



## Promoting dignified end-of-life care in the emergency department: A qualitative study



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### ABSTRACT

**Background:** Preservation of a dying person's dignity in the emergency department (ED) is fundamental for the patient, his/her relatives and healthcare professionals. The aim of this study was to explore and interpret physicians' and nurses' experiences regarding conservation of dignity in end-of-life care in dying patients in the ED.

**Methods:** A qualitative study based on the hermeneutic phenomenological approach, was carried out in the emergency department of two general hospitals. A total of 16 nurses and 10 physicians participated in the study. Data collection included 12 individual in-depth interviews and 2 focus groups.

**Results:** The findings revealed that two themes represent the practices and proposals for the conservation of dignity in the emergency department: dignified care in hostile surroundings and the design of a system focused on the person's dignity.

**Conclusion:** Dignifying treatment, redesigning environmental conditions, and reorienting the healthcare system can contribute to maintaining dignity in end-of-life care in the ED.

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## 1. Background

A human being's dignity lies in the autonomy of a rational being capable of giving him/herself rules of action. For Immanuel Kant [1], this implies recognizing an internal value that makes one susceptible to treat him/herself, and all human beings, as an end and not as the means. The respect towards the dignity of human life is also extended to the process of death, modifying the clinical relationship [2]. The hospitalization of a dying person in the Emergency Department (ED) has implications for maintaining his/her dignity, which can be a challenge for healthcare professionals [3,4]. In light of technological developments, the ED focuses on healing and maintaining life but this care framework is changing with regard to the dying patient [5]. Virginia Henderson has

already stated that the nurse contributes to the patient's health or recovery, or to a dignified death [6]. Concepts such as quality of life [7], the economic cost of the end-of-life care [8,9], or public awareness of matters relating to death [4], are modifying the care of these patients so, with a focus on saving lives, the ED must now also provide end-of-life care [10].

Our framework is supported by H.M. Chochinov's model of dignity preservation [11]. The model establishes three categories which define the problem of conserving dignity: 1) Illness-related concerns, 2) Dignity conserving repertoire, 3) Social dignity inventory [12]. Adapted to end-of-life care [13] it covers individuals' physical, psychological, social, existential and spiritual concerns [14]. Caring for dying patients is part of physicians' and nurses' daily work in the ED, who equipped with the latest technology to save lives, must also redirect their attention towards end-of-life care [15]. Clinical factors inability to recognize imminent death [16], lack of good-quality palliative care [17] or the overburden of the caregiver [18], can lead to the terminally-ill patient being admitted to the ED. As the access gate to in-hospital care, the ED is not designed for providing palliative care or looking after a dying

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person [19,20]. A dying person's dignity implies treating him/her as an end in itself [21], recognizing his/her value as a person, as well as his/her self-esteem and autonomy [22]. Currently, there is a mounting body of evidence to guide palliative and end-of-life care in the ED [23,24]. However, communication problems [25], loneliness, exposure to cold surroundings, and medical or family obstinacy continue to represent a constant threat to the dying person's loss of dignity in the ED [22]. In a technological environment, patients, family members and professionals face palliative sedation, futility of treatment [7] and the physician orders for life-sustaining treatment (POLST) [26,27]. The preservation of a dying person's dignity in the ED is fundamental for the patient, his/her relatives and healthcare professionals [28]. Understanding physicians' and nurses' point of view is key in preserving the dignity of a terminally-ill patient in the ED.

### 1.1. Aim

The aim of this study was to explore and interpret physicians' and nurses' experiences regarding conservation of dignity in end-of-life care in dying patients in the ED.

## 2. Methods

### 2.1. Study design

This study used a qualitative focus based on Gadamer's hermeneutic phenomenological approach. The study took place in two southeastern Spanish hospitals. The total population was comprised of 205 individuals working in both EDs – of whom 98 were nurses, 31 were physicians and 71 were physicians in training.

### 2.2. Participants

The participants met the following inclusion criteria: to be a physician or a registered nurse, have a minimum of two years' experience working in the ED and give consent for participation. The exclusion criterion was having suffered a personal loss within a year before starting the study.

### 2.3. Data collection

The data collection took place between October 2013 and June 2014. After receiving the approval from the ethical committee, two focus groups (FG) were carried out. The two FGs were respectively comprised of 6 physicians and 8 nurses, and lasted 45–57 min. For greater convenience, the FGs took place in a room adjacent to the ED. Furthermore, 8 nurses and 4 physicians from the ED who hadn't participated in the FGs took part in in-depth face-to-face interviews (lasting between 60 and 90 min). The interviewer was a member of the research team and worked as a nurse in the ED. An interview guide was used for both the FGs and the interviews (Table 1). The interviews were carried out in Spanish.

### 2.4. Ethical considerations

This research was approved by the Research Centre Ethical Committee (Andalusian Health Service, reference number 04/06/12). The participants received an Information Sheet to explain the nature of the study, the voluntary nature of their participation and the guarantee of confidentiality and anonymity, and signed an informed consent.

**Table 1**  
Interview guide.

Stage of interview	Subject	Content/Example questions
Introduction	Motives	The belief that their experience offers information which should be known to everyone.
	Aims	To carry out research in order to make the lived experience known.
Start	General introductory question	'If you don't mind, we'll start with you telling me about your experience of dignity in end-of-life care in the Emergency Department.'
Development	Guide for conversation	'When do you feel your patients conserve their dignity in end-of-life care?' 'What do you think about dignity in end-of-life care in the Emergency Department?'
Finish	Final question	'Is there anything else you would like to say on the subject?'
	Thanks	Thank them for taking the time to talk to us.

### 2.5. Data analysis

All the FGs and in-depth interviews were audio-recorded with consent. The audio-recordings were transcribed and analyzed. After completing the analysis, the participants' quotes were translated following a forward-backward procedure. Firstly, an independent native Spanish translator (proficient in English) translated the participants' quotes from Spanish to English. Secondly, an independent native English translator (proficient in Spanish) translated the English version of the participants' quotes back to Spanish. Thirdly, both translators and the researchers reviewed the English translation, the Spanish backward translation and the original version of the participants' quotes. It was agreed that the English version of the participants' quotes presented in this manuscript respected the original meanings. The analysis of the FGs and interviews was performed by using a modified form of the stages developed by Valerie Fleming [29]: (1) to decide if the research question was pertinent according to methodological assumptions; (2) to identify the researchers' pre-understanding of the study subject (reflexivity) – In this study, the researchers' pre-understanding was derived from their clinical experience in the ED and critical care, and their teaching and research experience in end-of-life care; (3) to gain an understanding through dialogue with the participants via the text, the coding was performed by three members of the research team; (4) to establish reliability – the researchers have tried to be faithful to the text and the context. The final list of themes, subthemes and units of meaning was subsequently confirmed by the participants. Computer-assisted qualitative data analysis software (ATLAS.ti version 7.0) was used to analyze the data.

## 3. Results

The final sample comprised 26 participants with an average age of 38.12 years old and an average experience of 14.3 years in looking after patients in the ED. The sociodemographic characteristics of the sample can be seen in Table 2. From the analysis, 150 open codes emerged and 203 quotes were selected. After an interpretation process, these codes were reduced to 12 units of meaning grouped into four subthemes and two main themes (Table 3).

### 3.1. Theme 1. Dignified care in unfavorable surroundings

The participants reported pro-active efforts in the search of dignity preservation in an unfavorable environment. Those efforts were directed to both making the act of providing care an element of dignity preservation, and minimizing the effects of the

**Table 2**  
Socio-demographic data of the participants.

	Sex		Profession		Age (years)		Experience (years)	
	Male	Female	Physician	Nurse	Range	Average	Range	Average
In-depth Interview (n = 12)	5	7	4	8	30–49	40	3–26	14.3
Focus Groups Physicians (n = 6)	1	5	6	–	33–54	41.8	7–28	15.3
Focus Groups Nurses (n = 8)	3	5	–	8	28–48	38.1	6–25	15.3
Total participants (n = 26)	9	17	10	16	28–54		3–28	

**Table 3**  
Themes, sub-themes and units of meaning.

Theme	Sub-theme	Units of meaning
Practices: Dignified care in unfavorable surroundings (hostile)	Dignity as a way of providing care	Provide spiritual solace Take care of the interpersonal relationship Caring with pleasure
	Interventions in the environment	Limit stays in the ED Safeguard intimacy Facilitate support
Proposals: The design of a system focused on the person's dignity	Dignifying the surroundings	Question futile measures Redesign training (of professionals)
	Redesign the conditions	Redesign the physical space of the ED Redesign paths, healthcare protocols and patient referral (in the ED)
	Reorienting the aim of healthcare provision	Reorient the aim of healthcare Ongoing at-home care

environment on the loss of dignity by dignifying the care surroundings themselves.

### 3.1.1. Subtheme 1. Dignity as a way of providing care

The participants declared that dignity can be understood as a way of caring that encompasses emotional, spiritual and even religious aspects of the patients and their families.

“...sometimes it is not about clarifying concerns, but about taking their hand and listening to them instead, and, of course, giving them privacy to be with their family members” (N-5)

The physicians expressed similar ideas, recognizing that sometimes comfort and companionship takes priority over therapeutic measures. For example, one of the physicians said:

“To be with and comfort them when I have nothing more to offer them”. (P-1)

The participants indicated that, in order to maintain dignity, they try “to take care of the interpersonal relationship”. This is achieved through maintaining an empathetic attitude, facilitating a dialogue about all topics (including death) between patients and family members. To maintain that attitude, healthcare professionals need to make an effort as they face painful situations which are difficult to handle.

“There is something basic and that is talking to the person, establishing an interpersonal relationship, eye-contact when speaking, physical contact (touching his/her hand for example), trying to have an empathetic attitude. The problem is that empathy hurts in those situations”. (N-2)

The patients can feel when they are a burden on their formal or informal caregivers, which can weaken their sense of dignity. To counteract that feeling of burden, the nurse can show the patient that what for him/her seems to be a burden, for the nurses, is part of their job.

“When they feel distress because of needing someone else to meet their needs, (hygiene, eating, etc.), I listen to them and I try to explain that in the hospital that is not a problem, it is part of our day-to-day routines, and we do it gladly”. (N-2)

### 3.2. Subtheme 2. Dignifying the surroundings

The physicians and nurses in EDs informed us that they adapt the surroundings to prevent loss of dignity at the end of life. The first of those interventions can be softening the lighting or moving them to a quieter more private space.

“It is important to avoid keeping them in a jammed place where they not only feel they're dying, but also dying in a noisy and dehumanized environment”. (P-3)

They also alluded to measures to safeguard patients' privacy and facilitate family members and loved ones to be with them. The nurses indicated that one way of preserving dignity in terminally-ill patients in the ED is to question futile measures and discuss them with the physicians in the case that they are prescribed. For example, questioning the carrying out of diagnostic tests or invasive interventions.

“I try to safeguard the intimacy of the patients as I carry out my work as a caregiver I question physicians' orders that go against measures of comfort taken to dignify death”. (N-4)

In this regard, according to the trajectories theory [30], the physicians admitted that at times they prescribe futile measures; they recognize that decision-making is not always easy, since they interpret that if the patient or the family goes to the ED, it is to request interventions. The personal trajectories of family members, physicians and nurses do not always coincide, thus having to be dealt with and managed by all involved:

“Sometimes we do not know where the limit is between trying to save a life or palliating the symptoms. Neither the family nor the patient are sure about it. Some of them ask you to do something. Or they contradict each other, two family members for example”. (P-FG)

### 3.3. Theme 2. The design of a system focused on the person's dignity

This theme refers to structural changes, which concern both the physical design and the mission and vision of healthcare settings and the healthcare system itself. The individual efforts that were analyzed in the previous theme may serve to palliate the situation, but are not enough to ensure the provision of dignified care at the end of life in the ED. One nurse summarized the extent of the necessary changes below:

“My service needs “A RESET”, it needs more responsible professionals and managers, it needs physical facilities (comfortable space to spend the last hours with a family member), it needs a legal framework to protect you”. (N-4)

### 3.3.1. Subtheme 1. Redesigning the conditions

In this subtheme we refer to the participants' proposals to redesign numerous aspects of care in the ED. Firstly, participants demanded training for all the professionals in the hospital, specifically for those in the ED. According to our participants, this training should focus on topics like 'advanced directives' and 'death', including the capacity to think of their own death as, this way, healthcare professionals will better understand others.

"I think that one cannot cope with someone else's death without first accepting and understanding one's own [death]". (P-2)

Secondly, the participants proposed changing the design of the physical space, adapting or creating a specific place in the ED for the terminally-ill patient care, with the adequate conditions to guarantee intimacy and support.

"A type of unit for short-term or long-term stays, a specific area, worthy and prepared given that we are increasingly receiving patients of this kind". (P-FG)

Thirdly, in order to guarantee greater comfort, provide rapid solutions to conflicts that may arise and avoid improvisation, the participants demanded protocols of action and referral pathways for the correct management of the of terminally-ill patients in the ED (Table 4).

### 3.3.2. Subtheme 2. Reorienting the aim of healthcare provision

Together with the aforementioned changes to space and procedures, the participants stated that a reorientation of the aims of healthcare provision is required when caring for terminally-ill patients who go to the ED to die. That reorientation should limit the therapeutic efforts, redirecting them towards comfort instead of towards treatment.

"Nursing care should be aimed towards the comfort of the patient and the family support and of course in all cases ensure and facilitate family members to be with the patients". (N-3)

The participants also proposed dedicating more time to patients and maximizing personal attention to make it more human. For instance, prioritizing emotional, affective and well-being needs over a mild pathology.

"We can dedicate more time to them, prioritizing comfort in the final hours of their life, instead of attending to the semi banal pathology that brought them to the ED" (P-1)

## 4. Discussion

This study contributes to understanding the actions and efforts made by physicians and nurses in the ED to preserve individuals'

dignity at the end of their lives. The participants have indicated that the ED is not an appropriate place for dignified end-of-life care. However, influenced by fragmented care, the overburden of the informal caregiver [18] and other clinical, demographic and environmental factors [16], many patients in the terminal phase, often due to acute exacerbation of symptoms, seek care in these departments. In contrast to our participants, some authors note that EDs can improve the quality of life of dying patients, delivering palliative interventions to control the pain and exacerbation of chronic conditions in end-of-life care [20]. The dignity of end-of-life care in the ED can be hindered by architectural and organizational characteristics, healthcare professionals' attitudes and family members' decisions. Our study therefore suggests the convenience of modifying the surroundings to safeguard intimacy and facilitate support as potential contributions to protect individuals' dignity at the end of their lives.

In accordance with our theoretical framework [11], our participants have identified that their way of caring for dying patients is a key element in preserving dignity in the ED. Similarly, other authors have insisted on the physicians' attitudes being paramount to quality of care [11] and on the need to take charge of spiritual matters in end-of-life care [31].

Among the elements that impair individuals' dignity, our theoretical framework highlights their feeling of being a burden on others [11,12]. Our participants fight this negative feeling by 'caring with pleasure', making patients see that the experience of caring for them is a privilege. This corresponds with the study by Marck et al. [32] where most physicians in the ED consider that helping someone to die in conditions of comfort, dignity and respect is one of the most gratifying clinical experiences. Likewise, nurses feel that providing dignifying care could alleviate not only their own distress, but also that of the family and patient [7].

Dignity is influenced by staff attitudes and behaviors, the organizational culture and the physical environment [9]. In our study, nurses and physicians showed concern over the lack of intimacy of dying patients. They proposed expediting patient flow and limiting their stays in the ED given its inadequate environmental conditions. Indeed, the lack of space, time and staff, together with the emotional toll when the resources are insufficient, were also identified as defining characteristics of the ED by Wolf et al. [33]. For the nurses, providing privacy is a key measure in preserving dignity in the ED [28]. Similarly, Komaromy [34] suggested providing trained nurses and quiet areas to attend to family members. To have a greater awareness of the threats to the dignity of a patient in the ED offers the opportunity to improve communication, autonomy and concerns about privacy [35].

The socio-familiar context has been identified as one of the attributes that characterizes end-of-life care in the ED [22]. Palliative care patients often go to the ED because their family members are distressed about their inability to manage end-of-life

**Table 4**  
Units of meaning and quotes of the subtheme Redesigning the conditions.

Units of meaning	Quotes
Redesign training	In my education (...) no one ever touched the subject of my own death, a reality that I surely will not escape, the topic has only been tiptoed around, assuming that "it is always others who die" (N-2) The staff should be trained not only in the technical aspects of care for these patients but they should also understand that it is a fundamental part of their job (P-1)
Redesign care and patient referral pathways and healthcare protocols	The referral pathways to other units such as palliative care or community home support should be improved and also transfers to other wards should be expedited (N-3) A parallel pathway should be established... a system for patients that only need care, privacy, some comfort... (P-3)
Redesigning the physical space	There should be a large isolated room, with access to human resources (psychologist, physician, nurse...) and adequate equipment (armchairs for family members...), even music that the patient likes, even if it seems utopian (N-5) To have spaces at your disposal to talk with the family before the death and where they can be afterwards a few minutes, in the first moments of mourning (P-1)

symptoms [10]. Facilitating support [36] and looking after the family in the process of death in the ED facilitates the appropriate expression of mourning, avoids depression and reduces the risk of suffering other health-related problems following the death of a loved one [10]. This matches other studies in which healthcare professionals identify the dying patient's family as the focus of care, especially after the mourning [37].

The nurses in our study informed us that sometimes they question diagnostic and therapeutic measures that they consider futile and they challenge the physicians about it. Nursing care faces futility when the medical treatment to avoid death continues beyond the limits that are considered acceptable [33]. The physicians, on the other hand, are concerned because many factors are involved in the decision-making process and this responsibility leads them to feel alone and pressured on numerous fronts. This conflict in the decision-making process about the limitations of therapeutic efforts is very common in other studies about end-of-life care [4,38]. Meanwhile, futile treatment sometimes persists in the ED because the therapeutic limitations are not always clearly documented or discussed with the patient or his/her family [32]. Furthermore, other authors have indicated that the social value of the treatments can be just as important in the evaluation of its usefulness as biomedical criteria. Teamwork [39] and the involvement of all the professionals, the patient and the immediate family in the decision-making process about the limitations of therapeutic efforts would help to minimize these tensions [2].

The need to reorient training for healthcare professionals is included among conditions for the conservation of dignity in the ED. In other studies, physicians and nurses in the ED have expressed the need for specialized training [10,26,40] for example, to know when to move on from a healing treatment to palliative care [3], how to effectively implement physician orders for life-sustaining treatment [26] or how to relieve pain and distress by administering opioids and other medication (e.g. IV paracetamol, anti-emetics, muscle relaxants etc.) [40]. In line with other studies [37], the participants believe that this training should reach all healthcare professionals—not only those who work in the ED, and it should include appropriate facilitating resources to face their own feelings with regard to death and dying [31].

Another topic that emerged from our study and is supported by a wide consensus in the consulted literature *concerns redesigning the physical space of the ED*. The proposed reforms range from offering comfortable rooms to dying patients and distressed relatives rooms to their families [28] to integrating palliative care services in the ED environment [15,23].

Our participants insisted on the need to *redesign care and referral pathways and protocols in the ED*. Therefore, it has been demanded that assessment tools are provided to facilitate an appropriate transition from active treatment to palliative care in the ED [3] and that ED professionals are familiarized with the referral criteria and the palliative care system [41]. Having clear procedures at hand, similar to those that already exist for the management of acute illnesses, which create a 'Comfort Code', could be of great use for medical decision-making. Other authors propose establishing alternative pathways in which patients can directly access palliative care units from their own homes [42] or establishing a warning system whereby the palliative care nurse could go with the ambulance and manage the situation in the patient's home.

Among the most far-reaching proposals that our participants made was to *reorient the healthcare system*. Some studies support the viability and convenience of including palliative care in the ED [36] to improve care provision and patient/family satisfaction, lowering costs and unnecessary hospital admissions [9,43]. Nonetheless, other studies have opposed this measure and opt instead for supporting the healthcare professionals who work in

elderly and primary care. This aims at improving the benefits of palliative care and advanced care planning [4], increasing staffing numbers [28], and changing the professional roles of nurses and primary care physicians to promote complete and ongoing care to patients [19]. Concurring with authors who demanded the implementation of a specific action plan that includes home support [42], our participants also proposed improving the outpatient care process. However, this can be a difficult challenge to overcome in the case of terminally-ill patients who live alone without a primary caregiver.

*Implications for future research:* This study considers the perspective of nurses and physicians in the ED. Interviewing patients and family members would be a further line of research which could produce complementary results.

#### 4.1. Limitations

The data were collected over a limited period of time, prolonging the data collection for a longer period or for successive sets of time could have offered a more complete vision of the phenomenon studied. Our study took place in public hospitals but including professionals from the private care sector could have produced different results mainly due to the fact that there is a lower demand for care in the EDs in said sector. Exploring differences in ideas/concepts depending on gender could also have enhanced the interpretation of our results.

## 5. Conclusions

The ED is not designed for end-of-life care provision, which may have negative effects on the dying patient's dignity. Among the practices that ED professionals can adopt to minimize these effects are: 1) to care for dying patients with a particular sensitivity and attention to emotional matters, and 2) to take small measures to dignify the surroundings or limit the stay in an environment that is not appropriate for that moment. More far-reaching proposals include redesigning training conditions, physical spaces and healthcare protocols, and reorienting the ED towards palliative care at the same time that outpatient care and mechanisms for accessing palliative care services are reinforced.

#### Declaration of conflicting interests

The Authors declares that there is no conflict of interest.

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#### Conflict interests

The Authors declares that there is no conflict of interest.

#### Ethical statement

This research was approved by Institutional Research Ethics Committee. The participants were all informed about the study and signed an informed consent.

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