

# 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 cared 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  $\alpha$  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.

*Keywords:* quality of dying and death, palliative care, outcome measure, cross-cultural adaptation, psychometric properties, informal carers

## **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 & Emanuel, 1998; Lorenz et al., 2008; Tenzek, & 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 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.

## **Methods**

### *Study design*

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

### *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.

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

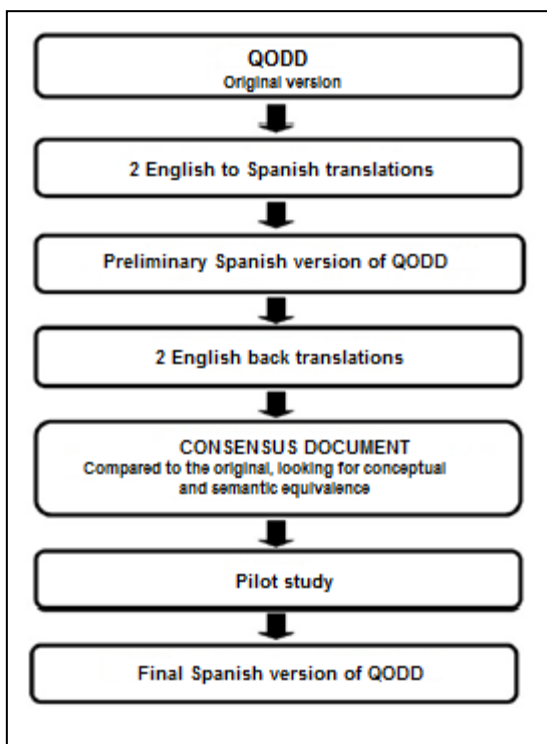


Figure1. Flowchart of the translation of the QODD from English to Spanish. There were two independent forward translations (English into Spanish). Both versions were compared and, after consensus, 'the preliminary Spanish version of QODD' was created. This preliminary version was translated back by two 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.

### *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.

#### *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., 2013).

#### *POS*

The POS is a 10-item questionnaire that has two forms, one for patients and one for staff (Hearn & Higginson., 1999).

The staff questionnaire is the focus of the present article. Both versions incorporate ten questions concerning the physical, psychological and spiritual domains of life within the field of PC (Hearn & Higginson., 1999). It assesses these domains over the previous three days of care. Each of these 10 items can be scored on a five-point Likert scale, ranging from 0 (no problem) to 4 (overwhelming problem) (Siegert et al., 2010). These items can be considered separately and can also be added together to yield a total score ranging from 0 to 40, where 0

represents the best possible care and 40 the worst (Siegert et al., 2010). The POS also includes two open questions on patients' main concerns. This questionnaire can be used to assess the quality of the PC provided. It has also been translated into several languages, including Spanish (Serra-Prat et al., 2004). The POS staff version was used in the present study as an indirect measurement to explore the concurrent criterion-related validity as in previous studies (Heckel et al., 2015).

#### *Participants, setting and procedure*

Informal carers were recruited at the Cudeca Foundation in Malaga (Spain), which is a regional hospice. Data on the informal carers (age, gender, religion, relationship to patient and days visited during the last seven days of patient's life) and the deceased patients (age, gender, religion and primary diagnosis) were collected. The inclusion criteria were: (1) Spanish-speaking adult informal carer who cared for an adult patient during their last days; (2) have signed an informed consent; (3) carer of deceased cancer patients cared for by the PC programme of the Cudeca Foundation.

By contrast, the exclusion criteria used was: mild cognitive impairment. Data were collected between January 2016 and October 2016.

Potential participants who met the inclusion criteria were selected after reviewing deceased patients' medical histories. One to six months after the patients' deaths, a letter was sent to the informal carers expressing condolences, and then they were contacted via telephone to inquire into their willingness to participate in the study. Those who wanted to take part were informed about the study procedure, personal data protection and the need to sign an informed consent form in order to participate. After giving written consent, they received the questionnaires to be answered and the instructions. All of these documents were returned to us once they were completed.

#### *Statistical analysis*

Descriptive analysis was applied to calculate the means and standard deviation of demographic and clinical variables. Kolmogorov–Smirnov test was performed to determine the distribution of the sample. A bivariate correlation by Pearson was used. Content validity was determined using the Lawshe method (Lawshe, 1975).

Statistical analysis was performed to evaluate internal consistency and criterion-related validity. To determine the internal consistency of the scale items, Cronbach's  $\alpha$  coefficients was calculated using the Intraclass Correlation Coefficient Type 2.1 (ICC<sub>2.1</sub>) (Cronbach, 1951). Criterion-related validity was determined through the concurrent use of the POS total score and the divergent use of the MSSE total score. This was performed using the Pearson correlation coefficient. Data was entered into a data file and analysed using a SPSS statistical program (version 20).

### *Ethical considerations*

This study has been approved by the Ethics Committee of Area of Costa del Sol of Málaga (Spain). Standards of good clinical practice and the ethical principles established for research on human beings, according to the Declaration of Helsinki and its subsequent revisions, were maintained at all times.

Clinical data were segregated from personal identification data and the databases were encrypted and stored on computers specifically reserved for this project. Prior to study participation, carers received information about the content and extent of the study.

## **Results**

### *Participants*

A total of 176 informal caregivers were identified after screening for the inclusion and exclusion criteria. Contact information was invalid in ten cases. A total of 85 surveys were returned and 13 cases were removed due to items missing (more than 25%). Seventy-two (72) carers (52 female, aged 51.11±11.69) finally participated in the present study. Most of the participants were daughters (29), sons (11) and spouses (11) who visited the patient on a mean of 6.33 days (SD±0.75) during the last seven days of the patient's life. The mean age of the deceased who were cared for by the Cudeca PC programme was 72.11 (SD±12.46), 39 of whom were females. All the deceased had a cancer diagnosis. The mean QODD total score was 64.56 (SD±20.97). Two items were dropped from the analysis because a high percentage of respondents answered as 'not applicable' (79% for spending time with pets and 75% for use of a mechanical ventilator or kidney dialysis to prolong life). The missing values do not exceed 2%.

Table 1. Demographic Data of Informal Caregivers (n=72)

<b>Characteristics</b>	<b>Frequency</b>
Age (mean, SD)	51.11 ( $\pm$ 11.69)
Gender	
Male	20
Female	52
Ethnicity	
Caucasian	72
Relationship to patient	
Spouse	11
Son	11
Daughter	29
Sister	4
Brother	0
Other relative	17
Days visited during last seven days of patient's life, (mean, SD)	6.33 ( $\pm$ 0.75)
Number of days between death and interview, (mean, SD)	172 ( $\pm$ 55)

Table 2. Patients' Demographic and Clinical Data (n=72)

<b>Characteristics</b>	<b>Frequency</b>
Age (mean, SD)	72.11 ( $\pm$ 12.46)
Gender	
Male	33
Female	39
Ethnicity	
Caucasian	70
Others	2
Place of Death	
Home	39
Hospice	8
Hospital	24
Others	1
Primary Diagnosis	
Malignant neoplasms of:	
lip, oral cavity and pharynx	1
digestive organs	24
respiratory and intrathoracic organs	10
Melanoma and other malignant neoplasms of skin	1
breast	10
female genital organs	6
male genital organs	4
urinary tract	4
eye, brain and other parts of central nervous system	7
lymphoid, haematopoietic and related tissue	5

### *Phase 1– Translation and cross-cultural adaptation*

After review by the expert panel, three items – ‘How often did X appear to have the energy to do most things that s/he wanted to do?’; ‘Did X attend any important events – for example, weddings, graduations and birthdays?’ and ‘Did X have the means to end her/his life if s/he needed to?’ – were deleted because less than eight experts rated these items as non-essential. Three items – ‘How often did X spend time with her/his spouse or partner?’; ‘How often did X spend time with her/his children?’ and ‘How often did X spend time with other family and friends?’– were merged into one item: ‘How often did X spend time with her/his family and friends?’

After using the formula suggested by Lawshe, the total content validity index (CVI) was 0.96 (item range from 0.78 to 1), which was acceptable according to Lawshe and Davis (Davis, 1992; Lawshe, 1975). None of the items was found problematic, confusing or upsetting. However, in the case of item 14 (‘Did X appear to find meaning and purpose in her/his life?’) one respondent reported that the question needed to be made more specific, because it is difficult to answer. This question was analysed and after consensus, minor language changes were made. The final 26-item Spanish version of the QODD (QODD-ESP-26) was demonstrated to be comprehensible readable and acceptable by the target population (Additional file 1).

### *Phase 2 – Psychometric analysis*

The internal consistency analysis was satisfactory. Cronbach’s alpha coefficient of the full questionnaire was 0.88, and the intraclass correlation coefficient was 0.88 (95% CI 0.82 to 0.94) (Table 3 and Table 4).

With regard to concurrent criterion-related validity, the total score of the QODD-ESP-26 showed a moderate correlation with the total score of POS ( $r = -0.61$ ).

Divergent criterion-related validity between QODD-ESP-26 and MSSE was also demonstrated, with a value of  $r = -0.64$  (Table 4).

Table 3. Descriptive statistics and internal consistency for items from the QODD-ESP-26

<b>QODD-ESP-26 Items</b>	<b>Mean <math>\pm</math> SD</b>	<b>Kurtosis</b>	<b>Corrected item-total correlation</b>	<b>Cronbach’s alpha if item deleted</b>
Pain under control	6.4 ( $\pm 3.19$ )	-1.08	0.82	0.88
Control over what was going on	5.73 ( $\pm 3.08$ )	-1.06	0.78	0.87

Ability to feed him/herself	5.16 ( $\pm$ 3.27)	-1.18	0.59	0.87
Control of bladder and bowels	5.26 ( $\pm$ 3.08)	-1.30	0.45	0.88
Breathing comfort	5.86 ( $\pm$ 3.04)	-1.30	0.57	0.88
At peace with dying	5.40 ( $\pm$ 3.65)	-1.19	0.88	0.87
Unafraid of dying	5.63 ( $\pm$ 3.73)	-1.35	0.86	0.87
Ability to laugh and smile	4.93 ( $\pm$ 3.48)	-1.14	0.79	0.87
Being worried about being a burden to their loved ones	5.13 ( $\pm$ 3.41)	-1.13	0.68	0.87
Maintained dignity and self-respect	6.80 ( $\pm$ 3.46)	-0.63	0.67	0.87
Time with family and friends	8.16 ( $\pm$ 2.56)	1.14	0.65	0.87
Time alone	8.76 ( $\pm$ 1.88)	1.89	0.58	0.89
Meaning and purpose in life	7.23 ( $\pm$ 3.10)	0.40	0.57	0.88
Physical expressions of affection	8.63 ( $\pm$ 2.45)	3.55	0.63	0.87
Health-care costs covered	8.23 ( $\pm$ 2.47)	1.14	0.58	0.88
Goodbyes said	6.50 ( $\pm$ 3.86)	-1.11	0.78	0.88
Spiritual advisor visits	7.16 ( $\pm$ 2.98)	-0.78	0.70	0.87
Spiritual ceremony before death	6.86 ( $\pm$ 2.86)	-0.67	0.68	0.88
Bad feelings cleared up	6.93 ( $\pm$ 3.75)	-0.94	0.74	0.87
Funeral arrangements in order	8.36 ( $\pm$ 2.39)	0.92	0.42	0.88
End-of-life care discussion with doctor	7.66 ( $\pm$ 2.49)	-0.51	0.45	0.88
Place of death	7.53 ( $\pm$ 2.97)	0.71	0.54	0.88
Having others present at time of death	8.03 ( $\pm$ 2.97)	0.50	0.57	0.88
State of consciousness in moment before death	6.50 ( $\pm$ 3.77)	-0.72	0.59	0.88

Table 4. Internal consistency, convergent and divergent validity of the QODD-ESP-26

Psychometric property	Results
Internal consistency, Cronbach's alpha	$\alpha = 0.88$
Convergent concurrent criterion-related validity with POS	$r = -0.61$
Divergent criterion-related validity with MSSE	$r = -0.64$

## Discussion

The current study provides evidence for the validity of the QODD-ESP-26. To the best of our knowledge, this study is the first cross-cultural adaptation and psychometric analysis of the QODD-ESP-26 performed in Spain, although a study in which a 12-item QODD was developed and validated in a Latin American population has been published recently (Pérez-Cruz et al., 2017). In this context, Spanish is one of the languages questionnaires are most often adapted to, the native speakers being distributed in more than 30 countries and having large cultural

differences (Lewis et al., 2014; Vallejo-Medina et al., 2017). Furthermore, QoD assessment is influenced by several elements, such as sociocultural factors from the context in which it is evaluated. For this reason, we decided to validate the QODD in Spain, given that there are differences between the Latin American and Spanish cultures.

QoD is a difficult construct to measure and define. In light of this, evaluations given by family members or close friends who cared for the deceased during their last days of life can be used as indirect measurements to assess the patient's QoD. In this study, an after-death assessment of deceased cancer patients given by informal carers was used to estimate the QoD. The results showed adequate values of QoD assessed by family members of patients cared for in our PC programme ( $64.56 \pm 20.97$ ). These values are higher than those reported by Mularski et al. for an intensive care unit population ( $60 \pm 14$ ) (Mularski et al., 2005) and ( $61.8 \pm 23.8$ ) (Glavan et al., 2008). In comparison with other studies in the cancer population, our results showed higher values of QoD than those found by Braun et al. ( $57.2 \pm 15$ ). In this sense, hospice care is associated with better symptom management and quality of end-of-life care (Braun et al., 2014). The cross-cultural adaptation and psychometric testing of this instrument were achieved satisfactorily following the recommendations of the international guidelines (Mokkink et al., 2010; Muñiz et al., 2013). In this regard, the QODD-esp-26 showed satisfactory psychometric properties in terms of content validity (Davis, 1992; Lawshe, 1975), internal consistency (Cronbach, 1951), and criterion validity (Terwee, 2007). This questionnaire has been shortened, after consensus, to create the 26-item Spanish QODD. This instrument has been demonstrated to be comprehensible and acceptable.

The content validity of the questionnaire was high, which indicates that all items are relevant for the construct measurement.

The internal consistency analysis was satisfactory (Cronbach's  $\alpha = 0.88$ ), suggesting a good homogeneity of the items. These values are in line with those reported in the initial validation of QODD (Cronbach's  $\alpha = 0.89$ ) (Curtis et al., 2002). In comparison to other recent adaptations of the QODD, the Cronbach's  $\alpha$  value of the 26-item Spanish QODD is higher than those found in the validation of the German Version of the Quality of Dying and Death Questionnaire for Informal Caregivers (QODD-D-Ang) (Cronbach's  $\alpha = 0.85$ ) (Heckel et al., 2015).

In terms of concurrent criterion-related validity, an adequate correlation with POS was demonstrated ( $r = -0.61$ ), which indicates that the QODD-ESP-26 is an adequate reflection of a previously validated tool that has been widely used to measure the outcome of PC for the last days of the patient's life. These values are higher than those found by the authors of the validation of the QODD-D-Ang ( $r = -0.54$ ) and the QODD-ESP-12 ( $r = 0.306$  with a question assessing quality of life during last week, and  $r = 0.249$  with moment of death) (Heckel et al., 2015; Pérez-Cruz et al., 2017).

Divergent criterion-related validity with MSEE was also demonstrated ( $r = -0.64$ ), suggesting that the QODD-ESP-26 measures a different construct that is not related with suffering, providing support for the evidence of construct validity.

An after-death assessment of patients with cancer will allow us to identify, evaluate and disseminate interventions that improve care at the end of life. If we want to identify these interventions, we must have reliable and valid measures of the quality of the dying experience of patients with cancer. Hence, the translation and validation of the QODD will allow the evaluation of the QoD in the Spanish population. This is an area where very little is currently known, but new knowledge is urgently needed. Thus, this study contributes to outcome assessment at the end of life in Spanish PC institutions.

A rigorous methodology for the translation, cross-cultural adaptation and validation process, following the recommended guidelines has been used in this study.

#### *Limitations of the study*

The validation study was based in only one PC centre. The results are not directly transferable to other settings.

It could be possible that informal carers who were satisfied with the conditions, treatment and care were willing to participate and give positive feedback in appreciation of the centre.

As carers might have had difficulties determining the QoD for patients who were unconscious or unable to communicate in their last days of life, their QoD is not represented in the findings.

Effects related to memory have to be taken into account for retrospective evaluations by carers.

In this context, the evaluation of the quality of dying and death could be affected by the time from death to the evaluation, the optimal timing for collecting data from informal carers being an

important topic of research (Fowler et al., 1999). Proxy reports after death can be obtained at varying time intervals post-death. In this regard, one to six months after a patient's death is a conventional time point for evaluating this construct, a similar period of time being used in other studies (Heckel et al., 2015). In this study, a letter was sent to the informal carers in this period of time after the death to ensure clear recall of events without being intrusive during acute grief. However, other intervals may provide more accurate data. Thus, future research should explore the optimal timing for collecting data from bereaved carers.

Inter-rater reliability, structural validity, sensitivity to change and minimally important differences have not been assessed in this study. Hence, further studies assessing these psychometric properties should be carried out across a wide sample, following the recommendations (Costello & Osborne, 2005).

## **Conclusions**

The 26-item Spanish version of the QODD showed good acceptability and psychometric properties, and provided a valid instrument to assess the QoD in the Spanish population.

Thus, the QODD-ESP-26 is a valid and reliable instrument for the assessment of the QoD that can be used in clinical and research setting.

A future study using a wide sample is needed.

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