

Introduction to Advance Healthcare Directives: Biological and Ethical

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Abstract.

The increasing sophistication of medical skills and expertise, in combination with the availability of diagnostic and therapeutic equipment has revolutionized the way health care is delivered, making possible the treatment of previously considered untreatable conditions and diseases. On the other hand, several studies have documented critical deficits in the medical care of the dying, reporting that in many cases this has been unnecessarily prolonged, being painful, expensive, and emotionally onerous for both patients and their relatives. Dynamic and occasionally belligerent medical intervention may result in many patients left confined to nursing homes, or medically frail as to survive only through the use of feeding tubes. Furthermore, a significant number of patients are kept alive in comatose and permanently vegetative states. Moreover cost burdens to individuals and families are substantial even if they had insurance in a certain percentage. Advance healthcare directives, also referred as living will, personal directives, advance directives, medical directives or advance decision, is a legal document in which a person specifies what actions should be taken for his/her health if he/she were no longer able to make decisions for themselves because of illness or incapacity. In the U.S. it has a legal status in itself, whereas in some countries it is legally persuasive without being a legal document.

Key words: advance healthcare directives, Biological and Ethical, illness or incapacity.

Introduction

The increasing erudition of medical technology and the availability of diagnostic and therapeutic equipment together with the changing practice pattern

of doctors have revolutionized the way health care is delivered, making the treatment of previously considered fatal conditions and diseases possible. Conversely numerous studies have documented critical deficits in the medical care of the dying, reporting that in many cases this has been unnecessarily prolonged (Callahan, 1983), painful (Solomon et al., 1996), expensive (Lubitz and Riley, 1993), and emotionally burdensome to both patients and their relatives (AMA, 1991). Forceful and occasionally aggressive medical intervention may leave many patients confined to nursing homes (Wilkes, 1996), or remain so medically frail as to survive only through the use of feeding tubes (Curie, 1987), and a significant number of patients are kept alive in comatose and permanently vegetative states (Curie, 1987, AAN, 1995). Furthermore cost burdens to individuals and families are considerable even if they had insurance in a percentage of 96% (Covinsky, Goldman and Cook, 1994). The burdens and diminishing benefits of invasive and aggressive medical treatment in poor prognosis states have led to the rise of advance directives (Childress, 1989), with the first formal reaction being the living will. The living will, or advance directive document, is prepared and signed by a person to instruct doctors and caregivers in advance on what should be done and not to be done, if and when that person is no longer able to make decisions on their own health on account of illness or incapacity (Emanuel et al., 1991). Living will or Advance Directives is legally valid and enforceable in the USA, Canada, Australia, Germany, in the UK and many other countries in Europe, and has been endorsed by the United Nations Convention on the Rights of Persons with Disabilities (Cornell University Law School 2016), (Barta and Kalchschmid 2004, United Nations 2016), however in many countries it is still virtually unknown, or the relative legal framework is not clear.

Historical Aspect

Living will was first proposed by Luis Kutner and the idea evolved as a repercussion to property law. It was suggested that as under the property law a person can control property affairs after their death, similarly a person could express and control one's healthcare wishes when he/she would not be in a position to do so (Kutner 1969). Advance Directives were incorporated by the

population and the Patient Self-Determination Act was registered in 1990 (Kelley, 1995).

The provisions of the Patient Self-Determination Act ensure that healthcare providers:

1. Provide all adults patients, residents and enrolees with written information on their rights under the state law to make decisions concerning medical care, including the right to execute a Living Will, as well as to maintain the policies of the provider on the implementation of this.
2. Provide a document in the patient's medical records whether they have a Living Will.
3. Educate the staff and community on the Living Will.
4. Do not make the provision of care depending on whether a patient has a Living Will or discriminate otherwise on this basis.
5. Ensure compliance with the state's law on Living Will.

As Living Wills began to be better recognized and became popular, key shortcomings were soon discovered. Most Living Will tended to be limited in scope (Annas, 1991), and often failed to completely address presenting problems and needs (Hashimoto, 1983), they were usually written in ways that might conflict with quality of medical practice (Campbell, 1995), and ultimately, it was determined that a living will alone might be insufficient to address many important healthcare decisions, leading to the development of the second generation advance directives, which are also called "health care proxy appointment" or "medical power of attorney" (Annas, 1991).

The proxy, or power of attorney plays the role of the legally authorised representative, and is a person named by the individual, however two main questions remained unanswered, first how correctly and clearly did the power of the attorney understand the wishes of the individual, and second, would they substitute the patient's wishes with their own? Third generation Advance Directives were introduced to overcome the deficits. The third generation Advance Directives include the so-called "Five Wishes", which were prepared by the non-governance organization, Aging and Dignity (Damato, 1993). According to the five wishes a person can make care decisions for oneself when he/she can't, they can choose the kind of medical treatment they want or don't want, they can

decide on how comfortable they want to be, and how they want to be treated by other people, and finally they can choose what they want their loved ones to know.

Biology, Theology, Law and Death: Essential Mediations

Although biology defines death as the cessation of all biological functions that sustain an organism (Zimmerman, 2012), and theology attempts to simply define death as the separation of the body and soul (Ecclesiastes 12:7 KJV n.d.), legal and forensic evaluation of death (mainly as a biological phenomenon) is not a self-contained event, but happens inside the regulation of legal or lawful goods, and more specifically of life, as well as the integrity of one's health, which are considered to be the definite legal criteria (Pellegrino, 2008). The integral and comprehensive protection of life by the law is connected to the property of the complete and comprehensive person. From the legal point of view the existence of life, after brain death, is considered to be problematic (Daggoglou, 1991). The legal evaluation of death is consistent with the historical and social development given that death has lost the naturalness had as an inescapable event, and has become a subject of medical, and/or pharmaceutical management and occurs as a result of either a direct or an indirect medical crisis and decision (Freud, 1998).

The criteria for the legal definition of life and health are not just internal, based on the rules of legal doctrine, but also external, while the reference to the findings of medical science and biology is mandatory in order to be socially effective (Broekman, 1997). Nevertheless the major issue for the legal and constitutional theory is the evaluation of the voluntary insult against health or life, and its justification on the grounds of one's autonomy.

Self-Determination

According to the Merriam-Webster dictionary, self-determination is defined as the free choice of one's own acts or states without external compulsion (Merriam-Webster Dictionary, 2017). The right to accept or refuse any treatment as suggested by doctors is a basic element of human dignity and elementary freedom. In German law it is closely related to one's physical autonomy (German Civil Code 2015). This right, on the basis of current legislation, applies to the same extent as for the healthy, and for patients with terminal diseases, regardless

of the severity of the disease and the imminent danger for their life (Hornett, 1995). Of particular interest is the case where one's higher mental functions or ability are impaired due to a chronic or acute disease or trauma, or where one is under the influence of toxic agents that affect their mental clarity and critical capability (Dresser, 1995).

It is certain that one's decision to refuse any offered medical assistance comes in contrast with the established social logic and could possibly lead the person to social isolation in the close or extended social context. Furthermore it should be clear, that beyond the given situation, for a person it is extremely difficult if not impossible to survive without assistance in matters of everyday life. Even in the terminal stages of an incurable disease, abandonment or neglect comes in contradiction with the basic principles of the respect of human rights, while the improvement of one's quality of life to the highest possible rates should be the major concern in terms of both morality and legal analysis.

The Right to Self-determination as a Basic Principle

The right of self-determination is not associated with any active assistance provision for faster occurrence of death, but is everyone's right to decide for themselves and the course of their life. In the majority of the cases the patients are not able to express their wish at a given time, and hence it is possible to formulate these in advance using the living will statement. However as it is already mentioned above the living will statement it is not always possible to predict every subcase or subcondition, and so being insufficient, it has been substituted by the second generation advance directives, which are also called "health care proxy appointment" or "medical power of attorney" where the person who would take the necessary decisions should act in accordance with the wishes of the person like those expressed by them. In the case of non a priori definition of the patient, it is possible for the Court of Law to appoint someone who would assume the necessary decisions (Stephen 2004).

Self-determination and Patient's Will

The mental state of patients at the time of expressing their advance directives must have necessarily been appreciated by more than one expert who will confirm that the patient is in excellent condition and capable of fully understanding the

information that will be provided by the physicians, as well as the potential risks. Otherwise the value of the contract can be challenged. In any case the patient has the right to search for detailed information, even for the simplest medical acts, while they also reserve the right at any time to alter the original declaration (Simitis, 2005). In case one is unable to express his /her desire for any reason, or if it is not possible for the Court of Law to ordain representative, providing medical assistance or treatment is considered self-evident, especially in life threatening situations. It is worth mentioning that when a power of attorney has been appointed by the patient, the former should always act and decide according to the patient's wills if they have been expressed into full alertness and mental clarity, even if the latter comes into contradiction with the established social logic (German Civil Code 2015).

Patient's Right to Seek Information

The validity of one's decision to accept or refuse medical assistance depends not only on the critical ability and integrity of their higher cognitive functions, but it is directly related to the extent of understanding of the medical act and the possible implications and consequences that this will have on the quality of life (Mattioli and Areni, 2012). When the patient does not wish to receive detailed information on the nature and characteristics of every medical act, the decision to carry or not lies in the determination and the integrity of the attending physician, the importance and purpose of this even need in this case to clarify to the side of the patient.

Advance Statement

The advance written expression of the desire of the patient to consent or not to medical assistance, or any medical act is of substantial significance when patients are no longer able to express their desire at the present time (Singer, Douglas and James, 1998). In this case the patient has the right to describe clearly the medical acts and operations that he would like to accept, and reject. Even if they don't clearly describe specific medical acts, they may set in advance the criteria which will be considered by the specialised personnel at the appropriate time, in order to act exclusively in accordance with the patient's wishes (Mattioli and Areni, 2012).

A significant question that arises is about the case where one's advance statement is not clearly or cannot be connected to the current situation. In this case, the decision is made either by a representative appointed by a Court of Law, or by the medical personnel. The balance in this situation is extremely delicate, since it is difficult to guarantee the absolute objectivity of any decision which may interfere with individual rights and general desires of the patient (Singer, Douglas and James, 1998).

The Civil Code of several countries has already anticipated this event, indicating that the advance declaration is valid only for certain medical conditions, or it could be related to the severity of a given situation, as this has been expressed by the patient to their better understanding. Specifically this applies to irreversible cases, where the fatal outcome cannot be prevented, or even in cases where any effort of treatment would have doubtful results. In both cases, however, it is contentious whether the advance declaration can be considered as a direct expression of the right of the patient's self-determination (German Civil Code 2015).

Special cases also raise some disputes about the validity of the advance statement. The experience of the period of National Socialism in Germany, where social, moral and legal criteria had changed dramatically, or some cases where one's personality and capability to make decisions are seriously affected as a consequence of pathological situations, such as dementia, reinforces the view of dissidents (Dute, 2012).

Another question that needs to be answered is whether any oral advance declaration should be considered equivalent to the official written statement. In the case of an oral declaration, the question which arises is that of the spontaneous and reflexive implementation and absolute transfer of the central meaning by the person who is determined to express it. The prevailing and most accepted view is that any advance declaration must be in written form, and officially signed (Stephen, 2004).

One's desires and wishes, if and when they are expressed under a solid mental state, are considered to have absolute and unconditional supremacy. However in the case of patients who undergo personality alterations and where their current

wishes come into disagreement with any previously defined advance statement what should be done? In this case specialists' opinions diverge (Stephen, 2004).

If a patient has in advanced stated his denial for further medical assistance, and in the given situation there are distinguished points which indicate an implicit desire for continuation of life, the advance statement only applies when: a. the current status and any medical acts described in that clearly, b. it describes the possible existence of points of desire for continuation of life, but the patient has clarified that these should not alter the decision, c) the advance declaration is official and written and d) the patient has made it clear that the quality of life and the ability to socialise outweigh any invisible points that would express the desire for survival (Dute, 2012).

Another equally important question that arises about the advance declaration is whether this should force the legal representative of a person, when the latter is called to make decisions. According to the German civil code, the legal representative should be bound by the advance statement if this is official and has been made by a person mentally sane (German Civil Code 2015) [civil code, par. 1901, (2) sentence 1 and (2) sentence 1].

In the case that the advance statement is not totally clear and the representative's decision comes into contradiction with the patient's desires and wishes, as it has been expressed in the advance statement, a Court of Law may be required to approve or not the decisions of the representative.

If any changes to the available medical treatments could ensure an outcome that was completely unknown and could not be predicted at the time the patient submitted their advance statement, the legal representative has the right to make a decision that would differ from what the advance declaration states, but always in accordance with the patient's previously expressed desires and wishes. When a representative is appointed by a Court of Law, his power of decision making can be defined in advance by the Court, however in the case of the termination of life of a mechanically supported patient, any decision must always be approved by a competent Court of Law (Buchanan and Brock, 1990).

The economically directed health systems are moving towards the prospect of the admission of any advance statement in order to ensure the most efficient economic conditions of hospitalization. The National Bioethics Council however

makes it clear that the expression of that desire or not is an inalienable right of the individual and must not in any case determine the way he should be treated by the wider social context or the medical treatment one should receive by medical professionals.

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