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DEWCOM DISCUSSION DOCUMENT

Advance directives – “Living Will”

March 2010

An advance medical directives, also know as a “living will”, is a document written in advance to give instructions regarding medical care in cases where the person is no longer able to do so directly. In evaluating this practice we will need to consider to what extent it affects our understanding of the sanctity of life, the dignity of life and the effect that it has on medical practitioners who are affected by advance directives. We also need to acknowledge that such directives take place within the Southern African Context and, as such are constrained by the legal guidelines of these countries.

As a church we affirm the sanctity of life and specifically human life. The sacredness of human life is a common scriptural theme that finds its origin in the creation narratives’ emphasis that humans are “created in the likeness of God” (Genesis 1:26, Genesis 5:1). Genesis 9:6 states this “divine likeness” is the reason for the prohibition on the shedding of blood. This prohibition on killing is repeated in the 10 commandments (Exodus 20:13) and is consistently affirmed throughout both the Old and New Testaments. In the Beatitudes (Matthew 5:17-22), Jesus affirms this stance on the taking of another human life. Within the Old Testament law, the motive for the taking of life was not a mitigating factor (except in the cases of capital punishment), hence the establishment of the cities of refuge for instances of (cf Numbers 35:22-25).

The respect for the sanctity of life is not only about the living, but also about the dying and death. Although Jesus and the disciples raised people from the dead, such individuals still went on to die again. The underlying principle is that God gives life and that it is God’s prerogative to take life (Deuteronomy 32:39; 1 Samuel 2:6). Death is not something that must be avoided, rather it is a natural end to all life (Psalm 90:9; Psalm 103:14; Hebrews 9:27) and thereafter ongoing eternal life with God (John 5:24,25).

Advance directives, as a legally binding document, are a recent development that was first tested in Illinois USA in 1969. The need for such a position has arising because of the benefits of modern medical techniques e.g. cardiopulmonary resuscitation, renal dialysis, artificial ventilation, and artificial nutrition and hydration. “However, life has a natural end and the existence of such techniques of life support may, in certain cases, sustain life artificially for many years for patients for whom there is little hope of recovery. The quality of life which may follow some treatments might raise questions as to whether it is in the best interests of the patient to start or continue treatment.” (Health Professions Council of South Africa: Booklet 12 - Guidelines for the Withholding and Withdrawing of Treatment, May 2008, p. 1). Advance medical directives are established to allow death to occur naturally, through the withholding or withdrawal of artificial life-support systems.

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The right for patients to refuse treatment is a constitutional right (South African Constitution and international and regional human rights conventions) based on the right to information and the medical principle of informed consent. (Nortjé, Gwyther, Kleinschmidt and Ezer: Ethical Issues, p. 15). This principle is reflected in Jesus' initial refusal to receive analgesic treatment on the cross (Matthew 27:34). A patient has the right to decide what treatment will or will not be received, even if that decision is contrary to medical advice. Advance directives are therefore the exercising of this right prior to occurrence of the anticipated condition. In some ways, advance directives merely confirm what good doctors would decide anyway. However, because medical practitioners operate under the principles of beneficence and non-maleficence, the possibility exists that a doctor could be held liable for failing to resuscitate or sustain a life. The intention of an advance directive is to remove the responsibility of that decision from the doctor and care givers and to ensure that the will of the patient is respected.

Advance directives operate within the context of affirming life. All life has a natural end. Advance directives do not seek to hasten that natural end and therefore are qualitatively different from euthanasia, where deliberate intervention hastens death. With an advance directive, the underlying disease or trauma takes its course and leads to the patient's death, not a direct act by the health worker. Because there is no deliberate intention to intervene to end life, advance directives cannot be seen as a rejection of the sanctity of life. Where an advance directive is implemented, a person has the capacity to live to the full extent of his/her life without medical intervention.

Legal considerations

At present, there is no clear legal guidelines regarding advance directives although there is a precedent in the Clarke vs Hurst case 1992 (4) SA 630 D where the wife of Dr Clarke won the right to halt the artificial feeding which was keeping him alive in a persistent vegetative state (PVS).

In terms of practise, advance directives have been actively respected where:

- a) patients are at the end of life / are terminally ill
or
- b) in a PVS.

It is also common practise that patients who are in frail care centres or who are regarded as being "medically futile" (no imminent and reasonable chance of recovery) are regarded as "Not for active resuscitation" (NFAR). The key is to be able to identify when active treatment will improve quality of life and prolong life, in contrast to when active care and medical technology will not positively influence the course of the illness but merely prolong the dying process. (Nortjé, Gwyther, Kleinschmidt and Ezer: Ethical Issues, p. 14-20)

Regarding PVS, there is at present no available laboratory diagnostic test can indicate that a patient is permanently vegetative. The diagnosis therefore depends on careful clinical observation over several weeks. For this reason, the diagnosis and prognosis must be beyond doubt and should be agreed on by more than one experienced doctor. (1994 UCT Bioethics Centre BENATAR S. R. (Director)

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Statement on withholding and withdrawing life-sustaining therapy, SAMJ Vol 84 May, p. 255)

The withdrawal of artificial intervention does not exclude providing relieve for the patient from any mental or physical pain and discomfort, even if medication administered exclusively for this purpose unintentionally hastens the moment of death. Deliberate abuse of medication moves the practise into the realm of euthanasia. The focus of an advance directive is to ensure maximal dignity and quality of life in the final stages of life. Whilst there may be many situations where the withdrawal of artificial aid is clear, there are other instances where it is more “grey”, such as in instances of advanced senile dementia where the person may not be able to feed him/herself, yet is neither terminally ill nor suffering from PVS. It would be inhuman to withhold food and water from a patient when the patient is still able eat and drink. However, the Institute of Medical Ethics document considers artificial feeding such as nasogastric feeding to be a form of medical treatment.

At present, the advance directive is being applied within a narrow context of end of life or PVS. When drawing up an advance directive, it is impossible to cover all the possible conditions that one might face. Moreover it is not always possible to predict the final outcome of an event. The emphasis needs to be on understanding the values of the patient. Thus a person may not wish to be revived from a stroke, assuming that the stroke may leave them with impaired functioning. However, the prognosis is seldom clear at the onset of the condition. Historically some patients have made an almost full recovery and in such an event most patients would clearly wish to be revived! In addition to this, medical advances continue and thus a condition which had a very negative prognosis a decade ago might now have a significantly better prognosis. For this reason is it recommended that advance directives no be applicable in outside those of end of life, terminal illness, or PVS.

The preclusion of a number of conditions from which a patient may well make a recovery addresses many of the concerns that critics of advance directives may have – the most common being that the directive would compel a doctor to follow a course of action that, in this specific instance, the patient, now unable to represent him/herself, would disagree with. This provision also minimises the possibility of the family or next of kin of the patient from drawing up a fraudulent advance directive as the decision to apply the directive will always require a medical diagnosis.

Because of the complexities of trying to predict every possible situation and pre-empt what medical intervention may become possible in the future, it recommended that in addition to the advance directive, a proxy be appointed. If a doctor does not know the patient, there is potential for disharmony between the wishes of the patient and the doctor. The proxy assists in the decision-making process based upon the patient’s previously known values as expressed in the dvance directive. There is not legal obligation to follow the will to the letter but is rather guided by the best know interests of the patient. It needs to be acknowledged that working in an African context some cultures place less weight on individualism and choose to defer to family or community values in decision-making.

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It needs to be acknowledged that doctors with a conscientious objection to withhold treatment in any circumstance should not be obliged to comply with an advance directive but should advise patient of their views and offer to step aside, transferring management of the patient's care to another practitioner.

Guidelines for an advance directive

- The advance directive should be drafted by an attorney following discussion between the patient and his/her doctor so that the criterion of informed consent may be met and the patient has a full understanding of the treatment and effects that are available.
- The directive needs to be completed whilst the person is mentally competent and has two witnesses.
- Copies of the directive need to be kept with the patient, the next of kin / proxy, the doctor and, in the case of institutional care – Management or the Clinic Sister. The Living Will Society <http://www.livingwill.co.za/>

Conclusion

Advance medical directives are guidelines to withhold medical treatment that life may end "naturally" and is not sustained by artificial means. As such, advance directives are qualitatively different from euthanasia and therefore do not violate the sanctity of life. However, to avoid abuse of advance directives so that they may border on euthanasia, it is recommended that advance directives be recognized only where there is a medical diagnosis of a persistent vegetative state or terminal illness.