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Greek version of MVQOLI - 15: Translation and cultural adaptation

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Abstract

Background: The Missoula-Vitas Quality-of-Life Index (MVQOLI) is a unique tool specifically designed to measure quality of life (QOL) in advanced illness in a palliative care setting.
Objective: The objective of this study was to translate and make the cultural adaptation of the Greek version of the MVQOLI-15R.
Methodology: The study counted with a sample of 10 patients undergoing in - centre haemodialysis. The process involved the following steps of translation back translation and semantic evaluation.
Results: The former revealed good acceptance of the translated version of the instrument, which participants considered having items of easy understanding.
Conclusions: After completing the process of validation in the country, the instrument will become available to Greek researchers to measure health-related quality of life, as well as to compare results from Greece to that of other cultures in which the instrument has already been validated.

Key Words: Translation, cultural adaptation, dialysis, kidney disease, quality of life

Introduction

There has been plenty of interest in quality of life (QOL) lately. Despite the lack of consensus about its definition, it can be understood as satisfaction or happiness with life in view of the domains the person considers important (Theofilou, in press). As for health - related quality of life (HRQOL), it is considered a health indicator that assesses a person's general physical condition, functional ability, housework activities, social interactions, cognitive function and emotional condition in relation to his/her health status (Theofilou, in press). HRQOL measurement instruments can facilitate clinical decision making, assess care quality, estimate a population's health service needs and understand the causes and consequences of health problems (Theofilou, in press). The impact of diseases on the physical health, in the work performance and its implications on the familiar and personal life increase the treatment context. Thus, improvements in the QOL become as important as the clinical – laboratorial responses to interventions, enlarging the scope of therapeutical results.

In 1990, the World Health Organization emphasized that the ultimate goal of palliative care is achievement of the best QOL for patients and their families (Hiller, 1988). Clinch and Schipper (1993) have suggested that QOL is the most appropriate outcome measure in terminal care because it is focused on what happens to the patient, measuring the effect of physiological change rather than only the fact of physiological change. Although there is no recognized gold standard for measurement of QOL (Spitzer, Dobson & Hall et al., 1981), over the past decades, two classes of complementary health status measures have emerged to fill this information gap - objective measures of functional health status and subjective measures of health and well – being (Cella, 1994). Various QOL measurement tools have been designed but most may not be ideal for use in palliative care patients, whose QOL assessment should focus on areas for which palliative care is most effective, such as psychosocial and spiritual problems (Cohen & Mount, 1992; Byock & Merriman, 1998).

In response to the need for a QOL measure that assesses the individual experience of people nearing the end-of-life (EOL), Byock and Merriman (1998) created the Missoula - VITAS Quality of Life Index (MVQOLI). The MVQOLI is an assessment instrument that gathers patient - reported information about QOL during advanced illness. Maintaining optimal QOL is a core goal of palliative and hospice care, and information gathered via the MVQOLI assists health care professionals in identifying and addressing patient concerns that affect QOL. The MVQOLI has been used in many different healthcare settings including hospice, hospital, home health, long-term care (including assisted living), outpatient palliative care, disease management and pre-hospice programs (Byock, 1996).

The framework of the MVQOLI is based on Ira Byock's work regarding growth and development at the end of life and the concepts of landmarks and tasks of life closure (Byock, 1996). The MVQOLI asks patients about 5 dimensions or domains of QOL: symptoms, function, interpersonal, well-being and transcendence. The instrument is specifically designed to assess the patients personal experience in each of these dimensions, hence the MVQOLI items are constructed with highly subjective language and no scores appear on the version of the tool seen by patients. The tool seeks to describe the qualitative and subjective experience of QOL in a way that can be quickly interpreted by professional caregivers (Theofilou, 2012).

Within each dimension, three kinds of information are gathered from respondents in order to illuminate their overall experience:

- Assessment (A) - subjective measurement of actual status or circumstance (What it is.) Example: I feel sick all the time.
- Satisfaction (S) - degree of acceptance or mastery of actual circumstance (How much does it bug you?) Example: I am satisfied with current control of my symptoms.
- Importance (I) - degree to which a given dimension has an impact on overall QOL (How much does it matter?) Example: Physical discomfort overshadows any opportunity for enjoyment.

Each dimension is defined by the patient's perception and/or experience - not the "judgment" of caregivers (family or professional). The definitions for the dimensions and examples of items for each response category are shown below.

Symptoms - experience of the physical discomfort associated with progressive illness; perceived level of physical distress.

(A) 1. I feel sick all the time.

(S) 2. I am satisfied with current control of my symptoms.

(I) 3. Physical discomfort overshadows any opportunity for enjoyment.

Function - perceived ability to perform accustomed functions and activities of daily living, experienced in relation to expectations.

(A) 4. I am no longer able to do many of the things I like to do.

(S) 5. I accept the fact that I cannot do many of the things that I used to do.

(I) 6. My contentment with life depends upon being active and being independent in my personal care.

Interpersonal - degree of investment in personal relationships and the perceived quality of one's relations with family and friends.

(A) 7. I have recently been able to say important things to the people close to me.

(S) 8. At present, I spend as much time as I want with family and friends.

(I) 9. It is important to me to have close personal relationships.

Well-Being - self-assessment of an internal condition; subjective sense of emotional "wellness" or "disease"; contentment or lack of contentment with self.

(A) 10. My affairs are not in order; I am worried that many things are unresolved.

(S) 11. I am more satisfied with myself as a person now than I was before my illness.

(I) 12. It is important to me to be at peace with myself.

Transcendent - experienced degree of connection with an enduring construct; degree of experienced meaning and purpose in life.

(A) 13. I have a better sense of meaning in my life now than I have had in the past.

(S) 14. Life has lost all value for me; every day is a burden.

(I) 15. It is important to me to feel that my life has meaning.

Each item uses a five-point Likert scale recorded so that the lowest score always indicated the least desirable situation and vice versa. The questions are general, which means that the MVQOLI provides information about the domains that detract from or augment the patient's QOL. The MVQOL also incorporates a single item quality-of-life status question, which was used to assess the convergent validity of the MVQOLI-M (Namisango, Katabira, Karamagi & Baguma, 2007).

There are two versions of the MVQOLI - 15 item and 25 item. The instrument was initially designed with 25 items. Clinicians reported that the tool was too long for some patients to complete. Using data from the original study of reliability and validity, a 15-item version was constructed that has a correlation coefficient of .93 with the 25-item version, indicating that little information is lost when only 15 items are used. The newest versions of the tool included with this guide have been revised using simpler language and item formats to make it easier to use for both patients and staff.

The MVQOLI can be scored using an EXCEL program or manually. Its scoring protocol is designed to turn the qualitative subjective experience of the patient into quantitative information that can be easily interpreted by the care team. The unique scoring system has the advantage of revealing how much each domain affects QOL. For example, efforts to make a patient comfortable may contribute little to QOL if that domain is not important to them. In addition, small changes in any domain may affect QOL a lot if that domain is very important to the patient.

The MVQOLI items are scored as follows:

Assessment	-2 to +2
Satisfaction	-4 to +4
Importance	1 to 5
(Assessment + Satisfaction) X Importance = QOL in each dimension	

Note that the assessment and satisfaction scores can range from -6 to +6 and indicate whether the patient assess his/her situation positively or negatively. When multiplied by the importance factor, the overall dimension score is magnified by how important that domain is. The final score in each dimension reflects the overall impact of that domain on QOL.

- Negative dimensions are reducing QOL,
- Positive dimensions are increasing QOL and
- The size of each dimension reflects the amount of impact.

Most questionnaires used to evaluate the QOL were developed for English speaking populations. In consequence, they are rarely adequate in terms of correct translation or correspondence to the reality of other countries (Guillemin, Bombardier & Beaton , 1993). So, these questionnaires have to be validated in order to be applied to the reality of each specific population.

A literature review in PubMed/Medline revealed that, among instruments for QOL/HRQOL measurement in nearing the EOL, the only tool specifically aimed at measuring the HRQOL of chronic disease patients in advanced stages is the MVQOLI. No studies are found on the translation and cultural adaptation of instruments for advanced disease patients in Greece. Given the lack of this type of instrument in Greece, the present research aimed to translate and culturally adapt the Missoula - VITAS Quality of Life Index 15 item (MVQOLI-15R).

Method

This methodological research consists of the translation and cultural adaptation of a HRQOL measurement instrument for chronic disease patients in advanced stages in Greece.

Data collection

A sample of 10 patients undergoing in - centre haemodialysis (HD) was recruited from a

General Hospital in the broader area of Athens. Selection criteria included:

1. > 18 years of age
2. Ability of communication in Greek
3. Diagnosed with chronic kidney disease (CKD)
4. Satisfying level of cooperation and perceived ability

The rate of response was very high, reaching 100%. Thus, the total sample includes all patients with a mean age of 58.4 years ± 13.06. Participants were Greek adults having signed a consent form for participation. All subjects had been informed of their rights to refuse or discontinue participation in the study according to the ethical standards of the Helsinki Declaration. Ethical permission for the study was obtained from the scientific committee of the participating hospital.

Table 1. Characteristics of the sample.

	HD N=10
Age (M±SD)	(58.4 ±13.06)
Gender	
Male	6
Female	4
Total	10
Marital status	
Single	1
Married	6
Divorced	1
Widowed	2
Total	10
Education	
Elementary	1
Secondary	7
University	2
Total	10
Length of HD treatment in years (M±SD)	(6.38±5.41)

Translation and back translation of the MVQOLI

Adaptation and translation of the MVQOLI was done according to the criteria for translation and adaptation of generic health-related QOL measures (Bowden & Fox-Rushby, 2003).

The MVQOLI-15R version was translated from the source language (English) to the target language (Greek). Translation was done according to the guidelines for adapting instruments in multiple languages and cultures (Hambleton, 2000). Translators who were conversant with both the source and target languages, and had skills in cross-cultural adaptation of instruments, made two independent forward translations and two independent backward translations. The final version was independently reviewed and translated by a bilingual health psychologist without previously seeing the original MVQOLI. The back translated version had very close concordance with the original MVQOLI, as verified by a professional linguist fluent in both the English and Greek languages. A social scientist conversant with both languages carried out the final step of smoothing out the language. This involved editing the target language version of the instrument in a consistent writing style. This helped to ensure that patients could easily understand the modified version of the MVQOLI. A HRQOL expert reviewed the final instrument to check for omissions.

Semantic validation of the MVQOLI

Next, semantic validation was carried out, which serves to verify the understanding of existing MVQOLI items by interviewing the respondents. This phase aimed to identify problems related to the research subjects' understanding and acceptance of the terms. For this phase of the cultural adaptation process, all 10 HD patients answered the MVQOLI-15R as well as the General Impression Instrument.

Results

As mentioned, 10 HD patients participated in the semantic validation phase, without any refusals. The goal of this study phase was to identify possible problems to understand the instrument's items and answer categories, with a view to adjusting terms for adaptation to the Greek culture if necessary. Therefore, an interview was held, in which patients, who agreed to participate in the study after receiving information, signed two copies of the Informed Consent Term (ICT) and answered the above mentioned forms. The analysis of answers to the General Impression instrument revealed that, in general, the participants accepted well the MVQOLI-15R and found it easy to understand. In total, 90.0% of the patients considered the instrument very good, and items were found relevant, easy to understand and with appropriate alternative answer categories for the chronic condition under analysis. The results are displayed in Table 2.

Discussion

In initial research, the QOL of people living with chronic conditions was assessed in terms of survival and signs of presence of the condition. Today, this panorama has changed and, besides the impact of symptoms and treatment, the people's physical, emotional and psychosocial aspects started to be valued (Clinch & Schipper, 1993). Due to the greater need and importance of measuring QOL/HRQOL in recent decades, construction, cultural adaptation and validation processes of instruments aimed as measuring subjective constructs has increased exponentially (Hiller, 1988), permitting result comparisons in multicenter studies (Hiller, 1988).

Table 2. Assessment results for the General Impression part of the semantic validation phase of the MVQOLI-15R instrument

Items from the General Impression Instrument	Alternative answers	Answer% HD patients (n = 10)
What did you think about our questionnaire in general?	Very Good Good	90.0 10.0
Are questions understandable?	Easy to understand Sometimes difficult	90.0 10.0
About the answer categories? Did you have any difficulties?	No difficulty Some difficulties	100.0 0.0
Are the questions important for your health condition?	Very relevant Sometimes relevant	90.0 10.0

Patients suffering from Chronic Kidney Disease (CKD) have to cope with many adversities, e.g. physical symptoms, limitations in food and fluid intake, changes in their body image, work and economic status, social roles, activity levels, self - image, health status and normal routines, while their control over treatment cannot always be predicted (Theofilou, 2012a; Theofilou, in press a; Theofilou, Synodinou & Panagiotaki, in press b; Theofilou, 2012b). Such constraints are expected to affect the patients' life and physical as well as social functioning, leading them to reconsider their personal and professional goals within the context of living with a chronic illness (Theofilou, 2011; Theofilou, 2011a; Theofilou, Synodinou & Panagiotaki, in press b).

There are few QOL/HRQOL measurement instruments for patients in advanced stages of their disease and, today, there is no specific instrument for use in Greece. Hence, an instrument was needed for this population. Therefore, in this study, internationally adopted procedures were followed for the cultural adaptation and validation of instruments to measure subjective constructs.

In this context, the introduction of methods like HRQOL assessment in clinical practice permits comprehensive knowledge on the subject's condition, in which HRQOL measurement instruments are aspects for consideration in clinical studies that assess the effect of new treatment modalities and their possible impact on participants' QOL, besides the objective data expected in a clinical trial. In this sense, some authors have highlighted the importance of measuring QOL and establishing it as an outcome indicator in health programs and interventions, beyond research (Clinch & Schipper, 1993; Theofilou, in press).

Every day, health professionals interact with patients who go through situations of anxiety and discomfort due to chronic conditions. The responsibility to relieve symptoms demands the assessment of physical, physiological, emotional, behavioral and environmental aspects that influence the patient's condition. Thus, in clinical medicine, QOL assessment instruments need to be used as indicators to direct actions with a view to comprehensive care delivery.

In the cultural adaptation and validation process of the MVQOLI-15R, in the semantic part, HD patients self-applied the instrument, followed by an interview, during which the understanding and acceptance of the terms deriving from the translation process were verified. As a result, 90.0% of them considered the items easy to understand and the answer categories adequate, providing answers without any difficulty.

This study permitted multidisciplinary contact, involving statisticians, physicians, nurses and psychologists, which was fundamental for the cultural adaptation process of an instrument that serves to measure a subjective health-related construct. As this instrument is directed at chronic patients in advanced stages, different professionals' involvement permitted greater knowledge on the several aspects involved.

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