



A key ethical dilemma in clinical practice in palliative care in Spain includes merging long-standing cultural traditions with advances in the care of terminally ill patients.

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Cultural Issues and Ethical Dilemmas in Palliative and End-of-Life Care in Spain

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Background: *The concept of palliative care differs according to cultures and traditions. In Spain, palliative care programs have expanded in recent years. The European Commission Research Project in Palliative Care Ethics has sponsored ongoing research to analyze and clarify the conceptual differences in providing palliative care to patients in European countries with diverse cultures and backgrounds.*

Methods: *The authors present key ethical issues in clinical practice in palliative and end-of-life care in Spain and how these issues are influenced by Spanish culture. They discuss typical characteristics of the Spanish conceptual approach to palliative care, which might be relevant in an even larger Latin palliative care context.*

Results: *The cultural tradition in Spain influences attitudes toward euthanasia, sedation, the definition of terminality, care in the last 48 hours of life, diagnosis disclosure, and information. The overall care of terminally ill patients with an Hispanic background includes not only the treatment of disease, but also the recognition and respect of their traditions and culture.*

Conclusions: *The Spanish palliative care movement has shifted its focus from starting new programs to consolidating and expanding the training of the professionals already working in the existing programs. Although there is a general consensus that a new philosophy of care is needed, the interpretation and application of this general philosophy are different in diverse sociocultural contexts.*

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Introduction

The expansion of palliative care programs in Spain (as in the rest of Europe) in recent years has been successful in terms of coverage of the target population and opioid consumption. This success, however, has occurred at the expense of deficiencies in the training of professionals and the scarcity of fully comprehensive palliative care systems. A balance has developed with an almost equal distribution of resources between home care and inpatient services, despite a strong tendency in recent years to prioritize domiciliary care in the wake of policies that limit health expenditure.¹

At this time, 206 palliative care programs are available in Spain, a country with a population of approximately 40 million inhabitants. A total of 1,729 full-time health care professionals (including close to 300 physicians) work in these interdisciplinary teams. The existing programs are caring for 17,484 new terminally ill patients who remain at home and 20,972 hospitalized patients. More than 40% of all cancer deaths occur within palliative care programs.²

The development of palliative care in Spain has had distinct peculiarities. The concept of care is not intemporal and universal, but rather it is related with the cultural and historical roots of a society. Caring differs depending on the context. Currently, there is a general consensus in our societies that a new philosophy of caring is needed, underpinning the emergence of “palliative care.” However, the interpretation and application of this general philosophy are different in diverse sociocultural contexts. The recent controversy in the United States involving the terms *hospice* and *palliative care* highlights the fact that there are distinct organizational models of delivering end-of life care around the world that are influencing the American debate.³ The differences between the old American “hospice” approach and the Canadian and European “palliative care” approach are summarized in Table 1.

The term *culture* could be defined as the set of beliefs, knowledge, art, morals, laws, customs, and any other habits or dispositions acquired by a human being as a member of a society. It is outside the scope of this article to give an overview of Spanish culture as a whole, but we will focus on the distinct nature of the bioethics school of thought in Spain compared with that in the United States.

In the canonical scheme of American bioethics, out of the four basic ethical principles (ie, autonomy of the patient, beneficence, nonmaleficence, and justice), autonomy and beneficence receive absolute priority. Beneficence is impossible without autonomy, and thus justice has only a compensatory role. From a European perspective, the basic theoretical underpinning of American bioethics is clearly utilitarian. On the other hand, the Spanish and Continental European tradition relies heavily on European philosophy that has, for most of the time, believed that there are absolute principles in which to ground morals. Therefore, there are absolute obligations prior to the empiric autonomy of the individual, and these may be synthesized in the two basic ethical principles of nonmaleficence and justice.⁴

In Spain and other countries with a Latin cultural background, the palliative care movement has developed some distinctive features perceived not only in the approach to bioethics mentioned earlier, but also in the role played by families of the terminal patients and in the attitude toward information and diagnosis disclosure that is clearly different from the Northern-European or Anglo-Saxon model. Although religion is no longer the relevant force generating these differences, a certain image of the world (and of the life and death cycle) that could be considered “Catholic” prevails in Spain. A predominantly external locus of control (LOC), a psychological construct by which we attempt to define the views of any given individual about the factors affecting events in his or her life and capability of influencing them, is a key part of this image. When

Table 1. — Differences Between the Old US Hospice Approach and the Canadian/European Palliative Care Approach*

Differences	Hospice	Palliative Care
Beginnings of the movement	Grassroots at the community level	Existing health care system
Hospital involvement	Low	Extensive
Physician involvement	Low	Extensive
Mainstreaming into academic medicine	Low priority	High priority
Economics	Independent affiliation, donations	Public health care
Programs other than home care	Free-standing inpatient hospices	Specialized hospital palliative care units and support teams

*These differences have been overemphasized for the sake of clarity in this table.

viewed as ideal types, an internal LOC involves a reported perception that life events and circumstances are the result of an individual's own actions, whereas an external LOC includes the perception that life events and circumstances are beyond a person's control.⁵ These cultural remnants of previous religious attitudes, which we perceive as influencing health care and palliation, differ from the "Protestant" ways predominant in North America or Northern Europe, where internal LOC is the norm.

A Nonhospice Tradition

In Spain, as in all other predominantly Catholic countries, the term *hospice* has negative connotations. The Spanish word for a hospice inpatient (*hospiciano*) still denotes either extreme poverty or orphanage; in Spain in the 18th century, hospices took the responsibilities of alms houses and prisons for the poor, and in the 19th century and the first half of the 20th century, hospices were involved in caring for orphans.⁶

This nonhospice tradition was assumed as a characteristic of the Spanish model by the first document on palliative care written by the Spanish Association for Palliative Care (SECPAL) in 1993, and it was endorsed by the National Ministry of Health.⁷ The first assumption of the document was that hospices had no room in Spain. The document also describes the Spanish palliative care model as based on palliative care units, support teams, and home care, not in classic hospices. The present census of palliative care programs in Spain bears witness to the previous assumption.²

The National Health Care system has taken the lead in the field of palliative care in Spain. The pioneering palliative care units were located mainly in tertiary academic institutions, where the term *hospice* might have been misinterpreted as a "second-rate quality" type of medicine. In this sense, the Spanish model is more closely related with the Canadian approach as envisaged by Mount⁸ when he coined the term *palliative care* than with the British "hospice" tradition. Perhaps this proximity in concepts has to do with the Catholic background of Quebec that similarly associates the term *hospice* with negative connotations. In the early stages of development of palliative care in both Canada and Spain, the same predominance was given to palliative care in tertiary hospitals seeking to mainstream effectively into academic medicine.¹ This differs from the British and American hospice that started as a grass-roots movement outside the hospital and academic environment. Certainly both the Canadian and Spanish experiences benefited enormously from the work of the British and American hospices.

Pain Relief and Sedation vs Euthanasia

The Catholic tradition perhaps also influences other characteristics in the delivery of palliative care in Spain. One such influence involves the rejection of active euthanasia and the widespread acceptance of pain relief to the point of sedation, even in cases where death might be accelerated. Within the Catholic tradition, the Thomistic "principle of double effect," broadly developed by the Spanish "School of Salamanca" in the 16th century, is commonly used by Spanish physicians to support the use of analgesics and sedatives.⁹ The Spanish Deontology Code, written by the Spanish Medical Association, includes the following statement¹⁰:

The physician will never intentionally provoke the patient's death, neither voluntarily nor at the request of the patient or relatives or due to other any other reasons. Euthanasia or "compassionate homicide" is contrary to medical ethics.

In case of incurable or terminal disease the physician should limit his intervention to the relief of physical and moral pain of the patient...promoting quality of life...and avoiding hopeless, futile and obstinate therapeutic interventions. The physician should attend the patient until the end paying due respect to human dignity.

The general acceptance by professionals and society at large of sedation for the relief of pain and suffering, in the context of impending death, has led in the past decades to the use and abuse of the so-called "lytic cocktail" (which combines chlorpromazine, meperidine, and promethazine) in France¹¹ and also in Spain. The intention in these cases was not only to relieve pain but also, in some cases, to accelerate the process of dying. Interestingly, in both countries the development of palliative care has resulted in the disappearance of the "cocktail," although it might have been replaced by new sedative drugs. Research around this sensitive issue is already underway,^{12,13} and there is a growing consensus on the current perception that the ethical dilemma is not "euthanasia — yes or no" but "sedation — when and how?"

The need to sedate for reasons other than the management of purely physical symptoms (eg, pain, dyspnea, and delirium) is also a common occurrence in palliative care in Spain. Psychological distress due to the peculiar cultural way of coping with terminal disease in Spain, where denial and rejection of diagnosis disclosure are prevalent, is at the heart of this situation.¹⁴ In a recent comparative international study,¹⁵ 22% of patients in Spain needed sedation for uncontrolled symptoms in the last week of life, which was similar to the other groups and published data.¹⁶ However, a Spanish palliative care unit was notable

because the reasons for sedation were strikingly unique; a high percentage of sedations were due to psychological and or family distress, as were also the large doses of midazolam needed in Spanish patients to put them to sleep, suggesting previous exposure to benzodiazepines in order to manage anxiety.¹⁶ A further extension of this collaborative research has compared the cultural coping mechanisms at work in two similar palliative care units in Canada and Spain. Preliminary data from this study suggest that somnolence and confusion are not relevant issues for a large percentage of Spanish patients and families, whereas the decrease in the patient's capability to be autonomous induced by these two symptoms is resented in the Canadian environment.¹⁷

In trying to explain this evidence, we must acknowledge that remnants of past attitudes towards death remain within us. The traditional way of dying, the so called "Spanish death," continues to be influential.¹⁸ Some interesting data on the high prevalence of sedation for symptom management in Italy, a country with similar Catholic traditions and background, might have a similar explanation.¹⁹ It is also interesting to note that only a minority of Italian general practitioners endorse euthanasia or assisted suicide. In common with physicians in other countries, agreement with the practice of euthanasia is correlated with non-Catholic religious affiliation, inexperience in treating terminally ill patients, and the burnout dimension of depersonalization.²⁰

In summary, within the predominant Spanish culture, an intervention with the direct intention of either accelerating death or killing the patient is considered morally wrong, but using sedation for the relief of physical or spiritual pain is not. The first moral duty is to comfort patients, not inform them about their prognosis, which implies that informed consent is not an important issue. It also implies that unconsciousness, either disease-induced or drug-induced, is generally perceived as the "best way out," especially when patients are aware of their prognosis, and regardless of whether life is shortened by the use of these drugs. This issue might be one reason why palliative care has been well received in Spain. On the one hand, since it links with existing cultural traditions, politicians and administrators are convinced that introducing palliative care programs is the best way of interpreting the actual wishes of the people and thus improving the quality of end-of-life care through better management of pain and suffering. On the other hand, these same politicians are probably convinced that developing palliative care is also the best way to avoid the politically difficult and disturbing debate about active euthanasia.

The Definition of "Terminality": The Tradition of the *Agonía*

The definition of palliative care by the World Health Organization (1990) and of palliative medicine when the medical specialty was accepted in the United Kingdom (1987) are widely quoted in Spain. Nevertheless, the most commonly used definition in Spain was coined by the Spanish Association for Palliative Care in 1993,⁷ and it is actually a definition of the stage of "terminal disease" that is susceptible of being managed with palliative care. Five conditions are required for a disease to be considered terminal and therefore appropriate for palliative care: (1) progressive, incurable, advanced disease, (2) lack of a reasonable possibility of response to active specific treatment, (3) multiple problems or symptoms that tend to be intense, multifactorial, and changeable, (4) high emotional impact in the patient, family, and team that is related, explicitly or not, to the proximity of death, and (5) expected survival of less than 6 months. The document continues as follows⁷:

This complex situation demands much attention and support, and we should respond adequately. Cancer, AIDS, motorneuron diseases, specific organ failure (renal, cardiac, hepatic...) fulfill the previous criteria up to a certain degree in the final stages of the illness. Classically the care of the terminal cancer patient has been the *raison d'être* of palliative care. It is ESSENTIAL not to label as terminal a patient potentially curable."

The definition also describes comfort as the main objective. The basis of the therapeutic approach is integral care, patient/family as a unit of care, promotion of autonomy and dignity, active therapeutic approach, and care of the therapeutic milieu. The basic therapeutic tools are symptom control, emotional support, honest communication, organizational changes, and a multidisciplinary team. This definition merits further discussion. It was born after the beginning of what we have called the universalization period (1992-1998)¹ of palliative care in Spain, but the authors of the definition were the pioneers who actually initiated the institutionalization of the movement. It is remarkable how focused and operational the definition is compared with the two standards mentioned previously. It includes a description of the symptoms and a time frame, and it embraces several illnesses but gives the priority to cancer.

The concerns of the authors can be detected by the emphasis on avoiding mistakes on diagnosing "terminality" and the avoiding the term "spiritual" in the definition (a sensitive issue in the early stages of the development of the SECPAL). Honest communication is encouraged, but there is no mention of information of prognosis.

The use of *terminal disease* instead of *palliative care* for the definition was a deliberate choice to find a common ground with nearby medical specialties and to avoid being mired in discussions on the birth of a new specialty. Nevertheless, there are probably other reasons behind this unique way of starting a palliative care movement.

The issue of "terminality," ie, the diagnosis of when a patient is actively dying and facing an impending death, has been of overriding importance in Spanish tradition. Starting in the late Middle Ages, treatises on the art of "dying well" (*Ars moriendi*) became popular in Spain and other Catholic countries, with their success in Spain enduring well into the 18th century. These books explained the events taking place during the last days of life and also later, while the corpse was decomposing. The purpose was to accept death and even wish it, as ending life was the way to reach eternity and behold God. This approach to death is the basis of what has been called the "Spanish death," examples of which were the deaths of the emperor Charles I and his son Philip II in the 16th century. The Spanish artistic heritage has many examples of its classical iconography of death — the "Vanitas" or "Postrimerías" style of painting.¹⁸

Key to understanding this tradition is the roles played by the family, physician, and confessor. One treatise, published in 1537, states the following²¹:

Those relatives (gathering around the dying patient) should be neither wife nor children nor father nor mother, because those do not help in avoiding temptations, even more, with their great passion in considering what they are losing they even increase the *agonía*... those companions should be two or three friends, very catholic, discreet and charitable... and above all, as soon as the physician is not trusting the patient's health, they should take from him any further hope of corporeal life.

Confession, last wills, and proper burials were important. However, defining when the *agonía* had started was essential because it identified when the physician and relatives would depart and friends and priest would step in. *Agonía* was defined then as "the space of time that takes place between the clouding of the senses and the departure of the soul from the body."¹⁸ There is no English word to compare with the term *agonía*. *Agony* means intense suffering and probably reflects a Protestant tradition, while the standard textbook in Spanish medical terminology still defines *agonía* as "the state prior to death in those instances in which life extinguishes gradually."²²

These past attitudes toward death and dying survive today in Spain, but they are culturally rather than

religiously driven. Elderly dying patients still reject the support of their relatives but no longer request "Catholic and pious" friends, and palliative care teams in Spain must deal with the grief and guilt in young relatives who are no longer attuned to these old ways. Patient simply lie down with their back facing the door and reject any invasive therapeutic or psychological procedures by the team. They always give a clear message to some relative or caregiver that they are actively dying. Recovery from *agonía* is almost nonexistent, except in rare cases where there is relevant unfinished business (eg, a relative who has yet to arrive before the final departure).

Diagnosing *agonía* today still sends a clear message: that death is impending, that confusion or somnolence is acceptable (even preferable), and that invasive procedures must be avoided. *Agonía* is a useful tool for palliative care teams in Spain as it allows a "breathing space" in which families prepare to witness the death of their relative within the next 48 hours. Standard Spanish textbooks in palliative care have a chapter on care in the state of *agonía*, which replace the usual Anglo-Saxon chapter on the last 48 hours of life.^{23,24}

In the early years of the movement, some Spanish authors attempted to challenge SECPAL's definition of palliative care. One of these alternative definitions actually pushed the boundaries of what was termed the "preterminal phase" up to almost the situation of *agonía*. In the view of these authors, the "terminal phase" could be diagnosed only when the expected survival was less than 2 months, performance status as measured by Karnofsky's scale was less than 40%, organ failure was documented, and irreversible end-stage complications were evident.²⁵ The authors introduced diagnosis criteria for the last 48 hours of life or *agonía* in their definition of "terminal disease." In doing so, they were expanding the indications of palliative chemotherapy up to the onset of death, as they considered it to be indicated in the preterminal phase. On the other hand, in light of Spanish tradition, it seems appropriate that the discussions were centered on the issue of terminality. Another factor at that time contributing to this alternative definition was the religious background of some of the authors.

Over time, institutions and associations not necessarily linked with the pioneering stages of the SECPAL have endorsed its definition in their own documents.^{26,27} The Spanish Association for Palliative Care is building on this recognition and is beginning to present policy documents on accreditation and training.^{28,29}

Information and Diagnosis Disclosure

The Spanish palliative care movement has championed the revision of the long-held assumption that diagnosis disclosure and open information are always in the best interest of the patient. Colleagues from other countries are often surprised to learn that in Spain — and in other nations similar in culture — a cancer diagnosis is not always transmitted to our patients.^{30,31} The treatment and prognosis of the disease in Spain, as well as the degree of development of oncology and palliative care, are similar to those in other neighboring countries. Are patients, their families, and physicians different in Spain? Are transcultural differences the basis for the dissimilarity? Is there a foreseeable change of attitude in the future?

A recent paper reviewed all research evidence available related to the subject in Spain.³² The word *cancer* or its semantic equivalents are frequently omitted when the patient is present. The patient does not ask whether it is cancer, and the physician does not specify the exact nature of the illness. Justifying this avoidance as a matter of comfort or lack of courage would be incorrect; the issue is much more complex in that there is a tacit agreement not to discuss cancer. The culturally established *modus operandi* obliges the health care professional to be discrete and to offer minimal information when discussing cancer.

From the studies available, it is estimated that 25% to 50% of all patients in our environment are informed of their diagnosis. Even in these cases, however, the information is neither direct nor unquestionable. One study has examined the anxiogenic weight of the terms *cancer* and *tumor* in patients and showed that, contrary to similar studies in other countries, the word *cancer* is associated with rejection, increased psychological distress, and extremist and stereotyped responses.³³ However, a significant percentage of patients in all studies in Spain suspect — or are even subjectively certain of — the true nature of their disease in spite of the absence of information, thereby increasing the proportion of patients who do know about their disease to more than two thirds. This degree of suspicion does not mean that suspicious patients want to know. In assessing the degree of knowledge of a diagnosis and the attitude toward that information, several Spanish studies reported that the majority of uninformed patients do not want to receive additional information.^{34,35} The demand for information is not uniform in our society; younger patients are more likely to want an open discussion. This statistically significant piece of evidence suggests that change is occurring, and it highlights the dynamic character of communicating the truth in our environment.

A majority of Spanish families (61%-73% of all cases) are opposed to informing the patient, which determines to a great extent the information given to the patient. As for Spanish physicians, the debate continues on whether it is appropriate to permit the established situation. One seminal study³⁴ showed that patients who were informed benefited psychologically in several areas. The problem is how to inform a patient who is not willing to be informed. Furthermore, another study³⁶ reported that those physicians and nurses with greater experience are more reluctant to habitually communicate the diagnosis to oncologic patients, perhaps because they are closer to the patients. A similar trend can be detected in the Spanish palliative care movement, which is no longer wholeheartedly supporting open diagnosis disclosure as it used to do in its early years.

Respect for individual and cultural differences in attitudes towards death and dying is considered an essential aspect of appropriate care for terminally ill patients. Adequate supportive care of patients with advanced diseases includes the decision of whether to disclose the diagnosis to the patients. In recent years, there has been a trend toward uniformity in Western society regarding candor and straightforwardness with patients. Truth disclosure is fast becoming the accepted pattern to younger generations of Western physicians trained under the influence of Anglo-Saxon models of medical practice. Conversely, published research³⁷ indicates that there is no common "European perspective" on this issue.

Spain is not alone in the "cultural continent" gradually emerging in the English literature confronting the Anglo-Saxon "cultural continent" (United Kingdom, United States, Northern Europe, Canada, Australia, and New Zealand) that up to now has provided the majority of patients mentioned in literature in English about truth-telling. Studies in Italy,³⁸⁻⁴¹ Greece,⁴² the former Soviet Union,⁴³ Latin America,⁴⁴ Japan,⁴⁵ and the Philippines⁴⁶ report results similar to Spanish results. Furthermore, recent studies in Australia⁴⁷ and the United States⁴⁸ show that there is more than is apparent in truth-telling societies. The US study by the National Hospice Foundation in 1999⁴⁸ noted that 50% of American adults will rely on family or friends to make end-of-life decisions, though many have not talked about plans with loved ones. Also, the proportion of American adults who are unlikely to discuss impending death with parents is 28%, which is higher than the proportion of those who are likely to discuss the topic of safe sex with children.

There are different cultural reasons in every country or region to support its degree of commitment to

truth-telling. The family acts as a focal social unit in much of Southern Europe at the interface between the patient and health care services. It is common practice in these countries to inform a member of the patient's family about the diagnosis and allow the family to determine what information the patient receives. As mentioned earlier, studies in Spain have showed that younger people have a more open attitude towards diagnosis disclosure.^{34,49} This move should not be interpreted as a "liberation" of the patients from the "tyranny" of the families. On the other hand, conspiracy of silence is so prevalent in our society because families are usually right about the coping needs of the patients. It is also true that autonomous patients are free to use their autonomy as they see fit, even to delegate it when this fits their own concept of beneficence. The patient must decide how much autonomy he or she wishes to exercise, and this amount can vary from culture to culture.⁵⁰

It is interesting to follow the debate in Spain as exemplified by the present Spanish General Health Law⁵¹:

All patients have the right to receive, both themselves and their closest relatives, full continuous information, written and verbal, of their disease including diagnosis, prognosis and treatment options.

This general principle is better connected to our own cultural background in the Spanish Deontology Code, which includes the following statement⁵²:

In general, the physician shall disclose the diagnosis to the patient and shall inform him with care, circumspection and responsibility of the most likely prognosis. The physician shall also inform the closest relatives or whomever the patient designates. . . It might be sensible not to immediately communicate a very poor prognosis, for the benefit of the patient, although this approach should be considered exceptional in order to safeguard the right of the patient to decide about his future.

The Spanish code closely resembles the Italian code.³⁰ In both, the possibility of withholding the truth still exists. Ethics are inevitably connected to cultural values; therefore, the Spanish and Italian ways are ethical in their contexts. The dilemma of the confrontation between the ethical principles of autonomy and beneficence is addressed differently in Spain and Italy than in Northern Europe or the United States. The explicit or implicit delegation of decision making by the patient is one of the choices of the individual and should be respected. It is a choice that not only should be respected, but also is linked with our cultural tradition. In one study,³⁴ the traditional "Spanish death" was detected in several of the older, less literate patients, albeit somewhat changed. On investigation,

it was realized that they were certain of the diagnosis without having been informed in most cases. The traditional "Spanish death" has the same qualities of the verses of our 15th century national poet Jorge Manrique. His poem, *Couplets on the Death of My Father*, is known by several generations of Spaniards who were perhaps only slightly aware of its sententious, stoic, Christian, solemn, and serene quality⁵³:

For my will is in agreement with the divine in everything; and I consent to my death with a joyful, clear and pure will, for it is madness that a man should wish to live when God wishes him to die.

Recent research performed by Donnelly,⁵⁴ a Scottish palliative care specialist, on the folklore associated with dying in the west of Ireland suggests that we should try to learn from the skills and attitudes of our ancestors toward death and dying. Furthermore, the author questions whether reflecting on our relevant past may challenge the modern direction in palliative care.

Confronted with the ethical dilemma of giving diagnostic information (or requesting informed consent) to a patient unwilling to know, the Spanish physician should balance the respect for the patient's attitude toward information with the knowledge that information might be beneficial. This approach involves not only informing the patient that there are no barriers to communication and the truth, but also being ready to respond to any occasion when the patient requests more information. This challenging approach is ethically inescapable for health professionals practicing in an Hispanic cultural background, where patients can provide statements such as the following⁵⁵:

I will always prefer not to know, or to know as little as possible. No human being knows when he is going to arrive in this world, therefore I believe that his natural state is also not to know when he will depart.

The Ethical Dilemma of Adequate Coverage

The development of palliative care in Spain, mainly through the Public Health Care System, has introduced a new consideration — a fair allocation of resources that recognizes the needs of terminally ill patients. The Catalanian palliative care program has been influential in helping to develop a new organizational culture in which provision of care is based on need rather than on demand. Adequate selection, placement, and follow-up of projects are considered critical to avoid burnout and wasted energy.⁵⁶

Table 2. — Preliminary Proposal of a Theoretical Construct Regarding Perceived Differences in Acceptance of Death Between Patients and Families in Spain and the US*

Differences	Patient Spain / USA	Family Spain / USA
Cognitive acceptance of death	No (denial) / Yes	Yes / Yes
Emotional acceptance of death	Yes / No (defiance)	No / No
Moral acceptance of death - culture	Yes / No	Yes / No

* The philosophical underpinning of this construct is the perception that Western society is coming to believe that a "good death" implies cognitive acceptance of that same death, and this notion in itself is debatable. Also, the perception that "autonomy" of the patient always implies a cognitive acceptance of the impending death is debatable. In this table, the differences are overemphasized for the sake of clarity.

Lessons Learned

Patients, relatives, and health care professionals are facing terminal disease and providing palliation always within a certain cultural "milieu," even if they are unaware of its relevance. Neglecting our mandate as caregivers to understand cultural influences might result in unwanted suffering. There is no simple approach to these issues. Research is warranted to expand our present limited knowledge. As part of our ongoing research project, Pallium, we are attempting to build a simple matrix that might explain perceived differences between Spanish and American cultures regarding the acceptance of death by patients and families. The proposal has been tested for its face value with different clinicians in both countries and is presented in Table 2.

History is never "too far away," and we should not presume that in the year 2001 our dying patients are willing to abandon long-established ways when confronting end of life. As Spanish physicians, we need to be aware of the changes taking place in our younger generations, which are bringing them closer to other cultures. We are slowly becoming a nonhomogeneous society as immigration brings new challenges to Europe. These challenges are part of American history and should not be a concern to our American colleagues, yet there is always the risk of misunderstanding cultural attitudes in minorities.

Conclusions

The Spanish palliative care movement has achieved a relative maturity that has allowed it to invest effort

and energy into studying its own peculiar ethical dilemmas. Palliative care as such is no longer under discussion; the focus has shifted from starting new programs to consolidating and expanding the training of the professionals already working in the existing programs. Our own cultural tradition is influencing our approach to euthanasia and sedation, the definition of terminality, care in the last 48 hours of life, diagnosis disclosure, and information.

References

1. Gracia D, Núñez Olarte JM. Report from Spain. *Support Care Cancer*. 2000;8:169-174.
2. Centeno C, Hernansanz S, Flores LA, et al. *Directorio de Cuidados Paliativos, 2000*. 3rd ed. Valladolid: Sociedad Española de Cuidados Paliativos; 2000.
3. Byock A. Hospice and palliative care: a parting of ways or a path to the future? *J Palliat Med*. 1998;1:165-176.
4. Gracia D. Planteamiento general de la bioética. In: Couceiro A, ed. *Bioética Para Clínicos*. Madrid, Spain: Editorial Triacastela; 1999:19-35.
5. Bates MS, Edwards WT, Anderson KO. Ethnocultural influences on variation in chronic pain perception. *Pain*. 1993;52:101-112.
6. Núñez Olarte JM. Care of the dying in 18th century Spain: the non-hospice tradition. *Eur J Palliat Care*. 1999;6:23-27.
7. Sanz Ortiz J, Gómez-Batiste X, Gómez Sancho M, et al. *Cuidados Paliativos: Recomendaciones de la Sociedad Española de Cuidados Paliativos (SECPAL)*. Serie guías y manuales. Madrid, Spain: Ministerio de Sanidad y Consumo; 1993.
8. Ajemian I, Mount BM, eds. *The R.V.H. Manual on Palliative/Hospice Care*. Salem, NH: The Ayer Co; 1982.
9. Giménez-Salinas E, Díez Ripollés JL, et al. *Documento Sobre Situaciones Al Final De La Vida*. Madrid, Spain: Ministerio de Sanidad y Consumo/Consejo General del Poder Judicial; 1998:10.
10. Organización Médica Colegial Española. *Código de Ética y Deontología Médica*. Art 28, 1 and 2. Madrid, Spain: Consejo General de Colegios Médicos de España; 1990.
11. Meunier-Cartal J, Souberbielle JC, Boureau F. Morphine and the "lytic cocktail" for terminally ill patients in a French general hospital: evidence for an inverse relationship. *J Pain Symptom Manage*. 1995;10:267-273.
12. Porta J, Guinovart C, Ylla-Catalá E, et al. Definición y opiniones acerca de la sedación terminal: estudio multicéntrico catalano-baleár. *Medicina Paliativa*. 1999;6:108-115.
13. Porta J, Ylla-Catalá E, Estibalez A, et al. Estudio multicéntrico catalano-baleár sobre la sedación terminal en Cuidados Paliativos. *Medicina Paliativa*. 1999;6:153-158.
14. Fainsinger RL, Waller A, Bercovitch M, et al. Symptom management and sedation in the last week of life. *J Palliat Care*. 1998;14:110. Abstract.
15. Fainsinger RL, Waller A, Bercovici M, et al. A multicentre international study of sedation for uncontrolled symptoms in terminally ill patients. *Palliat Med*. 2000;14:257-265.
16. Stone P, Phillips C, Spruyt O, et al. A comparison of the use of sedatives in a hospital support team and in a hospice. *Palliat Med*. 1997;11:140-144.
17. Núñez Olarte JM, Fainsinger RL, deMoissac D. Influencia de factores culturales en la estrategia de tratamiento. *Medicina Paliativa*. 2000;7:76-77.
18. Fernández-Shaw Toda M. Ars moriendi: images of death in Spanish art. *Eur J Palliat Care*. 1997;4:164-168.
19. Ventafredda V, Ripamonti C, De Conno F, et al. Symptom prevalence and control during cancer patients last days of life. *J Palliat Care*. 1990;6:7-11.
20. Grassi L, Magnani K, Ercolani M. Attitudes towards euthanasia and physician-assisted suicide among Italian primary care physicians. *J Pain Symptom Manage*. 1999;17:188-196.
21. De Venegas A. Agonía del tránsito de la muerte. Toledo: 1537.

22. AAVV. *Diccionario Terminológico de Ciencias Médicas*. 11th ed. Barcelona, Spain: Salvat Editores; 1974:24.
23. Porta J, Palomar C, Ramirez M, et al. Situación agónica: consideraciones sobre su manejo. *Medicina Paliativa*. 1994;1:15-25.
24. Lozano A, Borell R, Alburquerque E, et al. Cuidados en la situación de agonía. En: Gómez-Batiste X, Planas J, Roca J, et al, eds. *Cuidados Paliativos en Oncología*. Barcelona, Spain: Editorial Jims; 1996:237-248.
25. González Barón M, Jalón JJ, Feliú J. Definición del enfermo terminal y preterminal. In: González Barón M, Ordóñez A, Feliú J, et al, eds. *Tratado de Medicina Paliativa y Tratamiento de Soporte en el Enfermo con Cáncer*. Madrid, Spain: Editorial Médica Panamericana; 1996:1085-1090.
26. Atención domiciliaria con equipo de soporte. *Programa de Atención Primaria de Madrid*. Madrid, Spain: Area 1, 2 y 4 documento de atención domiciliaria - Insalud; 1998.
27. Benítez del Rosario MA, Llamazares González AI, García González G, et al. *Cuidados Paliativos. Recomendaciones de la SEMFYC*. Barcelona, Spain: Sociedad Española de Medicina Familiar y Comunitaria; 1998.
28. Gómez-Batiste X, Miró M, Alcalde R, et al. *Estándards de Cuidados Paliativos. Quadernos de Cuidados Paliativos, SCBCP*. Barcelona, Spain: Servei Català de la Salut; 1995.
29. Gorchs N, SanMartín J, Centeno C, et al. Recomendaciones básicas sobre formación en cuidados paliativos. *Medicina Paliativa*. 2000;7:23-25.
30. Surbone A. Truth telling to the patient. *JAMA*. 1992;268:1661-1662.
31. Stiefel F, Senn HJ. Cancer diagnosis disclosure in a Spanish hospital: how do they discuss treatment options? *Ann Oncol*. 1992;3:422.
32. Centeno-Cortés C, Núñez Olarte JM. Estudios sobre la comunicación del diagnóstico de cáncer en España. *Med Clín (Barc)*. 1998;110:744-750.
33. Gala FJ, Costa C, Díaz M, et al. Cáncer frente a tumor: estudio de la carga ansiosígena mediante diferencial semántico. *Neoplasia*. 1994;11:10-14.
34. Centeno Cortés C, Núñez Olarte JM. Questioning diagnosis disclosure in terminal cancer patients: a prospective study evaluating patients' responses. *Palliat Med*. 1994;8:39-44.
35. Morante E, Mateo D, Tuca A. Estado y necesidades informativas de los enfermos ingresados en una unidad de cuidados paliativos. *Medicina Paliativa*. 1995;2:58. Abstract.
36. Vega J, Martínez P. *Enfermo Terminal y Eutanasia Desde el Punto de Vista del Personal Sanitario*. Valladolid, Spain: Publicaciones Universidad de Valladolid; 1991.
37. Thomsen OO, Wulff HR, Martin A, et al. What do gastroenterologists in Europe tell cancer patients? *Lancet*. 1993;341:473-476.
38. Ventafridda V, De Conno F, Viganò A, et al. Comparison of home and hospital care of advanced cancer patients. *Tumori*. 1989;75:619-625.
39. Pronzato P, Bertelli G, Losardo P, et al. What do advanced cancer patients know of their disease? *Support Care Cancer*. 1994;2:242-244.
40. Mosconi P, Meyerowitz BE, Liberati MC, et al. Disclosure of breast cancer diagnosis: patient and physician reports. *Ann Oncol*. 1991;2:273-280.
41. Grassi L, Giraldi T, Messina EG, et al. Physicians' attitudes to and problems with truth-telling to cancer patients. *Support Care Cancer*. 2000;8:40-45.
42. Mystakidou K, Liossi C, Vlachos L, et al. Disclosure of diagnostic information to cancer patients in Greece. *Palliat Med*. 1996;10:195-200.
43. Ryan M. Ethics and the patient with cancer. *Br Med J*. 1979;2:480-481.
44. Fonnegra de Jaramillo I. Asistencia psicológica al paciente terminal. En: Bejarano PF, Jaramillo I, eds. *Morir con Dignidad*. Santa Fé de Bogotá: Fundación Omega; 1992:221-242.
45. Charlton R, Dovey S, Mizushima Y, et al. Attitudes to death and dying in the UK, New Zealand and Japan. *J Palliat Care*. 1995;11:42-47.
46. Ngelangel CA, Ramiro LS, Perez ES, et al. The process of disclosure in Philippine oncological practice. 13th Asia Pacific Cancer Conference, Penang (Malaysia). 1996:16. Abstract.
47. Chan A, Woodruff R. Palliative Care in a multicultural society: a comparison of the palliative care needs of English-speaking and non-English speaking patients. *J Palliat Care*. 1992;8:69. Abstract.
48. Harris S. Baby boomers, parents share few words about death. The National Hospice Foundation. *USA Today*. June 9, 1999:1.
49. Arraras JJ, Illarramendi JJ, Valerdi JJ, et al. Truth-telling to the patient in advanced cancer: family information filtering and prospects for change. *Psychooncology*. 1995;4:191-196.
50. Pellegrino ED. Is truth telling to the patient a cultural artifact? *JAMA*. 1992;268:1734-1735.
51. Normativa reguladora de los derechos de los pacientes. Ley general de sanidad (Art 10.5). In: *Insalud, Ministerio de Sanidad y Consumo*. Madrid, Spain: Ediciones del Ministerio de Sanidad y Consumo; 1990.
52. Organización Médica Colegial Española. Código de Etica y Deontología Médica (Art 11, 4 y 5). Madrid, Spain: Consejo General de Colegios Médicos de España; 1990.
53. Manrique J. *Coplas que Fizo por la Muerte de su Padre (1440-1479)*. Folemprise Publ; 1945.
54. Donnelly S. Folklore associated with dying in the west of Ireland. *Palliat Med*. 1999;13:57-62.
55. Anónimo. Memorias de un paciente atendido en la UCP del Hospital General Universitario Gregorio Marañón. Madrid, Spain; 1991.
56. Gómez-Batiste X, Fontanals MD, Via JM, et al. Catalonia's five-year plan: basic principles. *Eur J Palliat Care*. 1994;1:45-49.