Quality of life of Filipino elderly with dementia (QoL-FD) assessment tool: Its development, validation and standardization

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Abstract

Introduction Life value should also be considered in an elderly person with dementia, aside from the medical attention. An assessment of the quality of life will provide a substantial impact in the clinical practice, disease severity, and evaluation of treatment outcomes provided for this condition. In the Philippines, the use of a self-constructed instrument to assess the quality of life specifically among this group is very limited; hence developing a culturally sensitive quality of life measure was the thrust of this study.

Methods   The research utilized test construction methodology to develop the Quality of Life of Filipino Elderly with Dementia (QoL-FD) tool. In the item generation stage, a multi-source approach was done utilizing in-depth interviews with elderly with dementia, caregivers, a neurologist and other health allied practitioners specializing in dementia. The draft underwent face validation by the experts and was administered to a sample of 5 patients in a private hospital's memory clinic. The final form of Quality of Life of Filipino Elderly with Dementia (QoL-FD) tool was pretested in a sample of 211 community-dwelling elderly in a city in the metropolitan area.

Results From the pool of samples, 20 elderly were diagnosed to have mild to moderate level of dementia. During the preliminary testing, the items generated convergent validity with WHOQOL BREF. To test the internal reliability, a Spearman Brown formula and Cronbach's alpha coefficient were computed and showed that it was a valid and reliable instrument.

Conclusion In the final form, the tool had a validity value with Pearson r of 0.90, split half reliability value using Spearman Brown formula of 0.92 and Cronbach's alpha of 0.90. Thus, the QoL-FD is a psychometrically sound instrument for measuring quality of life.

Key words: Dementia, Alzheimer, Quality of Life

Quality of life (QoL) is a multidimensional concept and has been broadly defined by the World Health Organization (1995) as an individual's perception of his or her position in life in the context of his or her culture and value system. It is also the integration of cognitive functioning, activities of daily living, social interactions, and psychological well-being.[1] Health greatly affects one's component of achieving quality of life. In chronic neurodegenerative diseases like dementia which is prevalent in the elderly, a range of cognitive and behavioral symptoms and functional impairment occurs that makes the person gradually dependent on others for activities of daily living. It is always presumed that this lack of independence is always associated with poor quality of life. As a demented patient, the presence of cognitive decline and functional impairment make him vulnerable to a poor quality of life.

In dementia research and practice, there has been a long-unchallenged assumption that people with dementia cannot give a reliable account of their own quality of life.

This often leads to an assumption that people with dementia cannot achieve a positive QoL in the presence of physical disease. A study done abroad[2] showed little or no association between QoL and severity of cognitive impairment for people with mild to moderate-stage dementia. Just because an individual's cognition worsens, it cannot be assumed that this inevitably leads to worsening of QoL. The importance of developing QoL measuring instruments for people with dementia is as important as measuring the disease's severity, progression, symptom response, cognition, behavioral disturbances, and activities of daily living when assessing the impact of disease and intervention in dementia.[3] At present, Lawton's model of QoL is used as a framework of QoL tests that are foreign-made[4], but its utility may be limited in Philippine culture. Furthermore, the existing QoL instruments are mostly limited to health status assessment and do not deal with the impact of dementia among elderly. The thrust of this study is to develop a QoL instrument for the Filipino elderly with dementia where item-domains are generated from their own life experiences, values, perceptions and expectation of a quality life.

This endeavor will promote holistic quality of care for the demented elderly population since the primary goal of health care is geared towards increasing life expectancy and improving quality of life. Neurological illness may result in a limited means of expression, fatigue and cognitive decline that makes the QoL assessment and judgment of treatment efficacy difficult. Thus, with a tool that will measure the quality of life among Filipino elderly with dementia, appropriate intervention can be generated to improve the well-being of the elderly.

Methods

A test development framework design was utilized. It involved item construction, development of final form, and establishment of its psychometric properties by different reliability and validity procedures. The final phase involved standardization and establishment of norms.

Purposive sampling was utilized in this study. The participants came from a tertiary hospital's memory center and community dwellers in a city in the metropolitan area. The inclusion criteria were as follows: 1) age 60 years or older; 2) diagnosed to have probable dementia by the NINCDS-ADRDA criteria (Mini Mental State Examination score of 12 or above, signifying a mild to moderate stage); 3) MOCA scores below 26, signifying an impairment; 4) Clinical Dementia Rating (CDR) of 0.5 to 1, indicating mild stage; 5) availability of reliable collateral informant/s, preferably close family member/s who live/s with the patient or who is/are familiar with the patient's cognitive state.

Neuropsychological tests served as basis for selecting participants with dementia. The tests were also used in the psychometric testing during the validation of the Quality of Life in Filipino Elderly with Dementia (QoL-FD) assessment tool. The Montreal Cognitive Assessment (MOCA)[5] assessed different cognitive domains such as orientation, attention, memory, verbal fluency, naming, visuospatial /executive function, language, abstraction, and delayed recall. It has a cut-off score of 26. The MOCA detects 90% of mild cognitive impairment and its specificity is 100%. The Geriatric Depression Scale (GDS)[6] is probably the most common version currently used to measure depression in older adults with a cut-off score of 6/7. The GDS was found to have 92% sensitivity and 89% specificity when evaluated against diagnostic criteria. The Clinical Dementia Rating (CDR) is a global measure of dementia[7] used for detecting and staging the severity of dementia with a 5-point scale in which CDR-0 connotes no cognitive impairment and the remaining four points are for various stages of dementia. CDR detection of dementia among healthy elderly and questionable dementia are 86% and 80% sensitive, respectively, and 100% specific for both settings. The *WHOQOL-BREF* is a 26-item short form version of the WHOQOL-100[8]. It is a generic assessment of QoL across four domains: physical health, psychological, social relationships, and environment.[9]

IBM Statistical Product and Service Solutions (SPSS Statistics) version 17 was used to analyze data. Frequency and descriptive statistics (mean and standard deviation) were used. Internal consistencies of the scales used in the study were subjected to reliability and validity analysis using Pearson product moment correlation and Spearman Brown formula. Contrasted group method and item analysis were also employed to test the psychometric properties of the developed tool. Percentile scores were obtained for the conversion of the norms.

Results

During the preliminary phase of the test development, 211 elderly were screened. Of these, 20 were considered with dementia and met the inclusion criteria. Their Clinical Dementia Rating was within CDR = 0.5 (very mild dementia). For the final form, 360 elderly were screened and underwent a neuropsychological assessment. One hundred one met the inclusion criteria. Table 1 summarizes the demographic profile and characteristics of the participants.

Table 1. Demographics of the participants in the preliminary and final phases.

Characteristic	Preliminary Form (N=20)		Final Form (N= 101)	
	Frequency	Percentage	Frequency	Percentage
Gender				
Male	6	30	30	29.7
Female	14	70	71	70.3
Age				
60-65	6	30	27	26.7
66-70	6	30	25	24.8
71-75	2	10	26	25.7
76-80	4	20	12	11.9
81-85	2	10	11	10.9
Educational Attainment				
Elementary level	4	20	17	16.8
Elementary graduate	5	25	18	17.8
High school level	2	10	7	6.9
High school graduate	7	35	12	11.9
College level	2	10	13	12.9
College graduate	0	0	33	32.7
Vocational course	0	0	1	1
Level of Dementia				
CDR = 0.5	17	85	96	95.05
CDR = 1.0	2	10	4	3.96
CDR = 2	1	5	1	1
CDR = 3	0	0	0	0

Phase I: Conceptualization and Item Generation of QoL-FD

The domain compositions of QoL-FD tool were generated from experts in the discipline. The paradigm of WHOQOL and Lawton's Theory and in-depth interviews served as basis in the formulation of the items. Interviews were conducted with elderly with dementia, caregivers and a physician to identify their perceptions about quality of life and knowledge on dementia. From the five elderly respondents, experiences in their lives were expounded and variations from physical, psychological, social, and spiritual and memory constructs were generated from them. The caregivers, on the other hand, validated the actual changes that the elderly with dementia experienced they observed while taking care of their patients. The physician expert provided comprehensive information on the disease progression and validated the changes in cognition, memory, activities of daily living, and emotional and behavioral responses of elderly with dementia. The quantitative responses provided by the initial sample were organized into domains. These domains had ten items on each subscale. Verbatim quantitative responses were graded using a 4-point Likert scale as follows: 1 = poor, 2 = fair, 3 = good and 4 = excellent. A pool of 60 items generated across six domains (physical health, psychological, social, environmental, spiritual, memory) was then subjected to face and content validity by the following resource persons: neurologist, psychologist, nurse and Filipino professors.

Phase II: Preliminary Phase

The first draft of the QoL-FD tool which was pilot tested to establish its psychometric properties showed 20 (16.52%) elderly meeting the criteria out of 211 who were screened. Table 2 shows the convergent evidence of validity. The WHOQOL-BREF test adapted by a local investigator[10] was used to assess the quality of life among ambulatory and community dweller elderly. The Pearson correlation (0.96) showed a very high correlation between WHOQOL-BREF and the QoL-FD tool. Furthermore, a split half reliability type was

computed. Its reliability using Spearman Brown formula generated very high correlation (0.98) and the internal consistency of the items as indicated by the Cronbach's alpha (0.98) confirmed that the domains of the test and the items measured the same component. The validity and reliability of the QoL-FD preliminary form served as a basis for the Quality of Life of Filipino Elderly with Dementia (QoL-FD) tool.

Phase III: Final Phase

This phase involved the administration of the final form of the QoL FD tool. After item analysis, using percentage endorsement, the 60 items in the initial test were reduced to 33 questions. Table 3 shows the overall evaluation of each item. Percent endorsement statistics for each item indicate the proportion of the respondents who chose specific answers in the items.

To strengthen its psychometric property, the final form of QoL-FD was administered to 101 participants in the final phase. Table 4 shows very high correlation scores convergent validity scores using Pearson correlation. To test the internal consistency of the instrument, the degree of reliability was measured using the Spearman brown formula and showed a very high reliability. The internal consistency of the items as indicated by the Cronbach's coefficient alpha was also high enough to substantiate the reliability of the final form. Thus, the QoL-FD was shown

to be a valid and reliable instrument in measuring quality of life among elderly with dementia with very stable psychometric properties.

The QoL-FD final form was also subjected to reliability tests. Using split half reliability, the items were divided into two parts and were analyzed using Pearson r values and Spearman Brown formula. The physical, social, environment and memory Pearson r value and Spearman brown values ranged from 0.50 - 0.70, while high correlation values (0.71-0.80) were

Table 3. Percentage distribution of the items for the domains of final form.

Domains	N	% Item	Number
Physical Health	6	18.18%	1, 2, 5, 6, 9, 10
Psychological	7	21.21%	2, 3, 4, 6, 7, 8, 10
Social Relationship	2	6.06%	5, 9
Environmental	6	18.18%	1,4, 5,7, 9, 10
Spiritual	5	15.62%	4,6,7,9,10
Memory	7	21.21%	2,3,6,7,8,9,10
Total	33	100%	

Table 2. Convergent evidence of validity and split half reliability values in the preliminary form.

	Statistical Treatment	Coefficient values	Interpretation
Validity measures	Pearson correlation	0.96	Very high correlation
Split half reliability measures	Spearman Brown formula (equal length)	0.98	Very high correlation
	Cronbach's alpha coefficient	0.98	Very high correlation

Note: **. Correlation is significant at the 0.01 level (2-tailed). All the alpha values p< 0.05

Table 4. Convergent evidence of validity and split half reliability values in the final form.

	Statistical Treatment	Coefficient values	Interpretation
Validity measures	Pearson correlation	0.90	Very high correlation
Split half reliability measures	Spearman Brown formula (equal length)	0.92	High correlation
	Cronbach's alpha coefficient	0.90	High correlation

Note: **. Correlation is significant at the 0.01 level (2-tailed). All the alpha values p< 0.05

obtained for the psychological and spiritual domains. The QoL-FD final form domains show higher consistency in their responses to the items of the QoL-FD, thus the domains comprising the QoL-FD measured are reliable.

A test is standardized when it has clearly specified procedures for administration and scoring including normative data. The statistical treatment of the final form served as the basis for constructing the norms of the QoL-FD. Percentile scores were computed from the raw scores generated from the responses of the participants to the final form of QoL-FD. Furthermore, a computation of the z-scores and t-scores was also utilized to provide more comprehensive values generated from the QoL-FD. Table 5 describes the sample norm equivalent.

Table 5. General description of raw scores and percentile rank of QoL-FD.

Raw Scores	T scores	Verbal Equivalent
85-134	51-67	Excellent quality of life
60-84	42-50	Good quality of life
34-59	33-41	Fair quality of life
33-below	1-32	Poor quality of life

The scores obtained from the QoL-FD served as the basis for the percentile ranking. The verbal descriptions of the norms were: excellent, good, fair and poor, which were also the categorical choices in the items in the QoL-FD tool.

Discussion

Quality of life had been explored in foreign and local literature and is an issue for disorders like Parkinson's disease, dementia, Alzheimer's disease and epilepsy.[11] There have been studies conducted on the quality of life in different courses of health care.[12, 13] They showed that measuring the efficacy of any treatment involves understanding the mechanism of the quality of life of these patients. This holds true for Alzheimer's disease - the most common neurological disease in the elderly. Based on the estimated prevalence in America, at age 65, elderly are susceptible to have AD and it doubles every five years.[14]

In the recent trends in the development of QoL measures, utility-based, rather than psychometric measures of quality of life, are necessary before any cost-effectiveness analyses can be performed. This utility-based measurement of quality of life has assumed greater importance in AD research.[15] To date, no QoL instrument used in clinical trials of anti-dementia drugs appears to be satisfactory[16] not because of the ineffectiveness of QoL in clinical trial outcomes, but rather, the tool itself has limited psychometric properties. Currently, though other self-measure tests for QoL such as the BASQID[17] and QOLAS[18], which are self-rated instruments and are good predictors of quality of life measures in dementia outcome, their utility had not been tested in our current population and literature suggests that a tailored fit instrument that is culturally sensitive in assessing quality of life is warranted.[9] At present, there is no gold standard for assessment of quality of life among Filipinos. The available QoL instruments are very broad and not culturally-based to provide adequate measures of one's own perception of the quality of life of the elderly population. The need for the development of a QoL tool for a specific culture continues to intensify as the outcome of intervention and improvement of quality of life become significant in dementia. This tool may also be considered as an adjunct tool for neuropsychological assessment by the health practitioners.

A limitation of the current study is the sample size which was insufficient to provide a general norm. The utility of QoL-FD in various forms of dementia to strengthen its applicability in the evaluation of intervention outcomes can also be expanded to enhance the instrument's content and psychometric variability. Future larger scale studies utilizing the demographic data and treatment outcomes of demented elderly in relation to their quality of life measured by the QoL-FD are warranted. Moreover, further studies are needed to determine the most important predictor of quality of life among the six domains in the QoL-FD.

Based on the findings, we concluded that Quality of life of Filipino Elderly with Dementia (QoL-FD) tool is a valid and reliable instrument in measuring the perception and experiences of the elderly's quality of life in the course of their dementia.

Joseph Francisco, M.A., Laura Maguad, M.A., and Randy Jose.

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