


# Dimensions of good palliative nursing care: Expert panel consensus and perceptions of palliative professionals

Mar Zulueta Egea PhD, Professor<sup>1</sup>  | María Prieto-Ursúa PhD, Associate Professor<sup>2</sup> |  
Laura Bermejo Toro PhD, Collaborating Professor<sup>2</sup> |  
Ana María Palmar-Santos PhD, Associate Professor<sup>3</sup>

<sup>1</sup>University Centre for Health Sciences, San Juan de Dios Foundation, San Rafael, Nebrija University Madrid, Spain

<sup>2</sup>Psychology Department and Clinical Unit of Psychology (UNINPSI), Comillas Pontifical University, Madrid, Spain

<sup>3</sup>Nursing Department, Faculty of Medicine, Autonomous University of Madrid, Madrid, Spain

## Correspondence

Mar Zulueta Egea, University Centre for Health Sciences, San Juan de Dios Foundation, San Rafael, Nebrija University Madrid, Spain.

Email: [mzulueta@nebrija.es](mailto:mzulueta@nebrija.es)

## Abstract

**Aims and Objectives:** To analyse the dimensions of quality of palliative nursing care and to explore the perceptions of professionals for the development and validation of the Palliative Nursing Care Quality Scale.

**Background:** The study of palliative nursing care quality has been approached from analysis of the competencies of palliative care nurses, based on various theoretical models. However, there are fewer qualitative empirical studies that have evaluated what good palliative nursing care is and what its dimensions are.

**Design:** Mixed-method, Delphi approach and exploratory qualitative study.

**Methods:** Consensus by a panel of experts using the Delphi technique and semi-structured interviews. The study was reported in a comprehensive manner following COREQ criteria. Data collection took place between January and June 2018.

**Results:** The eight-person expert panel reached consensus on the following dimensions of the Palliative Nursing Care Quality Scale: control and relief of symptoms, family and/or primary caregiver, therapeutic relationship, spiritual support and continuity of care. Thematic analysis of ten interviews identified four emergent themes related to good nursing care: (1) the patient and family as a whole; (2) finding meaning; (3) responsible communication; and (4) caring for the human element.

**Conclusions:** The quality of palliative nursing care goes beyond providing comprehensive care; it means meticulously looking after every detail of what is important to the patient. The expectations of professionals are not as important. Instead, care should be based primarily on the needs and respect for the wishes of the patient and their family.

**Relevance to Clinical Practice:** Specifying the quality of nursing care in routine practice and reaching a consensus on its dimensions means moving towards excellence in care, as well as improving the professional profile of advanced practice palliative care nurses.

**Patient or Public Contribution:** Two primary caregivers participated in the panel of experts and the semi-structured interview.

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2022 The Authors. *Journal of Clinical Nursing* published by John Wiley & Sons Ltd.

## KEYWORDS

delphi technique, hospice and palliative care nursing, nursing, qualitative research, quality of care, semi-structure interviews

## 1 | INTRODUCTION

The study of palliative nursing care quality has been approached from analysis of the competencies of palliative care nurses, based on various theoretical models. However, there are fewer qualitative empirical studies that have evaluated what good palliative nursing care is and what its dimensions are.

## 2 | BACKGROUND

The key areas that make up palliative care quality are defined and agreed by consensus, and many measuring tools have been designed to assess them. Authors such as Mularski et al. (2007) establish nine domains reflecting such quality, including symptom control, holistic consideration of the person, functional aspects, satisfaction, interpersonal relationships, decision-making and care planning, continuity and communication, family burden and well-being, and finally the quality of death and end-of-life experience.

Assessment of the quality of palliative care should be multidimensional to encompass its holistic nature and consider not only the needs of the patient, family and caregivers, but also those of the professionals who form part of routine clinical practice (Bausewein et al., 2016). Within the interdisciplinary team of palliative care professionals, nurses occupy a priority role, as they are among the largest groups and also because they incorporate defence of the values of respect for life and dignity of the person in their code of ethics, as the foundation of nursing care (ICN, 2021).

Several studies have set standards to improve the quality of palliative nursing care (Canadian Hospice Palliative Care Association, CHPCA, Nursing Standards Committee, 2009) based on different theoretical models (Davies & Oberle, 1990; Reed, 2010; Walker & Avant, 2005), and describe the competencies or values required by palliative care nurses. These include values such as compassion, empathy and assertiveness (Codorniu et al., 2013), flexibility, being realistic and resolute (Kirkpatrick et al., 2017), stress coping strategies, emotional intelligence, authenticity, communication skills (Cameron & Johnston, 2015), ethics, coping with death and collaboration skills (Arahata et al., 2018; Feder et al., 2018).

Evaluating the quality of nursing care in the palliative setting is necessary for the profession and implies the search for excellence in our routine practice. So much so, that there are several instruments in the literature that measure the knowledge and skills needed to provide quality nursing care. The integrative review by Soikkeli-Jalonen et al. (2020) identifies 10 scales that measure the knowledge and skills related to care for the patient and their family and includes the following categories: general aspects of palliative care, patient

### What does this paper contribute to the wider global clinical community?

- Respect for the wishes and dignity of the patient in their suffering and vulnerability is a priority in palliative nursing care for a good death.
- The spiritual dimension of care in the end-of-life setting is particularly important, and it is this dimension that defines and represents the quality of nursing care.
- Considering the assessment and perception of nurses on the quality of their care and the experience of other professionals of the multidisciplinary team brings greater breadth and richness to the concept of good nursing care in the palliative setting.

involvement in self-care, psychosocial support, spirituality, cultural aspects of care, pharmacological treatment, symptom management and control, and end-of-life care.

Some of the most commonly used scales are the Palliative Care Quiz for Nursing (PCQN) developed by Ross et al. (1996), the Palliative Care Self-Reported Practices Scale (PCPS) by Nakazawa et al. (2010), the Palliative Care Nursing Self-Competence Scale (PCNSC) (Desbiens & Fillion, 2011), the End-of-Life Professional Caregiver Survey (EPCS) (Lazenby et al., 2012) and the End-of-Life Questionnaire (EOL-Q) (Montagnini et al., 2018). These scales assess the quality of palliative nursing care through the knowledge, competencies and skills of nursing professionals. Although all of them highlight the importance of collaboration and communication, personal and professional issues, decision-making, continuity of care and organisational support in the quality of palliative nursing care, as far as we are aware, the Palliative Nursing Care Quality Scale (PNCQS) (Zulueta Egea et al., 2020) is the only one that measures the quality of palliative nursing care in terms of specific actions of daily practice.

Furthermore, qualitative studies that address palliative care in general analyse the perceptions of both professionals and family members and/or caregivers. With respect to the perceptions of professionals, Hiatt et al. (2007) evaluated palliative care programmes through semi-structured interviews with professionals in the palliative care field. They highlighted the availability and quality of care as strong aspects, and education and more effective communication as areas for development. More recently, Wallerstedt et al. (2019) described what they understand by palliative care through focus group interviews, highlighting the lack of

definition and confusion regarding the concept, the challenge of communication and the need for interprofessional collaboration.

With respect to the perception of family members, different studies have found that relatives consider symptom control, teamwork and the availability of proactive professionals to be important in the quality of palliative care (Oosterveld-Vlug et al., 2019; Viridun et al., 2017).

In relation to palliative nursing care, fewer empirical studies have explored what quality in palliative nursing care means from the perspective of healthcare professionals and/or relatives. For example, Vachon et al. (2020) analysed the perception of four professionals of a palliative care team, considering 'connection to the self, to the other, and to the meaning of care' as necessary for the quality of care.

Other authors emphasise the need for compassion in nursing care with terminally ill patients, concluding that focusing care from this perspective means becoming aware of their needs, paying attention to their feelings and establishing a commitment and responsibility that give meaning to care (Devik et al., 2020).

Other studies, such as those conducted by Selman et al. (2018) and O'Callaghan et al. (2019), focus on meeting spiritual needs as part of care strategies.

In conclusion, quantitative studies focusing on the quality of palliative nursing care are based primarily on the analysis and measurement of professional competencies and standards needed to improve them, but do not allow us to specify what the routine practice actions related to quality should be. One scale that does measure and specify what these care actions are in terms of quality is the PNQCS, which is why the aim of our study was to design and validate this instrument. In this article, we present the qualitative work carried out to guarantee its design and content validity. On the contrary, from a qualitative approach, studies conducted with professionals do not specifically address the quality of palliative nursing care and focus on aspects mainly related to spirituality; accordingly, it seems appropriate to deepen and broaden the study to define the dimensions that make up this quality, from the perspective of palliative care professionals.

### 3 | AIMS AND OBJECTIVES

The aims of the study were to analyse the dimensions of quality of palliative nursing care and to explore the perceptions of professionals for the development and validation of the PNCQS.

### 4 | DESIGN

To meet the aims, we employed a mixed methods design based on the Delphi method and a qualitative exploratory design framed within a constructivist theoretical approach (Berger & Luckmann, 2011).

## 5 | METHODS

This study is part of one of the stages of the design and validation of the PNCQS (Zulueta Egea et al., 2020), which measures specific care actions in routine nursing practice. This mixed method approach aims to create a knowledge base to clarify actions to improve the quality of nursing care and consists of two phases: an expert panel and the conduct of semi-structured interviews.

### 5.1 | Phase 1: Expert panel

To begin with, an expert panel was established to analyse the dimensions of the PNCQS and the appropriateness and understanding of its items.

To select the group of experts, the following variables were considered: level of knowledge, years of work experience, prestige in the field of palliative care, motivation regarding the study subject and personal experience as main caregiver.

The panel of experts consisted of eight participants: three nurses with extensive experience in the field of palliative care, a nursing supervisor from a palliative care unit, a director of a hospice facility, a member of the Spanish Association of Palliative Care Nursing, a university professor of the subject of palliative care and a family member acting as primary caregiver for an end-of-life patient.

Based on the contributions and suggestions of the expert group regarding the dimensions that constitute the quality of palliative nursing care, the need arose to explore the inherent and intangible aspects of good nursing care through the conduct of semi-structured interviews.

### 5.2 | Phase 2: Semi-structured interviews

To meet the aims of the study and given that the dimensions of the quality of nursing care are oriented towards professionals, the people directly linked to the practice of nursing care were included in the analysis of these dimensions.

The study population was considered to be those professionals who form part of a palliative care team and/or family members who provide care to patients with advanced or terminal illness and who voluntarily agreed to participate in the research.

The study was carried out in the public network of hospitals that had integrated palliative care units, in home support care teams and in specific state-subsidised private hospitals of the Community of Madrid, in Spain. In order to select the sample, purposive sampling was carried out to select participants who met the inclusion criteria, guaranteed representativeness according to approach and feasibility, and showed the diverse reality and complementary statements. It was considered important to have the greatest possible sample diversification for data transferability.

Inclusion criteria were as follows:

- Healthcare professionals who form part of a multidisciplinary palliative care team in public and state-subsidised private hospitals of the Community of Madrid.
- Professionals with >2-year experience working in the palliative care setting.
- Primary caregivers of people with advanced or terminal illness.

Exclusion criteria included those professionals in the palliative care setting who did not provide continuous and direct care with the patient in their daily practice.

The selection criteria for the interviewees included variability in terms of age, sex, professional and personal role exercised in palliative care, years of care experience and type of palliative care service.

Access to potential interview participants was made progressively as the fieldwork proceeded, through the Spanish Society of Palliative Care (SECPAL) palliative services directory (Doblado et al., 2016) and professional and personal networks. The heads of the healthcare teams in the different palliative care settings were contacted to explain the aim of the study and to request their possible collaboration. The sample consisted of 10 participants based on inductive thematic saturation criteria. In this approach, saturation focuses on the identification of new codes or themes within the data and new theoretical insights are gained through the interview process (Guest et al., 2020; Saunders et al., 2018).

### 5.3 | Data collection

Data collection took place between January and June 2018.

First, an expert panel was conducted based on the Delphi technique to evaluate the dimensions of the PNCQS and the understanding and appropriateness of the items. To this end, the basic steps of the Delphi technique were followed, according to Hasson et al. (2000) and Varela-Ruiz et al. (2012).

The research team held a 60-min individual face-to-face meeting with each of the members of the expert group to explain the aim of

the study and the stages of the method. At the meeting, the following open-ended question was posed: What are the dimensions or factors that should be considered in the quality of nursing care at the end of life? Once the answers had been collected, the pre-set dimensions of the scale were described based on a review of the scientific literature. Each member was then asked to list the most important dimensions that make up the quality of palliative nursing care in order of priority from 1 to 5 (1 = not relevant at all, 5 = totally relevant). Once the individual responses had been received from each expert, two rounds of online sending and collection of information were carried out: a first round where the first draft of the questionnaire was presented and the experts were asked to evaluate the comprehension and relevance of each of the items on a scale of 1 to 5, and a second round, in which the second version of the questionnaire was sent to the experts and information was collected on the appropriateness of the final content of the questionnaire. During all phases, the iterative process, anonymity among group members and controlled feedback were ensured.

Second, semi-structured interviews were conducted based on the script in Table 1. The script addresses key questions related to the study aims and the following thematic areas: good palliative nursing care, appreciation of patients and family, assessment of the quality of nursing care and final compilation aspects.

The principal investigator, nurse and professor (MZ, first author of this article) with extensive experience as an interviewer and two other researchers from the team participated in the data collection. The authors ensured that there was no prior personal relationship with the participants and that the data analysis was also carried out by other researchers. No informant contacted refused to participate in the research.

The interviews were conducted in person at the location chosen by the key informants and lasted 50min on average, with a range of between 30 and 70min. All interviews were audio-recorded (with the prior explicit consent of the participants) and transcribed to facilitate further data analysis. Before and after each interview, impressions or memos were recorded (interviewee availability, contact information, content, location, time spent, atmosphere created or others), which were attached as field notes in the transcript. Once

TABLE 1 Interview script

Thematic areas	Professionals	Primary caregiver
Good palliative nursing care	What does providing good palliative care mean to you? What are the essential or most important aspects of good palliative nursing care?	What does it mean to you to take good care in an end-of-life situation?
Appreciation of patients and family	What do patients and families value or appreciate most about nursing care? How do patients and relatives usually thank you for your work?	What did you appreciate most about the team's nursing care? And, the rest of your family?
Assessment of the quality of nursing care	What do you consider essential to measure in order to assess the quality of palliative nursing care?	What do you consider essential to measure in order to assess good nursing care?
Final compilation aspects	Are there any aspects you would like to add to what we have discussed?	Are there any aspects you would like to add to what we have discussed?

the transcripts were made, they were given to each of the interviewees for review and approval.

## 5.4 | Ethics considerations

The ethical criteria of data confidentiality, participant anonymity, willingness of the interviewees and the right of the participants to withdraw from the study were applied. All participants received information about the project in writing and supported by verbal reinforcement, signing the informed consent document prior to conducting of the interview. For the literal transcription of interview data, anonymous codes were used for names in order to respect the confidentiality of the informants.

The attached approval report from the ethics committee of the institution where the research was conducted was presented to participating professionals, who were informed of the voluntary nature of participation and the anonymous and confidential treatment of data.

## 5.5 | Data analysis

The responses of each of the members of the expert panel on the most relevant dimensions of the quality of palliative nursing care were summarised and organised for presentation to the group members. The first round of analysis identified similarities in responses for the five main dimensions of the questionnaire and the relevance scores of the items were analysed according to the proposal by Abad et al. (2011). Based on the alternative explanations to the statements and suggestions of the expert panel on the comprehension of the items and content of the questionnaire, the research team evaluated the responses to draw up the final version of the questionnaire. During the rounds, similar, stable responses were identified in the expert group, which suggested a reliable consensus indicator (Crisp et al., 1997).

For analysis of the semi-structured interviews, a thematic analysis of the discourse was carried out following the proposal of Braun and Clarke (2006) with the following phases: (1) familiarisation with the data (2) generation of initial codes, (3) search for themes, (4)

review of potential themes, (5) definition and naming of themes and (6) production of the results report (Table 2).

Once the analysis had been carried out, the themes were identified and data, researchers and techniques were triangulated (Denzin, 2017). For triangulation of the data, different spaces of the palliative care setting (hospital, public health centre, home) and populations (professionals from different disciplines of the palliative team and a primary caregiver) were considered to increase the variety of observations. In triangulation of the researchers, two members of the research team jointly analysed the data.

The approach proposed by Lincoln and Guba (1985) was followed, according to which constructivist research should be supported by a key criterion, trustworthiness, which incorporates aspects such as credibility, authenticity, reflexivity, transferability and reliability. In this respect, we ensured that the data analysis was carried out by several researchers (Sandelowski, 1986). In relation to credibility, the results are presented by means of direct quotations and are accompanied by an explanation that qualifies and supports the richness of the data. A representative sample of the phenomenon and a detailed description of the process will allow us to transfer these results to homogeneous contexts. Reflexivity was part of the entire research process with field diaries completed by all members of the research team.

The study was reported in a comprehensive and transparent manner following Consolidated Criteria for Reporting Qualitative research (COREQ) (Tong et al., 2007) (Supplementary File 1) and Standards for Reporting Qualitative Research (SRQR) guidelines (O'Brien et al., 2014).

## 6 | RESULTS

### 6.1 | Expert panel

Based on the consensus of the expert panel, the main dimensions of the concept of 'quality of palliative nursing care' were verified and three prior reviews were carried out from the initial version of the PNCQS questionnaire with 19 items, to the final version with 20 items.

TABLE 2 Phases of thematic analysis (Braun & Clarke, 2006)

Phases	Development
(1) Familiarisation with the data	Transcribing interview data to generate preliminary insights Identify the most relevant text units
(2) Generation of initial codes	Group codes into possible thematic categories that respond to the research objective.
(3) Search for themes	Adapting themes with coded data and with the texts as a whole to establish relationships between categories and a map of meanings
(4) Review of potential themes	Check that the results correspond to the texts
(5) Definition and naming of themes	Selecting the most representative segments for the final analysis of these segments
(6) Production of the results report	Relate the analysis to the research question and the bibliography to produce a final academic report

There were five main dimensions that represented the quality of palliative nursing care: symptom control and management, family and/or primary caregiver, therapeutic relationship, spiritual support and continuity of care. The therapeutic relationship and spiritual support were the most prominent and representative dimensions of palliative nursing care quality. From each of the dimensions, the most relevant aspects were considered: pain control, dyspnoea and asthenia, emotional support and supporting the role of the caregiver, the importance of active listening and empathy of the nurse, meaning, connection, transcendence, communication and teamwork (Figure 1).

During and following the expert panel's review and analysis regarding the appropriateness and understanding of the questionnaire items, several items were amended for the definitive version and the importance of including the following in the final definition was identified: asthenia and anxiety in managing symptoms, support for family members in their care work, patient's values and review of life through honest communication, encouragement of decision-making or final wishes and evaluation of family and/or primary caregiver burden.

From the findings of the expert panel, it was observed that the most notable dimensions of the PNCQS questionnaire—the therapeutic relationship and spiritual support—represented intangible aspects of nursing care, which required a deeper analysis based on the feelings inherent to the person and the multidisciplinary experience of caregiving in the end-of-life setting. Accordingly, we thought it was important to complement the views of the expert group with that of professionals who, day after day, provide that invisible and imponderable care based on close observation and experience. Following this reflection, the need arose for semi-structured interviews with various palliative care professionals and a primary caregiver.

## 6.2 | Semi-structured interviews

Ten key informants participated: nine palliative care professionals (one nursing supervisor, four nurses, one nursing assistant, one psychologist, one doctor and one spiritual caregiver) and one family member, the primary caregiver. Nine were women and participants ranged in age from 35 to 50 years, with a minimum of two and maximum of 10 years of experience in palliative care. The home setting

and hospital units in the private, public and state-subsidised sector of the Community of Madrid were included. Table 3 shows the profile of the interviewees.

From the data collected from the interview, four emergent themes arose regarding good palliative nursing care: (1) the patient and family as a whole, (2) finding meaning, (3) responsible communication and (4) caring for the human element (Figure 2).

### 6.2.1 | (1) Patient and family as a whole

In order to approach the care process, the patient and their family should be considered as a whole, which involves, among other things, in-depth understanding of the person in order to be able to help them in their wishes. It also implies availability and collaboration of the different palliative care professionals, to whom this knowledge can be given as a requirement to provide the patient and family with comprehensive and personalised care.

'The first thing in knowing how to care is getting to know the patient and the family very well, that they allow you into the most intimate aspects of their lives, respecting their silence, their time and their wishes. It's simple. You will get to know a person and they you ... your openness'

(15)

'Family members are an active part in planning care. You enter their home. The family member is present throughout, and we need to remind them that they've been there every day, their sensitivity, especially at the time of death, when they fall apart'

(13)

Care units should be generated that empower and work on both; it is as important to work on patients as on their families:

'Patients and family members are constant elements and active agents of continuity of care'

(12)

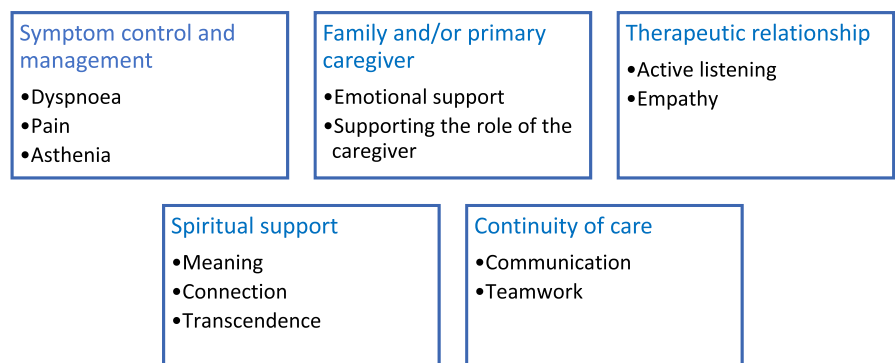


FIGURE 1 Dimensions of the quality of palliative nursing care [Colour figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]

TABLE 3 Profile of the interviewees

Interviewees	Age	Sex	Professional/personal role	Years of experience	Care resource
I1	50	Female	Nurse	10	PCU
I2	43	Female	Nursing supervisor	10	PCU
I3	48	Female	Doctor	10	HCST
I4	42	Female	Nursing assistant	3	PCU
I5	38	Female	Psychologist	3	PCU
I6	41	Female	Nurse	10	HCST
I7	49	Female	Nurse	9	PCU
I8	35	Female	Nurse	3	PCU
I9	50	Male	Spiritual caregiver	10	PCU
I10	43	Female	Primary caregiver	2	HCST

Abbreviations: HCST, Home Care Support Team; PCU, Palliative Care Unit.

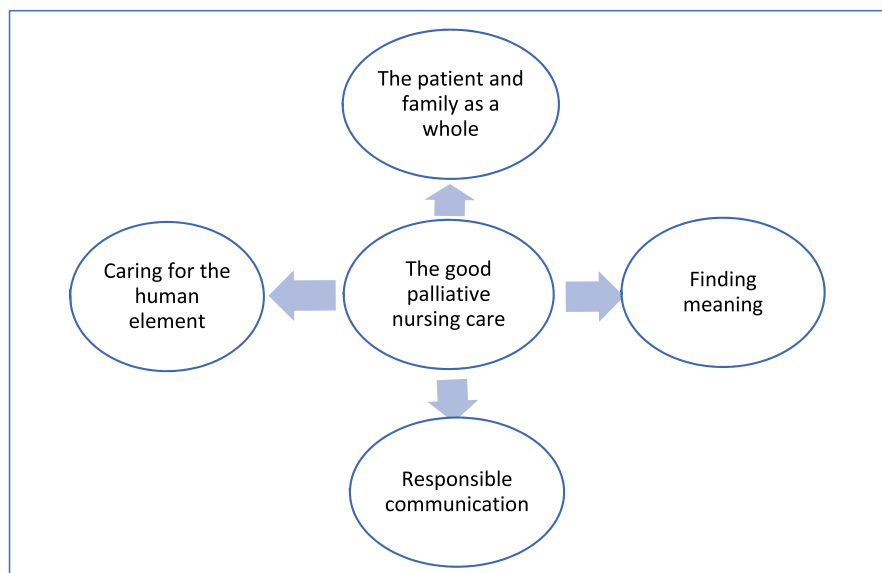


FIGURE 2 Emergent themes from semi-structured interviews [Colour figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]

### 6.2.2 | (2) Finding meaning

Finding meaning in this dimension of care implies connecting with the patient's meaning of life and death, but also with the professionals' meaning of life and death. Moreover, as nurses, it is necessary to internalise and reflect on our own meaning and/or spirituality, in order to share that meaning of life and death with the patient and provide good palliative care.

'Talk to the patient about the meaning of life and share the meaning of their life and their death. We need to understand that dying is a fundamentally spiritual act and it is part of life; just as being born and living is a mystery, death is a mystery. We must learn to live in uncertainty, accept the mystery and dedicate ourselves to providing support. If the professional has not disclosed what sustains her in her life and has not

revealed it, she cannot help the patient to disclose, reveal and evolve'.

(19)

'The gesture comes out of one's own spirituality. You can't make it up. You need a clear personal journey. It is at the core of all dimensions of care'.

(16)

### 6.2.3 | (3) Responsible communication

From responsible communication with the patient, family members and other professionals in the team, continuity of care is understood as negotiating care with the patient and empowering family members and patients in decision-making. This communication involves empathy skills and presence on the part of the nurse, which leads

them to show total or complete availability with the patient and family.

'To evaluate the quality of nursing care, there must be good communication, which is at the core of all care. When we talk about continuity, we refer to the fact that it is the patient who is directing how this care should be. When we refer a patient and their relative to the hospital, we give them all the information possible, because information is power, control and security. If you prepare them for what they will find, you greatly minimize the impact it may have, because all the consequences there are in palliative care are very intense, all of them'.

(I2)

'I appreciate your plain, honest and very affectionate way of speaking. The day she died they came very quickly and told me that my mother had died peacefully, and that the way we had taken care of her had been exceptional; they were especially warm, even going so far as physical contact'.

(I10)

Verbal and non-verbal communication is also required to accompany this situation of empathy, which strengthens the care environment.

'The professional's posture is important if he or she is standing or sitting when talking for a long time. To take care of that person without rushing ... that it is you, right now who matters most to me, being generous with time ... at the end of life we have to be sensitive. Our presence, knowing how to be in the here and now and giving it full attention is the most difficult thing'.

(I1)

#### 6.2.4 | (4) Caring for the human element

Quality care essentially entails respect for the dignity of the patient in their suffering and vulnerability. It involves attending to the essence of the human being as it is, normalising the patient's day-to-day, the everyday.

'There are many little things where professionals have to insist that what matters is the dignity of the patient. I think it's fundamental. Let's say that the person has to look nice; if they're wearing a diaper that doesn't fit them, then we look for the most comfortable one, the best position to sleep ... the goal is their comfort'.

(I10)

'Respect the patient's decisions. For example, if they are very weak and insist on going to the bathroom alone, don't tell them to 'save that energy for another time'. We don't realize that, for him, it is important and that the extraordinary is the ordinary in palliative patients. Prioritize according to the patient's value scale, even if it's not very exciting'

(I7)

In the search for meaning, we need to pay attention to what constitutes us as human beings, which is linked among other dimensions to creativity. Encouraging and tending to it help to generate motivation and well-being, even in a situation close to death.

'Creativity. There are people who ache everywhere, for example wearing nasal prongs that give them an ulcer. So, let's see what I can do for them and encourage their creativity with occupational therapies. Humans enjoy creating. Every minute a person can have to feel useful, because if I feel like a burden instead, my life has no meaning'

(I6)

## 7 | DISCUSSION

There is widespread agreement that symptom control and relief is the first critical step in providing quality care. Pain, dry mouth and dyspnoea are the signs and symptoms that have the greatest impact on the patient's quality of life, in line with the study by Martí-García et al. (2020). In addition, our findings add asthenia as one of the symptoms that generate the greatest distress in the patient and their family.

Interpersonal relationships, communication and spiritual support are the dimensions that best represent the quality of palliative nursing care. These results are consistent with studies by Viridun et al. (2017) and Kinley et al. (2018), where family members consider such aspects essential to providing good nursing care. Our findings indicate that empathy and active listening are the most important communication skills for the therapeutic relationship, as reported by several authors (Codorniu et al., 2013; Rawlings et al., 2019) who address the need to train nurses in these competencies.

Spiritual support is a fundamental part of nursing care and a core competency for all professionals working in palliative care, which, like in our study, recognises aspects such as meaning, connection and transcendence. The end-of-life experience fosters in professionals an authentic encounter with their self, an awakening of values that give meaning to their life and self-transcendence (Pereira Rocha et al., 2021). Moreover, in both the literature and the findings presented, palliative care professionals relate spirituality to connecting with others, being compassionate, having self-awareness and empowering patients and family members (Lalani et al., 2021). In this respect, Kang et al. (2021) addressed the importance of spiritual care



and analysed the experiences of palliative nurse focus groups and an expert panel on the meaning of spiritual care, highlighting four themes: helping prepare for a dignified death including religious support; providing comfort and empathy; supporting spiritual fulfilment by finding meaning; and providing comprehensive care for patients and family.

Finding the meaning in nursing care and connecting with our spirituality seems to be an important requirement to accompany the patient in the search for their meaning of life and death. Along the same lines, Vachon et al. (2012) report that nurses who are aware of their spirituality, values or meaning better identify the spiritual needs of the terminally ill person.

The dimension of nursing care towards the family and/or primary caregiver involves, above all, emotional support throughout the process of advanced and terminal illness, allowing the expression of their feelings without judging them and positive reinforcement towards their work of care and involvement with the patient. Authors such as Viridun et al. (2017) particularly highlight emotional support in times of overburden and grief, before, during and after the patient's death.

Continuity of care has been related to teamwork (agreement on actions and collaboration) and to the need for effective communication with the patient and/or family members, in line with authors such as Klarare et al. (2017), who show the relationship between good teamwork and continuity of care from the experience of patients and family members. Responsible communication involves not only knowing how to handle information well with the patient, family and team, through active listening skills and empathy, but also intangible aspects such as the presence and availability of the professional. Consistent with these findings, Engel et al. (2020) and Mertens et al. (2021), from the perspective of nurses, point to the need to move towards open interprofessional communication for shared decision-making, advance care planning, and improved quality of nursing care, while Vachon et al. (2020) consider presence a key attitude in the quality of nursing care.

Finally, our results show that prioritising the needs and desires of the patient and the family as a whole is a criterion of excellence in nursing care and the centre of all end-of-life care. Different palliative nursing models and studies address the importance of person-centred holistic nursing care (Reed, 2010; Walker & Avant, 2005), along with the need to listen to the patient and family members, and to use creative strategies that address their personal preferences and thus respect their dignity (De Voogd et al., 2021; Heyland et al., 2010).

## 7.1 | Limitations

One of the limitations of our study is the possible interpretation bias, despite the use of reflexivity, due to the researcher's own internal assumptions about the study phenomenon: the quality of palliative nursing care. However, the fact that the same researcher conducted the interviews, and transcribed and analysed the data facilitates understanding of the contextual and interactive environment of the interview process.

Another limitation related to the key informants is that most of the interviewees were women, nine out of 10, so the sample diversification was not as desired to increase the variety of observations. Furthermore, having a single family member, the primary caregiver, participate in interviews makes it difficult to generalise the results to the experiences of other family members, although it brings new perspectives and future research questions.

## 8 | CONCLUSION

The purpose of the study was to analyse the dimensions of quality of palliative nursing care and to explore the perceptions and experiences of palliative care professionals for the development and validation of the PNCQS.

The construct validity of the PNCQS questionnaire was confirmed based on the consensus of the expert panel on the main dimensions that make up the concept of 'quality of nursing care' and the appropriateness of its items.

It is necessary to identify the most relevant dimensions that represent the quality of palliative nursing care, not only from theoretical models or expert opinion, but from the personal and routine practice experience of professionals and/or family members in this field.

Our results suggest that, in good nursing care, the expectations or goals of professionals are not important, and that care should be based primarily on the needs and desires of the patient and their family. Furthermore, the spiritual dimension of care in the end-of-life setting is particularly important, and it is this dimension that defines and represents the quality of nursing care.

## 9 | RELEVANCE TO CLINICAL PRACTICE

Our study not only considers the assessment and perception of nurses on the quality of their care, but also the experience of other professionals of the multidisciplinary team, thus bringing greater breadth and richness to the concept of good nursing care in the palliative setting.

The implications for nursing practice include being able to evaluate the care actions of routine practice taking into account the importance of the dimensions of the practice that comprise it; developing training programs aimed at acquiring the communication skills of active listening, advanced empathy and spiritual attitudes of presence, hospitality and compassion; establishing periodic meetings between the entire multidisciplinary team for case management, collaboration and continuity of care; and finally, promoting the figure of the advanced practice nurse in palliative care.

## AUTHOR CONTRIBUTIONS

Study Planning, Data collection, Data analysis and manuscript and revision of the article and agreed on the final version.

## ACKNOWLEDGEMENTS

Our heartfelt thanks to all those palliative care professionals and family members whose testimonies have enabled us to explore what constitutes good end-of-life nursing care.

## FUNDING INFORMATION

This investigation was not supported by a specific grant from any public, commercial or non-profit funding agency.

## CONFLICT OF INTEREST

The authors declare no conflict of interest.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

## ORCID

Mar Zulueta Egea  <https://orcid.org/0000-0002-6922-3849>

## REFERENCES

- Abad, F. J., Olea, J., Ponsoda, V., & García García, C. (2011). *Medición en ciencias sociales y de la salud*. España.
- Arahata, T., Miyashita, M., Takenouchi, S., Tamura, K., & Kizawa, Y. (2018). Development of an instrument for evaluating Nurses' knowledge and attitude toward end-of-life care: End-of-life nursing education consortium--Japan Core quiz. *Journal of Hospice & Palliative Nursing*, 20, 55–62. <https://doi.org/10.1097/NJH.0000000000000393>
- Bausewein, C., Daveson, B. A., Currow, D. C., Downing, J., Deliens, L., Radbruch, L., & Higginson, I. J. (2016). EAPC white paper on outcome measurement in palliative care: Improving practice, attaining outcomes and delivering quality services - recommendations from the European Association for Palliative Care (EAPC) task force on outcome measurement. *Palliative Medicine*, 30(1), 6–22. <https://doi.org/10.1177/0269216315589898>
- Berger, P. L., & Luckmann, T. (2011). *La construcción social de la realidad*. Amorrortu.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Cameron, D., & Johnston, B. (2015). Development of a questionnaire to measure the key attributes of the community palliative care, specialist nurse role. *International Journal of Palliative Nursing*, 21(2), 87–95. <https://doi.org/10.12968/ijpn.2015.21.2.87>
- CHPCA Nursing Standards Committee. (2009). Hospice palliative care nursing standards of practice. [https://www.chpca.ca/wp-content/uploads/2020/02/Canadian\\_Hospice\\_Palliative\\_Care\\_Nursing\\_Standards\\_2009.pdf](https://www.chpca.ca/wp-content/uploads/2020/02/Canadian_Hospice_Palliative_Care_Nursing_Standards_2009.pdf)
- Codorniu, N., Guanter, L., Molins, A., & Utor, L. (2013). *Competencias enfermeras en cuidados paliativos*. Sociedad Española de Cuidados Paliativos. <http://www.secpal.com/%5CDocumentos%5CBlog%5C-MONOGRAFIA%203.pdf>
- Crisp, J., Pelletier, D., Duffield, C., Adams, A., & Nagy, S. U. E. (1997). The Delphi method? *Nursing Research*, 46(2), 116–118.
- Davies, B., & Oberle, K. (1990). Dimensions of the supportive role of the nurse in palliative care. *Oncology Nursing Forum*, 17(1), 87–94.
- De Voogd, X., Willems, D. L., Onwuteaka-Philipsen, B., Torensma, M., & Suurmond, J. L. (2021). Health care staff's strategies to preserve dignity of migrant patients in the palliative phase and their families. A qualitative study. *Journal of Advanced Nursing*, 77(6), 2819–2830. <https://doi.org/10.1111/jan.14829>
- Denzin, N. K. (2017). *Sociological methods: A source book*. Routledge.
- Desbiens, J., & Fillion, L. (2011). Development of the palliative care nursing self-competence scale. *Journal of Hospice & Palliative Nursing*, 13(4), 230–241.
- Devik, S. A., Enmarker, I., & Hellzen, O. (2020). Nurses' experiences meaning of compassion when giving palliative care at home. *Nursing Ethics*, 27(1), 194–205.
- Doblado, R., Herrera, E., Librada, S., Lucas, M. Á., Muñoz, I., & Rodríguez, Z. (2016). Análisis y evaluación de los recursos de Cuidados Paliativos de España. *Sociedad Española de Cuidados Paliativos*, 9, 1–139.
- Engel, M., van der Ark, A., Tamerus, R., & van der Heide, A. (2020). Quality of collaboration and information handovers in palliative care: A survey study on the perspectives of nurses in the southwest region of The Netherlands. *European Journal of Public Health*, 30(4), 720–727. <https://doi.org/10.1093/eurpub/ckaa046>
- Feder, S. L., Collett, D., Haron, Y., Conley, S., Schulman-Green, D., Meron, T., & Cherny, N. (2018). How skilled do Israeli nurses perceive themselves to be in providing palliative care? Results of a national survey. *International Journal of Palliative Nursing*, 24, 56–63. <https://doi.org/10.12968/ijpn.2018.24.2.56>
- Guest, G., Namey, E., & Chen, M. (2020). A simple method to assess and report thematic saturation in qualitative research. *PLoS One*, 15(5), e0232076. <https://doi.org/10.1371/journal.pone.0232076>
- Hasson, F., Keeney, S., & McKenna, H. (2000). Research guidelines for the Delphi survey technique. *Journal of Advanced Nursing*, 32(4), 1008–1015. <https://doi.org/10.1046/j.1365-2648.2000.t011-01567.x>
- Heyland, D. K., Cook, D. J., Rocker, G. M., Dodek, P. M., Kutsogiannis, D. J., Skrobik, Y., & Cohen, S. R. (2010). Defining priorities for improving end-of-life care in Canada. *CMAJ: Canadian Medical Association Journal*, 182(16), 747–752. <https://doi.org/10.1503/cmaj.l00131>
- Hiatt, K., Stelle, C., Mulsow, M., & Pearson Scott, J. (2007). The importance of perspective: Evaluation of hospice care from multiple stakeholders. *American Journal of Hospice and Palliative Medicine*, 24(5), 376–382. <https://doi.org/10.1177/1049909107300760>
- International Council of Nurses (ICN). (2021). ICN code of ethics for nurses. [https://www.icn.ch/system/files/2021-10/ICN\\_Code-of-Ethics\\_SP\\_WEB.pdf](https://www.icn.ch/system/files/2021-10/ICN_Code-of-Ethics_SP_WEB.pdf)
- Kang, K. A., Chun, J., Kim, H. Y., & Kim, H. Y. (2021). Hospice palliative care nurses' perceptions of spiritual care and their spiritual care competence: A mixed-methods study. *Journal of Clinical Nursing*, 30(7–8), 961–974. <https://doi.org/10.1111/jocn.15638>
- Kinley, J., Hockley, J., Stone, L., & Brazil, K. (2018). Family perceptions of care at the end of life in UK nursing care homes. *Journal of Research in Nursing*, 23(2–3), 203–217. <https://doi.org/10.1177/1744987117753276>
- Kirkpatrick, A., Cantrell, M., & Smeltzer, S. (2017). A concept analysis of palliative care nursing: Advancing nursing theory. *Advances in Nursing Science*, 40(4), 356–369. <https://doi.org/10.1097/ANS.0000000000000187>
- Klarare, A., Rasmussen, B. H., Fossum, B., Fürst, C. J., Hansson, J., & Hagelin, C. L. (2017). Experiences of security and continuity of care: Patients' and families' narratives about the work of specialized palliative home care teams. *Palliative & Supportive Care*, 15(2), 181–189.
- Lalani, N. S., Duggleby, W., & Olson, J. (2021). "I need presence and a listening ear": Perspectives of spirituality and spiritual care among healthcare providers in a hospice setting in Pakistan. *Journal of Religion and Health*, 60(4), 2862–2877. <https://doi.org/10.1007/s10943-021-01292-9>
- Lazenby, M., Ercolano, E., Schulman-Green, D., & McCorkle, R. (2012). Validity of the end-of-life professional caregiver survey to assess for multidisciplinary educational needs. *Journal of Palliative Medicine*, 15(4), 427–431.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. SAGE.

- Martí-García, C., Fernández-Alcántara, M., López, P. S., Ruiz, C. R., Martín, R. M., & García-Caro, M. P. (2020). Experiences of family caregivers of patients with terminal disease and the quality of end-of-life care received: A mixed methods study. *PeerJ*, 8, e10516. <https://doi.org/10.7717/peerj.10516>
- Mertens, F., Debrulle, Z., Lindsog, E., Deliens, L., Deveugele, M., & Pype, P. (2021). Healthcare professionals' experiences of inter-professional collaboration during patient's transfers between care settings in palliative care: A focus group study. *Palliative Medicine*, 35(2), 355–366. <https://doi.org/10.1177/0269216320968741>
- Montagnini, M., Smith, H. M., Price, D. M., Ghosh, B., & Strodtman, L. (2018). Self-perceived end-of-life care competencies of health-care providers at a large academic medical center. *American Journal of Hospice and Palliative Medicine*, 35(11), 1409–1416. <https://doi.org/10.1177/1049909118779917>
- Mularski, A., Rosenfeld, K., Coons, S., Dueck, A., Cella, D., Feuer, D., & Sloan, J. (2007). Measuring outcomes in randomized prospective trials in palliative care. *Journal of Pain and Symptom Management*, 34(1), 7–19. <https://doi.org/10.1016/j.jpainsymman.2007.04.004>
- Nakazawa, Y., Miyashita, M., Morita, T., Umeda, M., Oyagi, Y., & Ogasawara, T. (2010). The palliative care self-reported practices scale and the palliative care difficulties scale: Reliability and validity of two scales evaluating self-reported practices and difficulties experienced in palliative care by health professionals. *Journal of Palliative Medicine*, 13(4), 427–437. <https://doi.org/10.1089/jpm.2009.0289>
- O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine*, 89(9), 1245–1251. <https://doi.org/10.1097/ACM.0000000000000388>
- O'Callaghan, C., Brooker, J., de Silva, W., Glenister, D., Melia, A., Cert, I. V., & Michael, N. (2019). Patients' and caregivers' contested perspectives on spiritual care for those affected by advanced illnesses: A qualitative descriptive study. *Journal of Pain and Symptom Management*, 58(6), 977–988. <https://doi.org/10.1016/j.jpainsymman.2019.08.004>
- Oosterveld-Vlug, M. G., Custers, B., Hofstede, J., Donker, G. A., Rijken, P. M., Korevaar, J. C., & Francke, A. L. (2019). What are essential elements of high-quality palliative care at home? An interview study among patients and relatives faced with advanced cancer. *BMC Palliative Care*, 18(1), 1–10. <https://doi.org/10.1186/s12904-019-0485-7>
- Pereira Rocha, R. C. N., Ramos Pereira, E., Costa Rosa Andrade Silva, R. M., Bueno Bejarano Vale de Medeiros, A. Y., Morett Romano Leão, D. C., & da Fonseca Marins, A. M. (2021). Meaning of life as perceived by nurses at work in oncology palliative care: A phenomenological study. *Revista da Escola de Enfermagem da USP*, 55, e03753. <https://doi.org/10.1590/S1980-220X2020014903753>
- Rawlings, D., Devery, K., & Poole, N. (2019). Improving quality in hospital end-of-life care: Honest communication, compassion and empathy. *BMJ Open Quality*, 8(2), e000669. <https://doi.org/10.1136/bmjopen-2019-000669>
- Reed, S. M. (2010). A unitary-caring conceptual model for advanced practice nursing in palliative care. *Holistic Nursing Practice*, 24(1), 23–34.
- Ross, M., McDonald, B., & McGuinness, J. (1996). The palliative care quiz for nursing (PCQN): The development of an instrument to measure nurses' knowledge of palliative care. *Journal of Advanced Nursing*, 23(1), 126–137. <https://doi.org/10.1111/j.1365-2648.1996.tb03106.x>
- Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science*, 8(3), 27–37. <https://doi.org/10.1097/00012272-198604000-00005>
- Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2018). Saturation in qualitative research: Exploring its conceptualization and operationalization. *Quality & Quantity*, 52, 1893–1907. <https://doi.org/10.1007/s11135-017-0574-8>
- Selman, L. E., Brighton, L. J., Sinclair, S., Karvinen, I., Egan, R., Speck, P., Powell, R. A., Deskur-Smielecka, E., Glajchen, M., Adler, S., Puchalski, C., Hunter, J., Gikaara, N., & Hope, J. (2018). Patients' and caregivers' needs, experiences, preferences and research priorities in spiritual care: A focus group study across nine countries. *Palliative Medicine*, 32(1), 216–230. <https://doi.org/10.1177/0269216317734954>
- Soikkeli-Jalonen, A., Stolt, M., Hupli, M., Lemetti, T., Kennedy, C., Kydd, A., & Haavisto, E. (2020). Instruments for assessing nurses' palliative care knowledge and skills in specialised care setting: An integrative review. *Journal of Clinical Nursing*, 29(5–6), 736–757. <https://doi.org/10.1111/JOCN.15146>
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357. <https://doi.org/10.1093/intqhc/mzm042>
- Vachon, M., Fillion, L., & Achille, M. (2012). Death confrontation, spiritual-existential experience and caring attitudes in palliative care nurses: An interpretative phenomenological analysis. *Qualitative Research in Psychology*, 9(2), 151–172. <https://doi.org/10.1080/14780881003663424>
- Vachon, M., Goyette, C., & Guité-Verret, A. (2020). Presence and the paradox of time for palliative care clinicians: A phenomenological study. *The International Journal of Whole Person Care*, 7(2), 13–25. <https://doi.org/10.26443/ijwpc.v7i2.238>
- Varela-Ruiz, M., Díaz-Bravo, L., & García-Durán, R. (2012). Descripción y usos del método Delphi en investigaciones del área de la salud. *Investigación en Educación Médica*, 1(2), 90–95.
- Viridun, C., Luckett, T., Lorenz, K., Davidson, P. M., & Phillips, J. (2017). Dying in the hospital setting: A meta-synthesis identifying the elements of end-of-life care that patients and their families describe as being important. *Palliative Medicine*, 31(7), 587–601. <https://doi.org/10.1177/0269216316673547>
- Walker, L., & Avant, K. (2005). *Strategies for theory construction in nursing*. Pearson Education.
- Wallerstedt, B., Benzein, E., Schildmeijer, K., & Sandgren, A. (2019). What is palliative care? Perceptions of healthcare professionals. *Scandinavian Journal of Caring Sciences*, 33(1), 77–84. <https://doi.org/10.1111/scs.12603>
- Zulueta Egea, M., Prieto-Ursúa, M., & Bermejo Toro, L. (2020). Good palliative nursing care: Design and validation of the palliative nursing care quality scale (PNCQS). *Journal of Advanced Nursing*, 76(10), 2757–2767. <https://doi.org/10.1111/jan.14464>

## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

**How to cite this article:** Zulueta Egea, M., Prieto-Ursúa, M., Bermejo Toro, L., & Palmar-Santos, A. (2023). Dimensions of good palliative nursing care: Expert panel consensus and perceptions of palliative professionals. *Journal of Clinical Nursing*, 32, 3746–3756. <https://doi.org/10.1111/jocn.16583>