Cross-cultural adaptation and psychometric testing of the Quality of Dying and Death Questionnaire for the Spanish population

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ABSTRACT

Purpose: Many measurements have been developed to assess the quality of death (QoD). Among these, the Quality of Dying and Death Questionnaire (QODD) is the most widely studied and best validated. Informal carers and health professionals who care for the patient during their last days of life can complete this assessment tool. The aim of the study is to carry out a cross-cultural adaptation and a psychometric analysis of the QODD for the Spanish population.

Methods: The translation was performed using a double forward and backward method. An expert panel evaluated the content validity. The questionnaire was tested in a sample of 72 Spanish-speaking adult carers of deceased cancer patients. A psychometric analysis was performed to evaluate internal consistency, divergent criterion-related validity with the Mini-Suffering State Examination (MSSE) and concurrent criterion-related validity with the Palliative Outcome Scale (POS).

Results: Some items were deleted and modified to create the Spanish version of the QODD (QODD-ESP-26). The instrument was readable and acceptable. The content validity index was 0.96, suggesting that all items are relevant for the measure of the QoD. This questionnaire showed high internal consistency (Cronbach's α coefficient = 0.88). Divergent validity with MSSE ($r = -0.64$) and convergent validity with POS ($r = -0.61$) were also demonstrated.

Conclusions: The QODD-ESP-26 is a valid and reliable instrument for the assessment of the QoD of deceased cancer patients that can be used in a clinical and research setting.

1. Introduction

A high quality of death (QoD) and the dying process is currently considered an objective that should be attained in end-of-life patient healthcare (Emanuel and Emanuel, 1998; Lorenz et al., 2008; Tenzek and Depner, 2017). As such, the development and use of predictors that optimise the end-of-life experience is of particular relevance (Barbera et al., 2015; Lind et al., 2015). QoD assessment is, by definition, subjective and influenced by several elements, such as sociocultural factors or the stage and type of illness. There are other factors, e.g. the centre where the patient is treated in their final stages of life, which also play a role in the QoD. Specifically, evidence indicates that a greater quality of life for cancer patients is related to palliative care (PC) services and the use of fewer invasive treatments, such as chemotherapy (Temel et al., 2010; Zimmermann et al., 2014). Furthermore, dying at home or in a PC unit or hospice is associated with a more positive assessment of QoD than when patients die in non-specialist hospital units (Braun et al., 2014; Greer et al., 2012; Leung et al., 2010; Shih et al., 2015; Wright et al., 2010).

Due to the fact that it is not possible to assess the patient's experiences of the dying process after death, evaluations given by informal carers and by health professionals who cared for them during their last days of life can be used as indirect measurements of the patient's QoD.

There is limited information available on measuring the QoD in the Spanish culture from the point of view of informal carers. Therefore, we need instruments to help gather more evidence. There are various instruments available in the scientific literature that help to determine the QoD (Hales et al., 2010). One of the ranges of questionnaires, the Quality of Dying and Death Questionnaire (QODD) is the most widely studied tool and has demonstrated the best coverage of psychometric

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properties (Hales et al., 2010). The QODD comprises 31 items, which, upon the death of the patient, are posed to the informal carers or the health professional. The items concern the QoD in the last seven days of the patient's life (in the case of patients who were conscious throughout this period) or the last month (for patients who were unconscious during the last seven days) (Curtis et al., 2002).

These items cover six conceptual domains: symptoms and personal care; preparation for death; family concerns; treatment preferences; whole person concerns; and moment of death (Mularski et al., 2005; Patrick et al., 2001). The answer for each QODD item consists of two parts. In the first part, the participant estimates the frequency (0 = none to 5 = always) or existence (yes or no) of the aspect for the patient and, in the second part, the participant rates this aspect of the patient's dying experience. The ratings of the patient's dying experience added together, then divided by the number of items answered, divided by 10, and multiplied by 100 result in the total score (Curtis et al., 2002). The total score ranges from a minimum of zero to a maximum of 100. Higher scores indicate better QoD (Curtis et al., 2002; Heckel et al., 2015). The questionnaire has been adapted for different cultures, such as German and Latin America, where it has proven to be both a valid and reliable instrument (Heckel et al., 2015; Pérez-Cruz et al., 2017).

The aim of the study is to carry out a cross-cultural adaptation and a psychometric validation of the QODD for the Spanish population.

2. Methods

2.1. Study design

This study's design was a cross-cultural validation of the QODD.

2.2. Translation, cross-cultural adaptation and validation process

Translation, cross-cultural adaptation and validation of QODD were carried out in two principal phases: translation and cross-cultural adaptation, and validation.

2.2.1. Phase 1 – Translation and cross-cultural adaptation

The first step in the translation of the questionnaire was to ask the original author's permission and inform him of the intention to perform this study. The translation process of the QODD was authorized by the University of Washington End-of-Life Care Research Department.

An expert panel was used to assess the content validity of the questionnaire. We selected a modified Delphi technique to evaluate the content validity of the QODD tool (Boulkedid et al., 2011; Powell, 2003). The panellists were carefully selected. Professionals (experts in PC), researchers and carers were invited to join the expert panel. We invited experts from different PC services to respond to an online survey tool, and in the end, 10 experts with experience in palliative care (3 physicians, 3 nurses, 2 psychologists and 2 social workers) took part in the expert panel. These experts practised in various types of settings (hospice and regional teaching hospital).

Participants were asked to rank the items of the instrument according to their relevance. Content validity of the instrument was determined using the COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN) checklist (content validity box) (Mokkink et al., 2010). Next, the translation process was performed. In this phase, the aim was to attain semantic, idiomatic, conceptual and experiential equivalence between the Spanish and English versions (Muñiz et al., 2013). The translation was performed in accordance with the forward and backward method following recommended guidelines (Muñiz et al., 2013). First, there were two independent forward translations (English into Spanish), produced by two translators. Both versions were compared and, after consensus, 'the preliminary Spanish version of QODD' was created. Two native English translators were used to create, after consensus, a single document,
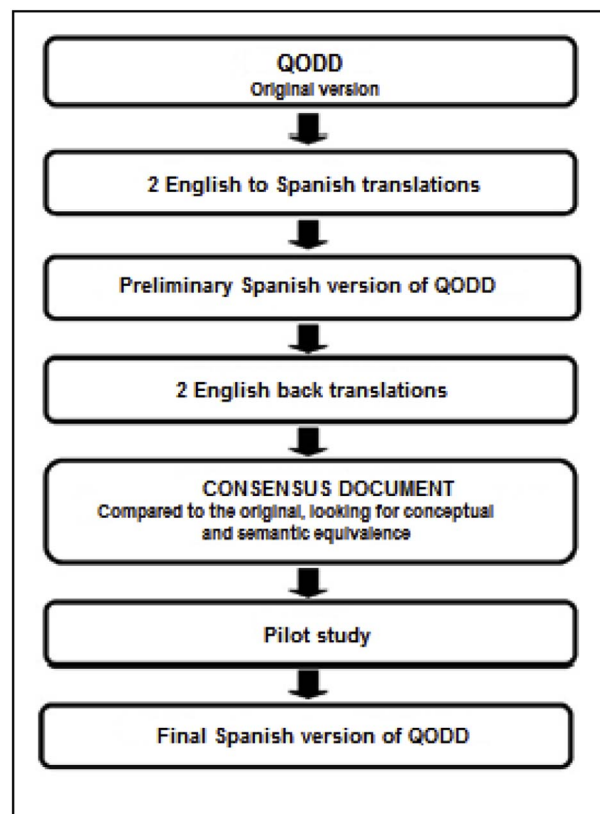

Fig. 1. Flowchart of the translation of the QODD from English to Spanish. There were two independent forward translations (English into Spanish). Both versions were compared and, after consensus, 'the preliminary Spanish version of QODD' was created. This preliminary version was translated back by two native English translators to create, after consensus, a single document. This document was compared with the original to make a consensus document ready for pilot testing. This pilot study was conducted with 32 carers to identify problematic items and to ensure that the adapted instrument was comprehensible and acceptable, following the recommendations (Muñiz et al., 2013). Participants were asked whether they found any of the questions difficult to answer, confusing or upsetting.

translating this version back into English. This document was compared with the original to make a consensus document ready for pilot-testing (Fig. 1).

2.3. Phase 2 – Psychometric analysis

Seventy-two carers participated in this phase. A psychometric analysis of internal consistency, divergent criterion-related validity with the Mini-Suffering State Examination (MSSE) and concurrent criterion-related validity with the Palliative Outcome Scale (POS) was performed.

2.3.1. MSSE

The MSSE is a valid and reliable instrument that has been designed for the assessment of the suffering level of patients with advanced dementia (Aminoff et al., 2004). This questionnaire assesses the presence of calmness, screaming, pain, pressure ulcers, malnutrition, eating disorders, performance of invasive procedures, stability of general medical condition, and patient's suffering according to medical and family opinion. These 10 items can be scored from 0 (no) to 1 (yes). A total score can be obtained by adding the individual score of each item, with a maximum possible score of 10 points (high level of suffering) (Aminoff et al., 2004). Although the MSSE was developed and validated in patients with advanced dementia, it can be used to evaluate the suffering in advanced cancer patients (Adunsky et al., 2007). This assessment tool has been translated into Spanish (Costa Requena et al.,