

PALLIATIVE CARE AS END-OF-LIFE PATIENT CENTERED MODEL

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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 provides the most appropriate model of patient-centered care for individuals at the end of life, equipping professionals with the knowledge and abilities necessary to offer holistic support not only to patients, but also to their relatives and caregivers (2,3). Understanding patient and caregiver experience is key to providing patient-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 objective of this qualitative study is to describe caregivers' experience of care during their loved ones' last hospital admission, contrasting the inpatient palliative care unit experience with that of conventional 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

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. Data were collected via semi-structured, based on an end-of-life Palliative Care clinical approach. Then a thematic analysis was performed.

Table 1. Interview

Areas	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	What was your experience of symptom control? Was medication used to control symptoms?
Attention	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?

Results

Data were collected collected from 24 participants (12 from the palliative care unit group, and 12 from the non-palliative care unit group).

Two principal themes were identified for analysis: **caregivers' experience of the technical quality of care received by their loved ones, and their experience regarding the professional excellence of healthcare staff providing end-of-life care.** The first theme included two categories: (1) diagnostic tests and treatment, and (2) symptom control. The second theme (professional excellence) included three categories: (1) communication, (2) emotional support, and (3) facilitating the farewell process. The results are illustrated by excerpts from participants' narratives

Table 2. Excerpts from participants' narratives

Theme	Category	PCU Group	Non-PCU Group
DIAGNOSTIC AND THERAPEUTIC QUALITY	MEDICATION AND TESTS	"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)
PROFESSIONAL EXCELLENCE	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 that was the last admission... it would have been different. We thought that he was going to be discharged." (Par7, Non-PCU) "The doctor informed us in the hallway and didn't give us time to ask any questions." (Par12, Non-PCU) "We asked questions and it seem as if that annoyed (the professionals)." (Par11, Non-PCU)
		EMOTIONAL SUPPORT	"Their attention was excellent, we talked with them as if they were friends. We could talk with them at any time." (Par7, PCU) "No, no-one took us into account, but we would have liked to have been taken into account and 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)

Discussion

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 adjusted-of-life treatment to the individual patient's wishes and needs (4). **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 (5,6). **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.**

The absence of end-of-life communication has been shown to affect the bereavement process negatively and lead to pathological mourning (7), while – paradoxically – death-talk is associated with acceptance of death and relationship quality. According to Wang *et al* (8), 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.**

References

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