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Has end-of-life decisions or Advance Directives become an economic strategy to contain health care costs has much as a way to respect patient's informed consent and private autonomy rights?

What can we learn from the American Advance Care Model?

A research by

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[1] At: https://law.duke.edu/fac/rice/.

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> **“*Every human being of adult years and sound mind has a right to determine what shall be done with his own body.*”**
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> **– Justice Benjamin Cardozo (*in Schloendorff v Society of New York Hospital: 1913*)**[2]

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[2] Back in 1914, case law established the requirement that health professionals obtain a patient’s consent for invasive medical procedures based on their right of self-determination.

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LIST OF KEYWORDS

advance care model, advance care planning, advance directive, decision-making, end-of-life, ethical dilemma, health care agent, health care costs, health care power of attorney, lesson, life-sustaining treatment, living will, medical treatment, patient's autonomy, POLST, proxy, rationing, recommendation, self-determination, surrogate, technology, withdrawing, withholding

INTRODUCTION

Purpose of the research

Over the last decades, there have been significant efforts to institutionalize advance directives, not only by legal means, but also by educational and public policy implementation means. In the United States (US), all fifty states and the District of Columbia have had specific legislation authorizing and regulating the use of these instruments for a long time. The Federal Patient Self-Determination Act (PSDA) enacted in 1990, requires all health care providers to inform patients of their rights under state law to make medical decisions and to execute advance directives. In Portugal, the Living Will Law, which regulates specifically these directives, has been in force since 2012, with its applicability still being tested in practice. Portuguese views about death influenced by Catholicism may be a significant obstacle to the implementation and use of these medical directives. In contrast, Macau has neither statute nor case law on the legal status of advance directives. Few Chinese are familiar with the concept of end-of-life planning. Chinese rooted in Confucianism often see death as a taboo and do not like to talk about it. Family members also affect the decision-making process and the execution of advance directives.

Since the 1960s, developments in medical technology have enabled physicians to extend surgical services and medical treatments, giving men unparalleled power to combat disease, leading to situations where life can be artificially extended. This resulted in the development of advance directives and more recently the advance care planning concept to address new kinds of end-of-life choices faced by individuals and families. Another impact of advances in medical technology is on health care costs. Modern technology is expensive. In addition, as the population continues to age, it is inevitable that health care costs, particularly at end of life, will continue to escalate at an unsustainable pace. Moreover, costs of caring for patients with long-term chronic diseases, like HIV/AIDS and cancer, also represent a large economic impact from society's point of view.

Evidence suggests that physicians and patients should engage in advance care planning in order to help ensure that medical treatment decisions are in accordance with the patient's wishes/values. However, if advance directives were implemented with the main goal of enhancing patients' autonomy and, ultimately, their well-being at the end of their lives, is it true that they can at the same time be effective in curbing rising health care costs? Research studies have revealed that savings are less that most people anticipate. A number of controversial issues around advance directives and end-of-life decisions remain unsettled, as medically appropriate care should never be withheld solely because of costs.

While these directives enhance patient autonomy in health care decision-making, in contradiction to a typical medical paternalism, presently health is a scarce resource. In Portugal, one of the main European countries hit by the economic crises, the social right to health can be extremely costly for the government. As such, several measures for rationing health resources have been recommended since the bailout[3]. There has been increased concern about how to reconcile this social right protected by the Constitution with the principle of economy in the delivery of public services[4]. Unfortunately, there may be an appetite for cutting medical costs that might jeopardize the rationale of advance directives, as they may easily be seen as or converted to an explicit tool for cost saving and rationing medical care at the end of life. Should that occur, it may be deemed too costly to society and to the health care system, as ethical dilemmas may arise.

Chapter One of the present work focuses on the development of advance directives starting with their rationale, followed by their historical evolution in the US. It also examines advance care planning and its tool POLST as a new communication paradigm that emerged more recently in the US, with its perceived benefits. Chapter Two makes a comparative analysis with the Portuguese legal framework on advance directives and refers also to my Macanese experience. Because law is not completely detached from each country's cultural background, this chapter examines the differences between these world regions, in terms of cultural mind-sets and demands, and how can they affect the implementation of advance directives, thus, enabling a multidisciplinary and transnational approach. Chapter Three is about the economics of dying. From the US SUPPORT study to more recent studies, this chapter discusses the effectiveness of advance directives and advance care planning in terms of reducing health care costs. It further covers the ethical implications of advance care planning becoming a purely economic strategy. As the US legal framework is far more developed than in other countries in the health care field and in the specific topic of advance care, Chapter Four is dedicated to the lessons and

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[3] BARROS, PP et al. (2016); OECD (2015).

[4] RUEFF, MC (2015).

recommendations we can take from the American model considering the current state of affairs of Portugal and Macau. The Conclusion offers a few final thoughts.

CHAPTER ONE

DEVELOPMENT OF ADVANCE DIRECTIVES

1.1 The Rationale

Advance directives have long been advocated as a principal means to maximize patient's autonomy and control over relevant medical decisions in the end-of-life context[5]. Until the 1970's, traditional medical practice was predominantly doctor-centered, based only in the expert opinion of the physician, who made the decisions considering what they thought best for the patient without regard to the patient's individual preferences and needs[6].

The directives grew out of the patient and consumer rights movements that started on the 1960's and 1970's[7]. Their need arose in a time of great technological developments in science and medicine[8], radically changing the practice of Western medicine. The introduction of new life-sustaining equipment and expertise brought new medical problems, as patients may survive longer and treatment may become futile. There was also a significant increase in medical awareness[9]. Patients gained easier access to medical information, reducing the informational gap that typically characterizes this relationship[10].

Hence, scholars typically frame the rationale for these directives in terms of *autonomy*[11],[12]. They emerged as an important tool to enhance patient autonomy and to guarantee that a person, if incapacitated in the future as a result, for example, of illness, injury, dementia or persistent vegetative state, may still make autonomous health care decisions. These instruments allow patients to consent to or refuse any medical treatment, namely, but not only, if excessive,

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[5] SULLIVAN, R et al. (2015).
[6] DONG, R (2011).
[7] LAMERS (2005).
[8] E.g., *Engstrom* Universal Respirator (Model 150) was introduced in 1954 (at: https://www.woodlibrarymuseum.org/.../engstrom-model-150).
[9] ANTUNES, JB (2010), pp.18-19.
[10] WEISS, GB (1985).
[11] SABATINO, CP (2010), p.219.
[12] WINZELBERG, G et al. (2005).

disproportionate or futile. This is related to the principle of beneficence for the patient, which is the duty to *do good*, and the principle of non-maleficence, which means to *do no harm*[13]. Decision-making is a complex process[14] and can be problematic at end-of-life when an individual becomes incompetent due to illness or age.

The living will, a document by which a patient states what treatments he or she would want at the end of life, was created originally to help prevent unwanted and invasive medical care at the end of life. It attempts to ensure that patients receive the treatment they want, promoting patient-centered care.

The health care power of attorney is a document in which the patient names an individual to make medical decisions when he or she is incapacitated and unable to do so. The rationale is to guarantee that health care decisions are made by someone patients trust in the event they become incapacitated.

The focus on patient's autonomy and right to self-determination is concomitant with a decline in or abandonment of medical paternalism[15]. This shift of paradigm in contemporary biomedical ethics towards a more interactive model, based on an ongoing dialogue and exchange of information, allowed patients to be active protagonists in their health care decision-making process, embracing a patient-centered approach. Thus, physicians should follow prior expressed wishes of adult competent patients, as they must be respected and take priority in relation to the doctor's technical opinion[16].

With the idea of paternalism in medicine becoming unpopular, autonomy or self-government, as its antithesis, is considered one of the ethical bases of the law of advance directives. Beneficence and non-maleficence, as stated above, equity and veracity, the foundation of informed consent in patient care, are also considered to be the basis of these directives.

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[13] THORNS, A (2010).

[14] LINDA, E AND SCANDRETT, KG (2010).

[15] SERRÃO, D (1997).

[16] KABA, R AND SOORIAKUMARAN, P (2007).

Types of Advance Directives	
Instructive directive *Living Will*	A document by which a patient while still capable expresses his or her wishes about the type of medical treatments or life-sustaining measures he or she wants or does not want if his or her condition becomes medically hopeless (i.e., when medical interventions will do nothing more than artificially delaying the moment of death). It goes into effect once a physician (sometimes more than one) determines that the patient is in a particular medical condition set out in the law, such as a persistent vegetative state, advanced dementia or terminal illness, and is unable to communicate his or her own wishes regarding medical treatment[17],[18]. It covers only situations where the patient has an end-stage medical condition or is permanently unconscious. In North Carolina, for example, the living will is a declaration of the patient's preferences and wishes for a natural death. Normally, this directive does not go into much detail in terms of treatments patients may choose to withdraw or maintain. Treatments can vary from cardiopulmonary resuscitation, artificial nutrition and hydration, mechanical ventilation, or kidney dialysis. It can also address organ and tissue donation.
Proxy directive *Durable Power of Attorney for Health Care*	A document by which a patient gives someone else, named *health care agent or proxy* (also referred to as *surrogate*), the power to make medical decisions on his or her behalf when he or she becomes incompetent (i.e., mentally or physically incapable to do so)[19],[20]. In contrast to the living will, which deals exclusively with end-of-life care, the health care power of attorney allows the patient to give powers to the proxy in a wide range of medical decisions. As the patient's appointed health care agent may make a broad range of medical decisions on the patient's behalf, it is important that such person knows the patient's wishes. Although the proxy need not be a family member, it should be someone the patients totally trusts. To appoint a second or alternate proxy is normally advisable in case the primary appointed one is unavailable to make the decision when the time comes or resigns.
Combination of features of both the proxy and the instruction	Patients may want both to give written instructions about medical treatment preferences and to appoint a health care proxy to make sure that such instructions are followed and honored. For example, in New Jersey[22] there is a standard form of a combined directive for health

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[17] DETERING, K AND SILVEIRA, MJ (2017).
[18] GUNTER-HUNT et al. (2002).
[19] DETERING, K AND SILVEIRA, MJ (2017).
[20] GUNTER-HUNT et al. (2002).
[22] At: https://www.njsharingnetwork.org/document.doc?id=199.

directive in a single document[21]	care. Another form, called *Five Wishes*[23], is also an example of a combined directive template. This one was created by a private non-profit organization called *Aging with Dignity*. It is not a state-sanctioned document, and its most notable feature is that it addresses more comprehensively other important elements related to comfort care and spirituality. It is used in many health care facilities in the US to promote a family discussion about end-of-life issues, often along with the official state forms.
Psychiatric advance directive (PAD) ***Declaration for Mental Health Treatment***	A relatively new tool to deal specifically with mental health decisions in advance. By executing this directive, patients inform medical providers about their specific preferences for future mental health care in the event they becomes incapacitated.[24]
Do Not Resuscitate **(DNR)** ***order*****, also DNAR –** ***Do Not Attempt Resuscitation Order***	These are medical orders prepared by the physician at the request of the patient. There are in-hospital and out-of-hospital DNR orders, depending on whether the patient is hospitalized or living at home or in a hospice[25]. A DNR order is done by a physician and states that resuscitative measures should not be performed on the patient in the event a patient suffers from a cardiopulmonary failure[26]. The goal of this medical order is also to promote patient's self-determination and avoid non-beneficial interventions[27]. With more states implementing a universal type of DNR order, this tool allows patients to express what they want in terms of resuscitation while being transported from one health care facility to another.

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[21] Detering, K and Silveira, MJ (2017).

[23] At: https://www.agingwithdignity.org/.

[24] At: https://www.psychiatry.org/news-room/apa-blogs/apa-blog/2016/12/psychiatric-advance-directives-planning-for-mental-health-care.

[25] Detering, K and Silveira, MJ (2017).

[26] Meehan, F (1991), p.144.

[27] Yuen, JK et al. (2011), p.791.

1.2 US history of Advance Directives

Considering the strengthening of the patient's right to self-determination and autonomy, in the last decades there have been ongoing efforts to institutionalize advance directives. The US was the leading country, where the living will was first proposed and described by Luis Kutner in 1969. According to this human rights lawyer from Illinois, "Th[is]document would provide that if the individual's bodily state becomes completely vegetative and it is certain that he cannot regain his mental and physical capacities, medical treatment shall cease."[28].

From this initial proposal, it took not even ten years until advance directives were officially inaugurated in 1976 with California's adoption of the first living will statute, *The Natural Death Act*, also known as *Death with Dignity Act*, which took effect in January 1, 1977. For the first time in history, there was a law that allowed patients to direct their physicians to withhold or withdraw life-sustaining treatments in the event of a terminal illness or permanent unconsciousness when death was imminent. Moreover, this document gave physicians statutory protection if they followed the patient's wishes in good faith. This first statutory document was perhaps the most recognized and available living will[29]. Appendix 1 sets out the text of the original California law.

Even though the California Natural Death Act was praised for its contribution to raising public awareness of the principle of autonomy[30], much public controversy and political debate affected its final version. The statute was criticized for containing ambiguous language and terminology, creating interpretation problems and bureaucratic burdens for physicians and patients. It was considered of very limited applicability.[31] Opponents also claimed it was not comprehensive and was overly formalistic[32]. One commentator remarked that the statute had only symbolic value[33].

Additionally, by establishing a statutory right to be allowed to die, there was the risk of opening the door to involuntary euthanasia (*mercy killing*)[34]. It should be noted that the California statute

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[28] KUTNER, L (1969), p.551.
[29] JOHNSEN, AR (1978), p.323.
[30] *Ibid* (p.323).
[31] CAPRON (1984), pp.647, 652.
[32] SABATINO, CP (1994), p.1238.
[33] WINSLADE, WJ (1977).
[34] JONSEN, AB (1978).

was drafted with the landmark case of Karen Quinlan in mind. That case was decided on an appeal by the New Jersey Supreme Court in 1976.

Case law 1: main facts and decision

Karen Quinlan was a twenty-one year old woman who became comatose after consuming alcohol along with barbiturate drugs while on a crash diet. Karen suffered severe brain damage and was diagnosed as being in a severe form of coma, called persistent vegetative state. She had laid in a hospital bed since April 1975 without any prospect of regaining consciousness, completely dependent of a ventilator.[35],[36] ***Karen's father requested that the doctor disconnect the life-sustaining equipment to allow the daughter to die naturally. The doctor refused the request on the grounds that he could be accused of murder. Then, Karen's father sought judicial approval to act as her legal guardian and to have the ventilator removed. The trial court did not allow the withdrawal of the ventilator. In spite of all the controversy around the case, in the appeal, the New Jersey Supreme Court ruled unanimously in favour of the Quinlans. The trial court granted the petition of Karen's father, based on the constitutional right to privacy. The court however required that a responsible physician first determine that Karen would never recover from her persistent vegetative state. Notions of murder or improper interference with medical judgment were rejected by the trial court.***[37]

As an aftermath of the *Quinlan* case, the living will was formally recognized as an important means of conveying the wishes of a patient while still competent. At that time, many doctors still regarded *pulling the plug* as an act similar to euthanasia, strictly forbidden by the law and by the medical ethical code. The withdrawing or terminating ventilation of unconscious patients was for the first time debated, setting the stage for the advance care model that we know today. Historically, there were also several other important cases that addressed issues regarding the maintenance of life by artificial means. *Quinlan's* case was one of the most significant[38], as its result gave theoretical support to living will legal statutes.

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[35] PENCE, GE (2008), pp.23-28.

[36] POLAND, SC (1997), p.4.

[37] ROSNER, R (2003), p.317.

[38] CHAPMAN, M (1989), p.328.

Other jurisdictions quickly followed California's lead in adopting living will statutes: Arkansas, North Carolina, New Mexico, Texas, Nevada, Idaho and Oregon[39]. In North Carolina, *The Right to Natural Death Act* was adopted in 1977. Appendix 2 develops the requirements and formalities that should be followed to prepare a valid advance directive pursuant to the updated North Carolina General Statutes[40].

Validity requirements and formalities[41],[42],[43]	
❖	**it must be made by a person with the necessary decisional competence and free from undue influence of others;**
❖	**it must be in writing, signed, witnessed and notarized;**
❖	**it must be currently in effect and not have been revoked;**
❖	**it must be applicable to the current circumstances, identifying the medical treatment proposed or refused.**

By 1992, forty-five states and the District of Columbia had adopted statutes to facilitate a natural death in various formats, but with some relevant common elements[44]. However, limitations of the living will became apparent. States began to recognize that having a surrogate decision-maker might be more effective than just having someone write out a directives that turned out to be excessively broad, too vague, or have limited application[45]. A more effective approach was thought to be the naming of a proxy, trusted by the patient, who could ensure that the patient's wishes were honoured. A proxy could give the necessary guidance to help physicians determine the wishes of the patient. The idea was to name a person who would speak for the patient.

As such, by the mid-1980s, legislators and policy makers began to adapt an already existing legal document: the power of attorney. While some concerns arose around the use of the

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[39] HORAN, DJ AND MARZEN, TJ (1978).

[40] At: https://www.ncleg.net/gascripts/statutes/Statutes.asp.

[41] Although requirements vary from state to state, generally speaking, to determine if an advance directive is legally valid, these criteria should be met. This list is based on the North Carolina legislation.

[42] A list of requirements of all the states is at: http://estate.findlaw.com/living-will/living-wills-state-laws.html.

[43] HUNT, G et al. (2002).

[44] STEINLE, SJ (1992), p.439.

[45] SABATINO, CP (2010), p.214.

traditional power of attorney in the medical context, the advantage of using these documents as a health care decision tool over the living will became clear. California once again was the first to enact the law: *The 1983 Durable Power of Attorney for Health Care*. By 1997, all US states had a version of health care power of attorney legislation[46].

Nevertheless, because of the complexity of the advance directives as legal documents, which constrained their use, states started to enact combined statutes merging the living will and the health care power of attorney into a single directive (e.g., the New Jersey standard form first dated from 1991)[47]. Over the years, statutes evolved so that, nowadays, many authorize default surrogate decision-makers for patients without decisional capacity in the absence of an advance directive. Organ donation directions are also options included in the legislation[48], as it is prescribed in the North Carolina General Statutes.

Although states intended to facilitate advance directives, laws varied from state to state, which led to the effort to draft uniform laws. These laws aimed to promote uniformity across the states in an area where consistency was needed[49]. Besides, with the movement of people between states, there was a risk that a person who had executed a directive in one state might become seriously ill/injured in another state, which was reluctant to honour the previously stated wishes[50]. Even if state courts concluded that there was a right to refuse life-prolonging treatment, there were differences in terms of principles and legal approach in some cases involving patients without decision-making capacity.

Initially, the National Conference of Commissioners on Uniform State Laws approved the *1985 Uniform Rights of the Terminally Ill Act* (URTIA). While this uniform act aimed at simplifying end-of-life decision-making, it did not gain acceptance. The main reason for its failure was that it was too narrow in its scope. It did not cover important issues, like treatment of patients who had not signed the declaration directing physicians to withdraw or withhold life-sustaining treatment. It also failed to address problems related to minors[51]. In spite of the drafting of the

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[46] *Ibid* (pp.214-215).
[47] SABATINO, CP (2010), p.216.
[48] *Ibid.*
[49] PUTMAN, WH (2010), p.262.
[50] CHAPMAN, M (1989), p.346.
[51] SHUGRUE RE (1993), p.758.

URTIA, the US continued to have a system of fragmented legislation, often in sufficiently comprehensive and inconsistent among states.

Consequently, in a second effort to achieve uniformity, in 1993 the Uniform Law Commissioners approved the *Uniform Health Care Decisions Act* (UHCDA) and replaced URTIA. The UHCDA consolidated several types of state laws dealing with decisions related to adult health care, end-of-life care and health care powers of attorney. This Act was designed to create a single document that would combine the existing living will and the health care power of attorney, which to that point were addressed in separate laws in most states. The UHCDA was intended to be a more comprehensive and “flexible combined advance directive and default surrogate law”[52]. This statute was described in contrast to URTIA as “strives[ing] to pave a health care decision-making superhighway”[53]. It is considered to be an important tool against the confusion, complexity and fragmentation of state health care decision legislation.

The UHCDA is mainly characterized by the simplicity of its rules and its recognition of almost any type of written or oral statement as an advance directive, including unwitnessed documents.[54] It provides an optional form for executing a health care power of attorney, which permits authorization of anatomical gifts. It further recognizes default surrogates in the absence of a directive. It affirms the legitimacy of close family decision-making and provides a ranking list of authorized surrogates.[55]

At the same time as uniform laws were being devised,[56] courts were deciding important cases linked with the public debate over honouring an individual’s wishes. The decision of the US Supreme Court in *Cruzan v. Director, Missouri Department of Health*, 497 US 261, in 1990, played an important role on the evolution of legislation regarding advance directives[57].

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[52] SABATINO, CP (2010), p.216.

[53] SABATINO, CP (1994), p.1239-1240.

[54] SABATINO, CP (2010), p.217

[55] SABATINO, CP (1994).

[56] Studies performed later found that there were still variations across the US (GUNTER-HUNT, G et al. (2002)).

[57] PENCE, GE (2008), pp.28-31.

Case law 2: main facts and decision

Nancy Cruzan was twenty-six years old in 1983 when she was rendered comatose after a car accident, never regaining consciousness. She was in a persistent vegetative state and was only kept alive by a feeding tube. She did not need artificial mechanical respiration.[58] ***Confronted with their daughter's medical situation, her parents started a legal battle to have the feeding tube removed. The case proceeded its way through the courts up to the US Supreme Court. While the Supreme Court did agree with the principal that there is a right for a competent person to refuse or stop life-preserving medical treatment, including artificial nutrition, the court also ruled that individual states could set their own standards for evidence showing what the formerly competent patient would have wanted done in terms of life-sustaining medical treatment. Hence, technically the state of Missouri won the case, because their clear and convincing evidence standard was upheld.***[59] ***After the decision, the Cruzans went back to the Missouri courts and offered additional evidence that met the clear and convincing evidence standard. Only at that point, did the court approve withdrawal of Nancy's feeding tube, allowing her wishes to prevail. She died a few days later on December 26, 1990.***[60]

The *Cruzan* case was important, because for the first time the US Supreme Court recognized the constitutional right of a competent American to refuse unwanted medical treatment. It concluded that removing a feeding tube is indistinguishable from removing a ventilator. However, the Supreme Court allowed states to set a rigorous standard - requiring *clear and convincing* evidence - for permitting surrogate decision-makers to withdraw life-sustaining treatment when the patient is incompetent.[61]

As a follow-up to this case, at the federal level, in 1991, *The Patient Self-Determination Act* of 1990 came into force. Under the Federal Statute, hospitals or extended care facilities, like nursing facilities, home health agencies, hospices, and Health Maintenance Organizations (HMOs), that receive Medicare or Medicaid reimbursement, are required to give patients at the time of their admission, written information on state's laws regarding their rights to make decisions about medical care, such as the right to accept or refuse medical or surgical treatment,

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[58] POLAND, SC (1997), p.5.

[59] Most states do not have such a high evidentiary standard.

[60] GRANT, ER (2015).

[61] *Ibid* (pp.29-30).

including the execution of advance directives. Notwithstanding its minimal role in this legislative evolution, the Congress hoped to reinforce individuals' constitutional right to determine their final health care (i.e., right to self-determination), and to increase public awareness about planning for future health care decisions.

Recently, the case of Terri Schiavo, which raised a factual question about whether the patient had expressed the desire to remove life support when in a persistent vegetative state, led to a highly political debate in the US.

Case law 3: main facts and decision

Terri Schiavo was an anorexic twenty-seven year women who fell into a persistent vegetative state after suffering a cardiac arrest in 1990. After a number of years, Terri's husband, appointed as her legal guardian, wanted to remove her feeding tube, arguing that she would not have wanted her life artificially prolonged. In contrast, her parents opposed their son-in-law's decision and never accepted the diagnosis of persistent vegetative state, even with physicians expressing the opinion that there was no hope of Terri's rehabilitation.[62] ***Schiavo's parents and husband initiated a long litigated battle that involved several state and federal courts. All ruled in favour of the husband's petitions. In spite of those rulings, in 2003 the Florida legislature passed a controversial bill - Terri's Law - that gave the Governor the authority to have the feeding tube reinserted (when a court had ruled that it could be removed). This bill was later declared unconstitutional. After several years of legal struggle that reached non-judicial branches, in March 2005, the feeding tube was finally removed by court order, and Terri passed away thirteen days later.***[63]

Although this case did not raise any novel legal or ethical issues - because the right to remove feeding tube was already well established - it provided a lesson on how religious and political debates on sanctity of life can inject themselves into what would otherwise have been an uncomplicated case that raised no new legal issues. Terri's story extended the legal debate about the end-of-life decisions beyond courts to the political arena, involving the Governor of Florida and Congress. It attracted religious conservatives who were pressing the right to life fight. The

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[62] PENCE, GE (2008), pp.31-36.

[63] *Ibid*.

Schiavo case illustrates that in spite of many efforts, there is still a lot of confusion and disagreement in the US about withdrawing life-sustaining treatment of incompetent patients. It shows what happens when there is no written directive to reveal what the incompetent person would have wanted, and family members are in conflict about end-of-life care. Ultimately, this case demonstrates the importance of communication and dialogue between clinicians and patients, including family members in solving ethical dilemmas.

Even though there are more current debates on health care reforms, federalization of advance care law will not happen at substantive level. In the US system, end-of-life law is a matter reserved to the states only and it is not within the power of the federal government, unless there is a conflict with the Constitution.

1.3 Advance Care Planning: a new paradigm

Presently, Americans are already in a third generation era of advance directives. Recognizing the limitations of these directives, with low completion rates despite decades of existence, *Advance Care Planning* or ACP emerged as a new and alternative communication paradigm[64] that emerged more recently[65]. It consists of an ongoing, flexible and interactive process of communication between patient and physician on the patient's preferences for end-of-life care. It goes beyond a mere execution of legal documents, although advance directives are a tool for making advance care planning[66]. An example of an ACP tool is the *Physician or Medical Orders For Life-Sustaining Treatment* (abbreviated as POLST or MOLST[67]), designed especially for seriously ill patients to have more control over their end-of-life care.

The POLST or MOLST is a much more detailed document that can put the patient's end-of-life wishes and preferences into a medical order. It is more situation specific than the traditional advance directive and it is created as a joint effort by the patient and physician. This tool requires interaction and communication between the patient or his or her surrogate and the

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[64] SABATINO, CP (2010), p.224.

[65] DETERING, K et al. (2010).

[66] SUDORE, RL AND FRIED, TR (2010).

[67] It is not typically framed as a traditional directive, as it does not serve exactly the same purpose. (SABATINO, CP (2010), pp.230-231); at: http://polst.org/.

physician in charge about the patient's end-of-life wishes that are integrated into the physician's orders.

In contrast to the traditional directives, which can be completed by all competent and healthy adults, POLST is a tool for seriously ill patients of any age, who have life expectancy of less than one year, to have more control over their end-of-life decisions. POLST[68] give specific actionable orders for current treatment, whereas advance directives give only general instructions for future treatment. Moreover, POLST is designed to direct care both in home and outpatient settings and to facilitate transfers within hospitals. These orders are kept by the patients and are portable, meaning that they travel with the patients throughout different health facilities[69].

A number of studies have evidenced the positive outcomes and effectiveness of ACP[70]. Some of the benefits found are less aggressive medical care[71] and better quality of life near death[72], with higher satisfaction and a reduction of psychological distress of both patients and families[73]. Evidence suggests as well that POLST are quite useful for patients who have progressive chronic illness and it has been shown to reduce the likelihood of receiving unwanted medical intervention in nursing home patients[74].

Oregon was the first state to develop the POLST in the early 90s, with more states authorizing it later on. It is now widely recognized among health care professionals. This new paradigm was considered as "a sea change in advance care planning policy standardizing provider's communications to prescribe a plan of care in a highly visible, portable way, rather than solely on standardizing patient's' communications"[75]. It represents an important step toward achieving the best outcomes for patients and their families in terms of end-of-life care[76].

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[68] At: http://capolst.org/wp-content/uploads/2017/09/POLST_2017_Final.pdf.
[69] DETERING, K AND SILVEIRA, MJ (2017).
[70] LINDA, E (2000).
[71] WRIGHT, AA et al. (2008).
[72] BRINKMAN-STOPPELENBURG, A et al. (2014).
[73] DETERING, KM et al. (2010), pp.340.
[74] HICKMAN, SE et al. (2010).
[75] SABATINO, CP (2010), p.230.
[76] DETERING, K AND SILVEIRA, MJ (2017); HAMMES, BJ AND ROONEY, BL (1998).

In 2008, Congress added the end-of-life planning[77] to the *Welcome to Medicare* exam. As part of this exam, the medical provider will also offer to talk to the beneficiary about advance directives and end-of-life planning. Moreover, from 2016, there is a Medicare[78] billing code for advance planning conversations.[79] These reforms facilitate a process of discussion and communication between an individual and the health care provider.

Advance Directives developments in a snapshot
1914 - Cardozo decision affirming patient autonomy and self-determination
1969 - The *living will* is first mentioned in the US by the Lawyer Luis Kutner
1976 - Karen Ann Quinlan Supreme Court decision
1977 - The *California Natural Death Act* entered into effect
1983 - California passed the first *Durable Power of Attorney for Health Care Statute*
1990 - Nancy Cruzan Supreme Court's ruling
1990 - The *Patient Self-Determination Act* was enacted (as an amendment to the Omnibus Budget Reconciliation *Act* of 1990)
1991 - New Jersey enacted the first combined statute
1995 - *Physician Orders for Life-Sustaining Treatment* (POLST) form, an important ACP tool, was first released for use in Oregon[80]
2003 - *Terri's Law* was passed giving the Florida's Governor the authority to order to reinstatement of Terri's nutrition and hydration
2016 - Began the Center for Medicare and Medicaid Services' reimbursement of physicians for advance care planning conversations

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[77] 42 US Code § 1395(x)vv(3).

[78] Government-funded social insurance for the elderly or disabled.

[79] At: https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/AdvanceCarePlanningText-Only.PDF

[80] At: http://oregonpolst.org/.

CHAPTER TWO

COMPARATIVE ANALYSIS

2.1 Portuguese framework: state of affairs in advance medical care

Unlike in the US, in European countries the public debate about the role of advance directives in medical practice was initiated only recently. Until 2005, the concept of advance directives was practically unknown in Portugal. Specific legislation on this matter was enacted much later. Throughout the years, across Europe, countries have adopted different approaches regarding this subject depending on their own backgrounds. While countries like the UK, Austria, Spain, Hungary, Belgium, The Netherlands and Finland were pioneers in passing specific laws to address advance directives, Portugal had no specific legislation on the matter until 2012[81].

In 2001[82], Portugal ratified the Europe's Convention of Human Rights and Biomedicine dated from 1997, known as Oviedo Convention, with its Article 9, being an important starting point in the introduction of the subject of advance directives in the country. This provision provides that, "The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account."[83].

Although the Oviedo Convention was part of Portuguese domestic legislation, advance directives remained without a specific legal status for a long time. In reality, "There [was] nothing to prevent a person making what is called a living will"[84]. Furthermore, "appointing a proxy to take care of health issues could, by analogy, be framed within the civil discipline of the institution of power of attorney"[85]. Nevertheless, the validity and efficacy of such documents was unclear until the enactment of Law no.25/2012, from July 16, called the *Living Will Law*[86].

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[81] ANDORNO, R et al. (2009).

[82] At: https://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/164/signatures.

[83] At: https://rm.coe.int/168007cf98.

[84] PEREIRA, AD (2002), p.712.

[85] *Ibid* (p.712); Advice of the Portuguese Association of Bioethics P/06/APB/06; LOUREIRO, JC (1994), p.41; MELO, HP (2012), pp.157, 176-177.

[86] At: https://dre.pt/web/guest/pesquisa/-/search/179517/details/maximized.

The traditional view considered a power of attorney in life and death matters highly doubtful. Some doctrine expressly denied the possibility of delegation of end-of-life decisions[87]. Even for scholars that considered this delegation possible[88], as well as having a living will for end-of-life care, they did not view these documents as binding in absolute terms[89]. The documents were seen as containing the strongest indication of the presumed will of the declarant – "mais forte indício da vontade presumida"[90] – or by having at least an advisory value – "mero valor indiciário"[91]. In addition, if doubts persisted, the decisions of physicians should always be made based on the principle *in dubio pro vita, pro salute, pro persona*[92]. Thus, specific legislation was necessary to confer binding power to the directives, or otherwise physicians could reject their content and not apply them[93].

While a specific law was not enacted, these directives were covered indirectly by other legislation[94]. In the European Charter of Fundamental Rights from 2000, Article 3, paragraph 2 ("Right to the integrity of the person") establishes that "In the fields of medicine and biology, the following must be respected (…): - the free and informed consent of the person concerned, according to the procedures laid down by law."[95]. It is broadly accepted that the right to informed consent of patients includes the possibility to refuse medical treatment[96].

Moreover, "there is a constitutional framework[97] that takes autonomy seriously (…). Second the Convention on Human Rights and Biomedicine came into force on December 2001; third, the appeal to general institutes of civil law[98] seem to mitigate the absence of special rules;

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[87] FARIA, PL (2010), p.151; VASCONCELOS. PLP (2006) (2012); SOUSA, RC (1995), pp.402-403.
[88] GONÇALVES, C (2004), pp.53-69.
[89] The National Council of Ethics of Life Sciences in 2005 issued the Opinion 46/CNECV/05, in respect to the objection to the use of blood and blood products for therapeutic purposes on religious basis: "The advance medical declaration is merely an indication of will, and informed consent must still be obtained (…)". In a previous Opinion 45/CNECV/05, on persistent vegetative state, the Council had advocated that the previous expressed will of the patient should be respected; and RAPOSO, VL (2011), p.183.
[90] DIAS, JF, pp.201, 211.
[91] ANDRADE, MC (2004), p.457.
[92] LOUREIRO, JC (1994), p.42
[93] RAPOSO, VL (2012), p.10.
[94] LOUREIRO, JC (2008), pp.5-6.
[95] At: www.europarl.europa.eu/charter/pdf/text_en.pdf.
[96] Also in Article 5 of the Oviedo Convention.
[97] Article 1, Article 25 ("Right to personal integrity") and Article 64, number 1 ("Health") at: www.en.parlamento.pt/Legislation/CRP/Constitution7th.pdf.
[98] Article 70 grants protection to individuals against any illicit offense or threat to their physical and moral personality. Rights that are linked to the notion of *persona*: right to life, physical integrity, a good name and reputation, dignity, privacy of personal and family life, health.

fourth, the Penal Code[99] should be taken into account as far as respect for the will is concerned"[100].

Additionally, Principle XIV of Law no.48/90, of August 24, which establishes the basic principles for health care in Portugal, states that every patient has the right to consent to or refuse health care and to be informed about his or her situation, alternative treatments and prognosis. The duty of informed consent was also prescribed in Article 44 of the Medical Deontology Code[101]. Article 46, number 2 expressly states that if there is a written statement/directive from the patient expressing his or her wishes about medical treatment, it should be taken into consideration by the health care provider.

The implementation of the law on advance directives in 2012 was not without controversy. Opinions diverged widely. Even among health care providers, this subject was controversial[102]. Some voices expressly rejected it and claimed that the living will would be a sort of *Trojan horse* aimed at the legalization of assisted suicide/euthanasia[103]. Others recognized the need of having specific and adequate legislation to regulate these directives[104] based on the principle of respect for autonomy[105].

Portuguese were not indifferent to overseas cases, like that of Terri Schiavo, involving life-extending technologies and surrogate decision-making of patients in a persistent vegetative state. An important case with impact in the country was of Eluana Englaro in Italy.

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[99] Article 150 ("Medical-surgical interventions and treatments"), Article 156 ("Arbitrary medical-surgical procedure") and Article 157 ("The duty to inform").

[100] LOUREIRO, JC (2008), pp-5-6.

[101] Approved by Regulation no.14/2009, of January 13.

[102] PEREIRA SM et al. (2011).

[103] PATTO, PV (2009), p.437.

[104] FARIA, PL (2010), p.151; LOUREIRO, JC (1994), p.41; PEREIRA, AGD (2004), p.251; MELO, HP (2012), pp.190-191.

[105] SANTOS, ECC (2014), p.107.

Case law 4: main facts and decision

Eluana Englaro was a twenty-one year old girl who was left in a persistent vegetative state after a car crash in 1992 and only in July 2008, the Italian Court of Appeal had given authorization for artificial life-support to be withdrawn. However, an emergency decree was enacted stating that assisted feeding and hydration must not be withdrawn for any patient in a state funded health facility, reversing the earlier court ruling.[106] ***This case gave rise to substantial political turmoil and public debate with the involvement of the courts, including the European Court of Human Rights, the government and even the Vatican.***[107]

What would have happened if Eluana was Portuguese? It was controversial. In 2009, some argued that in the case of Eluana, who had been in a persistent vegetative state for a long time, it was legitimate to suspend active treatments (i.e. antibiotics), because medicine has to be useful/beneficial. "If medicine is futile, is contrary to its basic principles."[108]. Likewise, others opined that withdrawal of artificial feeding in this case corresponded to the suspension of what is considered a disproportionate means of treatment. "From a human point of view, being in this condition is worse than being dead."[109]. Some, however, would have never suspended the feeding/hydration of a patient in this situation[110] or argued that food is a way of sustaining life, not a mere therapy, and thus cannot be withdrawn[111].

This case played a crucial role in Portugal, because it showed that physicians/specialists did not agree on how to solve this type of case. It brought into debate the idea that medicine does not have to keep people alive at all costs, and that questions of discontinuing feeding/hydration should be analyzed on a case-by-case basis. A doctor "does not have to feed and hydrate a patient at any cost if that means suffering for the person"[112], compromising the patient's quality of life. Eventually, it showed the importance of a document with the patient's previously stated

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[106] SANTOS, LF (2009), pp.304-319.
[107] ZULUETA, P AND CARELLI, F (2009).
[108] FRAGATA, J (physician), at: https://www.publico.pt/2009/02/22/jornal/o-que-aconteceria-se-eluana-englaro-fosse-portuguesa-296580.
[109] NUNES, R (president of the Portuguese Association of Bioethics), *Ibid*.
[110] FERRO, J (physician), *Ibid*.
[111] PIMENTEL, J (physician), *Ibid*.
[112] NETO, IG (physician), *Ibid*.

wishes – in the form of a living will – which could facilitate such decisions by medical providers[113].

The debate around these directives is connected with persistent vegetative state cases, terminal illnesses and therapeutic futility (i.e., permanent incapacity)[114]. However, the debate also arose in connection with refusals of blood transfusions by Jehovah's witnesses during surgical interventions (i.e., temporary incapacity)[115]. The National Council of Ethics of Life Sciences had issued in 2005 two Opinions, 45/CNECV/05 and 46/CNECV/05, covering both situations. The living will was first mentioned, but only briefly, in Opinion 11/CNECV/95 issued in relation to the ethical aspects of health care regarding the end-of-life[116].

In fact, it was only in May 2006 that the Portuguese Association of Bioethics initiated the debate specifically about advance directives through the Advice P/05/APB/06[117]. It covered different types of directives, their validity, limits and requirements, in line with the Recommendation 1418 (1999) on the Protection of the human rights and dignity of the terminally ill and the dying of the Parliamentary Assembly of Council of Europe[118]. One year later, the Association presented legislative Proposal P/06/APB/06, to specifically regulate advance directives and to create a National Registry. In 2009, another legislative Proposal, P/16/APB/09, was issued with the same goals[119]. In 2008, the Association issued Guidelines P/11/APB/08 on the withdrawing and withholding of treatments of terminal ill patients. In December of 2010, the National Council of Ethics for the Life Sciences had issued a favorable Advice 59/CNECV/2010 on these directives, providing several recommendations, including on providing of information about the possibility of registering these directives.

Subsequently, between 2009 and 2011, many legislative proposals were presented and discussed in the Parliament and several hearings were conducted with experts in the field. After long debates and numerous projects of law - 788/X, 413/XI/2ª, 414/XI, 428/XI, 429/XI/2ª and

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[113] FRAGATA, J AND ALCÂNTARA, J (physicians), *Ibid*.
[114] MONGE, C (2014), p.126.
[115] RAPOSO, VL (2012).
[116] At: www.cnecv.pt/admin/files/data/docs/1273059417_P011_FinalDaVida.pdf.
[117] At: http://www.apbioetica.org/fotos/gca/12802556471148471346directivas_medicas_parecer_05.pdf.
[118] At: http://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=16722&lang=en.
[119] PEREIRA, A (2009) pp.165-171.

21/XII/1ª, 62/XII/1ª, 63/XII/1ª, 64/XII/ª - presented by different wings of the Portuguese Parliament[120], the *Living Will Law* was enacted in 2012[121],[122],[123].

The Living Will Law has a triple object: i) to establish the legal regime of advance directives; ii) to regulate the appointment of the health care proxy; and, iii) to create the Living Will National Registry (RENTEV)[124]. According to the Law, any citizen at least eighteen years old and duly capable may declare in advance, and in a clear, conscious and informed manner, his or her wishes regarding medical care, by preparing an advance directive. These directives may take the form of a living will and a health care power of attorney. Appendix 3 summarizes the main components of Law no.25/2012. Needless to say, this Statute pays tribute to patients' self-determination.

2.2 My Macanese experience

Advance directives is a relatively new concept in Macau. To date, there is no law in the Region that specifically addresses the subject, due mainly to cultural reasons and lack of exposure to the matter. The majority are hesitant in deciding about future medical care, preferring to leave it in God's hands. Moreover, family views weight heavily on end-of-life issues. Decisions are mainly made collectively,[125] meaning that the concept of *autonomy* on which advance directives is based might not be important in this culture.

There is no local case law on the matter and there is not a project of law even in an embryonic stage being discussed by legislators. Moreover, in Mainland China, until now no specific law has been issued regarding end-of-law decision-making[126]. In Hong Kong, next to Macau, no law has been enacted so far, though in December 2009, the government published a

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[120] MONGE, C (2014), pp.44-96.

[121] At: http://spms.min-saude.pt/wp-content/uploads/2015/09/Lei-n-25.2012-de-16-de-julho.pdf.

[122] The Recommendation CM/Rec(2009)11 of the Committee of Ministers to member states on principles concerning continuing powers of attorney and advance directives for incapacity strongly promotes self-determination and autonomy (Principle 1).

[123] It was concomitant with the enactment of the Palliative Care Law no.52/2012, of September 5 (CAPELAS, ML et al. (2014), pp.7-13).

[124] MONGE, C (2014), pp.16-17.

[125] As there are no local data published on the preference of advance directives among Chinese older adults in Macau, this part is based in a Hong Kong study (CHU, LW et al. (2011)).

[126] Nevertheless, the living will has been promoted by a private non-governmental organization *Beijing Living Will Promotion Association* (at: www.xzyzy.com/); TENG IONG, MAN (2017), pp.89-91.

Consultation Paper on the *Introduction of Advance Directives in the Region*[127]. Macau is a Special Region in China, characterized by its bipolarity. It has strong influences from the Western legal tradition, through Portugal, but with an increasing Chinese influence, mainly after 1999[128].

Given the Portuguese heritage in Macau legal system[129], there are some provisions of local law that address advance directives. Decree-Law no.111/99/M, of December 13, establishes the legal framework on the protection of human rights and human dignity in the face of biology and medicine applications. This Law was issued during Portuguese administration and it is based on the Oviedo Convention. Article 8, number 2 ("Urgent situations") establishes that "It is taken into account the will previously expressed in respect to a health care intervention, by a person who, at the time of the intervention, is not in a position to express his or her will.". However, the expression "it is taken into account" does not mean that the doctor must compulsorily follow the previous expressed wishes of the patient.

Moreover, as per Article 30 of the Basic Law, "The human dignity of Macau residents shall be inviolable."[130]. The Macanese Civil Code (and its Article 67) is similar to the one in force in Portugal. As for the Criminal Code, it establishes in Article 150 ("Arbitrary medical-surgical procedure") that a physician who acts without the patient's consent, either expressed or presumed, commits the crime of arbitrary medical intervention. This crime aims to protect the person's self-determination in matters related to medical treatment. The duty to inform is prescribed in its Article 151, and presumed consent is in Article 38. This duty is also present in the legal regimes that regulate the physicians' and pharmacists' careers in the Region.

More recently, there were some voices from the medical community that started calling for awareness about the importance of these directives, namely in respect to the elderly. In Macau, the aging of the population is a public health concern. Some doctors have voiced the need for advance directives in the Region, as have experts in the field, including scholars, legal advisors and lawmakers[131]. As was the case in Portugal, in Macau, there is nothing in the law that prevents the execution of these directives, but they are not legally binding. Presently, the law

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[127] TING, FH AND MOK, E (2011).

[128] Macau belonged to Portugal until 1999, year of its handover to PRC.

[129] CARDINAL, P (2009), p.221.

[130] At: www.wipo.int/edocs/lexdocs/laws/en/mo/mo019en.pdf.

[131] TENG IONG, MAN (2017), where it is presented a proposal of advance directives law for the Region.

provides a sort of remedy to the current lack of guidance in the area of death and dying. These documents merely provide an indication of the patient's preferences.[132]

If a situation like the Schiavo case happened in Macau, with a patient maintained on life-sustaining treatments for a long period, unable to provide the required consent, the doctor must apply for presumed consent as per Article 150, number 2 of the Criminal Code. Unless trustworthy information is given by a family member or even by an advance directive[133] about the patient's health care wishes, "the doctor must treat the patient as if he has given the necessary consent, since this is the most reliable option from an objective perspective"[134]. Physicians would also tend to act in favor of life (*favor vitae*) of the patients, in order to avoid any criminal and civil liability.

Macau is predominantly made up of a Chinese population that practices Chinese cultural traditions. Death is a very sensitive issue[135]. "Because of Chinese people's culturally strong habit of denying death, health care professionals often find it difficult to discuss end-of-life care"[136]. Additionally, "Chinese tend to ask their doctors to try to prolong life as long as possible."[137]. In Hong Kong, where Western and Chinese medicine also coexist, a study showed that: "traditional Chinese societies place greater emphasis on such community values as harmony, responsibility, and respect for parents and ancestors. Specific areas of cross-cultural conflict include: the role of the patient and family in medical decision-making; the disclosure of unfavorable medical information to critically ill patients; the discussion of advance directives or code status with patients; and the withholding or withdrawal of life support."[138]. In Chinese culture, family relationships assume primary relevance and relatives play a decisive role in a patient's medical treatment plan.[139] In Macanese health care facilities, it is common practice for physicians to listen to the patient's family members.

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[132] *Ibid* (pp.70-72).

[133] However, while there is no legislation that grants binding force to the directives, doctors may easily reject their content. They can argue that took the directive into consideration, but reached the conclusion that its content was not clear enough to prevent them from pursuing treatment.

[134] RAPOSO, VL (2012), pp.3-5, pp.11-12.

[135] LAI WAN, CHAN, CECILIA AND YIN MAN CHOW, AMY (2006) pp.2-4, pp.17-19.

[136] *Ibid* (p.19); SEARIGHT, HR AND GAFFORD, J (2005).

[137] *Ibid* (p.26).

[138] IP, M et al. (1998).

[139] CHU LW, LUK JK, HUI E et al. (2011), p.150.

Notwithstanding potential difficulties of implementation of advance directives in the Region, some scholars assert that these instruments should be specifically legislated to grant them binding force[140].

2.3 Diverse cultural mind-sets and demands among world regions

Advance directives have been in place for several years in Western countries, but are relatively new for Asian people[141], mainly Chinese. There are factors beyond access to information or lack of awareness that may influence the decision not to complete an advance directive. Cultural and religious factors contribute greatly to the development of these directives being slower and less legalistic in Portugal, and especially in Macau, than in the US.

Americans

Are more organized, pragmatic and less sensitive to some issues, one being end-of-life planning. Usually, are less influenced by certain religious beliefs and philosophies about life and death. Consequently, are keener to engage in discussions about health care planning. In general, Americans are also more knowledgeable about advance directives, their content and goals, than Portuguese and Chinese/Macanese. When compared with Portuguese and Chinese/Macanese, Americans are more likely to have executed some sort of directive or at least having talked about their wishes for end-of-life medical care with a doctor. If in America completion rates of advance directives are relatively low (approximately 35%), in Portugal the execution of these documents is still rare.

Portuguese culture is strongly rooted in the Catholic religion. The Catholic Church proclaims that human life is sacred. Prominent Catholic views about the sacredness of life might be a constraint for completion of advance directives. This is true even though there are many people who described themselves as non-religious or non-practicing Catholics and the Catholic Church has already issued a favorable opinion to the Living Will Law[142]. Moreover, the typical

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[140] Teng Iong, Man (2017), pp.71-72.

[141] Except for Singapore (Advance Medical Directive Act 1996) and Taiwan (Hospice-Palliative Care from 2000), which have been innovative in this respect.

[142] At: https://www.dn.pt/portugal/interior/lei-do-testamento-vital-precisa-de-clarificacao-2721699.html (Pinto, F). Moreover, it was recognized that advance directives do not constitute the legalization of euthanasia/assisted suicide, practices forbidden by law and condemned by the Church. (Raposo, VL (online paper); Nunes, R in Study E/17/APB/10 about the living will (pp.10-17).

Portuguese does not like to talk about death and dying[143]. It is depressing to talk about this topic, some say. Unwillingness to talk about death may be another obstacle for execution of these directives. Nevertheless, if denial of death is a key part of the problem, general lack of awareness and inattention to the issue of advance care planning is also important. Lay people do not even know what these documents are, what is contained in them, and have not ever thought about the matter. They have never talked about the subject with their primary care physician.

While an estimated 35% of adults in the US have done an advance directive[144], in Portugal completion rates are approximately 1%. A study performed in 2013 by the Catholic University in partnership with the Palliative Care Association, found that 78% of Portuguese adults still did not know what a living will is[145]. This study also found that only 50,4% Portuguese knew what to do and where to go in order to execute an advance directive, and only 1,4%[146] actually had formally executed one.

Considering the above, in July 2015 there were only 1468 living wills[147] executed and registered at the Portuguese National Registry. According to official records published at the National Health Service website, in May 2017, this number went up to 12.019[148]. In February 2018, the total number of registered living wills was 18.809.

Appendix 4 shows updated official data from the Health National Service.

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[143] SIMÕES, JA (2010).
[144] CARR, D AND LUTH, E (2017), p.7.
[145] At: http://direitoeconomia.com/page/2/.
[146] This percentage may now be higher.
[147] At: http://spms.min-saude.pt/2015/07/rentev-um-ano-a-registar-testamentos-vitais/.
[148] At: https://www.sns.gov.pt/noticias/2017/05/25/mais-de-12-mil-com-testamento-vital/.

Portuguese

Continue not knowing what a living will is. In spite of having gained legal status, the concept of advance directives is practically unknown. Although the Catholic Church has expressed a favorable opinion[149] of the living will and Law no.25/2012, Portuguese are mainly Catholicism embodied. For Catholics, human life is a supreme value that should be preserved. Death is a subject that is generally avoided. An evident reason is that death is feared. This means that Portuguese are more reluctant to talk about death and what to do if diagnosed in the future with a terminal illness. Moreover, while most people procrastinate frequently, namely in respect to complex/sensitive issues, others often think that *this what if scenarios* will not happen to me.

Macau is a cross-cultural zone influenced by Western culture for historical reasons because of Portugal. However, the reality is that Macau is a Special Region part of China, hence, deeply rooted in Chinese traditions and values. Chinese culture, based mainly on Confucianism[150], is determinative in core issues like end-of-life care. For Confucians, death is something unwanted. Confucians hold a high moral value to life. If an individual does not struggle with effort to live and gives up life easily, he is seen morally as a defeated person. Thus, for Chinese, death is a very sensitive and a sacrilegious issue. For example, Chinese often do not have a fourth floor in their residential buildings and avoid using number four in their cars registration plates, as in Chinese number four (四, pinyin: sì) sounds similar to the word death (死, pinyin: sǐ).[151] Confucian thinking and culture also contributed to the creation of a system of Chinese traditional medical ethics which “contains concepts such as the need: to attach great importance to the value of life; to do one’s best to rescue the dying and to heal the wounded; to show concern to those who suffer from diseases;”[152].

Based on these religious beliefs, personal autonomy is less valued than family relationships. Obligations that are inherent and constitutive of key relationships in China take precedence over certain individual rights. In fact, family members play a decisive role in a patient’s health care plan. Reflecting Confucian teaching, a decision about end-of-life medical care without consulting the family, especially the oldest son, it is unthinkable. Confucian philosophy elevates

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[149] Pinto, F (priest), at: http://www.plmj.com/xms/files/noticias_imprensa/2012/AGOSTO/PMS_testamento_vital_DN.pdf.

[150] Yan-Fang Xing et al. (2017).

[151] Lai Wan, Chan, Cecilia and Yin Man Chow, Amy (2006), pp.3-5.

[152] Zhaojiang, Guo, (1995).

family values and respect for the oldest person. Filial piety is a virtue of respect for parents. Dying/death is perceived a family matter instead of a personal issue.[153] As such, the implementation of advance directives without direct involvement of the family members will be impossible. In a nutshell, death is taboo, life is attached to great moral value, and relatives take an influential part in this type of decision.

Chinese/Macanese

Chinese, with Confucian traditions, see death as taboo and something undesired. Talking about dying is considered to bring bad luck. In all cultures, American, Portuguese and Macanese/Chinese, people tend to involve their family members in these matters, relying mainly in their spouses and/or parents as decision-makers. Nevertheless, in Chinese culture, end-of-life decisions is seen primarily as a family responsibility. In Macau, Western culture is definitely present, but Chinese traditions say that they are more likely to prefer a collective/family-centered decision-making approach.

Cultural and racial differences and ethnic backgrounds have a powerful effect on advance directives completion and implementation. People's preferences, beliefs and values shaped by their own culture greatly influence end-of-life care discussions. Religion also affect how individuals view life, death and end-of-life health care. Based on my experience of having lived in three different Continents, complemented by an informal survey conducted for the purposes of this research, it was possible to reach some key findings detailed in Appendix 5.

Certainly, this analysis should be viewed with caution and consider the existence of overlap in attitudes among distinct ethnic and racial groups over the world in order not to stereotype patients. Moreover, there are other important factors to consider with respect to advance directives completion: level of education/higher income, access to information, geographical location (urban v. rural), gender, (older) age, marital status[154], exposure/presence of a chronic progressive condition or life threatening diseases[155].

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[153] Zheng Jie Marc Ho et al. (2010).
[154] Boehmerm, U et al. (2010).
[155] Jaya K, Rao et al. (2014).

CHAPTER THREE

ECONOMICS OF DYING

3.1 Effectiveness of Advance Directives and ACP in reducing health care costs

All over the world, health care systems are facing dramatic increases in expenditures, in great part because of medical technology innovations that allowed an extension of complex surgical procedures, changing the treatment of illness, and improving outcomes for sicker and older patients[156]. Our society is aging and with that, chronic diseases will rise globally. As the over-sixty-five age group keeps growing, so will the cost of health care. Medical technology[157] is considered one of the most important factors in the growth of health care costs[158].

In the US, a country that compared with other developed nations has a more expensive health care system, health care expenditures as a share of gross domestic product (GDP) have risen from 5% in 1960 to 18.3% in 2017[159]. As for Portugal, in 2013, public and private health expenditures as a share of GDP was 9.0%, compared with the Organization for Economic Cooperation and Development (OECD) average of 8.9%[160]. Portugal had the 14th highest level of spending as a share of GDP in the thirty-four OECD countries during that year. In terms of public expenditures, according to more recent data from Eurostat's database, the general government total expenditure on health in 2015 was 6.2% of the Portuguese GDP[161]. Thus, a large share of health care spending is financed by the public sector[162]. In Macau, as of the last data available in 2013, total health care expenditure was estimated at 1.5% of GDP, which is lower when compared with near countries/regions, like Mainland China[163] and Hong Kong[164].

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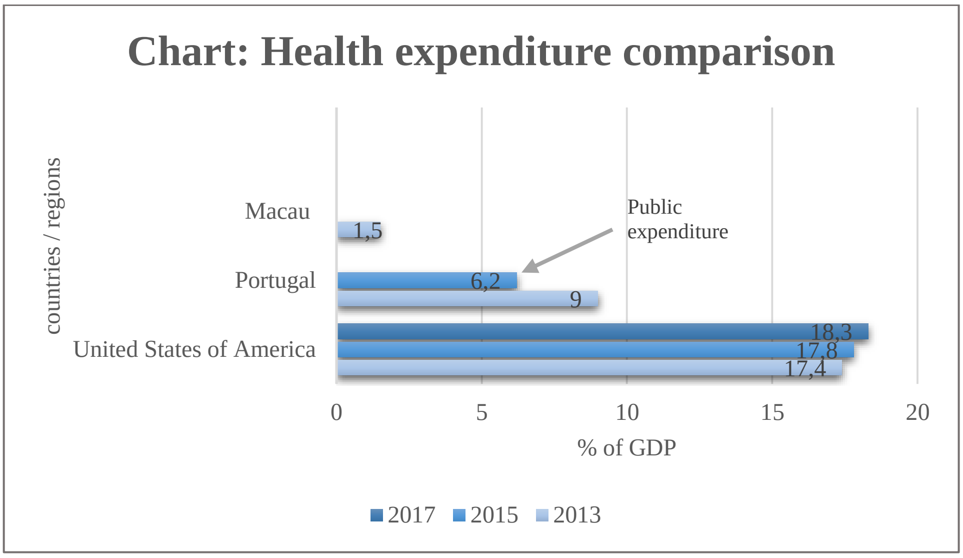
[156] ANTUNES, JB (2010), pp.161,189.
[157] DASTA, JF et al. (2005).
[158] NEWHOUSE, J (1992).
[159] At: https://www.statista.com/statistics/184968/us-health-expenditure-as-percent-of-gdp-since-1960/.
[160] At: https://www.oecd.org/portugal/Country-Note-PORTUGAL-OECD-Health-Statistics-2015.pdf.
[161] http://ec.europa.eu/eurostat/web/products-eurostat-news/-/DDN-20170825-1.
[162] BARROS, PP et al. (2007), p.127.
[163] At: http://www.who.int/countries/chn/en/.
[164] At: https://www.legco.gov.hk/research-publications/english/1617issh03-health-expenditure-in-hong-kong-20161024-e.pdf.



Data and charts are available in Appendix 6.

In addition, health care costs increase significantly in the last year of life[165]. In 1993, the exponential rise in Medicare expenditures in the last year of life was already prominent in the US, with payments per patient-year increasing almost four times[166]. Moreover, health care costs at end of life represent a high proportion of overall health care, with the "percentage of Medicare payments attributable to patients in their last year of life [at a rate of] 25.1% in 2006"[167]. Recently, another study found that approximately half of older Americans have high spending on health care a year before they died, mainly because of the care received for various chronic medical conditions, including visits to the doctor and regular hospital stays over that year.[168]

With the rising trend in per capita health care expenditure, especially at the end of life, there are strong economic interests in keeping such expenditure at a relatively stable growth rate. Advance directives, seen as a primary tool to promote patient autonomy, have also been discussed as a means to save and control medical costs at end of life[169]. How many billions in annual health care expenses could be saved if all adults had an advance directive formally executed? Terminal diseases require costly aggressive medical intervention[170]. Physicians often

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[165] Not necessarily linked to old age.

[166] LUBITZ, JD AND RILEY, GF (1993), p.1094; and a recent study, at: https://www.ncbi.nlm.nih.gov/pubmed/20148984.

[167] DONLEY, G AND DANIS, M (2011).

[168] KAVIN, G (2016); DAVIS, MA et al. (2016).

[169] LEVINSKY, NG (1996); EMANUEL, EJ AND EMANUEL, LL (1994), p.175.

[170] DONLEY, G AND DANIS, M (2011).

have to struggle with limited and quite expensive medical resources, namely in relation to life-sustaining treatments.

At first glance, it might not be absurd to link the use of advance directives with a decrease in health care costs, especially at end of life. According to a study, patients who had executed living wills tend to prefer limited or comfort care (92.7% and 96.2%, respectively) than all care possible (1.9%)[171]. If we think that directives are directly linked with fewer life-sustaining interventions, we would expect that less medical care consequently means lower medical costs[172]. Nevertheless, several other studies have found almost no effect of these directives on a number of outcomes from different features including, for instance, length of hospital stay, level of pain and on health care costs too.[173] In fact, there are many studies that reached the same conclusion: the use of advance directives do not affect health care expenditures.

In 1994, a study showed that cost savings for reducing the use of aggressive life-sustaining treatments for dying patients "is at most 3.3 percent of total national health care expenditures."[174], which is not substantial. The SUPPORT study, a randomized controlled trial reported in 1995 with over 4804 US patients with an average age of 65, measured patient's hospital charges during hospital stays. It concluded that the directives did not reduce use of hospital resources and had no overall impact on costs[175]. Moreover, a 1997 study on resource utilization concluded that the increasing use of advance directives was not linked with a reduction in hospital resource utilization[176].

Hence, promoting advance directives with the aim of reducing health care costs is not likely to be successful, and even if there are some savings, they may be overstated[177]. The fact that the directives are not widely used also contributes to their lack of impact in terms of resource use and costs of care at end-of-life. Furthermore, the promotion and implementation of programs of advance directives entail substantial costs as well[178]. Although most studies have failed to give evidence that directives contribute to decreased resource use and health cost control, a

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[171] SILVEIRA, MJ et. al (2010).
[172] FRIES JF et al. (1993).
[173] SHAPIRO, SP (2015), p.488.
[174] EMANUEL, EJ AND EMANUEL, LL (1994), p.543; EMANUEL, EJ (1996).
[175] The SUPPORT Principal Investigators (1995).
[176] TENO, J (1997).
[177] EMANUEL, EJ, EMANUEL, LL (1994).
[178] FAGERLIN, A AND SCHNEIDER, CE (2004), p.38.

recent study showed that the impact of these directives is dependent on the region where the patient receives care. In fact, in regions where health care expenditures are already low, advance directives execution seem to have no impact on health care costs. In areas with high levels of end-of-life care spending, these directives "were associated with significantly lower levels of Medicare spending"[179].

However, what about advance care planning, the new concept that has emerged and gained importance recently? In fact, from early studies that revealed no impact at all of traditional advance directives on health care costs, recent studies show something slightly different in respect to a *systematic implementation of a program* for the use of advance directives, and to end-of-life *conversations* and *counseling*.

In a randomized controlled trial from 2000[180], it was reported that per patient health care costs were significantly lower in nursing homes with a systematic implementation of a program to increase the use of advance directives (i.e., an average difference of $1,749CAN; 33.4%). This study also revealed that in these nursing homes there were fewer hospitalizations per patient and a lower average number of days spent in hospital.

An observational study reported in 2009 in hospital patients with advanced cancer measured the costs for hospital stays and hospice use in the final week of life. The study revealed that aggregate costs of treatment were 35.7% lower for patients that had communicated (by *conversations*) their end-of-life wishes with their doctor compared to those who had not.[181]. Another study reported in 2010 shown that end-of-life counseling, "can reduce costs by facilitating voluntary election of less intensive care" (i.e., a reduction of $1,913 USD (4.5%)[182]).

Although all these studies do not refer expressly to advance care planning, all demonstrate, at least, the potential to reduce end-of-life health care costs through the lifelong communicating process between patient and physician. Naturally, it is necessary to perform more randomized studies on ACP to produce reliable evidence on its possible costs implications[183].

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[179] NICHOLAS, LH et al. (2011).
[180] MOLLOY, DW et al. (2000).
[181] ZHANG, B et al. (2009), p.2.
[182] HAMLET, KS et al. (2010).
[183] DIXON, J et al. (2015).

In Portugal and Macau, which have a different public health financing system in place, local studies are important to assess if this apparent cost-effectiveness of ACP also applies. Portugal is quite a small country and Macau is a wealthy Special Region in China with lower levels of overall health care spending when compared with the US. Moreover, there are relevant cultural and social factors to consider in terms of end-of-life wishes, as demonstrated.

3.2 Ethical implications of Advance Care Planning becoming a purely economic strategy

If advance care planning is confirmed to have an impact on overall health care expenditures, with cost containment as one of its main and explicit goals, ethical concerns may be raised. There is a significant potential risk of an ethical conflict between the primary goal of advance care planning, which is the promotion of patient autonomy, and the goal of reducing health care costs.

In the US, a country with a health system based primarily on fee-for-service payment, there are strong incentives for physicians and health care institutions to prescribe more treatments and choose expensive ones[184]. They will make more money if they provide more intensive/aggressive procedures. [185] Hence, it may be tempting to encourage patients to pursue treatments, even if it is not truly necessary for the benefit of the patient. The Medicare system has been strongly criticized for rewarding the tendency to pay for increasing health care costs and for diminishing returns in terms of life expectancy[186].

However, since January 2016, physicians are eligible to receive reimbursement from Medicare for providing advance care counseling. One of the problems in the US is that there was a financial disincentive for physicians to discuss end-of-life care, because physicians generally could not bill for it[187]. This measure raised concerns that directives would lead to the denial of necessary health care. In 2010, a similar provision was removed from the Affordable Care Act prior to passage, because it had raised an intense political debate. Opponents argued that it

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[184] EMANUEL, EJ AND EMANUEL, LL (1994), p.165.
[185] SCHROEDER, SA AND FRIST, W (2013).
[186] CALLAHAN, D (2009).
[187] THE INSTITUTE OF MEDICINE OF THE NATIONAL ACADEMIES (2014), p.2.

would create *death panels*, i.e., commissions of officials that would make decisions that rationed health care and limited medical treatment[188].

In Portugal, which has universal health care coverage and a nearly free health care system offered by the National Health Service[189], there may be an incentive to use advance care planning to pressure patients to choose less intensive and, thus, less costly treatments. The promotion of advance directives may be involved in urging patients to refuse or limit end-of-life treatments in order to control overall health care expenditures. As discussed, ACP may have the potential to reduce expenditure if patients choose to limit costly life-sustaining treatments. The problem arises when pressure is placed on the patient to choose less expensive treatment than he or she truly desires and needs. If a patient choose between treatment A and B, or choses no treatment at all, by some sort of undue influence, the openness and sincerity of the communication process that characterizes advance care planning will be in danger, compromising its *rationale*. There may be ethical implications if these directives and ACP are used as a principal means to contain costs, constraining patients' autonomy.

Nowadays, these concerns are even more relevant, due to the shortage of health care resources. There is great social and economic pressure to save money on health care. Considering the current economic context, not only end-of-life sustaining interventions, but also palliative sedation and anti-pain therapy have a considerable weight in the nation's health care budget.

Rationing of care is unavoidable in any health care system, regardless of the economic situation. The problem is not rationing health care resources, but rather how best to ration, respecting our societal values.[190] Rationing may be justified if carried out by ethical and equitable means, safeguarding the relationship of trust between patients and health care professionals. Every day physicians take decisions based on cost-effectiveness motivations. According to the Portuguese Medical Deontology Regulation[191], physicians should seek the most effective and efficient management of existing resources (Article 4, number 4). Good medical practices (*leges artis*) determine that physicians should refrain from prescribing unnecessarily expensive examinations/treatments and from performing superfluous medical acts (Article 7, number 2).

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[188] At: https://www.pbs.org/newshour/health/doctors-bill-medicare-end-life-advice-death-panel-fears-reemerge (and at: http://kff.org/health-reform/poll-finding/march-2013-tracking-poll/).

[189] SIMÕES, JA et al. (2017), p-xviii.

[190] BARROS, PP AND MARTINS, B (2012).

[191] Regulation no.707/2016, of July 21.

It would be false not to admit that cost containment and medical resources allocation is currently on the minds of physicians and medical institutions.

Advances in medical technology have enabled physicians to prolong life of patients to an extent not known before. Medical costs rose. Consequently, today there are new pressures to limit costly health care procedures. Hence, in addition to the traditional medical practice to seek what *is best for the patient*, currently a cost-benefit analysis is also present, even if implicitly, in each treatment and medication administrated by physicians. They need to allocate and use resources responsibly.

At a time where a cost-effective care is encouraged, protections are much needed in order to advocate for ACP, which has important positive outcomes, but also to guarantee protection of patient autonomy, and not inappropriately leading to denial of care. Recommendation 1418 (1999) of the Council of Europe expressly warns of the need to ensure that "no terminally ill or dying person is treated against his or her will while ensuring that he or she is neither influenced nor pressured by another person"; and it further states: "safeguards are to be envisaged to ensure that their wishes are not formed under economic pressure;"[192].

For the same reason, financial incentives for advance care counseling as implemented in the US[193], are not advisable in Portugal. Any reimbursements to the physicians for time spent with patients discussing advance directives or to encourage talking about end-of-life care should be seen with caution. It may be linked to incentives to pursue less invasive and less expensive treatments, influencing decisions to avoid medical care with the risk of jeopardizing patient autonomy. Any decision about future wishes expressed in an advance directive has to be genuine and voluntary.

A last note to conclude this part: as per the Physician Survey, which results are in Appendix 7, Portuguese physicians believe that advance directives should be part of an overall clinical process, or a patient autonomy tool, instead of an administrative instrument for reduction of costs.

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[192] Paragraph 9.b).9.2.3.

[193] WOLF, SM et al. (2015), p.681.

CHAPTER FOUR

WHAT CAN WE LEARN FROM THE AMERICAN MODEL?

Lessons and recommendations

There are important lessons and key recommendations that we can draw from more than forty years of experience in the US regarding advance health care and continuous work on end-of-life care.

Lesson One There are many barriers to getting people to complete Advance Directives.

Advance directives are the embodiment of the principle of patient autonomy. They are intended to facilitate end-of-life decisions after incapacity. These directives aim to ensure that a patient’s wishes and preferences are followed in the event they are not able to make their own health care decisions[194]. They are meant to protect and respect patient’s dignity, promoting the well-being of the patient at the end of life. They may also offer some sort of comfort to family members, significantly reducing the stress and burden of making decisions for the patient[195].

Nonetheless, in spite of the early enthusiasm for advance directives and their envisioned benefits, in the US completion rates remain low. A systematic review of studies from 2011-2016 found that “Among the 795,909 people in the 150 studies we analyzed, 36.7 percent had completed an advance directive”. According to this recent study, completion of these directives was slightly higher among patients with chronic illnesses (38.2%) than among healthy adults (32.7%), and it was much higher among elderly patients with more than sixty-five years old (45.6%) compared with younger adults (31.6%)[196]. There is consistent evidence that presently advance directives have low uptake and people are reluctant to do them. Two out of three

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[194] SILVEIRA, MJ et al. (2010).
[195] TENO, JM et al. (2007).
[196] YADAV, KN et al. (2017).

American adults have not completed an advance directive[197]. Studies identify several barriers to advance directives completion[198] to which Portugal and Macau may also be vulnerable.

Reasons for non-completion can be on the side of the patient, due to lack of education or knowledge and difficulties with paperwork[199]. Another problem is fear and discomfort with the topic of death and dying. Talking about death is hard and problematic, especially when there is a terminal disease, as it involves thinking about deterioration of health and the process of dying[200]. One more limitation is the lack of physician initiative in bringing up the subject. Patients tend to believe that physicians are the ones that should start the conversation about end-of-life care planning[201], and want their doctor to raise this topic[202].

Barriers to completing Advance Directives

Physician-related

- **Discomfort with the topic**
- **Lack of institutional support**
- **Lack of reimbursement**
- **Lack of time**
- **Waiting for the patient to initiate the discussion**

Patient-related

- **Fear of burdening family or friends**
- **Health literacy**
- **Lack of interest or knowledge: "I don't want to think about it"**
- **Social isolation, lack of reliable proxy**
- **Spiritual, cultural, and racial traditions**
- **Waiting for the physician to initiate the discussion**

On the side of the physician, obstacles are mainly connected to reluctance to talk about end-of-life care with patients due to the degree of emotional upset it may create. Physicians fear that a full disclosure of the patient's prognosis may cause undue distress to the patient and that talking

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[197] At: https://www.sciencedaily.com/releases/2017/07/170705184048.htm.

[198] At: http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm.

[199] Glick, KL et al. (1998).

[200] Benson, WF and Aldrich, N (2012), p.3.

[201] Johnston, SC et al. (1995).

[202] Gesme, DH and Wiseman, M (2011).

about end-of-life issues may destroy hope for a positive outcome[203]. Time constraints of the health care providers in their daily medical practice should also be considered. The discussion of these directives is not only difficult and time-consuming, but also requires special training/skills. Billing for this service may also be a problem, raising reimbursement issues.[204]

Legal requirements for witnessing[205] and notarizing the directives may be too strict, becoming excessively burdensome and counterproductive for their completion[206]. Structural barriers include the lack of a formal system, like electronic health records indicating whether the patient has a directive. For example, in Portugal, registration of the directive in the National Registry is not compulsory. This makes difficult for medical providers to know if the patient has executed an advance directive.

Cultural and ethnic factors also influence their completion[207], as discussed. Because in Portugal and Macau religion and spirituality form the basis of meaning and purpose for the majority of people, options related to preferences of spiritual or religious needs and life-style may also be included in the text of the directives, as they serve as an important source of guidance. Although this is possible, it is not expressly stated in the Portuguese Law[208]. As discussed, under the North Carolina General Statutes, the patient may give instructions to the proxy regarding the disposition of remains and regarding burial or cremation. Details like this might be important for a Catholic who may prefer a burial in the ground, instead of a cremation. Moreover, *Five Wishes* is a user-friendly directive that merges both directives and tackles sensitive issues related to comfort measures, emotional suffering, spirituality and interpersonal needs.

Lesson Two **The living will has more shortcomings than benefits. The proxy is a better option.**

As currently implemented in the US, living wills are too vague and do not answer many of the specific questions that come up at the end of life. Most living wills do not give much detail

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[203] Keating, NL et al. (2010); Fried TR et al. (2007).

[204] Spoelhof, DG and Elliott, B (2012), p.463.

[205] In Portugal, directives should be notarized, but no witnesses are required.

[206] Castillo, LS et al. (2011).

[207] Kwak, J and Haley, WE (2005); Douglas, R and Brown, HN (2002).

[208] There is only a brief reference to the possibility of receiving religious assistance in the directive optional form approved by Ordinance no.104/2014.

about treatments. They do not provide adequate guidance for the complexity of issues they try to address. These documents often include vague and ambiguous terms (e.g., terminal condition) and complex, technical language that demands interpretation. They are often insufficient to ensure that all decisions about end of life will be covered and made 100% in accordance with the patient's wishes.

The living will is not always useful in cases of chronic diseases[209] that progress over a long period. Unpredictability of future situations and uncertainty connected with terminal medical conditions also makes decision-making difficult[210]. Additionally, there can be a problem accessing the documents in an emergency. Often the documents do not get into the medical records of the patient. Once executed they may be locked away in a safe deposit box or in a hidden place at home, becoming unavailable and useless when decisions need to be taken.[211]

The appointment of a surrogate decision-maker is considered as a better option than a living will. The health care power of attorney is seen as a much more flexible and versatile instrument.[212] Nevertheless, there are also a few reservations about proxy appointments. The appointed agent may later seem to be a wrong surrogate decision-maker, because when the time comes the surrogate may not want to bear the burden of such difficult task[213]. The proxy may have different beliefs than the patient and try to override the patient's stated preferences, acting instead according to his or her own convictions/values[214]. The agent may also be not sufficiently involved in the patient's health care plan[215].

Fear of the proxy/surrogate not entirely follow the patient's wishes is another negative point. In Portugal, some voices argue that the law should have established in detail the powers that can be granted to the proxy[216]. At least an option to place limits should exist. Unfortunately, lay people often do not know enough about the medical setting to make reasonable choices about

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[209] ABBO, ED et al. (2008).
[210] LEE, DH (2002).
[211] FAGERLIN, A AND SCHNEIDER, CE (2004).
[212] *Ibid* (p.38-39)
[213] WENDLER, D AND RID, A (2011).
[214] SHALOWITZ DI et al. (2006).
[215] WOLF, SM (1991).
[216] MONGE, C (2014), p.204.

limiting proxy powers. A combination of living will and appointment of a health care proxy may also be an alternative to address the complexities of end-of-life care.

Notwithstanding the criticisms to both directives, someone has to make a decision. Having a directive, even with flaws, is better than not having a directive at all. Meaning that these instruments do not need to be perfect to be worthwhile. In spite of all shortcomings, it is important to give the authority to take medical decisions to someone the patient named and trusts, rather than a list that is set out in statute.

Lesson Three **Advance Directives are not just a form or a piece of paper.**

Forms alone generally do not work. Forms should foster communication and not be a substitute for it. Once end-of-life care instructions are written down on paper, people have the tendency not to mention it anymore. As such, simply informing patients about their rights to self-determination and handing them the forms to fill out when admitted at the health care facility is not enough. A piece of paper will not suffice as a satisfactory means of doctor-patient communication. Just completing a form will do patients little good if all the planning process is completely ignored. Planning is almost as important as screening and other forms of preventive health care.

The American Bar Association (ABA) Committee on Law and Aging presented as one of the ten myths about health care advance directives, "Once I give my doctor a signed copy of my directive, my task is done!"[217]. This is false. Completing the directive is just a small part of an ongoing and multiple-step process of advance care planning[218].

Lesson Four **Advance Directives should be reevaluated and updated periodically.**

It is impossible to know if patients will change their minds about intentions and plans for their end-of-life care so that advance directives become useless if not revised/updated. Wishes and values change over time and circumstances, depending on the progress of the disease[219]. It is

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[217] At: https://www.bcan.org/wp-content/uploads/2017/12/ABA-Myths-and-facts-about-Advance-Directives.pdf.
[218] Levi, BH and Green, MJ (2010).
[219] Fried, TR et al. (2006).

difficult to anticipate what the preferences of a patient will be in a future medical situation. Therefore, the directives can fail or may not have the desirable outcome if patients do not reevaluate and update them periodically.

In Portugal, the Law establishes that the living will shall be valid for five years, renewable by means of a confirmation declaration. To establish that the directive is valid for a certain period of time reinforces the idea of updated consent[220]. This solution has been criticized, with authors arguing that five years is too long[221]. Having a limited time period may not be the best solution, though, because people may execute the living will and not re-execute it, leaving them with no directive. This may mean that they will receive more aggressive and even futile life-sustaining treatment.

According to ABA, after preparing a living will, health care wishes should be re-evaluated whenever any of the *Five Ds* occur: “a new Decade in age, the Death of a loved one, Divorce, a Diagnosis of a significant medical condition, or a Decline in your medical condition.”[222]. Re-examination of end-of-life care wishes according to other parameters, rather than only a time parameter, can be an alternative. Moreover, the review/revision should be a recommendation, and the document does not need to be considered necessarily invalid after a specified period of time.

Lesson Five Advance Care Planning is an improvement over the traditional Directives.

Advance care planning emerged as a concept worthy of attention in the context of end-of-life care, being an important improvement over the traditional directives[223]. Recognizing that medical decisions are complex and vary over time in the light of the disease progress, with suffering and pain playing an important role in the health care decisions, ACP was developed in the US as a continual process of communication and dialogue among physician and patient that goes beyond a mere written form or piece of paper[224].

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[220] RAPOSO, VL (2011), p.181.
[221] MONGE, C (2014), p.155.
[222] At: https://www.americanbar.org/groups/health_law/news/2016/04/a_call_to_actionon.html.
[223] PERKINS, HS, (2007).
[224] MILES et al. (1996).

Undeniably, advance care planning concept comprises advance directives, as they are documents in which the decisions coming from the ACP discussions can be recorded. Although talks are not legally binding, an ongoing physician-patient dialogue is the best guide for developing a personalized directive and to make sure end-of-life wishes are honored. ACP goes beyond the mere completion or execution of directives. Simply checking boxes on a form is of limited value as often patients need many conversations to consider their end-of-life pros, cons and options. Overcoming most of the completion barriers discussed above depends on an effective interactive discussion at multiple visits[225], and on giving the patient the opportunity to ask questions[226]. ACP is today widely recognized in the US by being much more effective than standard directives alone in guaranteeing that patients' preferences regarding end-of-life care are fully honored[227].

In Portugal, some criticisms of the Law are related to the fact that it stops shorts of compulsorily requiring health care providers to assist with the completion of an advance directive[228]. This is particularly important in relation to the living will, a document that gives rise to many preparation issues. The involvement of the physician can help to tailor the directive to the particular health situation of the patient. As such, there are doubts whether the preparation of a living will is indeed an exercise of informed consent without the physician giving the proper information, guidance and options available to the patient. Advance care planning could be effective in overcoming some of these difficulties. Although it does not serve exactly the same purpose as an advance directive, POLST is a good example of a tool that requires the physician's[229] direct involvement and signature. Considering that living wills are mainly executed by seriously ill people, why not think about these medical orders to at least complement the traditional directives?

In Macau, to better accommodate cultural needs, lawmakers may have to consider the inclusion in future legislation of a provision establishing family members' direct participation in the process of advance care planning. Taking into consideration the role of family members in health care decision-making, this ongoing communication process between physicians and

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[225] RAMSAROOP, SD et al. (2007).
[226] JEZEWSKI, MA et al. (2007).
[227] THOMAS, K et al. (2018), pp.18-19.
[228] MONGE, C (2014), p.136.
[229] The eight-step protocol, at: http://www.upmc.com/Services/AgingInstitute/partnerships-and-collaborations/Documents/POLST-8-step-protocol.pdf.

patients should be open to their families. Although it is imperative to ensure that patient autonomy is respected, the legal framework should simultaneously respect cultural traditions. Using a family covenant in planning end-of-life care maybe a solution[230]. In addition, when talking about death and dying is a taboo subject, encouraging patients to review and value their life experiences and complete unfinished business may help them to work on advance directive planning. A study on Chinese patients with advanced cancer revealed that encouraging patients to do a life review helps them to prepare for death[231].

Lesson Six **Physicians need specific and ongoing education and training on end-of-life communication.**

At least as an important recommendation based on the American experience, specific and ongoing education and training on advance care is essential for health care professionals who care for patients facing critical illnesses.[232] Primary care physicians[233] should also learn to initiate conversations about advance directives[234]. They should be aware of the existence of these directives and their legal standing, and be comfortable talking with their patients about end-of-life care. Education and training schemes in the graduate school curricula and after graduation, through simulation exercises, should focus on communication skills[235].

Communication interventions[236] help physicians and nurses[237] to improve their skills in discussing complex and sensitive end-of-life issues with patients[238]. It improves health care provider knowledge, comfort and self-confidence when discussing advance care. Conducting end-of-life conversations involves not only the logistics of directives preparation, the statement of wishes and/or the appointment of a proxy, but also a particular set of empathic and relational skills. Moreover, these conversations may also intersect with cultural, ethnic or religious beliefs that make the communication even more complicated.

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[230] DOUKAS, DJ AND HARDWIG, J (2003).
[231] XIAO, H et al. (2012).
[232] ALLEN, SL et al. (2015).
[233] Cooperation with nurses, caregivers and social workers is also relevant. Directives should be offered to all adult patients healthy and non-healthy, as an accident or a degenerative/chronic disease may happen at any age.
[234] TIERNEY, WM et al. (2001).
[235] SCHELL, JO AND ARNOLD, RM (2012); at: http://depts.washington .edu/oncotalk.
[236] BACK, AL et al. (2007).
[237] PEEREBOOM, K AND COYLE, N (2012).
[238] TULSKY JA et al. (1998).

Specific training for health care professionals is particularly important for the Chinese/Macanese. In Macau, education programs for health care professionals[239] are mainly characterized by a strong medical orientation, giving little or no attention to psychosocial aspects of care, communication skills or education regarding death. As discussed, physicians are reluctant to discuss disease and death openly with patients. They often use all available measures to avoid death.[240] Besides, physicians may tend to prolong life at any price so that will not to be accused of neglect (*defensive medicine*). Chinese doctors are not particularly communicative, and there is a sense of hierarchy that must be respected. Patients abide by the physician's recommendations without questioning.

Lesson Seven Studies are a good source of information.

Another key recommendation to be drawn from the American experience is that over the years, numerous studies, either randomized controlled trials or observational studies, have been performed in the US on end-of-life care and advance care planning, which are quite revealing and informative.

Studies are particularly important in Macau where there is no specific law regarding advance directives. Before legislation is adopted in this Region, research studies should be conducted. If legislation is to be enacted, it should be consistent with Chinese culture and values and suit local demands, namely ethnicity and religion that bear a significant influence on health care decisions. As per Decree-Law no.7/99/M, February 19, the Ethics Council for the Life Sciences, is competent to study and present a preliminary approach as to the possible applicability of these directives and end-of-life planning in the Region. Local studies in different groups need to be performed to assess the acceptability of the directives. Research across nearby jurisdictions with different legislation and advance directives options is essential.

Problems may arise as the concept might not be easily accepted in general by the Chinese population: "people fear that openly acknowledging an impending death is like casting a death curse on a person, so to engage in discussions of any such code or an AD is viewed as courting

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[239] Chinese physicians come mainly from Mainland China, as in Macau there is not a bachelor's degree of medicine (LIU BOLONG AND PANG XINXIN (2009), p.165).

[240] ZOU M et al. (2013).

bad luck."[241]. If acceptance is confirmed, community education programs should be initiated. It will certainly be a challenging mission due to the *hybrid* nature of the Region.

Lesson Eight **Dissemination of ACP and Advance Directives is a task shared by many.**

Notwithstanding their low rate of completion, there is a role for advance directives (as they protect a patient's right to self-determination), being widely advocated in the US, not only at state level, by the enactment of specific legislation[242], but also at federal level through the Patient Self-Determination Act, requiring Medicare-certified facilities to provide for the dissemination of information on advance directives to the public[243]. Medical providers and health care institutions, including HMOs, promote the execution of advance directives and advance care planning. They have the endorsement of professional organizations, such as the American Medical Association, and of non-state entities, like *Aging with Dignity*. The Center for Disease Control and Prevention also recognizes their relevance in the public health context due to the increasing number of chronic diseases[244]. Physicians, ethicists, legislators, attorneys, all participated actively in the dissemination of advance care over the years.

Even though directives seemed to some extent have failed, these instruments, as part of ACP, are desirable[245] and should keep being offered as a solution. There are some strategies/initiatives to promote them and to encourage their execution, that would overcome the barriers referred in lesson one. As in the US, in Portugal this is a responsibility to be shared by many. At the top of the list is the National Health Service through the development of a multichannel communication strategy. It should provide funding for studies. Public awareness and informational campaigns are important to clarify what these instruments are and what they aim for. Public policy can develop effective ways to advance care planning become standard practice to health care providers and routine for adults (and be more than providing brochures/pamphlets). Attention should be first given to elderly and patients with chronic

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[241] YONG, SY et al. (2012).

[242] And also in respect to connected matters, e.g. the California's Right to Know End-of-Life Options Act (2009), the New York Palliative Care Information Act (2011).

[243] By the time the PSDA was introduced, roughly 9% Americans had actually executed a directive (at: https://www.finance.senate.gov/imo/media/doc/hrg101-1168.pdf, p.152); now, the rate increased to approximately 35%.

[244] BENSON, WF AND ALDRICH, N (2012), p.15.

[245] WOOLLEN, J AND BAKKEN, S (2016).

illness, like cancer and dementia. The Portuguese Association of Bioethics has been actively promoting advance directives and informing the public about the relevance of end-of-life plan.

Lesson Nine There may be ethical implications of ACP becoming a purely economic strategy.

Last but not least: ACP may have the potential to affect overall health care costs. Such potential impact in containing costs may raise delicate ethical issues. Because of the increasing economic pressure to control health care expenditures due to the scarcity of resources, there may be concerns that cost considerations and motivations could unduly influence the free communication process between patient and physician, undermining patient autonomy. Moreover, if that occurs, it may be deemed too costly to society: "should people suspect they were being pressured to sign advance directives and that such directives might be used inappropriately to limit care, then the result might be both higher costs and more use of advance technology that patients or families would forego in an environment of greater trust."[246].

In principle, the fee-for-service payment model makes it less likely that ACP could be used to ration care in the US than in Portugal. However, with the new Medicare billing code things may be slightly different. Although the idea was to address the problem of doctors not taking the time for important end-of-life conversations, some worry that health care providers will be compelled to make decisions based on costs - discouraging treatments or, worse, withholding them entirely - than on best medical care[247]. Yet, the fact that Medicare is paying at a low rate[248] for end-of-life conversations, might not in reality overcome the other big incentive *to do more*.

Differently, in Portugal with a health care system subsidized mainly by the government, the fee-for-service incentive is not typically present. Advance care planning is essential to improve end-of-life quality and strengthen patient autonomy, but can easily be seen as a mechanism to save health care resources and money. Physician-patient end-of-life conversations have positive outcomes and should happen. People are encouraged to contemplate these decisions. However, if ACP is used only and explicitly to contain costs, there is a risk of patients' decision-making

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[246] EMANUEL, EJ AND EMANUEL, LL (1994), p.176.

[247] The National Right to Life Committee, at: https://www.nationalrighttolifenews.org/news/2014/09/advance-planning-for-treatment-denial-conversations-spread-but-what-is-driving-the-conversation/.

[248] $80-$86 for the first 30 minutes.

about end-of-life care be manipulated, causing a collision with their *autonomy*. While it is challenging to find an ethically feasible approach[249] to any cost control/rationing measure in the health field (a social right protected by the Constitution), strong influence of Catholic thoughts/views – based on protection of life, human dignity and well-being - have a role in balancing the rationing concern.

In any event, safeguards to guarantee the existence of a free and autonomous decision-making process should be put in place.[250] Ongoing monitoring and research by the competent government body should assess whether ACP and directives do cause rationing and undermining of patient's preferences. Education and training of health care providers that focuses on communications skills and specific knowledge (and certification) of advance care planning. The establishment of guidelines/standards to ensure the transparency and fair/openness of the decision-making process is another way to guarantee the care delivered at end-of-life is fully aligned with patient's preferences.

CONCLUSION

Final thoughts

The present work attempts to summarize and analyze the main outcomes in the US in respect to advance directives. It attempts to identify the main lessons learned from the American advance care model and a few recommendations based on the American experience. In order to improve older and sick adults' quality of end-of-life care, it is worthwhile considering alternative practices used in the US. There are a few aspects that are unique to the US context, such as problems associated with lack of uniformity of state laws or the need for financial incentives for end-of-life conversations in a fee-for-service payment model.

Nevertheless, Portugal and Macau may be to a great extent vulnerable to the same failures identified in the US, reflected in the poor uptake of advance directives by the public. Most of the barriers to completion and implementation of the living will identified in the US also have application in Portugal and Macau. The power of attorney is a more effective tool for patients

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[249] E.g., Advice 64/CNECV/2012, concerning a model for financing the cost of medicines, which attempted to ethically justify pharmaceutical expenses cuts, was highly criticized (NUNES, R, at: www.apbioetica.org/fotos/gca/1375264865parecer.pdf).

[250] BILLINGS, AJ (2012).

to plan for end-of life. It is a more gentle way to start thinking about end-of-life care. Besides, considering the important position of family in these decisions, it is more a matter of identifying who the patient trusts to make medical decisions on his or her behalf that will be the central spokesperson.

As advance directives showed many limitations, ACP arises as a new improved paradigm. It refocuses attention away from a specific document to a wider and continuing process of communication that can and should be constantly revised *vis-à-vis* the changing of medical circumstances and of evaluation of illness, disability and suffering of the patient. However, advance care needs to be evaluated within specific cultural and social contexts. Religious affiliations are also linked with end-of-life preferences. Community-based programs – e.g., The Conversation-Project (2017) - may be a possible method to bring more awareness about end-of-life care to the general population, better serving distinctive cultural, social, religious and language needs[251].

At the same time, advances in medical technology are undeniable. It allowed life-extension beyond anything that could ever have been imagined. We are facing worldwide a reality of an increasingly elderly population that needs more and special care, with inherent costs associated especially at the end of life. Advance directives that emerged to enhance patient's autonomy and to help them take control of end-of-life care, contribute to setting limits and putting technology on hold.

As nowadays there is an urgent call for health rationing and resource allocation, advance care planning promotes more appropriate care at the end of life and, at the same time, has – at least – some potential to reduce hospitalizations and to cut costs. However, some caution is warranted on promoting ACP as a cost-containment measure. If it is used for costs containment only, ethical dilemmas and medico-legal issues might emerge. As discussed, the intrinsic value of advance directives arose in Western societies from the notion of *autonomy*[252] in an era of huge technological developments. In this respect, any type of financially motivated intervention should end once medical practice begins. Other criteria beyond what is *the best for the patient* from a clinical point of view, should not count in terms of medical decisions. As such, the use

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[251] CARR, D AND LUTH, E (2017), pp.6-7 (at: https://theconversationproject.org/).

[252] The World Medical Association Declaration of Geneva (2017) now expressly includes: "*I WILL RESPECT the autonomy and dignity of my patient;*", at: https://www.wma.net/policies-post/wma-declaration-of-geneva/.

of these directives specifically, and more broadly of advance care planning model, for cost control and equitable allocation of resources is only justified if it reflects patient's authentic and genuine wishes.

For the sake of patient autonomy, safeguards should be put in place. A multi-faceted approach that considers ACP completion along with proper clinician's education/training is fundamental to deal with these sensitive issues. As once emphasized: "advance directives were designed to assure the private good, not the public (…) to give patients a safeguard against being overpowered by overzealous physicians or institutions"[253].

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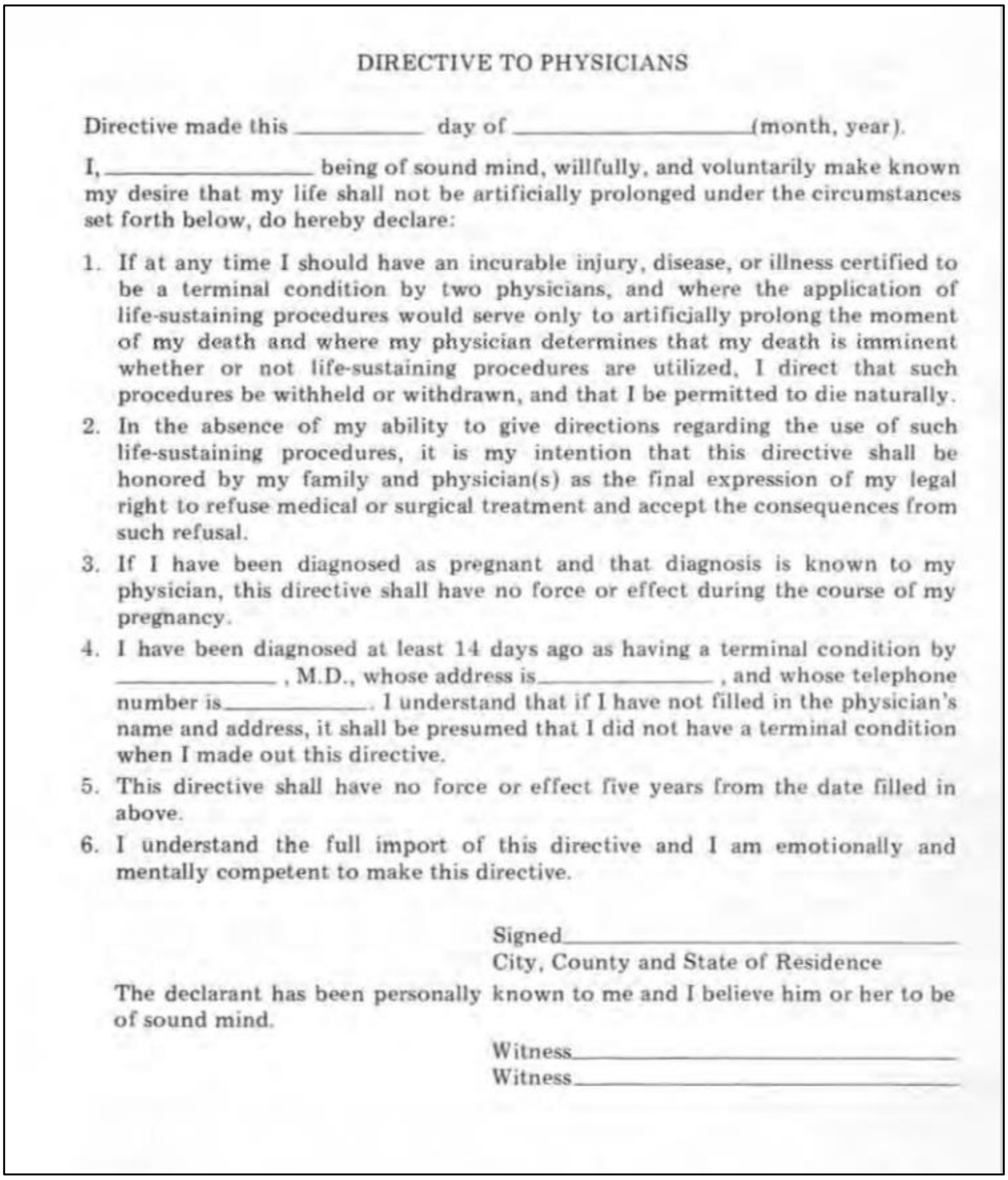
[253] CALLAHAN, D (1996).

APPENDICES

APPENDIX 1

The Natural Death Act, California Health & Safety Code (original text)

§§7185-7195 (West Supp. 1977)[254]



DIRECTIVE TO PHYSICIANS

Directive made this __________ day of __________________(month, year).

I, ________________ being of sound mind, willfully, and voluntarily make known my desire that my life shall not be artificially prolonged under the circumstances set forth below, do hereby declare:

1. If at any time I should have an incurable injury, disease, or illness certified to be a terminal condition by two physicians, and where the application of life-sustaining procedures would serve only to artificially prolong the moment of my death and where my physician determines that my death is imminent whether or not life-sustaining procedures are utilized, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally.
2. In the absence of my ability to give directions regarding the use of such life-sustaining procedures, it is my intention that this directive shall be honored by my family and physician(s) as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences from such refusal.
3. If I have been diagnosed as pregnant and that diagnosis is known to my physician, this directive shall have no force or effect during the course of my pregnancy.
4. I have been diagnosed at least 14 days ago as having a terminal condition by ______________, M.D., whose address is______________, and whose telephone number is____________. I understand that if I have not filled in the physician's name and address, it shall be presumed that I did not have a terminal condition when I made out this directive.
5. This directive shall have no force or effect five years from the date filled in above.
6. I understand the full import of this directive and I am emotionally and mentally competent to make this directive.

Signed______________________________

City, County and State of Residence

The declarant has been personally known to me and I believe him or her to be of sound mind.

Witness______________________________

Witness______________________________

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[254] HORAN, DJ (1979).

APPENDIX 2

Advance Directives Requirements and Formalities: North Carolina General Statutes

Table 1. Living Will[255]

Competence	The declarant must have at least eighteen years old and be competent i.e., able to think rationally and to communicate his or her wishes clearly[256].	
Effectiveness	Once the declarant loses the capacity to consent or to refuse medical treatment, the physician can and should be guided by the directives. Lack of capacity typically includes cases of persistent vegetative state due to a severe injury or terminal illness. The directives may also apply to situations of temporary loss of consciousness and where patients suffers from a mental disease, like advanced dementia, compromising their ability and perception to make autonomous decisions. For life-prolonging measures[257] be withdrawn or withheld, the attending physician must make a determination that the declarant is in one of the situations in which is authorized to withdrawal or withholding life-prolonging measures, followed by a second physician confirmation of this condition. Once the two physicians have concurred that the declarant is in one of the conditions in which is authorized to withholding or withdrawal life-prolonging measures, the attending physician will make specific medical orders to effect/implement the declarant desires. If there is a health care agent, the physician will be consulting with the agent of the declarant through the process.	**§ 90-321(b)**
End-of-life care options	The declarant may decline life-prolonging measures, if is alert and can make his or her own medical decisions. If is not competent, he or she can rely on the directives in the living will. There are tree situations in which the declarant may, in advance, decline life-prolonging measures: i) has an incurable or irreversible condition that will result in the declarant's death within a relatively short period of time; or ii) becomes unconscious and, to a high degree of medical certainty, will never regain consciousness; or iii) suffers from advanced	**§ 90-321(c)**

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[255] North Carolina’s Right to a Natural Death Act (§ 90-320 through 90-322), at: https://www.ncga.state.nc.us/EnactedLegislation/Statutes/HTML/ByArticle/Chapter_90/Article_23.html.

[256] HEALTH JUSTICE CLINIC DUKE MANUSCRIPT (2016): “*Legal and Practical Aspects of Advance Directives and Powers of Attorney*”.

[257] Life-prolonging measures are “Medical procedures or interventions which in the judgment of the attending physician would serve only to postpone artificially the moment of death by sustaining, restoring, or supplanting a vital function, including mechanical ventilation, dialysis, antibiotics, artificial nutrition and hydration, and similar forms of treatment. Life-prolonging measures do not include care necessary to provide comfort or to alleviate pain.”. It is important to distinguish life-prolonging measures from artificial hydration and nutrition. Although some patients would like to withdraw mechanical ventilation/respirator, they would still want to receive artificial hydration and nutrition (§32A-16(4)).

	dementia or any other condition resulting in the substantial loss of cognitive ability and that loss, to a high degree of medical certainty, is not reversible. The living will may operate in conjunction with a health care power of attorney. When both work together, the documents must be consistent with each other. If both directives are in operation, it is possible to leave the decision to the health care agent, especially if the declarant does not have strong feelings on what to do in terms of future medical treatment and feels uncomfortable about projecting what the circumstances may be like at the of his or her end-of-life.	**§ 32A-26, § 90-321(d1) (j)**
Requirements	The living will must be prepared in writing and signed by the declarant in the presence of two[258] qualified witnesses and a notary public. In order to be a witness some criteria need to be met: i) the witness must have at least eighteen years old; ii) is not an employee of the health care facility that treats the patient; iii) is not a person who would inherit under a will or intestate succession. A signed copy of the living will should be given to each of the declarant's physicians and to any medical facility involved to be included in the patient's medical chart. It is also possible to register the directive with the North Carolina Secretary of State. Health care providers normally use a standardized State form that a patient fills out with his or her own medical care wishes. A hospital will be able to provide a form prepared according to the law. North Carolina forms are available on the Internet, through the North Carolina Secretary of State[259].	**§ 90-321(c)(3),(4)**
Revocation	The living will may be revoked by the declarant "in writing or in any manner by which the declarant is able to communicate the declarant's intent to revoke in a clear and consistent manner, without regard to the declarant's mental or physical condition.". These directives will remain valid during declarant's lifetime unless he or she revokes[260] or unless a specific time limit is set out in the Directive.	**§ 90-321(e)**
Natural death in the absence of a declaration.	When an individual does not plan for incapacity by preparing a directive, physicians need to seek a decision-maker. Normally, family members are left with the burden of making such difficult decisions[261]. In case an individual does not plan for incapacity, the North Carolina General Statutes establish a list of persons to whom physicians should turn to: spouse, parents, adult child, siblings, and close friend.	

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[258] In almost all States, at least two witnesses are required. Some States do not require notarization.

[259] At: https://www.sosnc.gov/divisions/advance_healthcare_directives.

[260] HEALTH JUSTICE CLINIC DUKE MANUSCRIPT (2016).

[261] WOOD E (2015), p.10-12.

Procedure	The law establishes a procedure for removal of life-prolonging measures when the person is near death. Firstly, the physician must determine to a high degree of medical certainty, that the patient lacks capacity to make or communicate health care decisions, and that the patient will never regain that capacity. Secondly, the same physician must determine that the patient is in one of the following physical conditions: “a. Has an incurable or irreversible condition that will result in the person’s death within a relatively short period of time; or b. Is unconscious and, to a high degree of medical certainty, will never regain consciousness;” Thirdly, a second physician must concur in writing that the patient is in this condition and “A vital bodily function of the person could be restored or is being sustained by life-prolonging measures;”. If the patient meets all the conditions mentioned above, then life-prolonging measures may be withheld or discontinued upon the direction and under the supervision of the attending physician with the concurrence of the following persons: i) a legal guardian; ii) an health care agent, to the extent of authority granted; iii) an attorney-in-fact under a general power of attorney who has been given power to make health care decisions, to the extent authority granted; iv) the patient’s spouse; v) a majority of the patient’s reasonably available parents and children who are at least eighteen years old; vi) a majority of the patient’s reasonably available siblings who are at least eighteen years old; vii) an individual who has an established relationship with the patient, who is acting in good faith on behalf of the patient, and who can reliably convey the patient’s wishes. Moreover, “If none of the above is reasonably available then at the discretion of the attending physician the life-prolonging measures may be withheld or discontinued upon the direction and under the supervision of the attending physician.”.	**§ 90-322(a)(1a)** **§ 90-322(a)(2)** **§ 90-322(b)**

Table 2. Health Care Power of Attorney[262]

Competence	The principal must have eighteen years old and be mentally competent: “Any person having understanding and capacity to make and communicate health care decisions, who is 18 years of age or older, may make a health care power of attorney.”. As for the agent, “Any competent person who is not engaged in providing health care to the principal for remuneration, and who is 18 years of age or older, may act	**§ 32A-17**

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[262] North Carolina Health Care Power of Attorney Statute (§ 32A-15 through 32A-27), at: https://www.ncleg.net/gascripts/statutes/StatutesTOC.pl?Chapter=0032A.

	as a health care agent." It can be, but do not need to be the same person appointed as attorney in fact to make financial decisions on behalf of the patient. The principal may also name alternate(s) health care proxies.	**§ 32A-18**
Effectiveness	It becomes effective when the physician establishes in writing that the patient "lacks sufficient understanding or capacity to make or communicate decisions relating to the health care of the principal and shall continue in effect during the incapacity of the principal"; in case there is not a designated physician, then such decision is taken by the attending physician.	**§32A 20(a)**
Powers/Authority	Broad powers are granted in terms of health care decisions, being the principal able to limit the grant of such powers (e.g. blood transfusions limitations). The principal may include powers to make decisions regarding end-of-life care as well. Instead of withholding or withdrawing life prolonging measures, it may establish maximum treatment. It is also possible to incorporate an advance instruction for mental health treatment, for specific mental health treatments. Access to private health information about the patient is also possible to include in the document text. Organ donation, autopsy and disposition of remains are as well matters that can be covered by this directive.	**§ 32A-19**
Requirements	The power of attorney must be prepared in writing and signed by at least two qualified witnesses (criteria to be a witness is the same as above) and acknowledged before a notary public. A copy of the signed directive should be given to the physician of the principal and any medical facility involved to be included in the patient's medical chart. It should also be delivered to the agent appointed (or at least the health care agent should be informed of where the document can be found). It is possible to register the directive with the North Carolina Secretary of State.	**§ 32A-16(6)**
Revocation	The directive "may be revoked by the principal at any time, so long as the principal is capable of making and communicating health care decisions". Revocation is effective upon communication to the health care agent(s) and to the principal's attending physician. Except in relation to anatomical gifts, disposition of remains, and autopsy, power of attorney is also revoked by the death of the patient.	**§ 32A-20(b)**

Table 3. Guardianship[263]

Guardianship	If statutory decision makers cannot agree and are in conflict about the patient's wishes, it may become necessary for the appointment of a legal guardian, i.e., a person who has the authority and duty to care for another's person or property. Each State has its own rules on the requirements and process for the appointment of a legal guardian. In North Carolina, the law requires first the determination by the Clerk of Superior Court that the patient is legally incompetent. If incompetence is found and determined, a suitable guardian must be chosen for the incapacitated person, and his or her authority duly specified.	**§35A-1101 et seq.**
	The decision to pursue guardianship should not be taken lightly as it is often a time-consuming process and it involves removing of an individual's rights. It should be a last resort option especially in an end-of-life situation in which decisions may need to be made very quickly. Guardianship implies a court procedure and cannot happen in a matter of hours or days. It can be workable in a less emergency, such as Karen Quinlan case, where the patient was in a long-term persistent vegetative state, so time is not much of the essence.	

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[263] North Carolina General Statutes, Incompetency and Guardianship (Chapter 35A), at: https://www.ncleg.net/gascripts/statutes/StatutesTOC.pl?Chapter=0035A

APPENDIX 3

Main Components of the Portuguese *Living Will Law*

Law no.25/2012, from July 16[264]

1- LIVING WILL

The living will may specifically include the following: i) refuse artificial support of vital functions; ii) refuse futile, useless, disproportioned treatment[265], according to good medical practice, namely in relation to basic life-support and artificial feeding and hydration that only aim to delay the natural process of dying; iii) receive adequate palliative care, including symptomatic therapy in case of serious and irreversible illness; iv) refuse experimental treatments; and, v) authorize or refuse to participate in scientific research or clinical trials; (**Article 2, number 2**)[266],[267]. Hence, the living will serve two purposes, either to refuse or to expressly request certain medical treatments.

The living will must comply with the requirements stated by law, including the formal ones. As for the formal aspects, the living will should be in writing, and signed in the presence of an official from the Living Will National Registry or a notary (**Article 3, number 1**)[268]). The patient may request the cooperation of a physician in the elaboration of the document (**number 2**). Participation of the physician is not compulsory. By Ordinance no.104/2014, of May 15[269], the Ministry of Health approved an advance directive optional form. Moreover, a form is also provided by the National Health System (RENTEV)[270]. Although at first glance Portuguese law seems too formal, it applies a principle of *freedom of form*[271].

The Statute establish some legal limits to the directives (**Article 5**). For example, whenever the directive is found to be contrary to the law or against good medical practices, it shall not have any legal effect. Directives that take to non-natural and preventable deaths are strictly

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[264] At: http://data.dre.pt/eli/lei/25/2012/07/16/p/dre/pt/html.

[265] This provision covers the situations of dysthanasia (SANTOS, ECC (2014), pp.105-113).

[266] This is an exemplificative list only. Directives should not contain requests for euthanasia or assisted suicides that are against the law.

[267] Organ donation is not included in this list. In Portugal, all citizens are organ donors, unless the contrary is expressly stated by registering in the National Registry for Non-Donors.

[268] There are no witness requirements.

[269] At: http://data.dre.pt/eli/port/104/2014/05/15/p/dre/pt/html.

[270] At: http://spms.min-saude.pt/wp-content/uploads/2016/05/Rentev_form_v0.5.pdf.

[271] In line with no.12 of Opinion 59/CNECV/2010.

forbidden, as prescribed in Article 134 (‘*homicide by request of the victim*’) and Article 135 (‘*Induction/instigation or suicide aid*’) of the Criminal Code.

If there is a directive duly executed[272], the medical team shall follow the wishes/preferences previously stated in the document (**Article 6, number 1**). The directive applies once the patient becomes incapable[273]. If a physician does not comply with a directive validly executed and binding, he or she will be charged with a crime of arbitrary medical-surgical procedure under Article 156 of the Criminal Code[274]. However, the medical team may not follow the directive if it can be demonstrated that the patient would not want the directive to be respected anymore, if the directive is clearly outdated given the progress of medical technology, and if the directive does not correspond to the circumstances foreseen at the time of its execution (**number 2**). Moreover, the directive may not be respected in cases of emergency or of immediate danger to the patient’s life (**number 4**). A medical decision taken on the basis of a directive shall be documented in the patient’s medical chart (**number 5**).

The living will shall be valid for five years, renewable for equal and successive periods by means of a declaration of confirmation by the principal (**Article 7, numbers 1 and 2**). The living will can be revoked and modified at any time (**Article 8**). Conscientious objection may be invoked by health care providers in some circumstances. Health care professionals can refuse, on grounds of conscience, to withhold or withdraw a treatment that can lead to the death of a patient (**Article 9**). A non-discrimination principle is set forth in **Article 10**.

2- HEALTH CARE POWER OF ATTORNEY

The health care power of attorney is specifically regulated in **Articles 11 to 14** of the Law. Capacity requirements of the proxy are established in **Article 11, number 2**. Two proxies may be appointed, a primary and an alternative one (**Article 11, number 5**). The health care power of attorney must be in writing. It is applicable to the health care power of attorney, with necessary adaptations, the provisions of Articles 262, 264 and 265, number 1 and 2 of the Civil Code (related to the powers of attorney). The decisions taken by the health care proxy shall be respected by the health care providers (**Article 13, number 1**). The Law also allows a combination of these directives. If there is a conflict between a living will and the

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[272] If it was not executed, the physician should determine the patient hypothetic/presumed will. Family and close friends of the patient play a significant role in the decision making process and should be listened by the doctor (MONGE, C (2014), p.216).

[273] It is applicable not only when the patient is unconscious, but also when is conscious but suffers from a mental disease, such as Alzheimer, that impair the individual’s decision-making capacity (SANTOS ECC (2014), p.118).

[274] SANTOS, ECC (2014), p.108.

health care power of attorney, the wishes stated in the living will shall prevail. (**Article 13, number 2**). It may be freely revoked by the principal/patient (**Article 14, number 1**).

3- LIVING WILL NATIONAL REGISTRY

Article 15 created the Living Will National Registry (RENTEV), which was subsequently regulated by the Health Ministry by Ordinance no.96/2014, of May 15[275]. Registration is merely declarative. It is not a condition for the validity and efficacy of the directives (**Article 16**). If the living will and/or the health care power of attorney was executed, the respective document is attached to the patients' medical chart (**Article 17, number 2**). Confidentiality of personal data is protected by professional secrecy (**Article 18**).

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[275] At: http://data.dre.pt/eli/port/96/2014/05/05/p/dre/pt/html.

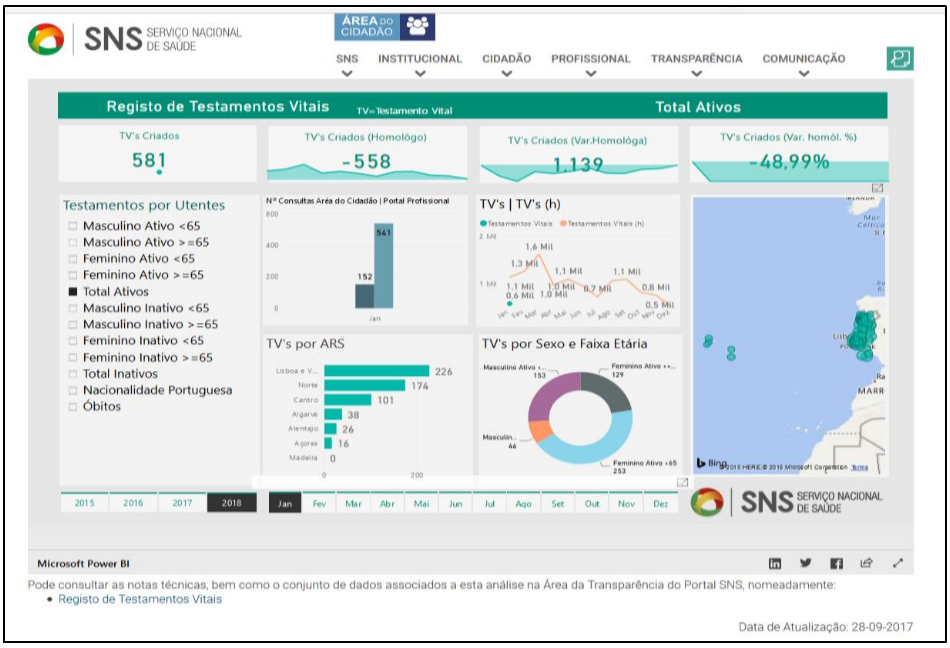
APPENDIX 4

Living Will National Registry (RENTEV) Information

Number of Living Wills registered in Portugal as of February 4, 2018[276] (organized by gender and age group)[277].

	Men	**Women**	**Total**
[18 ~ 25]	229	280	509
[25 ~ 35]	512	782	1294
[35 ~ 50]	1473	2190	3663
[50 ~ 65]	1594	3339	4933
[65 ~ 80]	2136	4380	6516
>= 80 years old	584	1310	1894
	6528	12281	**18809**

For additional information on the topic (by year and month), check the dashboard: https://www.sns.gov.pt/monitorizacao-do-sns/testamento-vital/.



Pode consultar as notas técnicas, bem como o conjunto de dados associados a esta análise na Área da Transparência do Portal SNS, nomeadamente:

- Registo de Testamentos Vitais

Data de Atualização: 28-09-2017

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[276] This information was provided, upon request, by email from the National Health System dated from February 14, 2018.

[277] More data with information updated up to January 31, 2018 is available **here**.

APPENDIX 5

Survey Questionnaire: Table & Key Findings

I. TABLE: DATA COLLECTION

Groups	Options	US Americans	Portugal Portuguese	Macau Chinese/Macanese
Total number of respondents		**8**	**21**	**10**
Gender	M	1	8	3
	F	7	13	7
Age	25-34	2	6	8
	35-44	---	12	---
	45-54	1	1	---
	55-64	2	2	2
	65-74	3	---	---
Ethnicity	White/Caucasian	7	21	---
	Asian	---	---	10
	Other	1	---	---
Education	High school graduate	1	---	1
	Technical training	---	2	---
	Bachelor’s degree	---	6	3
	Master’s degree	6	13	6
	Doctorate degree	1	---	---
Religion	Christian	---	1	
	Catholic	2	9	4
	Buddhist	1	---	1
	Atheist	1	---	---
	Agnostic	1	2	---
	Non-religious	3	9	5
Overall health status	Very poor	---	---	---
	Poor	---	---	---
	Fair	---	3	4
	Good	6	4	6
	Excellent	2	14	---
Feelings about death/terminal illness	I do not want to talk about it	---	5	---
	I prefer to leave it in God’s hands	---	4	5
	I do not accept death	---	1	---
	I am comfortable with the subject	8	11	4
	It is irrelevant for me	---	---	1

Advance Directives knowledge and comprehension	Gave a correct / approximate definition	8	11	6
	Documents with difficult wording, difficult to read/interpret	8	1	7
	Not aware of the content	---	19	3
Current legislation knowledge	Yes, know about it	7	6	---
	No, have no idea	2	15	10
Planning/discussion with physician about life-sustaining treatments	Yes, have discussed	1	--	---
	No, but would like to have such conversation	5	12	7
	No, and would not like to have such conversation	2	7	3
	The doctor took the initiative	2	---	---
	The doctor has not taken the initiative	7	21	10
Medical Directive Scenarios	Forego life-sustaining measures in all scenarios: Coma with small chance of recovering; persistent vegetative state (PVS); dementia with no other life threatening illness; dementia with a life threatening illness	2	4	6
	Forego CPR/Assisted ventilation/Artificial nutrition/hydration	3	5	2
	Keep artificial nutrition/hydration	4	13	7
	Would like to include special requests (organ/tissue donation, cremation/burial)	7	18	7
Advance Directive Proxies and Family	With a formal AD executed	5	---	---
	Without a formal AD executed	3	21	10
	Surrogate decision maker preference	3	5	4
	Statement preference	2	12	5

	Family should take the burden	8	13	9
Personal views of planning for medical care at the end of this survey	The participation on the survey changed the views on advance care planning	4	7	6
	Will have an advance directive in the near future	2	6	4

II. KEY FINDINGS[278]

1- US: American respondents[279]

All know what an advance directive is. The majority already have a directive formally executed, either in the form of a living will or of a health care power of attorney, being 55-64/65-74 years old and in good/excellent health condition. One respondent mentioned that they have already discussed the subject in detail with their spouse. Only one has talked specifically about advance directives with his or her physician. Generally, all would like the physician to take the initiative of bringing up the topic. In one situation, the doctor took the initiative of talking about these directives, and in other, the doctor just gave a pamphlet with information. A small number of respondents will forego life-sustaining measures in all scenarios, i.e., coma with small chance of recovering, persistent vegetative state, dementia with no other life threatening illness, and dementia with a life threatening illness. One respondent expressly wrote “NOTHING ARTIFITIAL. NO HOSPITAL STAY”. Another wrote that they want to have “quality of life”. One respondent stated, in relation to the withdrawal of artificial nutrition and hydration, “This would depend upon my condition! I don’t want to be starved to death!”.

When asked about their feelings and thoughts concerning death or an illness that may turn them completely incapacitated, either physically or mentally, all answered that they are comfortable with the subject. One of the respondents is African American/Caribbean, although not affiliated with any religion in particular (this respondent has already a directive formally executed). Almost all respondents answered that they are non-religious or non-practicing people, agnostic or even atheist.

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[278] Conducted for the purposes of this Master Thesis during January of 2018.

[279] To complement my findings, during my experience in the US, I observed that all clients of the Health Justice Clinic were well informed about advance directives, inclusively low-income African-American women living with HIV, who previously had a conversation with their health care provider about the subject. My clients, a Caucasian elderly couple in their eighties and an HIV sixty year-old man, were also well informed about the existence of these instruments and their content. During the legal meetings, it was easy to talk about topics of death, terminal diseases and end-of-life plan.

One respondent mentioned that they have no preference in appointing a surrogate decision-maker or in having a living will. One wrote in the questionnaire, “But why not both?”. They all have mentioned that it would not be asking too much of their family to decide on these matters. In cases where the respondent indicated that they would opt for a surrogate decision-maker, almost all said they would choose their spouse, a sibling, or an adult son/daughter. One commented that, “it is part of life, they must face the truth”. For half of participants, their participation in the survey changed their views on advance care planning. One respondent expressly noted, “This is making me realize that I need to do something. I think I will have the conversation. I would not guess a timeline for getting it done”.

2- Portugal: Portuguese respondents

Half of the respondents are comfortable with the subject. Four respondents, mainly Catholic, put their trust in God on these issues. Five answered that they do not want to talk about the topic, and one does not accept death. Almost all respondents are not aware of the content of these directives, with nearly half giving a correct or just a mere approximate response of what an advance directive is. Only six of a total of twenty-one respondents know about the existence of specific legislation regulating these directives. It is important to mention that all of them have at least a bachelor’s or master’s degree. Only one had correctly identified the specific law that regulates advance directives.

Zero respondents have ever discussed with their doctor which life-sustaining treatments they would want to pursue if they become so ill that they would not be able to make the decisions by themselves. The majority answered that they would like to have a discussion with their physician about advance directives. Only four would forego life-sustaining measures in all scenarios: coma with small chance of recovering, persistent vegetative state, dementia with no other life threatening illness, and dementia with a life threatening illness. Only five would forego cardiopulmonary resuscitation, assisted ventilation and artificial nutrition. The majority of respondents would like to keep artificial nutrition and hydration.

The majority would feel more comfortable to have a formal statement in the form of a living will stating their wishes directly to the physician. The main reasons for that are: “Because some decisions should not be left to other people to make,” “Not to burden someone with such a difficult decision”, “to make sure that what I want is followed” and, “I can’t think of a proxy”. Almost all respondents consider that it is not asking too much of their family to decide on these matters. None has ever formally executed an advance directive and only one mentioned that they had a conversation with their parents about end-of-life care wishes. The participation in the survey has not changed the views of most participants regarding end-of-life planning, and only a small number said they might prepare an advance directive in the future.

3- Macau: Chinese/Macanese respondents

Half of the respondents answered they would prefer to leave matters related to death and terminal illness in God’s hands. The other half is comfortable with the subject. One considers the subject matter irrelevant. The majority gave an approximate answer of what an advance directive is, which is a good input in terms of knowledge (the majority have a bachelor’s or master’s degree and work in the health care field). However, almost all consider that these documents often have dense legal wording, making them difficult to read and interpret.

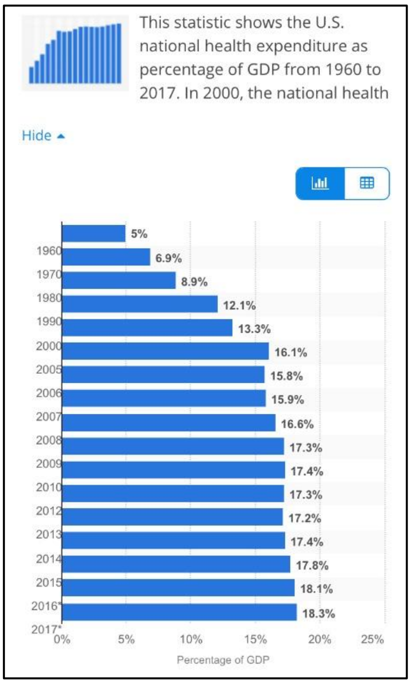
None of the respondents know about the existence of specific legislation in the Region that regulates advance directives. None has ever talked with his or her doctor about life-sustaining treatments, and none has ever formally executed an advance directive. The majority would like the doctor to initiate the conversation about the matter. The majority would like to forego life-sustaining measures in all referred scenarios. Only two replied that they would like to withdraw/withhold cardiopulmonary resuscitation, assisted ventilation and artificial nutrition and hydration. Almost all would like to keep the option of artificial nutrition and hydration, so they would not be left to starve.

While half of respondents would appoint a surrogate decision-maker, the other half would like to have a formal statement in the form of a living will. Except for one respondent, all would like to appoint a family member (spouse, sibling or parents), as a proxy for this purpose. The majority recognize that this type of decision entails a considerable burden to their family, being however their responsibility. Almost all noted that the participation in this survey changed their views on their wish to have an advance directive, or at least to engage in a conversation with their doctor about the subject. However, only a few respondents recognized they would probably have a directive formally executed in the near future.

APPENDIX 6

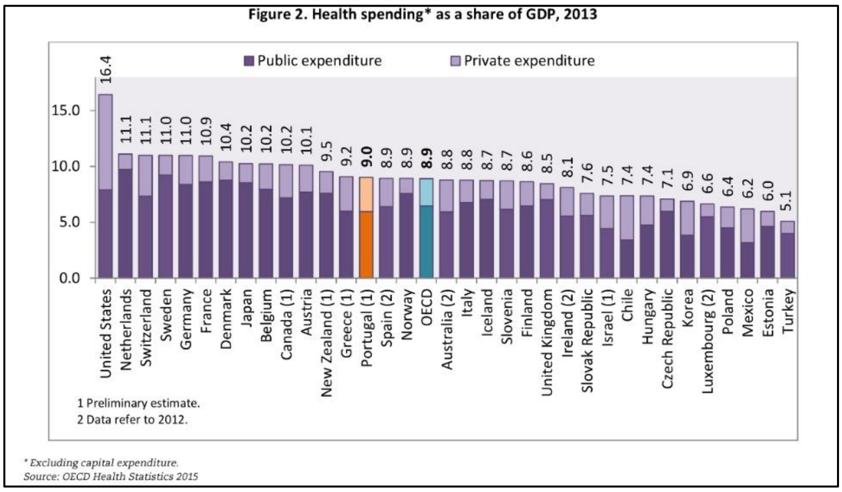
Health Care Expenditure: World Data & Charts

1- US[280] national health expenditure as % of GDP from 1960 to 2017[281]



This statistic shows the U.S. national health expenditure as percentage of GDP from 1960 to 2017. In 2000, the national health

2- Portuguese[282] health spending as a share of GDP in 2013[283]



1 Preliminary estimate.
2 Data refer to 2012.

** Excluding capital expenditure.*
Source: OECD Health Statistics 2015

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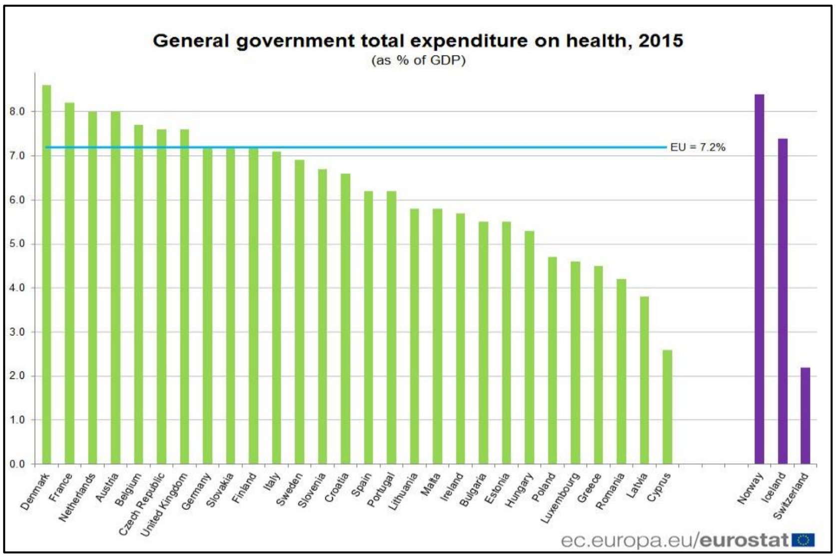
[280] In the US, health care is mainly funded by private insurance through employer, single-payer Medicare for those with 65 years old and older, and State managed Medicaid for low-income people. There is also private insurance through exchanges established by the Affordable Care Act. However, there are approximately 28 million people without any type of health insurance (at: https://www.cdc.gov/nchs/fastats/health-insurance.htm).

[281] At: https://www.statista.com/statistics/184968/us-health-expenditure-as-percent-of-gdp-since-1960/.

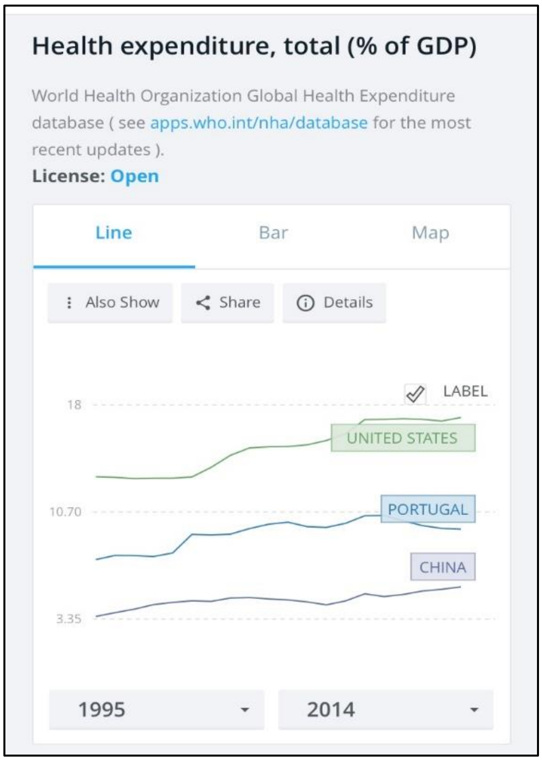
[282] In Portugal, health care is delivered by three co-existing systems. While one is universal (for everyone that contributes to social security, plus their families and retirees), the other two are characterized by encompassing both private and public health care providers and different levels of cost sharing.

[283] At: https://www.oecd.org/portugal/Country-Note-PORTUGAL-OECD-Health-Statistics-2015.pdf.

3- Portuguese government (public) total expenditure on health in 2015[284]



4- Health expenditure, public (% of GDP): comparison between US, Portugal and PRC (Mainland China)[285]



Health expenditure, total (% of GDP)

World Health Organization Global Health Expenditure database (see apps.who.int/nha/database for the most recent updates).

License: Open

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[284] At: http://ec.europa.eu/eurostat/web/products-eurostat-news/-/DDN-20170825-1.

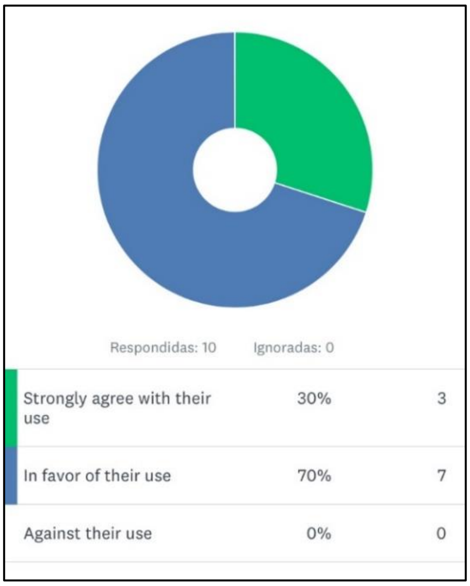
[285] At: https://data.worldbank.org/indicator/SH.XPD.TOTL.ZS?locations=PT-US-CN. There is no data available for the MSAR. In Macau, health expenditure has been increasing. From about 3.78 billion MOP in 2011, it has raised up to 6.32 billion MOP in 2016. Macau local residents benefit from a public type of financing health care system, which coexists with a private financing by two forms: health care subsidy scheme or cooperation with non-government health care providers.

APPENDIX 7

Physicians Survey Questionnaire: Charts & Findings

I. CHARTS

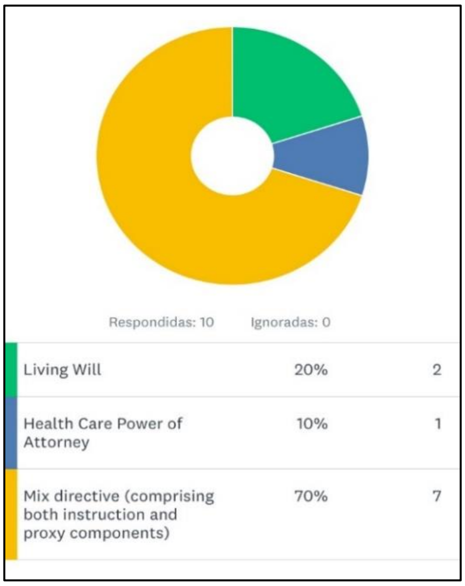
i) Opinion/attitude toward advance directives



Respondidas: 10 Ignoradas: 0

🟩	Strongly agree with their use	30%	3
🟦	In favor of their use	70%	7
	Against their use	0%	0

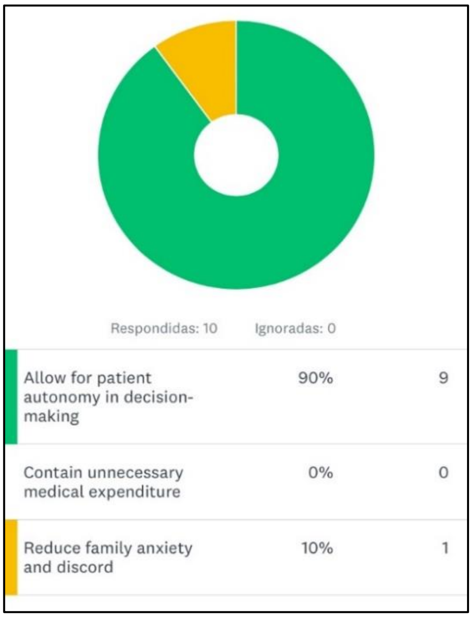
ii) What type of advance directive is preferred?



Respondidas: 10 Ignoradas: 0

🟩	Living Will	20%	2
🟦	Health Care Power of Attorney	10%	1
🟨	Mix directive (comprising both instruction and proxy components)	70%	7

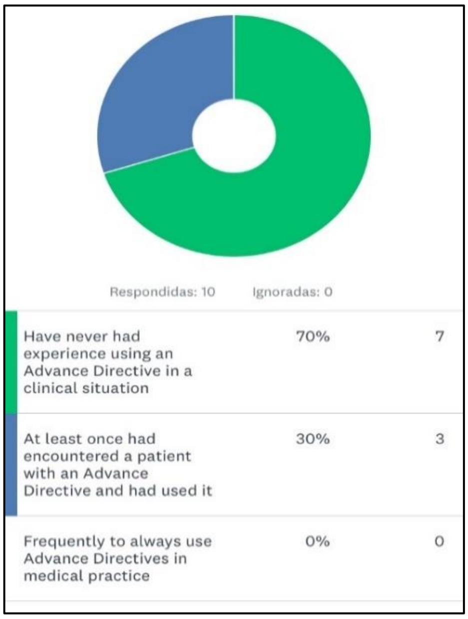
iii) Main advantage of advance directives



Respondidas: 10 Ignoradas: 0

🟩	Allow for patient autonomy in decision-making	90%	9
	Contain unnecessary medical expenditure	0%	0
🟨	Reduce family anxiety and discord	10%	1

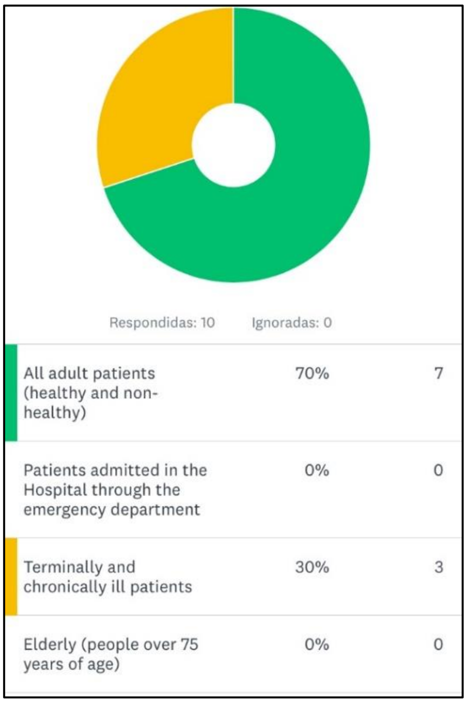
iv) Experience in medical practice of advance directives



Respondidas: 10 Ignoradas: 0

🟩	Have never had experience using an Advance Directive in a clinical situation	70%	7
🟦	At least once had encountered a patient with an Advance Directive and had used it	30%	3
	Frequently to always use Advance Directives in medical practice	0%	0

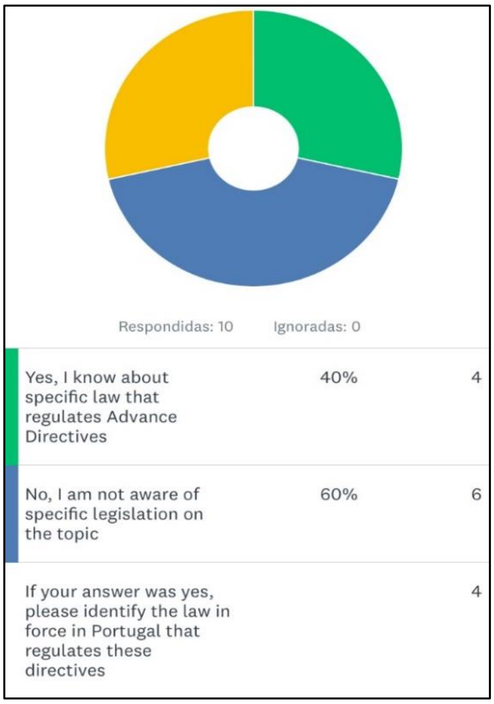
v) Who should be offered an advance directive?



Respondidas: 10 Ignoradas: 0

🟩	All adult patients (healthy and non-healthy)	70%	7
	Patients admitted in the Hospital through the emergency department	0%	0
🟨	Terminally and chronically ill patients	30%	3
	Elderly (people over 75 years of age)	0%	0

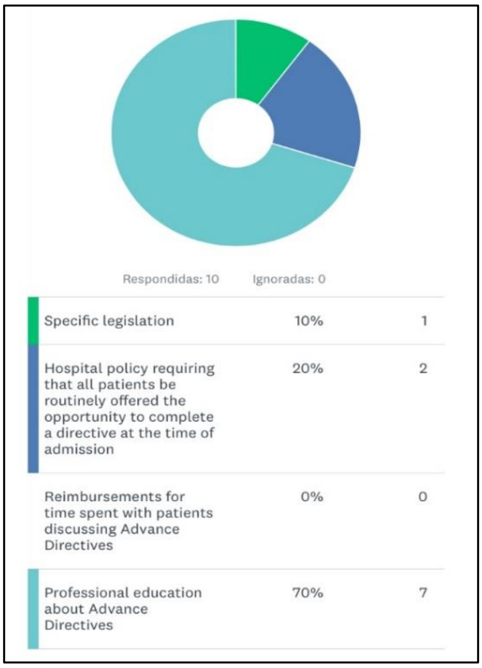
vi) Knowledge of legal standing on advance directives



Respondidas: 10 Ignoradas: 0

🟩	Yes, I know about specific law that regulates Advance Directives	40%	4
🟦	No, I am not aware of specific legislation on the topic	60%	6
	If your answer was yes, please identify the law in force in Portugal that regulates these directives		4

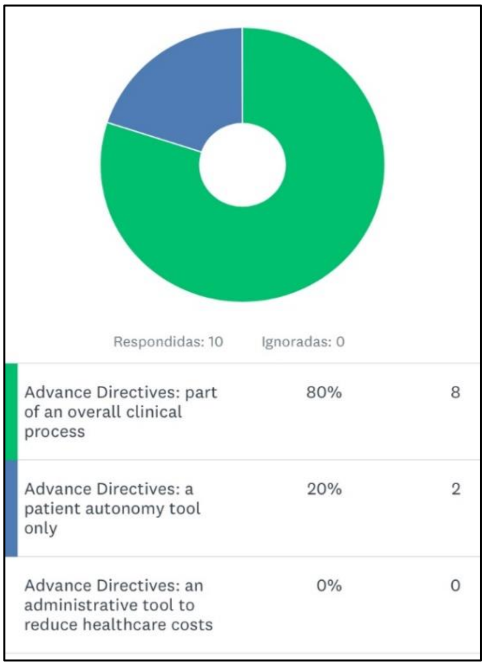
vii) What strategies will encourage physicians to offer advance directives?



Respondidas: 10 Ignoradas: 0

🟩	Specific legislation	10%	1
🟦	Hospital policy requiring that all patients be routinely offered the opportunity to complete a directive at the time of admission	20%	2
	Reimbursements for time spent with patients discussing Advance Directives	0%	0
🟦	Professional education about Advance Directives	70%	7

viii) What is the most appropriate answer?



Respondidas: 10 Ignoradas: 0

🟩	Advance Directives: part of an overall clinical process	80%	8
🟦	Advance Directives: a patient autonomy tool only	20%	2
	Advance Directives: an administrative tool to reduce healthcare costs	0%	0

II. FINDINGS

This survey was conducted to examine the attitudes toward the experience with, and the knowledge of, advance directives of physicians in Portugal. It was conducted during February of 2018 with a target of approximately twenty physicians, having ten respondents only, from general practitioners to different medical specialties, such as psychiatry, ophthalmology, internal medicine, rheumatologist, etc. Graduation dates range from 1976 to 2014.

According to the Survey:

- Respondents are mainly in favor of the use of advance directives (70%), with 30% reporting they strongly agree with their use. No physicians opined against the use of the Directives.
- Regarding the type of advance directives preferred, 70% of the respondents prefer a mix directive comprising both instruction and proxy components. While 20% are in favor of the living will, only 10% prefers the health care power of attorney.
- For physicians, the main advantage of advance directives is allowing for patient autonomy in decision-making. Only one answered that the directives reduce family anxiety and discord. No one answered that advance directives' main benefit is to contain unnecessary medical expenditure.
- In relation to experience of these directives in medical practice, the majority (i.e., 70%) answered they have never had experience using a directive in a clinical situation. In turn, 30% of the respondents had encountered at least once a patient with an advance directive. There were no answers in the option "frequently to always use advance directives on medical practice".
- Seven respondents consider that advance directives should be offered to all adult patients, both healthy and non-healthy. Three are of the view that these directives should be offered to the terminally and chronically ill patients only. No one considers that advance directives should be offered to patients admitted in the Hospital through the emergency department.
- In respect to knowledge of legal standing of advance directives, at least four respondents are aware of the existence of a law dated from 2012 that specifically regulates advance directives. Six of them are not aware of specific legislation in Portugal on the topic. Two physicians have indicated correctly the Law no.25/2012 (i.e., the *Living Will Law*).
- What strategies will encourage physicians to offer advance directives to their patients? One physician answered "specific legislation", two of them opted for "hospital policy requiring that all patients be routinely offered the opportunity to complete a directive at the time of

admission", and seven had chosen the option "professional education about advance directives". No one opted out for "reimbursements for time spent with patients discussing advance directives".

- As for the last question, the majority (i.e., 80%) of the respondents answered that advance directives are part of an overall clinical process, and two of them specifically answered that advance directives are a patient autonomy tool. There were no respondents answering that these directives should be an administrative tool to reduce health care costs.

The Survey only provides a very small sample of views of Portuguese physicians in respect to advance directives. Answers provided should be observed and evaluated with caution. Among the medical specialties, there are no physicians from oncology or neurological areas, which can be a limitation in terms or results, if we consider that physicians that care for patients with acute chronic diseases are more familiar with these types of directives.

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