Regulation of advance directives in Italy: further considerations

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Dear Editor,

we read the paper of Gristina and coll. with interest (1) and would like to add some considerations.

A first concern relates to the title of the proposed bill, "Provisions on the therapeutic alliance, informed consent and advanced declaration of treatment", which suggests an attempt to regulate all the complex issues surrounding end-of-life care. Yet, the issue is then tackled by means of a reductionistic approach. First, most of the problems of end-of-life care are reduced to the care of patients in vegetative state. Then, such care is reduced to the possibility of forgoing artificial nutrition and hydration (AHN). This is probably due to the fact that the bill was written on the wake of the controversy that followed the death of Eluana Englaro. As such, it seeks to specifically regulate the possibility of withdrawing ANH in vegetative patients. The result is that the bill is quite inadequate in regulating end-of-life care in patients affected by other (much more frequent) conditions, such as cancer, COPD or cardiac failure. More importantly, it represents an example of a state seeking to impose a specific moral view on every citizen and deciding how they ought to live their private lives, including their terminal phase. In this sense, the Italian College of Physicians specifically requested that Parliament should respect the relationship between the care provider and the patient, and proposed the adoption of '*diritto mite*' (a soft legislation)" (2).

A second concern is that - in an attempt to balance different values grounded in the Italian Constitution (life, health, dignity, self-determination, individual freedom) - the proposed bill grants a strong privilege to life, intended as physical survival, over and above all other values. Within this framework, the patient's right to care turns into a clinician's duty to treat.

A further point relates to the roles of advanced directives (AD) and of the clinician. The proposed bill assigns only a weak indicative value to the patient's will, which would then be evaluated by the clinician under no legal obligation to respect it. Much public opinion in Italy believes that a clinician's obligation is to fulfil the patient's wishes. We note, however, that making AD mandatory would be in contrast with the Oviedo Convention (3) and the Italian Medical Code of Ethics, which strongly support AD but maintain such AD should be "taken into consideration" and not mechanically fulfilled.

We believe a more effective approach to this issue can be achieved by recognising that situations are different, and, accordingly, AD should also be different. Some young, healthy people may want to define their level of care in case of a possible but unlikely clinical situation which they are not able to precisely understand and specify. This type of AD could be defined as **eventuality AD** and would represent a generic patient preference, which although important, needs to be interpreted by the family and the clinician before being applied (usually many years after its formulation). In these situations, the evaluation of the reliability of the expressed will is a necessary step to ensure the very respect of the patient's values and autonomy: it is the overall intention of the patient's will which must be fulfilled, not its mere literal expression.

A different form of AD might apply to patients affected by chronic and/or degenerative diseases. These patients know and understand their condition very well because they live with it every day. Moreover, the progression of their illness is well understood and well-

defined. These AD could be defined as **expectation AD**. They would represent the patient's specific will, which requires little interpretation by the family and the clinician and needs simply be known, shared and respected.

Even more important, we should ensure the decriminalization of the clinician's action when she/he respects the patient's will. The law should reassure the physician that, should she/he act in accordance with the patient's will, she/he will not be prosecuted. The proposed bill assigns the clinician the responsibility to decide but does not provide such reassurance (on the contrary, it stresses the overwhelming importance of physical survival over health, dignity, self-determination and individual freedom); in this sense, it risks forcing clinicians to deliver unwanted overtreatment to terminally ill patients.

References

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