

Original Article

The “Kidney Disease Questionnaire” for Haemodialysis Patients: Cultural Adaptation and Translation of the Questionnaire in the Greek Language

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Abstract

Background The kidney disease questionnaire is a tool constructed to measure knowledge of hemodialysis patients on topics related chronic kidney disease and renal transplantation.

Aim The aims of the study were the translation and cultural adaptation in the Greek language of the translation and cultural adaptation of the Kidney Disease Questionnaire.

Methodology The process included the forward and back translation of the questionnaire as well as its cultural adaptation according to World Health Organization guidelines. The questionnaire was translated from the source language (English) to the target language (Greek) by three independent translators. Next another person who had a very good command of both languages made the back translation of the questionnaire. The translation produced has not any important difference to the original one. Then the questionnaire was pilot tested on 10 hemodialysis patients who approved the cultural adaptation and then a semantic validation was followed.

Results The questionnaire was easily understood from the majority of the participants and a 90% of them considered the tool as very good, and found the questions easily understandable and important for their health condition.

Conclusions After the process of translation and cultural adaptation, the Kidney Disease Questionnaire is a reliable and available research instrument for Greek researchers in order to measure hemodialysis patients' knowledge on topics related to End Stage Renal Disease.

Key words: translation, cultural adaptation, hemodialysis, knowledge, Kidney Disease

Introduction

The majority of patients with End Stage Renal Disease (ESRD) under hemodialysis (HD) are faced

with variable health problems while they know little about their health status (Cavanaugh et al., 2009, Geronianni et al., 2014, Gerogianni, & Babatsikou,

2014, Kafkia, Vehvilainen-Jujkunen and Sapountzi-Krepia 2014, Cavanaugh et al 2009). According to previous studies knowledge about the disease and treatment may increase patient's empowerment, adherence to treatment and quality of life (Devins et al 1990, Galloway et al 1997,, Wiles et al 1998, Wells 2011). High levels of disease-related knowledge can lead to autonomy, self-efficacy and participation in clinical decision making. Moreover, a well-informed patient takes a collaborative role in ESRD management (Devins et al 2000, Devins et al 2005, Alikari & Zyga 2014). In a study related to the impact of patient knowledge on health outcomes, researchers found that dietary and fluid knowledge could significantly affect the adherence to diet and fluid intake (Lee & Molassiotis 2002). Controversially, low levels of knowledge about illness and treatment is associated with poor health outcomes (Affi et al 2005).

Clinicians have to fill knowledge gaps through patient training (Golper 2001, Curtin et al 2004b, Dunning & Manias 2005, Lingerfelt & Thornton 2011).

Therefore, the goal for health care professionals is to empower patients to acquire higher levels of knowledge about disease. In order to be able to increase knowledge, patients need to be educated through nurse-led individualized educational programs. (Galloway et al 1997, Curtin et al 2004a, Timmins 2006, Barnett et al 2008).

Before start implementing educational interventions and programs in order to increase the level of knowledge among HD patients, it is essential to have a tool to recognize the current level of knowledge about the ESRD and renal replacement. This could help health care professionals to identify the lack of knowledge. Moreover, clinicians could have a reference point from which they could compose an educational program.

Most of the questionnaires which measure knowledge are designed in English speaking population. Given the need of patient's information, education and increased of knowledge level, an instrument measuring patient knowledge is essential in Greece. As it is repeatedly stressed by Sapountzi-Krepia et al. (2003, 2008), the lack of validated instruments is common in most non-English-speaking countries, although the last years some significant efforts have been made towards this direction.

In this phase of study we perform the results of translation and cultural adaptation of the Kidney

Disease Questionnaire (KDQ) in Greek language as a tool for measurement patient knowledge about chronic kidney disease and therapeutic regimen. The next step of the study is to explore the psychometric properties of the scale.

Aim

The aim of this study was the translation and cultural adaptation in Greek of the Kidney Disease Questionnaire.

Methodology

Permissions

Firstly, authors informed via e-mail the creators of the questionnaire about the purposes of the research and asked for permission to make the translation and cultural adaptation of the KDQ in the Greek language. Permission was given electronically (10/06/2013) and the only requirement from the creators of the questionnaire was not to change the items content and to cite the reference of the original article in the list of references.

The instrument

The Kidney Disease Knowledge scale is a self-administered questionnaire created by Devins, et al. (1990). Binik, et al (1990) aimed to study the level of knowledge of patients undergoing hemodialysis. The tool was firstly designed with 43 items but the final version was consisted of 25 items. However, the 25-item KDQ did not satisfy the researchers who modified it dividing it in two forms of 13 items each (Form A and Form B). Each form consists of 13 multiple choice type questions.

The KDQ ask HD patients about eight fields of ESRD under HD: kidney anatomy, kidney function, hemodialysis, peritoneal dialysis, fluid intake, diet, transplantation, medication. The total score is calculated by adding the marks of the responses in 26 questions (0-26) with the highest values correspond to higher levels of knowledge (Devins et al 1990). Cronbach's alpha for the Form A was 0.75 while for the Form B was 0.85.

Steps of translation

Translation was carried out according to World Health Organization (WHO) guidelines (http://www.who.int/substance_abuse/research_tools/translation/en/).

The procedure included the independent translation of the original English questionnaire (forward translation) in the Greek language by two different health care professionals. After that a comparison of

the two translations was carried out by a third health care professional and a reconciled version was created. A backward translation of this version of the questionnaire was made by a bilingual person whose maternal language is English who was also a professional translator and was not aware of the original version of the questionnaire. The backward translation was sent to the creators of the questionnaire for comments. Their comments were incorporated giving a second Greek version of the questionnaire (2nd reconciliation version) which it was agreed to be used for the pilot testing of the questionnaire.

Cultural adaptation

A pilot testing of the questionnaire carried out in a purposive sample of 10 hemodialysis patients with a variation in their demographic characteristics, who were hospitalized in a General Hospital of Athens. Thus, a form of validation of the translation and of the cultural adaptation of the questionnaire was applied. The purposive sample, who were native speakers of the Greek language, were asked to determine whether the translation is acceptable in cultural terms and if the language used in translation is simple and whether the wording used was appropriate. For achieving that a cognitive debriefing process was followed. The researcher distributed the questionnaires, gave explanations about the process and asked the subjects to say if they had any difficulties in understanding the questionnaire. In case of a problem, HD patients were requested to propose an alternative wording (cognitive debriefing interview). Minimal corrections were made to the translated questionnaire following the subjects' suggestions and thus the final version of the Greek Version of the KDQ was produced.

Data collection

The selection criteria of the sample included:

- > 18 years old
- Ability to speak, read and understand and be able to communicate in the Greek language
- Diagnosed with end stage renal disease under hemodialysis

- Patients without psychiatric illnesses.
- For all the patents it was required to give their informed consent

The data collection was based on the patient's willingness to participate in research through self-completed questionnaire.

The response rate was 100%. The sample consisted of 6 men and 4 women. The mean of age of the participants was 61 ± 10 years old.

Ethics

Researcher, after having informed the patient about the purpose of research, summarizing the questionnaire and assured to ensure their anonymity. Patients were given the informed consent document, which should be signed by the patient. Permission to carry out the study was taken by the Scientific Council of the hospital.

Results

The translation of the questionnaire was carried out according to the following minimum criteria. An attempt was made to preserve the basic characteristics of the questionnaire making all the changes to adapt it to the Greek reality. During the production of the first two independent translations, no significant differences in their content were observed. As a result, the first reconciled version was created.

In the procedure of the cultural adaptation of the questionnaire, all the participants found the questionnaire easy to be filled. The problems that the HD patients faced were mainly focused on the specialized terminology used and less in understanding of the real questions.

The average completion time was 20 minutes. In general terms, participants found the KDQ easy to understand and to fill it. After the analysis of the General Impression Instrument, we can conclude that HD patients accepted the scale very well. Totally, 90% of HD patients found the tool very good, 90% did not have difficulties with the categories of the answers while 90% answered that the questions were understandable and very important for their health status (Table 2).

Table 1: Descriptive characteristics of the sample

	Patients N=10
Age (M±SD)	(61±10)
Gender	
Males	6
Females	4
Total	10
Marital status	
Unmarried	1
Married	7
Divorced	1
Widowed	1
Total	10
Education	
Primary School	2
Secondary School	7
University	1
Total	10
Duration under hemodialysis	
(Years) (M±SD)	(5±2)

M=Mean SD= Standard Deviation

Table 2: Results from the phase of semantic validation of the Kidney Disease Questionnaire

Items of General Impression Instrument	Answers	Answers of patients % (N=10)
What is your general opinion about the questionnaire?	<ul style="list-style-type: none"> • Very good • Good 	90.0 10.0
Are the questions understandable?	<ul style="list-style-type: none"> • Yes • Difficult sometimes 	90.0 10.0
Do you think that the questions are important for your health condition?	<ul style="list-style-type: none"> • Very important • Not so important 	90.0 10.0
Did you have difficulties with the categories of answers?	<ul style="list-style-type: none"> • No • Sometimes 	90.0 10.0

Discussion

In past years nursing role focused on survival and prevention of complications of diseases. Today, this aspect has changed as well as informed patient is the aim of many health centers. Because of the great need of informed patient, many studies aim to measure patient knowledge about the illness and treatment. Hemodialysis patients have to cope with many difficulties such as limitation of fluid intake and foods contained potassium, presence in HD session, pill burden, social and economic problems as well as changes in their work status or in family environment (Theofilou et al 2013). These situations can affect their personal and social life. Faced with these difficulties, the well informed patient can successfully cope with adversities keeping the current level of quality of life (Theofilou 2011).

Faced to these problems, it is general accepted that the increased levels of patients' knowledge about the illness and treatment can lead to increased levels of adherence in therapeutic regimen and quality of life. Therefore, instruments related to patient knowledge are essential for clinical practice.

There are few questionnaires about kidney disease knowledge for patients with ESRD (Chambers & Boggs 1993, and Cavanaugh et al 2009). Studies vary in the types of knowledge measured. Some of them focus on patients' perceptions of what they know about kidney disease (perceived knowledge) (Finkelstein et al 2008, and Tan et al 2010) and

others examine what patients actually know (objective knowledge). (Chambers & Boggs 1993, Devins et al 2003, and Curtin et al 2004b, Devins et al 2005, and Gordon & Wolf 2009, and Cavanaugh et al 2009, and Wright et al 2011).

There is no study on translation and cultural adaptation of instrument measuring knowledge of HD patients in Greece. Therefore, a tool for this population was needed. In this study we tried to translate and culturally validate into Greek language the KDQ. In future study, we will explore the psychometric properties of the Greek version of the KDQ in a larger sample of hemodialysis patients.

As the KDQ consists of items with medical terms, the translation required interdisciplinary collaboration with specialized professionals such as nephrologists, renal nurses, and an official translator. For the cultural adaptation, Greek hemodialysis patients were asked to complete the questionnaire.

Regarding the items with medical terms, these were explained by others supplementary words in parenthesis. For the semantic validation, HD patients were given an interview during which the understanding of the terms, resulted from the translation process, was confirmed. The KDQ will assist nurses and other health care professionals to identify information and learning gaps and to provide individualized training programs for pre-dialysis and hemodialysis patients.

Conclusions

This publication of the Greek version of the KDQ provides the first knowledge assessment tool for the use in Greek HD patients. This is a result of a translation and cultural adaptation process in accordance with international recommended guidelines. This process enables us to explore the psychometric properties of the Greek version of KDQ. Further studies are needed for the validation of the KDQ in critically ill patients.

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