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## The caregiver's perspective on end-of-life inpatient palliative care: a qualitative study

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### ABSTRACT

**Introduction:** Understanding patient and caregiver experience is key to providing person-centered care. The palliative care approach includes holistic assessment and whole-person care at the end of life, that also involves the patient's family and loved ones. The aim of this study was to describe the way that family caregivers experienced patients' deaths during their loved ones' last hospital admission, comparing inpatient palliative care (PCU) and non-palliative care (Non-PCU) units.

**Methods:** A qualitative case study approach was implemented. Family caregivers of terminally ill patients admitted to the Infanta Elena Hospital (Madrid, Spain) between 2016 and 2018 were included using purposeful sampling. Eligible caregivers were first-degree relatives or spouses present during the patient's last hospital admission. Data were collected *via* in-depth interviews and researchers' field notes. Semi-structured interviews with a question guide were used. A thematic inductive analysis was performed. The group of caregivers of patients admitted to the PCU unit and the group of caregivers of patients admitted to Non-PCU were analyzed separately, through a matrix.

**Results:** In total 24 caregivers (12 from the PCU and 12 from Non-PCU units) were included. Two main themes were identified: caregivers' perception of scientific and technical appropriateness of care, and perception of person-centred care. Scientific appropriateness of care was subdivided into two categories: diagnostic tests and treatment, and symptom control. Perception of person-centred care was subdivided as: communication, emotional support, and facilitating the farewell process. Caregivers of patients admitted to a PCU unit described their experience of end-of-life care as positive, while their Non-PCU unit counterparts described largely negative experiences.

**Conclusions:** PCU provides a person-centered approach to care at the end of life, optimizing treatment for patients with advanced disease, ensuring effective communication, establishing a satisfactory professional relationship with both patients and their loved ones, and facilitating the farewell process for family caregivers.

### KEY MESSAGE



This article describes a qualitative case study focusing on family caregivers' perception of end-of-life care during their loved ones' dying process in their last hospital admission. Differences were observed between palliative care and non-palliative care groups regarding the perception of scientific appropriateness of care and person-centered nature of care as reported by caregivers.

### ARTICLE HISTORY

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## Introduction

Healthcare is evolving towards personalized medicine, adapting scientific and technical possibilities to the values and preferences of the individual [1]. Palliative care (PCU) provides the most appropriate model of person-centered care for individuals who suffer from advanced illnesses [2], ref equipping professionals with the knowledge and abilities necessary to offer holistic support not only to patients, but also to their relatives and caregivers, at advanced stages of illness and at the end of life [3–5].

Worldwide, around 56.8 million people are estimated to need PCU (of whom 25.7 million are in their last year of life). Although PCU development is one of the World Health Organization's priorities, some geographical areas lack PCU resources, leading to inequities in access to PCU between countries [6–9] despite the well-known benefits of PCU for patients with advanced illness regarding symptom control, communication, and decision-making [10, 11]). PCU is not fully developed in Spain, with the growth of PCU units slowing down over the last decade [7, 12]. The 2019 European Palliative Care Atlas places Spain among the lowest-ranking countries regarding care for patients at the end of life [8], at 31<sup>st</sup> of 51 European countries where palliative care resources *per capita* are concerned; around 80,000 Spanish patients die each year without receiving appropriate palliative care [13].

Terminal illness puts patients and their families at risk for negative consequences, both socially and emotionally, with family caregivers presenting different coping strategies and behaviors which affect family function and patient wellbeing. PCU supports both patients and their families, to reduce levels of suffering for all individuals involved [14]. Previous studies describe that families receiving support from PCU specialists report gratitude and satisfaction [15–17]. However, to the best of our knowledge, no existing studies have focused on appropriateness of care in the last days of patient's life, during the last patient's hospital stay from the carer's point of view.

The objective of this qualitative study is to describe caregivers' experience of care during the dying process of their loved ones' last hospital admission, contrasting the inpatient PCU unit experience with that of conventional Non-PCU inpatient units. We focus on family caregivers' perception of whether patients were cared for correctly from a clinical point of view; whether patients' needs were addressed satisfactorily; and whether patients' values and wishes were considered in the clinical decision-making process.

## Methods

### Design

We performed a qualitative descriptive case study as part of a cost-effectiveness study on end-of-life care comparing in patient palliative care units to other inpatient units. Qualitative methods are useful for investigating the beliefs, values, and motivations behind individual health choices [18]. Furthermore, qualitative studies have been used to study other aspects of palliative care, such as patients' and caregivers' experience of transition to an inpatient palliative care unit [19], caregiver coping strategies when a family member is diagnosed with cancer [20–22], issues regarding the use of Whats App® to thank palliative care professionals [23], and family and patients' perception of integrated primary and palliative care [24].

A descriptive case study is formed of different units which help to describe a phenomenon. These units may include participants from different contexts and places whose only connection is the phenomenon under investigation [18, 25–27], which, in this study, is the presence or absence of palliative care during patients' last hospital admission.

This non-funded study was conducted according to the Consolidated Criteria for Reporting Qualitative Research (COREQ) and the Standards for Reporting Qualitative Research (SRQR) [28].

### Research team and reflexivity

Seven researchers were involved in this study (3 women). Of these, 1 had experience in qualitative research design (DPCU) and 3 held a PhD in health sciences (AHR, ANT, DPCU). All members of the research team worked as healthcare providers in the study context, and one (MHA) had been directly involved in the care of patients whose relatives were carers interviewed as part of the project. Before beginning the project, the researchers established their position regarding the study's theoretical framework and their beliefs, prior experience, and personal motivations for participating in the research. During the study, researchers made individual reflective reports, describing their experience of the research process (recruitment, data collection, and analysis). In these reports, each researcher noted his or her possible influence on the context and participants and identified how they had been influenced by the context and participants. Subsequently, the researchers held meetings where they shared and discussed events that had influenced their previous positioning and theoretical framework,

and the effect of these events on the study [29, 30]. In addition, of the four researchers participating in the analysis, three (RCV, LMGM, AHR) had not had contact with the patients (loved ones of the participants) admitted to the PCU and Non-PCU units. This helped us to carry out data analysis from a unified perspective [29, 30].

### Participants, sampling strategies and sample

We used purposive sampling, which involves searching for places and/or contexts where relevant information is expected to be obtained in order to answer the study question. As the goal of qualitative studies is not to extrapolate results or achieve statistical significance, there is no formula for the prior calculation of sample size. To determine the number of participants for this study, we applied the criterion of redundancy of information, recruitment ends when including additional participants or data fails to add relevant information [31].

Participants included family caregivers of patients with palliative care needs admitted to the Infanta Elena University Hospital (Madrid, Spain) between 2016 and 2018. Eligible caregivers were a) older than 18 years old, b) first-degree relatives or spouses, c) present during the patient's last hospital admission, and d) responsible for caring for the patient at least 50 h per week. Patients with palliative care needs were defined as those meeting NECPAL criteria [32], with a Risk of Mortality (ROM) and Severity of Illness (SOI)

score of 2 or more [33, 34]. Participants were divided into 2 groups (the inpatient palliative care unit group and the conventional inpatient unit group) according to the inpatient unit to which their loved ones had been admitted during their last hospital stay.

Participants were recruited using the Madrid Healthcare System's patient portal website. An informative message was published to invite potential participants to a first interview. Caregivers who were interested in participating contacted the research team and were interviewed after giving their written informed consent (sent by text messaging over the patient portal) to participate and publish their data for scientific purposes.

### Data collection

Semi-structured interviews with a question guide were used for data collection. The question guide (Table 1) was constructed using a total of 5 items, based on previous studies carried out in Spain by Fernandez Isla et al. [16], Hernandez Bello et al. [35], and Molina Linde et al. [15], together with items taken from the EORTC PATSAT-C32 questionnaire. The EORTC Satisfaction with Cancer Care Core Questionnaire (EORTC PATSAT-C32) is a comprehensive instrument for assessing the perception of appropriateness of care in any hospital unit or cancer care setting which can also be used in advanced non-oncological illness [36, 37]. The aim of using different sources, which provide information on the use of palliative care in cancer and other diseases or situations, was to achieve a broader perspective on the use of palliative care and to use the information in our study. The question guide presented areas of interest to ask about. The questions were open-ended, not aimed at eliciting a specific answer, and allowed participants to narrate what was most relevant to their experience, from their perspective. Telephone interviews were carried out by MHA and LMGM, due to restrictions imposed by the COVID-19 pandemic.

### Analysis

An inductive thematic analysis of the data (including interview transcripts and researchers' field notes) was performed. Four researchers with experience in qualitative studies analyzed the data (RCV, MHA, LMGM, AHR). Before starting the analysis, we identified relevant text fragments from the transcripts, which provided information to answer the study objectives [38]. The text fragments (narratives) were collected and

**Table 1.** Questions guide used to conduct semi-structured interviews.

Research items	Questions
Tests	What was your experience of the tests ordered for your loved one? What was the most relevant aspect of your experience? Were you informed of the tests that were carried out?
Medication	What was your experience of the medication prescribed to your loved one? What was the most relevant aspect of your experience? Could you explain which medication was prescribed, and how it was administered? Was your loved one prescribed rescue medication? What did that mean for you?
Symptom Control	What was your experience of symptom control? Was medication used to control symptoms?
Attention to relatives	What was your experience of the attention you received as a family? What was the farewell process like?
Information	What was your experience of the information you received? Would you modify the information received in any way? Were you informed about key aspects of care such as this being your loved one's last admission?

organized using the topics of interest from the question guide [38]. This preliminary data organization was not based on a predetermined theoretical model. After organization, inductive analysis was carried out to identify and code content that emerged from the participants' narratives. The most descriptive content was identified and coded. Subsequently, categories (groups of codes presenting a common meaning) were identified, and themes describing the participants' experience were obtained [39]. Interviews were analyzed separately and independently, with all researchers performing code and category analysis. A matrix was created to analyze the group of patients admitted to the inpatient palliative care unit (PCU) and the group of patients admitted to other (Non-PCU) units separately. Research meetings were carried out to share and compare results and identify themes. If opinions differed, a decision was reached by consensus. No qualitative analysis software was used.

### Trustworthiness criteria

We applied Guba and Lincoln's trustworthiness criteria [40]: (a) credibility, demonstrated by investigator triangulation and the use of multiple-source qualitative data collection (interview transcripts, quotations, and researcher notes); (b) transferability, achieved by providing in-depth descriptions of the design, participants, context, sampling, data collection, and analysis; (c) dependability, proven by an audit of the study conducted by external researchers; and (d) confirmability,

achieved by recording reflexive reports in data collection and analysis.

### Ethics

The present study was conducted in accordance with the Code of Ethics of the World Medical Association (Declaration of Helsinki) for human experimentation. Approval was requested and obtained from the Ethics Committee of the Hospital Universitario Fundación Jimenez Díaz (code:ER1\_EO151\_19).

### Results

A total of 24 participants were interviewed for the study. Twelve (8 women) were the relatives of patients admitted to the inpatient PCU during their last hospital stay, while another twelve (8 women) were relatives of patients admitted to other Non-PCU units (internal medicine ( $n=4$ ), general surgery ( $n=3$ ), geriatrics ( $n=3$ ), others ( $n=2$ ) (Table 2). Relatives were selected randomly in order of recruitment, independently of the patient's diagnosis; all patients were individuals at the end of life.

Two principal themes were identified for analysis: caregivers' experience of the technical appropriateness of care received by their loved ones, and their experience regarding the person-centred care of healthcare staff providing end-of-life care. The first theme included two categories: diagnostic tests and treatment, and symptom control. The second theme (person-centred care) included

**Table 2.** Socio-demographic data.

Group	Participant	Sex	Age	Relationship to patient	Unit	Malignant
PCU	Par1	Woman	49	Daughter	Palliative	No
	Par2	Man	52	Son	Palliative	No
	Par 3	Woman	54	Daughter	Palliative	No
	Par 4	Woman	83	Wife	Palliative Oncology	Yes
	Par 5	Man	54	Son	Palliative	No
	Par 6	Woman	45	Daughter	Palliative	No
	Par 7	Man	58	Husband	Palliative Oncology	Yes
	Par 8	Woman	81	Wife	Palliative	No
	Par 9	Woman	48	Daughter	Palliative	No
	Par 10	Woman	82	Wife	Palliative Oncology	Yes
	Par 11	Woman	53	Daughter	Palliative	No
	Par 12	Man	57	Son	Palliative	No
Non-PCU	Par1	Woman	46	Daughter	General surgery	No
	Par 2	Man	61	Son	Internal medicine	No
	Par 3	Woman	54	Daughter	Oncological surgery	Yes
	Par 4	Woman	51	Daughter	Neurology	No
	Par 5	Woman	80	Wife	Internal medicine	No
	Par 6	Woman	43	Daughter	Geriatrics	No
	Par 7	Man	53	Son	Geriatrics	No
	Par 8	Woman	78	Wife	Pulmonology (Lung Cancer)	Yes
	Par 9	Woman	44	Daughter	Geriatrics	No
	Par 10	Man	55	Son	Oncological Surgery	Yes
	Par 11	Woman	60	Daughter	Internal medicine	No
	Par12	Man	54	Son	Internal medicine	No

PCU: Inpatient Palliative Care Unit; Non-PCU: Other Inpatient Units.

three categories: communication, emotional support, and facilitating the farewell process. The results are illustrated by excerpts from participants' narratives (Table 3).

### Theme 1. Technical appropriateness of care

Our participants defined technical and scientific appropriateness of care as the correct use of diagnostic tests, invasive techniques, and treatments, as well as achieving control of symptoms. Different perceptions of care were described by participants from the PCU and Non-PCU groups.

#### Diagnostic tests and treatment: relatives' perception of therapeutic and diagnostic appropriateness

Caregivers from the two groups had different perspectives on the diagnostic tests and treatment which their loved ones received during their last hospital stay. On one hand, family members from the PCU group did not report under-testing and were comfortable with the diagnostic and therapeutic procedures ordered for their family members during admission:

All the tests were appropriate, the doctor came and explained everything. (Par5, PCU)

Also, they believed that the medication prescribed was well-adjusted to the end-of-life situation:

It wasn't too much medication; they did what they had to. It wasn't too much. (Par1, PCU)

On the other hand, relatives of patients admitted to other units viewed the tests and treatments prescribed during admission as detrimental to their family member's comfort. This was a recurrent theme in many of the Non-PCU group participants, who reported suffering not only the loss of a loved one, but also suboptimal symptom control. PCU group participants did not report suffering due to lack of symptom control, probably due to the fact that PCU specialists are used to controlling common symptoms at the end of life such as pain, delirium, and dyspnea:

They ordered a lot of blood tests and didn't tell us the results, (our family member) had swollen arms. It was a burden to force him to swallow the medication. (Par12, Non-PCU).

**Table 3.** Excerpts from participants' narratives.

Theme	Category	PCU Group	Non-PCU Group
Technical appropriateness of Care	Diagnostic tests and treatment	"It wasn't too much medication; they did what they had to. It wasn't too much." (Par1, PCU) "All the tests were appropriate, the doctor came and explained everything to us." (Par5, PCU)	"Loads of pills, I don't know what they were for, and lots of intravenous medication, I'm not sure if they were antibiotics or painkillers." (Par7, Non-PCU) "I didn't know what the medication was for; he lost the intravenous line and they placed another one, and he had a dreadful time." (Par7, Non-PCU) "They ordered lots of blood tests and didn't tell us the results, his arms were purple and swollen" (Par12, Non-PCU)
	Symptom control	"Yes, despite her condition, they certainly controlled her symptoms." (Par2, PCU) "...well-controlled symptoms with medication." (Par9, PCU)	"They had told us that he was going to be calm, and he didn't seem calm." (Par6, Non-PCU) "When he was suffocating, no-one came to help." (Par6, Non-PCU)
Person-centred care	Communication	"I understood what was happening perfectly, but at the same time, they told us very gently." (Par10, PCU) "They informed us using normal language. My father and I understood it all very well." (Par6, PCU) "It was easily understood... we didn't need any more information." (Par9, PCU) "They told us everything sensitively." (Par11, PCU)	"They told us that his condition was serious, but nobody told us that he could pass away at any moment, and (when the patient died) we were shocked." (Par4, Non-PCU) "A doctor came and left the room after two minutes, without informing us. Sometimes they came with informed consent forms, and we had to ask them to explain." (Par6, Non-PCU) "If we had known that it was the last admission... it would have been different. We thought that he was going to be discharged." (Par7, Non-PCU) "And when we asked questions, it seemed that we were annoying them." (Par11, Non-PCU) "The doctor informed us in the hallway and didn't give us time to ask any questions." (Par12, Non-PCU)
	Emotional support	"Their attention was excellent, we talked with them as if they were friends. I could talk to them whenever I wanted to." (Par7, PCU)	"No, no one looked after us, but we would have liked them to do so, and we would have liked them to keep us better informed." (Par4, Non-PCU) "They came to see him, not us." (Par6, Non-PCU)
	Facilitating the farewell process	"They informed us all, so that we could say goodbye to her." (Par2, PCU) "Yes, yes, of course, we knew that it was the last admission, they told us clearly and we made use of that to say goodbye." (Par11, PCU)	"We didn't get the chance to say goodbye, it seemed that we annoyed the professionals and so we stopped asking questions." (Par1, Non-PCU) "They never told us that it could be the last hospital admission. We would have liked to have some last words, to give other family members the chance to visit, we weren't able to say goodbye." (Par12, Non-PCU)

PCU: Inpatient Palliative Care Unit; Non-PCU: Other Inpatient Units.

...His arms were swollen, the intravenous catheters fell out, he was in a lot of pain. (Par4, Non-PCU)

...a load of tablets, I have no idea what they were for, and a load of intravenous medication, I don't know if they were antibiotics or pain medication (Par7, Non-PCU)

### ***Symptom control: relatives' perception of patient comfort and healthcare professionals' attention to symptoms at the end of life***

The caregivers of terminally ill patients perceive symptom control as an essential part of care. Relatives of Non-PCU patients complained of not understanding why their family members had to take substantial amounts of medication which did not contribute to keeping them comfortable and calm. The most common symptoms that relatives report included dyspnea, agitation, and pain:

They told us that he was going to be calm, but he didn't seem calm. (Par6, Non-PCU)

When he was suffocating, no-one came to help. (Par6, Non-PCU)

He had a hard week, we all had a hard time. (Par7, Non-PCU)

Forcing her to take medication was a pain. (Par12, Non-PCU)

On the other hand, participants whose family members were admitted to the PCU perceived adequate symptom control with the medication prescribed and reported feeling that the medication helped to ensure their loved one's comfort:

Yes, with the medication everything was fine again. (Par5, PCU)

Totally, well controlled, she didn't complain at all. (Par6, PCU)

... a lot better controlled than at home and during other admissions. (Par11, PCU)

...well-controlled symptoms with medication. (Par9, PCU)

### ***Theme 2. Perception of person-centred care***

Our participants underlined the importance of person-centred care. Caregivers included in this study defined an excellent healthcare professional as one able to communicate effectively, offer support to relatives, provide accurate information, answer questions, and help family caregivers with the farewell process.

In the results reported by Non-PCU relatives, it is sad to observe how families have suffered because of the lack of communication with the healthcare team. This suffering, which adds to the pain of losing a loved one, could have been avoided through effective communication.

### ***Communication about the end-of-life context and planning***

From the participants' perspective, effective communication was seen as an essential way of facilitating patient collaboration and providing support and understanding. Relatives of PCU patients commented that the healthcare professionals helped them to understand what was going on and provided accurate information in a realistic yet empathetic manner:

They informed us using normal language. My father and I understood it all very well. (Par6, PCU)

I have no complaints whatsoever. And neither would she, she was very happy with the way she was treated. (Par7, PCU).

It was easily understood... we didn't need any more information. (Par9, PCU)

I understood what was happening perfectly, but at the same time, they told us very gently. (Par10, PCU)

They told us everything sensitively. (Par11, PCU)

Very well informed, all the time, almost from the moment we were admitted we knew it was the last admission. (Par 12, PCU)

However, caregivers of Non-PCU patients reported that they were not given enough information about their loved one's situation. They perceived that they were given little time to communicate with healthcare professionals, and at times, they were made to sign informed consent forms without understanding the nature or necessity of the procedure to be performed. Non-PCU patients' caregivers did not understand changes made to treatment orders, and upon being informed that their loved one's clinical situation was deteriorating, they reported feeling 'perplexed' and 'shocked', and unprepared for the patient's death.:

They told us that his condition was serious, but nobody told us that he could pass away at any moment, and (when the patient died) we were shocked. (Par4, Non-PCU)

A doctor came and left the room after two minutes, without informing us. Sometimes they came with informed consent forms, and we had to ask them to explain. (Par6, Non-PCU)

If we had known that it was the last admission... it would have been different. We thought that he was going to be discharged. (Par7, Non-PCU)

They did not transmit information, such as blood test results, properly; we didn't understand the results, or why they needed so many machines, and they could have explained things better... (Par8, Non-PCU)

And when we asked questions, it seemed that we were annoying them. (Par11, Non-PCU))

They never told us that it could be the last hospital admission. We would have liked to have a conversation with him and brought some other family members to see him. (Par12, Non-PCU)

### **Emotional support**

For participants, effective emotional support from healthcare professionals included being accessible, forging a good relationship with relatives, and being understanding. Non-PCU relatives felt that they were not supported by healthcare professionals; they did not perceive their needs as being attended to, and they were not allowed to participate in the decision-making process:

No, no one looked after us, but we would have like them to do so, and we would have liked them to keep us better informed. (Par4, Non-PCU)

It was obvious that we were a pure procedure. (Par6, Non-PCU)

They came to see him, not us. (Par6, Non-PCU)

They treated us marvelously well, the psychologist, the doctor and the nurses. (Par10, PCU)

On the other hand, the PCU caregivers commented that the professionals gave them emotional support, and that their support also aided their loved ones:

Their attention was excellent, we talked with them as if they were friends. I could talk to them whenever I wanted to. (Par7, PCU)

### **Facilitating the last stage of patients' life**

Participants underlined the need for professionals to facilitate the moment of saying goodbye to their loved ones during the last moments of life.

Relatives whose loved ones were admitted to the PCU narrated how they were continually informed of the situation, were made conscious of the fact that their loved one was experiencing the last moments of life and were aided with the farewell process. They appreciated PCU professionals' advice on respecting patients' last wishes, resolving any pending affairs,

informing family and friends, and giving them the opportunity to say goodbye:

They informed us all, so that we could say goodbye to her. (Par2, PCU)

Yes, yes, of course, we knew that it was the last admission, they told us clearly and we made use of that to say goodbye. (Par11, PCU)

On the other hand, participants from the Non-PCU group commented that they were not given the chance to say goodbye. Relatives complained that they were not informed of the situation, some were made to feel a nuisance, and many were caught unawares and were unable to say goodbye.

We didn't get the chance to say goodbye, it seemed that we annoyed the professionals and so we stopped asking questions. (Par1, Non-PCU)

No, the farewell would have been different if we had known that it was the last admission. We thought that he would make it. (Par7, Non-PCU)

They didn't tell us that he was already dying. They told us that he was seriously ill, but they never told us that he could die at any moment. (Par 11, Non-PCU)

They never told us that it could be the last hospital admission. We would have liked to have some last words, to give other family members the chance to visit, we weren't able to say goodbye. (Par 12, Non-PCU)

## **Discussion**

This study presents a qualitative approach to analyzing relatives' experience of their loved one's last hospital stay, comparing inpatient palliative care units with conventional inpatient units, and focusing on relatives' perceptions of technical appropriateness of care and person-centred care.

The novelty of this study resides in the comparison of PCU and Non-PCU inpatients from the same hospital, instead of comparing patients receiving home-based or hospice care. Another original aspect of our research is the inclusion of patients from any end-of-life situation, without limiting our research solely to oncological or older patients.

Since Temel's groundbreaking study [41], research has demonstrated that palliative care is the gold standard of clinical care for patients with advanced illness, proving efficient for both oncologic and non-oncologic patients [42, 43]. The Centers for Medicare and Medicaid Services define palliative care as patient and family-centered care that optimizes appropriateness of life by anticipating, preventing, and treating suffering



[44]. Throughout the continuum of illness, palliative care involves addressing physical, intellectual, emotional, social, and spiritual needs, facilitating patient autonomy, access to information, and choice [45]. This study describes the contrasts experienced by family caregivers during their loved one's last hospital admission, depending on whether they were admitted to a PCU or a conventional inpatient unit. Caregivers of PCU patients perceived their experience as positive, whereas those of Non-PCU patients reported inadequate symptom control, lack of communication with healthcare professionals, and the impossibility of saying goodbye to their loved ones.

Appropriate treatment at the end of life can be defined as tailoring treatment to the clinical situation, which implies withdrawal of medication when no response to specific treatment is expected. An effective communication strategy is vital to adjust end-of-life treatment to the individual patient's wishes and needs. Studies have shown that patients receiving palliative care present improved quality of life and a lower risk of developing depressive symptoms [46, 47]; they also use fewer healthcare resources, giving rise to lower overall expenses [48]. As described in the methodology section, this qualitative study forms part of a cost-benefit study, in which we demonstrated that palliative care was associated with lower rates of iatrogenic events, fewer test orders, and fewer prescriptions, while ensuring optimal clinical and symptomatic control [49]. Participants interviewed in this study not only perceived excellent overall care from palliative care units, but also appropriateness of treatment with regards to their loved one's situation.

Engaging patients and their families through shared decision making is the cornerstone of effective patient care. Communication skills are required to coordinate care for the complex needs of patients with advanced chronic illness and are key to improving quality of life as well as patient and family satisfaction. Numerous studies on end-of-life patients and their families show that improved communication is clearly related to enhanced patient and family satisfaction with care [42, 50, 51]. Truthful, effective communication that permits shared decision-making is one of the factors that has proven to facilitate care at the end-of-life, both for patients and their families.

[2] We have observed that in all the interviews carried out for this study, communication is key for relatives to feel secure. Although a patient's clinical condition may be serious, families who are given time to talk with the care team, ask questions and understand explanations feel much calmer and report better experiences regarding care and healthcare professionals.

Family caregivers interviewed in this study described how clear explanations from the palliative care team helped them to understand their loved one's situation better and described the sensitivity with which PCU professionals communicated bad news as satisfactory and positive; this contrasts with the state of shock experienced by relatives from the Non-PCU group when transitioning from expectations of recovery to imminent death, pointing to a clear need for improved communication between patients, families, and providers.

Studies show that communication becomes increasingly difficult in the context of terminal disease, which inevitably entails conversations about dying and death. End-of-life conversations are often avoided due to fears of stirring up emotional distress and the perceived need to keep hope alive through engaging in positive conversations [52–54]. However, the absence of end-of-life communication has been shown to affect the bereavement process negatively and lead to pathological mourning [55], while – paradoxically – death-talk is associated with acceptance of death and relationship quality. According to Wanget al. [56], death-talk leads to a psychological state of death awareness and death acceptance for both patients and caregivers. Our study shows that relatives experienced being given the chance to prepare themselves for their loved ones' death as an aid to understanding and accepting the situation which facilitated the farewell process.

The World Health Organization (WHO) has defined the need for palliative care as a specialty to ensure quality of care during the course of advanced illness, recommending early referral to a PCU specialist [12]. However, our research points to the need for all healthcare professionals to receive specific formation in palliative care and communication, so as to improve end-of-life experience of patients and their relatives in Non-PCU wards. The communication skills necessary for delivering bad news and leading a goals-of-care meeting with the patient's family should be taught at all levels of medical education [57–59]. Periodic clinical rotations for residents and staff could be proposed to enable communication training in end-of-life situations which are frequent in many specialties.

## Limitations

The principal limitation of our research was the impossibility of recruiting the patients themselves, due to the study's design. Second, the study included a limited number of participants in each group. Due to the qualitative nature of this study, our main objective was to describe participants' experiences, and our findings cannot be generalized. In the present study all

members work in the same study context, Infanta Elena University Hospital, and one (MHA) had been directly involved in the care of patients whose relatives were interviewed. MHA had direct contact with the patients assigned to the PCU unit. This could influence the data collection. To resolve this, during the data collection, LMGM conducted the interviews of the CPU unit group, and MHA conducted the interviews of the Non-PCU group of patients. There is a need for studies to achieve better understanding of the elements required within an inpatient context to facilitate optimal evidence-based palliative care. Incorporating the perspective of professionals who provide palliative care without belonging to a PCU is a future line of investigation that should be explored.

## Conclusions

Our results demonstrate that family caregivers of patients admitted to a PCU at the end of life perceived high scientific and technical appropriateness of care and healthcare person-centred care which facilitated the farewell process, in contrast with caregivers of patients admitted to a Non-PCU.

This study allows us to perform an analysis of various aspects of quality in care surrounding the end-of-life. This should encourage hospital managers to reflect on the importance of complete palliative care teams for acute care hospitals, in order to meet the needs of patients and their families both in the PCU unit and in other clinical departments. The lack of communication skills reported by members of the Non-PCU group points to a need for further studies on barriers for effective communication in Non-PCU specialties and how to overcome them. Finally, continuous formation at both pre and post-graduate levels is important to train physicians to provide quality care for patients and their relatives at the end-of life.

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## Authors' contributions

MHA, DPCU, CAR and ANT contributed to the conception of the manuscript and the design of the qualitative study. MHA and LMR participated in the data collection. MHA, RCV, DPCU

and ANT contributed to the qualitative analysis and the revision of the manuscript. All authors contributed to the article and approved the submitted version.



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## Data availability statement

The data that support the findings of the study are available on request from the corresponding author, upon reasonable request. The data are not public due to ethics restrictions.

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