Original paper

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Cross-cultural adaptation and validation of a tool to assess dementia specific quality of life: Evidence from a South Asian population

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Abstract

Background

Dementia is now fast becoming a public health priority worldwide, including in South Asia. But research about the quality of life of patients with dementia in this part of the world is limited.

Aims

The present study was aimed at cross-cultural adaptation and validation of the Sinhala version of the Dementia Specific Quality of Life (DEMQOL) and DEMQOL-Proxy tools among patients with dementia and their caregivers in Sri Lanka.

Methods

The 28-item DEMQOL and 31-item DEMQOL-Proxy tools which were originally developed and validated in the United Kingdom were initially translated, culturally adapted using modified Delphi process with a panel of experts and tested for judgmental validity. Construct validity was assessed by using multi-trait scaling analysis and confirmatory factor analysis (CFA), based on data obtained from 100 dyads of patients with mild-moderate dementia and their primary caregivers attending state hospital psychiatry clinics in the Gampaha district. The structure of the DEMQOL and DEMQOL-Proxy was evaluated based on a variety of fit indices. Reliability was assessed using the test-retest method and internal consistency.

Results

All the items showed good psychometric properties in judgmental validity and item convergent-discriminant validity. In CFA, using robust maximum likelihood method, the original four-factor model emerged with DEMQOL validation data, whereas a five-factor model was best fitted with DEMQOL-Proxy validation data. The reliability of the DEMQOL (Cronbach's alpha=0.87; correlation coefficient =0.864) and DEMQOL-Proxy (Cronbach's alpha= 0.874; correlation coefficient=0.834) was satisfactory.

Conclusions

The Sinhala versions of the DEMQOL and DEMQOL-Proxy scales are valid and reliable in assessing the QOL of dementia patients of mild-moderate severity in Sri Lanka. This tool can be used by healthcare professionals to understand the current level of QOL as well as to give direction towards improvement required.

Key words: quality of life, dementia, validation, cultural adaptation

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Introduction

The goal post in managing patients with long-term degenerative disorders such as dementia is to enable them to lead a respectful and dignified life, with the best quality of life as possible. Therefore, disease specific quality of life (QOL) is increasingly recognized as a key outcome measure in healthcare practice. Dementia is now fast becoming a public health priority worldwide, including in South Asia (1). Given this burden, South Asian countries should be prepared to face this challenge in the future, and as the first step, should have the capacity to quantify the current burden in terms of the QOL of dementia patients. In this regard, disease specific QOL assessments that are valid and reliable are important for planning of service provision and as a quality indicator of care (2).

The Dementia Specific Quality of Life (DEMQOL) and DEMQOL-Proxy have been widely used internationally, as interviewer-administered questionnaires among

patients with dementia (3-7). It was initially developed by Smith et al. in the United Kingdom, using gold standard psychometric techniques (8). The 28-item DEMQOL (applied to patients with dementia) and 31-item DEMQOL-Proxy (applied to their caregivers) encompass both self and proxy reports on the QOL of patients with dementia. Both scales give different but complementary perspectives on the QOL, while demonstrating satisfactory psychometric properties (8).

Even though a plethora of research has been conducted on the QOL among dementia patients across the globe, there is a paucity of literature in the South Asian context, mainly owing to the lack of valid assessment tools (3, 9, 10). Although the DEMQOL and DEMQOL-Proxy have been translated to several languages and validated among different study populations in the world, there has been no scientific validation of these tools in South Asia (8). South Asia has a unique socio-cultural background as well as healthcare structure, which is more geared for provision of health care for women and children, with elderly care is predominantly being provided through family-based informal care (11). Given this backdrop, tools for assessment of dementia specific QOL in South Asian regions, including Sri Lanka, should be culturally relevant and population specific. Hence, the present study was designed to assess the applicability of the used DEMQOL and DEMQOL-Proxy tools among patients with dementia and their caregivers in Sri Lanka.

Methods

This study entailed cross-cultural adaptation of DEMQOL and DEMQOL-Proxy tools for assessment of patients with dementia in Sri Lanka; and an assessment of the validity of tools by employing several validation procedures using the triangulation method, in the absence of a gold standard to assess dementia specific QOL. The reliability of the tools was also assessed.

Cross cultural adaptation of the tools

The DEMQOL and DEMQOL-Proxy comprise of five domains: Daily activities and looking after self, health and well-being, cognitive functioning, social relationship and self-concept. The DEMQOL and DEMQOL-Proxy tools produce continuous scores, with responses in each item recorded on a 4-point Likert scale.

Initially, the tools were translated to the Sinhala language by using the forward-backward translation method (12-14). The cultural adaptation of the translated tools was carried out using the modified Delphi technique among a panel of 10 multi-disciplinary experts from the fields of psychiatry, neurology, community medicine, sociology and psychology. Each item in the questionnaires was assessed on relevance for assessment of QOL among the dementia patients, appropriateness of the wording used, and acceptability, in the local context. The culturally adapted tools were then pre-tested among 10 patients diagnosed to have mild to moderate dementia (confirmed by a MMSE score>10) and 10 of their informal caregivers. In a subsequent structured cognitive interview, the clarity in understanding, acceptability, comprehension of items and feasibility were assessed.

Assessment of validity of the tools

The judgmental (face, content, and consensual) validity of the tools was assessed. Face validity was assessed by lay persons in the target group. Content and consensual validity was assessed by another independent panel of multi-disciplinary experts in the fields of psychiatry, neurology, community medicine and social services who did not participate in the process of translation and cultural adaptation.

In order to assess the construct validity of the tools, a hospital-based cross-sectional validation study was conducted among patient-caregiver dyads of dementia in government hospitals in the Gampaha district, which conduct routine psychiatric clinics under the purview of consultant psychiatrists. Patients diagnosed with dementia being followed up at psychiatric clinics for at least six months, and their primary caregivers were selected for the study. All patients had their diagnosis confirmed according to the DSM IV classification. Patients with severe dementia (with a MMSE score less than 10), those with speech or hearing impairment, institutionalized patients and those with coexisting psychiatric diseases were excluded.

The sample size for confirmatory factor analysis (CFA) is a matter of controversy. Absolute number of cases ("rule of thumb") and the subject to variable ratio (STV) are the two most widely used recommendations according to literature (15,16). MacCallum et.al. have demonstrated that the minimum sample size depends not only on the STV ratio or absolute number, but also on other aspects of the study design (16). In addition, there are practical issues when applied in behavioural research studies related to constructs (16). In the current study, recruiting more than 100 patients with dementia for the validation study, while adhering to the eligibility criteria was an issue, owing to time and pragmatic constraints. Therefore, the sample size was limited to 100 patient-caregiver pairs, giving an STV ratio of 1:3.5 for the 28-item DEMQOL.

One hundred pairs of patients and their primary caregivers who fulfilled the eligibility criteria were selected consecutively from the clinics. Their QOL was assessed by trained pre-intern medical graduates using the culturally adopted DEMQOL and DEMQOL-Proxy.

Data analysis

The construct validity of both tools was assessed using multi-trait scaling analysis and confirmatory factor

analysis (CFA) (17,18). Multi-trait scaling analysis assessed the convergent and discriminant validity of each item with scores of the four subscales, namely Positive Emotion (PE), Negative Emotion (NE), Memory (Mem) and Daily life (DL). Item convergent validity was ensured based on a stringent criterion (correlation of 0.4 or greater between an item and its own subscale), while the item discriminant validity was ensured based on items that correlated significantly higher (more than 1.96 standard errors) with its own subscale than with the other two subscales (17). The CFA was assessed using Linear Structural Relations (LISREL) software version 9.1. It determined the extent to which the original four-factor models of DEMQOL and DEMQOL-Proxy were replicated in the observed data of the validation study. This was done using a variety of fit indices (absolute, relative and parsimony fit indices).

The reliability of the tools was assessed using internal consistency and test-retest reliability, by re-administering the DEMQOL and DEMQOL-Proxy tools to a sub-sample of 20 patient-primary caregiver pairs after 2 weeks.

Results

In both samples, the majority were females, while the patients with dementia were much older and less educated than their primary caregivers (Table 1). The mean MMSE score among the patients was 17.32 (SD= 4.8), within a range of 14-25 (100). Most often the patients were looked after by their own children (48.3%), followed by spouse (28.3%), siblings (15%), in-laws (3.3%) and other relatives (5.1%).

Cultural adaptation

At the end of third round of the cultural adaptation, all items except for item 4, 9 and 26 in the DEMQOL and 4, 6 and 8 in the DEMQOL-Proxy had obtained a median rating score of more than 7. In addition, three experts commented that items 1 and 3, as well as 2 and 4 were somewhat similar, and therefore they were re-assessed and modified in consensus with the experts. In the final round, all 28 items of the DEMQOL and 31 items of the DEMQOL-Proxy were retained in the Sinhala translation. In the pre-test among 10 patients, none of the items was reported to be difficult to understand. When applying the DEMQOL, patients with dementia achieved a mean total score of 77.7 (SD=11.63) and a mean item score of 2.95 (SD=1.14). In comparison, care providers achieved a mean total score of 74.31 (SD=14.11) and a mean items core of 2.32 (SD=0.95) for the DEMQOL-Proxy. The aggregate scores ranged from 28 to 112 for the DEMQOL, and from 31 to 124 for the DEMQOL-Proxy.

The suitability of the validation datasets for the CFA was demonstrated. The Kaiser-Meyer-Olkin (KMO) measure was higher than 0.5 (scores of 0.682 and 0.648 were obtained for the DEMQOL sample and DEMQOL-Proxy sample, respectively). The Bartlett's Test of sphericity was significant for both samples. Hence, sampling adequacy was assured for both samples.

Table 2 summarizes the results of the multi-trait scaling analysis as per predetermined cut-off values. Item convergent validity was established for the DEMQOL, with strong correlations seen with the items and their total scores; for example, items pe1, pe3, pe5, pe6 and pe10, which assess positive emotions (PE) of a patient with dementia, showed good correlation with the total positive emotion score (PE score) (Table 2). Item discriminant validity was also established; for instance, item pe1 versus the negative emotion (NE) score was lower than when compared to its own (PE) subscale.

The robust maximum likelihood (RML) method, which was adjusted for non-normality of the data was used (18). Models included in the CFA with the fit indices are

Table 1. Socio-demographic characteristics of the study population

Characteristic		Patient with dementia	Caregivers
Age (years)	Mean (SD)	72 (7.6)	55 (14)
	Range (n)	58-86 (100)	27-81 (100)
Sex	Female (n)%	63 (63%)	73 (73%)
	Male (n)%	37 (37%)	27 (27%)
Level of education	Upto O/Level (n)%	48 (48%)	42(42%)
	A/Level and above (n)%	52 (52%)	58 (58%)
Total		100	100

shown in table 3. The four-factor model showed comparatively better indices, which were closer to the desired values. Model improvement in the four-factor model could be clearly seen when compared with the goodness of fit index (GFI), adjusted goodness of fit index (AGFI) and standardized root mean square residual (SRMR) indices across the models. Both relative and parsimony fit indices also showed desirable values for the four-factor model.

Two models were evaluated for the DEMQOL-Proxy using the RML method (Table 4). The RMSEA value of the five-factor model was closer to the desired value of a good model (less than 0.08). Other absolute fit indices also showed an improvement compared to the three-factor model. Both relative and parsimony fit indices showed desirable values for the five-factor model. Therefore, of the two models, the five-factor model showed the best model fit statistics for the DEMQOL-Proxy.

Table 2. Multi-trait/ Multi-item correlation matrix for the DEMQOL Scores (n=100)

Item	Sub-scales of DEMQOL			
	PE score	NE score	Mem score	DL score
pe1	**0.771**	0.211	-0.002	0.220
pe3	**0.725**	0.083	-0.290	0.187
pe5	**0.782**	0.153	0.031	0.346
pe6	**0.815**	0.213	-0.084	0.268
pe10	**0.768**	0.311	0.102	0.284
ne2	0.157	**0.796**	0.505	0.459
ne4	-0.039	**0.665**	0.316	0.179
ne7	0.225	**0.726**	0.336	0.134
ne8	0.303	**0.710**	0.206	0.346
ne9	0.262	**0.712**	0.381	0.416
ne11	0.194	**0.742**	0.238	0.398
ne12	-0.094	**0.669**	0.332	0.268
ne13	0.342	**0.739**	0.285	0.574
mem14	0.163	0.542	**0.785**	0.445
mem15	0.189	0.335	**0.673**	0.384
mem16	0.044	0.388	**0.775**	0.469
mem17	0.269	0.365	**0.761**	0.156
mem18	0.113	0.433	**0.746**	0.327
mem19	0.465	0.351	**0.766**	0.386
dl20	0.199	0.321	0.159	**0.753**
dl21	0.105	0.283	0.484	**0.681**
dl22	0.181	0.270	0.388	**0.732**
dl23	0.336	0.427	0.304	**0.783**
dl24	0.251	0.587	0.382	**0.761**
dl25	0.246	0.172	0.327	**0.712**
dl26	0.250	0.178	0.283	**0.674**
dl27	0.246	0.235	0.197	**0.698**
dl28	0.321	0.505	0.298	**0.654**

pe=positive emotions, ne=negative emotions, mem=memory, dl=daily life (items); PE=positive emotions, NE-negative emotions, Mem=memory, DL=daily life (total score)

Table 3. Model fit indices of the Two-factor, Three-factor and Four-factor Models of the DEMQOL

Model fit indices	Model		
	Two-factor	Three-factor	Four-factor
Absolute fit indices			
X^2	1224.6	1167.6	768.4
df	230	312	242
p	0.000	0.000	0.000
RMSEA (90% CI)	0.16 (0.15-0.17)	0.15 (0.14-0.16)	0.09 (0.09-0.17)
GFI	0.513	0.537	0.796
AGFI	0.433	0.458	0.884
SRMR	0.146	0.147	0.0521
Relative fit indices			
CFI	0.354	0.394	0.962
NNFI	0.300	0.340	0.951
Parsimony fit indices			
PGFI	0.441	0.459	0.628
PNFI	0.271	0.299	0.820

X^2 = Satorra-Bentler scaled chi square test (desired value p> 0.05); RMSEA = Root mean square error of approximation (desired value<0.08); GFI = Goodness of fit index (desired value > 0.9); AGFI = Adjusted goodness-of-fit index (desired value > 0.9); SRMR = Standardized root mean square residual (desired value < 0.05); CFI = Comparative fit index(desired value >0.95); NNFI = Non-normed fit index (desired value >0.95); PGFI = Parsimony goodness-of-fit index (desired value >0.5); PNFI = Parsimonious normed fit index (desired value >0.5)

Table 4. Model fit indices of the Three-factor and Five-factor Models of DEMQOL-Proxy

Model fit indices	Model	
	Three-factor	Fiver-factor
Absolute fit indices		
X^2	1524.6	706.3
df	330	232
p	0.000	0.000
RMSEA (90% CI)	0.178 (0.174-0.188)	0.086 (0.086-0.116)
GFI	0.517	0.896
AGFI	0.438	0.794
SRMR	0.142	0.0567
Relative fit indices		
CFI	0.464	0.972
NNFI	0.364	0.967
Parsimony fit indices		
PGFI	0.479	0.389
PNFI	0.672	0.811

Reliability

A high internal consistency was demonstrated within all main domains of the DEMQOL and DEMQOL-Proxy scales. The Cronbach's alpha value for the overall DEMQOL, as well as for the DEMQOL-Proxy was similar (0.87). For the four main domains of the DEMQOL it ranged from 0.76 to 0.77; while it ranged from 0.7 to 0.8 for the DEMQOL-Proxy. All domain values exceeded Nunnaly's criteria of 0.7, implying satisfactory internal consistency (19). There were strong positive statistically significant ($p<0.001$) correlations for each of the four sub scales of the DEMQOL and five subscales of DEMQOL-Proxy. The test-retest reliability values also ranged from 0.72 to 0.82 for the main domains of the DEMQOL, with a total score of 0.86; whereas for the DEMQOL-Proxy, it ranged from 0.66 to 0.91, with a total score of 0.83. This confirms a satisfactory level of reliability for the two scales.

Discussion

The present study was designed to validate the DEMQOL and DEMQOL-Proxy among Sri Lankan patients with dementia and their caregivers, addressing an important research gap on QOL research among dementia patients in the South Asian context. The validated Sinhala version of the DEMQOL and DEMQOL-proxy emerged as a valid and reliable tool to assess the QOL among patients with mild to moderate dementia in Sri Lanka.

In order to appraise the construct validity of a questionnaire, it is common practice to assess the factor structure via factor analysis (20). With regards to the DEMQOL and DEMQOL-Proxy, during the development stage of the original version, exploratory factor analysis had been used to establish its factor structure (8). This was however not attempted in the current study, as the original factor structure did not change during its translation and cultural adaptation, and thus the assessment of construct validity was limited to CFA. This implies minimal cultural influence on the QOL constructs related to dementia, despite differences that may exist in the way the QOL is perceived by patients in developed and developing countries. The modified Delphi technique is a well-accepted method for consensus building among multi-disciplinary teams of experts (21).

During the CFA, the four-factor model of DEMQOL showed the best model fit statistics accounting for 49% of its variance. This result is consistent with the validation study of the original tool, where it too produced a four-factor model as the best fitting one accounting for 43.3% of the variance (8). In contrast, the best model fit statistics in relation to DEMQOL-Proxy in this study was for the five-factor model, which is not consistent with the original validation study, where the best fit was seen with a two-factor model (8). In the original tool, positive and negative emotions have been loaded into one factor (emotions), and memory, daily life and social life into another factor (daily life). This difference may be due to the fact that the current study had only family caregivers, while in the original validation study, it was a community sample of caregivers recruited from secondary care, where 79% were living in their own homes and 21% under residential care. However, another validation study of the same tool yielded a five-factor model in a larger sample of UK general population, where only the family caregivers were involved (22). Hence, the five-factor model of DEMQOL-Proxy could be taken as the best fitting model for Sri Lanka. The DEMQOL-proxy is recommended to be used to complement the information provided by the DEMQOL, but this also provides additional information on the perspectives of both patient and caregiver regarding the QOL. This is important, especially in the South Asian context where only limited, if any, social services are available for the patient, and most of the care is provided by the family. The family members' perception is therefore as important as the patient's.

Reliability is a crucial factor in the assessment of QOL, especially in dementia patients, as they have poor short-term memory that could affect recalling of events. In the current study, both internal consistency and test-retest methods demonstrated satisfactory reliability for both tools. This is consistent with the validation study by Smith and Lamping, where Cronbach's alpha values for the main domains varied between 0.65-0.79 and 0.89 for the scale total score (8). When considering the internal consistency among the DEMQOL-Proxy, the Cronbach's alpha values for the five main domains and of the total score produced similar results as for DEMQOL. Only the 'social life' domain of DEMQOL-Proxy obtained a Cronbach's alpha value less than 0.7. The values for the test-retest reliability too ranged for the main domains and for the total of DEMQOL and DEMQOL-Proxy in a similar manner. This confirmed satisfactory levels of reliability for the two scales. Comparable reliability have been shown with regards to other QOL scales for use among patients with dementia patients (23,24).

Limitations

The strengths of this study include having a cross-sectional design and an adequate sample size, which are deemed appropriate for achieving the study objective. However, one main limitation was that the current validation was done on a consecutive sample of hospital patients who might have better QOL than patients not attending clinic at all, which is therefore not captured well in the current study. Further, this tool has been validated only for patients with mild to moderate dementia.

Conclusions

In conclusion, the findings of this study indicate that the culturally adapted and validated Sinhala versions of the 28-item DEMQOL and 31-item DEMQOL-Proxy scales are valid and reliable tools to assess QOL among patients with mild to moderate dementia in Sri Lanka. It could be used as an effective screening tool to assess QOL even at a clinic setting. This would enable us to understand the current QOL of these patients and indicate directions for improved provision of care and support.

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Statement of Contribution

SJ and CA were involved in the conception and design of the study. SJ collected, analyzed and interpreted data. CA made substantial contribution to data analysis and interpretation. SJ prepared the manuscript. CA made substantial contribution to revise the manuscript. Both authors read and approved the final manuscript.

Conflicts of interest

None declared.

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