, patients often present with advanced CKD requiring kidney replacement therapies, including haemodialysis and kidney transplantation [7,8]. Unfortunately, the costs of these therapies are too high for the majority of patients, necessitating the implementation of palliative care [4,9]. This includes symptom alleviation and providing spiritual, social and psychological support. The focus is on improving the quality of life (QOL) of patients and their families, rather than prolonging life [10,11].



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The World Health Organisation defines QOL as the "individual's perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns". QOL is an important indicator of successful chronic disease care, and many tools have been developed to assess it. The Kidney Disease Quality of Life-Short Form version 1.3 (KDQOL-SF<sup>™</sup>) instrument is one of the most frequently used tools to assess QOL in patients with kidney disease (see Table 1). It scores patients in three domains: physical health, mental health, and kidney disease-specific domains. Patients with lower scores are identified as having a poorer quality of life than patients with higher scores.

This tool, and all others, are not culturally adapted or validated for use in the Ugandan setting. Culturally adapting interventions is one of the keys to successful implementation [12] and has been defined as "the systematic modification of an evidence-based treatment (or intervention protocol) to consider language, cultural, and context in such a way that it is compatible with the user's cultural patterns, meaning, and values" [13]. User's attitudes towards a tool, and therefore the likely utility of the tool, can be improved by incorporating cultural elements, including spiritual beliefs, social norms and routine activities of life in society [14].

Because the validity and cultural appropriateness of the KDQOL-SF are uncertain for use in Uganda, the purpose of the study reported here was to culturally adapt and test the instrument for use in Ugandan patients with end-stage kidney disease.

#### **METHODS**

We conducted a mixed-methods study to culturally adapt, translate into Luganda and evaluate the psychometric properties of the Ugandan version of the KDQOL-SF. The study was carried out in four phases, detailed in Table 2. It involved translation, evaluation and improvement of face and content validity, cultural adaptation and field testing with psychometric evaluation.

The KDQOL-SF version 1.3 is a publicly available tool which combines the generic SF 36 instrument with kidney disease-specific items. The questionnaire consists of 80 items divided into 19 subdomains (Table 1). Items are scored on a 0–100 point scale, with higher scores indicating better health-related quality of life (HRQOL), and summarised into a physical composite summary (PCS) score, mental composite summary (MCS) score and a kidney disease composite summary score (KDCS) [15,16]. A final item, the overall health rating item, asks respondents to rate their health on a 0–10 scale.

#### **Phase I: Translation**

The translation was conducted at the Makerere-Mulago Palliative Care Unit and Makerere University in accordance with the guidelines provided by Rand Health. The tool was translated into Luganda, the most-spoken language in central Uganda. This was done by three bilingual native Luganda speakers, working together. Back translation into English was then performed by a professional Luganda language specialist. Two of the original native speakers reviewed and adjusted the tool based on the translated and back-translated versions. Revisions were made until the Luganda language specialist and the original native speakers

Short form 36 (SF 36)		
tal health components		
tions caused by emotiona		
(3 items)		
tion (2 items)		
well-being (5 items)		
tigue (4 items)		



Phase	Year	Design/method	Participants	Process	Evidence for reliability and validity
Ι	2017	Tool translation	Three bilingual native Luganda speakers and one bilingual linguist	Forward and backward translation	Arrival at a consensus by all parties
ll	2018	Focus group discussion	Healthcare workers (n = 9)	Discussants' words and phrases used to reword items and assess applicability	Input from experts to optimise face and content validity
111	2018	Cognitive interviews	Patients with end-stage kidney disease (n = 5)	All items reviewed, with rewording and reformatting for clarity, as required	Consensus reached on acceptability of instructions, items and response choices
IV	2019	Field testing with descriptive and correlational analysis	N = 363	Evidence accumulated for construct validity	Correlations of item scores with the general health score, analysis of floor and ceiling effects, and calculation of Cronbach's <b>a</b> coefficient

were all in agreement that the wordings were appropriate to the regional vernacular and linguistically and conceptually equivalent to the English version. See Appendix 1 for the Luganda version of the tool.

# Phase II: Focus group discussion with healthcare providers

The focus group discussion was held in the haemodialysis unit at Kiruddu National Referral Hospital and involved nine healthcare workers and two interviewers. It aimed to determine face and content validity and the practicability of employing the tool, the utility of the results obtained and the integrability of the tool into daily work routines. Participants were given copies of the questionnaire and, during the discussion, both the English and Luganda versions were read aloud. Participants were asked about clarity of the questions, relevance of the content to daily patient care, comprehensibility, feasibility for integration within routine care and the practicability of using the questionnaire. The focus group discussion was audio recorded and later transcribed verbatim by a bilingual native Luganda speaker, who then translated the Luganda sections into English. The first author (PB) took field notes while a bilingual research assistant with extensive experience in qualitative interviews moderated the discussion. Participants' responses and reactions were noted. The lead author read and re-read the transcript to familiarise herself with the data to determine thematic areas of interest, face and content validity, comprehensibility, feasibility of integration into routine care and practicality of use. These were then reviewed by the study team and some changes were made to improve the content relevance. Recommendations for integration into routine care were documented as well.

# Phase III: Cognitive interviews with individual patients

Interviews took place in the outpatient clinic, the inpatient ward and the haemodialysis unit, and aimed to determine the acceptability, comprehension, comprehensiveness and interpretability of the tool, as described earlier. The first author (PB) and a palliative care nurse with extensive experience of qualitative research methods interviewed five participants aged >18 years who had stage 5 CKD (estimated glomerular filtration rate <15 mL/min/1.73 m<sup>2</sup>). Questionnaire items were read out to the participants, and answers and reactions recorded. Participants were asked what the items meant to them and whether they were clear or unclear; they were also asked about relevance of the items. Recordings of the interviews were transcribed and translated as in phase II. We used thematic analysis to summarise the concerns regarding acceptability, comprehension, comprehensiveness and meaning.

# Phase IV: Field testing the modified questionnaire

The participants for this phase were again adult patients with stage 5 CKD. Consecutive non-probability sampling was used to recruit participants, using a 1:2 ratio of patients on haemodialysis (HD) treatment relative to patients not receiving HD. This was because of the low HD patient numbers. We followed the sample size recommendations of Mundfrom et al. [17], who have suggested a minimum number of participants of 3–20 times the number of variables, with absolute numbers ranging from 100 to over 1,000 participants. Participants were recruited by two trained research assistants, who understood the need to develop rapport and establish trust with participants, to avoid influencing their responses and to accurately interpret the meanings expressed by participants. The questionnaire

was administered by the two research assistants as our experience in a pilot study had revealed that self-administration of the questionnaire by patients resulted in poor data quality.

The analyses used baseline data which were previously collected [18]. Demographic data were summarised using medians and interquartile ranges or counts and proportions, where appropriate.

**Floor and ceiling effects:** ceiling effects were taken as being the percentage of respondents with scores of 100 and floor effects were the percentage having a score of 0. Ceiling and floor effects should be less than 20% to ensure that the scale captures the full range of potential responses within the study population, and that change over time can be detected [19].

**Reliability:** we assessed the internal consistency of reliability using Cronbach's  $\alpha$  coefficient. A value of 0.70 and above was adopted as the criterion of adequate internal consistency reliability [20].

Validity: Besides face and content validity, we also assessed discriminant validity. We postulated that people who had greater morbidity and older subjects would have lower QOL scores. We thus examined QOL scores for patients with hypertension, diabetes mellitus and also based on treatment modality. In addition, we explored variation in QOL scores based on education level and work status. The QOL scores were compared using correlation analysis.

Pearson's correlation was applied to the normally distributed variables and Spearman's rho when criteria of normality were violated. The tests were two-tailed and a P value of <0.05 was considered to indicate statistical significance. Data were analysed using Stata version 12.0 (StataCorp LLC, Texas, USA).

Ethical approval for this study was provided by the Makerere University School of Medicine Research and Ethics Committee (#Rec Ref 2018-005) and the Mulago Hospital Research and Ethics Review Committee (MHREC 1543). The Uganda National Council for Science and Technology also reviewed and approved the study (HS 2573). All participants provided informed consent and were fully aware of their right to withdraw from the study at any time.

#### RESULTS

The numbers and characteristics of the participants involved in the various study phases are summarised in Table 3.

#### Phases I, II and III

During the process of forward and back translation (phase I) as well as the item-by-item review (phases II and III), we identified items for modification whereas those found to be comprehensible and consistently interpreted by participants were left unchanged. English words, phrases and activities which are not common in Uganda, such as somewhat, groceries, flight of stairs and vacuum cleaning, were replaced with more frequently used words and activities such as slight, items bought from the market, climbing ten steps and mopping (Table 4). Modifications were made based on suggestions by the participants and the research team members.

The focus group discussion lasted 168 minutes, whereas the cognitive interviews variously lasted from 42 to 87 minutes. Regarding feasibility and practicability of employing the tool, participants found it to be feasible but identified its length as a limitation. Both health workers and patients identified the questions and results as useful and felt that it was justified to integrate the tool into daily work routines.

Phase	I	П	III	IV
Sample size	4	9	5	364
Female (%)	3 (75)	5 (56)	2 (40)	137 (40)
Median age in years (IQR)	48 (36–51)	29 (24–40)	42 (30–52)	46 (35–58)
Age group (%) 18–50 years ≥50 years	2 (50) 2 (50)	8 (89)   (  )	4 (80) I (20)	223 (62) 137 (38)
Marital status: married (%)	4 (100)	6 (67)	2 (40)	218 (62)
Education level (%) Secondary or less Post-secondary	0 (0) 4 (100)	(  ) 8 (89)	4 (80)   (20)	281 (77) 83 (23)
Employed (%)	4 (100)	9 (100)	I (20)	335 (92)
Bilingual (%)	4 (100)	7 (78)	4 (80)	



ltem no.	Previous item/option	Modified item/option
QI	Poor	Not good
Q2	Much better now than one year ago Somewhat better now than one year ago About the same as one year ago Somewhat worse now than one year ago Much worse now than one year ago	Big difference compared to the previous year Slight difference in the way I feel Still in the same condition Situation has deteriorated I feel much worse
Q3	<ul> <li>a: Vigorous activities such as running, lifting heavy objects, participating in strenuous sports</li> <li>b: Moderate tasks, for example, moving a table, pushing a vacuum cleaner, bowling or playing golf</li> <li>c: Lifting or carrying groceries</li> <li>d: Climbing several flights of stairs</li> <li>e: Climbing one flight of stairs</li> <li>f: Bending, kneeling, or stooping</li> <li>h: Walking several blocks</li> <li>i: Walking one block</li> </ul>	<ul> <li>a: Vigorous activities such as running, lifting heavy objects, participating in tiring games</li> <li>b: Moderate tasks, for example, moving a table, sweeping or mopping the house or sweeping the compound</li> <li>c: Carrying domestic items you have bought</li> <li>d: Climbing over thirty steps</li> <li>e: Climbing ten steps</li> <li>f: Bending, kneeling or squatting</li> <li>h: Walking around the village</li> <li>i: Walking to visit a neighbour</li> </ul>
Q9	<ul> <li>a: Did you feel full of pep?</li> <li>b: Have you been a very nervous person?</li> <li>c: Have you felt so down in the dumps that nothing could cheer you up?</li> <li>g: Have you felt downhearted and blue?</li> </ul>	a:You felt you were full of energy b:You have been feeling worried and afraid c:You have been feeling low with nothing to give you happiness g:You have had a miserable and heavy heart
Q12	a: My kidney disease interferes too much with my life b: Too much of my time is spent dealing with my kidney disease d: I feel like a burden to my family	a: My kidney disease affects my life so much b: I spend much of my time treating this disease d: I feel I am a burden to my family
Q13	a: Did you isolate yourself from the people around you? b: Did you react slowly to things that were said or done? c: Did you act irritable towards those around you? d: Did you have difficulty concentrating or thinking?	a: You distanced yourself from the people you live with b: You reacted slowly or took your time to talk and act c: You felt intolerant and impatient with the people you live with d: You would have difficulty thinking or you would get confused
Q14	a: Soreness in your muscles f: Shortness of breath i: Washed out or drained j: Numbness in the hands or feet	a: Muscle pain f: Difficulty breathing i: Feeling tired j: Feeling paralysed in the hands and legs
Q23	Think about the treatment for dialysis that you receive. How satisfied are you with the way the doctors handle you, how they show you love and care for you as an individual?	Think about the medical care that you receive in the hospital. How satisfied are you with the way the doctors handle you, how they show you love and care for you as an individual?
Q24	a: Dialysis staff encourage me to be as independent as possible b: Dialysis staff support me in coping with my kidney disease	a: Hospital staff would like to see me becoming independent or self-reliant b: Hospital staff help me to cope with this kidney disease

Both groups identified the question items as acceptable but queried the comprehension and meaning of some items.

Selected quotes from the interviews are presented below. FGD indicates comments from the focus group interview and ICI indicates comments from the individual cognitive interviews.



"They are too many (questions) because remember it's voluntary, if the other one here is interviewing the other one for that long the other would say "aaaaa" (patient might be discouraged from participating) ...but if you reduce too much it's also not good, you rather ask for time from the patient." FGD P8

"Yes, patients complain about sleep ..., they do, getting enough sleep, the day they come for dialysis, they don't sleep at all. It's a big problem, ... true, the men don't have sex." FGD P1

Comments were noted about activities and wording not commonly used in everyday Ugandan English.

"As part of the activity, not this one (vacuuming), this is more pointing to the luxurious things than the occupational work we see here." FGD P5

"Then I wondered how you can say I feel 'perturbed', it's a bit complex. How is this word 'perturbed' in Luganda, how would you say 'perturbed'?" FGD P7

Participants gave and discussed suggestions of wording and activities which would be more acceptable and easy for the Ugandan population to relate with.

"moderate tasks, for example, moving a table, pushing things, ... pushing a vacuum cleaner, for us we do the mopping with the mopping stick and maybe cleaning the compound, things like that." FGD P1

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In the individual cognitive interviews, participants noted that the questions were relevant and helped them talk about their illness in more detail than they had ever done before.

"... it also gives us an opportunity to talk about things that we have been wanting to talk about, like sexual issues." ICI P2

They also commended the flow of questions, especially for topics they considered sensitive.

"Others are shy but even it depends on when you bring in these questions, especially that one (question on sexual health), if it is coming in for the very first time, they may find it hard to answer, but here it is okay." ICI P5

Some appreciated the duration of the interview and viewed it as an opportunity to get their questions answered.

"... for us in dialysis, you have the four hours so it's not too much, unless someone wants to be sleeping, but there is time." ICI P3

Following these suggestions, culturally relevant adaptations were made to the tool, as shown in Table 4.

#### Phase IV (Table 6)

There were 364 participants recruited for field testing the questionnaire, an adequate sample size according to the recommendations of Mundfrom et al. [17]. There were approximately 4.5 respondents per item, and more than 19 per domain. Most respondents were male (60%), married (62%), aged less than 50 years (62%) and had some form of employment (92%). The highest response rate was noted for the emotional well-being subdomain (363/364) and the lowest rates were for the staff encouragement (135/364) and patient satisfaction (148/364) subdomains. Most subdomains (16/19) had a response rate of over 90%.

The highest mean QOL score was noted for staff encouragement (97) and the lowest for burden of kidney disease (24).

Regarding the distribution of responses to each subdomain, physical functioning (33%), work status (24%) and burden of kidney disease (15%) had the highest proportion of floor effects with the other subdomains having less than 10% floor effects. Social support (44%), patient satisfaction (28%) and pain (26%) had the highest proportion of ceiling effects with the other subdomains having less than 10% ceiling effects. See Table 5.

	No. of items	No. of observations	Mean QOL score	Standard deviation	% Floor	% Ceiling	Internal consistency reliability
Symptom burden	12	358	70.7	14.5	0.0	1.7	0.81
Effects of kidney disease	8	359	52.9	19.5	0.0	1.4	0.88
Burden of kidney disease	4	356	24.3	7.	15.2	2.2	0.70
Work status	2	343	41.7	26.4	23.6	7.0	0.64
Cognitive function	3	357	68.5	19.3	0.3	6.7	0.64
Quality of social interaction	3	358	62.2	14.3	0.3	2.8	0.60
Sleep	4	354	55.3	17.5	0.9	0.3	0.58
Social support	2	351	78.4	25.7	3.1	43.9	0.74
Dialysis staff encouragement	2	135	97.4	4.	1.5	0.0	0.50
Patient satisfaction	I	148	58.2	31.9	5.4	27.7	NA
Physical functioning	10	359	25.3	25.8	32.9	2.2	0.93
Role physical	4	356	4.0	18.6	0	3.2	0.96
Pain	2	356	68.8	27.3	0.6	26.1	0.88
General health	5	358	39.6	13.6	0	1.7	0.59
Emotional well-being	5	363	39.3	12	0.6	0.3	0.41
Role emotional	3	356	4.0	18.7	0	3.2	0.95
Social functioning	2	346	48.0	9.6	0.2	0	0.90
Energy/fatigue	4	358	48.6	3.	0.6	1.7	0.5
Physical health	4	355	34.5	13.7			0.56
Mental health	4	344	34.7	6.5			0.52
Kidney disease health	10	134	58.4	10.8			0.65



	PCS	MCS	KDCS	Overall
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
ex				
Eemale	34.8 (8.7)	46.7 (5.2)	55.1 (6.3)	45.9 (5.8)
Male	36.7 (9.3)	47.5 (4.7)	55.5 (6.3)	46.7 (5.6)
<sup>o</sup> value	0.328	0.480	0.705	0.535
ge				
<50	37.0 (9.3)	47.4 (4.7)	55.9 (6.2)	46.9 (5.6)
≥50	34.0 (8.5)	46.7 (5.3)	54.5 (6.4)	45.5 (5.9)
<sup>o</sup> value	0.132	0.515	0.268	0.261
arital status				
lot married	36.0 (9.8)	47.6 (4.9)	54.8 (6.8)	46.5 (6.2)
farried	35.8 (8.5)	46.8 (4.9)	55.8 (5.9)	46.3 (5.3)
value	0.931	0.407	0.419	0.863
	0.701	0.107	0.117	0.005
lucational level	2(2,02)			
None/primary	36.2 (8.2)	46.7 (4.9)	55.7 (6.7)	46.7 (5.4)
econdary +	35.7 (9.6)	47.4 (4.9)	55.2 (6.1)	46.2 (5.9)
' value	0.798	0.497	0.683	0.694
mily size				
≤5	36.5 (9.0)	46.4 (5.4)	55.3 (5.7)	45.9 (5.6)
>5	35.0 (8.2)	47.6 (4.3)	55.3 (6.5)	46.5 (5.2)
° value	0.446	0.265	0.985	0.658
eligion				
hristian	35.8 (9.1)	47.6 (4.8)	55.4 (6.5)	46.5 (5.6)
Jon-Christian	36.8 (8.8)	45.3 (5.1)	55.0 (5.9)	46.0 (6.3)
value	0.842	0.085	0.759	0.758
ccupation				
mployed	35.8 (12.1)	46.9 (5.7)	52.8 (6.6)	45.8 (7.6)
Inemployed	35.9 (8.9)	47.2 (4.9)	55.6 (6.3)	46.4 (5.6)
value	0.969	0.901	0.218	0.813
	017 07		01210	01010
ain source of income Donations/others	262 (00)	47.9 (4.4)	55 5 (6 4)	470 (55)
	36.2 (8.9)	47.8 (4.4)	55.5 (6.4)	47.0 (5.5)
)wn job	35.5 (9.4)	46.1 (5.5)	55.0 (6.3)	45.5 (6.0)
value	0.697	0.118	0.697	0.255
ead winner				
es	37.1 (10.2)	48.3 (4.4)	56.1 (6.3)	47.3 (6.4)
10	35.5 (8.6)	46.7 (5.0)	55.0 (6.3)	46.0 (5.4)
value	0.447	0.163	0.374	0.348
pertension				
es	36.3 (9.3)	47.4 (5.1)	55.5 (6.3)	46.7 (5.8)
10	34.5 (7.8)	46.2 (3.9)	54.6 (6.5)	45.4 (5.1)
value	0.482	0.369	0.520	0.417
iabetes mellitus				
és	31.9 (6.5)	45.6 (4.3)	52.8 (5.2)	43.6 (4.6)
No	37.3 (9.4)	47.7 (5.0)	56.3 (6.5)	47.4 (5.8)
value	0.013*	0.074	0.008*	0.007*
evious stroke				
lo	36.4 (8.9)	47.3 (4.7)	55.5 (6.3)	46.7 (5.5)
és	26.3 (5.5)	44.0 (8.3)	51.8 (6.2)	40.7 (6.8)
' value	0.029*	0.192	0.159	0.039*
eatment modalities				
Conservative	36.3 (9.1)	47.5 (4.9)	51.1 (6.2)	41.9 (6.1)
Haemodialysis	35.2 (8.9)	46.6 (4.8)	52.5 (2.6)	40.9 (5.9)
value	0.287	0.196	0.891	0.221

Abbreviations: KDCS, kidney disease composite summary; PCS, physical composite summary; MCS, mental composite summary.

\*Statistically significant variables (P < 0.05).



Cronbach's  $\alpha$  ranged from 0.96 (role limitations due to physical well-being) to 0.41 (emotional well-being). Eight out of the eighteen subdomains scored below 0.70.

The presence of comorbidities, especially stroke and diabetes, was associated with lower QOL scores (Table 6). Having diabetes was associated with the kidney disease

composite score (P = 0.008) and the overall score (P = 0.007), whereas a history of stroke was associated with the physical composite score (P = 0.029) and the overall QOL score (P = 0.039). Of note, we found no difference in QOL scores based on sex, age, treatment modality and socio-economic factors such as educational level and employment.

#### DISCUSSION

The KDQOL-SFTM version 1.3 questionnaire has successfully been adapted culturally and is fit for purpose as well as valid and reliable in Ugandan patients with end-stage kidney disease. Validation of a tool is important if it is being introduced into a different setting [21] and, to the best of our knowledge, this is the first validation study of this tool in East Africa.

We encountered differences in the terms used in daily language. Terms and activities such as playing golf, bowling and walking a block are not common in our setting and were substituted by phrases such as sweeping the compound or walking a mile. Similar substitutions have been made in other cultural settings such as in Brazil [22] and Turkey [23] and this increases comprehension and the usability of the tool.

The KDQOL-SF questionnaire was designed to be selfadministered but, in our setting of a low literacy rate, we found that response rates were better when the questionnaire was administered by a research assistant. This may affect answers provided because some questions are sensitive to the data collection method [24,25]. This could have been the reason for low response rates seen in the staff encouragement and patient satisfaction subdomains. The training of research assistants in this setting is very important to reduce biases such as social desirability bias, interviewer bias and acquiescence bias [25].

The floor and ceiling effects were used to assess the distribution of responses to each item during field testing. This suggested a fair distribution of responses, with most items having less than 10% floor and ceiling effects. Physical functioning (32%) had the highest proportion of floor, followed by work status (24%) and burden of kidney disease (15%); these proportions were lower than has been seen in other settings in Mexico [26], South India [27] and Egypt [28]. On the other hand, social support (43%), patient satisfaction (27%) and pain (26%) had the highest proportion of ceiling effects in our study, similar to several reports from other settings [26-28]. Careful attention to clarification of the meaning of items is important, especially for items which might overlap (and therefore might not be specifically distinguished) such as burden of kidney disease and symptom burden.

Internal consistency reliability scores were below 0.7, the standard required, for eight out of eighteen items, with emotional well-being (0.41) scoring lowest, followed by staff encouragement (0.50) and energy/fatigue (0.51). In an Egyptian study [28], the lowest scores were for quality of social interaction (0.23) and work status (0.28) and in a Danish study, the lowest scores were for quality of social interaction (0.43) and social support (0.67) [29]. These low scores may be due to the varying interpretations of items which might appear similar and the scores of these items therefore need to be interpreted with caution.

Regarding discriminant validity, the scores on our tool could distinguish between subgroups of patients based on their comorbidities but not on age, sex or socioeconomic factors, as has been found in other studies [22,26,28]. Differences in scores among study populations may be due to variations in the composition of their demographics; for example, our patients were relatively young compared to the more elderly participants in other settings. Also, in a public hospital setting such as ours, the socioeconomic status of patients is uniformly low, leading to the possibility that the questionnaire is unable to discriminate different subgroups due to the absence of variation.

Future studies involving the questionnaire could explore why employment and social support did not lead to differences in quality of life, as has been seen in other settings [16]. Moreover, a confirmatory factor analysis could be completed to evaluate whether a shorter version of the scale can be used with the same measurement validity in our setting to reduce the length burden and therefore complete the questionnaire more quickly.

#### CONCLUSIONS

The Ugandan version of the KDQOL-SF version 1.3 is reliable and valid. It may be used in research or in routine clinical care to measure HRQOL and changes in response to interventions.

Users of this tool in resource-limited settings should be aware of poor response rates when self-administered, as well as for items such as staff encouragement and patient satisfaction when the tool is administered by healthcare workers, and the need for care in the administration and interpretation of items which may seem similar.

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#### APPENDIX I: LUGANDA VERSION OF THE KDQOL-SF<sup>™</sup> QUESTIONNAIRE

## **OBULAMU BWO**

# n'embeera

# Y'OBULAMU BWO

## Endwadde Z'ensigo N'Eby'obulamu (KDQOL-SF<sup>™</sup> 1.3)

Okunoonyereza kuno kugenderedwa kumanya endowooza z'abantu ku bulamu bwabwe nga balina obulwadde bwensigo. Ebinaava mu kunoonyereza kuno bijja kutuyamba okugoberera nga bw'owulira ate nga bw'osobola okukola emirimu gyo egya bulijjo mu bulwadde buno.

Weebale nnyo okuddamu ebibuuzo bino.



## Okunoonyoreza ku mbeera z'abantu abalina enddwadde y'ensigo

#### Kiki Ekigendererwa mu kunoonyereza kuno?

Okunoonyereza kuno kukolebwa abasawo abajjanjaba abalwadde bano nga bafunye olukusa okuva eri balwadde bano. Ekigendererwa kwe kumanya embeera z'obulamu bw'omuntu ariina obulwadde bw'ensigo.

#### Kiki kye banansaba okukola?

Mu kunoonyereza kuno bajja kukubuuza ku bulamu bwo, bw'owulila, n'ebikukwatako ebirala

#### Ebinaabuuzibwa binaaba bya nkizo?

Tetujja kubuuza linnya lyo. Bwe tunaaba tuwa alipoota oba mu biwandiiko byona mu kukoononyereza kuno, by'onootugamba tujja kubigatta wamu n'eby'abalala bonna abaneetaba mu kunoonyereza kuno bireme kulaga wa gye biva. Byonna by'onootugamba nga biyinza okumanyisa abalala nti byava mu ggwe tujja kubikuuma nga bya nkizo (kyama). Byonna bye tunajja mu kunoonyereza kuno bijja kukozesebwa mu kunonyereza kuno kwokka. Tetujja kubiwa muntu mulala yenna oba okubikozesa awalala wonna okuggyako nga otuwadde olukusa.

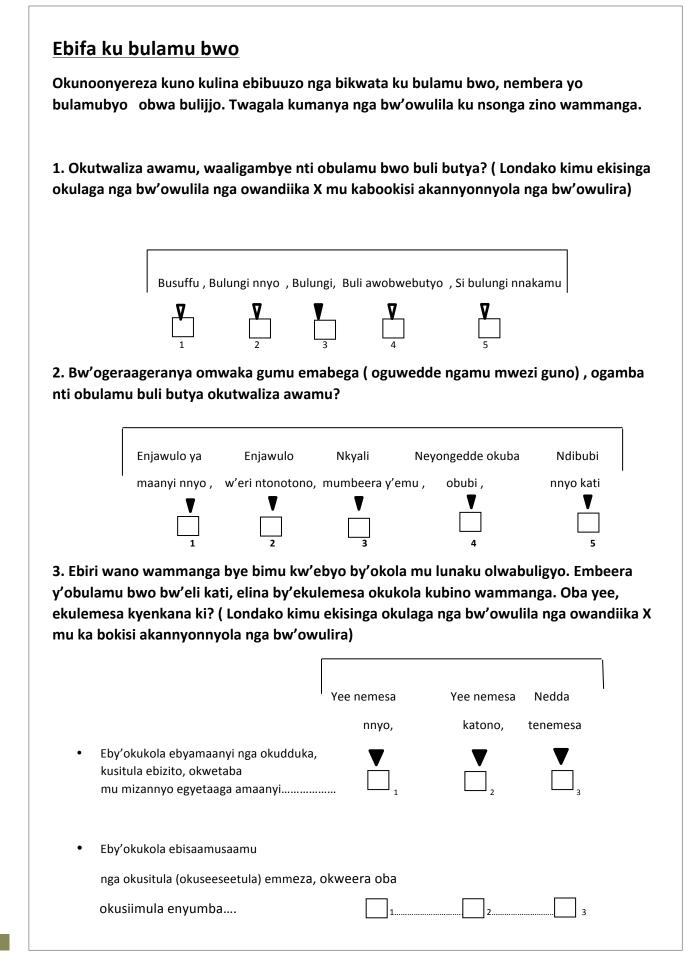
#### Okwetaba mu kunoonyereza kuno, kinangasa ki?

By'onootugamba bijja kutuyamba okumanya nga bw'owulira ku bujjanjabi bw'ofuna ate'ra n'okumanya obujjanjabi buno kye bukyusa ku bulamu bw'abalwadde b'ensigo. Bino bijja kutuyamba okwekebejja obujjanjabi obuweebwa.

#### Kya tteeka nti nnina okwetaba mu kunoonyereza kuno?

Si kya tteeka, okwetaba mukunonyereza kuno kwakyeyagalire, era oyinza obutaddamu bibuuzo ebimu bw'oba oyagala. Ky'onoosalawo oba kwetabamu oba nedda, tekijja kukulemesa kufunna bujjanjabi bw'oyina okufuna.





•	Okusitula by'oguze eby'awaka	1 2 3
•	Okulinnya amadaala nga kkumi	<u>1</u> 2 3
•	Okukutama, okufukamira,	
	oba okusitama	<u>1</u>
•	Okutambula olugendo olususa mayilo	1 2
•	Okutambulako ku kyalo	1 2
•	Okutambulako ng' ogenda okukyalira muliraanwa	<u> </u>
•	Okwenaaza oba okweyambaza	<u>1</u> 2 3

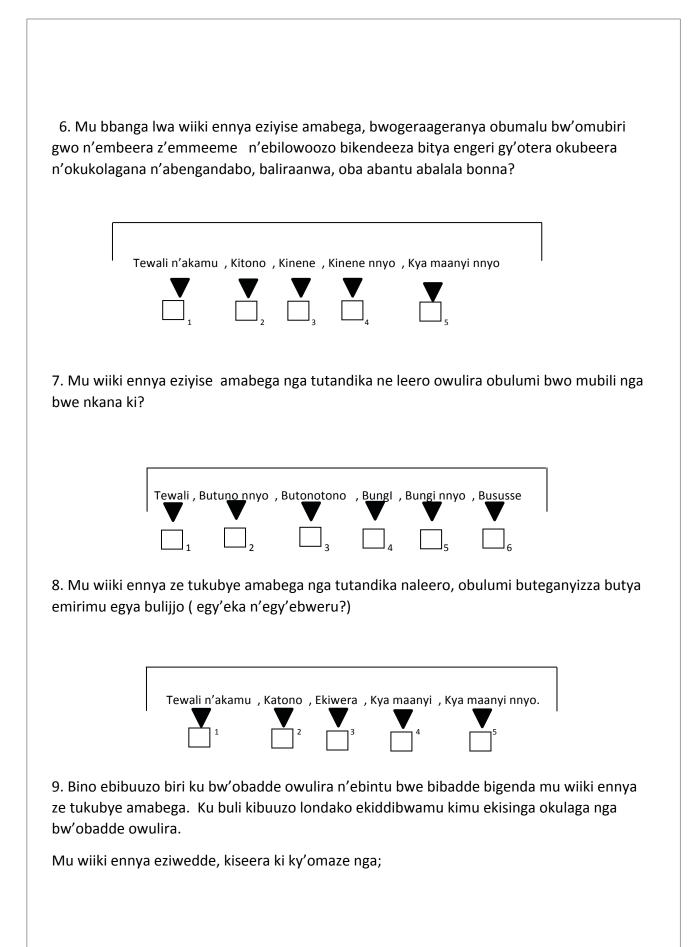
4. Mu wiiki ennya eziyise emabega obadde olina ebizibu byonna, ng'okola emirimu gyo egyeweka, oba egy'okupakasa nga biva ku mbeera y'obulamu bwo?

		Yee Nedda
•	Okusalako kubudde bw'okupakasa oba obw'okukola emirimu egya bulijjo	2 1 2
•	Obutatuukiriza bye waaliyagadde okukola	1 2
•	Walemesebwa okukola emirimu gy'okupakasa oba egy'ewaka?	12
•	Walina obuzibu okukola emirimu gy'okupakasa oba egy'eka?	1 2

5. .Mu wiiki ennya eziyise emabega obadde olina obuzibu buno ngo okola emirimu gyo egy'ekka oba egy'okupakasa nga biva ku kubanga owulira toli musanyufu oba nga owulira ebiriowoozo tebiteredde?

	Yee	Nedda
<ul> <li>Okusalako ku budde bw'okupakasa oba obw'okukola emirimu egya bulijjo?</li> <li>Obutatuukiriza bye waaliyagadde okukola</li> </ul>		2 2
Obutakola emirimu gy'okupakasa	1	2
Oba egy'eka n'obwegendereza nga bulijjo?	1	2





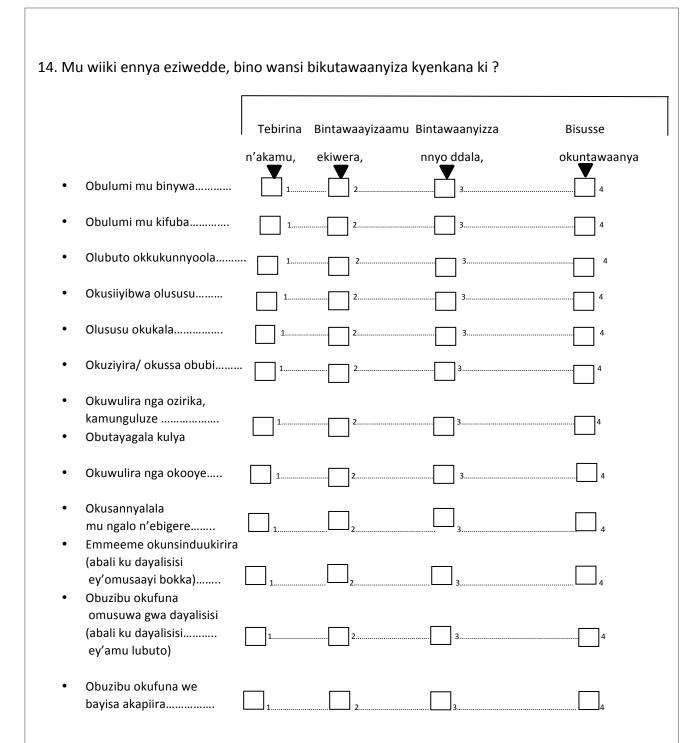
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3	4	
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kiseera kitor	no nnyo , tew	vali n'akamu
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nanyi Kikya	mu Kikyamu	
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	14 1 15	
	ki obuzib nesezza ol kiseera kitor V 4 re	ki obuzibu obuva ku nesezza okukola ebir

N AJN

Olwobulwadde bw'olina obw'ensig 12. Londako kimu okulaga, oba binowansi bituu Obulwadde bwange obw'ensigo buteganya nnyo obulamu bwange buteganya nnyo obulamu bwange	- ufu oba sibitufu okusinziira kuggwe Kituufu Kituufu Simanyi Sikitufu Kikyam nnyo ddala, , nnyo ↓ 1 ↓ 2 ↓ 3 ↓ 4 ↓ 5 ↓ 1 ↓ 2 ↓ 3 ↓ 4 ↓ 5 
<ul> <li>Obulwadde bwange obw'ensigo</li> <li>buteganya nnyo obulamu bwange</li> <li>Ebisera byange ebusinga mbimala nga nzijanjaba bulwadde buno obw'ensigo</li> <li>Mpulira nga binsobedde</li> </ul>	Kituufu       Kituufu       Simanyi       Sikitufu       Kikyam         nnyo $\blacksquare$ , nnyo $\blacksquare$
<ul> <li>Obulwadde bwange obw'ensigo</li> <li>buteganya nnyo obulamu bwange</li> <li>Ebisera byange ebusinga mbimala nga nzijanjaba bulwadde buno obw'ensigo</li> <li>Mpulira nga binsobedde</li> </ul>	Kituufu       Kituufu       Simanyi       Sikitufu       Kikyam         nnyo $\blacksquare$ , nnyo $\blacksquare$
<ul> <li>buteganya nnyo obulamu bwange</li> <li>Ebisera byange ebusinga mbimala nga nzijanjaba bulwadde buno obw'ensigo</li> <li>Mpulira nga binsobedde</li> </ul>	nnyo ddala, , nnyo $2 \dots 2 $
<ul> <li>buteganya nnyo obulamu bwange</li> <li>Ebisera byange ebusinga mbimala nga nzijanjaba bulwadde buno obw'ensigo</li> <li>Mpulira nga binsobedde</li> </ul>	nnyo ddala, , nnyo $2 \dots 2 $
<ul> <li>buteganya nnyo obulamu bwange</li> <li>Ebisera byange ebusinga mbimala nga nzijanjaba bulwadde buno obw'ensigo</li> <li>Mpulira nga binsobedde</li> </ul>	$ \begin{array}{c} & & & \\ & $
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Mpulira nga binsobedde	
<ul> <li>Mpulira nga ndi mugugu eri ab'omumaka gange</li> </ul>	е <u> </u>
<ul><li>13. Ebibuuzo bino ebiddako bibuuza nga bw'ow butambula mu wiiki ennya emabega. Ku buli kib nga bw'obade owulira.</li><li>Mu wiiki ennya eziwedde, ekiseera kyenkana ki</li></ul>	buuzo londako kimu ekisinga okunnyonnyola
tewali kiseer	ra ekiseera ekiseera ekiseera ekiseera ekiseera
kyonna,	kitono, ekimu, eky'ekigero, ekisinga, kyonna
Nga weeyawula ku bantu	
b'obeera nabo	2
<ul> <li>Nga oyogera mpola oba nga ofunye okusooba mu</li> </ul>	
njogera ne mu bikolwa	2 <u></u> 46
<ul> <li>Nga owulira toyina bugumiikiriza n'abantu b'oli nabo oba nga</li> </ul>	
bakunyiiza mangu	2
<ul> <li>Nga ofuna obuzibu mu kulowooza oba nga owunga</li> </ul>	
obadde okolagana bulungi	
<ul> <li>n'abantu bonna</li> <li>Obadde owulira nga</li> </ul>	L2



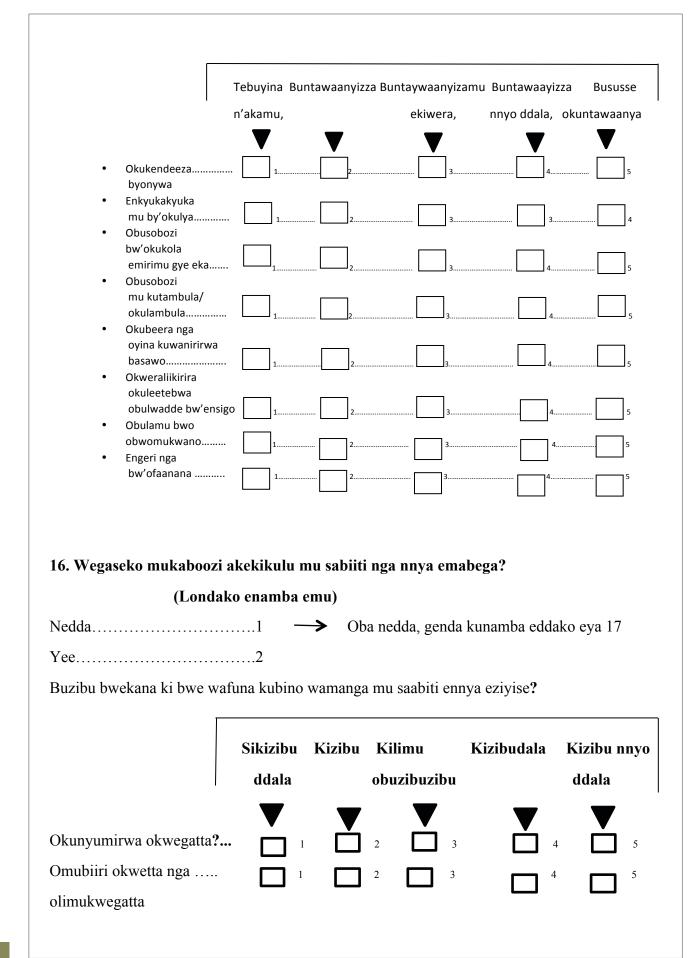
|3|



## Obulwadde bw'ensigo nga bwe bukyusa obulamu bw'omuntu owa bulijjo

15. Abantu abamu batawaanyizibwa olw'enkyukakyuka obulwadde bw'ensigo ze buleeta mu bulamu bw'omuntu, naye abalala tebayina mutawaana. Ggwe buno obulwadde bukutawaanya butya mu bino wansi

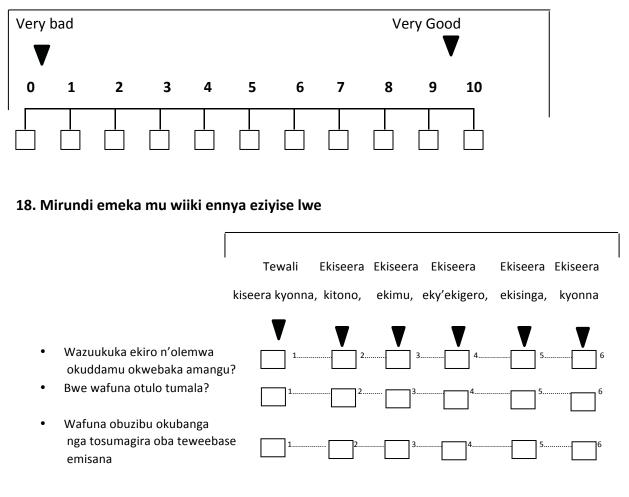




17. Mu bino ebibuuzo ebiddako tubuulire nga bwobadde webaaka, nga opiima ekigero kino ku minzani eva ko zero 0 okuttuka ku number 10. Zero nga etegeeza weebaka bubi nnyo ate nga 10 etegeeza weebaka bulungi nnyo

Bw'oba olowooza nti okwebaka kwo kuli mu makkati ga obubi nnyo ne bulungi nnyo londa akabookisi aka wansi wa 5 olambe mu X . Bw'oba nga okwebaka kwo kusinga ko katono ku namba 5 lamba mu kabookisi akali wansi wa namba mukaaga. Bw'oba olowooza ekwebaka kwo kuli wansi ku namba 5 lamba X mu kabookisi akali wansi wa namba 4.

Singa opima ku minzaani, epima okuva ku zero okutuuka ku 10 , gwe webaka bulungi kyenkana ki ?



#### 19. Ebikwata ku b'engandazo n'abemikwano, owulira nti omatidde kwekanawa, ne



	Siri	Siri	Ndi	Ndi
	mumativu n'akar	nu, mumativ	u mu, mumativu m	iu, mumativu ddala
<ul> <li>Obudde bw'osobola okubeera nabomumaka g ab'enganda, n'emikwano</li> </ul>		<b>V</b>	<b></b>	▼
Obuyambi bw'ofuna okuv	a 1	2		

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