








ORIGINAL RESEARCH:
EMPIRICAL RESEARCH - QUALITATIVE

Patients' experiences and perceptions of dignity in end-of-life care in emergency departments: A qualitative study

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Funding information

Ministerio de Asuntos Económicos y Transformación Digital, Gobierno de España, Grant/Award Number: FFI2016-76927-P

Abstract

Aims: To explore and understand the experiences of patients with advanced illness in relation to dignity during end-of-life care in emergency departments.

Design: Qualitative study based on Gadamer's hermeneutics.

Methods: Between September 2019 and February 2020, 16 in-depth interviews were carried out with advanced illness patients who attended emergency departments. The participants were informed priorly and signed informed consent. The data were analysed using an inductive strategy for finding emerging themes. The Consolidated Criteria for Reporting Qualitative Research was used for writing the study's report.

Results: In the data analysis process, two main themes emerged that glean the experiences of patients in relation to dignity during end-of-life care in emergency departments. 'Dignity as an individual's attribute' and 'Acting with dignity: Dignity as a behavioural attribute'.

Conclusion: Patient dignity in end-of-life care is centred around the principle of control (of oneself, one's death and one's emotions). The strategies required for patients to preserve their dignity can be somewhat incompatible with the dynamics and objectives of healthcare professionals who work in emergency departments.

Impact statement: The dignity of patients with advanced illness who attend emergency departments is a relevant issue that merits being addressed from the patients' perspective. Participants have identified that dignity is a way of being and behaving in the face of illness. Emergency departments need to respect end-of-life patients' desires by supporting and accompanying them, avoiding therapeutic obstinacy. We recommend care to be centred on patients' well-being, to respect their autonomy and decision-making processes, and to allow prompt referrals to palliative care services.

Patient or Public Contribution: Managers from the Emergency Departments participated in the study design and patients' recruitment. Patients' relatives were informed about the study's aim, and they contributed to the development of the interview protocol.

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KEYWORDS

advanced illness, dignity, emergency departments, end-of-life care, nursing, qualitative research, hermeneutics

1 | INTRODUCTION

Patients with advanced illness (AI) attend the emergency department (ED) relatively frequently. In fact, it is estimated that around 70% of patients with AI go at least once during the last months of their lives (Heymann et al., 2019). High incidences of mortality have been recorded amongst this group of patients in the week following their visit to the ED (Verhoef et al., 2020). The most frequent reasons for attending the ED are pain and dyspnoea, with more than 75% of patients admitted as a consequence (Verhoef et al., 2020). In developed countries, the number of end-of-life patients attending the ED has increased due to the rise in the elderly population (Mierendorf & Gidvani, 2014). The high frequency of attending ED among patients with AI puts them in contact with patients from technological environments that are highly dynamic (Schneider et al., 2019) and depersonalized (O'Shay, 2022). This particular type of contact could make patients with AI who attend ED more aware of their vulnerability (Muñoz-Terrón, 2021). Emergency situations at the end of life are an intense experience (Collier & Broom, 2021), that exacerbate the problems related to these patients' dignity (Rogmark & Lynøe, 2021; Ruíz-Fernández et al., 2021). It is, therefore, vital to address the issue of end-of-life care in ED (Fernández-Sola et al., 2018).

2 | BACKGROUND

Dignity is a key element in end-of-life care (Viftrup et al., 2021). It refers to a good death (Fernández-Sola et al., 2017), autonomy (Rodríguez-Prat et al., 2016) and the fundamental values of quality care towards a person (Pols et al., 2018). The notion of dignity can be summarized in two ways: Dignity as a basic and inherent element of any human being or dignity as a dynamic element that depends on the context and the patient, whose individual autonomy is a key factor (Horn & Kerasidou, 2016; Rodríguez-Prat et al., 2016). However, the concept of dignity at the end-of-life remains a controversial topic as its definition is influenced by cultural (Horn & Kerasidou, 2016), religious, racial and geographical (Frost et al., 2011) factors. These aspects are relevant because different conceptions can lead to different needs amongst patients with AI (Bovero et al., 2020; Horn & Kerasidou, 2016). Even in the same cultural context, perspectives can change depending on the person involved (Bovero et al., 2020). In fact, healthcare professionals themselves differ in their understanding of patient dignity, including physical, psychological, social and spiritual aspects (Bovero et al., 2020). From the patient's point of view, aspects such as control, identity and autonomy are determining factors in safeguarding dignity (Rodríguez-Prat et al., 2016). The end-of-life process can be seen differently with varying nuances

depending on the service the patient is provided or the type of pathology they have (O'Sullivan et al., 2021). For example, the experience of a family caregiver could be more positive when a cancer patient is attended to in hospital, whereas for a family member of a patient who does not have cancer, they might prefer to be attended to at home (Martí-García et al., 2020).

Chochinov's (2004) model of dignity-conserving care divides the phenomenon of dignity into three categories: illness-related concerns, the patient's dignity-conserving repertoire (preserving one's individual role, leaving a legacy, self-esteem, hope, autonomy, acceptance and resilience) and social dignity inventory (social factors that increase or decrease the the person's sense of dignity). The phenomenon of dignity in ED has been explored from professionals' point of view, (Alqahtani & Mitchell, 2019; Díaz-Cortés et al., 2018), identifying socio-environmental factors that contribute to the perception of loss of dignity (Fernández-Sola et al., 2017). However, there is a lack of research about how patients with AI who attend ED perceive their own dignity (Granero-Molina et al., 2016). In recent years, there has been a rise in research about end-of-life care in EDs (McCallum et al., 2018). Nonetheless, a recent report suggest the need to align research into end-of-life with the priorities of the patients, the public and policies (Sallnow et al., 2022). The emergency health situation makes these patients more vulnerable (Muñoz-Terrón, 2021), which creates a solid and vivid experience of dying that can exacerbate issues related to personal dignity.

3 | THE STUDY

3.1 | Aim

The aim of this study was to explore and understand the experiences of patients with AI in relation to dignity during end-of-life care in ED. The research question was: What are the experiences of patients with AI in relation to dignity during end-of-life care in ED?

3.2 | Design

A qualitative study based on Gadamer's hermeneutic philosophy (2013) was carried out. Although it is difficult to discuss end-of-life in situations of AI, the researchers decided to consider their own pre-understanding alongside the narrated experiences to understand the phenomenon of dignity among people with AI who are attended in ED. The study adhered to the phases proposed by Fleming et al. (2003), translating Gadamer's philosophy into a method. The first step entails creating a research question consistent with hermeneutic research (see previous section). Secondly, one must specify

the researchers' pre-understanding of the phenomenon. This pre-understanding stemmed from previous experience in researching end-of-life care as well as clinical experience in ED. All of the researchers are nurses who have worked in ED at some point in their professional careers. Two researchers still work with patients with AI at the end of their lives (AFF, RPR). The rest of the researchers are currently university teachers with an academic understanding of the topic. The researchers' prior theoretical knowledge is based on Chochinov's (2004) dignity-conserving model described in the previous section. This model was used as the basis for designing a research project financed by the Spanish Government and the European Union (Fernández-Sola et al., 2018). In this study, pre-understanding was contemplated alongside the data provided by the participants.

3.3 | Participants and setting

The participants were recruited in various southeastern Spanish hospitals: two general hospitals and one regional hospital. All the hospitals have an ED that does not have a specific ED for AI or end-of-life patients. Purposive sampling was used to achieve maximum heterogeneity in terms of gender and age.

The criteria for inclusion were as follows: (1) Patients with AI attended to by ED at least once in the 6 months prior to the study, (2) to be clinically stable enough to maintain a conversation and (3) to provide consent for participation. Exclusion criteria were as follows: (1) To have suffered a personal loss in the year prior to the study, which could have affected bias due to being in a period of mourning,

(2) to have any type of cognitive impairment and (3) to have a diagnosed disorder related to depression or state of mind.

To recruit the participants, their data were obtained in the ED where they were seen. Consequently, the interviewer contacted them to inform them of the study's objectives and ask for consent. When the participants granted consent, the researcher organized a meeting to carry out the interview. Of the 21 patients who were invited to participate in the study, five declined stating that they did not want to recall the experience (three of them) or because their family members or caregivers were not in agreement (two of them). Ultimately, a total of 16 patients with an average age of 73.44 years (68% male), the majority of whom had been diagnosed with cancer (93.75%), and all of whom were attended to in ED, accepted to participate voluntarily in the study. The sociodemographic characteristics of the participants can be found in Table 1.

3.4 | Data collection

The third stage of Fleming et al's method (Fleming et al., 2003) is dialogue with the participants, an opportunity to challenge our previous knowledge to reach a new level of understanding (Fleming et al., 2022). The researchers reflected on the process and decided that the interviews should be conducted by authors working with patients (not academics). For data collection purposes, in-depth interviews were carried out between September 2019 and February 2020 by two nurse researchers (A.F-F and R.P-R) who had provided the patients with health care at home

TABLE 1 Sociodemographic data of the participants

| Participant | Sex | Age | Diagnosis | Profession | Year of diagnosis | Nationality | Number of children | Number of visits to ED ^a |
|-------------|-----|-----|-----------------|---------------------|-------------------|-------------|--------------------|-------------------------------------|
| P-1 | M | 65 | Gastric cancer | Retired | 2010 | Spanish | 2 | 4 |
| P-2 | M | 88 | Prostate cancer | Retired | 2016 | Spanish | 2 | 2 |
| P-3 | F | 83 | Colon cancer | Retired | 2017 | Spanish | 3 | 1 |
| P-4 | M | 83 | Gastric cancer | Retired | 2016 | English | 0 | 3 |
| P-5 | F | 76 | Bladder cancer | Retired | 2017 | Spanish | 0 | 2 |
| P-6 | M | 63 | Lung cancer | Retired | 2016 | Spanish | 3 | 1 |
| P-7 | F | 77 | Ovarian cancer | Retired | 2013 | Spanish | 4 | 2 |
| P-8 | M | 58 | Lung cancer | Marble worker | 2015 | Spanish | 2 | 4 |
| P-9 | M | 72 | Lung cancer | Retired | 2012 | Spanish | 1 | 2 |
| P-10 | M | 78 | Liver cirrhosis | Retired | 2012 | Spanish | 4 | 6 |
| P-11 | M | 72 | Colon cancer | Retired | 2016 | Spanish | 1 | 2 |
| P-12 | M | 83 | Bladder cancer | Retired | 2017 | Spanish | 2 | 1 |
| P-13 | M | 73 | Lung cancer | Retired | 2015 | Spanish | 1 | 1 |
| P-14 | F | 81 | Cardia cancer | Retired | 2018 | Spanish | 3 | 5 |
| P-15 | M | 72 | Melanoma | Artist | 2016 | Spanish | 7 | 2 |
| P-16 | M | 51 | Stomach cancer | Construction worker | 2018 | Spanish | 1 | 6 |

^aSince advanced illness diagnosis.

or in hospital with the purpose of avoiding unfamiliarity. The interviews were carried out in the participants' homes or a hospital unit after having been discharged from the ED. The interviews followed a protocol (Table 2) that had been practised beforehand and piloted by two researchers who suggested changes to some questions for clarification purposes or to make them open-ended. Interviews lasted 45 min on average, and were recorded with the participants' prior consent. When the researchers deemed that no new information was being provided, they considered that data saturation had been reached and thus stopped the interviews and data collection.

3.5 | Ethical considerations

This study was approved by the Andalusian Ethical Research Coordinating Committee (Reference number FFI2016-76927-P). The participants were informed about the nature of the study in person and in writing, and they signed informed consent. Their participation was voluntary, and full confidentiality and anonymity was guaranteed at all times in accordance with current legislation.

3.6 | Data analysis

All the interviews were transcribed in a text document for posterior analysis, using ATLAS.ti software. The analysis was carried out adhering to Fleming et al.'s method (Fleming et al., 2003):

1. During data collection and transcription, the researchers obtained a spontaneous understanding of what the participants were saying. To obtain the whole picture (Gadamer, 2013), an open reading based on the participants' experiences was carried out by the researchers in charge of analysis. During this phase, the researchers wrote memoranda including pre-analytical intuitions and reflexions.

2. Our pre-understanding was placed into a dialogue with the participants' accounts using the transcriptions. In this phase, all the participants' stories were juxtaposed to reach a fusion of horizons between their points of view and our own (Fleming et al., 2003; Fleming et al., 2022). For this to happen, each interview was analysed, and the most important quotations were chosen. These quotations were assigned initial codes and when there were similar codes, they merged into 'Units of meaning', which also group themes that represent the wider picture. In this process, there is a back and forth between the quotations and the 'whole' (themes, overall vision), all whilst ensuring consistency. Each part gives meaning to the whole and to understand each part, we need to appreciate the whole. An example of this codification process can be found in Table 3. The researchers wrote down their reflections on the codes and their meaning (Through the ATLAS.ti functions 'comment code' and 'memos'). Codification was carried out by three researchers who reached a consensus on the codes and emerging themes.

3.7 | Trustworthiness

The final stage of the method is to ensure trustworthiness of the study. Fleming et al. (2003) adhere to the criteria of Guba and Lincoln (1994). Credibility: the researchers who carried out the interviews already knew the patients (health care at home or in hospital), which can facilitate dialogue with the participants. Researcher triangulation was used for decisions about the codification process, and for data analysis and interpretation. The researchers elaborated a reflexive diary in which they stated how their values and pre-understanding could affect the decisions made in each phase of the research process (Fleming et al., 2003). In line with the hermeneutic method, the views of the researchers were used to generate themes so that the data could be integrated into a cohesive whole. Due to the participants' clinical situation, transcripts were not sent back for them to comment on the data analysis. The Consolidated Criteria for

| Phase | Matter | Content/ example questions |
|--------------|-------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------|
| Introduction | Purpose | The belief that their experiences provide information that should be known |
| | Objectives | To carry out research to understand these experiences |
| Opening | General introductory question | Could you tell me about your experience in emergency services? Why did you go? |
| Development | Specific questions | What does the word 'dignity' mean to you? How do you maintain or conserve your dignity when you attend the ED with an advanced illness? |
| Closing | Final question | Would you like to add anything else in relation to this topic? |
| | Thanks | We would like to thank you for your time. We remind you that your statement is of great value to us |

TABLE 2 Interview protocol

Reporting Qualitative Research (Tong et al., 2007) (Supplementary file 1) were followed when producing the manuscript.

4 | FINDINGS

Two main themes and four subthemes grouping 16 units of meaning were developed from the data analysis. They helped explore and understand the experiences of patients with AI in relation to dignity during end-of-life care in ED (Table 4).

4.1 | Theme 1. Dignity as an individual's attribute

This theme refers to the way in which the participants faced their situation, accepting the calm and rational reality of it and maintaining their dignity intact. 'Dignity is surrendering to the time you have left...to what it offers you' (P10). Dignity was understood as an individual's attribute, something that you are owed (respect, freedom). The participants also understood it as an attitude towards life, adversity and death. They identified dignity as a way of coping characterized by hope, satisfaction with life and acceptance of death.

When the time comes, I will get the family together and we will have a glass of wine before they sedate me (P1).

4.1.1 | Subtheme 1. Dignity as well-deserved respect and freedom to decide

The participants stated that dignity was an inherent and invaluable part of a person, that must be conserved above all else and that transcends our own existence. They related dignity to honour and the most important human attribute. With clear Kantian overtones, they defined dignity as an invaluable legacy, a non-economic wealth that

they could leave to their family. From this perspective, to conserve dignity, it is enough just 'to be' without any need 'to do' anything else.

Dignity is the only thing that I can leave to my family; honour... is the most important thing in my life, (...). I can't sell that for anything in the world. To conserve it I don't do anything, I'm just loyal to who I am. I don't do anything (P8).

TABLE 4 Themes, subthemes and units of meaning

| Theme | Subtheme | Units of meaning |
|---------------------------------------------------------|---------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Dignity as an individual's attribute. | Dignity as well-deserved respect and freedom to decide | Invaluable legacy Developing one's own potential and doing good Well-deserved respectful treatment Freedom to decide Deciding the moment and time Defending the right to a dignified death |
| | Overcoming the fear of death to feel dignified in the last stages of life | Not fearing death Managing time Being strong Maintaining hope Living a fulfilling life |
| Acting with dignity: Dignity as a behavioural attribute | Living life until the end... also in ED | Keeping up with daily routines Doing special things |
| | A mental activity to maintain dignity | Reminiscing about the past Reminiscing about one's youth Maintaining a sense of humour |

TABLE 3 Example of the analytical process of the transcriptions (from the quotation to the theme)

| Quote | Initial codes | Units of meaning | Subtheme | Theme |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------|---------------------------------------------------------------------------|---------------------------------------------------------|
| I'm not desperate, I'm not scared. It's much better to live without fear. I hope to manage the time I have left well. There are many things I can't do but I can talk to my loved ones and hold their hands. I'm not afraid (P 11) | Not being afraid Managing time well Talking Holding hands | Not fearing death Managing time | Overcoming the fear of death to feel dignified in the last stages of life | Dignity as an individual's attribute |
| And when she (his wife) visits me and she comes to sit with me for a while, we get to talking and then, we start reminiscing about our youth or what we are going to do when we get home (P5) | Visits from a family member Talking to a family member Talking about household routines Reminiscing about the past | Reminiscing about the past Keeping up with daily routines | A mental activity to maintain dignity | Acting with dignity. Dignity as a behavioural attribute |

The second you don't have dignity, you basically don't have anything. Awareness and dignity are the most important things in a person for me (P15).

Some participants expressed an idea of developing one's own potential, in which dignity is a characteristic that makes them a better person, contributing to gaining the respect of others. For these participants, being dignified meant relinquishing the material to share or help in an effort to be good and thus be well regarded and respected by others.

If I can't give it my all, I give what I can, trying to help as much as possible (P16).

Having dignity is being able to say, 'I've done things right with these people'. It's being honest, telling the truth and being a person that people will speak well of and respect (P7).

For other participants, dignity was associated with reciprocal, respectful treatment that one deserves, just for being human. It is identified with manners and mutual respect. This perspective of dignity was seen as intrinsic, as an attribute of behaviour that must be mutual. It complemented the pre-understanding of the researchers who tended to see it as something external that is owed to patients by the health-care professionals.

Dignity is when people are polite to you and treat you well, (...) with respect. I don't lack respect to anyone so I want the same treatment. (P9).

Dignity is respecting each other with manners and common sense. (P14).

According to the participants, one of the characteristics of dignity was personal freedom and autonomy when making decisions in everyday life. However, they also associated it with capacity; the ability to do what you desire and execute a decision that has been taken freely.

Dignity is the ability to make decisions, be autonomous and say, 'now I feel like going there' and to be able to go. I feel like doing this and I'm able to do it. (P10).

In line with dignity equating freedom, the participants included the importance of freedom to make a decision about the time and mode of death, highlighting that third parties should not take measures or try to influence them to prolong their lives. Some participants associated palliative sedation with a loss of alertness and cognitive capacity that they do not wish for themselves. They also considered that palliative care or religious services deny them the right to make decisions and they do not welcome the unsolicited attempts to save a life that cannot be saved.

Now I just hang on, I don't die because I have some physical strength. It doesn't make sense to wait until I don't anymore. I don't want to be obfuscated with morphine. (I don't want) a priest or palliative care. I want to decide. Why does someone think they have the right to save you when you don't want to be saved? (P6).

One participant told us about his experience, relating how some medical protocols in ED and therapeutic obstinacy can cause suffering. If the objective of medical care is to keep the body going until one loses mental capacity, the patient can feel that they are being forced to fully deteriorate, to be physically consumed to the point of losing consciousness.

The doctor comes and tells me to hang on in there because I'm still of sound mind. But that's exactly why I want to go now. I don't want to wait until I'm fully consumed and have lost consciousness. I told the doctors that we should just leave it, that it's useless. But they insisted I carry on because it was protocol. What the hell do I care about the protocol if I'm going to die? (P12).

This desire for autonomy was recognized as a right that allows the patient to die in a 'dignified' way, which includes being able to make decisions about when and how to do so. Some participants talked about how they became activists in defending the right to a dignified death.

What I want is to be able to decide, it is a right. One must decide when one is going to die. And you have to do it with a smile on your face. (P1).

Over the last few months, when I've had the strength, I've taken out my laptop and sent letters to members of parliament in favour of regulating euthanasia and a dignified death (P6).

4.1.2 | Subtheme 2. Overcoming the fear of death to feel dignified in the last stages of life

Dignity also implies having emotional control through which the patient is capable of overcoming their fear of death. This helps them to focus on managing the time that they have left. This idea reinforces some previous ideas about dignity such as 'perspectives for conserving dignity', one of the categories of the theoretical framework.

It's much better to live without fear. I hope to manage the time that I have left well. There are lots of things that I can't do but I can speak to my loved ones and hold their hands. I'm not afraid (P11).

This time management could involve putting one's life on hold and being fully aware that it is ending. It is a time of peace that culminates

in accepting finitude itself. One participant used a literary device to explain his feelings.

Over the last year, I've had to put my life on hold. As Cortázar said, 'there is nothing left to do, the match is extinguished'. Well, in my case, the match is already burning my fingers (P13).

Emotional control could also imply that the patient has the perception of needing to remain strong and determined to be able to face the situation. Some of the participants identified dignity as not giving up in the face of death, being strong, and taking the advice that they had given their predecessors in the past.

I used to say to my father, 'Dad, fucking hell, you need balls even to die, you've been so strong your whole life, don't give up now'. So how can I let myself give up now? (P8).

This acceptance and resilience do not exclude the hope of getting better. Some participants turn to their faith to ask for 'strength' and an improvement that would allow them to leave the ED or even a 'pact' to gain the necessary time to attend or witness important family events.

I couldn't breathe properly and now I can. I don't know. I tell the Virgin Mary: 'strength, Virgin, strength'. My Virgin helps me so that I can go home. (P7).

The truth is that I would love to get a little better because my granddaughter is getting married in October and I say: 'Please God, let me see my granddaughter'. Sometimes I think: 'If I can't attend on my own two feet, they can take me in a wheelchair' (P3).

They also alluded to how having lived a dignified life and felt that they had fulfilled their purpose allowed them to feel dignified at the time of death. The prospect of living a fulfilled life usually comforts patients, but our participants also stated that when a person can see themselves dying, it also provides peace of mind to know that they have fulfilled their life.

I feel fulfilled as a person. I have my son, my granddaughter. I was a rocker for a long time. I've also been a flamenco fan because music is really important to me and, in general, I think I've lived to the full, I'm not afraid of death (P15).

4.2 | Theme 2. Acting with dignity. Dignity as a behavioural attribute

This theme refers to the different ways in which the patients behave to protect their dignity. This includes having a good attitude, showing

affection to their loved ones, the day to day, self-care, sense of humour etc. The sense of autonomy referred to in the previous theme allows them to maintain their dignity in the small details of daily life.

4.2.1 | Subtheme 1. Living life until the end..., also in the ED

One way in which the participants acknowledged maintaining their dignity was to continue being the same person. They stated that they make an effort to continue with their routines in their means. They do everything possible to minimize the effect of their illness on their daily lives.

I can't do much more than this. I get up in the morning and do what I've always done, take a book, read it and not much else. As I know I can't do more than that, I simply can't. (P13).

When you're well, you don't remember that you're ill. The other day I went out with my daughter and sister and we spent all day out and about, eating, I had such a great time. (P1).

Staying true to oneself and maintaining self-image is not just achieved through keeping up with routines but also on special occasions, by doing things that are out of the ordinary that defy one's own limits.

A few months ago, I went kayaking in the Cabo de Gata National Park and I saw the 'Mermaid's Reef' from the water (...). I was as happy as a pig in mud. (P6).

We made the most of my wife's birthday, we celebrated it on 14th April. It is a tradition we have. The only thing is that I was full of pus, a side effect of the medication. (P5).

Even frequent visits to ED are integrated into their lives, which is an inevitable consequence of living with AI. For some, normalizing visits to ED as part of their daily routines actually enabled them to avoid suffering, thus preferring to go to hospital than to suffer.

I don't want to suffer. If I have to come every few days in order not to suffer, I prefer to normalize it as something I have to do today (P4).

4.2.2 | Subtheme 2. A mental activity to maintain dignity

The subtheme relates to the psychological resources that the participants use to maintain their dignity. One of them is remembering

the past, either through talking with their partner or through thinking about it themselves as a way of distracting themselves.

When she (his wife) comes in, it's cold outside and she comes towards me, we start a conversation about something and then we get to talking and reminisce about our youth. (P5).

Now, when I'm about to think about sad things, I switch mindset and say 'OK, come on, let's think about what I did when I was younger'. (P10).

Other participants highlighted keeping a good sense of humour in spite of the circumstances and the impact that it can have. They tell jokes, equating their partner's survival with a certain amount of luck. Others mentioned how they tell jokes to the doctor during their visits to the ED.

When the haematologist saw me in the emergency room she said, 'I'm so happy to see you Antonio!' and I said, 'why, my dear?' She said, 'because everyone comes in saying 'it hurts here and there' and you come in telling me jokes.' (P13).

5 | DISCUSSION

This study contributes to understanding the experiences of patients with AI in relation to dignity during end-of-life care in ED. The participants indicated that one of the dimensions of dignity can be related to a series of personal attributes. In line with other studies (Clancy et al., 2021; Rodríguez-Prat et al., 2016), participants identified dignity with an inherent value of a person, thus meaning they deserve to be treated respectfully, which includes autonomy in making decisions in daily life. The important notion of losing autonomy in the last stages of life has been identified as a key factor in patients suffering emotional distress (Bovero et al., 2018). Dignity and autonomy are inextricably linked to one another and to the concept of personal identity (Rodríguez-Prat et al., 2016). A part of this notion of autonomy includes maintaining cognitive capacity, explaining why some patients do not wish to be sedated. However, the majority of nurses are in favour of sedation (Guttormson et al., 2019). Although, on an ethical level, social isolation following sedation is an issue that concerns them (Heino et al., 2021). The majority of doctors state that when the patient is of sound mind, they can ask for sedation in their last days (Bretonniere & Fournier, 2021). However, only a minority consider it possible to alleviate the patient's suffering through different means (Heijltjes et al., 2022). Muñoz-Terrón (2021) uses the term relational autonomy to highlight that in vulnerable situations such as an advanced or terminal illness, the patient does not have full control. For example, there are patients who are taken to the ED because the family members are overwhelmed (Díaz-Cortés et al., 2018). In such a context, the respect for dignity amongst those

who feel alive is based on a notion of autonomy that recognizes the shared vulnerability of those who provide care and those who are being cared for (Muñoz-Terrón, 2021).

The right to privacy and respect are other important attributes related to dignity, which have consequences during end-of-life care (Hemati et al., 2016). This respect is not compatible with the attempts of healthcare professionals to persuade patients to make a particular decision (Weber et al., 2017). For example, in countries in which current legislation supports assisted dying, the patient has the right to be informed of their different options. This should be done by a qualified professional who considers the individual intentions of the patient and is able to present the advantages and disadvantages of making a particular decision in an objective way (Zhou & Shelton, 2020). In fact, the participants referred to rejecting measures that were proposed to them that entailed lengthening their lives, which is a very common practice in EDs. The healthcare professionals themselves warn that the ED is not an appropriate place to provide dignified end-of-life care (Díaz-Cortés et al., 2018), as therapeutic obstinacy is still an impediment to maintaining a dying patient's dignity (Fernández-Sola et al., 2017). The patient wants to decide how and when to die, a right that can be exercised following the recent approval of the law that regulates euthanasia and assisted suicide in Spain (Velasco Sanz et al., 2021).

Our findings concur with previous conceptions (Hemati et al., 2016; Li et al., 2014), that consider intrinsic characteristics of dignity to include having felt mental or spiritual peace, alongside understanding the meaning of existence and having lived a fulfilling life. This component is being applied to a psychotherapeutic intervention called 'dignity therapy', which intends to reinforce a sense of purpose, meaning and dignity amongst terminal patients, thus promoting a more positive vision of acceptance and hope (Testoni et al., 2022; Vuksanovic et al., 2017).

Dying with dignity does not only imply controlling how and when to do so (McCallum et al., 2018). According to the participants, there is also a factor of emotional control. The patient must be able to face death and accept it (Xiao et al., 2021). From the point of view of the participants, dignity implies accepting the situation and the ability to continue making decisions, thus maintaining a sense of fulfilment and serenity in achieving their life objectives. Conserving dignity also relates to what we leave behind (our legacy) (Julião et al., 2022), acceptance and resilience, as well as how those around us respond to our situation and whether we are treated with respect and given independence. The definition of dignity in the last stages of life in EDs not only requires recognizing the inherent value of an individual, a notion supported by healthcare professionals (Fernández-Sola et al., 2017), but also social and individual acceptance of death. This is hindered by concealment and obstinacy about death, which influences end-of-life care (Ruiz-Fernández et al., 2021). The death of a patient often leads to the healthcare professional providing inappropriate answers as part of a personal strategy to avoid difficult situations, thus representing an obstacle for a patient to die with dignity (Puente-Fernández et al., 2020). To promote dignity, healthcare professionals, as well as healthcare and academic institutions,

must approach death in a natural way and recognize it as part of our existence (Ruiz-Fernández et al., 2021). In accordance with Chochinov (2004), our participants saw their own dignity reflected in the eyes (or look) of the carer.

Our participants have underlined the need to 'live life to the end', maintaining certain daily routines, to maintain their dignity. Other studies have also described strategies to preserve their dignity, that often include the need to protect their personality in daily life (Choo et al., 2020), mental distractions, recalling happy memories and maintaining a good sense of humour (Holmberg & Godsken, 2022; Vuksanovic et al., 2017). However, it must be considered that the majority of these strategies are incompatible with the dynamic in the ED, as the priority there is to manage symptoms that cause discomfort (Alqahtani & Mitchell, 2019). Therefore, the care that these patients receive in the ED should be comprehensive and as brief as possible, to allow the patient to transfer to another unit where they can continue with their daily routines or even go home, without losing sight of the human nature of the care provided (Díaz-Cortés et al., 2018). A change in mentality is required so that healthcare professionals shift the focus of care based on 'saving lives' to instead 'preserving human dignity' (de Medeiros et al., 2021). This change can be driven by changes in training or educating the team (Alqahtani & Mitchell, 2019). Key measures to be taken into account in providing end-of-life care in the ED should include an individualized and flexible care plan that facilitates access to palliative care, is focused on managing symptoms and promotes empathetic communication (de Medeiros et al., 2021).

These findings have significant implications for clinical practice. Patients and healthcare professionals can have different expectations and objectives about end-of-life care, which can be due to cultural or sociodemographic factors such as religion or race (Frost et al., 2011; Horn & Kerasidou, 2016). This is why the patient needs to be provided with care that takes these factors into account and facilitates communication in the shared decision-making process (Frost et al., 2011). Maintaining dignity at the end of a patient's life must not be seen as merely an option; it must be considered as a determining factor in whether or not a patient has a good death (Ito et al., 2020), especially given that many of these patients die shortly after visiting the ED (Verhoef et al., 2020). It is necessary for all end-of-life care providers to understand the meaning of dignity, especially if the service that provides care to the patient is focused on saving lives (Parkinson et al., 2021). It is therefore important to consider the necessary interventions without letting therapeutic obstinacy get in the way, as respecting a patient's dignity reduces their suffering and prepares them for a more comfortable death (Hemati et al., 2016). Maintaining the freedom to make decisions and choices must prevail to preserve dignity (Staats et al., 2021).

6 | LIMITATIONS

Some of the limitations of this study are related to the participants' sociodemographic characteristics. Almost all of them are retired (81.25%), due to their age or health situation. Interviewing people

in active employment would have allowed us to explore how continuing working or having to stop working to be admitted to the ED influences one's sense of dignity.

Furthermore, almost all of the participants have an AI as a consequence of cancer. If we had found a more heterogeneous sample (degenerative, neurological, cardiac illnesses etc.), it would have enriched the findings.

Other limitations are related to data collection: the interviews were carried out in the patients' homes or in hospital units following being admitted to or visiting the ED. As they did not take place immediately in the ED itself or directly after being discharged, their memory of the experience could be less intense. The researchers who carried out the interviews knew the patients as they had provided them with care at some point prior to the study. Although it was taken into account that they did not provide care in ED, the participants could have linked the researchers to the same public institution. The clinical situation of the patients (AI or terminal stage) prevented us from having various in-depth conversations. Instead, they were very brief and ended when the interviewer perceived that the patient was tired or that they found it difficult to talk or recall information.

7 | CONCLUSION

According to the experiences of patients in the last stages of life, dignity is related to the control that they exert over themselves, their death and the emotions that the situation evokes. To maintain their dignity, they have a variety of resources for these situations both in the hospital context and in their daily lives. The way in which they conceive the concept of dignity and the strategies used to conserve it can be hindered by the dynamic in the ED and the healthcare professionals' vision of providing care that focuses on saving lives.

Our study suggests the need to respect the patients' wishes in the last stages of their lives and to support and accompany them through a phase of acceptance, avoiding therapeutic obstinacy, even when the patient attends the ED. We recommend empathetic and individualized care that focuses on the patient's well-being, respects their autonomy and freedom to make decisions, and that facilitates a swift referral to palliative care.

AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE*): (1) Substantial contributions to conception and design, acquisition of data or analysis and interpretation of data and (2) Drafting the article or revising it critically for important intellectual content. *<http://www.icmje.org/recommendations/>

ACKNOWLEDGEMENTS

Thanks to the study's participants for sharing their experiences and perceptions with the researchers. Thanks to the University of

Almería's Expert University Course in Qualitative Research with ATLAS.ti for what was learned and for the corrections provided. To CTS-451 Health Science Research Group.

FUNDING INFORMATION

This study has received funding from the Spanish Government, Project FFI2016-76927-P financed by MINECO/AEI/ 10.13039/501100011033 and FEDER 'Una manera de hacer Europa' (ERDF 'a way of making Europe').

PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1111/jan.15432>.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

CONFLICT OF INTEREST STATEMENT

No conflict of interest has been declared by the author(s).


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How to cite this article: Martí-García, C., Fernández-Férez, A., Fernández-Sola, C., Pérez-Rodríguez, R., Esteban-Burgos, A. A., Hernández-Padilla, J. M., & Granero-Molina, J. (2023). Patients' experiences and perceptions of dignity in end-of-life care in emergency departments: A qualitative study. *Journal of Advanced Nursing*, 79, 269–280. <https://doi.org/10.1111/jan.15432>

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