

End of life decisions and advance directives

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In a recent study conducted by Dr Saul Weiner, it was established that 'patients tend to do better when their doctors pay attention to their individual needs and circumstances' (Seaman, 2013). The health care system in general has been steadily shifting its approach from a paternalistic approach to one in which both the doctor and the patient work together to achieve the best possible results. This also applies for the local scenario where measures have been proposed to promote patient rights and patient autonomy, particularly through a new patients' charter for rights and responsibilities.

Advance directives for medical care, also known as living wills, have been advocated as a means of extending patient autonomy to those situations when a patient becomes incompetent. The term 'advance directive' is generic so as to incorporate an act whereby a competent person makes arrangements about his future healthcare decisions should he lose his ability to do so. Advance directives may take two forms – a living will or a lasting power of attorney for healthcare, which are not necessarily exclusive of each other but may be complementary (Andorno, 2009). A living will refers to a written document drawn up when the patient is in full possession of his faculties, giving instructions to his doctor or other healthcare providers regarding the circumstances under which he wants life-sustaining treatment to be provided, withheld or withdrawn (Andorno, 2009). The measures usually relate to the requesting or the refusal of certain forms of extraordinary treatment aimed at preserving or prolonging the person at the end of his life such as cardio pulmonary resuscitation (CPR). Advance directives may also serve as a means by which the patient expresses his wish to receive treatment such as artificial nutrition and hydration (ANH) (Andorno, 2009).

Conversely, a lasting power of attorney for healthcare allows individuals to appoint an agent to make healthcare decisions on their behalf in specified matters of healthcare, if and when they lose the ability to do so (Andorno, 2009). The power of attorney has the significant advantage of clarifying the patient's wishes

when they have been formulated in ambiguous terms within a living will. It also allows the agent to address unexpected developments that were not specifically addressed by the patient (Andorno, 2009).

The difference between the two is that in a living will, the patient expresses his own choices, whereas when the patient grants a lasting power of attorney for healthcare, the patient delegates the authority to decide to another person. The power of attorney is an attempt to allow decision-making about treatment decisions to be influenced by the patient's own view through a substitute, who is chosen by the patient to make such decisions on his behalf, usually a person who has an in-depth knowledge of the patient, his history and his preferences. Certain codes of laws such as the California Natural Death Act requires that the person chosen is of a good moral character having a certain practical wisdom, is known to make sound decisions in difficult circumstances and someone who understands and is willing to fulfill the responsibility of acting in accordance with the patient's needs and wishes (California Health and Safety Code - The Natural Death Act, 1978).

In so far as the expressed wishes of the patient are in conformity with the law of the respective country, are still valid and there are no indications whatsoever that the patient would have changed his or her mind under the present circumstances, the medical practitioner is obliged to follow the patient's living will (Andorno, 2009).

Advance directives go back to tell the story of twenty-one year old Karen Ann Quinlan who passed out and ceased breathing for two fifteen minute periods after a night of drinking alcohol and ingesting tranquilizers. After it was determined that she was in a permanent vegetative state (PVS), her father requested the removal of the artificial ventilator which was the only means of keeping his daughter alive. Both Quinlan's primary physician and the hospital decisive board turned down his request. Quinlan's father took this up to be decided by the Court and a year later the New Jersey Supreme Court, on March 31, 1976, held that the father could authorize

the cessation of ventilation, and the hospital was bound to proceed with this order. After having the ventilator removed, young Quinlan continued to breathe until her death several years later. This prompted the enactment of the first living will statute in the USA, the Natural Death Act of California in 1976. This law established certainty about the legal position on advance directives in the United States.

More recently, another legal battle, fought in Italy's courts, was the case of Eluana Englaro. Nineteen year old Eluana was involved in a very bad car accident back in 1992. After spending two months in a coma, she started breathing spontaneously. She was subjected to ANH even though clinical reports by two prominent neurologists showed she would never regain consciousness again due to the severe brain damage she had suffered as a result of the accident. Notwithstanding all efforts, including attempts at sensory stimulation, Eluana's condition did not improve and in 1994, she was diagnosed as in a PVS (Moratti, 2012).

After a seventeen year legal battle fought by her father, the court ruled that ANH may be withdrawn in cases where the patient is in a PVS. However, two conditions must be present for this to apply: the patient's condition must be medically irreversible, and artificially prolonging the patient's life would be inconsistent with his or her express wishes, character, or outlook on life (Supreme Court, 2007). Evidently, not much attention was given to the futility of the treatment to which Eluana was subjected to, which treatment was not benefiting her.

Although such treatment was initially considered as 'basic care' by the court and therefore could not be withdrawn, in the year 2000 the Italian Minister of Health appointed a working group, the Oleari Commission, to analyse the nature of such medical treatment as ANH in PVS patients (Moratti, 2012).

The Oleari Report, which expressly refers to the Englaro case, concludes that ANH amounts to medical treatment and its withdrawal is legitimate if based on the will of the patient. The report further held that if the patient did not express his or her wishes before becoming incompetent, such as through a living will, decisions may be taken by the patient's guardian.

In an opinion issued by the Maltese Bioethics Consultative Committee (The Bioethics Consultative Committee, 2010), it was established that whilst ordinary treatment refers to life prolonging treatment which is available and offers 'a reasonable hope of benefit and do not cause unbearable pain and suffering', extraordinary

treatment refers to such measures 'which are not usually available, do not offer a reasonable hope of benefit and cause unbearable pain and suffering' (The Linacre Centre for Healthcare Ethics, 2000). The Committee agrees that 'there is no obligation for a patient to take extraordinary or disproportionate measures to promote life and health if these measures will involve excessive burdens' (The Bioethics Consultative Committee, 2010).

With respect to the nature of ANH and whether it is considered as ordinary or extraordinary treatment, Malta's Bioethics Consultative Committee (The Bioethics Consultative Committee, 2010) held that ANH should be considered as an extraordinary medical procedure in those circumstances where a patient is at the end of his life, and as claimed by Agius, its withdrawal would be considered 'as a procedure done in order to let nature take its course' (1994, p. 29). To the contrary, where the patient is not considered as a 'dying' patient, then ANH shall be considered as ordinary and morally obligatory treatment, the omission of which would be inappropriate (Agius, 1994). The Committee advocates the presumption in favour of providing ANH to all patients; however, medical practitioners shall take individual characteristics of patients and their circumstances into consideration. Studies have shown that although ANH may benefit terminally ill patients, if carried out in inappropriate circumstances, it may actually also cause suffering and also itself be the cause for shortening life (The Bioethics Consultative Committee, 2010).

In the absence of an advance directive, the patient's consent to life-prolonging treatment is generally presumed. However, it is open to question whether any of us would actually consent to be kept alive artificially in PVS where there is no hope that the condition will reverse itself, a scenario that is at odds with our intuitive notion of a life worth living. But to what extent should advance directives for medical care be binding?

Advance directives are at times seen as controversial, with the main concern being that competent people when drawing up an advance directive, which, when the patient loses his competence, will have binding force on his medical practitioners, may not be well placed to make decisions concerning their future incompetent selves. It has been argued that giving advance directives binding force places all the responsibility for the decision on the patient whereas under arrangements in which they are not binding, doctors retain some discretion and assume responsibility for the decision. Others argue that advance directives reflect the will of the person at the time that

they are written and cannot anticipate how this may change as the illness develops. Everyone may experience changes of mind at any moment in time.

The need for a written document is not disputed as it produces certainty. Furthermore, the more binding advance directives are considered to be, the stricter the formal requirements become, including certain formalities such as the validation by the medical practitioner (attesting the patient's mental state and the reliability of his instructions). Another issue to be decided regards the storage of such documents and whether it should be kept by the patient or entrusted to the health authorities or recorded in a national register.

During a Medicine and Law conference organized by the Bioethics Research Programme of the Faculty of Medicine and Surgery in collaboration with the Medicine and Law Programme of the Faculty of Laws and the Faculty of Theology within the University of Malta entitled "End of Life Decisions" in March 2013, the need to address the gap in Maltese law when it comes to health was highlighted. In Malta, end-of-life decisions are generally taken in a legal vacuum.

Maltese law does not provide for situations where a health practitioner refrains from administering extraordinary treatment such as ANH or CPR to a

terminally ill patient. Article 9 of the Convention on Human Rights and Biomedicine (Council of Europe, 1997) states that doctors must always 'take into account' previously expressed wishes and this implies that they have a duty to seek out any that exist once the decision-making process begins. In some legal systems, advance directives are legally binding, meaning that doctors are legally bound to comply with them. In others, they do not have any binding force and are considered only as indicators of the person's wishes which doctors 'take into account' in this light, without being bound by them; they retain some discretion in the light of the actual situation and the potential advances in medical knowledge by the time the decision must be taken.

Advance directives should be regarded as an instrument conducive to dialogue between the patient and his medical team, which goes beyond informed consent as part of their end of life care plan.

Fundamentally, medicine cannot remain detached from law, and in this respect the Minister of Health Dr Godfrey Farrugia at the end of the conference, augured 'the medical and legal profession to work together to create a law that respects our values and at the same time protects both the patient and the professional' (Dalli, 2013).

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