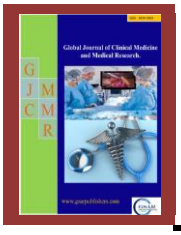

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End-of-life care: perceptions and coping with death among healthcare professionals in the Balearic Islands A multicenter study.

By

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Abstract

Aim: *the objective of this study was to explore and compare the perspectives of physicians and nurses about end-of-life care (EOL), palliative care, coping death and determining care practices involved in the EOL decision-making.*

Methods: *we conducted a descriptive, quantitative and multicentre study with in the Balearic Island (Spain) from different hospitals units and primary care related to patient care at the EOL. It was an anonymous questionnaire and was structured around 3 themes (EOL care, different aspect of attention to terminal patient and coping death).*

Results: *a total of 422 professionals participated, 292 (66%) are nurses and 150 (34%) are physicians. Differents therapeutic measures like pain relief medication, sedation medication and care of the mouth were classified by a similar percentage of nurses and physicians as basic EOL care. However, body hygiene, positional changes, wound and ulcer care, nasogastric tube, urinary catheterization and fluid therapy were classified by a higher percentage of physicians as basic EOL care. A lower percentage of nurses consider that the care plan is carried out according to the patient and family preferences and that pain is effectively evaluated and treated. A higher percentage of nurses believe that professionals are not familiar with the procedure for accessing the Advance Directives Registry and that the Advance Directives Document is not consulted. A lower percentage of nurse's report having received the necessary training to support and communicate with the families of dying patients and having had a rewarding experience providing palliative care to terminal patients. To be a physician improves coping with death.*

Conclusion: *decision and perception about EOL care and attitudes about palliative care are influenced by profession, experiences, environment, values, emotions and beliefs. More emphasis on interprofessional education and collaboration between the two disciplines may enhance future decision making processes and there is a need to improve training in ethics and end-of-life processes.*

Keywords: *end of life care, nurses, physicians, terminal patient, death.*

INTRODUCTION

Caring for patients at the end of life represents a challenge for professionals and healthcare systems. According to the Spanish Society for Palliative Care (SECPAL), only half of the population in need of palliative care actually receives it. In many cases, patients with terminal illnesses are treated in non-specialized services by professionals who are not familiar with palliative care. In this context, and when the disease does not respond to curative treatment, palliative care emerges as a form of total and active care through the control of pain and

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other physical, psychological, social, and spiritual symptoms. (1)

In end-of-life care, many professionals encounter difficulties in coping with care and loss due to various factors. Additionally, modern society does not teach how to face death, which results in difficulty confronting it in an adaptive way. (2)(3)

In terminally ill patients, the appearance of symptoms closely related to death causes a significant emotional impact on the patient, family, and even the therapeutic team. The WHO and SECPAL identify as basic objectives pain control, addressing physical, psychological, and spiritual problems, emotional support for the patient and family, and the patient's well-being and quality of life. (4)

Various studies (5–7) show that the general level of knowledge about palliative care is poor among healthcare professionals. One of the important factors influencing the success of palliative care is professionals' knowledge, as well as their attitudes, beliefs, and experiences, enabling them to address the physical, emotional, social, and cultural dimensions of care. (4)

The literature describes various difficulties professionals experience regarding end-of-life care due to the medical, philosophical, anthropological, and political debate surrounding it and the uncertainty of defining the end-of-life moment. (8) All of this creates challenges in establishing homogeneous criteria for end-of-life care, since life is not an absolute value; it has never been considered the fundamental or most important value. Often, other values—religious, social, familial—prevail, and in cases of conflict in clinical care, these may take precedence over prolonging life. (9)

The study by Blanco Portillo et al. (10) reveals that end-of-life management, incompetent patients, and clinical relationship issues are the most frequent ethical conflicts in healthcare. Campos Calderón C, et al. (11) describe the difficulties hospital professionals face in changing therapeutic goals according to end-of-life situations. Sepúlveda Sánchez JM, et al. (12) identify other difficulties such as lack of homogeneous criteria for prescribing palliative sedation, insufficient training in delivering bad news, shared decision-making, and lack of understanding of therapeutic effort limitation.

However, few studies in our country provide a comprehensive and comparative analysis of nurses' and physicians' perceptions of palliative care, quality of professional practice, daily work with terminal patients, and coping with death. This analysis is necessary to capture professionals' opinions and diagnose the current situation to identify appropriate measures to improve the quality of end-of-life care.

To identify differences and similarities between nurses and physicians in caring for terminal patients, a study was conducted to explore perceptions, ethical dilemmas, experiences, barriers, and facilitators encountered when providing care at the end of life.

METHOD

Study design

A descriptive, cross-sectional, quantitative, multicentre study was conducted in March 2022 with nurses and physicians working in the Balearic Islands Health Service involved in end-of-life care. Professionals were selected from two care settings:

- Hospital Care (HC): emergency departments, ICU, oncology, palliative care, and multi-pathology units.
- Primary Care (PC): primary care management of Mallorca, Ibiza, and Menorca.

Participants worked in different hospitals: Hospital Universitario Son Espases, Hospital Universitario Son Llàtzer, Hospital de Manacor, Hospital de Inca, Hospital General, Hospital San Juan de Dios, Hospital Mateu Orfila, and Hospital Can Misses.

Study population

A total of 442 nursing and medical professionals who provided end-of-life care to patients participated. Therefore, a selection of participants was made on purpose, taking into account professional category, unit, and time worked in the same. The inclusion criteria were that the participant be a nurse or doctor and have worked for at least 6 months in that unit. The participants were recruited by unit managers via telephone, email, or in person. The participants received information about the study via email and in-person talks. Each participant agreed to participate in the research freely and voluntarily.

Data collection

The data collection period took place from March 1 to May 30, 2022. The survey was conducted online based on a literature review and validated instruments related to this topic. (1, 9–18) The study was disseminated via corporate email and a link sent via mobile phone.

Statistical analysis

The data analysis was performed using the Stata/IC version 15.1 statistical program. Continuous variables will be presented by mean and standard deviation. Categorical variables are described through their proportions. For the comparison of two means between quantitative variables, parametric tests (t-Student) were applied. If the assumptions for its application are not met, a non-parametric test (Wilcoxon's W) will be chosen. For comparing means among more than two groups, parametric tests of analysis of variance (ANOVA) will be used. In the event that the assumptions for its application were not met, a non-parametric test (Kruskal-Wallis) was chosen. Categorical variables were compared by analysing contingency tables using Pearson's chi-square statistic for large samples and Fisher's exact test for small samples.

Ethical considerations

The study has been authorized by the respective research ethics committees of each participating healthcare center and by the respective regional research ethics committee. The research was conducted after receiving a favourable report

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from the Balearic Islands Clinical Research and Ethics Committee (CEIC-ib) and adhered to its ethical guidelines.

The participants were informed about the study and its objectives, and their informed consent was obtained prior to the survey. During the course of the investigation, the confidentiality and anonymity of the participants were maintained, respecting the bioethical principles of the Declaration of Helsinki. The data obtained has been stored and protected in compliance with the data protection regulations in effect in our country.

RESULTS

A total of 442 professionals were included after applying the inclusion and exclusion criteria. In terms of profession, 292 were nurses (66%), of which 16 were resident nurses. The remaining 150 professionals were physicians (34%), of whom 26 were resident physicians.

The average age of nurses is 41.5 years, and that of doctors is 45.9 years. 15.8% of nursing professionals are male, and 84.3% are female. Among doctors, 39.3% are male, 59.3% are female, and 1.3% are of another gender. 38.1% of nursing professionals and 47.33% of medical professionals are religious. The average work experience of nurses is 17.6 years, and that of doctors is 19.2 years. The average years of work experience in the current position for nurses is 9.2 years, and for doctors, it is 12.7 years. *See Table 1*.

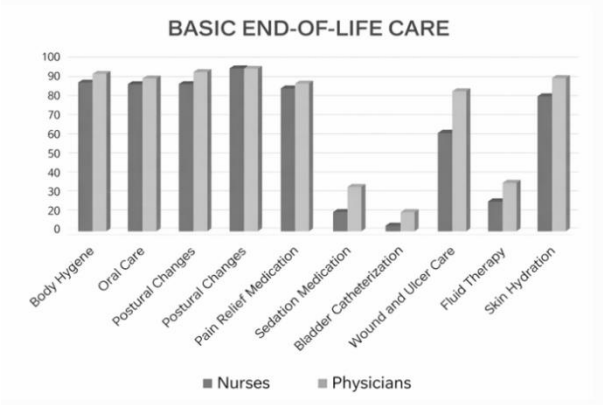
WORKPLACE	NURSES	PHYSICIANS	TOTAL
Primary Care Management	177	88	265
Hospital Universitario Son Espases	28	18	46
Hospital de Manacor	23	15	38
Hospital Universitario Son Llàtzer	20	10	30
Hospital de Inca	12	4	16
Hospital Mateu Orfila	12	2	14
Hospital Can Misses	7	6	13
Hospital General	9	1	10
Hospital San Juan de Dios	4	6	10

Basic care at the end of life

Regarding a relationship of therapeutic measures, nurses and doctors could include or exclude these measures under the concept of basic care at the end of life according to their criteria and experiences, and the following results were obtained:

- Body hygiene is classified as a basic care at the end of life by 85.6% of nurses and 94% of physicians (p=0.009).
- Postural changes are considered by 76.4% of nurses and 86% of physicians as basic care at the end (p=0.017).
- 11.3% of nurses and 28% of physicians consider bladder catheterization a basic end-of-life care (p<0.001).
- Nasogastric suctioning is classified as basic care by 3.8% of nurses and 13.3% of physicians (p<0.001).
- Wound care are considered a basic care at the end of life by 53.1% of nurses and 83.3% of physicians.
- 14.4% of nurses and 27.3% of physicians classified hydration therapy as basic end-of-life care (p=0.001).
- Skin hydration is considered a basic care at the end of life by 74.3% of nurses and 88% of physicians (p=0.001).
- Mouth care, pain relief, and sedation medication were rated by a similar percentage of nurses and physicians as basic end-of-life care.

See Graph 1.



***Graph 1*. Percentage of nurses and doctors who include the following measures as basic care at the end of life.**

There were no significant differences in responses based on profession regarding various therapeutic effort adjustment actions in terminally ill patients: a similar percentage of nurses and doctors considered enteral nutrition disproportionate in a patient unable to eat by mouth (p=0.931); however, only 53.4% of nurses and 50% of doctors considered intravenous therapy a disproportionate measure in a patient unable to drink by mouth (p=0.495).

A similar percentage of nurses and doctors are in favor of not initiating or removing a nasogastric tube if mechanical restraints would be needed to feed a terminally ill patient (p=0.915). Less than half of both groups (46.9% of nurses and 47.3% of doctors) think that it is the same not to initiate a form of treatment as to withdraw it if it has already been initiated (p=0.934) and if it were a direct family member, a high percentage of both groups (96.9% of nurses and 97.3% of doctors) would agree to suspend extraordinary measures if it were an irretrievable case (p=0.807). Nearly half of both groups (52.1% of nurses and 50% of physicians) have made

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public their desire not to apply extraordinary measures in the event of a critical or terminal illness (p=0.682).

End-of-life care.

Some aspects of end-of-life care were evaluated through a battery of questions, and statistically significant differences were found between nurses and physicians:

68.3% of nurses and 81.5% of physicians believe that the care plan is carried out according to the patient's and family's preferences (p=0.01); 55.6% of nurses and 69.2% of physician's state that pain is evaluated and treated effectively (p=0.011). 53.4% of nurses and 33.3% of physician's report that physical, psychological, and spiritual aspects are considered in the treatment of pain and symptoms, and that pharmacological and non-pharmacological measures are incorporated as supportive therapy (p<0.001); 35.2% of nurses and 48.3% of physicians support the idea that the transition to agony is recognized, documented, and properly communicated to the patient, family, and attending staff (p=0.001).

50% of nurses believe that patients and their families are given options about where they die, compared to 71.8% of doctors (p<0.001); a higher percentage of nurses (45.3%) believe that professionals do not know the procedure for accessing the Advance Directive Registry compared to 30.8% of doctors (p=0.015). A higher percentage of nurses (41.2%) say that the Advance Directive is not consulted compared to the percentage of doctors (33.1%) who say the same (p=0.049).

The differences found in other items were also interesting, although no significant differences were obtained: the percentage of nurses (11%) was higher than the percentage of doctors (4.8%) who believe that other symptoms such as dyspnea, agitation, and vomiting are not evaluated and not treated properly; 46.5% of nurses and 54.9% of doctors believe that meetings with family members are held to provide information and help with decision-making; a higher percentage of nurses (37.8%) report availability and access to a spiritual guide as needed according to their beliefs compared to the percentage of doctors who report this (25.9%); and a lower percentage of nurses (25.6%) believe that patients and family members are informed about the existence of the Advance Directives Registry compared to the percentage of doctors who believe this (35.4%).

See Table 2.

End-of-life care	Physicians (%)	Nurses (%)
Do-not-resuscitate orders are recorded in the medical record	72	75
In case of ethical conflict, the Ethics Committee is consulted	50	52
The patient has expressed end-of-life care preferences and they are recorded	48	55
The Advance Directives Document is consulted	30	52
Professionals know how to access the Advance Directives Registry	25	45
Patients and families are informed about the Advance Directives Registry	24	44
Families know the signs and symptoms of approaching death	23	23
Options are offered to the patient/family about the place of death	60	72
The transition to death is recognized and properly communicated	35	55
Cultural aspects of the patient and family are considered	45	60
Access to spiritual care according to beliefs is available	25	40
Families receive support during severe illness and dying	55	62
Meetings are held with families for information and decision-making	48	60
Pain management includes physical, psychological, and social aspects	32	58
Dyspnea, agitation, and vomiting are assessed and treated properly	65	68
Pain is evaluated and treated effectively	58	70
Availability of a case manager nurse	72	78
Staff have the necessary skills to care for patients and families	42	42
Care plans follow patient and family preferences	68	70

Table 2. Level of agreement among professionals on different aspects of end-of-life care.

Good Coping with Death Scale (BUGEN Scale).

This death coping scale has a theoretical maximum value of 210, and poor coping is indicated when subjects score below the 33rd percentile, good coping when they score above the 66th percentile, and neutral coping when they score in the middle range.

In relation to our subjects, the results show that nurses scored an average of 138.8 with a standard deviation of 26.2, while

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doctors scored an average of 145 with a standard deviation of 26.2.

The results show that 31% of the total number of professionals have a poor coping mechanism for death. This percentage is higher among nurses (36%) than among doctors (23%).The percentage of neutral coping is similar among nurses (35%) and physicians (36%), and the percentage of respondents with good coping of death is lower among nurses (29%) than physicians (41%).

The data shows statistically significant differences between profession and degree of coping with death, so it can be concluded that the health profession influences the degree of coping with death. According to our data, belonging to the medical profession improves coping with death.

See Table 3.

BUGEN SCALE			
	Nurses	**Physicians**	**Total**
Poor coping	104 (36%)	35 (23%)	139 (31%)
Neutral coping	103 (35%)	54 (36%)	157 (36%)
Good coping	85 (29%)	61 (41%)	146 (33%)
TOTAL	292 (100%)	150 (100%)	442 (100%)
			p=0.012

Table 3. Degree of coping with death of nurses and doctors.

DISCUSSION

Disease, suffering, and death are inherent to the human condition, which makes it coherent to understand that the progress of medical sciences, biotechnology, as well as the growing human needs and the increase in life expectancy have generated the need to rethink the goals of medicine and its scope. Personal experience is a determining factor in the type of care and attention given to the patient. (23) Additionally, interprofessional collaboration has proven to be the most effective method used for complex end-of-life decisions due to the reduction of complications and the improvement in the relationship of trust and communication between the doctor and nurse, (24)(25) as well as communication strategies with the patient and their family that improve the patient's goals and care and minimize conflicts when implementing end-of-life decisions. (26)(27)(28)

The results found have allowed us to answer the initial objectives of this study. In line with other studies (29)(10)(25), the professionals surveyed reported difficulties in making end-of-life decisions related to different actions such as the use of palliative treatments, therapeutic effort adjustment (TEA) orders, and fear when it comes to dealing with end-of-life care planning.

The study reflects discrepancies between nurses and doctors when classifying basic care at the end of life. These differences were significant in terms of body hygiene, postural changes, bladder catheterization, nasogastric intubation, intravenous therapy, wound and ulcer care, and skin hydration, all of which were considered to be basic care by medical professionals at a higher rate. Regarding pain medication, both groups of professionals showed high awareness of this measure, as it is considered the most common basic care at the end of life. However, nurses report that pain is evaluated and treated effectively less often.

These discrepancies may be due to the different roles of both professionals, as well as the differences in the training they receive and the type of work they do. Nurses dedicate their care activities to patient care and sometimes to carrying out medical orders set by these professionals (which they do not always have to agree with), which can produce different perceptions and levels of satisfaction in care and decisions related to the end of life. The impact of poor interdisciplinary communication directly affecting effective collaboration in decision-making is historic. (25) However and according to our research, there are no statistically significant differences in the actions of nurses and doctors in relation to artificial nutrition and hydration in the terminally ill patient, despite the fact that these therapeutic measures present great ethical and emotional challenges in the decisions related to their withdrawal or maintenance in end-of-life processes. (30) (31,32) (33)

Like other authors (6)(26), it is interesting to note from this study that nurses report a clear deficit in training in palliative care and end-of-life communication, which is associated with the fact that they also express to a greater extent that their experiences providing palliative care have not been rewarding. Less than half of both groups of professionals indicate that they have received the necessary training to assist patients who need palliative care. These factors may also influence the greater perception of nurses that curative care is more important than palliative care. The reason for this may be related to the longer training time that doctors have in their degree, where they can gain more knowledge and experience through the rotation they do in various specialties. Other studies (34) describe the agreement among professionals in equating the importance of palliative care and curative care.

The results showed nurses and physicians considered ethically sensitive situations in healthcare activities with some differences, which were probably due to their different educational curricula, roles and level of responsibility towards health institutions. Since these curricula do not always include psychology, ethics, and communication teachings, it would be desirable to integrate these topics into basic and post-basic interprofesional educational pathways.(26)

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Our research data reveal that physicians have a higher percentage of "good coping" with death, and nurses show greater vulnerability on this scale. Less than a third of both groups of professionals believe that their personal attitudes toward death affect their willingness to provide palliative care. Other studies (2)(26) show that death is related to providing adequate care to the terminally ill, which makes it essential to improve the emotional, psychological, and spiritual support of professionals who provide EOL care to reduce their distress in these situations and indirectly improve the professional's relationship with the patient and their family. (35)

This study identifies that a smaller percentage of nurses believe that the care plan is being carried out according to the patient's and their family's preferences, that the procedure for accessing the Advance Directive Registry is known, and that the Advance Directive is consulted. Some of the causes related by other authors (36)(35) may be the lack of inclusion of the nursing professional in the decision-making process about EOL care, either because the physician does not consider other professionals in this process or because nurses believe it is not part of their competencies, the lack of ethics training for health professionals, the lack of institutional support, and the biomedical concept of care that promotes the dehumanization of care in patients with EOL care. The need to improve communication within the multidisciplinary team is then identified, as well as their perceptions and those of the family about end-of-life care.

Like other studies (35)(37), this research concludes the need to reinforce the theoretical knowledge of future communication professionals and the bioethical aspects associated with clinical practice in end-of-life processes. Additionally, there is a need for ethical clarification regarding the decision-making process and basic care in terminal stages.

It is crucial that healthcare professionals implement strategies to overcome gaps in staff education and support, to ensure all patients and families receive quality end of life care. The importance of having staff who feel equipped, knowledgeable and supported in end of life care delivery cannot be underestimated.

Therefore, this study can serve as a basis for future research, leaving the challenge in the development of new protocols for the implementation and improvement of end-of-life care processes, with the priority being the design of training programs in ethics, communication strategies and skills in end-of-life care and palliative care to more accurately address and recognize those processes and patients that require the adaptation of therapeutic effort.

Limits of the study

The study was carried out in a local context (Balearic Island); moreover, the utilization of closed-ended questions could have hidden some aspects of healthcare workers' point of view. Therefore, the generalization of the results should be cautious.

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CONFLICT DE INTERESTS

The authors declare that they have no conflict of interest regarding the research, authorship, or publication of this article.

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