

Un instrumento para medir la calidad de muerte en  
instituciones de larga estancia: Adaptación cultural,  
validación y otros análisis relevantes



**UNIVERSIDAD  
DE GRANADA**

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**TESIS DOCTORAL**

PROGRAMA DE DOCTORADO EN MEDICINA CLÍNICA Y SALUD PÚBLICA

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*Muere lentamente quien no viaja,  
quien no lee,  
quien no oye música,  
quien no encuentra gracia en sí mismo.*

*Muere lentamente  
quien destruye su amor propio,  
quien no se deja ayudar.*

*Muere lentamente quien se transforma en esclavo del hábito  
repetiendo todos los días los mismos trayectos,  
quien no cambia de marca,  
no se atreve a cambiar el color de su vestimenta  
o bien no conversa con quien no conoce.*

*Muere lentamente quien evita una pasión y su remolino de emociones,  
justamente estas que regresan el brillo  
a los ojos y restauran los corazones destrozados.*

*Muere lentamente quien no gira el volante cuando esta infeliz  
con su trabajo, o su amor,  
quien no arriesga lo cierto ni lo incierto para ir detrás de un sueño  
quien no se permite, ni siquiera una vez en su vida,  
huir de los consejos sensatos...*

*¡Vive hoy!*

*¡Arriesga hoy!*

*¡Hazlo hoy!*

*¡No te dejes morir lentamente!*

*¡No te impidas ser feliz!*

Martha Medeiros. Escritora.



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## Artículos:

Esta tesis doctoral se presenta como un compendio de 4 estudios. Cada uno de ellos responde a los distintos objetivos planteados en el plan de investigación de la tesis doctoral y aprobado el diez de mayo de dos mil dieciocho por La Comisión de Evaluación del Programa de Doctorado de Medicina Clínica y Salud Pública de la Universidad de Granada. A continuación, se desglosan los artículos publicados de los que derivan:

### Estudio 1:

- **Título:** Prospective Evaluation of Intensity of Symptoms, Therapeutic Procedures and Treatment in Palliative Care Patients in Nursing Homes.
- **Autores:** Daniel Puente-Fernández, Concepción B Roldán-López, Concepción P Campos-Calderón, Cesar Hueso-Montoro, María P García-Caro, Rafael Montoya-Juarez.
- **Revista:** Journal of Clinical Medicine.
- **Factor de impacto por Journal Citation Report:** 4.242.
- **Categoría:** MEDICINE, GENERAL & INTERNAL.
- **Posición en la categoría:** 39/167.
- **Cuartil:** Q1.
- **Año de publicación:** 2020.

### Estudio 2:

- **Título:** Palliative care symptoms, outcomes, and interventions for chronic advanced patients in Spanish nursing homes with and without dementia.
- **Autores:** Daniel Puente-Fernández, Concepción Petra Campos-Calderón, Ana Alejandra Esteban -Burgos, César Hueso-Montoro, Concepción Beatriz Roldán-López, Rafael Montoya-Juárez.
- **Revista:** International Journal of Environmental Research and Public Health.
- **Factor de impacto por Journal Citation Report:** 3.390.
- **Categoría:** PUBLIC, ENVIRONMENTAL & OCCUPATIONAL HEALTH.
- **Posición en la categoría:** 41/176.
- **Cuartil:** Q1.
- **Año de publicación:** 2020.

### Artículo 3

- **Título:** Nursing Professionals' Attitudes, Strategies, and Care Practices Towards Death: A Systematic Review of Qualitative Studies.
- **Autores:** Daniel Puente-Fernández, María Mercedes Lozano-Romero, Rafael Montoya-Juárez, Celia Martí-García, Concepción Campos-Calderón, César Hueso-Montoro.
- **Revista:** Journal of Nursing Scholarship.
- **Factor de impacto por Journal Citation Report:** 3.176.
- **Categoría:** NURSING.
- **Posición en la categoría:** 10/124.
- **Decil:** D1.
- **Año de publicación:** 2020.

### Artículo 4:

- **Título:** Cultural adaptation and validation of the quality of dying in long-term care scale (Qod-ltc) for spanish nursing homes.
- **Autores:** Daniel Puente-Fernández, Rosel Jimeno-Ucles, Emilio Mota-Romero, Concepción Roldán, Katherine Froggatt, Rafael Montoya-Juárez.
- **Revista:** International Journal of Environmental Research and Public Health.
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Además de los artículos publicados se han presentado las siguientes comunicaciones en congresos internacionales.

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## *Summary (In English)*

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## **1. Summary (In English)**

How is the end-of-life care in Spanish nursing homes? How does the attitude of the professional providing the care influence its quality? How can we evaluate the quality of care objectively? This Doctoral Thesis titled "An instrument to measure the quality of death in long-term care settings: cultural adaptation, validation and other relevant analyses" investigates these questions. This work bridges research projects financed by two separate regional grants (which ones?). The author belongs to the research group "Psychosocial and transcultural aspects of health and illness" (CTS-436).

This thesis follows the format of a grouping of publications, in which four articles published in journals with high impact factors measured by the Journal Citation Report have been included. The articles were published as follows: Article 1 in a Q1 journal in the MEDICINE, GENERAL & INTERNAL category; Articles 2 and 4 in a Q1 journal in the PUBLIC, ENVIRONMENTAL & OCCUPATIONAL HEALTH category of social sciences; and Article 3 in a D1 journal in the NURSING category.

Population aging is accompanied by an increasing level of dependence, a prevalence of chronic diseases, and a growth in the demand for care among people over 65 years old. To face these situations, more and more people are moving from their home into a nursing home, either by their own decision or because they require a complex long-term care.

With an average age of 80 years old, the nursing homes' residents include a higher proportion of women. Furthermore, a higher prevalence of chronic diseases has been observed amongst these residents compared to the general population. These patients also have a higher prevalence of dependency, cognitive impairment, frailty and complexity (of what?).

It has been reported that symptoms such as pain, anxiety, confusion, shortness of breath, and nausea are common in the last week of life in nursing home residents. Specifically for patients with dementia, symptoms such as pain, urinary and faecal



incontinence, infections, restlessness, oedema, and psychological and behavioural conditions are particularly prevalent at the end of life.

In order to improve palliative care provision in nursing homes, two European projects (PACE and Namaste) and one regional project (NUHELP) have been developed with the aim of providing knowledge, protocols and tools to improve palliative care in these centres.

The end of life and death is imbued with social and cultural meanings. This event generates feelings of frustration, fear, and insecurity in health professionals who have to take care of people at the end of life. Within this group, nursing professionals are the most numerous. Therefore, the way in which professionals deal with the end of life and death of their patients may influence their perspective of what is a good or bad death and the care they provide.

Quality of Death and Dying (QoD) is defined as the degree to which a person's preferences for dying and the timing of death are consistent with other people's observations of how that person dies. This concept refers to an external observation of the phenomenon and includes aspects such as comfort and convenience, preferences and expectations, and the relationship and communication with professionals.

While the concept is well-defined, we do not have an objective way of assessing it. This thesis is the first work to introduce a validated instrument for nursing homes in Spain that assesses this construct. Internationally, we find the *Quality of Dying in Long-Term Care* (QoD-LTC) scale, which consists of eleven items and three factors. This post-mortem scale assesses the last month of life of the nursing home resident from the perspective of nurses and family members.

For the cultural adaptation and validation of the QoD-LTC to the Spanish context, the psychometric characteristics of the instrument (validity, reliability and feasibility) must be evaluated. Besides, the Likert-type scale is a categorical scale, and it cannot be assumed that the psychological distance is the same between subsequent response options. Therefore, it is convenient to use a visual analogue scale (VAS) which results in

a continuous variable and gives the option of using the Likert scale instead of the five-choice Likert scale.

The objectives were developed in four studies: two observational studies, one systematic review with meta-synthesis, and one questionnaire validation study.

1. Exploring the perception of symptom control, pharmacological treatments, and therapeutic procedures provided to patients in their last six months of life (Article 1).

A longitudinal study was carried out in a sample of 107 residents who met the criteria of the Spanish Society of Palliative Care (SECPAL). Symptom intensity was assessed using the Edmonton Symptom Assessment Scale (ESAS), therapeutic procedures and pharmacological treatment. Month-to-month evolution and differences between those patients who died during the follow-up and those who did not, were evaluated.

Results showed that all symptoms increased in intensity in the last week of life. When comparing between the deceased and non-deceased cohorts, symptoms were more intense in those who had died during the follow-up ( $p < 0,05$ ). The use of aerosols ( $p = 0,008$ ), oxygen therapy ( $p < 0,001$ ), opioids ( $p < 0,001$ ), antibiotics ( $p = 0,004$ ) and bronchodilators ( $p = 0,003$ ) increased in the last week of life. Peripheral venous catheters ( $p = 0,022$ ), corticosteroids ( $p = 0,007$ ), antiemetics ( $p < 0,001$ ) and antidepressants ( $p < 0,05$ ) were used more in the cohort of patients who died.

2. Describing the symptoms perceived by professionals, the quality of palliative care, diagnostic tests, diagnostic procedures, and pharmacological treatments, and comparing the differences in clinical management between patients with and without dementia (Article 2).

A descriptive cross-sectional study was carried out in six nursing homes with a sample of 107 residents who met the criteria of the Spanish Society for Palliative Care (SECPAL). This study compares differences in symptoms, palliative care outcomes and prevalence of diagnostic tests, pharmacological treatments, and therapeutic procedures between patients identified with and without dementia.

The results showed that pain, fatigue, and nausea were significantly higher in the group without dementia, whereas insomnia, lack of appetite, and drowsiness were significantly higher in the group with dementia. Patient anxiety, support, feeling that life was worth living, self-esteem, and coping with practical issues were higher in the non-dementia group. In terms of medication, corticosteroid use was higher in the non-dementia group, while anxiolytic use was higher in the dementia group. Diagnostic procedures, such as urinalysis and x-rays, were higher in the dementia group.

3. Understanding the attitudes, strategies, and experiences of nursing professionals in relation to end-of-life care provided to patients and their relatives (Article 3).

A systematic review with meta-synthesis was conducted using the Web of Science, CINAHL, and CUIDEN databases. This study includes 17 articles from 2011 to February 2017.

From the 17 studies included in this review, three themes emerged: meanings and feelings during the dying process; coping strategies in the face of death; and the importance of education, experience, and providing a dignified death. The results of our study show that death has a great negative emotional impact on nursing professionals, that participants complained about the lack of prior training in the care of dying patients, and that avoiding these complex situations was one of the strategies most commonly used by professionals to cope with the death of a patient.

4. Adapting the Quality of Dying in Long Term-Care (QOD-LTC) scale culturally to the Spanish context and validating this scale on the attributes of validity and reliability, as well as testing the validity of the QOD-LTC scale as an indicative measure of the dying process by comparing its score with validated instruments (Article 4).

A total of 153 residents from seven nursing homes were assessed by 14 nurses (who had an average of 58.86 months of clinical experience in nursing homes) in order to determine the validity, reliability, and feasibility of the instrument. The eleven items of the Spanish scale had acceptable reliability ( $\alpha = 0,681$ ). In terms of factor structure, the Spanish version had three factors, such as the original version. The instrument showed good inter-observer reliability 0,753 (95% CI: 0,391-0,900,  $p < 0,001$ ) and intra-

observer reliability 0,855 (95% CI: 0,568-0,951  $p = 0,001$ ). In terms of convergent validity, weak correlations were observed: positive with the single-item question (0,322); negative with the Eastern Cooperative Oncology Group (ECOG) with a value of (-0,321); and negative with the Integrated Palliative outcome scale (IPOS) with a value of (-0,252).

As a result, the four papers that constitute this Doctoral Thesis provide relevant knowledge about the end of life in nursing homes, the attitudes of professionals, and the development of a new instrument that helps assess the quality of dying in nursing homes. The main conclusions of this group of publications are the following:

- Symptom intensity, therapeutic procedures, and pharmacological treatments increase in the last week of life. The increase in both the number of therapeutic procedures (peripheral venous catheter, aerosols, and oxygen therapy) and pharmacological treatments (opioids, antibiotics, and bronchodilators) are directly related to the increase in symptom intensity.
- Interventions such as peripheral venous catheter placement, and drugs such as antibiotics and new antidepressant prescriptions should be carefully considered in this clinical setting in order to improve patient comfort and avoid futile treatments.
- Pain, fatigue, and nausea were found to be significantly higher in patients without dementia. In contrast, insomnia, lack of appetite and drowsiness were significantly higher in patients with dementia.
- The use of medications such as corticosteroids was higher in the group without dementia, while the use of anxiolytics was higher in the group with dementia. Besides, the use of diagnostic procedures such as urinalysis and x-rays were higher in the dementia group.
- Patient anxiety, and the lack of perceived support and management of other practical matters were higher in patients without dementia, while more time was spent in health appointments in the dementia group.
- Specific tools are needed to assess symptoms and outcomes of palliative care in patients with dementia.

- Nurses consider that providing a good quality to the end of life is an important part of their work, but the experience of death generates feelings and emotions that have a negative impact on the care they provide and their own well-being. This is attributed to the lack of training, which shows itself in the lack of information for the patient and avoidance of spending time with patients, but it is corrected by experience itself. It is therefore necessary to improve the training professionals receive in providing a good end-of-life experience or death with dignity, while developing a series of coping strategies for them in this new situation with the aim of protecting themselves of these negative emotions and thus providing a better care for patients and their families.
- The Spanish version of the QoD-LTC scale shows psychometric properties comparable to the original version when assessing its validity, reliability and feasibility. Therefore, the Spanish version of the QoD-LTC is a useful and applicable scale in the Spanish-speaking context to assess the psychosocial quality of dying.

**Keywords:**

Nursing Homes, Terminal Care, Palliative Care, Hospice Care, Holistic nursing, Geriatric Nursing, Chronic Disease

## *Resumen*

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## 2. Resumen

¿Cómo es el final de la vida en residencias de mayores españolas?, ¿cómo son los cuidados que se prestan?, ¿cómo influye la actitud del profesional que presta los cuidados a los mismos?, ¿cómo podemos evaluarlos de manera objetiva y garantizando una buena calidad del proceso de la muerte? Con estas cuestiones se iniciaba esta tesis doctoral titulada “Un instrumento para medir la calidad de muerte en instituciones de larga estancia: Adaptación cultural, validación y otros análisis relevantes”. Esta tesis doctoral es un nexo de unión entre dos proyectos autonómicos que han permitido financiar parcialmente las investigaciones desarrolladas en esta tesis y, cuyos equipos de trabajo, se han formado principalmente a partir investigadores del grupo de investigación (CTS-436) “Aspectos Psicosociales y transculturales de la salud y la enfermedad”, grupo al que pertenece el doctorando.

La presente Tesis Doctoral ha sido elaborada bajo el modelo de agrupación de publicaciones, por lo que se han incluido cuatro artículos publicados en revistas del Journal Citation Report (JCR) con factor de impacto alto. Un trabajo se publicó en una revista situada en el primer decil (D1) del JCR en la categoría NURSING, otro en una revista del primer cuartil (Q1) en la categoría de MEDICINE, GENERAL & INTERNAL y otros dos en revistas del Q1 en la categoría PUBLIC, ENVIRONMENTAL & OCCUPATIONAL HEALTH de ciencias sociales.

El envejecimiento de la población viene emparejado a un incremento en la dependencia, prevalencia de enfermedades crónicas y de un incremento en la demanda de cuidados entre las personas mayores de 65 años. Ante esta situación, cada vez más personas cambian su domicilio por una residencia de mayores, ya sea por voluntad propia, o porque requieren cuidados complejos a largo plazo.

En estos centros, se ha observado una población con una edad media de 80 años, una mayor presencia de mujeres y una alta prevalencia de enfermedades crónicas, dependencia, afectación cognitiva, fragilidad y complejidad.



Con respecto al final de la vida, se ha reportado que síntomas como el dolor, la ansiedad, la confusión, la falta de aire y las náuseas, son habituales en la última semana de vida de los residentes de residencias de mayores. Son especialmente prevalentes el dolor, incontinencia urinaria y fecal, infecciones, inquietud, edemas y sintomatología de carácter psicológico y conductuales al final de la vida en pacientes con demencia.

Con el fin de mejorar la prestación de cuidados paliativos en las residencias de mayores, varios proyectos a nivel europeo (PACE y Namaste) y uno autonómico (NUHELP) han sido desarrollados con el fin de dotar de conocimientos, protocolos y herramientas para mejorar la asistencia paliativa en estos centros.

El final de la vida y la muerte esta impregnados de significados sociales y culturales. Este acontecimiento genera sentimientos de frustración, miedo e inseguridad en los profesionales sanitarios que tienen que prestar cuidados a las personas al final de la vida. Dentro de este colectivo, los profesionales de enfermería son el grupo más numeroso. Por ello, la forma cómo los profesionales afrontan el final de la vida y la muerte de sus pacientes, puede condicionar la perspectiva de lo que consideran una buena o una mala muerte y los cuidados que se prestan.

El término calidad de la muerte y del morir o “Quality of Death and Dying” (QoD) se describe como el grado en que las preferencias de una persona para morir y el momento de la muerte concuerdan con las observaciones de cómo esa persona muere realizadas por otras personas. Haciendo referencia este concepto a una observación externa del fenómeno e incluyendo aspectos como la comodidad y el confort, aspectos relacionados con las preferencias y expectativas y la relación y comunicación con los profesionales.

A pesar de existir una definición, no contamos con una forma objetiva de evaluarlo. Antes de la presentación de este proyecto de tesis doctoral no se encontró en España ningún instrumento validado para residencias de mayores que evaluara este constructo. A nivel internacional encontramos la escala Quality of Dying in Long-Term Care (QoD-LTC) que consta de 11 ítems y tres factores. Esta escala post mortem evalúa

el último mes de vida del residente de residencias de mayores, desde la perspectiva del enfermero y del familiar.

Para la adaptación cultural y validación del QoD-LTC al contexto español, se deben evaluar las características psicométricas del instrumento (validez, fiabilidad y factibilidad). Además, debido a que la escala tipo Likert es una escala categórica y no se puede asumir que la distancia psicológica sea la misma entre las distintas opciones de respuesta, es conveniente emplear una escala visual analógica (VAS) una alternativa posible a las escalas tipo Likert, que permite superar las desventajas que generan este tipo de escalas ya que da como resultado una variable continua.

Los objetivos de esta tesis doctoral se han desarrollado en 4 estudios; dos de tipo observacional, una revisión sistemática con metasíntesis y un estudio de validación de cuestionarios. Son los siguientes:

1. Explorar la percepción del control de los síntomas, los tratamientos farmacológicos y los procedimientos terapéuticos prestados a los pacientes en los últimos seis meses de vida (Estudio 1).

Se realizó un estudio longitudinal que contó con una muestra de 107 residentes que cumplían los criterios de la Sociedad Española de Cuidados Paliativos (SECPAL). Se midió la intensidad de los síntomas mediante la escala de Evaluación de Síntomas de Edmonton (ESAS), los procedimientos terapéuticos y el tratamiento farmacológico. Se evaluó la evolución mes a mes y las diferencias entre aquellos pacientes que fallecieron durante el seguimiento y los que no.

Los resultados obtenidos indicaron que todos los síntomas aumentaron de intensidad en la última semana de vida. Al comparar entre la cohorte de fallecidos y de no fallecidos, los síntomas fueron más intensos en los que habían fallecido durante el seguimiento ( $p < 0,05$ ). El uso de aerosoles ( $p = 0,008$ ), oxigenoterapia ( $p < 0,001$ ), opiáceos ( $p < 0,001$ ), antibióticos ( $p = 0,004$ ) y broncodilatadores ( $p = 0,003$ ) aumentó en la última semana de vida. Los catéteres venosos periféricos ( $p = 0,022$ ), los corticoides ( $p = 0,007$ ), antieméticos ( $p < 0,001$ ) y antidepresivos ( $p < 0,05$ ) se utilizaron más en la cohorte de pacientes que fallecieron.

2. Describir los síntomas percibidos por los profesionales, la calidad de los cuidados paliativos, las pruebas diagnósticas, los procedimientos diagnósticos y tratamientos farmacológicos y comparar las diferencias existentes en el manejo clínico entre pacientes con demencia y sin demencia (Estudio 2).

Se realizó un estudio descriptivo transversal en seis residencias de mayores, que contó con una muestra de 107 residentes que cumplían los criterios de la Sociedad Española de Cuidados Paliativos (SECPAL). En este trabajo se compararon las diferencias en síntomas, resultados en cuidados paliativos y porcentajes de pruebas diagnósticas, tratamientos farmacológicos y procedimientos terapéuticos entre pacientes identificados con y sin demencia

Los resultados obtenidos mostraron que la presencia de dolor, fatiga y náuseas fue significativamente superior en el grupo sin demencia. Mientras que el insomnio, la falta de apetito y la somnolencia fueron significativamente mayores en el grupo con demencia. La ansiedad del paciente, el apoyo, la sensación de que la vida valía la pena, la autoestima y el manejo de asuntos prácticos fueron mayores en el grupo de no demencia. En cuanto a los fármacos, el uso de corticoides fue mayor en el grupo sin demencia, mientras que el uso de ansiolíticos fue mayor en el grupo con demencia. Los procedimientos de diagnóstico, como los análisis de orina y las radiografías, fueron mayores en el grupo con demencia.

3. Conocer las actitudes, estrategias y experiencias de los profesionales de enfermería en relación con los cuidados al final de la vida prestados a los pacientes y a los familiares de estos (Estudio 3).

Se realizó una revisión sistemática con metasíntesis en las bases de datos Web of Science, CINAHL, and CUIDEN incluyendo estudios desde el 2011 hasta febrero del 2017. Este estudio incluyó 17 artículos.

De los 17 estudios que incluye esta revisión, surgieron tres temas, del que emanan trece categorías: significados y sentimientos durante el proceso de morir; estrategias de afrontamiento ante la muerte; y la importancia de la formación, la experiencia y de proporcionar una muerte digna. Los resultados de nuestro estudio

muestran por un lado, que la muerte tiene un gran impacto emocional negativo en los profesionales de enfermería. Por otro, que los participantes se quejaron de la falta de formación previa en la atención a los pacientes moribundos. Y por último, que evitar estas situaciones complejas era una de las estrategias más utilizadas por los profesionales para afrontar la muerte de un paciente.

4. Adaptar culturalmente la escala Quality Of Dying in Long Term-Care (QOD-LTC) al contexto español y validar esta escala atendiendo a su validez y fiabilidad, así como comprobar la validez de la escala QOD-LTC como medida indicativa del proceso de morir comparando su puntuación con instrumentos validados (Estudio 4).

Un total de 153 residentes de siete residencias de mayores fueron evaluados por 14 enfermeras (las cuales, tenían una experiencia clínica en residencias de 58,86 meses) con el fin de determinar la validez, fiabilidad y factibilidad del instrumento. Los once items de la escala española presentaban una fiabilidad aceptable ( $\alpha = 0,681$ ). En cuanto a su estructura factorial, la versión española presentaba 3 factores al igual que la versión original. El instrumento mostró una buena fiabilidad inter-observador 0,753 (95% CI: 0,391-0,900,  $p < 0.001$ ) e intra-observador 0,855 (95% CI: 0,568-0,951  $p = 0,001$ ). En cuanto a la validez convergente, se observaron correlaciones débiles; positiva con la pregunta monotemática (0,322) y negativa con el Eastern Cooperative Oncology Group (ECOG) con un valor de (-0,321) y la Integrated Palliative outcome scale (IPOS) con un valor de (-0,252).

Estos cuatro artículos que conforman esta memoria, aportan un conocimiento relevante sobre el final de la vida en residencias de mayores y sobre las actitudes de los profesionales y han llevado al desarrollo de un nuevo instrumento que ayuda a valorar la calidad del morir en residencias de mayores. Como principales conclusiones de esta agrupación de publicaciones destacamos las siguientes:

- La intensidad de los síntomas, los procedimientos terapéuticos y los tratamientos farmacológicos aumentan en la última semana de vida. Este aumento tanto de procedimientos terapéuticos (catéter venoso periférico, aerosoles y oxigenoterapia) como de tratamientos farmacológicos (opioides,

antibióticos y broncodilatadores) se encuentra totalmente relacionado con el incremento en la intensidad de los síntomas.

- Intervenciones como la colocación de catéteres venosos periféricos y la administración de fármacos como los antibióticos, y las nuevas prescripciones de antidepresivos deben considerarse cuidadosamente en este entorno clínico, con el fin de mejorar el confort del paciente y evitar los tratamientos fútiles.
- Se observó que el dolor, la fatiga y las náuseas resultaron significativamente mayores en los pacientes sin demencia. Por el contrario, el insomnio, la falta de apetito y la somnolencia fueron significativamente mayores en los pacientes con demencia.
- El uso de medicamentos como corticoides, fue mayor en el grupo sin demencia, mientras que el uso de ansiolíticos, fue mayor en el grupo con demencia. Por otro lado, el uso de procedimientos diagnósticos como análisis de orina y radiografías fueron mayores en el grupo con demencia.
- La ansiedad del paciente, la falta de apoyo percibido y la falta de gestión de asuntos prácticos fueron mayores en los pacientes sin demencia, mientras que se perdía más tiempo en las citas sanitarias en el grupo con demencia.
- Se necesitan herramientas específicas para evaluar los síntomas y los resultados de los cuidados paliativos en pacientes con demencia.
- Las enfermeras consideran que proporcionar una muerte de calidad es una parte importante de su trabajo, pero la experiencia de la muerte genera sentimientos y emociones que tienen un impacto negativo en los cuidados que proporcionan y en su propio bienestar. Esto se atribuye a la falta de formación, que se manifiesta con falta de información a los pacientes, con la evitación y se corrige a medida que se adquiere experiencia. Por ello, es necesario aumentar la formación en buena muerte o muerte digna que reciben los profesionales, al tiempo que se desarrollan y elaboran estrategias de afrontamiento ante esta nueva situación, todas ellas con el objetivo de protegerse y así prestar una mejor atención a los pacientes y sus familias.
- La versión española de la escala QoD-LTC presenta unas propiedades psicométricas comparables a la versión original al evaluar su validez, fiabilidad y

viabilidad. Por lo que la versión española del QoD-LTC es una escala útil y aplicable al contexto hispanohablante para evaluar la calidad psicosocial del morir.

**Palabras clave:**

Residencias de ancianos, Cuidados a pacientes terminales, Cuidados Paliativos, Cuidados de Hospice, Enfermería integral, Enfermería Geriátrica, Enfermedad crónica



# *Introducción*

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## **3. Introducción.**

### **3.1. Envejecimiento de la población y residencias de mayores.**

Es casi inevitable comenzar esta tesis doctoral recordando que se está produciendo un envejecimiento de la población en los países desarrollados, pero especialmente en Europa.

Según la oficina estadística de la Unión Europea Eurostat, el 1 de enero del 2019, 90,7 millones personas, es decir, el 20,3% de la población europea, tenía más de 65 años. Esto supuso en ese momento, un aumento de 2,9 puntos porcentuales con respecto a la determinación anterior, que databa del año 2009 (Commission, 2020). Se estima que esta tendencia al alza continúe en los países de la Unión Europea (UE). Según este mismo organismo, para el año 2050 se espera que 149,2 millones de personas, el 28,5% de la población total de los países de la Unión, tenga más de 65 años.

En el caso de España, la previsión no es distinta. El instituto Nacional de Estadística (INE) prevé un envejecimiento de la población residente en España. Actualmente, 9,28 millones de personas en España (19,6%) tienen más de 65 años y se estima que este porcentaje se situará en el 31,4% para el año 2050 (INE, 2020).

Este envejecimiento viene acompañado también de un incremento de la dependencia. Según la comisión europea, en el año 2019, un 34% de las personas mayores de 65 años de la UE presentaban algún tipo de dependencia. Al igual que con el envejecimiento, se estima que el porcentaje de personas dependientes se incremente en los próximos años. Se prevé que para el año 2070, un 59% de la población europea mayor de 65 años tenga dependencia (European Commission, 2021). De la misma manera, en el caso de España, la tasa de dependencia de esta parte de la población pasaría según el INE del 30,2% en el 2020 al 56,9% para el año 2050 (INE, 2020).

Esta proyección nos tiene que hacer reflexionar sobre la capacidad para cuidar de nuestras sociedades y a la necesidad de desarrollar estrategias que permitan poder hacer frente al cuidado de las personas mayores dependientes (Eurostat, 2020).

Estas estrategias deben de abordar necesariamente la creación de recursos específicos para las personas mayores. Concretamente, aquellos que permitan la asistencia a estas personas dependientes la mayor parte del día como los recursos residenciales.

En este sentido, aunque tanto a nivel europeo, como en España, la mayoría de las personas mayores siguen viviendo en sus domicilios, cada vez más personas se desplazan a instituciones como residencias de mayores, bien por voluntad propia, o porque requieren cuidados a largo plazo. Según los últimos datos publicados por la Oficina de Estadística de la Unión Europea, Eurostat, el 3,8% de las mujeres y el 1,9% de los hombres mayores de 65 años vivía en residencias de mayores (Eurostat, 2020).

En España, se ha observado una tendencia ascendente en el número de centros residenciales desde el 2013 hasta nuestros días (Abellán-García et al., 2021; Spasova et al., 2018). Mientras que en el año 2013 el número de centros residenciales en España era aproximadamente de 5.343 centros, en el año 2020 el número de centros se sitúa en 5.556 (Abellán-García et al., 2021; (CSIC., 2013), lo que supone un incremento del 4% respecto al año 2013.

Se estima que el número total de plazas ofertadas en residencias de mayores en España es de 384.241 plazas, en su mayoría de financiación privada (71%) (Abellán-García et al., 2021; Campos-Calderón et al., 2016), aunque algunas están parcialmente financiadas por el gobierno. Según datos de la Organización Mundial de la Salud, en 2013 en España había un total de 796 camas por 100.000 habitantes (World Health Organization, 2019). Esto supone una media de 4,2 plazas por cada 100 personas mayores, una cifra inferior a lo recomendado por la Organización Mundial de la Salud (OMS), que recomienda que deben existir al menos 5 plazas residenciales por cada 100 personas mayores de 65 años (Abellán García A, Aceituno Nieto P, Pérez Díaz J, Ramiro Fariñas D, Ayala García A, 2019)

### 3.2. Situación de las residencias de Mayores en España y en Andalucía

La atención prestada en estos centros y su normativa viene regulada, en el caso de España, en el artículo 148.1.20 de La Constitución Española que determina que las competencias en materia de servicios socio-sanitarios están transferidas a las comunidades autónomas a través de sus estatutos de autonomía (Constitución, 1978).

En el caso de la comunidad Autónoma Andaluza, los centros residenciales de esta comunidad se encuentran legislados bajo la Normativa sobre Centros Residenciales de Personas Mayores (Consejería para la Igualdad y Bienestar social, 2007).

Esta normativa los define como “centros de carácter social que ofrecen alojamiento, convivencia y atención integral. Tienen una función sustitutoria del hogar familiar, ya sea de forma temporal o permanente, para personas mayores en situación de dependencia” (Consejería para la Igualdad y Bienestar social, 2007).

Actualmente existen en Andalucía 668 centros residenciales de estas características. La mayor parte de los centros residenciales andaluces son de titularidad privada (76,34%) y el 35,1% cuentan entre 25 y 49 plazas (Abellán-García et al., 2021). Aunque gran parte de ellos tienen concertadas sus plazas con servicios sociales. El 77,27% de las plazas que ofertan los servicios sociales de Andalucía son concertadas con centros privados (Consejería de Igualdad, 2019).

Los requerimientos normativos de los centros están condicionados por el carácter de cada centro: centros residenciales con plazas para personas mayores en situación de dependencia; centros residenciales con plazas para personas mayores con trastornos graves y continuados de conducta (necesidades especiales); centros de día o Unidades de Estancias Diurnas (UED) y centros de Noche o Unidades de Estancias Nocturnas (UEN).

El tipo de centro, junto con el número de camas, va a condicionar el número y disponibilidad de profesionales que debe de tener. En Andalucía, la ratio de profesionales por cada paciente en el caso de un centro residencial es diferente para cada categoría profesional, encontrando que, para un centro residencial con plazas para

personas mayores con trastornos graves y continuados de conducta, la ratio de gerocultores o auxiliares de enfermería es de 0,384, para enfermería es de 0,04, y de médico 0,012, entre otros. Los centros tienen la obligación de organizar los turnos para que se preste una atención adecuada y designando a una persona responsable por turno incluso en turno de noche (Consejería para la Igualdad y Bienestar social, 2007).

### 3.3. Perfil de las personas que viven en residencias

Es necesario reflexionar también sobre el perfil de personas que viven en las residencias de mayores. Normalmente, las personas que recurren a este tipo de centros, no lo hacen por elección propia, sino que presentan algún tipo de dependencia que hacen que precisen cuidados especializados, los cuales no pueden ser prestados en el domicilio (Fundación "Instituto Edad y Vida," 2015).

En estos centros se ha reportado una edad media superior a los 80 años, un mayor porcentaje de mujeres (67,1-81,8%) y una alta prevalencia de enfermedades crónicas como; demencia (45-70%), cáncer (1,3%-16,1%), enfermedad cardíaca crónica (38,3%) y enfermedad pulmonar crónica (22,8%), entre otras (Esteban-Burgos et al., 2021; Gómez-Batiste et al., 2014).

Se ha observado que, entre los pacientes con patologías crónicas institucionalizados en estos centros, un 57,8% presentaba dependencia absoluta o severa y un 30,9% dependencia moderada. También se observó una alta prevalencia de deterioro cognitivo, donde un 31,5% de los residentes padecía deterioro cognitivo severo y un 24,8 moderado (Mota-Romero, Tallón-Martín, et al., 2021).

Por otro lado, se han reportado datos de comorbilidad medidos con el índice de Charlson, con valores que oscilan entre 2-3, un rango considerado como comorbilidad baja (Charlson et al., 1987; Esteban-Burgos et al., 2021; Gómez-Batiste et al., 2014; Mota-Romero, Tallón-Martín, et al., 2021). Otro aspecto que se ha visto determinante para valorar pacientes geriátricos ha sido la fragilidad. Se entiende por fragilidad a un estado multidimensional caracterizado por una vulnerabilidad ante factores estresantes debido a la limitación de los mecanismos compensadores, siendo más frecuente en

pacientes crónicos y con multimorbilidad (Amblàs-Novellas et al., 2017). En estos centros se ha reportado una alta prevalencia de fragilidad (80%), donde un 60% de estos pacientes presenta una fragilidad inicial y un 19,5% presenta fragilidad intermedia (Esteban-Burgos et al., 2021; Mota-Romero, Tallón-Martín, et al., 2021).

También se ha observado una alta prevalencia de complejidad clínica. Se entiende por complejidad a una situación que no engloba solo problemas de salud, sino que también incluye circunstancias sociales, culturales, medioambientales y de estilos de vida. El término de la complejidad de caso surge ligado a la cronicidad (manejo de patologías, tratamientos, situaciones psico-sociales, etc) (Ruiz Miralles, 2016). Se ha detectado que más del 80% de los pacientes con patologías crónicas eran complejos y un 66,4% tenían una alta complejidad (Blay, Martori, Limon, et al., 2019; Charlson et al., 1987; Esteban-Burgos et al., 2021; Gómez-Batiste et al., 2014; Mota-Romero, Tallón-Martín, et al., 2021).

Por otro lado, la comorbilidad (Esteban-Burgos et al., 2019) y la fragilidad (Amblàs-Novellas et al., 2017) han sido identificadas como factores pronósticos de una temprana mortalidad. A más comorbilidad y fragilidad, peor pronóstico.

De acuerdo con este perfil, es lógico considerar que las residencias de mayores suponen el último lugar de residencia para muchos ancianos. Un reciente estudio de base poblacional, que evalúa el lugar de residencia registrado en el Certificado médico de defunción, muestra una tendencia ascendente en el porcentaje de fallecimientos en residencias en la cohorte de fallecidos entre el 2012 y 2015 en España (Cabañero-Martínez et al., 2020).

El perfil más frecuente de fallecidos en estos centros sociosanitarios son mujeres de edad avanzada, sin pareja actual y de municipios grandes (Cabañero-Martínez et al., 2020; Cabañero-Martínez et al., 2019). Mientras que la causa de muerte más asociada a las residencias de mayores españolas corresponde a la enfermedad del Alzheimer, demencia y enfermedades neurodegenerativas (Cabañero-Martínez et al., 2019).

Todo esto nos lleva a la necesidad de profundizar en la atención que se le presta en estos centros, a los cuidados paliativos y al final de la vida.

### **3.4. Cuidados paliativos en residencias de mayores**

Los cuidados paliativos son un enfoque de la asistencia dirigido a mejorar la calidad de vida de los pacientes (adultos y niños) y sus familias, que se enfrentan a problemas relacionados con enfermedades que amenazan la vida o un sufrimiento grave relacionado con la salud (WHO, 2021).

La identificación de necesidades paliativas es un elemento esencial para integrar tempranamente este enfoque de la atención. Las necesidades paliativas son aquellas necesidades bio-psico-sociales y espirituales que emergen como consecuencia de la evolución de una situación de enfermedad crónica en estado avanzado y pronóstico de vida limitado, cuya presencia trae aparejado un deterioro de la calidad de vida del paciente (Blay, Martori, Limón, et al., 2019; Esteban-Burgos et al., 2021; Gómez-Batiste et al., 2017).

En cuanto a su distribución en la sociedad española, se ha descrito que casi una cuarta parte de las personas con necesidades paliativas en la población general española viven en residencias de mayores (Blay, Martori, Limón, et al., 2019). Otro estudio realizado en 2014 estimó que cerca del 72,2% de la población institucionalizada en estos centros presentaba necesidades paliativas (Gómez-Batiste et al., 2014). Según un estudio reciente, realizado en España, el lugar de fallecimiento más común para personas con necesidades paliativas fue el hospital (54,6%), seguido del domicilio con un (30,4%) y las residencias de mayores con un (14,5%) (Cabañero-Martínez et al., 2020). En países europeos como Alemania (Dasch et al., 2015) y Portugal (Sarmiento et al., 2016), se ha observado distribuciones similares en cuanto a fallecimientos para estos centros.

A pesar de la evidencia de la existencia de necesidades paliativas en residencias de mayores, los estudios publicados nos indican que no existe una adecuada atención de estas necesidades en estos centros (Blay, Martori, Limón, et al., 2019).

Por un lado, estudios recientes han indicado que existe una alta prevalencia de síntomas físicos y psicológicos en el último mes de vida en las residencias de mayores. Síntomas como el dolor, la ansiedad, la confusión, la falta de aire y las náuseas son síntomas comunes en la última semana de vida de los residentes institucionalizados. (Boyd et al., 2019; Estabrooks et al., 2015; Hendriks et al., 2014; Hoben et al., 2016; Sandvik et al., 2016; Tanghe et al., 2020). Se ha observado que estos síntomas empeoran la calidad de vida de los residentes institucionalizados (Smedbäck et al., 2017) aumentando en intensidad y prevalencia a medida que se acerca el final de la vida (Boyd et al., 2019; Hendriks et al., 2015; Koppitz et al., 2015).

Otros estudios demuestran que las terapias agresivas, siguen siendo habituales en los residentes de residencias de mayores (Mitchell, Kiely, et al., 2004; Mitchell, Morris, et al., 2004). Los profesionales de la salud en estos centros a menudo se enfrentan a dilemas sobre si ha llegado el momento de no iniciar o retirar los tratamientos e intervenciones porque no mejoran la calidad de vida del paciente (Goodman et al., 2015). Muchos pacientes siguen recibiendo medicamentos no prescritos como tratamientos paliativos o para el control de los síntomas, a pesar de encontrarse en la fase final de la vida (Honinx et al., 2021; Poudel et al., 2017). Varias revisiones (Kua et al., 2019; Tjia et al., 2013) han señalado que son pocos los estudios que se centran en la deprescripción farmacológica en el final de la vida, y han concluido que la esperanza de vida no suele utilizarse como criterio para la interrupción de la medicación, a pesar de que los fármacos innecesarios pueden causar efectos secundarios perjudiciales para los pacientes como puede ser el incremento del riesgo de caídas o incluso aumentar la mortalidad.

### 3.5. Cuidados paliativos en demencia

Como hemos visto anteriormente, en residencias de mayores existe una alta prevalencia de deterioro cognitivo y distintos tipos de demencia (Mota-Romero, Tallón-Martín, et al., 2021; Zimmerman et al., 2015), describiéndose esta como una de las principales causas de muerte en estos centros (Cabañero-Martínez et al., 2019). Las personas con demencia o deterioro cognitivo presentan unas necesidades específicas y



complejas en relación al final de la vida, distintas al resto de pacientes, por lo que es necesario evaluarlos de manera específica y diferenciada (Schmidt et al., 2018).

Síntomas como la incontinencia urinaria y fecal, los síntomas psicológicos y conductuales, el dolor, las náuseas, las infecciones, la inquietud, la disnea, el edema y el delirio son específicos de los pacientes con demencia (Hendriks et al., 2014; Hoben et al., 2016; Smedbäck et al., 2017; Vandervoort et al., 2013).

Se ha subrayado repetidamente la importancia de abarcar las necesidades físicas, psicosociales y espirituales de las personas con demencia al final de la vida (Schmidt et al., 2018). Sin embargo, los profesionales que trabajan en residencias de mayores contemplan la provisión de cuidados integrales al final de la vida a estos pacientes como un desafío no exento de dificultades (Hermans et al., 2017) .

El desarrollo de complicaciones clínicas y síntomas, que dificultan la provisión de unos cuidados óptimos al final de la vida, es común en este tipo de pacientes (Vandervoort et al., 2013). Los problemas más prevalentes en la población institucionalizada con demencia descritos en la bibliografía son: el dolor, la agitación, dificultad para respirar, el miedo, la ansiedad o los trastornos de conducta que suponen una resistencia al cuidado (Hendriks et al., 2014, 2015; Vandervoort et al., 2013).

La dificultad a la hora de identificar, diagnosticar y tratar distintas necesidades paliativas en los pacientes con demencia o con deterioro cognitivo severo, ha llevado a identificar estas situaciones clínicas como un criterio de complejidad (Salvador-Comino et al., 2017) por lo que será necesario tener en consideración esta condición en la provisión de cuidados paliativos en residencias de mayores.

### 3.6. Programas de Implementación de Cuidados paliativos y fin de vida en residencias de mayores.

Ante la situación anteriormente descrita, cada vez son más los autores que afirman que son necesarias intervenciones estructuradas para mejorar la práctica asistencia en el final de la vida en residencias de mayores en pacientes con y sin demencia (Andersson et al., 2018; Hendriks et al., 2014, 2015).

De hecho, la Organización Mundial de la Salud (OMS) (World Health Organization, 2011) y la Asociación Europea de Cuidados Paliativos (EAPC) (Reitinger et al., 2013) animan a la implementación de programas de cuidados paliativos en los centros de cuidados de larga estancia como las residencia de mayores. Actualmente existen experiencias exitosas de integración de cuidados paliativos en residencias de mayores. Algunos ejemplos de programas de intervención a nivel europeo son el European PACE project (PAlliative Care for older people in care and nursing homes in Europe) (Smets et al., 2018; Van Den Block et al., 2020) o el programa Namaste específico para pacientes con demencia (Froggatt et al., 2018). Recientemente en España, se ha desarrollado una iniciativa similar sin resultados concluyentes todavía (Mota-Romero, Esteban-Burgos, et al., 2021).

No obstante, para la aplicación y evaluación de estos programas, se hacen necesarios instrumentos validados en el contexto cultural en el que se aplican, que permitan evaluar todas estas dimensiones. Muchas de estos instrumentos se basan en la percepción de los profesionales y familiares de los procesos de fin de vida, lo que supone tener en cuenta la perspectiva de estos actores sobre la muerte y el morir.

### 3.7. Percepción de la muerte de las enfermeras

La muerte y el morir están sujetos a una serie de percepciones y normas sociales que cambian con el tiempo según los valores culturales, las creencias y actitudes de la población objeto de estudio (Cottrell & Duggleby, 2016; Krikorian et al., 2020). Aunque la muerte en sí puede ser un acontecimiento predominantemente físico o biológico,

tanto la muerte como el proceso de morir están impregnados de significados sociales, culturales y políticos (Cottrell & Duggleby, 2016).

Históricamente, la muerte se consideraba un acontecimiento natural en el que el individuo enfermo participaba expresando sus últimos deseos, reuniendo a sus familiares para despedirse y buscando el perdón de sus faltas (Janaina Luizados Santos & Bueno, 2011). Sin embargo, con el paso del tiempo, la muerte se ha institucionalizado, ya que se ha trasladado del hogar al hospital: hasta el 80% de las muertes ocurren en una institución sanitaria, lo que la convierte en una muerte fría, desapegada y medicalizada (Celma Perdigon & Strasser, 2015; Ignorosa-Nava & González-Juárez, 2014; Kent et al., 2012; Janaina Luizados Santos & Bueno, 2011). Todo ello se ve agravado por un contexto social en el que la incapacidad de prevenir la muerte es sentida como un fracaso (Celma Perdigon & Strasser, 2015).

Las sociedades generan en sus integrantes unas perspectivas de vida en las que no forma parte la muerte, generando así situaciones de evitación y ocultamiento (Cui et al., 2011; Freitas et al., 2016; Ignorosa-Nava & González-Juárez, 2014).

Esta dificultad para gestionar el proceso de morir afecta directamente al sistema sanitario, especialmente a los profesionales de la salud (Ignorosa-Nava & González-Juárez, 2014). Ya que, según algunos estudios, la muerte despierta sentimientos de frustración, miedo e inseguridad en los profesionales (Cavaye & Watts, 2014; Costello, 2006; Janaina Luizados Santos & Bueno, 2011).

Entre todos los profesionales de ciencias de la salud, son los profesionales de enfermería los que tienen un contacto más amplio con los pacientes que se enfrentan al final de su vida (Peterson et al., 2010; Souza et al., 2013; J. Wilson & Kirshbaum, 2011), siendo su perspectiva una de las más interesantes para abordar este fenómeno.

Hay muchos factores sociales, religiosos, culturales y económicos que, en gran medida, determinan la actitud de las enfermeras hacia la muerte (Frutos, M; Iglesias, JA; Frutos, J.M; Calle, 2007). En los últimos años se han publicado varios estudios

cualitativos sobre la percepción de la muerte por parte de las enfermeras, así como varias síntesis de estudios cualitativos (Zheng et al., 2018).

Zheng et al., (2016) estudiaron las percepciones de las enfermeras recién graduadas a la hora de afrontar la muerte de los pacientes (Zheng et al., 2016). En un estudio posterior, estos mismos investigadores examinaron las estrategias de afrontamiento utilizadas por las enfermeras cuando se enfrentan a la muerte del paciente (Zheng et al., 2018).

Entre las principales estrategias de afrontamiento recogidas en ambos estudios se mencionaron la desconexión emocional, la gestión de las emociones, el papel de la educación y la espiritualidad. También se han publicado otras revisiones centradas en aspectos específicos del tema, como las percepciones de la muerte entre las enfermeras de cuidados críticos que han atendido a pacientes y familias durante la retirada del soporte vital (Vanderspank-Wright et al., 2018). Además, se han realizado revisiones con otras poblaciones, como familiares (Wallace et al., 2018) y pacientes (Monforte-Royo et al., 2012; Rodríguez-Prat et al., 2017).

En este sentido, el cómo los profesionales afrontan el final de la vida y la muerte de sus pacientes, puede condicionar la perspectiva de lo que consideran una buena o una mala muerte.

### **3.8. Buena muerte**

El término de buena muerte, “Good death”, emergió en la década de los años 60 como un concepto clave de los cuidados paliativos en los países occidentales (Krikorian et al., 2020). Este concepto fue inicialmente utilizado como un sinónimo de eutanasia (Krikorian et al., 2020), para posteriormente ser descrito como una experiencia multifacética e individualizada en el final de la vida (A. Meier et al., 2016), pero siempre en función de unos patrones sociales y culturales (Cottrell & Duggleby, 2016).

La primera definición de buena muerte fue realizada por O’Neil en 1983 (O’Neil, 1983), el cual consideró que una buena muerte se daba si el individuo era capaz de

mantener el control y la autonomía sobre el proceso de morir y el momento de la muerte. (Krikorian et al., 2020).

Según un informe del Instituto de Medicina publicado hace 19 años (Field & Cassel, 1997), una buena muerte es aquella que está "libre de angustia y sufrimiento evitables para el paciente, la familia y los cuidadores, que está de acuerdo en general con los deseos del paciente y de la familia, y que es razonablemente coherente con las normas clínicas, culturales y éticas". Este concepto ha recibido algunas críticas en varias disciplinas, como la medicina, la psicología, la teología, la sociología y la antropología. En particular, se ha planteado la preocupación de que no existe un criterio externo de buena muerte y que éste depende más de las perspectivas del moribundo.

Investigadores posteriores concluyeron que una buena muerte podía lograrse bajo las siguientes condiciones: conciencia de morir, preparación para la muerte, abandono de roles y responsabilidades y la despedida (Borgstrom, 2020; Krikorian et al., 2020).

Según Borgstrom (2020) el concepto de la buena muerte describe tanto las propiedades del proceso del morir, como las circunstancias del momento del fallecimiento y del momento posterior. Este concepto se suele asociar con conceptos como dignidad, paz, ausencia de dolor o sufrimiento, e incluiría preparativos y acontecimientos que pueden ser catalogados como buenos o deseables.

En cambio, Cottrell & Duggleby (2016) consideraron que para tener una buena muerte es necesario al menos que el paciente controle el momento, el lugar y las circunstancias que la acompañan al fallecimiento como el control del dolor. Con este control, el individuo puede aceptar la muerte, tomar decisiones y planificar el final de la vida.

Meier et al. (2016) observó que los elementos que caracterizan una buena muerte tenían una mayor importancia en función de si se asumía la perspectiva de los pacientes, de los familiares o de los profesionales. En su revisión observaron que el tema que apareció con más frecuencia para una buena muerte en todos los grupos fue el de las

"preferencias para el morir", seguido de "estado sin dolor" y "bienestar emocional" (Meier et al., 2016).

Por otro lado, Krikorian et al. (2020) en su revisión bibliográfica concluyó que los pacientes de los estudios revisados compartían algunos elementos centrales de la buena muerte como el control del dolor y otros síntomas, la claridad en la toma de decisiones, sensación de cierre del proceso vital, ser visto y percibido como una persona y la preparación para la muerte (Krikorian et al., 2020).

Para resumir y facilitar la visión y comprensión de los distintos elementos de la buena muerte propuestos por Krikorian et al. (2020) y Meier et al. (2016) en sus revisiones son sintetizados en la Tabla 1.

TABLA 1. Temas centrales de la definición de buena muerte.

Krikorian et al., 2020	Meier et al., 2016
Control del dolor y otros síntomas	Estar libre de dolor Estar dormido mientras mueres
Claridad en la toma de decisiones	Preferencias sobre el proceso del morir (cómo, quién, dónde y cuándo). Preparación para la muerte (voluntades anticipadas, arreglos de funeral) Indicación de las preferencias de tratamiento
Sensación de cierre	Sentimiento de finalización de la vida, de cierre.
Ser visto y percibido como una persona	Mantenimiento de la dignidad Buena relación con los profesionales y buena comunicación y coordinación dentro del equipo Mantenimiento de la Calidad de vida
Preparación para la muerte	Encontrarse emocionalmente bien.
Ser aún capaz de aportar a la sociedad	Familia Tipo de enfermedad.

Tabla de elaboración propia.

### 3.9. Calidad de los cuidados, calidad de muerte y calidad del morir.

En las últimas décadas han surgido distintos conceptos relacionados con la buena muerte que es necesario distinguir, dado que tienen repercusiones desde el punto de vista práctico en la forma de evaluarlos.

Estos conceptos son Calidad de los cuidados "*Quality of care*", calidad de la muerte y del morir "*Quality of Death an dying*" y calidad del proceso de la muerte "*Quality of Dying*".

La calidad de los cuidados "*Quality of care*" cuenta con varias definiciones. En la década de los noventa se definió como "el grado en que los servicios de salud para individuos y poblaciones aumentan la probabilidad de obtención de resultados de salud deseados y son consistentes con el conocimiento profesional actual" (Lohr, 1990). Haciendo referencia a elementos del entorno donde se produce la muerte. Una década después, (Campbell et al., 2000) en otro reporte, lo definió como "la capacidad de acceder a una asistencia eficaz con el objetivo de maximizar los beneficios sanitarios en relación con las necesidades". En esta definición no sólo se centró en la disponibilidad de los recursos, sino en la capacidad de acceder a los mismos. Por consiguiente, el acceso a unos buenos cuidados paliativos mediante medios materiales y humanos garantizaría una buena calidad de cuidados a pacientes fin de vida.

Por otro lado, encontramos los conceptos de calidad del morir "*Quality of Dying*" y el de calidad de la muerte y el morir "*Quality of Death and Dying*". Aunque en la literatura, muchos autores pueden utilizarlos de forma indistinta, ambos conceptos presentan según la bibliografía consultada una serie de matices que hacen distintos ambos términos.

En este sentido, se considera que la calidad del morir "*Quality of Dying*" es sinónimo de la calidad de vida "*Quality of Life*" mientras se está en un estado de final de la vida (Van Soest-Poortvliet et al., 2011). Esta interpretación de la calidad del proceso de la muerte la vincula a los cuidados paliativos y lo hace esencial para la consecución de los mismos.

Pero, como hemos visto antes, la buena muerte, no solo depende de la existencia y acceso a unos buenos recursos materiales y humanos, sino que debe de reflejar las expectativas y preferencias de los pacientes.

La calidad de la Muerte y el Morir o *Quality of Death and Dying* (QoDD) se describe como el grado en que las preferencias de una persona para morir y el momento de la muerte concuerda con las observaciones de cómo esa persona actualmente muere, según lo informado por otros (Curtis et al., 2013; Downey et al., 2010; Meier et al., 2016; Patrick et al., 2001). Por lo cual, este concepto no es propio de la persona, sino que es una observación externa del mismo. Este concepto incluye aspectos como el confort y la comodidad, que se encuentran relacionados con la calidad de los cuidados, pero también otros aspectos relacionados con las preferencias y expectativas, así como la comunicación y relación con los profesionales.

En cuanto a la evaluación de la calidad del proceso de la muerte, son pocas las investigaciones que han evaluado la calidad de la morir, "*Quality of Dying*" (QoD), de los residentes tanto con demencia como sin demencia. En un estudio europeo en el que se evaluó la QoD de 6 países, se observó que las personas con demencia en residencias de mayores presentaban una valoración peor por la QoD que los residentes sin demencia (Pivodic et al., 2018).

En esta evaluación, el papel de la enfermera es esencial, puesto que conocen las necesidades del paciente moribundo y de la familia para lograr una buena QoD (Krishnan, 2017).

### 3.10. Instrumentos que evalúan la calidad de la muerte y el morir.

A nivel internacional, distintos instrumentos se han desarrollado para la evaluación de distintos aspectos relacionados con el fin de la vida (Lendon et al., 2015; Mularski et al., 2007; Van Soest-Poortvliet et al., 2011; Zimmerman et al., 2015). Según Mularski en su revisión sistemática de 2007 clasifica los distintos instrumentos en distintas categorías: Aspectos como la calidad de vida "*Quality fo life measures*", síntomas físicos, síntomas emocionales y cognitivos, estado funcional, sobre espiritualidad, contra el



dolor y el duelo, de satisfacción y calidad del cuidado y de bienestar del cuidador (Mularski et al., 2007).

Hasta ahora, las escalas validadas en el contexto español más empleadas para valorar el final de la vida en residencias de mayores presentan bastantes limitaciones. Por un lado, la Palliative Outcome Scale (POS) (Serra-Prat et al., 2004) evalúa únicamente aspectos relacionados con la calidad de los cuidados paliativos y es clasificada por Mularski et al. (2007) en medidas de satisfacción y calidad del cuidado. Por otro lado, la escala Edmonton Symptom Assessment SYSTEM (ESAS) (Carvajal Valcárcel et al., 2013) sólo evalúa la intensidad de los síntomas al final de la vida y se encuentra calificada por Mularski et al. (2007) en medidas de los síntomas físicos.

En España no encontramos ninguna escala que evalúe la calidad del morir y que haya sido adaptada y validada al contexto español para residencias de mayores. A nivel internacional, una de las escalas más utilizadas para evaluar la calidad de la muerte en centros de cuidados de larga duración es la "*Quality-of-dying in Long Term-Care*" (QOD-LTC) (Munn et al., 2007). Se trata de una escala validada en Estados Unidos, que evalúa la calidad psicosocial de la muerte en el último mes de vida de los residentes fallecidos y que puede ser utilizada tanto por los profesionales de enfermería como por los familiares. Consta de pocos ítems y puede completarse en pacientes fallecidos con o sin deterioro cognitivo (Pivodic et al., 2018; Swagerty, 2017). Este instrumento, se emplea tras el fallecimiento del paciente, por lo que puede servir como indicador de calidad del morir.

### 3.11. Adaptación y validación de la escala QOD-LTC al castellano.

Cuando se utiliza una herramienta en una cultura diferente, es importante ir más allá de la mera traducción directa, con el fin de garantizar la validez y fiabilidad del constructo que pretende medir y reducir el riesgo de introducir sesgos en el estudio (Sousa & Rojjanasrirat, 2011). La validación de una escala en un contexto concreto no significa que sea automáticamente válida en otro momento, cultura o contexto (Abbas et al., 2018). Esto es especialmente necesario con constructos tan individuales y dinámicos como es el de la calidad del morir (Krishnan, 2017). En este proceso

intervienen una serie de relaciones entre los deseos del moribundo, la capacidad de los demás para satisfacer sus expectativas y el grado de control social que se ejerce sobre este proceso, todo ello muy dependiente de la cultura y el contexto (Krishnan, 2017). Por lo tanto, es preciso adaptar al contexto español, cualquier instrumento que se decida emplear para evaluar la calidad del morir, como es el caso de la "*Quality-of-dying in Long Term-Care*" (QOD-LTC) (Munn et al., 2007).

Para poder utilizar un cuestionario validado en otro idioma y país en nuestro contexto clínico, primero es necesario realizar una adaptación cultural y, posteriormente, una validación (Ramada-Rodilla et al., 2013; Sousa & Rojjanasrirat, 2011).

Para garantizar la calidad de medición de un cuestionario, previamente a su utilización en un entorno clínico, es necesario comprobar que es capaz de medir apropiadamente el constructo para el cual se diseñó, que lo mide de la misma manera ante distintas situaciones clínicas y que no presenta dificultades a la hora de su aplicación. (Ramada-Rodilla et al., 2013). Este proceso, necesario e imprescindible al que hay que someter a todos los instrumentos de medida, se denomina validación. Por consiguiente, se podría definir la validez de un instrumento como "la capacidad del cuestionario de medir aquel constructo para el que ha sido diseñado (García de Yébenes Prous et al., 2009)".

Si la escala es una versión que va a ser utilizada en un país (o zona) culturalmente diferente de aquel donde originalmente fue validada, la primera fase para proceder a validar dicha escala, es la adaptación cultural del cuestionario al medio donde se quiere utilizar. El proceso de traducción se acompaña del proceso de adaptación cultural, que generalmente es validado por un comité de expertos. El realizar un proceso de traducción de manera simple, sin una adaptación cultural, puede desencadenar interpretaciones erróneas como resultado de las diferencias del lenguaje y culturas. Por lo que este proceso puede considerarse tan importante como el proceso de validación (Abbas et al., 2018; Ramada-Rodilla et al., 2013).

El siguiente paso es la validación del instrumento, es decir, estudiar si mantiene las características psicométricas que le permiten medir aquello para lo que se diseñó. Es importante destacar que no todo instrumento que sea fiable es válido. Un instrumento puede ser fiable porque mide una variable de manera constante, pero inválido si no mide el fenómeno que se quiere medir. Para ello, se debe evaluar su fiabilidad mediante el coeficiente alfa de Cronbach (Bonett & Wright, 2015), su validez convergente mediante la correlación con otros instrumentos que evalúen constructos parecidos (Akoglu, 2018; Schober & Schwarte, 2018), su estructura factorial mediante estudio de componentes principales (Gaskin & Happell, 2014), su fiabilidad inter- e intra-observador mediante el coeficiente de correlación intraclass (Koo & Li, 2016), y su factibilidad mediante la evaluación del tiempo de cumplimentación. Todas estas mediciones son imprescindibles para poder utilizar el instrumento en el nuevo contexto.

Por tanto, el proceso de validación de una escala es un proceso complejo que requiere, por un lado, un conocimiento teórico profundo del concepto que queremos medir y, por otro lado, un conocimiento y manejo de las técnicas estadísticas específicas en cuanto a la validación de escalas. Evaluar cada una de las cualidades psicométricas de una escala es esencial para determinar la calidad de la medición de ésta.

Otro de los aspectos a tener en cuenta a la hora de construir y validar un cuestionario es evaluar la forma de cumplimentación, una de las formas más comunes en ciencias de la salud es la utilización de la escala tipo Likert, aunque esta presenta limitaciones.

### **3.12. Escalas Likert vs Escalas Visuales Analógicas**

Los seres humanos, para poder transmitir experiencias sensoriales, debemos transformar en primer lugar esa experiencia sensorial de una descripción verbal o numérica (Hayes et al., 2013; Weigl & Forstner, 2021). Es habitual, en ciencias de la salud, la creación de escalas cuya forma de cumplimentación es la asignación a las experiencias vividas de adjetivos o valores numéricos en una escala ordinal, lo cual puede ayudar a cuantificar esas experiencias subjetivas y ayudar a la toma de decisiones clínicas (Bartoshuk et al., 2004; D'Negri & De Vito, 2010; Hayes et al., 2013; Weigl &

Forstner, 2021) así como comparar experiencias subjetivas entre sujetos (Bartoshuk et al., 2004; Goffin & Olson, 2011).

Sin embargo, al realizar esta comparación, debemos tener en cuenta que ante un mismo estímulo, la percepción y valoración del mismo puede ser distinta (Bartoshuk et al., 2004). Un ejemplo paradigmático es la valoración del dolor. La valoración del dolor de un paciente individual puede ser útil para tomar decisiones clínicas, pero puede producir comparaciones erróneas entre los pacientes dado que existen diferentes umbrales de dolor y diferentes respuestas moduladas en función a la experiencia previa de cada sujeto (Bartoshuk et al., 2004; Weigl & Forstner, 2021).

Se ha reflexionado mucho sobre este asunto, y se discute actualmente las distintas implicaciones de los diferentes métodos de puntuación de escalas.

Una de las maneras más conocidas para cuantificar la experiencia subjetiva es el uso de una escala de Likert (Bartoshuk et al., 2004; Weigl & Forstner, 2021). Esta escala fue ideada para la medición de actitudes, aunque es ampliamente utilizada como una escala categórica, es decir, el paciente tiene que elegir entre un grupo de opciones la que mejor refleje su estado actual (Bartoshuk et al., 2004; Weigl & Forstner, 2021). Dentro del tipo de escala Likert, se incluyen escalas con distinto número de categorías (Munshi, 2014; Wakita et al., 2012). Las escalas de Likert más habituales son aquellas que consideran 5 o 7 categorías o etiquetas (Hamby & Levine, 2016). El tipo de variable que se genera mediante este tipo de escalas de medición son variables ordinales (Hamby & Levine, 2016).

A pesar de que las escalas Likert han sido ampliamente usadas en la literatura científica, con el tiempo, se han identificado una serie de problemas en su utilización.

En primer lugar, el número de categorías o etiquetas de las escalas depende habitualmente más de las preferencias de los investigadores que las han desarrollado, o de convencionalismos, que de las propiedades psicométricas de cada una o del nivel de comprensión del sujeto que cumplimenta la escala (Munshi, 2014).

En segundo lugar, no se puede asumir que la distancia psicológica entre las categorías sea la misma (Hamby & Levine, 2016; Weigl & Forstner, 2021). Si retomamos el ejemplo del dolor, considerando una escala tipo Likert de evaluación del dolor del 1 al 5, puede que no exista la misma experiencia entre las categorías 3 y 4, que entre las categorías 4 y 5. En este sentido, la elección de tipo de escala y del número de categorías de la misma, puede afectar a la distancia psicológica percibida por los encuestados entre las distintas opciones de respuesta (Wakita et al., 2012), afectando a la capacidad de comparar las puntuaciones entre distintos sujetos.

La bibliografía científica no es concluyente en cuanto a qué tipo de escala tipo Likert es mejor (Hamby & Levine, 2016), aunque muchos autores entienden que cuanto más categorías o etiquetas plantee una escala menor será el error (Munshi, 2014).

Una forma de evitar las numerosas desventajas que presentan las escalas tipo Likert, es usar Escalas Visuales Analógicas (VAS). El uso de estas escalas se remonta a los años 1960 (Bartoshuk et al., 2004). Están compuestas por una línea limitada en sus extremos por dos etiquetas lingüísticas que marcan la calificación mínima y máxima para la variable de interés. Este método comenzó siendo utilizado por Aitken (1969) para cuantificar emociones y estados de ánimo (Aitken, 1969; Bartoshuk et al., 2004; Manuguerra et al., 2020; Yeung & Wong, 2019). En el contexto sanitario, han sido ampliamente utilizadas en estudios para el dolor y otros síntomas, ya que son escalas sencillas de aplicar y fáciles de entender (Hayes et al., 2013; Manuguerra et al., 2020; Yeung & Wong, 2019). La principal ventaja frente a las escalas de Likert, es que dan lugar a variables continuas, lo que ofrece ventajas desde el punto de vista estadístico, ya que permite el uso de pruebas paramétricas (Chang & Little, 2018; Hjermstad et al., 2011; Kuhlmann et al., 2016; Sung & Wu, 2018; Weigl & Forstner, 2021).

La versión más utilizada en la bibliografía es VAS-100 mm o la VAS-10 cm en formato papel, aunque también se ha reportado el uso de una versión de plástico o mecánica (Hjermstad et al., 2011; Manuguerra et al., 2020; Yeung & Wong, 2019).

Las escalas VAS ofrecen solución a algunos de los problemas inherentes a la escala tipo Likert (Hjermstad et al., 2011; Weigl & Forstner, 2021). Al asignar el sujeto

un valor determinado en cualquier lugar en una línea continua, se evita la necesidad de etiquetas o categorías, y permite obtener datos de medición continuos, es decir, con rango de intervalos (Hjermstad et al., 2011; Weigl & Forstner, 2021). No existen en estas escalas etiquetas o categorías por lo que no se induce a la persona que la cumplimenta a ningún error.

En principio, puede pensarse que las escalas VAS son menos aplicables en grandes escalas, con varios ítems, por el trabajo extra de medir cada valor para, posteriormente, transcribirlo a una base de datos. No obstante, hoy en día, este problema se ha resuelto con el uso de aplicaciones informáticas de recogida de datos online, incluso con mediante un Smartphone, que permiten implementar esta forma de evaluación de una manera rápida y sencilla (Abend et al., 2014).

Las características del final de la vida y los cambios significativos de los residentes cuando están cerca de la muerte (Hendriks et al., 2014; Hoffmann et al., 2014; Koppitz et al., 2015; Smedbäck et al., 2017) hace que la evaluación sea un proceso complejo. Por ello, se recomienda que, en lugar de utilizar medidas tipo Likert, los ítems se evalúen de forma continua, con escalas visuales analógicas (VAS).

Por lo anteriormente expuesto, a pesar de que en su validación original la escala QOD-LTC presentaba una escala de tipo Likert, es fácilmente adaptable al uso de una escala tipo VAS.



## *Justificación*

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## **4. Justificación**

Debido al envejecimiento de la población tanto en España como en Europa, cada vez más personas fallecen en residencias de mayores. Las personas que viven en estos centros presentan una elevada dependencia, multimorbilidad, fragilidad, complejidad y múltiples necesidades paliativas.

Los estudios publicados al respecto en España indican que no se presta unos adecuados cuidados paliativos en residencias de mayores. Distintas instituciones a nivel mundial y europeo defienden la necesidad de conocer cómo se muere en los centros residenciales (Reitinger et al., 2013; World Health Organization, 2011). En España, según el atlas de la Sociedad europea de cuidados paliativos, no se han realizado suficiente investigaciones en estos centros (Arias-Casais et al., 2019).

Entre los cuatro estudios desarrollados y publicados que conforman esta tesis doctoral, los dos primeros (Estudio 1 y Estudio 2) aportan mucha información sobre cómo se está produciendo el proceso fin de vida en estos centros.

En el estudio 1 se realiza un seguimiento de 6 meses a pacientes identificados con una esperanza de vida limitada y susceptibles de recibir cuidados paliativos en residencias de mayores. En este seguimiento se evalúan aspectos claves identificados en la literatura como es la evolución de síntomas (Boyd et al., 2019; Estabrooks et al., 2015; Hendriks et al., 2015; Hoben et al., 2016; Sandvik et al., 2016; Tanghe et al., 2020), procedimientos terapéuticos y tratamientos farmacológicos (Givens et al., 2010; Honinx et al., 2021; Mitchell, Kiely, et al., 2004; Poudel et al., 2017).

En el estudio 2, se compara el final de la vida de los residentes con y sin deterioro cognitivo. Como se ha mencionado anteriormente, la demencia es una de las enfermedades más prevalentes entre las personas que viven en residencias de mayores y presenta una serie de necesidades específicas en el final de la vida (Esteban-Burgos et

al., 2021; Gómez-Batiste et al., 2014; Hendriks et al., 2014, 2015; Smedbäck et al., 2017; Vandervoort et al., 2013). Por ello, se plantea la necesidad de explorar las características que le son propias a esta población y analizar las diferencias existentes con la población sin demencia que convive en residencias de mayores.

Por otro lado, la perspectiva de cada sujeto sobre la muerte y su experiencia al respecto condiciona, de manera determinante, el cómo perciben conceptos como buena muerte o calidad de muerte y del morir (Meier et al., 2016; Van Soest-Poortvliet et al., 2011).

Con el objetivo de conocer cómo puede afectar la muerte a los cuidados que realizan los profesionales sanitarios, en el Estudio 3, se ha realizado una revisión de estudios cualitativos para conocer la actitud de los profesionales de enfermería, que son los que más tiempo pasan cuidado a los pacientes en las residencias de mayores (Peterson et al., 2010; J. Wilson & Kirshbaum, 2011).

Por último, destacar la ausencia de instrumentos validados al castellano que evalúen, de manera holística, la calidad de la muerte y el morir en residencias de mayores. A nivel internacional se han desarrollado diferentes cuestionarios que evalúan constructos como la *Quality of Death o la Quality of Dying* (Mularski et al., 2007; van Soest-Poortvliet et al., 2013). La escala *Quality of Dying in Long-Term Care* (QoD-LTC) (Munn et al., 2007) es una escala diseñada específicamente para residencias de mayores, sencilla de cumplimentar por profesionales y familiares tras el fallecimiento del paciente, y que puede ser aplicada tanto a pacientes con y sin demencia.

Las ventajas analizadas anteriormente para esta escala nos llevaron a plantear en el proyecto de esta tesis la adaptación al castellano y la validación de la misma. En el estudio 4 se describe el proceso de validación realizado para esta escala. Con respecto a la escala original se ha cambiado el sistema de puntuación de tipo Likert a VAS por los motivos argumentados en la introducción de esta memoria.

## *Objetivos*

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## 5. Objetivos

### 5.1. Objetivo general:

1. Adaptar culturalmente y validar la escala Calidad del morir en instituciones de cuidados a largo plazo (*Quality Of Dying in Long Term-Care*), conocer la actitud de los profesionales de enfermería ante la muerte y describir aspectos clave de cómo se muere en residencias de mayores en el contexto español.

### 5.2. Objetivos específicos:

2. Explorar la percepción del control de los síntomas, los tratamientos farmacológicos y los procedimientos terapéuticos recibidos por los pacientes susceptibles de recibir cuidados paliativos ingresados en residencias de mayores en los últimos seis meses de vida (Estudio 1).
3. Describir los síntomas percibidos por los profesionales, la calidad de los cuidados paliativos, las pruebas diagnósticas, los procedimientos diagnósticos y los tratamientos farmacológicos que se utilizan en el tratamiento de pacientes susceptibles de recibir cuidados paliativos en residencias de mayores y comparar las diferencias existentes en el manejo clínico entre pacientes con demencia y sin demencia (Estudio 2).
4. Conocer las actitudes, estrategias y experiencias de los profesionales de enfermería en relación con los cuidados al final de la vida prestados a los pacientes y a los familiares de estos (Estudio 3).
5. Adaptar culturalmente la escala *Quality Of Dying in Long Term-Care* (QOD-LTC) al contexto español y validar esta escala atendiendo a su validez y fiabilidad, Así como comprobar la validez de la escala QOD-LTC como medida indicativa del proceso de morir comparando su puntuación con instrumentos validados (Estudio 4).



*Breve descripción de la Metodología de los estudios incluidos en esta tesis doctoral.*

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## 6. Breve descripción de la metodología de los estudios incluidos en esta tesis doctoral.

Esta tesis doctoral se compone de cuatro estudios publicados en revistas de alto impacto.

### 6.1. Estudio 1:

El primer estudio, publicado en *Journal of Clinical Medicine*, es un estudio prospectivo multicéntrico realizado en seis residencias de mayores andaluzas. Se realizó un seguimiento de seis meses a pacientes susceptibles de recibir cuidados paliativos. Se evaluó la Escala de Evaluación de Síntomas de Edmonton (ESAS), los procedimientos terapéuticos y el tratamiento. Se utilizaron pruebas paramétricas y no paramétricas para evaluar la evolución mes a mes y las diferencias entre aquellos pacientes que fallecieron durante el seguimiento y los que no. Este estudio fue financiado por la Consejería de Salud de Andalucía mediante los proyectos “Factores Condicionantes en la Implementación de Los Procesos de Atención Al Final de la Vida en Residencias de Ancianos y en Centros Gerontológicos” (PI-0619-2011) y el “Proyecto Elaboración e implantación de un programa de atención al final de la vida en residencias de ancianos” (AP-0105-2016).

### 6.2. Estudio 2:

El segundo estudio de esta tesis doctoral se publicó en la revista *International Journal of Environmental Research and Public Health*. Se trata de un estudio transversal multicéntrico realizado en seis residencias de mayores. Se comparan las diferencias en síntomas, resultados en cuidados paliativos y prevalencia de pruebas diagnósticas, tratamientos farmacológicos y procedimientos terapéuticos entre pacientes identificados con y sin demencia. Este estudio fue financiado por la Consejería de Salud

de Andalucía mediante los proyectos “Factores Condicionantes en la Implementación de Los Procesos de Atención Al Final de la Vida en Residencias de Ancianos y en Centros Gerontológicos” (PI-0619-2011) y el “Proyecto Elaboración e implantación de un programa de atención al final de la vida en residencias de ancianos” (AP-0105-2016).

### 6.3. Estudio 3:

En el tercer estudio, publicado en la revista “*Journal of Nursing Scholarship*”, se realizó una revisión sistemática y una síntesis interpretativa, utilizando el enfoque meta-etnográfico desarrollado por Noblit y Hare (1988), de la actitud de las enfermeras hacia la muerte. Se realizó una búsqueda en las bases de datos Web of Science, CINAHL, and CUIDEN incluyendo estudios desde el 2011 hasta febrero del 2017.

### 6.4. Estudio 4:

En el cuarto estudio de esta tesis, publicado en la revista “*International Journal of Environmental Research and Public Health*”. Se realizó la adaptación cultural y la validación cultural de la escala *Quality of Dying in Long-Term-Care* (QoD-LTC). Aspectos como la validez, la fiabilidad y la factibilidad fueron evaluados siguiendo el procedimiento propuesto por Ramada, Serra and Delclós (Ramada-Rodilla et al., 2013). Este estudio fue financiado por la Fundación Pública Andaluza Progreso y Salud mediante el proyecto titulado “Elaboración e implantación de un programa de atención al final de la vida en residencias de ancianos” (AP-0105-2016).

## *Resultados*

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## 7. Resultados

### 7.1. Estudio 1

**Título:** Prospective Evaluation of Intensity of Symptoms, Therapeutic Procedures and Treatment in Palliative Care Patients in Nursing Homes.

**Autores:** Daniel Puente-Fernández, Concepción B Roldán-López, Concepción P Campos-Calderón, Cesar Hueso-Montoro, María P García-Caro, Rafael Montoya-Juarez.

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## Article

# Prospective Evaluation of Intensity of Symptoms, Therapeutic Procedures and Treatment in Palliative Care Patients in Nursing Homes

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**Abstract:** The aim of the study is to evaluate the intensity of symptoms, and any treatment and therapeutic procedures received by advanced chronic patients in nursing homes. A multi-centre prospective study was conducted in six nursing homes for five months. A nurse trainer selected palliative care patients from whom the sample was randomly selected for inclusion. The Edmonton Symptoms Assessment Scale, therapeutic procedures, and treatment were evaluated. Parametric and non-parametric tests were used to evaluate month-to-month differences and differences between those who died and those who did not. A total of 107 residents were evaluated. At the end of the follow-up, 39 had (34.6%) died. All symptoms ( $p < 0.050$ ) increased in intensity in the last week of life. Symptoms were more intense in those who had died at follow-up ( $p < 0.05$ ). The use of aerosol sprays ( $p = 0.008$ ), oxygen therapy ( $p < 0.001$ ), opioids ( $p < 0.001$ ), antibiotics ( $p = 0.004$ ), and bronchodilators ( $p = 0.003$ ) increased in the last week of life. Peripheral venous catheters ( $p = 0.022$ ), corticoids ( $p = 0.007$ ), antiemetics ( $p < 0.001$ ), and antidepressants ( $p < 0.05$ ) were used more in the patients who died. In conclusion, the use of therapeutic procedures (such as urinary catheters, peripheral venous catheter placement, and enteral feeding) and drugs (such as antibiotics, anxiolytics, and new antidepressant prescriptions) should be carefully considered in this clinical setting.

**Keywords:** palliative care; nursing homes; symptom assessment; drug therapy; therapeutics; longitudinal studies

## 1. Introduction

The World Health Organization (WHO) [1] and the European Association of Palliative Care (EAPC) [2] encourage an increase in the quality of dying in long-term care settings. In fact, several articles call for more research on end-of-life interventions in these centres, in order to improve care practice [3,4]. Meanwhile, nursing homes have become a plausible alternative in situations where the home is not the most suitable place for the end of life, due to clinical complexity or lack of resources [5].

Recent studies have indicated that there is a high prevalence of physical and psychological symptoms in nursing homes [3,6–8]. All of these symptoms increase in intensity and prevalence as the



end of life approaches [4,9]. Most of the studies that have evaluated end-of-life symptoms in nursing homes are retrospective studies [3,6,9–11]. They may exhibit selection bias and problems caused by poorly recorded or unrecorded data. Prospective studies may be very helpful to properly assess the changes in symptom control when death is about to occur.

Hospices in Spain are not widely developed, so end-of-life care must be provided by other institutions. In the case of elderly patients, this care is mostly provided by nursing homes. In these centres, most of the beds are privately funded (71%) [12], although some are partially government-funded. In Andalusia, only nursing homes with more than 60 beds are required to offer twenty-four hour nursing services and their own medical care [13].

Beyond this, little is known regarding routine therapeutic procedures and pharmacological treatments in palliative patients in nursing homes. In a recent retrospective study in Spanish hospitals, patients who were at the end stage of their lives received similar therapeutic and diagnosis procedures to acute care patients [14]. This is congruent with other papers published previously: procedures such as catheter insertion, the use of aspirators, and other actions that are common for patient care in a general hospital can make the difference between comfort and discomfort for end-of-life patients [8,15,16].

Regarding pharmacological treatments, a recent review highlighted that many patients continue to receive medications that are not prescribed as palliative treatments or for symptom control, despite being in the end stage of life [17]. A previous review [18] pointed out that few studies focus on pharmacological de-prescription in end-of-life and concluded that life expectancy is not often used as a criterion for medication discontinuation, even though unnecessary drugs might cause side effects that may increase suffering for patients.

In this context, the European Association of Palliative Care [19] emphasises that, in Spain, there are no specific documents on palliative care in long-term care facilities, nor publications regarding the provision of palliative care in this type of centres in Spain.

The purpose of this study is to prospectively explore perception of symptom control, pharmacological treatments, and therapeutic procedures received by palliative patients admitted to nursing homes in the last six months of life. This is one of the first studies to use a prospective approach, and the first one to show the end-of-life situation in Spanish nursing homes with this methodology. We hypothesize that, when death is near, intensity of symptoms and pharmacological treatments linked to symptom control will increase, whereas the frequency of routine therapeutic procedures will be the same as in previous months.

## 2. Experimental Section

### 2.1. Design

This is a multi-centre prospective study which has been conducted in nursing homes in Spain.

### 2.2. Sample

Six nursing homes were selected for convenience based on their institutional characteristics: Presence of a multidisciplinary team, the possible involvement of professionals, and the presence of both public and private beds. All centres included in the study have more than 50 beds. In each centre, one or two nurses with close knowledge of the patient who have been working at the nursing home for at least 6 months were responsible for data collection. All of the nurses that participated signed an informed consent form and received training prior to data collection. In order to control bias and to produce reliable data for the research, these professionals completed a training course designed to explain the study, to ensure that the same data collection methods were followed, and to avoid the dropout of patients at the follow-up stage. The research team was in contact with them via email, and they visited the centres regularly, i.e., at least once a month.

### 2.3. Recruitment

Each nursing home nurse recruited residents with chronic diseases that met the following criteria according to the Spanish Society of Palliative Care (SECPAL):

- Advanced, progressive, and incurable disease
- Little to no possibility of response to any specific treatment
- Presence of numerous problems or intense, multiple, multifactorial and changing symptoms
- Great emotional impact on patient, family, and staff
- Life expectancy limited to 6 months.

Within each nursing home, twenty patients were randomly selected among all the patients that met the aforementioned inclusion criteria. They were observed and the data of interest were recorded without interfering with the natural course of events. Data were collected between June 2016 and January 2017. All participants, patients, or representatives of patients (in the case of cognitively impaired patients) were fully informed and signed informed consent forms.

### 2.4. Data Collection Procedure

Nurses collected demographic and clinical information from the clinical records of the patients. A structured questionnaire was used to collect socio-demographic (age, gender, years in the centre, marital status, and number of children) and clinical (medical diagnosis, Charlson Comorbidity Index) data from patient records.

For the systematic symptom assessment, we used the Edmonton Symptom Assessment System (ESAS) [20]. The ESAS has been validated for both patient and care partner report in different settings, including those with older people with multiple morbidities [21]. ESAS was used regularly in all the nursing homes that participated in the study for symptom assessment. The patient version of the ESAS was self-administered by cognitively intact patients. For cognitively impaired residents, the professional version of the ESAS was completed by trained nurses. The relatives of the patients were not involved in data collection. Cognitive impairment was defined as the patient making three or more mistakes in the Pfeiffer test. The Pfeiffer test was used in all the nursing homes that participated in this study.

The prescription of therapeutic procedures such as urinary catheterisation, enteral feeding, peripheral venous catheter placement, use of aerosol sprays, oxygen therapy, and pharmacological treatments such as non-opioid analgesics, opioid analgesics, antibiotics, bronchodilators, corticosteroids, antiemetics, antihistamines, antidepressants, anxiolytics, hypnotics, and barbiturates was also evaluated.

Data were collected between June 2016 and January 2017. For this study, outcome data were collected from clinical records of the first month (T1) and of the following months (T2, T3, T4, and T5) if residents were still alive. For all the residents who died within these six months, the same data were collected from the clinical records of the last week before death (CT = closure test). All participants, residents, and the care partner were fully informed and signed informed consent forms.

### 2.5. Statistical Analysis

A descriptive analysis was carried out to describe the main characteristics of the study sample. Numerical variables were described with the mean and standard deviation (SD) and the median and interquartile range (P25-P75). Categorical variables were described using absolute frequencies and percentages. Quantitative data were assessed for normality using the Kolmogorov-Smirnov test, and all of the quantitative data collected were found to deviate significantly from the normal distribution ( $p < 0.001$ ). Due to this, non-parametric inferential tests were used. Pearson's chi-squared test was used to evaluate between-group differences and McNemar's test was used to compare the prevalence rates. Wilcoxon's signed-rank test was used in order to compare month-by-month the symptoms reported



using the ESAS for nursing home residents. Statistical analyses were conducted using IBM SPSS v.24. *p*-values of less than 0.05 were considered to be statistically significant.

### 2.6. Statement of Ethics

All participants (or when appropriate, a representative) signed a form to give their informed consent. The study received the approval of the Research Ethics Committee (PI-0619-2011). In compliance with Spanish Law (Article 16, Law 41/2002), patients' data were anonymised.

### 3. Results

Thirteen patients dropped out of the study. Two of them moved to another nursing home. Ten patients or representatives of patients refused to give their informed consent during follow-up. One of the residents died before the beginning of the follow-up. As a result, the final sample consisted of 107 residents. Most of them were women (63.6%) and they had a mean age of 84.6 (SD = 7.4) years. The characteristics can be seen in Table 1.

**Table 1.** Socio-demographic and clinical characteristics of the patients.

Socio-Demographic and Clinical Characteristics of the Patients.	Total Sample <i>n</i> = 107		Dying within 6 month <i>n</i> = 39		Alive ≥ 6 month <i>n</i> = 68		<i>p</i>
Age, md (P25-P75)	84	(81–89)	86	(83–95)	84	(78.5–89)	0.011 <sup>1</sup>
Female, <i>n</i> (%)	68	(63.6)	24	(64.8)	44	(62.9)	0.835 <sup>1</sup>
Years in the centre, md (P25-P75)	2	(1–4)	2	(0.6–5)	2	(1.3–4)	0.946 <sup>2</sup>
Marital status widower, <i>n</i> (%)	63	(60.8)	25	(67.6)	38	(54.3)	0.012 <sup>2</sup>
Number of children, md (P25-P75)	2	(0–3)	2	(0–2)	3	(2–5)	0.222 <sup>1</sup>
CCI, md (P25-P75)	3.5	(2–6)	4	(4–6)	3	(2–5)	0.007 <sup>1</sup>
Primary diagnosis							
Myocardial infarction, <i>n</i> (%)	6	(5.6)	2	(5.3)	4	(6.0)	1.000 <sup>2</sup>
Heart failure, <i>n</i> (%)	28	(26.2)	12	(31.6)	16	(23.3)	0.492 <sup>2</sup>
Peripheral vascular disease, <i>n</i> (%)	10	(9.3)	9	(23.7)	1	(1.5)	0.000 <sup>2</sup>
Thromboembolic disease, <i>n</i> (%)	7	(6.5)	6	(15.8)	1	(1.5)	0.009 <sup>2</sup>
Stroke or other cerebral lesions, <i>n</i> (%)	45	(42.1)	22	(57.9)	23	(34.3)	0.024 <sup>2</sup>
Hemiplegia, <i>n</i> (%)	14	(13.1)	7	(18.4)	7	(10.4)	0.370 <sup>2</sup>
Arterial hypertension, <i>n</i> (%)	63	(58.9)	15	(38.5)	41	(60.3)	0.044 <sup>2</sup>
Dementia	51	(47.7)	20	(52.6)	43	(64.2)	0.301 <sup>2</sup>
COPD, <i>n</i> (%)	25	(23.4)	12	(31.6)	13	(19.4)	0.233 <sup>2</sup>
Arrhythmia, <i>n</i> (%)	21	(19.6)	14	(36.8)	7	(10.4)	0.002 <sup>2</sup>
Renal disease, <i>n</i> (%)	19	(17.8)	6	(15.8)	13	(19.4)	0.794 <sup>2</sup>
Diabetes, <i>n</i> (%)	34	(31.8)	10	(27.8)	24	(38.1)	0.380 <sup>2</sup>
Tumour, <i>n</i> (%)	17	(15.9)	8	(20.5)	9	(13.2)	0.308 <sup>2</sup>
Solid tumour with metastasis, <i>n</i> (%)	10	(9.3)	4	(10.5)	6	(9.0)	1.000 <sup>2</sup>

Charlson Comorbidity Index, CCI; <sup>1</sup> Mann-Whitney *U*-test; <sup>2</sup> Pearson's chi-squared; COPD: chronic obstructive pulmonary disease.

Residents who died within the follow-up period (*n* = 39, 34.6%) were generally older and widowers, had a higher Charlson comorbidity index (CCI), and had more peripheral vascular and thromboembolic diseases, stroke or other cerebral lesions, arterial hypertension, and arrhythmia.

#### 3.1. Perception of Symptom Intensity

In the comparison from T1 to T5, the perception of intensity of all symptoms was scored as moderate, except nausea and dyspnoea, which were scored as mild. No statistical differences were found in symptom intensity between T1 and T2 to T5 (Table 2). However, all differences were found to be statistically significant between T1 and symptoms in the last week of life (CT). In the comparison with CT, the median ratings for nausea (*p* = 0.040) and depression (*p* = 0.033) increased by up to 2 points; pain (*p* = 0.026), fatigue (*p* = 0.003), drowsiness (*p* ≤ 0.001), dyspnoea (*p* ≤ 0.001), and insomnia (*p* = 0.032) increased by up to 3 points; anxiety (*p* = 0.001), poor appetite (*p* ≤ 0.001), and malaise

( $p = 0.004$ ) increased in intensity by up to 4 points. In this case, all symptoms were scored as moderate except nausea, which was scored as mild, and fatigue and malaise, which were scored as severe.

**Table 2.** Month-by-month comparison of symptoms using Edmonton Symptom Assessment System (ESAS) for residents in nursing homes.

Symptoms	T1 vs. T2 ( $n = 102$ )		T1 vs. T3 ( $n = 95$ )		T1 vs. T4 ( $n = 84$ )		T1 vs. T5 ( $n = 82$ )		T1 vs. CT ( $n = 39$ )	
	md (P25-P75)	$p^1$	md (P25-P75)	$p^1$	md (P25-P75)	$p^1$	md (P25-P75)	$p^1$	md (P25-P75)	$p^1$
Pain										
T1	4 (2-6)		4 (2-6)		5 (2-7)		4 (2-6.5)		4 (2-7)	
T(2-5) or CT	3.5 (2-6)	0.563	3.5 (2-6)	0.934	5 (2-7)	0.718	5 (2-7.5)	0.741	7 (2-9.5)	0.026
Fatigue										
T1	5.5 (3-7)		5 (2-7)	0.485	5.5 (3-7)	0.443	4 (2.5-8)	0.559	5 (3-7)	0.003
T(2-5) or CT	5.5 (3-8)	0.225	5 (2-8)	0.485	5.5 (3-8)	0.443	5 (2.5-9)	0.559	8 (3.5-9)	0.003
Nausea										
T1	0 (0-3)		0 (0-2)	0.728	0 (0-2.5)	0.228	0 (0-2)	0.836	0 (0-3)	0.040
T(2-5) or CT	0 (0-3)	0.721	0 (0-2)	0.728	0 (0-1)	0.228	1 (0-3)	0.836	2 (0-7)	0.040
Depression										
T1	3 (0-6)		3 (0-6)	0.833	3 (0-6)	0.654	3 (0-6)	0.589	3 (0-7)	0.033
T(2-5) or CT	3 (0-5.5)	0.773	2 (0-7)	0.833	3.5 (1-6)	0.654	3.5 (1-7)	0.589	4.5 (1-9)	0.033
Anxiety										
T1	3 (0-6)		3 (0-5.5)	0.470	3 (0-6)	0.889	3 (0-6)	0.553	3 (0-6)	0.001
T(2-5) or CT	2 (0-5)	0.298	2 (0-6)	0.470	3 (0-6)	0.889	4 (0-6)	0.553	7 (1-9)	0.001
Drowsiness										
T1	2 (4-7)		4 (2-7)	0.777	3.5 (2-7)	0.985	3 (0.5-5)	0.850	4 (3-6)	<0.001
T(2-5) or CT	2 (1-7)	0.357	4 (1-6)	0.777	4 (1-7)	0.985	4 (1-5)	0.850	7 (6-10)	<0.001
Poor appetite										
T1	3 (0-6)		3 (0-6)	0.479	3 (0-7)	0.332	3 (0-6)	0.473	3 (1-7)	<0.001
T(2-5) or CT	4 (0-6)	0.624	2 (0-5.5)	0.479	2 (0-6.5)	0.332	2 (0-4)	0.473	7 (3-10)	<0.001
Malaise										
T1	5 (0-7)		5 (0-7)	0.284	5 (0-7)	0.210	4 (0-7)	0.357	5 (0-7)	0.004
T(2-5) or CT	4.5 (0-6)	0.114	4 (0-6)	0.284	5 (1-8)	0.210	4 (3-7)	0.357	9 (2-9.5)	0.004
Dyspnoea										
T1	1 (0-6)		1 (0-6)	0.765	1 (0-6)	0.602	1 (0-6)	0.187	4 (0-6)	<0.001
T(2-5) or CT	1 (0-5)	0.522	1 (0-6)	0.765	0 (0-6.5)	0.602	0 (0-5.5)	0.187	7 (5-9)	<0.001
Insomnia										
T1	2.5 (0-6)		2 (0-6)	0.480	2.5 (0-7)	0.119	2 (0-6)	0.955	3 (0-7)	0.032
T(2-5) or CT	2 (0-6)	0.991	2 (0-5)	0.480	3 (0-6)	0.119	3 (0-6)	0.955	6 (1-9)	0.032

Wilcoxon's signed-rank test<sup>1</sup>; T1: Initial follow-up time; T2, T3, T4, T5: Different follow-up times; CT: Closure Test. Week before death; P25: 25th percentile; P75: 75th percentile.

Residents who died during the follow-up period rated symptom intensity as higher for all symptoms, compared to those who were alive for the entire duration (Table 3).

**Table 3.** Comparison of symptoms using ESAS in residents of nursing homes who died with those who did not die.

Symptoms	Dying within 6 months $n = 39$ n(Range)	Alive $\geq 6$ months $n = 68$ n(Range)	$p^1$
Pain, md (P25-P75)	7 (2-9)	4 (2-6)	0.012
Fatigue, md (P25-P75)	8 (3.5-9)	6 (3-8)	0.005
Nauseas, md (P25-P75)	1 (0-7)	0 (0-1)	0.003
Depression, md (P25-P75)	4 (1-9)	3 (0-6)	0.050
Anxiety, md (P25-P75)	4 (1-9)	3 (0-6)	0.002
Drowsiness, md (P25-P75)	7 (1-9)	4 (0-7)	< 0.001
Poor appetite, md (P25-P75)	7 (6-10)	4 (2-7)	< 0.001
Malaise, md (P25-P75)	9 (2-9.5)	5 (2-7)	< 0.001
Dyspnoea, md (P25-P75)	7 (5-9)	1 (0-6)	< 0.001
Insomnia, md (P25-P75)	6 (1-9)	2 (0-6)	0.011

<sup>1</sup>Mann-Whitney *U*-test.

### 3.2. Therapeutic Procedures and Pharmacological Treatments

No statistical differences were found in the comparison of therapeutic procedures between T1 and T2 to T5. Nevertheless, the analysis showed significant differences between T1 and CT (Table 4). The most repeated procedures (oxygen therapy ( $p \leq 0.001$ ), use of aerosol sprays ( $p = 0.008$ ), and peripheral venous catheter placement ( $p = 0.039$ )) had an increase of between 20 and 40 percentage points. Despite this, the percentage of procedures related to urinary catheters ( $p = 1000$ ) and enteral feeding ( $p = 0.221$ ) was not significantly different between T1 and CT.

**Table 4.** Comparison of therapeutic procedures and pharmacological treatments by months for patients in nursing homes.

Therapeutic Procedures/Pharmacological Treatments	T1 vs. T2 (n = 102)		T1 vs. T3 (n = 95)		T1 vs. T4 (n = 84)		T1 vs. T5 (n = 82)		T1 vs. CT (n = 37)	
	%	p <sup>1</sup>	%	p <sup>1</sup>	%	p <sup>1</sup>	%	p <sup>1</sup>	%	p <sup>1</sup> 95% CI <sup>2</sup>
Therapeutic procedures										
Urinary catheter										
T1	14.7		14.7		11.9		14.6		21.1	
T(2-5) or CT	13.7	1.000	14.7	1.000	14.3	0.752	8.5	0.267	23.7	1.000
Peripheral venous catheter placement										
T1	26.5		24.2		22.9		24.4		25.6	
T(2-5) or CT	24.5	0.860	28.4	0.522	18.6	0.502	19.5	0.480	48.7	0.039 4.1–39.9
Enteral feeding										
T1	11.8		14.0		15.5		14.6		5.3	
T(2-5) or CT	11.8	1.000	14.0	1.000	15.5	1.000	17.1	0.789	15.8	0.221
Aerosol sprays										
T1	23.5		18.9		19.3		18.3		28.2	
T(2-5) or CT	21.6	0.789	26.4	0.248	25.3	0.267	22.0	0.248	61.5	0.008 11.5–51.9
Oxygen therapy										
T1	30.4		28.4		27.4		24.4		36.9	
T(2-5) or CT	32.4	0.803	31.9	0.450	33.3	0.511	29.3	0.343	79.5	<0.001 17.6–65.3
Pharmacological treatments										
Non-opioid analgesics										
T1	58.8		54.7		54.8		51.2		71.8	
T(2-5) or CT	64.7	0.263	61.1	0.345	60.7	0.404	61.0	0.170	64.1	0.628
Opioid analgesics										
T1	12.7		11.6		8.3		12.2		17.9	
T(2-5) or CT	15.7	0.375	16.8	0.131	11.9	0.445	11.0	1.000	61.5	<0.001 25.6–37.3
Antibiotics										
T1	21.6		20.0		21.4		17.1		30.8	
T(2-5) or CT	29.4	0.185	29.5	0.109	31.0	0.136	25.6	0.211	66.7	0.004 14.9–53.4
Bronchodilators										
T1	27.5		26.3		28.6		32.9		25.6	
T(2-5) or CT	32.4	0.302	32.6	0.114	31.0	0.814	29.3	0.505	53.8	0.003 12.4–41.2
Corticosteroids										
T1	20.6		18.9		15.5		17.1		28.2	
T(2-5) or CT	21.6	1.000	20.0	1.000	20.2	0.453	18.3	1.000	41.0	0.267
Antiemetics										
T1	7.8		9.5		6.0		8.5		17.9	
T(2-5) or CT	7.8	1.000	9.5	1.000	7.1	1.000	12.2	0.505	30.8	0.227
Antihistamines										
T1	7.8		6.3		6.0		3.7		10.3	
T(2-5) or CT	7.8	1.000	8.4	0.500	7.1	1.000	3.7	1.000	2.6	0.248
Antidepressants										
T1	33.3		34.7		32.5		33.7		28.2	
T(2-5) or CT	33.3	1.000	32.6	0.617	30.1	0.479	27.7	0.131	12.8	0.114
Anxiolytics										
T1	32.4		35.0		28.6		29.3		41.0	
T(2-5) or CT	30.4	0.773	28.4	0.181	25.7	0.752	34.1	0.386	25.6	0.150
Hypnotics/barbiturates										
T1	49.0		46.3		41.7		50.0		51.3	
T(2-5) or CT	44.1	0.267	46.3	1.000	47.6	0.383	43.9	0.424	71.8	1.000

<sup>1</sup>McNemar's test; <sup>2</sup>Agresti Min 95% confidence interval for p2-p1.; T1: Initial follow-up time.; T2, T3, T4, T5: Different follow-up times.

Regarding pharmacological treatments, no significant differences were found between T1 and T2 to T5. However, some statistical differences were found between T1 and CT (Table 4). Opioid analgesics ( $p \leq 0.001$ ), antibiotics ( $p = 0.004$ ), bronchodilators ( $p = 0.003$ ) had a significant increase in usage, that increase being of 45, 35, and 29 percentage points, respectively.



CT: Closure Test. Week before death. Statistical differences were found in the use of peripheral venous catheters ( $p = 0.022$ ), aerosol sprays ( $p = 0.001$ ), and oxygen therapy ( $p = 0.001$ ) between the patients who died in the follow-up and those who survived (Table 5).

**Table 5.** Comparison of therapeutic procedures and pharmacological treatments in nursing home patients who died with those who did not die.

Therapeutic Procedures/Pharmacological Treatments	Dying within 6 months, $n = 39$	Alive $\geq 6$ months, $n = 68$	$p^*$	OR (95% CI)
Therapeutic procedures				
Urinary catheter, (%)	23.7	13.2	0.176	
Peripheral venous catheter placement, (%)	48.7	25.0	0.022	2.850 (1.238–6.562)
Enteral feeding, (%)	15.8	14.7	0.867	
Aerosol sprays, (%)	61.5	20.6	<0.001	6.171 (2.578–14.771)
Oxygen therapy, (%)	79.5	26.5	<0.001	10.764 (4.181–27.713)
Pharmacological treatments				
Non-opioid analgesics	65.8	54.4	0.350	
Opioid analgesics	63.2	10.3	<0.001	14.939 (5.372–41.546)
Antibiotics	65.8	16.2	<0.001	9.965 (3.930–25.268)
Bronchodilators	55.3	16.2	<0.001	6.401 (2.580–15.880)
Corticosteroids	42.1	16.2	0.007	3.769 (1.514–9.379)
Antiemetics	31.6	4.4	<0.001	10.000 (2.607–38.359)
Antihistamines	2.6	7.4	0.417	
Antidepressants	13.2	33.3	0.026	.278 (0.096–0.805)
Anxiolytics	26.3	29.4	0.909	
Hypnotics/barbiturates	52.6	48.5	0.839	

\*Pearson's chi-squared; OR (95% CI), odds ratio (95% confidence interval of the odds ratio).

Finally, the comparison of pharmacological treatments showed differences for use of antibiotics ( $p < 0.001$ ), bronchodilators ( $p < 0.0001$ ), opioids ( $p < 0.001$ ), corticosteroids ( $p = 0.007$ ), antiemetics ( $p < 0.001$ ), and antidepressants ( $p = 0.026$ ) between those who died and the survivors (Table 5). The administration of these treatments was significantly greater in all deceased patients than in those who survived, except for antidepressants, whose usage was significantly lower.

#### 4. Discussion

This is one of the first studies that prospectively describes the last months of life of nursing home residents, and the first that has been conducted in Spain. Our results suggest that there is a sudden increase in symptoms, therapeutic procedures, and pharmacological treatments in the last week of life, in comparison with previous follow-up times. In addition, an increasing number of invasive therapeutic procedures, which may result in decreased comfort for residents, was observed, such as urinary catheter placement, peripheral venous catheter placement, and enteral feeding. Similarly, increased drug use, such as antibiotics, anxiolytics, and new antidepressant prescriptions was also observed.

The perception of the intensity of symptoms remains stable between T1 and the following months, but increases substantially between T1 and the last week of life. This finding is consistent with the previous literature, which details a worsening of symptoms in the last days of life [6,9]. Nevertheless, it is necessary to point out that the consulted studies used prevalence, not intensity, to assess symptoms. Thompson et al. [10] conducted a prospective study in which they assessed pain in the last six months of life of residents in nursing homes, showing that the intensity of their pain remained stable during a short follow-up period, except in the last days of life, when it increased.

In the same way, in relation to therapeutic procedures, there are significant differences in the use of peripheral venous catheters, oxygen therapy, enteral feeding, and aerosol sprays in the last week of life compared to at T1. These differences are greater if we compare the therapeutic procedures between patients who died within the follow-up period and survivors. Regarding oxygen therapy and the use of aerosol sprays, Hendriks et al. [4] highlighted that, unlike what the results of the present study show, there was a decrease in the use of these procedures when death was near. Similarly, a retrospective

study conducted in four Spanish hospitals [14] showed that oxygen therapy was a very frequently used intervention at the end of life. This study also reported that there is an increase in the use of peripheral venous catheters during the last days of life [14].

Enteral feeding is another intervention that might be considered to be futile [22], as this does not improve the wellbeing of patients in a significant way and may even be prolonging the dying process [22]. One of the factors that may influence the continuation of enteral feeding is that some professionals and relatives consider this intervention to be a measure of comfort that should not be removed [23].

With respect to urinary catheters, previous studies are not clear about the use of these interventions at the end of life. A literature review by Farrington et al. [24], which included clinical practice guidelines, pointed out that, even though some of the studies reviewed stated that urinary catheterisation could be used to provide comfort to patients, this procedure may cause or increase patient discomfort [24].

This could be interpreted as the performance of futile interventions in the last week of life in the nursing homes analysed.

As expected, the use of some medications linked to symptom control such as opioids, corticosteroids, and antiemetics increased in the last days of life. Opioids were one of the most used drugs in this study, which corresponds to what is described in the literature [4,9]. In relation to the use of non-opioid analgesics, Jansen et al., [25] unlike our study, reported an increase in the use of this group of drugs at the end of life.

On the other hand, there is a decrease in the use of antidepressants in the last week of life, although the consumption of other psychotropic drugs remains stable, compared to in previous months. The use of this kind of drug in end-of-life care is controversial: Some of them could be considered futile since they are not used to improve symptoms typical of the end of life [26]. The time delay before certain antidepressants have a noticeable effect is long (usually 4–6 weeks), so their usage may be considered futile for this reason. In fact, although psychotropic drugs may be indicated for the control of psycho-emotional symptoms, authors point out that they can cause undesirable side effects in the geriatric population and an increased risk of mortality [27].

Regarding the use of antibiotics at the end of life, our results indicate an increase in the last week of life. This may be due to the high percentage of patients with dementia in the sample, in whom infections are a common cause of death. Although, previous studies indicate that the use of antibiotics improves the prognosis of patients and the relief of symptoms [28–30], other studies provide evidence that not administering antibiotics improves comfort [31]. Furthermore, using antibiotics is not without risk in fragile patients with chronic diseases, due to drug reactions, drug-drug interactions, and infections [32]. Even so, there is no consensus as to whether or not they should be used at the end of life.

Furthermore, there has been no decrease in the prescription of drugs for any of the drugs evaluated. According to the consulted bibliography, one of those that would be expected to decrease according to current recommendations would be anxiolytics [33]. In our sample, the prescription of anxiolytics did not diminish at the end of life. According to Westbury [33], 'these psychotropic agents should be prescribed cautiously, at the lowest therapeutic doses for as short a time as possible, and be monitored regularly'. The literature consulted shows that identification of the terminal state increases the likelihood of a de-prescription occurring [34]. In the case of nursing homes, this identification is critical for facilitating patients' access to palliative care and, consequently, for improving the quality of care they receive, their satisfaction with it, and their symptoms [35]. Our results may be due to the lack of use of predictive survival tools that could be used in these centres. Therefore, in the absence of a prediction of the end of life, professionals do not question the utility of the interventions that can be carried out.

The present article tried to demonstrate part of the reality of the care provided by Spanish nursing homes, the study of which has had its importance emphasised by institutions, such as the EAPC. It would have been interesting to have assessed patient comfort, in order to clarify the suitability of



controversial interventions, due to their possible futility in an end-of-life context. This work is a first approach to the end of life in Spanish nursing homes, being the stepping stone on which it can be developed into an intervention programme to improve end-of-life care in these centres. At the same time, it could well help to validate specific tools, in order to assess the quality of the dying process and to improve the detection of palliative care needs.

It should also be highlighted that some limitations of this study may affect the reliability of our results. It should be noted that the sample size is small in comparison with other published studies, so it has not been possible to complete further analyses. Furthermore, characteristics of this study's sample are similar to those in other studies conducted in nursing homes regarding age, sex, and diseases [4,6,9,36], so the results should be extrapolated carefully.

In this study, SECPAL criteria were used for case selection. Our results pointed out that only the 36.4% of patients of the sample have died, so a discussion on whether these criteria are the most appropriate is needed, particularly the limitation of a life expectancy of six months.

Several tools have been proposed to identify palliative care needs and prognosis [37]. For instance, White et al. [38] highlighted in a meta-analysis that the accuracy of the 'Surprise Question' referring to a one-year period was higher than 70% in trained professionals. For further studies, a year-long follow-up period could be considered.

## 5. Conclusions

In this prospective study, intensity of end-of-life symptoms increased in the last week of life. There is also an increase in therapeutic procedures and pharmacological treatments, but not all the procedures and drugs are linked to symptom management. Interventions (such as urinary catheters, peripheral venous catheter placement, and enteral feeding) and drugs (such as antibiotics, anxiolytics, and new antidepressant prescriptions) should be carefully considered in this clinical setting, in order to improve patient comfort and avoid futile treatments.

Primary care workers and stakeholders might support nursing home professionals in order to provide better symptom control and decide which interventions and drugs are to be recommended in the last days of life.

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## 7.2. Estudio 2

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Article

# Palliative Care Symptoms, Outcomes, and Interventions for Chronic Advanced Patients in Spanish Nursing Homes with and without Dementia

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**Abstract:** The aim of this study was to compare the symptomatology, palliative care outcomes, therapeutic procedures, diagnostic tests, and pharmacological treatments for people with dementia (PWD) and without dementia (PW/OD) admitted to Spanish nursing homes. Design: This was a cross-sectional study which is part of a long-term prospective follow-up of elderly people performed in nursing homes to measure end-of-life care processes. Participants: 107 nursing home patients with advanced or terminal chronic diseases were selected according to the criteria of the Palliative Care Spanish Society. Setting: Two trained nurses from each nursing home were responsible for participant selection and data collection. They must have treated the residents and had a minimum seniority of 6 months in the nursing home. Measurements: Sociodemographic data; Edmonton Symptom Assessment Scale; Palliative Care Outcome Scale; and prevalence of diagnostic tests, pharmacological treatments, and therapeutic procedures were evaluated. Results: Pain, fatigue, and nausea were found to be significantly higher in the nondementia group and insomnia, poor appetite, and drowsiness were significantly higher in the dementia group. Patient anxiety, support, feeling that life was worth living, self-worth, and practical matters management were higher in the nondementia group. Regarding drugs, use of corticoids was higher in the nondementia group, while use of anxiolytics was higher in the dementia group. Diagnostic procedures such as urine analysis and X-ray were higher in the dementia group. Conclusions: Differences in symptom perception, diagnostic tests, and pharmacological procedures were found between patients with and without dementia. Specific diagnostic tools need to be developed for patients with dementia.

**Keywords:** validation studies; nursing; nursing students; palliative care; self-efficacy

## 1. Introduction

Dementia is one of the main causes of disability and death in the elderly, affecting 35.6 million people worldwide and steadily increasing [1]. Dementia currently affects around 10 million people in the European Region, and its prevalence is expected to double by 2030. There is no cure for dementia, and its development eventually leads to a loss of cognitive and physical functions.

The probability of institutionalization increases significantly with occurrence of dementia (odds ratio (OR) = 154.1) [2]. According to a recent review, poorer cognition, lack of community resources, and uncontrolled behavioral and psychological symptoms are factors that have been linked to institutionalization of older adults with dementia [3].

Because of that, there is a high prevalence of dementia in nursing homes among European countries. A German study published in 2014 showed that the prevalence of dementia was 51.8% in nursing home residents versus 2.7% in community-dwelling elderly [4]. Dementia prevalence was even higher (77.0%) in a study conducted in East London [5].

In Spain, the functions attributed to hospices are assumed by other long-stay centers. In the case of elderly patients, these functions are carried out mostly by nursing homes. Of all Spanish nursing homes, 71.53% were private in 2019, for a total of 3844 private nursing homes. Private centers generally offer a number of places arranged with the Public System [6]. Depending on the number of beds, case complexity, and the legislation of each State, services are offered. In Andalusia (southern Spain), for example, only nursing homes with over 60 beds are required to offer 24 h nursing services and their own medical care [7].

In a three-year prospective study in northern Spain on a cohort of patients with palliative needs, it was observed that almost a quarter of people with palliative needs live in nursing homes [8]. This population is mainly female and elderly, and the prevalent disease is dementia.

Nevertheless, research has demonstrated that in nursing homes, there is a high prevalence of poorly controlled symptoms, such as urinary and fecal incontinence, psychological and behavioral symptoms, pain, nausea, infections, restlessness, dyspnea, edema, and delirium [9–12].

A palliative care approach is needed for older people with dementia (PWD) institutionalized in nursing homes. High-quality palliative care in nursing homes requires structured evaluation and treatment of physical, psychosocial, emotional, and spiritual symptoms, as well as recognition of and satisfaction with the information needs of patients with dementia and their relatives.

One of the pillars of the palliative approach is to reduce burdensome interventions that might not have value at end of life and to focus on optimizing quality of life. Despite this, aggressive therapies, prescription of futile drugs, and burdensome interventions are still commonplace in older nursing home residents with advanced dementia [13,14]. Health professionals often face dilemmas regarding whether the time has come to not start or to withdraw treatments and interventions because they do not add quality of life [15]. A study conducted in the Netherlands [16] recommended that professionals should respond early to palliative care needs and encourage discussions with patients with dementia and their families about how to deal with therapeutic procedures and drug therapy at the end of life.

Nevertheless, differences in palliative care outcomes, symptoms, and interventions between residents with or without dementia who potentially require palliative care have not yet been examined. Furthermore, no studies have been found that quantitatively evaluate these outcomes in residents with or without dementia in the Spanish context.

We hypothesized that patients without dementia (PW/OD) would have different symptoms and palliative outcomes, consume different drugs, and undergo different diagnostic and therapeutic procedures than patients with dementia.

Related to symptoms, our hypothesis was that patients without dementia would experience more frequently and more intensely symptoms requiring self-identification as pain, fatigue, anorexia, nausea, depression, or anxiety than patients with dementia, while other symptoms would be experienced equally by both groups of patients.

Concerning palliative outcomes, the starting hypothesis was that patients with dementia would present worse outcomes in those aspects related to communication and self-esteem, as well as family anxiety, than those patients without dementia. Patients with dementia would consume more psychopharmaceuticals (anxiolytics, hypnotics, and barbiturates) and fewer analgesics, antiemetics, and antidepressants than patients without dementia due to the limited assessment of pain and other patient-referred symptoms in patients with cognitive impairment. On the other hand, we hypothesized



that the use of antibiotics would be higher in patients with dementia. The use of diagnostic procedures would be higher in patients with dementia due to the difficulty in diagnosing concurrent pathologies. On the contrary, the use of therapeutic procedures would be lower in patients with dementia than in the rest of the patients.

The aims of this study were (i) to describe symptoms perceived by professionals, palliative care outcomes, pharmacological treatments, diagnostic tests, and therapeutic procedure interventions and of older adults identified as palliative care patients in Spanish nursing homes and (ii) to compare existing differences between palliative care patients with dementia and those without dementia.

## 2. Materials and Methods

### 2.1. Design

A cross-sectional study was carried out in 6 nursing homes in the Metropolitan Health District of Granada.

### 2.2. Setting and Participants and Data Collection Procedure

Nursing homes were selected based on their institutional characteristics. All had more than 60 beds and were privately funded. The selection of the nursing homes was performed as a convenience selection based on the presence of a multidisciplinary team, professionals interested in the possible involvement in the study, and the offer of both public and private beds. The research team explained the aims of the study to nursing homes managers. In each center, one or two nurses with close knowledge of the residents and who had been working at the nursing home for at least 6 months were responsible for data collection. All the nurses who participated gave their informed consent. In order to control bias and to produce reliable data for the research, these professionals received a training course designed to explain the study in order to ensure uniformity of data collection. The research team was in contact with them by phone if new questions or scenarios were presented and they visited the centers regularly, at least once a month.

Each nursing home professional selected patients with chronic diseases that met the following criteria according to the Spanish Society of Palliative Care (“Sociedad Española de Cuidados Paliativos”—SECPAL):

- Advanced, progressive, and incurable disease
- Lack of reasonable possibilities of response to a specific treatment
- Presence of numerous problems or intense, multiple, multifactorial, and changing symptoms
- Great emotional impact on patient, family, and staff
- Life expectancy limited to 6 months.

Twenty patients meeting the above inclusion criteria were selected from each center for randomized follow-up. They were observed and the data of interest were recorded without interfering with the natural course of events. Data were collected between June 2016 and January 2017. All participants, patients, and caregivers were fully informed and signed the informed consent agreement. Informed consent was given by the patient if he or she did not have dementia and by the patient’s representative in the case of patients with dementia. Thirteen patients dropped out of the study: 3 of them moved on to another nursing home and 10 did not provide informed consent by either the patient or the representative. Among these 10, 6 had dementia and 4 did not.

### 2.3. Instruments

A structured questionnaire was used to collect sociodemographic (age, gender, years in the center) and clinical (medical diagnosis, Charlson Comorbidity Index) data from patient records.

For the systematic symptom assessment, we used the Edmonton Symptom Assessment System (ESAS) [17], the Spanish version of which has been validated in palliative care settings and is easy



to complete and to interpret. The ESAS has been validated for both patient and caregiver reports in different settings, including those with older people with multiple morbidities [18]. ESAS was used regularly in all the nursing homes that participated in the study for symptom assessment.

Palliative care outcomes were measured with the Palliative Outcome Scale (POS). The POS is a 10-item multidimensional scale that covers physical, psychological, emotional, and spiritual domains of life. It is a suitable instrument for evaluating palliative care needs coverage and symptoms of people with or without dementia [19]. The Spanish version of the POS [20] was found to be internally consistent (patient version  $\alpha = 0.64$ , staff version  $\alpha = 0.62$ ). The Spanish POS correlated with emotional function and quality of life scales. For dementia patients, ESAS and POS were assessed by trained professionals.

An ad hoc questionnaire was used to identify whether certain interventions had been performed (at least once) in the past month. We evaluated interventions such as common drug prescriptions at end of life (nonopioid analgesics, opioid analgesics, antibiotics, bronchodilators, corticoids, antiemetics, antihistamines, antidepressants, anxiolytics, and hypnotics/barbiturates), diagnostic tests (urine analysis, spirometry, electrocardiograms, X-rays, endoscopy, blood cultures, ultrasound, gammagraphs, electrocardiograms, blood analysis, and gasometry), and therapeutic procedures (urinary catheter, nasogastric catheter, peripheral catheter, enteral nutrition, aerosol sprays, and oxygen therapy) which were used in the past month.

#### 2.4. Data Analysis

A descriptive analysis was carried out to describe the main characteristics of the study population. Numerical variables were described by medians and interquartile ranges (P25–P75) and categorical variables by absolute frequencies and percentages.

Quantitative variables were assessed for normality using the Kolmogorov–Smirnov test and all were found to deviate significantly from the normal distribution ( $p < 0.01$ ). Because of this, nonparametric inferential tests were used.

A chi-squared test was used to assess independence between categories and the Mann–Whitney *U* test was used to assess differences between two independent samples. Statistical analysis was performed using IBM SPSS v.25© (IBM Corporation, Armonk, New York, United States); *p*-values of less than 0.05 were considered significant. OR and 95% confidence interval were calculated for each variable in which statistically significant differences were found between the two groups.

#### 2.5. Ethical Considerations

All participants (PW/OD) or representatives (PWD) gave their informed consent. The study received the approval of the Granada Research Ethics Committee (PI-0619-2011). In compliance with Spanish law (Article 16, Law 41/2002), patients' data were anonymized.

### 3. Results

#### 3.1. Participants

Overall, 120 patients were selected, but 13 of them were lost for various reasons, such as transfers to other centers. A total 107 nursing home residents were assessed. Residents' mean age was 84 (81–89) years, and 63.6% of the residents were women. The median length of the nursing home stay was 2.0 years. Chronic Obstructive Pulmonary Disease (COPD) had a significantly higher prevalence among PW/OD than in the PWD group ( $p = 0.05$ ). Other sociodemographic and clinical data of the sample are shown in Table 1.

**Table 1.** Sociodemographic and clinical characteristics of the patients.

Variables	Total Sample (n = 107)		PWD (n = 51)		PW/OD (n = 56)		p
Age, md (P25–P75)	84	(81–89)	85	(82–92)	83.5	(77–89)	0.142a
Female, n(%)	68	(63.6)	33	(64.7)	35	(62.5)	0.972a
Years in the center, md (P25–P75)	2	(1–4)	2	(1.7–5)	2	(1–4)	0.500b
CCI, md (P25–P75)	3.5	(2–6)	4	(3–6)	3	(2–6)	0.228a
<b>Coexisting conditions</b>							
Myocardial infarction, n(%)	6	(5.6)	3	(6.1)	3	(5.4)	0.866b
Heart failure, n(%)	28	(26.2)	11	(22.4)	17	(30.4)	0.488b
Peripheral vascular disease, n(%)	10	(9.3)	6	(12.2)	4	(7.1)	0.579b
Thromboembolic disease, n(%)	7	(6.5)	3	(6.1)	4	(7.1)	1.000b
Vascular brain ictus/damage, n(%)	45	(42.1)	25	(51.0)	20	(35.7)	0.167b
Hemiplegia, n(%)	14	(13.1)	4	(8.2)	10	(17.9)	0.242b
Arterial hypertension, n(%)	63	(58.9)	28	(57.1)	35	(62.5)	0.719b
COPD, n(%)	25	(23.4)	5	(10.2)	20	(35.7)	0.005b
Arrhythmia, n(%)	21	(19.6)	12	(24.5)	9	(16.1)	0.406b
Renal disease, n(%)	19	(17.8)	8	(16.3)	11	(19.6)	0.852b
Diabetes, n(%)	34	(31.8)	17	(36.2)	18	(32.7)	0.879b
Malignant tumor, n(%)	17	(15.9)	6	(12.2)	11	(19.6)	0.447b
Solid tumor with metastasis, n(%)	10	(9.3)	2	(4.1)	8	(14.3)	0.149b

PWD, patients with dementia; PW/OD, patients without dementia; CCI, Charlson Comorbidity Index; COPD, Chronic Obstructive Pulmonary Disease; a: Mann–Whitney; b: chi-squared; md, median; (P25–P75) interquartile range.

### 3.2. Perception of Symptom Intensity

In terms of end-of-life-related symptoms evaluated through the ESAS (Table 2), the most intense symptom for the group with dementia was dyspnea ( $\bar{x} = 7$ ; range = [4–9]), followed by drowsiness ( $\bar{x} = 6$ ; range = [4–8]), while for the group without dementia, the most intense symptoms were fatigue ( $\bar{x} = 7$ ; range = [5–8]) and depression ( $\bar{x} = 7$ ; range = [3–8]). In both groups, the most prevalent symptom was pain. Statistically significant differences were observed in pain ( $p = 0.002$ ), fatigue ( $p = 0.025$ ), nausea ( $p = 0.035$ ), poor appetite ( $p = 0.004$ ), and insomnia ( $p = 0.042$ ), with higher scores in the group without dementia. Drowsiness ( $p = 0.002$ ) was rated higher in the dementia group. No differences in total scale score were observed when comparing groups (Table 2).

**Table 2.** Comparison of intensity of perceived symptoms using the Edmonton Symptom Assessment System (ESAS) in patients of Nursing Homes with or without dementia.

Symptoms and Concerns	% (Total)	PWD <sup>a</sup>	PW/OD <sup>a</sup>	p <sup>b</sup>
1. Pain	87.9 (94)	3.5 (2–6)	6 (4–7)	0.002
2. Fatigue	82.2 (88)	5 (4–7)	7 (5–8)	0.025
3. Nausea	33.6 (36)	3 (2–4)	4.5 (3–6)	0.035
4. Depression	61.7 (66)	4 (3–7)	7 (3–8)	0.115
5. Anxiety	62.6 (67)	5 (4–6)	5.5 (4–8)	0.184
6. Drowsiness	86.0 (92)	6 (4–8)	4 (2–6)	0.002
7. Poor appetite	68.2 (73)	4 (2–6)	6 (5–8)	0.004
8. Not feeling well	74.8 (80)	6 (4–7)	6 (5–7)	0.197
9. Dyspnea	54.2 (58)	7 (4–9)	6 (2–8)	0.194
10. Insomnia	64.5 (69)	3 (2–7)	6 (4–8)	0.042
TOTAL	92.5 (99)	3 (2–5)	4 (2–6)	0.613

<sup>a</sup> median score and interquartile range; <sup>b</sup> Mann–Whitney.

### 3.3. Palliative Care Outcomes

Regarding palliative care outcomes, the mean score of the global POS of the group with dementia ranked between one and two, while those of the group without dementia ranked between two and three. More intense anxiety ( $p = 0.05$ ) and depression ( $p = 0.05$ ) were observed in the nondementia group compared with the dementia group. As shown in Table 3, the group with dementia spent

more time waiting or repeating tests than the group without dementia ( $p = 0.49$ ). However, the group without dementia showed higher scores for sharing their feelings with their family ( $p = 0.001$ ) and more practical matters ( $p = 0.002$ ) than patients with dementia. As for the Eastern Cooperative Oncology Group (ECOG), patients in the dementia group were more dependent than those in the nondementia group ( $p = 0.001$ ). The total score was lower in the group of patients with dementia.

**Table 3.** Perception of palliative care outcomes reported by the Palliative Outcome Scale (POS) in patients of NH with dementia (PWD) and without dementia (PW/OD).

Palliative Care Outcomes	% (Total)	PWD	PW/OD	$p^a$
1. Has the patient been affected by pain? (from 0 = "Not at all" to 4 = "Overwhelmingly")	87.9 (94)	1 (1–2)	1 (1–2)	0.069
2. Does the patient's other symptoms (e.g., nausea, coughing, or constipation) seem to be affecting how well s/he feels? (from 0 = "Not at all" to 4 = "Overwhelmingly")	74.8 (80)	2 (1–2)	2 (1–2)	0.775
3. Has s/he been feeling anxious or worried about her/his illness or treatment? (from 0 = "Not at all" to 4 = "The patient does not seem to think of anything else")	59.8 (64)	2 (1–2)	2 (2–3)	0.050
4. Have any of their family or friends been anxious or worried about the patient? (from 0 = "Not at all" to 4 = "Yes, they always seem preoccupied with worry")	89.7 (96)	3 (2–3)	2 (2–3)	0.111
5. How much information has been given to the patient and his/her family or friends? (from 0 = "Full information or as much as wanted" to 4 = "None at all")	83.2 (89)	3 (3–4)	4 (3–4)	0.232
6. Has the patient been able to share how s/he is feeling with family or friends? (0 = "Yes, as much as s/he wanted to" to 4 = "No, not at all with anyone")	60.7 (65)	1.5 (1–3)	3 (2–4)	0.001
7. Do you think the patient has felt good about his/herself? (from 0 = "Yes, all the time" to 4 = "No, not at all")	52.3 (56)	2 (1–2)	2 (1–4)	0.050
8. Do you think s/he felt life was worth living? (from 0 = "Yes, all the time" to 4 = "No, not at all")	60.7 (65)	2 (1–2)	2 (1–3)	0.065
9. How much time do you feel has been wasted on appointments relating to the healthcare of this patient (e.g., waiting around for transport or repeating tests)? (from 0 = "None at all" to 4 = "More than half a day wasted")	85.0 (91)	2 (2–2)	2 (1–2)	0.049
10. Have any practical matters resulting from his/her illness, either financial or personal, been addressed? (from 0 = "Practical problems have been addressed and his/her affairs are as up to date as s/he would wish" to 4 = "Practical problems exist which were not addressed")	45.8 (49)	2 (2–3)	3 (2–3)	0.002
11. Eastern Cooperative Oncology Group (ECOG)	100.0 (107)	3 (3–4)	2 (1–3)	0.001
Total	96.3 (103)	18 (15–21)	20 (18–24)	0.022

<sup>a</sup> Mann–Whitney.

### 3.4. Pharmacological Treatments, Diagnostic Tests, and Therapeutic Procedures

The most commonly used drugs for patients with dementia were hypnotics and barbiturates (62.7%), followed by analgesics (60%) and antidepressants (33%). For the group without dementia, 60.7% received nonopioid analgesics, followed by anxiolytics and bronchodilators (32.1%). Statistically significant differences were observed for corticoids ( $p = 0.035$ ) and anxiolytics ( $p = 0.005$ ). The percentage of patients with corticosteroids was higher in the nondementia group, while the percentage of patients with anxiolytics was higher in the dementia group.

Patients with dementia showed a higher probability of taking anxiolytics than those without dementia (OR = 3.521). Patients with dementia showed a lower probability of taking corticoids than those without dementia (OR = 0.306), as shown in Table 4.



**Table 4.** Comparison of pharmacological treatments in patients of NH with dementia (PWD) and without dementia (PW/OD).

Pharmacological Treatments	PWD (n = 51)	PW/OD (n = 56)	p <sup>b</sup>	OR (95% CI)
Nonopioid analgesics, (%)	60.0	60.7	1.000	
Opioid analgesics, (%)	14.9	16.4	1.000	
Antibiotics, (%)	23.5	21.4	0.978	
Bronchodilators, (%)	23.5	32.1	0.438	
Corticoids, (%)	11.8	30.4	0.035	0.306 (0.109; 0.853)
Antiemetics, (%)	9.8	8.9	1.000	
Antihistamines, (%)	9.8	8.9	1.000	
Antidepressants, (%)	33.3	32.1	1.000	
Anxiolytics, (%)	49.0	21.4	.005	3.521 (1.520; 8.198)
Hypnotics/barbiturates, (%)	62.7	32.1	.839	

<sup>b</sup> chi-squared; OR (95% CI), odds ratio (95% confidence interval of the odds ratio).

Regarding the diagnostic tests, almost half of the patients in the dementia group (45.1%) had a urine test and 38.3% had a blood test. On the other hand, in the group without dementia, 32.7% had a blood analysis and 19.6% had a urine analysis. It is notable that in the case of X-rays, in the group with dementia, 17.5% were performed, while in the group without dementia, no case was reported. Greater use of urine analysis ( $p = 0.009$ ) and X-rays ( $p = 0.009$ ) was observed in patients with dementia compared with patients without dementia (Table 5).

Patients with dementia showed 3.356 (1.422; 7.937) and 25.393 (1.430; 446.200) times the probability of having a urinalysis and X-ray performed than those without dementia, respectively.

**Table 5.** Comparison of diagnostic tests in patients of NH with dementia (PWD) and without dementia (PW/OD).

Diagnostic Tests	PWD (n = 51)	PW/OD (n = 56)	p <sup>b</sup>	OR (95% CI)
Urine analysis, (%)	45.1	19.6	0.009	3.356 (1.422; 7.937)
Spirometry, (%)	2.0	3.6	1.000	
Electrocardiograms, (%)	3.0	3.6	1.000	
X-rays, (%)	17.6	0.0	0.003	25.393 (1.430; 446.200)
Endoscopy, (%)	3.9	0.0	0.225	
Blood cultures, (%)	5.9	0.0	0.105	
Ultrasound, (%)	5.9	3.6	0.668	
Gammagraphs, (%)	2.0	0.0	0.477	
Electrocardiograms, (%)	19.1	14.5	0.722	
Blood analysis, (%)	38.3	32.7	0.705	
Gasometry, (%)	9.8	3.6	0.254	

<sup>b</sup> chi-squared (Fisher's exact test); OR (95% CI), odds ratio (95% confidence interval of the odds ratio).

For the group with dementia, 25.5% had an IV peripheral catheter and 23.7% carried a urinary catheter. Only 19.6% and 15.7% had oxygen therapy and aerosol sprays, respectively. For the group without dementia, the most frequent interventions were oxygen therapy (39.3%) and aerosol sprays (32.1%). The use of oxygen therapy was significantly less frequent among patients with dementia (OR = 0.378) (Table 6).

**Table 6.** Comparison of therapeutic procedures in patients of NH with dementia (PWD) and without dementia (PW/OD).

Therapeutic Procedures	PWD (n = 51)	PW/OD (n = 56)	p <sup>b</sup>	OR (95% CI)
Urinary catheter, (%)	23.7	13.2	0.176	
Nasogastric catheter, (%)	19.6	10.7	0.309	
IV peripheral catheter, (%)	25.5	26.8	1.000	
Enteral nutrition, (%)	15.7	7.1	0.275	
Aerosol sprays, (%)	15.7	32.1	0.079	
Oxygen therapy, (%)	19.6	39.3	0.045	0.378 (0.329; 0.994)

<sup>b</sup> chi-squared; OR (95% CI), odds ratio (95% confidence interval of the odds ratio).

#### 4. Discussion

Intensity of perceived symptoms, diagnostic and therapeutic procedures, and quality of palliative care were found to differ between residents with or without dementia in Spanish nursing homes. Our results showed that pain, fatigue, and nausea were significantly higher in the nondementia group. On the other hand, insomnia, poor appetite, and drowsiness were significantly higher in the dementia group. Concerning drugs, use of corticoids was higher in the nondementia group, while use of anxiolytics was higher in the dementia group. Diagnostic procedures such as urine analysis and X-ray were higher in the dementia group. Patient anxiety, lack of perceived support, lack of self-worth, and lack of practical matters management were higher in the nondementia group. Below, the implications for practice and research are discussed.

Although no differences were observed between groups in terms of total ESAS scale score, significant differences were observed between different symptoms. Pain is one of the most studied symptoms in residents with dementia institutionalized in nursing homes [11,12,21–23]. As our results highlighted, this symptom is usually one of the most prevalent in advanced stages and at the end of life [11]. Despite this, there is great difficulty in assessing pain in dementia patients because nonverbal signs of pain can be misinterpreted as neuropsychiatric or behavioral symptoms [11,21,23]. Smedbäck et al. [11] pointed out the need to develop specific scales for patients with dementia to help assess this and other symptoms.

According to our hypothesis and previous studies [12,24,25], other self-reported symptoms such as fatigue, nausea, poor appetite, and insomnia were rated higher in nondementia patients. As it happens with pain, this may be linked to a lack of assessment tools [11,26] rather than a real low prevalence/intensity of these symptoms in dementia patients [24].

Regarding palliative care outcomes, contrary to our initial hypothesis, the mean score of the POS was higher in nondementia patients, who also showed more anxiety, a lack of family support, and felt worst about themselves than dementia patients. Again, this could be linked to the absence of specific validated tools in the Spanish context to report anxiety and depression in dementia patients. As with the ESAS, POS data of dementia patients were reported by professionals. Nevertheless, professionals of nursing homes are not well trained in recognizing and treating emotional problems in dementia patients [12,27].

Although family anxiety was found to be higher in dementia patients, this difference was not statistically significant. It could be expected that families of dementia patients in nursing homes report higher levels of anxiety [24,28]. However, the anxiety of family members is high in dementia and nondementia patients, especially when faced with situations related to end-of-life decision-making [29,30].

According to our results, having dementia does not seem to be an impediment to receiving information, compared to those without dementia. It is necessary to highlight that the POS includes all the information that has been given both to the patient or the family. Communication is a challenge for dementia patients' relatives, but it is not only for them. In fact, Hermans et al. [31] showed in their results that patients with dementia received less information and received less support from their families



than the patients in the group without dementia. In our study, there were no statistically significant differences for given information between groups. Differences found between Hermans et al. [31] and our results may be due to different cultural patterns in dealing with institutionalized patients [32].

On the other hand, professionals and families spend more time on appointments related to healthcare. This may be due to greater difficulty in diagnosing pain or other symptoms and their possible causes [21].

In terms of the drugs used, contrary to the initial hypothesis, although more pain was reported in patients without dementia than in patients with dementia, no differences were observed in analgesic consumption. This absence of differences may indicate that pain is undervalued and undertreated in nursing homes [23,33,34]. However, it is difficult to know if patients are receiving enough analgesia, even in nondementia patients [23]. In a study carried out in Polish nursing homes, only 30% of residents with moderate or severe cognitive impairment were treated with analgesics. Most of them received medication from the first step of the analgesic scale, and only a few received opioids even if they experienced moderate pain [23].

Physicians have shown a preference to start with a weak analgesic, such as a Nonsteroidal Anti-Inflammatory Drug (NSAID), and gradually move upwards, rather than begin with powerful analgesics such as opioids [21]. In our study, although no differences were observed between groups, the percentage of opioid intake was lower than in other studies conducted in nursing homes with similar samples. Hendriks et al. [9] found that pain was recognized in 73% of patients, but in this study, patients were evaluated only in the last week of life, where pain is more prevalent and intense.

Regarding antibiotic consumption, a study carried out by van den Noortgate et al. [33] in Belgian nursing homes observed the last 48 h of life in these institutions. In this study, 63.6% of the patients consumed antibiotics.

In our results, contrary to the initial hypothesis, no statistically significant difference was found in antibiotic consumption between groups, as opposed to what was observed by Hendriks et al. [16] in their study, which showed greater antibiotic intake in patients with dementia.

According to our hypothesis, no differences were found in reported anxiety between dementia and nondementia patients, and a greater administration of anxiolytics and hypnotics/barbiturates was observed in the group with dementia. Agitation and restlessness can have several causes, such as pain or emotional distress [21]. Diagnosing the cause in dementia patients is very complicated because most of the time, these patients cannot verbally report these symptoms and this may lead to undertreatment or mistreatment. Other psychotropic drugs such as antipsychotics or barbiturates should be analyzed in further studies.

Due to the difficulties in diagnosing concurrent diseases or complications in dementia patients, according to our hypothesis, higher percentages of diagnostic procedures were observed in these patients for many of the evaluated tests, although statistically significant differences were only found in urine analysis and X-ray tests. The difficulty of diagnosing urinary tract infections has been previously reported in patients with advanced dementia in nursing homes [35]. Similarly, the high prevalence of microfractures in older adults with dementia (men and women, 80 years or more) has been reported in other study [36]. Hommel et al. [36] additionally remarked that these fractures are often underdiagnosed and may be considered as a cause of pain-related signs in dementia patients.

Regarding therapeutic procedures, contrary to the initial hypothesis, there were no differences between groups. This is consistent with the literature, where patients with dementia are not usually subjected to onerous interventions [16]. Nevertheless, we found statistically significant differences between groups for aerosol sprays and oxygen therapy. This may be due to difficulty in evaluation as well as other symptoms such as pain, which is reflected in undertreatment [33,34].

Some limitation should be pointed out. For this study, palliative patients were identified according to current Spanish Society of Palliative Care ("Sociedad Española de Cuidados Paliativos"—SECPAL) criteria, but since the data collection procedure finished, specific tools such as the NECPAL-CCOMS-ICO © tool [37] have been developed and improved to assess palliative needs of advanced chronic patients,

like those selected for this study, in the Spanish context. Nevertheless, the SECPAL criteria were the most widely used criteria for the Spanish population at the beginning of data collection. On the other hand, as it has been pointed out in the discussion section, although the ESAS and POS have been used for dementia patients before [19], it is necessary to develop and adapt to the Spanish context specific tools to evaluate symptoms and palliative care outcomes in these patients. It should be remembered that data on symptom intensity and prevalence as well as POS items have been reported by professionals. This carries a potential bias, as professionals may over- or underestimate certain aspects.

Finally, sample size may be a limitation for analysis in order to find other statistically significant differences between the two populations. Regardless, our study showed numerous differences with a high level of significance in spite of the sample size. However, the results of this study should be interpreted with caution, as they refer to a specific geographical context. Comparisons between different countries should be made in the future so that the differences found can be generalized.

## 5. Conclusions

Pain, fatigue, and nausea were found to be significantly higher in patients without dementia. In contrast, insomnia, poor appetite, and drowsiness were significantly higher in the dementia patients. Regarding drugs, use of corticoids was higher in the nondementia group, while use of anxiolytics was higher in the dementia group. Diagnostic procedures such as urine analysis and X-ray were higher in the dementia group. Patient anxiety, lack of perceived support, and lack of practical matters management were higher in nondementia patients, while more time was wasted on healthcare appointments in the dementia group. Specific tools are needed in order to evaluate symptoms and palliative care outcomes in dementia patients.

This is one of the first studies to evaluate and compare symptoms, pharmacological treatments, diagnostic and treatment procedures, and palliative outcomes between dementia and nondementia patients in nursing homes. This study provides valuable data about which symptoms are more prevalent and intense in dementia and nondementia patients, which are the most performed procedures, and which are the unmet palliative care needs.

**Author Contributions:** Conceptualization, C.H.-M. and R.M.-J.; Data curation, D.P.-F. and C.P.C.-C.; Formal analysis, D.P.-F. and C.B.R.-L.; Methodology, C.H.-M. and R.M.-J.; Project administration, C.P.C.-C.; Supervision, C.B.R.-L. and R.M.-J.; Validation, C.B.R.-L.; Writing—original draft, D.P.-F., C.P.C.-C., A.A.E.-B., C.B.R.-L. and R.M.-J.; Writing—review & editing, D.P.-F., C.P.C.-C., A.A.E.-B., C.H.-M., C.B.R.-L. and R.M.-J. All authors have read and agreed to the published version of the manuscript.

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**Conflicts of Interest:** The authors declare that there is no conflict of interest.

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### 7.3. Estudio 3

**Título:** Nursing Professionals' Attitudes, Strategies, and Care Practices Towards Death: A Systematic Review of Qualitative Studies.

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**ABSTRACT**

**Purpose:** To explore the attitude of nursing professionals towards death.

**Design:** Systematic qualitative review methods were used.

**Methods:** A search was conducted in the PubMed, Web of Science, CINAHL, and CUIDEN databases. This study included 17 articles.

**Findings:** Thirteen categories emerged, which were grouped into three themes: *meanings and feelings during the dying process; coping strategies in the face of death; and the importance of training, experience, and providing a dignified death.* In the different accounts of the participants, it was found that death had a large negative emotional impact on them, that the participants complained about the lack of previous training in the care of dying patients, and that avoiding these complex situations was one of the strategies most commonly used by professionals to face the death of a patient.

**Conclusions:** The lack of training in the basic care of terminally ill patients, as well as today's preconceived negative idea about death, both cause health professionals to experience situations of great stress and frustration. This results, on many occasions, in resorting to avoiding these situations, thus preventing dying with dignity.

**Clinical relevance:** In this paper, we explore the consequences of this process for nursing professionals, common coping strategies, and possible areas for improvement, such as the need for the training of nursing professionals in the care of terminally ill patients and their families.

**Key Words:** Death, Attitudes towards death, Healthcare professionals, Nurses

**INTRODUCTION**

Despite being an unavoidable fact, there is generally a reluctance to discuss death in society. Societies envision perspectives of life in which death is never a part of them, thus generating situations of avoidance and concealment (Cui et al., 2011; Freitas et al., 2016; Ignorosa-Nava & González-Juárez, 2014).

Historically, death was considered to be a natural event in which the sick individual participated by expressing their last wishes, by gathering their relatives to bid farewell, and by seeking forgiveness for their trespasses (Janaina Luizados Santos & Bueno, 2011). However, over time, death has become institutionalised, as it has moved from home to the hospital: up to 80% of deaths occur in a health institution, making it a cold, detached, and medicalised death (Celma Perdigon & Strasser, 2015; Ignorosa-Nava & González-Juárez, 2014; Kent et al., 2012; Janaina Luizados Santos & Bueno, 2011). All of this is compounded by a social context in which the inability to prevent death is felt as a failure (Celma Perdigon & Strasser, 2015).

This difficulty in managing the dying process directly affects the health system, especially health professionals (Ignorosa-Nava & González-Juárez, 2014). Several authors agree that nursing professionals have more extensive contact with patients than any other health professional (Peterson et al., 2010; Souza et al., 2013; J. Wilson & Kirshbaum, 2011), and therefore both their attitude towards death and their perception of death directly influence the quality of the care they provide.

There are many factors that, to a great extent, determine the attitude one has towards death, such as social, religious, cultural, and financial factors (Frutos-Martín, Iglesias-Guerra, Frutos-Martín, & Calle-Pardo, 2007). According to some studies, death awakens feelings of frustration, fear, and insecurity in professionals (Cavaye & Watts, 2014; Costello, 2006; Janaina Luizados Santos & Bueno, 2011). In recent years, several qualitative studies have been published on nurses' perception of death, as well as several syntheses (Zheng, Lee, & Bloomer, 2016; Zheng, Lee, & Bloomer, 2018).

The review by Zheng et al. (2016) focused on new graduate nurses' perceptions when coping with patient death. In a subsequent study, these authors (Zheng et al., 2018) examined the coping strategies used by nurses when dealing with patient death. Emotional disconnection, emotion management, the role of education, and spirituality were mentioned among the main coping strategies.

Other reviews have also been published focusing on specific aspects of the subject matter, such as the perceptions of death critical care nurses who have cared for patients and families during life support withdrawal have (Vanderspank-Wright, Efstathiou, & Vandyk, 2018). Furthermore, reviews have been conducted with other populations, such

as relatives (Wallace, Adorno & Stewart, 2018) and patients (Monforte-Royo, Villavicencio-Chávez, Tomás-Sábado, Mahtani-Chugani, Balaguer, & 2012; Rodríguez-Prat, Balaguer, Booth, & Monforte-Royo, 2017).

However, research on this group's attitude towards death has traditionally been carried out using other approaches, primarily quantitative methods, such as by administering ad hoc scales and validated questionnaires.

For this reason, we have decided to carry out a systematic review of qualitative studies in order to answer the following research question: What are the nursing professionals' attitudes towards the end-of-life care delivered to patients and towards their families? The meta-ethnographic approach has been used, as it allows the understanding and transfer of ideas and concepts by comparing different studies.

## **METHODS**

A systematic review and an interpretative synthesis were carried out using the meta-ethnographic approach developed by (Noblit & Hare, 1988). This approach is an inductive method which consists of making constant comparisons of the concepts found in different qualitative studies in order to facilitate the critical appraisal of a phenomenon and to draw common conclusions.

The search strategy combined the following MeSH and DECS terms: "death," "attitude to death," "health personnel," and "nurse" in English or Spanish, depending on the database language. The formula used was the following: (death or "attitude to death") AND ("health personnel" or nurse). The inclusion criteria were the following: (1) studies which included the assessment of the attitude of nurses towards death; (2) qualitative research; (3) studies including a sample of nurses. The selection was made by reading the titles, the abstracts, and the full texts, in this order. The selection of qualitative studies was conducted manually, by reviewing the titles and abstracts of the records identified.

The search was conducted in February 2017 in the PubMed, Web of Science, CINAHL, and CUIDEN databases, including studies published from 2011 onwards. This period of time was established in order to provide the most up-to-date evidence, and was based on the finding that, since 2011, many qualitative studies have been published on the subject. Two researchers conducted the search using the reference management

software Mendeley. Flow chart is shown in supporting information (File 1, online publication). After eliminating duplicates, two researchers selected and screened 198 articles. 29 articles were selected and a further 4 from other sources were added. These articles were subjected to a critical appraisal process by two independent reviewers with knowledge of qualitative research. As a result, 17 studies were selected and included in the final synthesis.

The critical appraisal was carried out using the Critical Appraisal Skills Programme (CASP), making use of its tool for the appraisal of qualitative studies. This tool includes 10 questions relating to methodological quality, relevance of the results, and applicability of the study. At the outset, we excluded the studies which did not pass the first two questions of the CASP checklist, which are eliminatory questions. The decision to include the articles was then made on the basis of a judicious discussion by the review team about the methodological rigour of the study in question. Finally, applicability was not assessed, as it is not an inclusion criterion according to the meta-ethnographic approach.

Relevant data (author(s), year, country, design, sample, main conclusions) were extracted from the articles by the main author of the study and were subsequently checked by another member of the research team. The main characteristics of the selected studies are shown in supporting information (File 2, online publication).

The selected studies were synthesised using the seven-stage method by Noblit and Hare (1988). In the first stage, the topic of interest was identified, which is part of the authors' field of research. The second stage consisted of selecting the qualitative studies based on the inclusion criteria, as well as on their quality. This stage has already been described above.

In the third stage, the findings of each study were read in detail (line by line). The informants' quotations (first-order construct) and the descriptions or interpretations made by the authors (second-order construct) were extracted from each article. Each study was used as a unit of analysis, and the texts extracted from each of them were imported for analysis using the Atlas.ti 7.0 software. One hundred and two author descriptions or interpretations were extracted with their quotations.

Key metaphors (second-order construct) were extracted using concepts or phrases that established preliminary assumptions, and similarities between the findings of the studies were outlined, including the exceptions observed. The process was sequential, comparing the metaphors of each study. The criteria for the adequacy of metaphors established by Noblit and Hare (1988) were taken into account: economy, cogency, range, apparency, and credibility. An example can be found as supporting information (File 3, online publication).

The fourth and fifth stages consisted of determining how the studies were related and translating the studies into one another. The concepts obtained in the previous stage were grouped by themes and categories (third-order construct), which allowed the construction of what Noblit and Hare (1988) called “line of argument”. Subsequently, the themes and categories were translated across the entire sample and into each individual study.

In the sixth stage, the final synthesis was conducted, which implied further reading of the included studies, yielding a total of 13 categories, which were grouped into 3 main themes (supporting information, file 4, online publication). In this phase, it was possible to reconceptualise the findings into a new interpretation, which facilitated the generation of an explanatory model that implied a new interpretation of the phenomenon on the basis of the data obtained from each study.

The analysis was carried out by two researchers and then triangulated by the rest of the team. The team members who participated in the triangulation also oversaw the entire process.

In the seventh stage, the synthesis is expressed through different ways of disseminating the findings. In our case, we opted for a research article. As such, in order to contribute to the uniformity of qualitative synthesis publications, this work is in line with *Improving reporting of meta-ethnography: The eMERGe reporting guidance* (France et al., 2019).

The team of authors is made up of 5 nurses and 1 psychologist, all with previous experience in end-of-life research. Neither the reviewers nor the institutions they work for have commercial or political interests in obtaining any particular results.



The validity of the study was ensured with a variety of procedures. On the descriptive level, each study included in the synthesis was described in detail and was assessed for quality using an instrument designed for this purpose, as well as for universal use. From an interpretative point of view, it should be noted that a sequenced analysis was carried out, based on both first order and second-order constructs, in order to subsequently generate new themes and categories that incorporate all of the above and go beyond the descriptions and/or interpretations of each one of the studies included.

## **FINDINGS**

The selected studies were conducted in China, Brazil, English-speaking countries (New Zealand, Australia, and the USA) and Spanish-speaking countries (Spain, Colombia, Chile, and Mexico). Fourteen of the seventeen articles analysed the accounts of nurses exclusively. One of them analysed the accounts of nursing students and two others analysed the attitude towards death of both nurses and other health professionals. The study setting was mainly hospitals (cancer and intensive care units in particular), as well as universities, in the case of the study with students. Thirteen of the selected articles analysed attitude towards death in adult patients, while the other four analysed it in paediatric patients.

Regarding the methodological quality assessment of the selected studies, and following the criteria established by the review approach employed, it should be noted that the studies received very good ratings in terms of the definition of the research question, the consistency of the qualitative methodology with respect to the objectives of each study, and the consistency of the data collection techniques with respect to the objectives and methods chosen. The consideration of ethical aspects and clarity in the presentation of the results also stand out. Criteria such as the description of the strategy for selecting participants and the thoroughness in the analysis of the data also obtained positive ratings, although they were slightly lower. Reflectivity received the worst rating, as only 5 of the 17 studies addressed this issue in their manuscripts.

After the synthesis and analysis of the results, thirteen categories emerged, which were grouped into three main themes.

### **Meanings and feelings during the dying process**

A key theme in all of the included studies was the perception of the feelings that surfaced in different professionals after the death of a patient. It was reported that being responsible for taking care of an individual during their dying process caused a great impact and emotional distress. Sadness, helplessness, and frustration were the feelings perceived in the testimonies of the participants, who expressed that these are the first feelings they experience when the death of a patient occurs. One of the informants of one of the studies (Anderson et al., 2015) referred to this as follows: “Actually, I couldn’t

sleep for two days. At all. And my [partner] was very worried about me. I couldn't come back the next day, because I was –sort of– traumatised myself...”

In addition, in some of the studies selected, reference was made to the fact that participants sometimes interact with patients and their families in such a way that they end up establishing affective ties with them. Many of the participants admitted that they had repeatedly “crossed the line” by allowing themselves to become “friends” with patients and family members: “...that was just memorable because of the emotional bond I'd had with her because I'd had her so many times. I just forget” (Hinderer, 2012, p. 255). Another participant stated: “He sort of becomes your son... One feels as if there's a greater bond... You feel as though you were his mum... He called me mum... I would take him to my place at the weekend” (García & Rivas, 2013, p. 119).

The category “Accepting death” was characteristic of 11 articles. One of the thoughts that some of the participants reported to be most useful referred to accepting death as part of the life cycle and to having this in mind: “...we all need to remember that just as we were born into this world, one day we will die” (Edo-Gual, Tomás-Sábado, Bardallo-Porras, & Monforte-Royo, 2014, p. 3506). However, the rest of the studies in which this category was notable showed that, on some occasions, the families were not willing to or could not accept the death of the patient, thus adding to the complexity of the professionals' experience.

Furthermore, the professionals understanding the death of a patient as a failure, and therefore not accepting it, resulted in the patient not dying in a dignified manner: “Some families still focus on curative treatments... I totally understand them, but there is no possibility to cure... these treatments make the patient lose his dignity” (Zheng, Guo, Dong, & Owens, 2015, p. 292).

Relief was another recurring theme. Cases have been reported where death was not conceived as a loss, but as a gain or liberation, both on the part of the family and the nursing team: “When the patient has been suffering for a long time, the family and even you, as a nurse, wish this would come to an end” (Pérez-Vega & Cibanal, 2016, p. 1214)”.

### **Coping strategies in the face of death**

All of the subcategories are interrelated by the supportive and coping nature that arises in events in which death plays the leading role. Participants in some of the studies reported that venting to a family member or friend at home after work helped them manage the stress caused by the death of a patient. They saw this as a tool for dealing with bad experiences. The importance of peer and family support thus becomes even more relevant in these situations: “Debriefing after the death of a patient has always been a good thing. Everybody talks openly, it’s nobody’s fault. It’s – these things happen. Those kind of talks afterwards, I’ve always found them to be a good thing” (Anderson et al., 2015, p. 699).

One of the most repeated coping strategies were estrangement, running away from family issues, escaping from the care that patients need, escaping from their own fears, and delegating responsibility to others. Emotional disconnection was reported by many of the nurses as a way in which they regularly coped with death. Some of the participants also reported having an emotional wall in their relationships with patients and their families. Other coping strategies were also mentioned from the point of view of spirituality, as narrated by one participant: “To better face a situation I pray after death, and it makes me feel better...” (Santos, Corral-Mulato, Villela-Bueno, & do-Carmo-Cruz-Robazzi, 2016, p. 515).

In addition to providing end-of-life care, supporting and improving the family’s ability to care for patients is also one of the professional duties of nurses. Participants felt a duty to promote family function by providing families with certain care skills. They thought this was an effective way for family members to show their affection for the patient through care. One of the nurses in the Lopera Betancur study (2015) addressed this issue as follows: “Helping is being with the relatives [...], you help them and teach them; you are there, but they are the ones caring for the patient” (Lopera Betancur, 2015, p. 300).

It is of note that three of the selected studies (Dong et al., 2016; Lopera, 2015, 2016) emphasised that loneliness during the death process is regrettable, and stressed the importance not only of caring for and supporting patients and their families, but also of just accompanying them. One of the participant in the study by (Dong et al., 2016) touched on this as follows: “I stayed in the hospital, went to their bedside every ten

minutes, looked at their vital signs, or just let them know I was there and available at any time..." (Dong et al., 2016, p. 191).

### **The importance of training, experience, and providing a dignified death**

A prominent theme was the importance participants attached to training in providing health care to a dying patient, as well as other factors that condition coping with death. Informants voiced feelings of frustration at the lack of death-related knowledge and skills, as well as a lack of confidence in their professional role.

They felt that they had been inadequately trained for their experience with death and did not know how to work on the emotional reactions that arose from providing care and support to patients and their families. In fact, they advocated the need to acquire competencies that would facilitate the expression of emotions. One of the participants in the study by (Dong et al., 2016) put it in these terms: "I should provide some specific help to relieve their fear about death, and talk death with them; just like the Western countries' nurses do for their patients... talk about death openly, and say goodbye with them... However, I absolutely have no idea on how to do it... we should learn something..." (Dong et al., 2016, p. 194).

Professional experience was considered to be an ally in dealing with adverse and unpredictable situations, including the event of death, which facilitated acceptance. In fact, compared to young people or students, the most experienced nurses showed themselves to be more skilled and confident when it came to providing high-quality care to dying patients: "I remembered those years of caring for the dying... extremely nervous, frightened. Later on, I become calm and deal with that smoothly... I have gained a lot from the experience" (Zheng et al., 2015, p. 294).

Another of the informants in the study by (Hinderer, 2012) referred to experience as a process of maturation, of change in perception and in the meaning that death has for professionals, hoping that the time will not come when they become insensitive to death: "I think I've gotten more mature about it. I hope I haven't gotten to where [death] doesn't mean anything" (Hinderer, 2012, p. 254).

In addition, the importance of providing and helping patients to have a "dignified death" was another of the major themes addressed in numerous studies. In order to do

this, it is necessary to be well trained and to be well aware that, in patients who are at the end of their lives, it is paramount to respect their will and autonomy, so that they feel comfortable and pain-free. Participants emphasised the importance of providing humane care and treating the patient with respect and dignity, even after their death: “...when he died, I tried to be there for the family... to be respectful, to say goodbye in my own way... removing the line, closing his mouth, and making him as presentable as possible for the relatives to see” (Edo-Gual et al., 2014, p. 3506).

Participants felt that it was important to meet the spiritual needs and respect the beliefs of patients and their families, going so far as to affirm that spirituality and religion were important aspects of care that improved coping with illness and symptoms, as well as strengthening the quality of end-of-life care. This is how a participant in the study by (Dong et al., 2016) put it: “Spirituality provides a foundation that helps them transcend suffering and despair... Trying to find some meaning or purpose might do some help...” (Dong et al., 2016, p. 192).

Although there is talk of dignified death and respect for the rights of the patient, some studies, especially those conducted in China, pointed to the fact that patients are “not being informed” of their real state of health in order to preserve their hopes, beliefs, and confidence in the fight against their illness, despite being terminally ill: “If they knew the truth, they would probably be depressive, gloomy or even commit suicide. So we keep it a secret along with their families” (Zheng et al., 2015, p. 293).

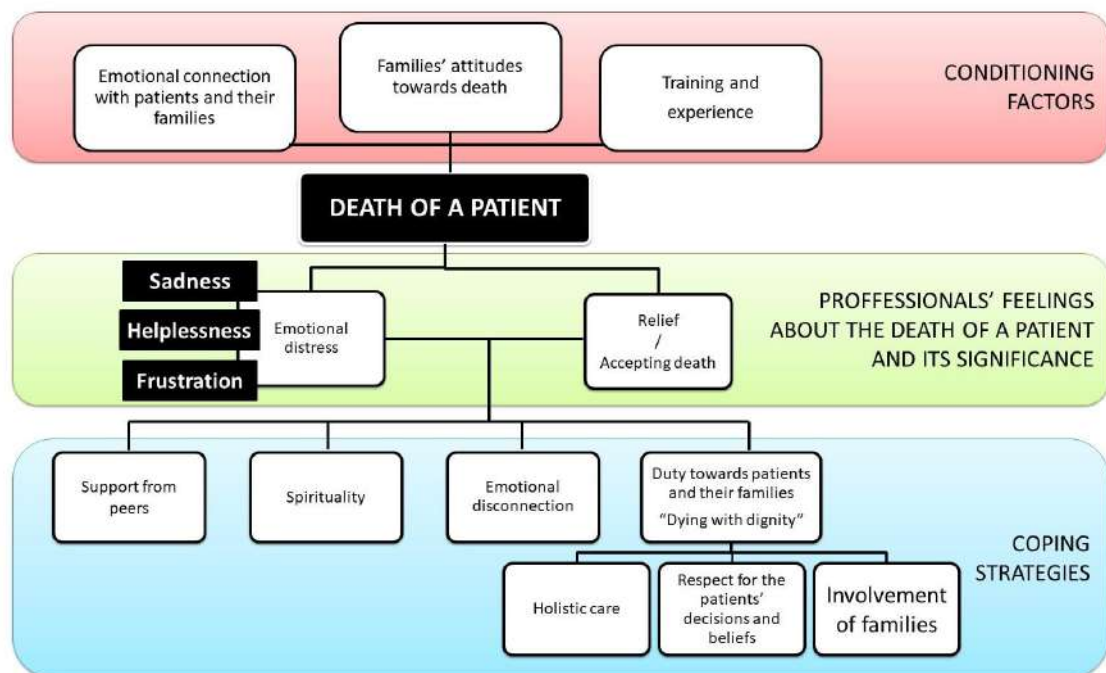
In turn, another informant in the study by (Stayer & Lockhart, 2016) mentioned the fact that some professionals avoided discussing the subject with patients by beating around the bush and talking about everything but their illness: “I was really disheartened in the palliative care meeting. Everyone [the physicians] beat around the bush” (Stayer & Lockhart, 2016, p. 354)

### **Explanatory model**

The explanatory model derived from these results showed that death and the dying process have a great impact on professionals and cause emotional distress. The death of a patient may be perceived as a failure or as a relief from the situation. This generates emotional distress in professionals due to the following: the bonds they develop with patients and families during the delivery of care; the attitudes of family members and

professionals towards death; and the experience of professionals and/or the training received by professionals in order to face this process. The professionals' main coping strategies included in this study are the following: the support they receive from their family and friends; emotional disconnection; training and supporting the families of patients in delivering holistic care to patients and facilitating a dignified death; and good spiritual care. The findings of the whole synthesis are summarised in figure 1.

Figure 1. Nursing professionals' attitudes, strategies, and care practices towards death



## DISCUSSION

The systematic review and the interpretative synthesis confirm that death and the dying process cause professionals a great impact and emotional distress. Many of the participants in the selected studies (Anderson et al., 2015; Costa et al., 2014; da Silva & da Silva, 2015; Dong et al., 2016; Edo-Gual et al., 2014; Forster & Hafiz, 2015; R. S. Zheng et al., 2015) ascribe the stress and suffering after a patient's death to a lack of training to cope and care for them in the terminal stage. Due to the insecurity and fear caused by dealing with patients in the terminal stage without having been previously trained, health professionals find in avoidance a strategy to deal with the situation.

They avoid talking to family members, they avoid entering the patient's room, they avoid making eye contact, any conversation related to death, etc. (Albuquerque, 2016; Costa et al., 2014; Edo-Gual et al., 2014; Forster & Hafiz, 2015; García & Rivas Riveros, 2013; Hinderer, 2012; Lopera, 2016; Miranda, Moura, Leite, & Privado, 2014; Mota, Gomes, Coelho, Lunardi Filho, & Sousa, 2011; Pérez-Vega & Cibanal, 2016; Santos et al., 2016;). This results in an uncomfortable death for patients, their families, and health professionals, this being a cold and detached death, an undignified death, since patients are being prevented from expressing their feelings and last wishes (Anderson et al., 2015; Costa et al., 2014; da Silva & da Silva, 2015; Dong et al., 2016; Edo-Gual et al., 2014; Forster & Hafiz, 2015; Miranda et al., 2014; R. S. Zheng et al., 2015).

How death affects healthcare professionals, what coping strategies, and what deficiencies or needs healthcare professionals have, is a topic that has been the focus of few qualitative synthesis studies in recent years. Of note are the syntheses published in 2016 and 2017 (Zheng et al., 2016; Zheng et al., 2018), in which the nurses' experiences and coping strategies in treating dying patients are discussed.

The present study gathers more updated evidence than the evidence gathered in the previous studies, therefore being an update and an extension both in terms of time and geographical context, as well as in the clinical setting in which the selected studies were carried out. It is important to include studies carried out in different geographical and cultural contexts, since the role of nurses, nurses' access to means to control pain and other symptoms, their relationship with other professionals, and their degree of



reluctance to accept a patient's death differs across countries (Sekse, Hunskår, & Ellingsen, 2018), and all of these factors may affect nurses' attitudes towards death.

In this sense, it should be taken into account that only two studies (Hinderer, 2012; Kent et al., 2012) included in the review by Zheng et al. (2018) coincide with the ones included in our review. As a result, the similarities observed in these findings reinforce their applicability to different settings.

The two aforementioned reviews (Zheng et al., 2016; Zheng et al., 2018) make clear the need for professionals to accept death, although our results suggest that death is referred to more as a biological process. This may be due to cultural differences in understanding the dying process, since different contexts are covered in this review. This study also concurs with the review by Zheng et al. (2018), in which students understand death as inherent in their work. As a new development, our study brings out the category of relief. This category was not represented in the other reviews but is a possible response in the event of someone's death.

The feeling of relief, tied to serenity and acceptance, is common among caregivers once the patient has died, especially if their illness was causing a great deal of suffering (Holtslander, et al., 2017). However, there are not many studies exploring whether or not clinicians experience relief after a patient's death, either because the clinicians' grief is not taken into account or because previous studies have placed the emphasis on cases in which there are negative grief-related emotions (Funk, Peters, & Roger, 2017).

The references found link health care professionals' relief to feelings of acceptance and satisfaction with the care provided. Nurses in nursing homes for elderly people with dementia in Norway (Midtbust, Alnes, Gjengedal, & Lykkeslet, 2018) reported that the feeling of relief was linked to their ability to take proper care of patients and not having conflicts with their families regarding end-of-life decision-making.

The present study also shows the different coping strategies used by professionals to face death. It has been shown that nurses talk to relatives and friends about their experiences at work in order to let off steam, a fact also reported in another study (R. Zheng et al., 2018).

In addition, it was observed that nurses resorted to fleeing from the end-of-life situation, delegating their responsibilities to others. So much so that, in order to not face

the patient's questions and expose themselves, some studies highlight that patients are not being informed about their state of health, which is not reflected in other reviews. Therefore, professionals need this "emotional disconnection" in order to find a balance between their social and professional life. Strategies of a spiritual nature, such as praying, were also reported to be useful and are used by professionals (R. Zheng et al., 2018).

Our results suggest that professionals often feel inadequately educated and trained to deal with death, due to the heavy emotional burden that this process entails (R. Zheng et al., 2016). As in our study, feelings of frustration become clear when faced with a lack of knowledge and skills, with a lack of confidence in their professional role, or with the need to acquire competencies, thus finding their own professional experience as the only learning mechanism available (R. Zheng et al., 2016, 2018).

#### *Limitations*

One of the limitations found in this study was the scarcity of qualitative studies with these objectives. However, the number of studies analysed, together with the discussion conducted with the two meta-syntheses cited in the discussion, provide sufficient evidence to understand the attitude of nursing professionals towards death.

Another discussion topic in qualitative research synthesis studies has to do with the relevance of the critical appraisal process. Recent studies suggest that opinions are divided concerning the evaluation of the quality of qualitative evidence (Noyes et al., 2018), which is why we have also chosen to test certain methodological aspects of the articles. Another limitation of this study has to do with the sources consulted. Although we believe that they cover the subject matter sufficiently, it would be advisable to include further sources in future reviews in order to confirm the findings.

It should also be taken into consideration that there may have been studies prior to 2011 that would have been of interest to the research.

Finally, it is also worth mentioning that one of the studies included in the review (Hinderer, 2012) is a pilot study. Nevertheless, it obtained good and relevant results in the critical appraisal.

#### **CONCLUSIONS**

Nurses consider that providing a dignified death is an important part of their job, but the experience of death generates feelings and emotions that have a negative impact on the care they provide and on their own well-being. This is attributed to a lack of training, which is only initially replaced with not providing information to patients, with avoidance, and, over time, with experience. For this reason, it is necessary to increase the training in dignified dying that professionals receive, while they develop and produce a series of coping strategies in the face of this new situation, all of which have the aim of protecting themselves and thus providing better care for patients and their families.

### **CLINICAL RELEVANCE**

The attitude of professionals towards death is influenced by external factors (society, culture, experiences, etc.). For this reason, in order to avoid the emotional exhaustion associated with taking care of terminally ill patients, the appropriate training, guidance, and development of care become essential in this process. In this sense, this review presents, in a clear and orderly manner, what happens in this process, what are the main coping strategies that professionals have, and the deficiencies or needs of professionals. We believe that these are findings which may guide the training programmes developed both in health institutions and in university settings. Additionally, these findings may also guide the individualised care that may be required by the professionals who work in such direct contact with death.

### **CLINICAL RESOURCES**

- Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation:  
<https://www.kcl.ac.uk/cicelysaunders>
- End-of-Life Care Research Group: <http://www.endoflifecare.be/>
- The National Coalition for Hospice and Palliative Care:  
<https://www.nationalcoalitionhpc.org/>
- Center to Advance Palliative Care (CAPC): <https://getpalliativecare.org>

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#### 7.4. Estudio 4

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## Article

# Cultural Adaptation and Validation of the Quality of Dying in Long-Term Care Scale (QoD-LTC) for Spanish Nursing Homes

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**Abstract:** Background: There is a need for instruments that can evaluate the psychosocial quality of dying in nursing homes. The aim of this study was to adapt and validate the Quality of Dying in Long-Term Care scale (QoD-LTC) to the Spanish context. Methods: Descriptive cross-sectional study. Fourteen nurses from 7 facilities in southern Spain assessed 153 residents who died in the centers; validity, reliability, and feasibility were evaluated. Results: The Spanish version consists of 11 items with acceptable reliability ( $\alpha = 0.681$ ). Three factors model was validated by principal components analysis. A mean of 180.62 (SD = 86.66) seconds is needed to fill it in. An inter-observer 0.753 (95% CI: 0.391–0.900,  $p < 0.001$ ) and intra-observer 0.855 (95% CI: 0.568–0.951  $p = 0.001$ ) reliability were observed. Weak correlation was observed; positive with mono-item question (0.322) and negative with Eastern Cooperative Oncology Group (ECOG) with a value of (−0.321) and Integrated Palliative outcome scale (IPOS) with a value of (−0.252). Conclusions: The QoD-LTC scale presents an adequate factorial structure, internal consistency, and feasibility to evaluate psychosocial quality of dying in nursing homes. It can be used as a quality indicator.

**Keywords:** terminal care; nursing homes; long-term care; palliative care; quality of health care; quality indicators

## 1. Introduction

There is an increasing demand for long-term care services such as nursing homes in Western societies [1–3]. This is due to an ageing population and the increasing chronicity and prevalence of multiple diseases [1,2] amongst older people. Nursing homes become the usual place of residence for older people when their care needs become continuous and specialized, beyond the capacity of informal caregivers [2,4]. Therefore, these settings are gaining importance as a place of residence in the last stage of life, given that a significant percentage of older people die in these places [1,5].

Spanish nursing homes offer integral accommodation, either temporary or permanent, to people in a situation of dependence. Their objectives are to achieve a better quality of life and to promote people's personal autonomy, through the provision of intervention programs and activities that respond to the specific needs of its users [6].

The literature shows that residents at the end of life in nursing homes experience symptoms that worsen their quality of life; Smedbäck et al. (2017), in his retrospective study evaluating the last week of life in Swedish nursing homes, showed that the most

frequent symptoms in the last week of life were pain, anxiety, confusion, shortness of breath and nausea [7]. Similar results have been observed for the Spanish context, where interventions that can be considered futile have also been reported [8].

At the end of life, there are several concepts that need to be identified (“quality of care”, “quality of dying” and “quality of death”). Quality of care refers to elements of the environment that occur at death, while quality of dying includes the resident’s symptom burden and other experiences that may be influenced by care and various resident-related factors [9]. Quality of dying is considered to be synonymous with quality of life [9]. Quality of death and dying, on the other hand, is defined as “the degree to which a person’s preferences for dying and the timing of death are consistent with observations of how the person actually died, as reported by others” [10]. In a recent review, Meier et al. (2016) [10] defined the most representative characteristics of successful dying. Aspects present included “preferences for the dying process” (preparation for death such as advance directives, funeral arrangements), absence of pain, emotional well-being (absence of fear and depression), end of life, treatment preferences, dignity, and family. Since the goals of palliative care include improving the quality of life of patients until death and assisting the family in this process, we can say that palliative care plays a key role in the quality of dying.

Dementia may be another key factor in care provision in these facilities, given that there is a high prevalence in this population [7,8,11,12]. Symptoms and treatments at the end of life are different depending on the presence or absence of dementia [11]. Many tools have been developed to assess the quality of dying and deaths [9,13,14], although none of them have been adapted and validated for the Spanish population and for use in nursing homes. One of the most widely used scales to assess the quality of dying in long-term care facilities is the “Quality of dying in Long-Term Care” (QoD-LTC) [15]. This is a scale validated in the United States, which evaluates psychosocial quality of dying at the last month of life of deceased residents and can be used by professionals and family members alike. One of the advantages is that it takes a short amount of time to complete. It can be completed for deceased patients with or without cognitive impairment [16,17]. Due to the retrospective design of this instrument, it can be used as a quality indicator for care provided by nurses at the end of life.

The validation of a scale in one context does not mean that it will automatically be valid at another time, culture, or context [18]. Therefore, when using a tool in a different culture, it is important to go beyond just direct translation to ensure construct validity and reliability and to reduce the risk of introducing bias into the study [19]. This is especially necessary with such individual and dynamic constructs [20]. A number of relationships are involved in this process between the wishes of the dying person, the ability of others to meet their expectations and the degree of social control exercised over this process, all of which are highly dependent on the culture and context [20]. The end-of-life characteristics and significant changes in residents as they are near death [7,8,21–23] make assessment a complex process, with the presence of dementia increasing the difficulties in an assessment [7,24]. This is why it is recommended that instead of using Likert-type measures, the items should be evaluated on a continuous basis, with visual analogue scales (VAS). VAS also allow for greater precision in statistical analysis [25–28].

The aim of this study was to adapt the QoD-LTC for Spanish nursing homes and evaluate its psycho-metric properties. It is hypothesized that the Spanish version of the QoD-LTC shows an adequate feasibility, reliability, internal consistency, and satisfactory criterion validity. Also, it is hypothesized that QoD-LTC shows a good convergent validity with different scales that assess the quality of palliative care such as the Integrated Palliative Care Outcome Scale (IPOS), Edmonton Symptom Assessment Scale (ESAS) and nurses’ perception of quality of the patient’s death process.



## 2. Materials and Methods

### 2.1. Design

A two-part study was carried out: (1) cultural adaptation using a Delphi method; (2) validation was carried out by conducting a descriptive cross-sectional study in seven nursing homes in the provinces of Granada and Jaén (Spain) following the procedure proposed by Ramada, Serra and Delclós [29]. A cultural adaptation and validation of the QoD-LTC scale was carried out. Data were collected between May 2018 and February 2019.

### 2.2. Sample

For part one, the cultural adaptation used a Delphi procedure. Thirteen experts in the fields of geriatrics, end-of-life or palliative care were contacted. For this study, an expert is understood as any person with extensive clinical, research and/or teaching experience in one of the fields described above.

For part two, two participating nurses in each nursing home with at least 6 months of experience in the center were recruited. They selected and assessed deceased residents who met the following inclusion criteria: (a) Patients who had died within the last 3 months at the nursing home; (b) Who had spent most of the last month of life (at least three weeks) in the nursing home.

All cases who met the above criteria were consecutively sampled and all the informed consents were obtained. No participant loss was reported by nursing home nurses.

This study was undertaken in accordance with basic ethical principles for the responsible conduct of research involving people. The study received the approval of the Research Ethics Committee (1642-N-17), in compliance with Spanish Law (Law 2/2018). Informed consent was sought from participants. All data were anonymized.

### 2.3. Procedure

#### 2.3.1. Cultural Adaptation

For cultural adaptation, the QoD-LTC original scale [15] was translated from English to Spanish and then back to English by two independent bilingual translators. To assess content validity, a synthesis of the translations was evaluated by a committee of experts using the Delphi technique [30]. Experts in geriatrics, end-of-life or palliative care evaluated the relevance, clarity, and levels of meaning and difficulty in response compared to the original language using a Likert-type scale. The agreement was set at 80%.

Once a definitive version was obtained, cognitive interviews were carried out with the first 13 nurses participating in the study. This kind of interview provides information on the way in which individuals process and respond mentally to a questionnaire, to identify factors that may affect the response [31,32]. Cognitive interview records were also used to evaluate feasibility. They were transcribed and read to check that the participants understood the different items.

#### 2.3.2. Validation

A form was developed which included the Spanish version of the QoD-LTC scale and sociodemographic and clinical data. Each of the forms was filled in by the nurses for each of the residents. After measurement, the data were entered into a database for further analysis. To assess convergent validity, the Edmonton Symptom Assessment Scale (ESAS) [33], the Integrated Palliative Outcome Scale (IPOS) [34,35], Eastern Cooperative Oncology Group Scale of Performance Status (ECOG) and Quality of dying during the last month (QoD-LM) were included in the form.

To check reliability among observers, 40% of the cases were randomly selected, and assessments were repeated both by the same nurse (intra-observer reliability) and by another nurse (inter-observer reliability) one week after the first assessment.

#### 2.4. Tools

QoD-LTC [15] is a post-death scale designed to evaluate psychosocial quality of dying at the last month of life of institutionalized residents in nursing homes with 11 items, to which professionals or family members who have cared for the deceased respond to the question “How true is it that . . . ?”. In its original version, it has an internal validity of  $\alpha = 0.66$  with three subscales (personhood, closure, and preparatory tasks). Higher mean scores reflect a higher quality of end of life in LTC. The original score is proposed in a Likert-type scale from 1 (not true) to 5 (totally), although for our study it was collected using VAS for reasons previously expressed. Once the questionnaires were obtained, they were measured on a millimetric scale [24–27]. For correct use, an explanation of how the scale should be answered was included, with a practical example [27].

The following tools were used to assess convergent validity with the QoD-LTC Spanish Scale.

- Edmonton Symptom Assessment System (ESAS) [33]. The ESAS scale has been validated to be filled in by professionals, patients, and caregivers with different diseases, being easily completed and interpreted [35]. ESAS was used regularly in all the nursing homes that participated in the study for symptom assessment. Symptoms have been observed on a conceptual level that may interfere with quality of dying [10].
- Integrated Palliative Outcome Scale (IPOS)[34]: IPOS evaluates palliative care needs in the domains of physical and psychosocial functioning. It is a 17-item scale. Symptoms are assessed on a 0–4 Likert scale. The IPOS was found to be internally consistent,  $\alpha = 0.77$ . Lower scores indicate a better palliative care outcome, the maximum score would be 68. The QoD-LTC scale has been considered to assess the quality of care [9]. In order to assess convergent validity, we have used the IPOS scale.
- Eastern Cooperative Oncology Group Scale of Performance Status (ECOG): it was developed in 1982 and assessing performance status is one such measurement [36]. It describes a patient’s level of functioning in terms of their ability to care for him/herself, daily activity, and physical ability (walking, working, etc.). Functional status has been associated with quality of the dying [16].
- Quality of dying during the last month (QoD-LM): How do you consider the quality of the patient’s death process to have been during his last month? It was evaluated by means of a Likert scale of 1 Terrible, 2 Bad, 3 Normal, 4 Good, 5 Very Good.

#### 2.5. Data Analysis

Descriptive analyses were carried out for sociodemographic and clinical data as well as for feasibility.

The Kaiser–Meyer–Olkin (KMO) test and the Bartlett sphericity test were performed to check whether the scale could be subjected to the factorial analysis of principal components carried out later.

Cronbach’s Alpha was calculated for the full scale as well as for each of the subscales. For inter-observer and intra-observer reliability, intra-class correlation coefficient (ICC) was calculated. An ICC of  $<0.50$  indicates poor to fair agreement, ICC = 0.5–0.75 moderate agreement, ICC = 0.75–0.90 good agreement and ICC  $> 0.90$  excellent agreement [37]. Kolmogorov–Smirnov normality tests were performed. Due to the non-normal distribution, non-parametric tests were performed for concurrent validity. Spearman’s rho correlation coefficients between the QoD-LTC score and the results were obtained for the ECOG, ESAS, IPOS, and QoD-LM.

A Spearman’s coefficient of  $r < 0.39$  indicates weak correlation,  $r = 0.40$ – $0.69$  indicates moderate correlation,  $r > 0.7$  indicates strong correlation [38].  $p < 0.05$  was considered significant. IBM SPSS v22.0 [39] was used for data analyses.

### 3. Results

#### 3.1. Cultural Adaptation

The expert committee was composed of 13 experts with an average age of 43.3 (32–58) with an average experience of 13 (6–27) years in geriatric, end-of-life or palliative care. An agreement was arrived at for all the items of the scale and the modification of some items was proposed (Tables A1 and A2). For eight of the items, this consensus was achieved in the second round. For the remaining three items, consensus was achieved in the third round.

A total of 13 cognitive interviews were conducted, in which it was identified that they understood the response mode on the VAS and confirmed the understanding of the modified items. Regarding feasibility, nurses' average response time for the questionnaire was three minutes (180.62 s), with a standard deviation (SD) of 86.66 s.

#### 3.2. Validation

##### 3.2.1. Sample Description

Fourteen nurses from seven centers participated. The mean age was 32.79 (SD = 7.434) years with a mean nursing home experience of 58.86 months and a standard deviation of 48,648.

A total of 153 patients were included. The majority of patients who died in nursing homes were women (56%); the mean age was 86.12 (SD = 11.56) years old at the time of death, widows (60.7%) and most of them died in the facility (57.5%). The most prevalent conditions were dementia (54.9%) and chronic heart disease (39.9%) (Table 1).

**Table 1.** Sociodemographic and clinical characteristics of the residents.

Variables	Total Sample <i>n</i> = 153	
Age, M (SD)	87.62	(11.56)
Female, <i>n</i> (%)	91	(59.5)
Marital status widower, <i>n</i> (%)	92	(60.7)
Place of death		
Home, <i>n</i> (%)	1	(7)
Hospital, <i>n</i> (%)	64	(41.8)
Nursing-Home, <i>n</i> (%)	88	(57.5)
Coexisting conditions		
Oncologic disease, <i>n</i> (%)	26	(17)
Chronic lung disease	22	(14.4)
Chronic heart disease	61	(39.9)
Dementia	84	(54.9)
Vascular neurological disease	31	(20.3)
Degenerative neurological disease	21	(13.7)
Chronic liver disease	2	(1.3)
Chronic kidney failure	19	(12.4)

##### 3.2.2. Factorial Analysis

The KMO test and Bartlett's test of sphericity were carried out before a factorial analysis (KMO = 0.653;  $\chi^2 = 363.090$ ,  $p < 0.001$ ). This scale presented three factors (Table 2): Quality of Care, End-of-life communication, and End-of-life appearance.



**Table 2.** Factorial load of the QoD-LTC scale adapted to the Spanish context.

Items	Factor 1. Quality of Care	Factor 2. End-of-Life Communication by the Resident	Factor 3. End-of-Life Appearance
[RESIDENT] received compassionate physical touch daily.	<b>0.593</b>	−0.154	0.351
[RESIDENT's] dignity was maintained.	<b>0.730</b>	0.074	0.136
[RESIDENT's] physician knew [HIM/HER] as a whole person.	<b>0.848</b>	−0.177	0.096
There was a nurse or aide with whom [RESIDENT] felt comfortable.	<b>0.737</b>	0.136	0.020
Someone was designated to make decisions in their place [Resident] in the case that they could no longer do so.	<b>0.647</b>	0.100	0.082
[RESIDENT] indicated [HE/SHE] was prepared to die.	−0.182	<b>0.728</b>	0.178
[Resident] communicated their preferences with respect to treatment.	0.094	<b>0.820</b>	0.085
[Resident] expressed how they wanted their funeral and/or other matters concerning their body to be after their death.	0.258	<b>0.638</b>	−0.419
[RESIDENT] was kept clean.	0.362	−0.094	<b>0.410</b>
[RESIDENT] was able to retain [HIS/HER] sense of humor.	0.085	0.333	<b>0.763</b>
[HE/SHE] appeared to be at peace.	0.316	0.113	<b>0.785</b>

The extraction was based on Principal Component Analysis using the Varimax rotation method with Kaiser normalization. Bold font indicates the factor loading of the item on the factor to which it was assigned.

### 3.2.3. Reliability

The QoD-LTC scale showed an adequate reliability ( $\alpha = 0.681$ ). The  $\alpha$  score oscillated among dimensions (Quality of Care  $\alpha = 0.737$ ; End-of-life communication  $\alpha = 0.579$  and End-of-life Appearance  $\alpha = 0.575$ ). For each item, statistically significant intra- and inter-class correlation was obtained. Scores correlation ranged from 0.411 to 0.915 for the intra-observer and from 0.371 to 0.837 for the interobserver (Table 3). An inter-observer ICC = 0.753 (95% CI: 0.391–0.900,  $p < 0.001$ ) and an intra-observer ICC = 0.855 (95% CI: 0.568–0.951  $p = 0.001$ ) was observed for total score scale.

**Table 3.** Results of intra- and inter-observer variability.

Items	Intra-Observer (n = 46)		Inter-Observer (n = 65)	
	ICC	p	ICC	p
[RESIDENT] was kept clean.	0.588 **	0.002	0.371 *	0.033
[RESIDENT] received compassionate physical touch daily.	0.755 ***	0.000	0.637 **	0.000
[RESIDENT's] dignity was maintained.	0.672 **	0.000	0.404 *	0.022
[RESIDENT's] physician knew [HIM/HER] as a whole person.	0.714 **	0.000	0.548 *	0.001
There was a nurse or aide with whom [RESIDENT] felt comfortable.	0.440 *	0.027	0.741 **	0.000
[RESIDENT] was able to retain [HIS/HER] sense of humor.	0.615 **	0.000	0.773 ***	0.000
[RESIDENT] indicated [HE/SHE] was prepared to die.	0.758 ***	0.000	0.660 **	0.000
[HE/SHE] appeared to be at peace.	0.411 *	0.040	0.421 *	0.015
[Resident] communicated their preferences with respect to treatment.	0.726 **	0.000	0.823 ***	0.000
Someone was designated to make decisions in their place [Resident] in the case that they could no longer do so.	0.633 **	0.026	0.837 ***	0.000
[Resident] expressed how they wanted their funeral and/or other matters concerning their body to be after their death.	0.915 ****	0.000	0.787 ***	0.001

ICC: Intraclass Correlation Coefficient. \* poor agreement, \*\* moderate agreement, \*\*\* good agreement, \*\*\*\* excellent agreement.

### 3.2.4. Convergent Validity

A positive correlation was observed between the QoD-LTC scale and its different dimensions with the QoD-LM ( $r = 0.322$ ) question, and a negative correlation with the IPOS ( $r = -0.252$ ) and with the ECOG ( $r = 0.321$ ) scale. It does not correlate with the ESAS scale, although some of its dimensions do (Table 4).

**Table 4.** Convergent validity of the QoD-LTC scale.

Scales	ECOG		ESAS		IPOS		Mono-Item	
	r	p	r	p	r	p	r	p
Total score	-0.321 *	0.000	-0.153	0.067	-0.252 *	0.002	0.322 *	0.000
Factor 1	-0.157	0.120	-0.237 *	0.004	-0.303 *	0.000	0.210*	0.010
Factor 2	-0.190 *	0.019	0.272 *	0.001	0.232 *	0.005	0.235 *	0.004
Factor 3	-0.292 *	0.000	-0.198 *	0.017	-0.298 *	0.000	0.270 *	0.001

ECOG: Eastern Cooperative Oncology Group Scale of Performance Status; ESAS: Edmonton Symptom Assessment System; IPOS: Integrated Palliative Outcome Scale. Mono-item: Quality of dying during the last month; QoD-LTC: Quality of Dying in Long-Term Care.  $r$  = Spearman's rho; \* = weak correlation.  $p$  =  $p$  value.

#### 4. Discussion

In the present study, we carried out the adaptation and validation of the QoD-LTC scale evaluated by nurses in Spanish nursing homes. The culturally adapted version presented an adequate factorial structure and internal consistency. In addition, it showed good internal reliability, as well as inter- and intra-observer reliability. The adapted version of the QoD-LTC correlates with the IPOS scale and the single-item question and conversely with the ECOG scale. The modified response method is feasible for use in clinical environments and has not affected the reliability of the scale.

During the cultural adaptation process, the expert group changed items that reflected cultural differences between the Spanish and the American context where the instrument was developed. In a Mediterranean culture, family, community ties and the Catholic religion are seen as important factors that influence experiences toward the end of life [40]. Meñaca et al. [40] identified that the Catholic religion with its associated paternalism shapes how family members participate in the entire process of care. This, combined with a resistance to discuss death with older people, means that in many cases residents delegate end-of-life decisions completely to family members [41].

Regarding the item "[RESIDENT] had treatment preferences in writing", although there is legislation in Spain regulating this practice and advance directives are seen as a positive tool by health professionals, there is evidence that advance directives are not being implemented systematically [42], and a large percentage of the population is unaware of their existence and have never been informed by their doctor about them [43]. The expert group proposed the modification of this item to note the verbal expression of wishes, even if these were not documented, to better reflect cultural practices.

The Spanish version of the QoD-LTC scale showed the same number of factors but a different distribution than the original scale. Our factors are consistent with the qualitative study of the items carried out by Van Soest-Poortvliet et al. (2011) [9], which reported that QoD-LTC primarily assesses the quality of care and the quality of the dying process. Our results coincide with those reported in these studies, where our first factor deals with the quality of care, and the third and fourth items deal with the quality of death.

According to our hypothesis, the adaptation of the QoD-LTC scale presents a similar reliability to the original one ( $\alpha = 0.681$  vs.  $\alpha = 0.66$ ) [15]. This indicates that the adapted scale and the original scale have the same validity. This is also the case for other scales such as the Palliative Outcome Scale (POS) in its original and Spanish version for patients [44,45]. All items showed a statistically significant degree of agreement between different evaluators in assessing the same case with a different grade of agreement. In the same way, the test-retest shows a statistically significant result in all evaluated scores.

The negative correlation observed with the IPOS scale reinforces that QoD-LTC evaluates a construct which is similar to the quality of palliative care, having among its components aspects that have been identified as potentially forming part of this construct [9]. Although the weak negative correlation indicates that they are not the same construct. Conversely, the better the scores on the QoD-LTC scale, the better the quality of palliative care.

The non-correlation observed with the ESAS scale shows that psychosocial quality of dying is not related to symptom intensity, as has been observed in other studies [46].

In terms of functionality, it is observed that the worse the functionality, the worse the quality of dying. Low correlation indicates that it is not the same construct. Finally, it has been observed that the general assessment of QoD-LM correlates positively with the results of our scale.

The QoD-LTC scale evaluates psychosocial quality of dying. This construct is different if it is from the perspective of the professional, the family member or the patient [10]. As they are different populations, these changes could affect the psychometric characteristics of the scale, so an individual validation for each population is necessary. Nevertheless, the literature is clear in demonstrating that the QoD-LTC is a useful tool [9,14,16].



The availability of this revised instrument when adapted will allow researchers in the Spanish context to undertake comparisons with other contexts [16], thus facilitating the extrapolation of data and the development and comparison of intervention programs at the end of life. This approach can be complemented by qualitative analysis and generate mixed-method studies that provide an integrative approach to the clinical reality in this regard, as well as evaluate end-of-life interventions.

It must be pointed out as a limitation that the nursing home facilities are usually private (71.53%) [43], so their participation in research studies is voluntary. Similarly, it was not possible to select the original cases randomly, but rather, these were chosen according to whether the patients died within the data collection period (consecutively). Although cases were not randomly selected, the characteristics of the sample coincide with those of other studies in the Spanish population [8,11,47,48]. Despite having been evaluated by the expert committee, it would be interesting to test the acceptability and practicability of the scale in nursing homes.

As regards future lines of research, it would be recommended to carry out the adaptation and validation of this instrument into Spanish for its completion by family members, as well as to compare the views of professionals with those of family members, which are different<sup>41</sup>. It would also be interesting to see if this instrument can be filled in by other care home professionals such as physicians, psychologists or social workers. There is further research to be undertaken with specific variables such as underlying health conditions, or the way death occurs, on the QoD-LTC score.

## 5. Conclusions

Validity, reliability, and feasibility of the Spanish version of the QoD-LTC scale have been evaluated, showing psychometric properties comparable to the original version. QoD-LTC is a useful scale applicable to the Spanish-speaking context to assess psychosocial quality of dying.

QoD-LTC is an instrument administered and interpreted by nursing professionals that can facilitate resource and care management. It can also guide the evaluation of protocols that aim for a good quality of dying in nursing homes. This instrument can be an indicator of the quality of the end-of-life processes in these centers.

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**Institutional Review Board Statement:** The study was conducted according to the guidelines of the Declaration of Helsinki, and approved by the Ethics Committee of the Research Ethics Committee of Granada (1642-N-17).

**Informed Consent Statement:** Informed consent was obtained from all subjects involved in the study.

**Data Availability Statement:** The data presented in this study are available upon request from the corresponding author. The data are not publicly available due to privacy restrictions

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## Appendix A

Table A1. Changes proposed by the experts for the items of the QoD-LTC scale.

Original	Adaptation.
[RESIDENT] had treatment preferences in writing.	[Resident] communicated their preferences with respect to treatment.
[RESIDENT] had named a decision-maker in the event that [HE/SHE] was no longer able to make decisions.	Someone was designated to make decisions in their place [Resident] in the case that they could no longer do so.
[RESIDENT] had funeral arrangements planned.	[Resident] expressed how they wanted their funeral and/or other matters concerning their body to be after their death

## Appendix B

Table A2. ESCALA -QoD-LTC.

Ítem	¿Cómo de Cierto es Que (el Paciente) ... ? Item How True Is It That (the Patient) ...	Para Nada/Not at All	Completamente/Completely
1	Se mantuvo aseado. [RESIDENT] was kept clean.		
2	Se le proporcionó un contacto físico cariñoso todos los días. [RESIDENT] received compassionate physical touch daily.		
3	Se preservó su dignidad. [RESIDENT's] dignity was maintained.		
4	Su médico lo trató de forma integral, atendiendo a todas sus facetas. [RESIDENT's] physician knew [HIM/HER] as a whole person.		
5	Tenía un enfermero o auxiliar con quien se sentía cómodo. There was a nurse or aide with whom [RESIDENT] felt comfortable.		
6	Mantuvo el sentido del humor que lo caracterizaba. [RESIDENT] was able to retain [HIS/HER] sense of humor. [RESIDENT]		
7	Expresó que estaba preparado para morir. [RESIDENT] indicated [HE/SHE] was prepared to die.		
8	Parecía estar en paz. [HE/SHE] appeared to be at peace. [RESIDENT]		
9	Comunicó sus preferencias con respecto al tratamiento. [Resident] communicated their preferences with respect to treatment.		

Table A2. Cont.

Ítem	¿Cómo de Cierto es Que (el Paciente) ... ? How True Is It That (the Patient) ...	Para Nada/Not at All	Completamente/Completely
10	Se nombró a alguien que tomara las decisiones en su lugar en caso de que ya no pudiera. <i>Someone was designated to make decisions in their place [Resident] in the case that they could no longer do so.</i>		
11	Expresó como quería que fuera su funeral y/o otras cuestiones relativas a su cuerpo después de su fallecimiento. <i>[Resident] expressed how they wanted their funeral and/or other matters concerning their body to be after their death.</i>		

The background colour of the table is where the participants should mark the point where the answer is located.

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## *Discusión*

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## 8. Discusión

Esta tesis doctoral compendia una serie de estudios, previamente publicados en revista de alto impacto JCR, cuyo denominador común son los procesos de fin de vida de las personas que viven en residencias para mayores. Los resultados de los diferentes estudios, así como la bibliografía previa, ponen de relieve la necesidad de analizar de manera urgente las condiciones en las que se producen los fallecimientos en estos centros, ya que estas distan mucho de ser las idóneas.

El abordaje de la mejora de estas condiciones tiene que contemplar, necesariamente, la experiencia sobre el proceso de muerte de los profesionales que trabajan en las residencias de mayores. Esta experiencia, como la de todos los profesionales de la salud, está mediada por factores sociales y culturales (Cottrell & Duggleby, 2016).

De igual manera, es necesario, contar con instrumentos válidos y fiables para plasmar esta experiencia, como es la escala QoD-LTC que refleja, desde la óptica de los profesionales, los distintos aspectos del final de la vida de las personas que viven en residencias de mayores (van Soest-Poortvliet et al., 2013).

En esta breve discusión, se integran los resultados de todos los estudios compilados en esta tesis doctoral, haciendo especial énfasis en las repercusiones en la práctica clínica y en futuras líneas de investigación. Finalmente, se hace una breve exposición de cómo ha podido condicionar los procesos de fin de vida en las residencias de mayores la irrupción de la pandemia debido a la expansión del SARS-Cov2.

Con respecto al estudio 1, se planteó un estudio prospectivo multicéntrico con el objetivo de evaluar la intensidad de síntomas, tratamiento y procedimientos terapéuticos que se producen al final de la vida y cómo varían a medida que se acerca el fallecimiento del paciente. Para ello, se evaluó el final de la vida de residentes de 6 residencias de mayores.

Los resultados de este primer estudio confirmaron que todos los síntomas, evaluados durante el seguimiento, aumentaron en intensidad en el último mes de vida. Esto no es sorprendente, ya que estudios previos habían llegado a la misma conclusión (Estabrooks et al., 2015; Koppitz et al., 2015; Thompson et al., 2017). Síntomas como el dolor ( $p= 0,026$ ), náuseas ( $p= 0,040$ ), ansiedad ( $p= 0,001$ ), somnolencia ( $p< 0,001$ ), poco apetito ( $p< 0,001$ ), malestar ( $p= 0,004$ ), disnea ( $p< 0,001$ ), son síntomas ampliamente presentes en el final de la vida e identificados en la literatura (Boyd et al., 2019; Hoben et al., 2016; Sandvik et al., 2016; Smedbäck et al., 2017).

Los resultados del estudio 1 también señalan que el aumento de la sintomatología en el último mes de vida trae aparejado el aumento en el uso de fármacos como aerosoles ( $p= 0,008$ ), oxigenoterapia ( $p< 0,001$ ), y opioides ( $p< 0,001$ ), vinculados con la progresión de enfermedades crónicas como la insuficiencia cardiaca o el EPOC, como ya han señalado algunos estudios (Campos-Calderón et al., 2016; Hendriks et al., 2015; Koppitz et al., 2015). También se ha observado un aumento en el uso de antibióticos en el último mes de vida. En este sentido, algunos estudios, indican que la administración de antibióticos mejora el pronóstico del paciente y puede aliviar síntomas (Rosenberg et al., 2013), mientras que otros consideran que no mejora el confort del paciente y por consiguiente debe de eliminarse (Givens et al., 2010).

Con respecto a los fármacos, el estudio 1 muestra como los corticoides, antieméticos ( $p< 0,001$ ) y antidepresivos ( $p= 0,026$ ) fueron utilizados más en los pacientes que fallecieron. El uso de corticoides y antieméticos está asociado con el aumento de la sintomatología en fin de vida. Sin embargo, el uso de antidepresivos es considerado fútil, ya que no mejoran los síntomas del final de la vida y requieren mucho tiempo para hacer efecto (entre 4-6 semanas). Pudiendo superar la expectativa de vida del paciente (McNeil et al., 2016).

En relación con los procedimientos terapéuticos, se ha observado un aumento estadísticamente significativo, y un mayor riesgo, en el uso de catéter periférico (OR= 2,850), aerosoles (OR=6,171) y oxigenoterapia (OR=10,764), a medida que se acerca el fallecimiento, y al comparar la cohorte de pacientes fallecidos con los no fallecidos.

Con estos datos, sobre los principales síntomas, procedimientos terapéuticos y tratamientos farmacológicos que se producen y administran al final de la vida en residencias de mayores, se pueden generar mejores criterios de derivación y coordinación entre los distintos centros residenciales y sus referentes de atención primaria. Además, es necesario dotar con más recursos materiales, mejorar el control de síntomas y organizar mejores protocolos sobre intervenciones y fármacos que deben de recomendarse en los últimos días de vida en estos centros.

Por otro lado, los resultados del Estudio 2 sugieren que los profesionales no perciben el final de la vida de la misma manera si el paciente tiene deterioro cognitivo o si no lo padece.

Se realizó un estudio descriptivo transversal en seis residencias de mayores. Los objetivos de este trabajo fueron por un lado; describir los síntomas percibidos por lo profesionales, los resultados de los cuidados paliativos, los tratamientos farmacológicos, las pruebas diagnósticas y los procedimientos terapéuticos de los residentes institucionalizados en residencias de mayores diferenciando entre pacientes con demencia y sin demencia; y por otro lado, comparar las diferencias existentes entre los pacientes de cuidados paliativos con demencia y sin demencia en centros residenciales de mayores.

Los enfermeros participantes, en este segundo estudio, reportaron mayor dolor ( $p= 0,002$ ), fatiga ( $p= 0,025$ ) y náuseas ( $p=0,035$ ) en el grupo de no demencia, mientras que el grupo con demencia el insomnio ( $p= 0,042$ ), el poco apetito ( $p= 0,004$ ) y la somnolencia ( $p= 0,002$ ) era mayor en el grupo con demencia. Esta tendencia también ha sido observada en otros estudios (Koppitz et al., 2015; Vandervoort et al., 2013; Yang et al., 2017).

Una posible explicación a estas diferencias es que la correcta interpretación de estos síntomas requiere la expresión o la identificación por parte del paciente. Los pacientes con deterioro cognitivo presentan dificultades en la expresión de síntomas como el dolor, que puede ser malinterpretados como síntomas neuropsiquiátricos o trastornos de comportamiento (De Witt Jansen et al., 2017; Nowak et al., 2018; Smedbäck et al., 2017). Es por eso, que el aparente bajo impacto de estos síntomas está

más relacionada con la falta de herramientas de evaluación específicas para demencia (De Witt Jansen et al., 2018; Smedbäck et al., 2017), que con una baja prevalencia/intensidad de estos síntomas en estos pacientes (Yang et al., 2017).

Por otro lado, el estudio 2 muestra que los tratamientos farmacológicos evaluados, no fueron distintos entre el grupo de pacientes con deterioro cognitivo y sin deterioro, salvo en el caso de los corticoides ( $p= 0,035$ ), que fue mayor en los pacientes sin demencia y, los ansiolíticos ( $p= 0,005$ ), cuyo uso fue superior entre los pacientes con demencia.

La agitación y la inquietud pueden tener varias causas, como el dolor o la angustia emocional (De Witt Jansen et al., 2017). Diagnosticar la causa en pacientes con demencia es muy complicado porque, la mayoría de las veces, estos pacientes no pueden informar verbalmente de estos síntomas y esto puede llevar a un infra tratamiento o a un mal tratamiento.

También se han observado en este estudio un mayor uso de pruebas diagnósticas, como análisis de orina ( $p= 0,009$ ) y pruebas de imagen ( $p= 0,003$ ), entre los pacientes con demencia. Esto se puede producir por un lado, a la dificultad en el diagnóstico de infecciones del tracto urinario en pacientes con demencia (D'Agata et al., 2013). De manera similar puede ocurrir con las microfracturas en adultos mayores con demencia, observándose que este tipo de fractura suele estar infradiagnosticadas y pueden considerarse una causa de dolor en pacientes con demencia (Hommel et al., 2012). Siendo necesario el desarrollo de aplicación de herramientas de valoración para valorar el final de la vida.

Tanto el estudio 1, como el estudio 2 nos informan que es necesario mejorar el enfoque paliativo en las residencias de mayores, incidiendo especialmente en una evaluación temprana y eficaz, así como en un tratamiento de la sintomatología asociada al final de la vida, especialmente en los pacientes con demencia. Para una mejora en el tratamiento, sería necesaria una valoración exhaustiva de qué tipo de tratamientos y de fármacos están justificados en el final de la vida en este tipo de pacientes.

Para ello, la formación de los profesionales es fundamental, dado que la falta de formación ha sido identificada como una barrera para la aplicación de unos buenos cuidados paliativos en estos centros (Bükki et al., 2016). Se ha descrito que esta falta de formación, tanto para el desarrollo de los cuidados a las personas con demencia, para los cuidados paliativos, como para la combinación de ambos por parte de los profesionales de enfermería de residencias de mayores, influye en la actitud que tienen estos a la hora de realizar estos cuidados (Chen et al., 2018; O. Wilson et al., 2016).

El estudio 3 de esta tesis doctoral aborda de lleno este problema, dado que se responde a la cuestión “¿Cuáles son las actitudes de los profesionales de enfermería hacia los cuidados al final de la vida prestados a los pacientes y a sus familias?”.

Con el fin de comprender este fenómeno de estudio, se realizó una metátesis de estudios cualitativos, ante la carencia de trabajos de esta naturaleza, que abordaran este tema e incluyeran el contexto hispanohablante.

Los resultados de este estudio muestran que la actitud de los profesionales ante la muerte de sus pacientes se encuentra condicionada por una serie de factores. Se ha observado que la conexión emocional con el paciente y su familia, la actitud de la familia hacia la muerte de su familiar y la experiencia y formación de los profesionales pueden agravar los sentimientos y/o emociones negativas o favorecer el alivio que experimentan los profesionales antes el fallecimiento de un pacientes que estaba sufriendo (Zheng et al., 2018). Esta sensación de alivio es común entre los cuidadores especialmente si su enfermedad estaba causando mucho sufrimiento (Holtslander et al., 2017). Para enfrentarse a esta experiencia, los profesionales generan una serie de estrategias de afrontamiento como pueden ser la desconexión emocional, el desarrollo de la espiritualidad, proporcionar unos cuidados de calidad al final de la vida y el apoyo de compañeros y familiares.

Los resultados de este estudio sugieren que, no solamente es necesario aumentar la formación en fin de vida que reciben los profesionales, sino que esta formación debe de estar enfocada al desarrollo de estrategias de afrontamiento con el objetivo de protegerse y así prestar una mejor atención a los pacientes.



Los resultados encontrados en la bibliografía indican que la experiencia clínica mejora tanto los conocimientos en cuidados paliativos y en fin de vida (Fernández-Rodríguez et al., 2021; Wilson et al., 2016) como la actitud de estos profesionales ante la misma (Wilson et al., 2016), mejorando de esta manera el afrontamiento inherente a este proceso. Varios estudios han constatado que ante la falta de experiencia, una intervención educativa en cuidados paliativos y demencia, dirigida a profesionales de enfermería de residencias de mayores, no solo mejoraba su conocimiento sino su actitud hacia los cuidados fin de vida (Chen et al., 2018; Fernández-Rodríguez et al., 2021; O. Wilson et al., 2016).

Una de las estrategias que presentan las enfermeras, descritas en los trabajos que componen el estudio 3 de esta tesis doctoral, es proporcionar unos cuidados de calidad al final de la vida que conduzcan a una buena muerte y a una muerte digna. Como ya se ha remarcado en el apartado de introducción, no existe una interpretación única de buena muerte. La buena muerte es una experiencia multifacética e individualizada en el final de la vida, enmarcada dentro de unos patrones sociales y culturales determinados (Cottrell & Duggleby, 2016; A. Meier et al., 2016).

Es por eso por lo que, conociendo cómo se fallece en las residencias de mayores y las distintas interpretaciones de los profesionales sobre lo que es buena muerte, basadas en sus propias experiencias y actitudes, se hace necesario contar con instrumentos validados y adaptados al contexto español que permitan evaluar este concepto.

En esta tesis se optó por la validación de la escala QoD-LTC (Munn et al., 2007), que además de estar específicamente diseñada para residencias de mayores e instituciones de cuidados de larga estancia, contempla la calidad del morir teniendo en cuenta tanto a pacientes con deterioro cognitivo como sin él. Este último punto es crítico, de acuerdo con las diferencias remarcadas en el estudio 2, incluido en esta memoria, y lo expuesto en la bibliografía sobre la distinta consideración de los profesionales sobre la situación de los pacientes con demencia.

La versión validada en castellano del QoD-LTC, en el estudio 4 de esta tesis doctoral, cuenta con 11 ítems y el mismo número de factores que la escala original, pero

con una distribución diferente (Munn et al., 2007). Esto muestra que la percepción del concepto de calidad de la muerte puede actuar de forma distinta en la cultura española en comparación a la americana y muestra la necesidad de las adaptaciones y validaciones de instrumentos (Abbas et al., 2018). La versión española cuenta con tres factores; Quality of care (5 items), End-of-life communication by the resident (3 items), and End-of-life appearance (3 items). Esta distribución de factores es consistente con el estudio cualitativo de los ítems realizado por Van Soest-Poortvliet et al. (2011), que indicaba que la escala QoD-LTC evalúa principalmente la calidad de los cuidados y la calidad del proceso de la muerte. Nuestros resultados coinciden con el resultado de este estudio, donde el primer factor de la versión española evalúa la calidad de los cuidados, mientras que el segundo y tercer factor se refieren a la calidad del proceso de la muerte.

En cuanto a la validez convergente de la escala, se observó una correlación estadísticamente significativa positiva con la escala mono-ítem (“¿Cómo considera que ha sido la calidad del proceso de la muerte del paciente?”) y negativa con las escalas ECOG y IPOS. Nuestros resultados sugieren que, a peor funcionalidad y calidad de los cuidados paliativos, peor calidad del proceso de la muerte. La ausencia de correlación con la escala ESAS, indica que los aspectos psicosociales del proceso de la muerte no se ven influidos por los síntomas del final de la vida (Caprio et al., 2008).

En cuanto a la fiabilidad, la versión de la escala QoD-LTC validada en esta tesis, muestra una fiabilidad aceptable ( $\alpha=0,681$ ) y similar a la de la versión original (Munn et al., 2007), mostrando además una correlación intraclase estadísticamente significativa para todos los ítems tanto para la validez inter-observador (0,404-0,837) como para la validez intra-observador (0,411-0,915) (Koo & Li, 2016).

Si se observa de manera pormenorizada la distribución de las puntuaciones de la escala, observamos que, desde la perspectiva de los profesionales, en general, se prestan buenos cuidados al final de la vida, aunque la comunicación sobre aspectos al final de la misma, dista mucho de ser la idónea. El factor con mejor puntuación fue el de calidad de los cuidados, con una media de 40,82 (SD = 7,26) sobre una puntuación total de 50. Estos resultados son ligeramente superiores a los observados en la bibliografía (Pivodic et al., 2018). Por otro lado, el factor con una puntuación más baja,

“comunicación al final de la vida por el residente”, obtuvo una media de 3,84 (SD = 3,61) sobre una puntuación total de 30. Estos resultados responden a un aspecto cultural, ya que en el contexto español, sanitario y social (familiar), existe de forma generalizada una deficiente comunicación sobre la muerte, el final de la vida, las preferencias de los pacientes y la toma de decisiones previas (Herreros et al., 2020). Por lo que, la situación de fin de vida, aún estigmatizada, requiere una estrategia por parte de los profesionales y los centros para promover que los pacientes con deterioro cognitivo comuniquen sus preferencias a sus familiares y a los profesionales. Esta comunicación deberá de ser adaptada a las capacidades de comprensión de los pacientes y a la evolución de la enfermedad (Alsawy et al., 2020).

Por todo lo anterior, la escala QoD-LTC administrada por profesionales de enfermería puede, por un lado, facilitar la gestión de recursos y cuidados, y, por otro lado, puede ser un indicador de calidad que ayude a evaluar distintos protocolos sobre cuidados fin de vida en estos centros.

No es posible cerrar esta discusión sin hacer alusión a la situación vivida en España, debido a la pandemia originada por la expansión del virus SARS-Cov2. Su rápida propagación y el hecho de que las formas más graves afectaran a mayores de 65 años con patologías crónicas previas. Por lo que hizo especialmente vulnerables a los residentes de residencias de mayores (Sanidad, 2020). Las medidas de contención de la propagación del virus han tenido un gran impacto en los procesos de fin de vida que se producen en estos centros.

El 11 de marzo de 2020, la OMS declara la situación de pandemia por la nueva enfermedad por coronavirus 2019 (COVID-19), ante la rápida propagación de los casos de contagios a nivel mundial y la gravedad de los cuadros que provocaba (Alocución de Apertura Del Director General de La OMS En La Rueda de Prensa Sobre La COVID-19 Celebrada El 11 de Marzo de 2020, 2020). En España, de acuerdo a las recomendaciones para la prevención de contagios (distanciamiento físico, medidas de protección individual respiratorio, etc.) se limitó la libre circulación de los individuos por el territorio nacional y el uso de espacios públicos (The WHO-China Joint Mission on Coronavirus Disease 2019 & World Health Organization (WHO), 2020).

En el caso de las residencias de mayores, estas suprimieron las visitas a los centros por parte de la familia y personas ajenas a la institución. A pesar de este aislamiento, el COVID-19 castigó especialmente a las residencias de mayores. Se han reportado en estos centros prevalencias de infección aproximada del 60% de los residentes, con una letalidad l 50% de los casos (Delgado-Cuesta et al., 2021). Se ha hipotetizado que esta alta incidencia se debe a la pluripatología de los residentes, la falta de recursos materiales y humanos y la crisis de gobernanza del sistema de servicios sociales, donde son cada comunidad o región la que asume las competencias de manera desigual en las residencias (Marbán-Gallego et al., 2021).

Esta limitación de la esfera social, ante la privación de las visitas de los familiares, unido a una afectación de la esfera física (padecimiento de COVID-19 como limitación en la atención especializada por el mismo), de la esfera psicológica (ante la angustia de la situación y sensación de abandono) como de la esfera espiritual (imposibilidad de despedirse, de cerrar su ciclo vital) ha podido tener un fuerte impacto en el final de la vida de las personas institucionalizadas en residencias de mayores durante el período de confinamiento realizado en la pandemia COVID-19.

Es preciso, por tanto, actualizar los datos sobre cómo se muere en residencias de ancianos. Los estudios 1 y 2 de esta tesis doctoral pueden servir como punto de referencia para comparar la situación actual de las residencias de mayores con la previa a la pandemia. En esta comparación es necesario tener muy en cuenta el hecho de que los residentes padezcan o no deterioro cognitivo, de acuerdo con los resultados del estudio 2. Por otro lado, el instrumento QOD-LTC puede permitir la evaluación de la calidad del proceso de morir en las residencias de mayores en la actualidad, dado que se encuentra adaptado al contexto español y muestra unos parámetros adecuados de fiabilidad y validez.

Por otro lado, es posible que haya habido un cambio en la percepción de los profesionales debido a la pandemia. De la misma manera que los estudios 1 y 2 pueden ser utilizados para comparar los cuidados antes y después de la pandemia, el estudio 3, puede servir como punto de partida para ver las diferencias en cuanto a las actitudes de los profesionales de enfermería ante la muerte de sus pacientes.

La bibliografía reciente muestra que, en general, los profesionales sanitarios, que han ejercido durante la pandemia, sufren altos niveles de estrés, ansiedad y síntomas depresivos (Hanna et al., 2021; Shreffler et al., 2020). Se ha observado que esta situación de pandemia se ha visto agravada por el agotamiento producido por la escasez de personal, acompañada de una sobrecarga de trabajo, la carga emocional debido a la situación de aislamiento o de confinamiento en los residentes, a la patología del SARS-CoV-2 propiamente dicho, y al fallecimiento de muchas de estas personas (White et al., 2021).

## *Fortalezas y limitaciones*

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## 9. Fortalezas y limitaciones

Los estudios que componen esta tesis doctoral presentan una serie de limitaciones que se han de tener en cuenta para el desarrollo de futuras investigaciones.

De manera general, se puede considerar una fortaleza la variedad de metodologías utilizadas en esta tesis; revisión de estudios cualitativos, estudios cuantitativos y de validación de instrumentos. Las diferentes metodologías permiten un abordaje integral de un concepto tan complejo como es el final de vida en residencias de mayores españolas.

Por otro lado, esta tesis ha sido el puente de unión entre dos proyectos de investigación financiados por la junta de Andalucía. Estos proyectos son: “Factores Condicionantes en la Implementación de Los Procesos de Atención Al Final de la Vida en Residencias de Ancianos y en Centros Gerontológicos” (PI-0619-2011) y el “Proyecto Elaboración e implantación de un programa de atención al final de la vida en residencias de ancianos” (AP-0105-2016). A lo largo de los diferentes estudios que comprenden esta tesis se han mostrado resultados parciales de ambos proyectos.

A continuación, se detallan las limitaciones de los diferentes estudios:

En cuanto al estudio 1 y el estudio 2, hay que tener en cuenta que el tamaño de muestra es pequeño en comparación con otros estudios publicados. Debido a esto y a pesar de que la caracterización de la muestra es similar a la de otros estudios publicados, la extrapolación de estos resultados debe de hacerse con cautela.

Por otro lado, para la selección de la muestra de ambos estudios se utilizaron los criterios de la Sociedad Española de Cuidados Paliativos (SECPAL) que eran los que en el momento de la recogida de datos se empleaban para la identificación de pacientes susceptibles de recibir cuidados paliativos. Con dichos criterios, durante el seguimiento de seis meses solo falleció el 36,4% de la muestra. Cabe plantearse si con criterios que se emplean en la actualidad, se hubiera identificado de manera más precisa a los



pacientes con pronóstico de vida más limitado. Durante el transcurso de la presente tesis doctoral se generalizó una herramienta específica para evaluar necesidades paliativas al final de la vida. El instrumento NECPAL-CCOMS-ICO © (Gómez-Batiste et al., 2013) permite evaluar las necesidades paliativas de los pacientes crónicos avanzados además de incorporar elementos pronósticos como la pregunta sorpresa “¿le sorprendería que este paciente falleciera en los próximos 12 meses?” como instrumento pronóstico.

En relación con el estudio 2, no está comprobada la validez en la utilización de escalas como la ESAS y POS en pacientes con demencia, a pesar de que se han empleado previamente para este tipo de pacientes en otros estudios de investigación (Brandt et al., 2005; Ekström et al., 2020; Jiménez et al., 2011; Ruiz Miralles, 2016). Los propios resultados de este estudio ponen de manifiesto que es necesario desarrollar y adaptar nuevas herramientas que sean válidas para población con y sin demencia.

También es necesario recordar que tanto los síntomas (ESAS) y calidad de los cuidados paliativos (POS) han sido reportados por los profesionales de enfermería. A pesar de que las escalas empleadas permiten su utilización de esta manera, no se puede olvidar que esto puede suponer un sesgo potencial, ya que los profesionales pueden sobre estimar o subestimar ciertos valores.

Tanto en los estudios 1 y 2, como en el estudio 4, la selección de los centros participantes se realizó de manera intencional. Esto fue imperativo dado que se precisaba la completa colaboración de los centros para el estudio de investigación. Conviene señalar que todas las residencias de este estudio fueron privadas, aspecto que va en consonancia con la realidad española (Abellán-García et al., 2021). Cabe plantearse si los resultados en relación con los procesos de fin de vida en residencias de carácter público serían diferentes, dado que no hay estudios que comparen ambos modelos de gestión en este sentido. Por otro lado, las enfermeras participantes en este estudio debían de reunir unos criterios de selección y recibir una formación específica para la cumplimentación de los cuestionarios por lo que la aleatorización en este sentido era complicada de realizar.

Con respecto al estudio 4, y en contraste con los estudios 1 y 2, no fue posible seleccionar los casos originales de forma aleatoria, sino que éstos se eligieron de manera consecutiva en función de que los pacientes fallecieran dentro del periodo de recogida de datos. Nada hace suponer que el periodo de tiempo seleccionado condicionara los resultados de ninguna manera.

En cuanto al Estudio 3, una de las limitaciones más importantes fue la escasez de estudios cualitativos que trataran la actitud de los profesionales de enfermería, unido al uso de procedimientos de valoración crítica, para la evaluación de la calidad de la evidencia cualitativa, y que condicionó su selección. Sin embargo, los resultados obtenidos y la concordancia con las otras metasíntesis publicadas anteriormente, proporcionan evidencia suficiente para entender la actitud de los profesionales de enfermería hacia la muerte y el papel que juega la experiencia y la formación en estos aspectos.



## *Conclusiones*

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## 10. Conclusiones.

De los análisis y de los objetivos que orientan los cuatro estudios que componen la presente Tesis Doctoral, se derivan las conclusiones que se exponen a continuación.

**Objetivo 1: Explorar la percepción del control de los síntomas, los tratamientos farmacológicos y los procedimientos terapéuticos recibidos por los pacientes susceptibles de recibir cuidados paliativos ingresados en residencias de mayores en los últimos seis meses de vida (Estudio 1)**

- La intensidad de los síntomas, los procedimientos terapéuticos y los tratamientos farmacológicos aumentan en la última semana de vida. Tanto los procedimientos terapéuticos (catéter venoso periférico, aerosoles y oxigenoterapia) como los farmacológicos (opioides, antibióticos y broncodilatadores) cuya administración aumenta, se encuentran totalmente relacionados con el incremento en la intensidad de los síntomas.
- Intervenciones como la colocación de catéteres venosos periféricos y los fármacos como los antibióticos, y las nuevas prescripciones de antidepresivos deben considerarse cuidadosamente en este entorno clínico, con el fin de mejorar el confort del paciente y evitar los tratamientos fútiles.

**Objetivo 2: Describir los síntomas percibidos por los profesionales, la calidad de los cuidados paliativos, las pruebas diagnósticas, los procedimientos diagnósticos y los tratamientos farmacológicos que se utilizan en el tratamiento de pacientes susceptibles de recibir cuidados paliativos en residencias de mayores y comparar las diferencias existentes en el manejo clínico entre pacientes con demencia y sin demencia (Estudio 2).**

- Se observó que el dolor, la fatiga y las náuseas eran significativamente mayores en los pacientes sin demencia. Por el contrario, el insomnio, la falta de apetito y la somnolencia fueron significativamente mayores en los pacientes con demencia.
- El uso de medicamentos como corticoides fue mayor en el grupo sin demencia, mientras que el uso de ansiolíticos fue mayor en el grupo con demencia. Por otro lado, el uso de procedimientos diagnósticos como análisis de orina y radiografías fueron mayores en el grupo con demencia.

- La ansiedad del paciente, la falta de apoyo percibido y la falta de gestión de asuntos prácticos eran mayores en los pacientes sin demencia, mientras que se perdía más tiempo en las citas sanitarias en el grupo con demencia.
- Se necesitan herramientas específicas para evaluar los síntomas y los resultados de los cuidados paliativos en pacientes con demencia.

**Objetivo 3: Conocer las actitudes, estrategias y experiencias de los profesionales de enfermería en relación con los cuidados al final de la vida prestados a los pacientes y a los familiares de estos (Estudio 3).**

- Las enfermeras consideran que proporcionar una muerte de calidad es una parte importante de su trabajo, pero la experiencia de la muerte genera sentimientos y emociones que tienen un impacto negativo en los cuidados que proporcionan y en su propio bienestar. Esto se atribuye a la falta de formación, que se manifiesta con falta de información a los pacientes, con la evitación y se evita a medida que se adquiere experiencia. Por ello, es necesario aumentar la formación en buena muerte o muerte digna que reciben los profesionales, al tiempo que desarrollan y elaboran una serie de estrategias de afrontamiento ante esta nueva situación, todas ellas con el objetivo de protegerse y así prestar una mejor atención a los pacientes y sus familias

**Objetivo 4: Adaptar culturalmente la escala Quality Of Dying in Long Term-Care (QOD-LTC) al contexto español y validar esta escala atendiendo a su validez y fiabilidad. Así como comprobar la validez de la escala QOD-LTC como medida indicativa del proceso de morir comparando su puntuación con instrumentos validados (Estudio 4).**

- La versión española de la escala QoD-LTC presenta unas propiedades psicométricas comparables a la versión original al evaluar su validez, fiabilidad y viabilidad. Por lo que la versión española del QoD-LTC es una escala útil y aplicable al contexto hispanohablante para evaluar la calidad psicosocial del morir.

## *Conclusions (in English)*

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## 11. Conclusions (in English)

The resulting conclusions of this Doctoral Thesis are the result of the analyses of the four studies included. Below, the objectives from which these analyses derive are shown with their corresponding conclusions:

**Objective 1: Exploring the perception of symptom control, pharmacological treatments, and therapeutic procedures received by palliative care patients admitted to nursing homes in the last six months of life (study 1)**

- Symptom intensity, therapeutic procedures, and pharmacological treatments increase in the last week of life. The increase in both the number of therapeutic procedures (peripheral venous catheter, aerosols, and oxygen therapy) and pharmacological treatments (opioids, antibiotics, and bronchodilators) are directly related to the increase in symptom intensity.
- Interventions such as peripheral venous catheter placement, and drugs such as antibiotics and new antidepressant prescriptions should be carefully considered in this clinical setting in order to improve patient comfort and avoid futile treatments.

**Objective 2: Describing the symptoms perceived by professionals, the quality of palliative care, diagnostic tests, diagnostic procedures, and pharmacological treatments used in the treatment of patients with palliative care in nursing homes and comparing the differences in clinical management between patients with and without dementia (Study 2).**

- Pain, fatigue, and nausea were found to be significantly higher in patients without dementia. In contrast, insomnia, lack of appetite and drowsiness were significantly higher in patients with dementia.
- The use of medications such as corticosteroids was higher in the group without dementia, while the use of anxiolytics was higher in the group with dementia.

Besides, the use of diagnostic procedures such as urinalysis and x-rays were higher in the dementia group.

- Patient anxiety, and the lack of perceived support and management of other practical matters were higher in patients without dementia, while more time was spent in health appointments in the dementia group.
- Specific tools are needed to assess symptoms and outcomes of palliative care in patients with dementia.

**Objective 3: Finding out the attitudes, strategies, and experiences of nursing professionals in relation to end-of-life care provided to patients and their relatives (Study 3).**

- Nurses consider that providing a good quality to the end of life is an important part of their work, but the experience of death generates feelings and emotions that have a negative impact on the care they provide and their own well-being. This is attributed to the lack of training, which shows itself in the lack of information for the patient and avoidance of spending time with patients, although it is normally corrected by experience itself. It is therefore necessary to improve the training professionals receive in providing a good end-of-life experience, or death with dignity, while developing a series of coping strategies for them in this new situation. The aim is to be able to protect themselves from negative emotions and thus provide a better care for patients and their families.

Objective 4: Culturally adapting the Quality of Dying in Long Term Care (QOD-LTC) scale to the Spanish context and validating this scale in terms of its validity and reliability, as well as to test the validity of the QOD-LTC scale as an indicative measure of the dying process by comparing its score with validated instruments (Study 4).

- The Spanish version of the QoD-LTC scale shows psychometric properties comparable to the original version when assessing its validity, reliability and feasibility. This is why the Spanish version of the QoD-LTC is a useful and applicable scale in the Spanish-speaking context to assess the psychosocial quality of dying.

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## *Anexos*

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## 13. Anexos

### 13.1. Versión en Castellano de la Escala QOD-LTC

Table A2

ESCALA -QOD-LTC	
Ítem ¿Cómo de cierto es que (el paciente)...? <i>Item How true is it that (the patient)...</i>	Para nada/ <i>Not at All</i> <span style="float: right;">Completamente/ <i>Completely</i></span>
1 Se mantuvo aseado. <i>[RESIDENT] was kept clean.</i>	
2 Se le proporcionó un contacto físico cariñoso todos los días. <i>[RESIDENT] received compassionate physical touch daily</i>	
3 Se preservó su dignidad <i>[RESIDENT's] dignity was maintained.</i>	
4 Su médico lo trato de forma integral, atendiendo a todas sus facetas <i>[RESIDENT's] physician knew [HIM/HER] as a whole person.</i>	
5 Tenía un enfermero o auxiliar con quien se sentía cómodo <i>There was a nurse or aide with whom [RESIDENT] felt comfortable</i>	
6 Mantuvo el sentido del humor que lo caracterizaba <i>[RESIDENT] was able to retain [HIS/HER] sense of humor. [RESIDENT]</i>	

<p>7</p>	<p>Expresó que estaba preparado para morir  <i>[RESIDENT] indicated [HE/SHE] was prepared to die.</i></p>		
<p>8</p>	<p>Parecía estar en paz.  <i>[HE/SHE] appeared to be at peace. [RESIDENT]</i></p>		
<p>9</p>	<p>Comunicó sus preferencias con respecto al tratamiento.  <i>[Resident] communicated his preferences with respect to treatment</i></p>		
<p>10</p>	<p>Se nombró a alguien que tomara las decisiones en su lugar en caso de que ya no pudiera.  <i>Someone was designated to make decisions in his place [Resident] in the case that he could no longer</i></p>		
<p>1 1</p>	<p>Expresó como quería que fuera su funeral y/o otras cuestiones relativas a su cuerpo después de su fallecimiento  <i>[Resident] Expressed how he wanted his funeral and/or other matters concerning his body to be after his death</i></p>	