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**TITLE: Characterization, conservation and loss of dignity at the end-of- life in the
Emergency Department. A qualitative protocol**

RUNNING HEAD: Dignity in Emergency Department.

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CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

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ABSTRACT

Aims: to explore and understand the experiences of terminally-ill patients and their relatives regarding dignity during end-of-life care in the emergency department.

Background: the respect given to the concept of dignity is significantly modifying the clinical relationship and the care framework involving the end-of-life patient in palliative care units, critical care units, hospices and their own homes. This situation is applicable to in-hospital emergency departments, where there is a lack of research which takes the experiences of end-of-life patients and their relatives into account.

Design: a phenomenological qualitative study.

Methods: the protocol was approved in December 2016 and will be carried out from December 2016 - December 2020. The Gadamer’s philosophical underpinnings will be used in the design and development of the study. The data collection will include participant observation techniques in the emergency department, in-depth interviews with terminally-ill patients and focus groups with their relatives. For the data analysis, the field notes and verbatim transcriptions will be read and codified using ATLAS.ti software to search for emerging themes.

Discussion: emerging themes that contribute to comprehending the phenomenon of dignity in end-of-life care in the emergency department are expected to be found. This

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study's results could have important implications in the implementation of new interventions in emergency departments. These interventions would be focused on improving: the social acceptance of death, environmental conditions, promotion of autonomy and accompaniment and assumption (takeover) of dignified actions and attitudes (respect for human rights).

Keywords: dignity, dying, nursing, emergency medicine, palliative care, end-of-life care, patient experiences

Why is this study needed?

- Many terminally-ill patients attend the emergency department when they experience the exacerbation of end-of-life symptoms.
- Emergency departments are spaces designated for looking after acutely-ill patients where death is considered to be a failure. This leads to disproportionate healthcare interventions which can cause a loss of dignity amongst end-of-life patients.
- The experiences of terminally-ill patients and their relatives should be studied. This would contribute to understanding how end-of-life patients' dignity can be preserved in emergency departments, which in turn can inform the design and implementation of more appropriate care protocols and frameworks.

INTRODUCTION

Historically, most healthcare interventions have focused on illness prevention and patient recovery. In Western societies, scientific and technical developments are changing the understanding of concepts such as human being, life and death (Tellett et al., 2012). The progress of scientific knowledge and the technologies applied to health

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sciences have contributed to prolonging life expectancy. For example, between 1992 and 2013, life expectancy in Spain increased by 6 years for men and 4.4 years for women (INE, 2017). Consequently, the current life expectancy in Spain is 86 years old for women and 80 years old for men (WHO, 2015). Together with increasing longevity (Matus-López & Cid-Pedraza, 2014), preserving people's quality of life (Sagha Zadeh et al, 2017) should be a primary objective of healthcare systems (Durán Agüero & Vasquez Leiva, 2015). Science does not always offer a cure to diseases such as cancer, AIDS, organ failure (renal, cardiac, hepatic) or neurodegenerative diseases, which after long and painful processes lead to death. We understand a terminal disease to be an advanced, progressive and incurable disease without reasonable possibilities of response to treatment, for which life expectancy is less than 6 months (SECPAL, 2014). This is often accompanied by intense, multifactorial and changing symptoms and it has a strong emotional impact on patients, relatives and healthcare professionals (SECPAL, 2014). It is therefore a challenge for our healthcare systems to provide care and quality of life in diseases associated with advanced ages (Durán Agüero & Vasquez Leiva, 2015) or terminal processes, where patients continue to encounter inadequate and poorly prepared structures for their care (Admi et al., 2013).

However, since the last century, it is also undeniable that beyond scientific and technical advances, disciplines such as bioethics have put the dying process at the centre of biomedical, ethical and philosophical research. In this respect, whilst the increase of life expectancy is indisputable, the debate over quality of life and the dying process remains open (Scanlon & Murphy, 2014). Matters such as the gradual aging of the population or the healthcare expenses for patients with chronic illnesses and/or at the end of their lives, are still sources of discussion and controversy (Forero et al., 2012;

Sepúlveda et al., 2014). Beyond economic or demographic aspects, a new care framework has been consolidated in this process, which includes profound changes in the way people are experiencing, treating and caring at the end of life (Phillips, 2013; Granero-Molina et al., 2014). The repercussion is unquestionable across all levels of health and social care, but it is even more so in highly technified care contexts such as Intensive Care Units (ICU) and/or Emergency Departments (ED).

In these settings, phenomena such as the objectivization of death and the objectification of the body lead to the dissociation with the dying person, which may also lead to disregarding important aspects such as accompaniment, rituals and mourning (Scott, 2013). Respecting individual, cultural and social differences of terminally-ill people and their relatives can contribute to the preservation the dying patient's dignity in ICUs and EDs. However, the lack of social acceptance of death, together with the absence of tradition in complying with advanced guidelines, can generate anguish, suffering, anger and frustration for all those who are involved in the phenomenon (Jiménez-Herrera & Axelsson, 2015). Not recognising the imminence of death, the lack of knowledge or the inadequacy of palliative care all continue to contribute to the dying patient's arrival in the ED. However, the ED is a space designated for looking after those who are acutely ill, where death is associated more with the failure of science than an unavoidable stage of life (Fernández-Sola et al., 2017).

For terminal patients, the EDs are access points for hospital care; a crossover point on the way to hospital, community care settings or home. Whilst the new palliative care policies foster home care and contribute to redirecting the situation (Richards et al., 2013; Becze, 2016), patients at the end of their lives are still attending the ED (Smith et al., 2009). The ED is a place where the dying patient's body is "out of

place” (Bailey et al., 2011); here, the patient with terminal cancer or a chronic/degenerative disease faces inadequate healthcare services that are rarely prepared for their care (Admi et al., 2013). This can lead to the loss of fundamental aspects of human dignity such as confidentiality, accompaniment or privacy (Nayeri and Aghajani, 2010). In light of acute conditions that threaten his/her life, the dying patient in the ED is confronted with overcrowding, stress, lack of communication, fear and loneliness (Limehouse et al., 2012). In this setting, patients, relatives and healthcare professionals encounter technical interventions (Nikki et al., 2012), futility, therapeutic limitations (Ache et al., 2011; Scanlon & Murphy, 2014), ‘Do-Not-Resuscitate’ orders (Jesus et al, 2014), palliative sedation (Escalante et al., 2008), advanced directives (Lee and Kim, 2010; Scheck, 2012) and even the loss of dignity (Latour & Albarran, 2012; Molan, 2012).

In these highly technified services that are focused on saving lives, the dignity of people in the process of dying can be strongly undermined (Seale, 2009). This situation not only affects patients and relatives but also healthcare professionals who show signs of anxiety (Peters et al., 2013) or burnout syndrome (Adriaenssens et al., 2015). Despite the introduction of palliative care and the generally fallow attempts to implement advanced planning (Wong et al., 2012, Van Tricht et al., 2012), the threat to the individual and his/her functional impairment, together with the absolute dependence on others in the ED, continue to threaten a basic right of terminally-ill patients: human dignity.

Background

In Kantian terms, dignity lies in the autonomy of individuals to use reason to assign themselves rules for their actions; autonomous beings act according to this maxim: “use humanity as much in your own person as much in the person of every other; always at the same time as end and never merely as means” (Kant, 2002, p.5). The “end in itself” condition is based on the inherent value of rational personal existence and dignity, which places individuals above everything that may have value (Kant, 2002, pp.52-53). This gives people a characteristic of self-respect and a certain satisfaction with themselves (Formosa, 2014). This principle presents itself to one’s will as a duty that doesn’t lie in feelings but rather demands human beings to only obey their own law, which they must try to transform into a universal principle (Kant, 2002, pp. 54-58). The notion of dignity emphasises the value and demand of unconditional respect of every individual, which cannot be reduced to a mere tool of means outside of those chosen by oneself. In the biolaw field, dignity has been incorporated as a concept with two opposing facets that, in reality, are complementary: dignity as “empowerment” and “constraint”. The role of dignity in the field of bioethics and biolaw on an international level has been consolidated due to UNESCO’s implementation of the Universal Declaration of Bioethics and Human Rights in 2005 (Andorno, 2011).

Every human being has dignity as well as the right for it to be preserved at all times. Human dignity is reflected in a set of choices, values, ideals, lifestyles (and ways to confront end of life) for each individual (Edlund et al, 2013). Dignity at the end of life can be seen as the ability to maintain cognitive capacity, comfort or control over one’s own behaviour (Guo and Jacelon, 2014). It can also be understood as a source of respect, autonomy and the ability to make decisions and communicate (Haugen, 2010). For Kant, autonomy is the central phenomenon of dignity; therefore, life in itself does

not represent the greater good that has been entrusted to us nor one which we should attend to first, but rather that there are higher ranking duties. For those who hold themselves in high esteem, acting freely is not based on fearing death but rather on facing it calmly (Kant 2001, pp. 149-150). The importance, therefore, lies not in the human being having a long life but rather in feeling that, even at the end of life, he/she has lived with dignity (Kant 2011, pp.150-151).

The respect of people's dignity is profoundly changing the clinical relationship and care framework of the dying patient (Fernández-Sola, et al., 2012). Although dignity is a vague, multifaceted concept that is difficult to measure (Griffin-Heslin, 2005), it has become a fundamental issue for patients, their relatives, professionals and healthcare providers (Guo & Jacelon, 2014). Although research in this field is exhaustive, phenomenological studies have demonstrated their value in exploring patients' experiences at the end of life in areas such as critical care (King and Thomas, 2013). The Gadamerian hermeneutic phenomenology (Gadamer, 2013), which includes concepts like 'preunderstanding' and 'fusion of horizons' as the nuclear axis of the interpretation phenomenon; together with Chocinov's model (Chocinov 2002, Chocinov et al., 2002, Chocinov 2004, Fernández-Sola et al., 2017), which explains the phenomenon of dignity at the end of life in categories such as 'problems related to illness', 'dignity-conserving repertoire' and 'social dignity inventory', have proven to be appropriate theoretical and methodological frameworks for the study of dignity in end-of-life care.

In relation to dignity, there are various countries that have introduced important legislation with substantial changes in the regulation of dying peoples' rights (Fernández-Sola et al., 2012). In this regard, the debate about the limitations of therapeutic efforts and the artificial prolongation of life (García & Rivas, 2013;

Morales, 2015) has given rise to regulatory laws. Legislative changes aside, cultural change is slow and difficult, and it is not having the expected effects (Sepúlveda et al., 2014).

Contrary to general opinion, good professional care and a support network can contribute to preserving the dignity of dying patients in their homes (Oosterveld-Vlug et al., 2014); however, a large proportion of these patients are still attending the EDs when faced with the exacerbation of symptoms. It continues to be a space where the meaning of dying with dignity remains ambiguous, a context where it can even pass unnoticed (Griffin-Heslin, 2005). Although the debate surrounding the dignity of a human being in the process of dying is longstanding, its current materialisation in EDs raises technical and moral questions that need to be addressed (Iglesias & Lafuente, 2010; Van Tricht et al., 2012). Even though the inclusion of palliative care in EDs can facilitate comfort and the alleviation of physical suffering and pain (Grudzen et al., 2013), the results are still insufficient and/or controversial in the comprehensive care of dignity at the end of life.

It is necessary to understand the viewpoints of all participants in the process and the experiences of the patients, relatives and ED professionals (Nikki et al., 2012; Marck et al., 2014). Various studies have already noted the need to define dignity, identify its loss and promote its preservation in places such as the ED (Beckstrand et al., 2012; Sepúlveda et al., 2014). Some phenomenological studies have already incorporated the experiences of healthcare professionals, mostly ED physicians and nurses (Fernández-Sola et al., 2017, Granero-Molina et al., 2016, Díaz-Cortés et al., 2017). However, it is necessary to research the phenomenon in other contexts and to incorporate the experiences of the patients and their relatives.

THE STUDY

Aims

To explore, describe and understand the experiences of professionals, patients and relatives, related to the characterisation, loss and preservation of dignity in end-of-life care in Emergency Departments.

To create protocols (or clinical pathways) for the care of terminally-ill patients in the Emergency Departments of participating hospitals.

Design / Methodology

A qualitative study based on the hermeneutic phenomenology of H. G. Gadamer was designed. In alignment with Gadamer's philosophy, the existential nature of a human being means "being-in-the-world", which allows a human being to understand him/herself in a historical context and a horizon of understanding. Understanding a phenomenon requires the combination of pre-understanding, theoretical understanding, values and experiences of "being-in-the-world" (Gadamer, 2013). Moreover, this understanding encompasses an interpretative process known as the hermeneutic circle, which constitutes the circularity of movement between parts and the whole (Debesay et al., 2008). The hermeneutic circle involves a dialogue with another "you" in a fusion of horizons marked by finitude. According to Gadamer, a phenomenon is understood through conversation and a meeting with the truth of others, which allows one to go beyond the process of understanding and expand horizons of meaning of "being-in-the-world" (Gadamer, 2013).

The study's work plan (including objectives, tasks, milestones and deliverables) can be seen in Table 1.

Participants

Participants will be recruited through purposive sampling and maximum variation and will comply with the following inclusion criteria:

- Patients with terminal illnesses, treated at least once in the ED in the six months prior to data collection, with clinical stability and without cognitive deterioration, who grant consent for their participation.
- First degree relatives of terminal patients, treated at least once in the ED in the six months prior to data collection, with clinical stability and without cognitive deterioration, who grant consent for their participation.
- Healthcare professionals (nurses and physicians) who work in the ED and who have cared for terminal patients in ED and who grant consent for their participation.

Exclusion criteria will be: 1) to have suffered a personal loss in the year prior to the study (the mourning period could lead to bias), 2) to have any type of cognitive deterioration and 3) to have a diagnosed disorder related to depression or state of mind.

Data collection

The following qualitative research techniques will be carried out: participant observation (PO); focus groups (FG); and in-depth interviews.

For the participant observation, permission will be gained from the institutions participating in the project. The PO will be conducted by the research team; 6 months of participant observation in the treatment of dignity in terminal patients in the observation area of the ED at *Hospital Torrecárdenas*, *Hospital La Inmaculada* and *Hospital de*

Poniente. The researcher will be an employee from each centre and will collect field notes during their observation period.

For the interviews and focus groups, the participants will be identified when they attend one of the Emergency Departments. Once they have been transferred back to their home or to another hospital ward, they will be contacted by the researcher to see if they would like to grant informed consent and be interviewed (patients) and/or take part in a focus group (relatives). A researcher trained in conducting qualitative interviews will go to the patient's home or hospital ward to carry out the interview. The following is planned:

- Three Focus Groups (spouses of terminal patients): each consisting of 6-8 participants, who will attend the ED. Place: *Hospital Torrecárdenas*, *Hospital La Inmaculada* and *Hospital de Poniente*. Duration (approx.): 1 h.
- In-depth interviews (patients-1): 25 thorough interviews of terminal patients who have only received treatment once in an ED. Place: patient's home. Duration: between 20-50 minutes, depending on the needs/situation of the patient.
- In-depth interviews (patients-2): 25 thorough interviews of patients who have received treatment more than once in an ED. Place: patient's home. Duration: between 20-50 minutes, depending on the needs/situation of the patient.
- In-depth interviews (professionals): 15 participants, ED professionals (physicians and nurses). Place: *Hospital Torrecárdenas*, *Hospital La Inmaculada* and *Hospital de Poniente*. Duration (approx.): 1 h.
- Workshops: Workshops will be created in each participating hospital as part of the knowledge transfer strategy. Strategies and clinical pathways focused

on the conservation of dignity will be designed using consensus techniques such as nominal group technique (NGT) or analysis of Strengths, Weaknesses, Opportunities and Threats (SWOT) and will be based on the views and experiences of the healthcare professionals, family members and patients.

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Data analysis

All the field notes, along with the transcriptions of FGs and in-depth interviews will be transcribed and incorporated into the Hermeneutic Unit for posterior analysis with the software Atlas.Ti 7.0. The analysis, superimposed in the theoretical and methodological framework of Gadamer's hermeneutic phenomenology, will take the following steps described by V. Fleming (Fleming et al, 2003):

Phase 1. The first step will be focused on reflecting and deciding if the research question is pertinent in relation to the methodological hypotheses. Being treated with dignity in the ED at the end of life is a phenomenon from which a hermeneutic understanding can be gained as it represents an experience in the lifeworld.

Phase 2. The second step will be focused on researchers identifying the pre-understanding of the study phenomenon. The researchers have previous experience in the study of end-of-life care, as well as having clinical experience in the Emergency Department. This aids in the formulation of significant questions, in accessing the field and in carrying out participant observation, interviews and focus groups.

Phase 3: The third step will be focused on obtaining an understanding of the phenomenon through dialogue with the participants:

- During the data collection and transcription, researchers will gain an immediate understanding of what the participants say.
- To integrate the reader and the text, an open reading will be conducted to gain a general impression of the experiences.
- In this phase, the content of the text will be corroborated and new possibilities will be explored.

Phase 4: The fourth step will be focused on carrying out a conversation between the researchers and participants through the text. This will be done through:

- Coding the most significant phrases taken from the text and assigning codes to represent their meaning.
- Grouping codes in units of meaning (an intermediate analytical construct).
- Grouping units in meaning of subthemes and themes.

Together with the results of the literature review, the information obtained in the workshops will be analysed and used to create documents on care protocols and clinical pathways. Experts in end-of-life care and ED professionals will review these documents to reach an agreement on the final version through consensus techniques.

Ethical considerations

The protocol was assessed and approved by the Almeria Biomedical Research Ethics Committee in their meeting on 29 March, 2017, with the protocol number FFI2016-76927-P (AEI/FEDER, UE).

The ethical principles regarding studies and research involving human beings set down in the Declaration of Helsinki (2008) were considered.

- Project of Scientific and Social interest, based on the high rates of terminal patients in EDs and studies regarding the loss of dignity during their care.
- Prior to obtaining consent, the research team will inform the participants about the study. Each participant will receive an information sheet about the study, be given verbal explanations and sign an informed consent form.
- The voluntary nature of participation will be guaranteed. The participants will be informed that failure to participate or complete the study will not hold any negative implications for their treatment or care.
- The risk-benefit ratio is ensured; although qualitative studies do not imply a physical risk, unnecessary inconveniences for the patients and their relatives will be avoided, adapting data collection to their needs and preferences and always considering the participants' well-being.
- The integrity and privacy of information will be protected at all times, in line with the Organic Law 15/1999 of 13 December for the Protection of Personal Data in Spain. Confidentiality of the information provided by the participants will be guaranteed, together with their anonymity. For this reason, the participants' names will be changed in the interview and focus group transcripts as well as in the field notes, using pseudonyms or codes (EP-1, EP-2... EPn). Any identifying characteristics which are not pertinent to the study will be modified. The names of professionals who are interviewed or mentioned will be removed, leaving only their professional role.

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- Access to information will also be protected; only members of the research team will be able to access the information. This information will be stored in computer and audio files, protected during the study and destroyed when it finishes. The participants will be informed of the protocols for the protection, storage, access and destruction of the information obtained.

Rigour

Although, according to Gadamer, it is not possible to achieve objectivity in a hermeneutic research project, we will be faithful to the texts as well as the research context. This, along with the identification of all of the stages of research, will contribute to maximizing the reliability of the study. Measures planned in other qualitative research protocols (Groot et al., 2017) will be implemented to reinforce the reliability and validity of the study. The researchers will attend meetings where they will reflect on and discuss the design, data collection and data analysis processes. Furthermore, to analyse how subsequent interviews can be improved, the researchers will review the interview protocol and listen to the first two recorded interviews. Credibility will be obtained by guaranteeing that all the participants' opinions and points of view are represented in the study results. Likewise, confirmability will be achieved by going back to the participants in all stages of the research process. Lastly, with the objective of reinforcing reliability, credibility and confirmability of the study, we will guarantee that:

- The final list of topics and quotes will be confirmed by the participants in the FGs and the in-depth interviews.
- The coding will be carried out by three members of the research team.

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- To ensure reflexivity, all elements of the study will be reflected on and discussed at each stage of the design: an examination of pre-understanding and the motivation for the research question will be conducted, a reflexive diary will be kept during the field work and data analysis methods that incorporate reflexivity will be employed (Green & Thorogood, 2014, Mauthner et al., 2003).

DISCUSSION

Incorporating the perspectives of patients and their relatives into the study of issues related to end-of-life care is a necessary step to improve the care of these patients (Díaz-Cortés, et al., 2017, Marck et al., 2014). We trust that the emerging themes will be able to contribute to comprehending the phenomenon of the dignity in end-of-life care in the Emergency Department. Previous studies have shown that dignity in end-of-life care should be understood as a person's inherent value, where socio-environmental conditions and conscious actions/attitudes are also involved as attributes of dignity (Fernández Sola et al., 2017). Other studies have identified the main problems that, according to professionals, affect dignity in the ED. Issues such as the exposure of bodies to "a cold world", undignified actions from the professionals themselves and the care culture of "family obstinacy and hospital rescue" could lead to a loss of dignity for end-of-life patients in the ED (Beckstrand et al., 2012, Granero Molina et al., 2016). Promoting dignity in these environments involves redesigning the services focused on human dignity and providing care with a particular sensitivity and focus on emotional aspects (Díaz-Cortés, et al., 2017).

This study's results could have important implications in the implementation of new interventions in the Emergency Departments. These interventions would be

focused on improving the following: the social acceptance of death or dignity (Rannikko et al., 2017), environmental conditions, promotion of autonomy and accompaniment and assumption (takeover) of dignified actions and attitudes (respect for the human rights) (Díaz-Cortés et al., 2016).

Changes

Changes suggested by reviewers from the funding entity (the Spanish government) have been made to the protocol. One of the problems identified was the difficulty to access participants through a project led by university researchers. To address this limitation, the team has been expanded to include physicians and nurses from the three participating hospitals. Also, further information regarding the expected participants has been included. The ethical considerations have also been expanded and the study protocol has been evaluated and approved by the 'Public Health Service Biomedical Research Ethics Committee'. The reviewers highly valued the interdisciplinary nature of the team, which is comprised of nurses, philosophers, physicians, anthropologists and psychologists. They also valued the methodological approach based on the combination of qualitative research and the Gadamerian hermeneutic. The reviewers expect a philosophical reflection which helps to "turn the project into something more than an interesting psychosocial study; it could even provide an interesting model to understand the contribution of philosophy in this type of research". To respond to these suggestions, a team of researchers from the areas of philosophy and nursing has been formed.

Limitations

In Spain, there has been recent legislation about the dignity of a person in end-of-life care (Fernández-Sola et al., 2012). This could change the paradigm of care in such a way that the concern arising among Spanish professionals might not be seen in other

countries. Furthermore, as in other European countries (Fassier et al., 2016), emergency care in the public healthcare system is universally available. Our study will take place in public hospitals, where the cost of healthcare may not be a concern for the participants and decision-making processes may not be influenced by it. Including participants from the private care sector could lead to different results as the influx of users in this setting is notably smaller and more matters relating to comfort are addressed. Nonetheless, it is worth mentioning that, in our context, the proportion of end-of-life care provision at a private level is irrelevant compared with public healthcare.

CONCLUSION

The development of the protocol could contribute to the incorporation of the participants' experiences in the development of Plans for admission, placement, care and accompaniment of terminal patients and relatives in the ED. Furthermore, the knowledge gained through this project could prove beneficial in the diversifying of care provided for terminal patients and their relatives in the ED (e.g. psychological and spiritual support). The anticipated outcomes of this protocol include the need to restructure the physical spaces designated for the care of terminal patients and their relatives in the ED and the development of plans to restructure the organisation of work in the care of terminal patients and their relatives in the ED.

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;
- 2) drafting the article or revising it critically for important intellectual content.

* <http://www.icmje.org/recommendations/>

REFERENCES

- Ache, K.A., Wallace, L.S. & Shannon, R.P. (2011). Evaluation of limitation-of-medical-treatment forms used in emergency medicine residency programs in the United States. *Journal of Emergency Medicine*, 41(6): 713–717.
- Admi, H., Muller, E., Ungar, L., Reis, S., Kaffman, M., Naveh, N., & Shadmi, E. (2013). Hospital–community interface: A qualitative study on patients with cancer and health care providers' experiences. *European Journal of Oncology Nursing*, 17(5), 528-535.
- Adriaenssens, J., De Gucht, V., & Maes, S. (2015). Determinants and prevalence of burnout in emergency nurses: A systematic review of 25 years of research. *International journal of nursing studies*, 52(2), 649-661.
- Andorno, R. (2011). Dignidad humana. In C.M. Romeo Casabona (Ed.), *Enciclopedia de bioderecho y bioética*. Vol I (pp. 658-663) Comares, Granada.

Bailey, C. J., Murphy, R., & Porock, D. (2011). Dying cases in emergency places: caring for the dying in emergency departments. *Social science & medicine*, 73(9), 1371-1377.

Beckstrand, R. L., Wood, R. D., Callister, L. C., Luthy, K. E., & Heaston, S. (2012). Emergency nurses' suggestions for improving end-of-life care obstacles. *Journal of Emergency Nursing*, 38(5), e7-e14.

Becze, E. (2016). Palliative Care Initiated in the Emergency Department Improves Patients' Quality of Life. *ONS connect*, 31(3), 38.

Chochinov, H. M. (2002). Dignity-conserving care—a new model for palliative care: helping the patient feel valued. *JAMA*, 287(17), 2253-2260.

Chochinov, H. M. (2004). Dignity and the eye of the beholder. *Journal of Clinical Oncology*, 22(7), 1336-1340.

Chochinov, H. M., Hack, T., McClement, S., Kristjanson, L., & Harlos, M. (2002). Dignity in the terminally ill: a developing empirical model. *Social Science & Medicine*, 54(3), 433-443.

Debesay, J., Nåden, D., & Slettebø, Å. (2008). How do we close the hermeneutic circle? A Gadamerian approach to justification in interpretation in qualitative studies. *Nursing Inquiry*, 15(1), 57-66.

Durán Agüero, S., & Vásquez Leiva, A. (2015). Caracterización antropométrica, calidad y estilos de vida del anciano chileno octogenario. *Nutrición Hospitalaria*, 31(6), 2554-2560.

Edlund, M., Lindwall, L., Post, I. V., & Lindström, U. Å. (2013). Concept determination of human dignity. *Nursing Ethics*, 20(8), 851-860.

Escalante, C. P., Manzullo, E. F., Lam, T. P., Ensor, J. E., Valdres, R. U., & Wang, X. S. (2008). Fatigue and its risk factors in cancer patients who seek emergency care. *Journal of Pain and Symptom Management*, 36(4), 358-366.

Fassier, T., Valour, E., Colin, C., & Danet, F. (2016). Who am I to decide whether this person is to die today? Physicians' life-or-death decisions for elderly critically ill patients at the emergency department–ICU interface: a qualitative study. *Annals of Emergency Medicine*, 68(1), 28-39.

Fernández-Sola, C., Díaz Cortés, M. M., Hernández-Padilla, J. M., Aranda Torres, C. J., Muñoz Terrón, J. M., & Granero-Molina, J. (2017). Defining dignity in end-of-life care in the emergency department. *Nursing Ethics*, 24(1), 20-32.

Fernández-Sola, C., Granero-Molina, J., Aguilera-Manrique, G., Castro-Sánchez, A. M., Hernández-Padilla, J. M., & Márquez-Membrive, J. (2012). New regulation of the right to a dignified dying in Spain: Repercussions for nursing. *Nursing Ethics*, 19(5), 619-628.

Fleming, V., Gaidys, U., & Robb, Y. (2003). Hermeneutic research in nursing: developing a Gadamerian-based research method. *Nursing Inquiry*, 10(2), 113-120.

Forero, R., McDonnell, G., Gallego, B., McCarthy, S., Mohsin, M., Shanley, C., ... & Hillman, K. (2012). A literature review on care at the end-of-life in the emergency department. *Emergency Medicine International*, 2012. DOI: 10.1155/2012/486516.

Formosa, P. (2014). Dignity and respect: how to apply Kant's formula of humanity. *The Philosophical Forum*, 45(1), 49–68.

Gadamer, H.G. (2013) *Truth and Method*. 1rst. Paperback edition. Bloomsbury Academic, London/New York.

García, V. & Rivas, E. (2013) Experiencias de enfermeras intensivistas pediátricas en la muerte de un niño: vivencias, duelo, aspectos bioéticos. *Ciencia y Enfermería*, 19(2), 111-124.

Granero-Molina, J., Diaz Cortes, M. M., Marquez Membrive, J., Castro-Sánchez, A. M., Lopez Entrambasaguas, O. M., & Fernández-Sola, C. (2014). Religious faith in coping with terminal cancer: what is the nursing experience? *European Journal of Cancer Care*, 23(3), 300-309.

Granero-Molina, J., Díaz-Cortés, M.M., Hernández-Padilla, J.M., García-Caro, M.P., & Fernández-Sola, C. (2016). Loss of dignity in end-of-life care in the emergency department: a phenomenological study with health professionals. *Journal of Emergency Nursing*, 42(3), 233-239.

Green J. & Thorogood N. (2014) *Qualitative methods for health research*, 3rd edn. Sage, London.

Griffin-Heslin, V. L. (2005). An analysis of the concept dignity. *Accident and Emergency Nursing*, 13(4), 251-257.

Groot, M., Ebenau, A. F., Koning, H., Visser, A., Leget, C., van Laarhoven, H. W. M., ... Garssen, B. (2017). Spiritual care by nurses in curative cancer care: Protocol for a national, multicentre, mixed method study. *Journal of Advanced Nursing*. <http://doi.org/10.1111/jan.13332>

Grudzen, C. R., Richardson, L. D., Major-Monfried, H., Kandarian, B., Ortiz, J. M., & Morrison, R. S. (2013). Hospital administrators' views on barriers and opportunities to delivering palliative care in the emergency department. *Annals of Emergency Medicine*, 61(6), 654-660.

Guo, Q., & Jacelon, C. S. (2014). An integrative review of dignity in end-of-life care. *Palliative Medicine*, 28(7), 931-940.

Haugen, H. M. (2010). Inclusive and relevant language: the use of the concepts of autonomy, dignity and vulnerability in different contexts. *Medicine, Health Care and Philosophy*, 13(3), 203-213.

Iglesias, M.L., & Lafuente, A. (2010). Asistencia al paciente agónico que va a fallecer en urgencias. *Anales del Sistema Sanitario de Navarra*, 33(1), 173–191.

INE. (2017). Esperanza de vida. In: INE. Mujeres y hombres en España 2017. Madrid, España: Instituto Nacional de Estadística (INE). Available at: http://www.ine.es/ss/Satellite?L=es_ES&c=INESeccion_C&cid=1259926380048&p=1254735110672&pagename=ProductosYServicios/PYSLayout. (Accessed July 2017).

Jesus, J. E., Geiderman, J. M., Venkat, A., Limehouse, W. E., Derse, A. R., Larkin, G. L., ... & ACEP Ethics Committee. (2014). Physician orders for life-sustaining treatment and emergency medicine: ethical considerations, legal issues and emerging trends. *Annals of Emergency Medicine*, 64(2), 140-144.

Jiménez-Herrera, M. F., & Axelsson, C. (2015). Some ethical conflicts in emergency care. *Nursing Ethics*, 22(5), 548-560.

Kant, I. (2001). *Lectures on ethics*. Cambridge University Press, Cambridge, UK.

Kant, I. (2002). *Groundwork for the Metaphysics of Morals*. Yale University Press, New Haven, CT, USA.

King, P. A., & Thomas, S. P. (2013). Phenomenological study of ICU nurses' experiences caring for dying patients. *Western Journal of Nursing Research*, 35(10), 1292-1308.

Latour, J. M., & Albarran, J. W. (2012). Privacy, dignity and confidentiality: a time to reflect on practice. *Nursing in Critical Care*, 17(3), 109-111.

Lee, J., & Kim, K. H. (2010). Perspectives of Korean patients, families, physicians and nurses on advance directives. *Asian Nursing Research*, 4(4), 185-193.

Limehouse, W. E., Ramana Feeser, V., Bookman, K. J., & Derse, A. (2012). A Model for Emergency Department End-of-life Communications After Acute Devastating Events—Part II: Moving From Resuscitative to End-of-life or Palliative Treatment. *Academic Emergency Medicine*, 19(11), 1300-1308.

Marck, C. H., Weil, J., Lane, H., Weiland, T. J., Philip, J., Boughey, M., & Jelinek, G. A. (2014). Care of the dying cancer patient in the emergency department: findings from a national survey of Australian emergency department clinicians. *Internal Medicine Journal*, 44(4), 362-368.

Matus-López, M., & Cid-Pedraza, C. (2014). Costo de un sistema de atención de adultos mayores dependientes en Chile, 2012 - 2020. *Revista Panamericana de Salud Publica*, 36(1),31-36.

Mauthner, N. S., & Doucet, A. (2003). Reflexive accounts and accounts of reflexivity in qualitative data analysis. *Sociology*, 37(3), 413-431.

Molan, E. (2012). Opinion Piece: A 'good enough death' in the emergency department—It is possible. *Contemporary Nurse*, 42(1), 105-106.

Morales, G. (2015). Limitación del esfuerzo terapéutico en cuidados intensivos pediátricos. *Revista Chilena de Pediatría*, 86(1), 56-60

Nayeri, N. D., & Aghajani, M. (2010). Patients' privacy and satisfaction in the emergency department: a descriptive analytical study. *Nursing Ethics*, 17(2), 167-177.

Nikki, L., Lepistö, S., & Paavilainen, E. (2012). Experiences of family members of elderly patients in the emergency department: a qualitative study. *International Emergency Nursing*, 20(4), 193-200.

Oosterveld-Vlug, M. G., Pasman, H. R. W., Gennip, I. E., Muller, M. T., Willems, D. L., & Onwuteaka-Philipsen, B. D. (2014). Dignity and the factors that influence it according to nursing home residents: a qualitative interview study. *Journal of Advanced Nursing*, 70(1), 97-106.

Peters, L., Cant, R., Payne, S., O'Connor, M., McDermott, F., Hood, K., ... & Shimoinaba, K. (2013). Emergency and palliative care nurses' levels of anxiety about death and coping with death: a questionnaire survey. *Australasian Emergency Nursing Journal*, 16(4), 152-159.

Phillips, J. (2013). What will it take to put talking about death on our agenda?. *Collegian*, 20(4), 205-206.

Richards, N., Ingleton, C., Gardiner, C., & Gott, M. (2013). Awareness contexts revisited: indeterminacy in initiating discussions at the end-of-life. *Journal of Advanced Nursing*, 69(12), 2654-2664.

Sagha Zadeh, R., Eshelman, P., Setla, J., & Sadatsafavi, H. (2017). Strategies to Improve Quality of Life at the End of Life: Interdisciplinary Team Perspectives. *American Journal of Hospice and Palliative Medicine*, [Epub ahead of print], doi: 10.1177/1049909117711997.

Scanlon, A., & Murphy, M. (2014). Medical futility in the care of non-competent terminally ill patient: nursing perspectives and responsibilities. *Australian Critical Care*, 27(2), 99-102.

Scheck, A. (2012). Special Report: When the ED's Job Isn't Saving a Life but Helping One End with Dignity. *Emergency Medicine News*, 34(6), 16-17.

Scott, T. (2013). Sudden death liminality: Dehumanisation and disengagement. *International Emergency Nursing*, 21(1), 10-16.

Seale, C. (2009). Hastening death in end-of-life care: a survey of doctors. *Social Science & Medicine*, 69(11), 1659-1666.

SECPAL. (2014). *Guía de cuidados paliativos*. Sociedad Española de Cuidados Paliativos (SECPAL), Available at: <http://www.secpal.com/guia-cuidados-paliativos-1> (accessed May 2017).

Sepúlveda, J. M., Morales Asensio, J. M., Morales Gil, I. M., Canca Sánchez, J. C., Pérez Tueba, E., & Rueda Dominguez, A. (2014). Impact of a legislative framework on quality of end-of-life care and dying in an acute hospital in Spain. *International Journal of Palliative Nursing*, 20(5), 225–231.

Smith, A. K., Fisher, J., Schonberg, M. A., Pallin, D. J., Block, S. D., Forrow, L., ... & McCarthy, E. P. (2009). Am I doing the right thing? Provider perspectives on improving palliative care in the emergency department. *Annals of Emergency Medicine*, 54(1), 86-93.

Tellett, L., Pyle, L., & Coombs, M. (2012). End of life in intensive care: is transfer home an alternative?. *Intensive and Critical Care Nursing*, 28(4), 234-241.

Van Tricht, M., Riochet, D., Batard, E., Martinage, A., Montassier, E., Potel, G., & Le Conte, P. (2012). Palliative care for patients who died in emergency departments: analysis of a multicentre cross-sectional survey. *Emergency Medicine Journal*, 29(10), 795–797.

WHO. (2015) Global health observatory data by Countries/Spain. Geneva, Switzerland, World Health Organization (WHO). Available at: <http://www.who.int/countries/esp/en/> (accessed July 2017)

Wong, R. E., Weiland, T. J., & Jelinek, G. A. (2012). Emergency clinicians' attitudes and decisions in patient scenarios involving advance directives. *Emergency Medicine Journal*, 29(9), 720-724.

Table 1. Work Plan

PHASE 1: State of the issue, make contacts, prepare permissions					
Timeline	Objective	Tasks	Milestones	Deliverables	
Semester-1	To explore the state of knowledge	Review bibliography	State of knowledge	Updated bibliography. DI and FG Guides	
	Look for contacts	ED visits	Make contacts	Calendar of observations.	
	Request Ethics Committee permissions (CREC)	Complete CREC reports.	Request permissions	CREC permissions granted	
PHASE 2: Data Collection					
Timeline	Objective	Tasks	Milestones	Deliverables	Analysis
Semester-2	Observe care of terminally-ill patients in the ED	PO-1	Complete field notebook.	Notebook completed.	Data analysis
	Observe care of terminally-ill patients under observation in the ED	PO-2	Complete observation notebook.	Notebook completed.	
Semester-3	Experiences of spouses	FG-1	Conduct FG-1	FG-1 Transcription	
	Experiences of children	FG-2	Conduct FG-2	FG-2 Transcription	
	Experiences of professionals	FG-3	Conduct FG-3	FG-3	

		FG-4	FG-4	Transcription FG-4 Transcription
	Experiences of professionals.	DI-1	Conduct DI-1	DI-1 Transcription
	Experiences of terminally-ill patients (1st visit to the ED)	DI-2	Conduct DI-2	DI-2 Transcription
Semester-4	Experiences of terminally-ill patients (> 1 visit to the ED)	DI-3	Conduct DI-3	DI-3 Transcription
	Training of ED professionals	Course design	Designing a course	Course designed (Training for professionals)
	Knowledge transfer (Design a care guide)	Workshops (NGT, SWOT)	Workshops carried	Report of workshops
PHASE 3: Data analysis, report writing and publication of results				
Timeline	Objective	Tasks	Milestones	Deliverables
Semester-4	Analyze data	Data analysis	Data analyzed	Results available.
	Design a care guide	Design guide	Guide published	Terminally-ill ED patient Care Guide
Semester-5	Write results	Write a scientific article.	Submitting articles to JCR journals	3 submitted articles. Presentations prepared.
Semester-6	Publication of results	Look after the review process. Preparation of conferences and presentations.	Articles published (JCR) Conferences in the National Health Service and congresses.	3 published articles (JCR) Presentations in International Congresses.