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Advance directives as autonomy enhancers: reality or myth?

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I would like to start my presentation by thanking the European Association of Global Bioethics for allowing me to present a free paper today. In the last few decades there has been a wealth of literature and legislation on advance directives. As you all know, it is an instrument by which a person can express their wishes as regards what treatment they should be given or, more to the point, not to be given, when he is in a situation when he can not do so himself. Regulations in the western world seem to promote advance directives as a way to enhance patient's autonomy in the context of human rights, and the media has presented advance directives as another milestone in this era of self-determination. However, if we look closely at some of those regulations we will see that there are a few elements which may undermine their efficacy, shattering this nicely presented picture. I will focus on two elements. First, formal requirements, and secondly, certain limits or what I like to call "escape clauses".

Formal requirements

Some regulations are very precise and detailed on formal requirements (for example, they call for witnesses, and set out in detail who can be a witness and who can not). Others seem very flexible, allowing for advance directives to be issued in written or oral form, without many specific requirements. Although it may seem that by admitting a verbal expression of those wishes the person's autonomy is enhanced, it is, indeed, curtailed, since it is unlikely that the physician will find out about such decision, particularly if the person is not ill at the time he issues the advance directive.

Let's say that after today's seminar, I meet a colleague for a drink, and say "Listen, I have been thinking, if I am ever in a persistent vegetative state, I do not want to be connected to a ventilator, and I reject artificial nutrition, and artificial resuscitation in the case of cardiac arrest." My colleague, perfectly aware of the importance of what I am saying (she did, after all, attend the seminar) says to me "Don't worry; I will make sure your life is not prolonged unnecessarily". If I know verbal expression of advance directives outside the health care context are valid, I can leave it that at. Let's assume now that I have an accident and am in a PVS. When the situation arises for the advance decision to be communicated to the attending physician, my colleague may not come forth, either because she, God forbid, may be dead, or incompetent herself, or maybe we have stopped talking to each other over the years, or she might be living abroad, or she might have joined a religious group and disagrees with my personal decision so she doesn't want to come forth. So the wishes expressed to my colleague are valid, but how will they be effective? Also we have to bear in mind that if wishes are expressed to more than one person, people might remember different things, in particular if different instructions for different scenarios are given.

When the person is ill, an advance directive made orally to the attending physician might seem to guarantee that those wishes will be complied with, since the physician knows about them and both patient and physician have been given a chance to discuss different possible outcomes of the illness. But if the patient's personal decision does not coincide with what the physician deems to be the patient's best interest, it will be very easy for the physician to override those wishes, simply because there will be no written proof that the patient told him otherwise.

I think there is a strong case for some formal requirements. These are justified

1. To provide reliable evidence of the person's preferences and instructions.
2. To reduce the possibilities of the advance directive to be contested or doubted. Since formalities provide a safeguard against hasty or ill-considered decisions, it is a way to ensure that the issuer is aware of the consequences of making an advance directive, and therefore it becomes untouchable on that ground.

In a general context, any consent or refusal of consent can be made orally or even implicitly, but I am focusing on advance directives. It is a special situation because the time lapse between the moment when that refusal is expressed and the moment when it may be called to come into play makes a case for formal requirements.

Another instrument to help make advance directives effective in practice is a special registry (if not compulsory, at least voluntary). It allows for physicians to be aware of the existence and contents of the advance directive. The need to create such a registry stems from two factors. First, although the issuer should give the attending health care

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provider a copy of the advance directive so it can be incorporated to the medical records, the issuer is not necessarily an ill person in a hospital with an open medical record. Secondly, although the family members and the proxy (if any) have a duty to supply the advance directive to the health care provider when the patient cannot do so personally, there is no sanction for not doing so.

The key to the effective application of an advance directive is to make it known to the attending physician. It serves no purpose if locked in a drawer. And, again, although it may seem that any regulation that requires formalities for the validity of advance directives will make it difficult for individuals to issue them, such formalities may be the only way to ensure that they actually serve their purpose.

Limits

Different laws introduce "escape clauses" that may effectively allow physicians to ignore advance directives. There are several ways by which these loopholes have been introduced:

1. Unforeseen circumstances

When issuing an advance directive, a person has to define the particular circumstances which will trigger the use of the advance directives. But if that person is not suffering an illness at the time, will generally not be able to foresee all the possible situations that may eventually arise. One way to avoid the advance directive to be overruled on this ground is to focus on the effects of illnesses, by way of defining what the individual considers an unbearable situation or a quality of life incompatible with dignity, inadequate to fulfil his personal life project.

Although it is necessary for the person to define a general framework under which the advance directive will be effective, it seems unnecessary to require a high degree of accuracy in the description of circumstances that will call for the advance directive to be applicable. It seems excessive to disregard an advance directive simply because the condition the patient is in does not coincide exactly with what the document says. The mere evidence that a person has taken the time to think about this matter, and issue an advance directive shows that that person is concerned about life-sustaining treatments when there is no possibility of recovery, and his fear of futile medical treatments. There should be room for interpretation, but lack of exact coincidence should not lead to absolute disregard for the person's wishes.

2. Sound medical practice.

This is a loophole through which paternalism can make its way back into the scene of decision making. If physicians act according to reasonable *medical* standards they can, in effect, veto the patient's decision. What professional practice regards as sensible**,** tolerable measures to prolong a life may differ radically from what that patient considers tolerable or acceptable to him. If *ultimately* physicians do what they think is best with complete disregard of the patient's express choice, there will be no point in advance directives.

Who is, after all, the best judge of one's own interests? From a medical viewpoint the answer might have to be that physicians are. But in ascertaining such best interests, issues other than specifically medical considerations come into play: socio-economic factors, the emotional support a person receives from his family or close relations, the person's ideology or beliefs, the freedom to pursue happiness according to his or her own set of values, the person's dignity, his peace of mind, factors which have much to do with the patient's well-being. If we are to respect patient's autonomy it should be with disregard to the cause of such refusal to medical treatment. In the often quoted words of Lord Donaldson in *Re T. (Adult: Refusal of Medical Treatment)* (1992), 4 All E.R. 645 at 652, the right to autonomy "exists notwithstanding that the reasons for making the choice are rational, or irrational, unknown or even non-existent".

Finally, I would like to say a word about the effects of advance directives. The Oviedo Convention on Human Rights and Biomedicine (4 April 1997) states in article 9 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". It does not say that an advance directive should be complied with. The rationale is that given that the matter to be decided on is very grave, advance directives are to be taken into consideration as an important element in the decision making process, but should not be mandatory. But what does "taken into account" mean? Such imprecise language would seem to allow a physician to override or ignore an advance directive altogether.

Should we take one step further and make the advance directive binding for the physician? Nothing should be done in the medical field automatically, there are always a number of factors to analyse and evaluate. However, physicians should not have substantial discretion to override the patient's express wishes. It makes no sense for regulations, which are designed to extend autonomy, to allow physicians to choose to ignore advance directives.

So to answer the question: do advance directives enhance autonomy or is that merely a myth? Regulations are

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a step in the right direction, but we have not gone far enough. It has a chilling effect to remember that advance directive regulations did not stem solely from the desire to enhance patient's rights, but to clarify the position of physicians and to determine the legal consequences of decisions to discontinue treatment. The rules were not aimed primarily at protecting patients at all, but physicians. But if advance directives are to be an instrument of promoting real autonomy they have to be taken seriously or they will offer nothing more than a mere illusion of autonomy.