



REVISIONES

The Quality of Death Perceived by Caregivers of Patients in Palliative Care

Calidad de la muerte percibida por los cuidadores de pacientes en cuidados paliativos

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ABSTRACT:

Objective: To determine the quality of dying and death in an advanced oncology population, and to analyze the association with the suffering and the quality of attention at the end of life.

Methods: A cross-sectional, descriptive, correlational design was used. For the evaluation of the quality of dying and death, the Spanish version of the Quality of Dying and Death Questionnaire was used. Suffering was assessed with the Mini-Suffering State Examination and the quality of end-of-life care was evaluated with the Palliative care Outcome Scale.

Results: 74 relatives of deceased patients were included in this study. The mean total score of the Spanish version of the Quality of Dying and Death Questionnaire was 64.58 (\pm 20.98). A negative correlation between the quality of dying and death and the suffering was found ($r = -0.63$), and a positive correlation between the quality of dying and death and the quality of the attention at the end of life was found ($r = 0.62$).

Conclusion: Quality of dying and death in advanced cancer population is positively related to the quality of the attention at the end of life and negatively related to suffering. Palliative care can contribute to achieving a satisfactory quality of dying and death of advanced cancer patients.

Keywords: Quality of dying and death; Outcome measure; Palliative care; Nursing; End of life care.

RESUMEN:

Objetivo: Determinar la calidad de la muerte y del proceso del morir en población oncológica avanzada, y analizar su asociación con el sufrimiento y la calidad de la atención al final de la vida.

Método: Estudio descriptivo, correlacional, de corte transversal en el que participaron los cuidadores principales de los pacientes oncológicos fallecidos en cuidados paliativos. Para la evaluación de la calidad de la muerte y del proceso del morir se utilizó la versión española del Quality of Dying and Death Questionnaire. El sufrimiento fue evaluado con el Mini-Suffering State Examination y la calidad de la atención al final de la vida con la Palliative care Outcome Scale.

Resultados: 74 cuidadores familiares de pacientes paliativos fallecidos participaron en este estudio. La puntuación media de la versión española del Quality of Dying and Death Questionnaire fue de 65,58 (\pm 20,98). Se encontró una correlación negativa entre la calidad de la muerte y el sufrimiento ($r=-0,63$) y positiva entre la calidad de la muerte y la calidad de la atención al final de la vida ($r=0,62$).

Conclusión: La calidad de la muerte de los enfermos oncológicos avanzados en cuidados paliativos se relaciona positivamente con la calidad de la atención al final de la vida y negativamente con el sufrimiento. La atención paliativa contribuye a alcanzar niveles satisfactorios en la calidad de la muerte y del proceso del morir de los pacientes oncológicos avanzados.

Palabras clave: Calidad de la muerte; Medida de resultados; Cuidados paliativos; Enfermería; Cuidados al final de la vida.

INTRODUCTION

The incidence and prevalence of cancer has increased in recent years and it is the second most common cause of death worldwide^(1,2). In this regard, palliative care (PC) in advanced cancer patients have a special relevance⁽³⁾. The prevention and relieving of suffering in PC is essential for achieving the “good death” of patients with life-threatening diseases^(4,5). A high quality of death (QoD) is currently considered an objective that should be attained in end-of-life patient healthcare⁽⁶⁻⁸⁾. In this context, the development and use of indicators that optimise the end-of-life experience is of particular relevance^(9,10). The evaluation of the QoD is subjective by definition, and is influenced by several factors, such as sociocultural, or the stage and type of disease. In addition, there are other factors, such as the place where the patient is treated at the end of life, the suffering experienced by the patient, and the quality of care received which also play an important role in the QoD⁽¹¹⁻¹⁶⁾. Because it is difficult to evaluate the patient’s experiences of their own death process when they are still alive, the evaluations performed by the informal caregivers and by the health professionals who looked after them can be used as indirect measures from the patient’s QoD (proxy)⁽¹⁷⁾. There is little available evidence on the measurement of QoD perceived by informal caregivers in the Spanish context.

The aims of this study were to: (1) analyse the QoD of advanced cancer patients in PC, (2) explore the association between QoD and suffering, and (3) explore the association between QoD and the quality of care at the end of life.

METHOD

Participants and procedure

This research was conducted using a multicenter cross-sectional and correlational design. The informal caregivers of the deceased advanced cancer patients participated in this study. Caregivers were recruited in two PC centres of Málaga (Regional University Hospital of Málaga and Cudeca Foundation) as part of a larger study in which we carried out a cross-cultural adaptation and validation of an instrument for measuring QoD in the Spanish culture⁽¹⁸⁾. Data were collected on the deceased patients and on their informal caregivers. The inclusion criteria were: (1) Spanish-speaking adult informal caregivers who cared for an adult patient during his or her last days of life; (2) those who had signed an informed consent; and (3) informal caregivers of deceased patients cared for by the PC programme of the participating centres. The exclusion criteria used was cognitive impairment. The data were collected between January and November 2016.

Informal caregivers who met the inclusion criteria were selected after consulting medical records of deceased patients. One to six months after the death of an advanced cancer patient, a letter of condolence was sent to the informal caregivers of the deceased. After that, they were contacted to inquire about their availability to participate in the present study. Informal caregivers who accepted to participate in the study were informed about the methodology, procedure and the protection of personal data. After giving their written consent, the informal caregivers received the questionnaires to complete. All questionnaires were sent to the participating centres.

Instruments

Spanish version of the Quality of Dying and Death Questionnaire (QODD-ESP-26)

This is one of the most used instruments for assessing QoD and with better psychometric properties⁽¹⁷⁾. This questionnaire has been adapted to different cultures such as German, Latin American and Spanish⁽¹⁸⁻²⁰⁾. The Spanish version of the Quality of Dying and Death Questionnaire (QODD-ESP-26) was used in this study. This is a valid and reliable instrument to assess the QoD in Spanish population⁽¹⁸⁾. This questionnaire comprises 26 items, which, upon the death of the patient, were posed to the informal caregivers⁽¹⁸⁾. The items concern the QoD in the last seven days of the patient's life (for patients who were conscious throughout this period) or the last month (in the case of patients who were unconscious during the last seven days)⁽²¹⁾. The original version of the instrument cover six conceptual domains: symptoms and personal care; preparation for death; family concerns; treatment preferences; whole person concerns; and moment of death⁽²²⁾. The items of this instrument consist of two parts. In the first part, the caregiver evaluate the frequency (0 = none to 5 = always) or existence (yes or no) of the aspect for the patient and, in the second part, the caregiver rates this aspect of the patient's dying experience. As the original version, 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 an overall score. An overall score can be obtained by adding the ratings of the patient's dying experience, then divided by the number of items answered, divided by 10, and multiplied by 100⁽¹⁹⁾. The overall score ranges from zero to 100, with higher scores indicating better QoD⁽¹⁸⁾. The overall score can be grouped into three categories: "terrible to poor" (0-29), "neither good nor bad" (30-69), and "good to almost perfect" (70-100).

Mini-Suffering State Examination (MSSE)

The MSSE has proved to be a valid and reliable questionnaire to measure suffering in patients with advanced dementia⁽²³⁾. This questionnaire comprises 10 items assessing the presence of restlessness, screaming, pain, pressure ulcers, malnutrition, eating disorders, performing invasive procedures, stability of the general medical condition and the suffering of the patient according to medical and family opinion. These 10 items can be classified as 0 (no) or 1 (yes). An overall score of the MSSE is calculated by adding the score of each item, with a maximum score of 10 points (high level of suffering)⁽²³⁾. Although MSSE has proved to be a valid and reliable instrument to measure suffering in patients with dementia, it has been used to assess suffering in advanced cancer population⁽²⁴⁾. This tool for evaluating suffering has been translated into Spanish⁽²⁵⁾.

Palliative Outcome Scale (POS)

This questionnaire comprises ten items about the physical, psychological and spiritual dimensions of the PC⁽²⁶⁾. Each of these 10 items is scored with a Likert scale of five points⁽²⁶⁾. Although these items can be considered separately, an overall score can be calculated. The overall score range from 0 (the best possible care) to 40 (the best possible care)⁽²⁷⁾. The POS also includes two open questions about the main concerns of patients. This measure can be used to evaluate palliative concerns, needs, and quality of care at the end of life. This instrument has been translated into different languages including the Spanish⁽²⁷⁾.

Statistical analysis

A descriptive analysis was performed to estimate the demographic and clinical variables. The questionnaire items' responses were calculated with percentages. Distribution and normality were determined by one-sample Kolmogorov-Smirnov test. Pearson correlation coefficient was used to explore the associations of the QoD with the suffering and the quality of care provided at the end of life. The value of $p < 0.05$ was taken as statistically significant. The statistical programs SPSS version 20.0 was used to carry out the statistical analysis.

Ethical aspects

This study was approved by the Provincial Ethics Committee of Málaga and the Ethics Committee of Area of Costa del Sol of Málaga (Spain). The study complied with the principles laid out in the Declaration of Helsinki. Clinical data were segregated from personal identification data and the databases were encrypted and stored on computers specifically reserved for this project. Each participant received a detailed explanation of the study and gave written informed consent before participation.

RESULTS

Socio-demographic and clinical characteristics of the sample

179 family caregivers were identified and assessed for eligibility. The contact information was not valid in ten cases. Eighty-eight surveys were returned and 14 cases were eliminated due to the high percentage of unanswered responses (more than 25%). 74 informal caregivers participated in the present study. Most of participants were daughters (31), sons (11) and spouses (11) who visited the patient an average of 6.39 days (± 0.75) during the last 7 days of the patient's life (Table 1). The average age of the deceased patients was 72.41 (± 12.56), 41 of whom were females. All of the deceased had a diagnosis of cancer (Table 2). The mean total score of QODD-ESP-26 was 65.58 (± 20.98). The mean total score of QoD per category is described in Table 3.

Table 1. Demographic data of informal caregivers (N=74)

Characteristics	Frecuency
Age (mean, SD)	52.21 (±11.79)
Gender	
Male	20
Female	54
Ethnicity	
Caucasian	74
Relationship to patient	
Spouse	11
Son	11
Daughter	31
Sister	4
Other relative	17
Days visited during last seven days of patient's life, (mean SD)	6.39 (±0.75)
Number of days between death and data collection, (mean, SD)	174 (±56)

Source: Research data
Values represent frequency (n) or mean (SD)

Table 2. Demographic and clinical data of patients (N=74)

Characteristics	Frequency
Age (mean, SD)	72.41 (±12.46)
Gender	
Male	33
Female	41
Ethnicity	
Caucasian	72
Others	2
Place of Death	
Home	41
Foundation	8
Hospital	24
Others	1
Primary diagnoses	
Malignant neoplasms of: digestive organs	26
respiratory and intrathoracic	10

organs	
breast	10
eye, brain and other parts of central nervous system	7
female genital organs	6
lymphoid, haematopoietic and related tissue	5
male genital organs	4
urinary tract	4
others	2

Source: Research data

Values represent frequency (n) or mean (SD)

Association between QoD and suffering

After exploring the association between QoD and suffering, the results obtained indicated that there was a negative and statistically significant relationship between these two variables ($r = -0.63$, $p=0.000$), and therefore the QoD was higher in those patients with a lower level of suffering.

Association between QoD and the quality of care at the end of life

The association between QoD and the quality of care provided at the end of life was also explored. The results indicated that there was a positive and statistically significant relationship between these two variables ($r = 0.62$, $p=0.000$), and therefore the QoD was higher when the quality of care was high.

Tabla 3. Total score of QODD-ESP-26 per category

Overall QoD per category	Frequency	Percentage
Terrible to poor	5	6.8
Neither good nor bad	37	50
Good to almost perfect	32	43.2
Overall score (mean, SD)	65.58	± 20.98

Source: Research data

Values represent frequency (n) or mean (SD)

DISCUSSION

Callahan identifies two goals in the field of health, considered to be of equal priority and importance: (1) prevent and cure diseases, the traditional goal of medicine; and (2) help people die in peace⁽²⁸⁾. Hence, it is not only a matter of preserving life at any price, but also of alleviating suffering and trying to preserve the life that, in the patient's opinion, deserves to be lived⁽²⁰⁾. In this sense, PC plays a fundamental role in the prevention and relieving of suffering through the multidimensional approach.

This is to the best of our knowledge the first study carried out in Spain in which the QoD and its association with suffering and quality of care in an advanced oncology population in PC is analysed. In this context, factors, such as the place where the

patient is treated at the end of life, play an important role in the QoD. The evidence indicates that higher levels of quality of life in advanced cancer population are related to the care received in PC units and to the use of fewer invasive treatments, such as chemotherapy^(11,12). In addition, dying at home or in a PC unit is related to a higher positive evaluation of QoD; otherwise it occurs when patients die in non PC units^(13,14). In this context, the results of this study showed satisfactory values of QoD of patients cared for by the PC program of the participating centers (65.58 ± 20.98). These values were negatively associated with suffering and positively associated with the quality of care at the end-of-life. These results are comparable to those obtained in other studies^(21,29). The values of QoD of this study are higher than those of patients in intensive care units (60 ± 14) and (61.8 ± 23.8)⁽²²⁾. In comparison with others studies carried out in advanced cancer population, the values of QoD of this study are higher than those reported by Braun et al. (57.2 ± 15)⁽¹¹⁾. In this sense, PC services are related to a better symptom management and quality of care at the end of life⁽¹¹⁾. Although the QoD is a difficult construct to measure and define, the evaluations carried out by informal caregivers could be used as an indirect measure of the QoD. In this study, the information provided by the informal caregivers of the deceased patients was used to estimate the QoD. Thus, an after-death evaluation of advanced cancer patients through an informal caregiver who was with the patient in his last days of life will allow us to identify, assess and disseminate interventions that improve the end-of-life care in the advanced cancer population. If we want to identify these interventions, we must use valid and reliable QoD measures such as the QODD-ESP-26. This is an area where very little is currently known, and more evidence is needed. In this regard, the present study provides evidence on QoD in Spanish PC institutions.

There are some limitations in the present study. This is a study with a cross-sectional and correlational design that was conducted in only two centres and the results are not directly transferable to other centres. It could be possible that the informal caregivers, who were satisfied with the care provided by the participating centres, were willing to participate and give positive feedback in gratitude to the centres.

Informal caregivers may have experienced difficulties in determining the QoD of patients who were unconscious or unable to communicate in their last days of life, therefore the QoD of these patients may not be represented in the findings. The measure of the QoD could be affected by the time elapsed between the death and the moment of the evaluation, the optimal moment to collect data from the family caregiver of the deceased patient being an important area in the investigation.

CONCLUSIONS

The QoD of advanced cancer patients in PC is positively related to the quality of care at the end of life and negatively related to suffering. The QoD is a difficult construct to measure and define. In this context, evaluations carried out by informal caregivers can be used as an indirect measure of the QoD of the patient. PC contributes to achieving satisfactory levels in the QoD of advanced cancer patients.

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