

# Legislative knowledge and preparation of health personnel for the care process of death

CONHECIMENTO EM LEGISLAÇÃO E PREPARAÇÃO DOS PROFISSIONAIS DE SAÚDE SOBRE O PROCESSO DE CUIDADO DA MORTE

CONOCIMIENTO DE LA LEY Y PREPARACIÓN DEL PERSONAL SANITARIO SOBRE EL PROCESO ASISTENCIAL DE LA MUERTE

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## ABSTRACT

The aims of this study were to ascertain the perception that health professionals (doctors, nurses and nursing assistants) have about their preparation for the care of terminally ill patients and to determine their knowledge about palliative care legislation. This cross sectional study was performed at a hospital in Granada (Spain); we administered an 'ad hoc' questionnaire. The results indicated that although most of the staff had worked with terminally ill patients, only half believed that they have been trained to care for them. A significant proportion stated that they did not know about the current palliative care legislation. Most professionals would question the withdrawal of therapies for the maintenance of life; most of them are also unaware of the mechanism for reporting on the completion of a *Living Will*, as well as a *Plan for Palliative Care* in Andalusia (Spain).

## DESCRIPTORS

Palliative care  
Health personnel  
Patient care team  
Death, Legislation

## RESUMO

Os objetivos deste estudo são determinar a percepção que os profissionais de saúde (médicos, enfermeiros e auxiliares de enfermagem) têm sobre a sua preparação sobre o cuidado dos doentes terminais e determinar seu conhecimento da legislação sobre cuidados paliativos. Realizou-se um estudo transversal em um hospital em Granada (Espanha), através da aplicação de um questionário *ad hoc*. Os resultados mostram que a maioria do pessoal trabalha com pacientes no fim de sua vida, mas apenas a metade crê que têm o treinamento adequado para cuidar deles. Uma proporção significativa disse que não conhece a legislação vigente sobre cuidados paliativos. A maioria dos profissionais propenderia a retirada de terapias para a sustentação da vida e não sabem o mecanismo de comunicação sobre a realização do *Living Will*, como indica o *Plano de Assistência Paliativa* de Andalusia (Espanha).

## DESCRITORES

Cuidados paliativos  
Pessoal de saúde  
Equipe de assistência ao paciente  
Morte  
Legislação

## RESUMEN

Este estudio apunta a conocer la percepción que los profesionales de la salud (médicos, enfermeras y auxiliares de enfermería) tienen acerca de su preparación en el cuidado de los enfermos terminales y determinar sus conocimientos sobre la legislación de cuidados paliativos. Se ha realizado un estudio transversal, en un hospital de Granada (España), mediante la aplicación de un cuestionario *ad hoc*. Los resultados muestran que la mayoría del personal ha trabajado con pacientes en el final de su vida, pero sólo la mitad cree tener la formación adecuada para cuidarlos. Una parte considerable dice no conocer la legislación actual en cuidados paliativos. La mayoría de los profesionales plantearía la retirada de terapias para el mantenimiento de la vida y desconocen el mecanismo para informar sobre la cumplimentación del *Testamento Vital*, como indica el *Plan de Cuidados Paliativos* de Andalusia (España).

## DESCRIPTORES

Cuidados paliativos  
Personal de salud  
Grupo de atención al paciente  
Muerte  
Legislación

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## INTRODUCTION

As of 1990, the World Health Organization (WHO) has adopted the definition of Palliative Care (PC) as the total care for patients whose illnesses do not respond to healing treatments, particularly when the illness is in an advanced and progressive phase.

The conclusions from the WHO Expert Committee Report on Pain Relief and Active Support Treatment in Cancer underline the principle of patient autonomy and emphasize not prolonging agony<sup>(1)</sup>.

The Parliamentary Assembly of the European Council has issued Recommendation 1418 (1999)<sup>(2)</sup> on the protection of human rights and the dignity of terminal and moribund patients urging member countries to legislate in favor of terminally ill patients. It establishes that the obligation to respect and protect the dignity of these people results from the inviolability of human dignity in all stages of life and is expressed by providing an adequate means that will allow a human being to die with dignity<sup>(3)</sup>.

In 1999, in its September 14 session, the Spanish Senate urged the Interterritorial Council of the National Health System (NHS) to establish a National PC Plan. An Interterritorial Council Working Group was formed in October 1999, and they developed the National PC Plan document. In 2000, responding to these recommendations, the Spanish Ministry of Health and Consumption published the basis for developing the National PC Plan, which was approved by the Interterritorial Council on December 18, 2000.

In Andalusia, an autonomous community with competencies over this matter, the Act on a *Declaration of Living Will* (VVA) was published in the Official Bulletin of the Andalusian Autonomous Government (BOJA) on October 31, 2003<sup>(4)</sup>, ensuring the autonomous right of people to express their will concerning clinical decisions that affect them. As a requirement for validity, it provided that the will must be expressed in writing, with proper identification of authorship, and must be filed in the VVA Registrar created for that purpose. It established mandatory consultation of the Registrar by all health professionals in charge of providing health care to a person in a situation that keeps him/her from making his/her own decisions.

Still, in this autonomous community of Andalusia, the April 8 Act 2/2010 on Rights and Guaranties of People in the Process of Death<sup>(5)</sup> developed by the autonomous government and discussed and ratified by the Andalusian Parliament recognized the patient's right to state his Living Will and to receive clinical information about his/her diagnostic and treatment to make decisions and reject therapies. A major novelty was incorporated in this law: palliative sedations were authorized for the first time in Spain,

thus ensuring legal coverage to professionals caring for terminal patients. Before deciding to withdraw life support, those measures that only contribute to prolonging a clinical situation without improving expectations, a physician must seek similar opinions from at least two professionals on his team. The law also requires physicians to check the VVA Registrar and to refrain from imposing his/her own moral or religious beliefs.

This rule fully develops the autonomous competencies provided for in article 20 of the 2007 Andalusian Statute of Autonomy, which states that all people are entitled to adequate treatment pain, total palliative care, and full dignity in the process of his/her death. This law permits palliative sedation and enforces the right to reject treatment, although assisted suicide and active euthanasia are still banned. The latter, however, are typified under the Criminal Code and are to be legislated upon by the Spanish Parliament. The Andalusian law contemplates that a patient in a terminal situation can reject treatment to extend his/her life or advanced life support<sup>(4)</sup>. Caring for terminal patients is further complicated because it is hard to draw boundaries between what it is to care for or alleviate suffering in favor of comfort and a dignified death and what it is to use invasive and painful measures that will only prolong suffering for a while<sup>(6)</sup>.

It is important that health professionals know the legal bases supporting health related actions in the end-of-life process.

Since the beginning of history, mankind has been characterized by suffering from illnesses, which has been inherent to evolution. Diseases have been accompanied by a wide variety of symptoms, including pain and suffering, which have been permanent, inevitable, and have limited the lives of human beings. Part and parcel of human life, death is not only a biological factor but also a process of social construction<sup>(7)</sup>. For this reason, health professionals must train to face the situation of terminal disease and the process of death; only by understanding existence and death<sup>(8-9)</sup> will we be able to envisage the possibilities of education that offers care in the end-of-life process<sup>(8)</sup> and to ensure quality care to patients in a terminal situation and to their families.

It is important that health professionals know the legal bases supporting health related actions in the end-of-life process. The objectives of this paper include identifying the perception health professionals have of their skills in the care of terminally ill patients and determining the knowledge health professionals must have about PC legislation.

## METHODS

A descriptive transversal study was conducted in a traumatology hospital in Granada, Spain. The study population included health professionals working in the hospitalization area of the hospital in the intensive care unit (ICU), resuscitation, and emergency. The study period was

April 1-30, 2011. The sample population was obtained from the list of health professionals published on the hospital's web site. The following inclusion criteria were applied: basic health professionals working in the hospital's hospitalization area, ICU, resuscitation and urgencies. Health professionals working in intermediary and management positions were excluded.

A total of 219 of the 531 people composing the study population worked in the hospitalization area, and 312 worked in the ICU, resuscitation, urgencies, and operating theater. Thirty-eight sample members were on vacation, and 18 were on a leave, leaving a total sample of 475 people, 215 of whom worked in the hospitalization area and 260 in the ICU, resuscitation, urgencies, and operating theater.

The hospital's ethics commission approved the study on February 2011, and that approval is reflected through code N. 11/02-16.

A research introduction letter was prepared; the letter explained the study objectives and included a research questionnaire and an envelope to introduce the filled-out questionnaire as a method of ensuring anonymity. Participation was on a volunteer basis.

All units and work shifts were visited (morning, afternoon, and night). Each care unit received as many questionnaires as there were people working there at the time. During the data gathering period, all of the hospital units and shifts were visited for the collection of completed questionnaires, which were returned in sealed envelopes by each professional.

The questionnaire contained questions about the following variables: gender, age, professional category, year of graduation, work unit, and type of contract. Other questions were based on PC preparation and knowledge of PC legislation:

Q1: Have you had contact with end-of-life patients?

Q2: Do you believe you are well prepared to handle moribund patient care?

Q3: Can you comfortably assist a terminal patient and his/her family?

Q4: Would you offer the patient and/or his/her family to remove all life support therapies, if the case came to that?

Q5: Did your course program include studies on palliative care?

Q6: Were you aware of the existence of the Law on Rights and Guarantees of the Dignity of Persons in the Process of Death?

Q7: From a legal point of view, is the limitation of therapeutic effort (LTE) a legal or illegal practice, according to the national or autonomous legislation?

Q8: From a legal point of view, is assisted suicide a legal or illegal practice, according to the national or autonomous legislation?

Q9: From a legal point of view, is euthanasia a legal or illegal practice, according to the national or autonomous legislation?

Q10: From a legal point of view, is respect for a patient's rejection of treatment a legal or illegal practice, according to the national or autonomous legislation?

Q11: From a legal point of view, is palliative sedation a legal or illegal practice, according to the national or autonomous legislation?

Q12: From a legal point of view, is the limitation of life support measures a legal or illegal practice, according to the national or autonomous legislation?

Q13: I know the mechanism to inform on fulfilling the Living Will.

Q14: Health professionals should be legally underpinned to help people who reiterate their desire to end their lives, when capable of deciding about their future, but when affected by an incurable disease that has been experienced as unacceptable. This disease cannot be mitigated by palliative care.

Q15: Health professionals are forced to provide treatment that only prolong the process of death and do not cure, if the family so desires.

The first six questions and question thirteen had two alternative answers, YES or NO. Questions seven through twelve inquired about the legal grounds at the regional and national levels for a certain statement. The answers to these questions were evaluated as correct or incorrect. For questions fourteen and fifteen, a five-answer Likert scale was used, and the participants were asked to mark the alternative that best represented his/her desire and knowledge.

The SPSS statistical package version 15.0 (supplied you by the University of Granada, Spain) was used for data analysis. A descriptive analysis of the variables, frequencies and percentages was made for the qualitative variables (gender, professional characteristics, and PC skills and knowledge about PC legislation), averages and standard deviation for the quantitative variables (age).

The  $\chi^2$  test was used for the bivariate analysis among the different professional categories. Likewise, answers were compared among the professionals who had some or none palliative care training. Differences were considered significant as of  $p < 0,05$ .

## RESULTS

A total of 259 questionnaires were collected, 2 of which were incomplete, leaving 257 valid questionnaires. The response rate was 54.52%.

The results showed that the average age in the sample was 43.47 with a standard deviation of 9.569 (minimum age 21 and maximum 64). Responses were received from 89 men (34.6%) and 168 women (65.4%); 87 physicians (33.9%), 119 nurses (46.3%), and 51 nurse's aides (19.8%); 66 hospitalization wards (25.7%) and 191 (74.3%) ICU's, resuscitation, urgency, and operating theaters. Concerning the types of contract, 153 (59.5%) responders were permanent staff members, 49 (19.1%) were temporary, and 55 (21.4%) were substitutes.

According to professional category and the number of years since graduation, the results showed that 47.1% of the medical staff graduated between 2000 and 2010; 38.7% of the nursing staff graduated between 1980 and

1989, and 52.9% of the nurse's aide staff graduated between 1980 and 1989.

Table 1 shows the perception each health professional has of his/her own training to handle terminally ill patients. Significant differences were found among the various professional categories concerning the perception of their own training to handle moribund patient care; note that most nurse's aides said that they were prepared. There were differences concerning whether the staff members would offer the patient and/or his/her family the opportunity to remove all life support therapies, if the case reached this conclusion. In this regard, the medical staff would mostly say yes in this situation. Lastly, regarding studying palliative care in the course of their training programs, where significant differences were found, the nurses provided the most affirmative answers.

**Table 1** – Health professionals' perception of their own skills in the care of terminally ill patients, Traumatology Hospital – Granada, 2011

		Total Frequency (%)	Frequency (% per professional category)			p*
			Physicians	Nurses	Nurse's Aides	
P. 1	YES	250 (97.3)	85 (97.7)	114 (95.8)	51 (100)	0.291
	NO	7 (2.7)	2 (2.3)	5 (4.2)	0 (0)	
P. 2	YES	137 (53.3)	38 (43.7)	65 (54.6)	34 (66.7)	0.030
	NO	120 (46.7)	49 (56.3)	54 (45.4)	17 (33.3)	
P. 3	YES	202 (78.6)	66 (75.9)	92 (77.3)	44 (86.3)	0.318
	NO	55 (21.4)	21 (24.1)	27 (22.7)	7 (13.7)	
P. 4	YES	176 (68.5)	79 (90.8)	74 (62.2)	23 (45.1)	0.000
	NO	81 (31.5)	8 (9.2)	45 (37.8)	28 (54.9)	
P. 5	YES	108 (42)	24 (27.6)	62 (52.1)	22 (43.1)	0.002
	NO	149 (58)	63 (72.4)	57 (47.9)	29 (56.9)	

\* Pearson's Chi-squared test for the three titles. (p< 0.05)

Table 2 shows the responders' perception of their own skills in comparison with taking PC course programs during their professional training. Significant differences were found among the participants who expressed adequate skills in the care of a moribund patient according to having had PC training or not. In this sense, a remarkable 50.4% of the staff claimed to have the necessary skills to care for a moribund patient and stated that they had been trained for such care.

**Table 2** – Perception of training in terms of taking PC course programs, Traumatology Hospital – Granada, 2011

		Have you studied palliative care in your professional training?		Total	p*
		YES	NO		
		Frequency (%)	Frequency (%)		
P. 2	YES	69 (50.4)	68(49.6)	137	0.004
	NO	39(32.5)	81(67.5)	120	
P. 3	YES	90(18)	112(55.4)	202	0.115
	NO	18(32.7)	37(67.3)	55	
P.4	YES	74 (42)	102 (58)	176	0.992
	NO	34 (42)	47 (58)	81	

\* Pearson's Chi-squared test according to providing palliative care or not. (p<0.05)

Table 3 shows health professionals' knowledge of the Law on Rights and Guarantees of the Dignity of Persons

in the Process of Death, which rules on LTE, assisted suicide, euthanasia, rejection to treatment, and palliative sedation. Remarkably, 59.1% of the participants were unaware of the legislation concerning LTE. Still, there are significant differences in this question concerning professional category; medical staff provided the most correct answers.

Concerning the legal situation of assisted suicide, there were significant differences among the various professionals; the medical staff responded correctly in the greatest proportions.

Similarly, there were significant differences concerning the legality of the question: *From a legal point of view, is respect for a patient's rejection of treatment a legal or illegal practice?* In this case, the nurse's aides responded correctly in a lesser proportion compared to the other professional categories.

Remarkably, a large percentage (93.4%) of the professionals was unaware of the legislation concerning the limitation of life support measures.

Also remarkable, an important percentage (78.2%) of the responders expressed that they did not know the mechanism to inform to fulfill a Living Will.

**Table 3** – Health professionals’ knowledge on the legislation, concerning the law, LTE, assisted suicide, euthanasia, rejection of treatment, and palliative sedation, Traumatology Hospital – Granada, 2011

		Total Frequency (%)	Frequency (% per professional category)			p*
			Physicians	Nurses	Nurse’s Aides	
P. 6	YES	160 (62.3)	55 (63.2)	71 (59.7)	34 (66.7)	0.671
	NO	97 (37.7)	32 (36.8)	48 (40.3)	17 (33.3)	
P. 7	R. correct	105 (40.9)	51 (58.6)	38 (31.9)	6 (31.4)	<b>0.000</b>
	R. incorrect	152 (59.1)	361 (11.4)	81(68.1)	35(68.6)	
P.8	R. correct	179 (69.6)	71 (81.6)	72 (60.5)	36 (70.6)	<b>0.005</b>
	R. incorrect	78(30.4)	16(18.4)	47(39.5)	15(29.4)	
P. 9	R. correct	169 (65.8)	62 (71.3)	76 (63.9)	31 (60.8)	0.363
	R. incorrect	88(34.2)	25(28.7)	43(36.1)	20(39.2)	
P. 10	R. correct	202 (78.6)	73 (83.9)	98 (82.4)	31 (60.8)	<b>0.002</b>
	R. incorrect	55 (21.4)	14(16.1)	21(17.6)	20(39.2)	
P. 11	R. correct	202 (78.6)	67 (77)	99 (83.2)	36 (70.6)	0.168
	R. incorrect	55(21.4)	20(23)	20(16.8)	15(29.4)	
P. 12	R. correct	17(6.6)	8 (9.2)	8(6.7)	1 (2)	0.256
	R. incorrect	240(93.4)	79(90.8)	111(93.3)	50(98)	
P. 13	YES	56 (21.8)	20 (23)	25 (21)	11 (21.6)	0.943
	NO	201 (78.2)	67 (77)	94 (79)	40 (78.4)	

\* Pearson’s Chi-squared test for the three titles. (p<0.05)

**Table 4** - Perception of health professionals’ legislative support, Traumatology Hospital – Granada, 2011

		Total (%)	Physicians	Nurses	Nurse’s Aides	p*
P. 14	Totally disagree	42 (16.3)	16 (18.4)	16 (13.4)	10 (19.6)	0.705
	Disagree	12 (4.7)	3 (3.4)	7 (5.9)	2 (3.9)	
	Neutral	31 (12.1)	7 (8)	19 (16)	5 (9.8)	
	Agree	33 (12.8)	12 (13.8)	17 (14.3)	4 (7.8)	
	Totally agree	113 (44)	40 (46)	50 (42)	23 (45.1)	
	Not know/No answer	26 (10.1)	9 (16.3)	10 (8.4)	7 (13.7)	
P. 15	Totally disagree	83 (32.3)	38 (43.7)	29 (24.4)	16 (31.4)	<b>0.047</b>
	Disagree	35 (13.6)	13 (14.9)	15 (12.6)	7 (13.7)	
	Neutral	52 (20.2)	18 (20.7)	21 (17.6)	13 (25.5)	
	Agree	19 (7.2)	3 (3.4)	11 (9.2)	5 (9.8)	
	Totally agree	36 (14)	8 (9.2)	24 (20.2)	23 (45.1)	
	Not know/No answer	32 (12.5)	7 (8)	19 (16)	51 (100)	

\* Pearson’s Chi-squared test for the three titles. (p<0.05)

Table 4 shows health professionals’ perception of their professional performance in the final stage of life.

## DISCUSSION

Responding percentage by professionals has been similar to that in other studies delving into this theme<sup>(10)</sup>.

Our data showed that most health professionals have had contact with patients who were reaching the end of their lives. As a whole, slightly more than half of these professionals believe that they have adequate training to act in the care of these patients, whereas the medical staff members consider themselves to have the least training. This result aligns with the answers obtained from the question on specific training in palliative care, in which the medical staff achieves the lowest percentage in comparison with nurses and nurse’s aides<sup>(11)</sup>. In the study<sup>(12)</sup>, training in the care of people in a final stage of their lives is recommended, considering the patients’

cultural differences. In our study, approximately half the professionals had undergone any palliative care training, and there were significant differences between this result and the perception of the training manifested by the responders.

Although law 2/2010 of April 8 on Rights and Guarantees of the Dignity of Persons in the Process of Death is a recent one, it is known to most health professionals.

Remarkably, all professionals feel they are capable of *treating* terminally ill patients. This result is in contrast with the fact that they are unaware of the content of the law as well as of the mechanism to inform patients about a living will, as required by the Andalusian Plan for Palliative Care<sup>(13)</sup>. All professionals involved with palliative care must have adequate training; furthermore, the anticipation of decisions made at the end of life deserves a holistic approach, and nurses are in a privileged situation because of the amount of time they are in direct contact with patients and their surroundings<sup>(14)</sup>.

At the end of life, most professionals would offer to remove life support therapies. Remarkably, a high percentage of physicians favor this option. Note that, as previously mentioned in another study<sup>(15)</sup>, from the professional's perspective, family demands often dictate therapeutic obstinacy over treatment when the patient's opinion is not part of the decision making process. We believe that eliminating the patient's opinion shows a vulnerability of the right to be informed,<sup>(16)</sup> and it indicates bad professional practice.

Nevertheless, most professionals feel capable of relating with terminally ill patients and their families. However, the negative consequences in the care of terminally ill patients and their families may be explained by the difficulties perceived by health professionals in the control of emotions<sup>(17)</sup>.

Training in palliative care helps overcome the difficulties faced by professionals in regard to informing the terminally ill patient and his/her family of the diagnosis and prognosis<sup>(18)</sup>. It also ensures safety, as it provides the professional with greater competence and better perception, and generates a change of attitude toward the terminally ill patient<sup>(8-9)</sup>.

Most professionals show adequate knowledge of the existence of the law. Nevertheless, when asked about precise aspects, different professional categories show different degrees of knowledge. Remarkably, when asked about the material aspects of the law, nurse's aides provided a smaller percentage of correct answers compared to other professional categories. Medical staff showed greater knowledge. In our environment, most decisions about care are made by this staff, which would justify the results found. However, the nurse's aides perform mostly delegated tasks, and the results will be adjusted to the role performed by the care team.

In concrete terms, concerning the limitation of therapeutic effort, approximately half of the responders know the legal situation, and medical professionals know greater proportions compared to other responding professional categories.

Most responders know that assisted suicide and euthanasia are practices that are penalized in Spain. In the first scenario, there are significant differences among the various professional categories, and the medical staff answers correctly in a greater proportion. This result would be explained by the professional competencies developed by these health care professionals. Concerning the second scenario, mention must be made that in the *Care of terminally ill patients*<sup>(10)</sup> study conducted by the Center of Sociological Research, more than half of Spaniards approve of legalizing euthanasia.

The health professionals know the patient's right to reject treatment, whereas nurse's aide professionals answer correctly in the least proportions. The roles performed by these professionals would explain the result. The limitation of life support measures is a legal fact, although most responders do not know this answer. Nevertheless, they know the legality of palliative sedation. This health care provision is covered in Spain's Andalusian PC Plan 2008/2012, which is intent on training professionals in PC<sup>(18)</sup>.

Most professionals would offer the patient and/or his/her family the removal of life support therapies. Nevertheless, concerning life support therapy removal, or *dealing* with a terminally ill patient and his/her family, there are no significant differences between having and not having had PC training<sup>(17)</sup>.

These data make us think about the difference between knowing the existence of a law and knowing its content.

More than half of the health professionals totally agreed with being legally required to help people who have reiterated their desire to end their lives in the case of incurable diseases experienced as unacceptable and in cases that cannot be mitigated by palliative care<sup>(18)</sup>. Usually, they do not agree with administering treatments that will only prolong the process of death, even though the patient and his/her family indicate that this is their wish.

The limitations of this study include time and localization factors. Namely, the period of time between publication of the law and the study (less than a year). Still, the study was performed in a single hospital, with 54.52% of responders. Another similar study must be conducted after the law has been fully implemented. Furthermore, the study should be extended to various geographic zones of the community, thus reaching greater diversification and a larger number of participants.

## CONCLUSION

Most health professionals have had contact with patients who were at the end of their lives; nevertheless, only slightly more than half of them believe that they are adequately trained to handle these patients.

Most responders know the Law on Rights and Guarantees of the Dignity of the Person in the Process of Death and its contents, although they are unaware of the legal aspects of limiting life support measures. Additionally, they are unaware of the mechanism to inform to fulfill a Living Will. Still, they feel capable of acting in the care of these patients and their families.

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