

Living will legislation: between advance healthcare directives and advance care planning, which is the better way to go?

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Abstract

Following drawn out, contentious parliamentary deliberations, the Italian legislature has enacted bill n.219/17, meant to regulate advance healthcare directives. The letter's authors are critical of some key aspects relative to advance directives, contending that it would be preferable to opt for advance care planning, which enables already severely ill patients who are fully aware of the consequences of their disease to choose what therapeutic pathway to undertake. *Clin Ter* 2021; 172 (1):e46-48. doi: 10.7417/CT.2021.2279

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Dear Editor,

We have read the paper authored by J. Giammatteo M. Treglia M. Pallocci, G. Petroni et al, titled LAW n.219/17: Reflecting on shared care plan, published in issue 5 of 2020 of Your distinguished journal, on which we would like to briefly comment herein (1).

For decades was a law on advance health care directives (ADTs) hoped for and needed in Italy; still, the country's underlying political conditions and partisan divisions had made it all but impossible to legislate on the issue. That had led to a legislative void at the very moment when tragic cases, significantly different from each other, unfolded; among those, the widely covered and debated cases of Luca Coscioni, Piergiorgio Welby, Eluana Englaro, Walter Piludu, Fabio Antoniani, known as DJ Fabo (2), all of which laid bare the daunting challenges and complexities of the core issues at the heart of end of life care. The DJ Fabo case in particular has greatly contributed to the enactment of Law 219/17, which codified a set of "norms governing informed consent and advance healthcare directives" (3). Overall, advance directives are a tool which enables patients to exercise

their right to self-determination, both when fully aware and in a state of unconsciousness, with no need to prove their will through the testimony of third parties (4).

The legislation does not acknowledge conscientious objection rights for doctors (5-9), though it does lay out three scenarios in which doctors may legally disregard advance directives: unreasonable requests, directives that no longer reflect the patient's current clinical conditions, and the availability of new forms of treatment, unpredictable at the time the directives were drawn up, and potentially capable of significantly improving the patient's quality of life. In such cases, doctors have a duty to disregard the advance directives; patients in fact are not entitled to demand forms of treatment that are unlawful, or run counter to medical ethics and clinical best practice guidelines (10, 11).

ADTs are drawn up by healthy individuals potentially long before they hypothetically lose their decision-making capacity. Hence, they become effective in case a sudden incapacitating illness should occur, such as heart attack, anoxic brain injury following accidents or similar traumas. Essentially, ADTs are meant to codify and record the patient's will when the disease and ensuing disability has not happened yet. From that perspective, they should be viewed as a means to facilitate an exchange and dialogue between patients and the doctors taking care of them, and to prevent forms of futile treatment through early refusal (12-14). Still, such methods have been met with widespread skepticism (15). First and foremost, some argue that acceptance or refusal of any given treatment is only justifiable if the disease has already set on. Living wills therefore do not necessarily reflect a current refusal, since they will only apply if and when the patient becomes incapacitated and doctors need to decide if and how to treat them. In such a scenario, however, an extremely challenging issue comes to the fore: how to understand whether the intentions expressed in the directives are still current and applicable once the healthy individual becomes a severely ill patient incapable of making decisions based on the current conditions (16). Furthermore, it is worth noting that such directives are often unclear for doctors to interpret, particularly when the signatory has not exhaustively defined the clinical conditions to which the directives

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should apply. In addition, it should be considered that DATs cannot obviously be revoked once the signatory becomes incapacitated. His or her life may therefore depend on a choice made when they were healthy, and nobody is in any condition to determine whether said patient would confirm those same decisions once he or she becomes a patient in need of care. Most likely, they would decide to undergo any form of treatment, including the most invasive ones, just to have a chance to survive. DATs may therefore no longer be applicable, in that they reflect wishes that the patient might no longer hold in the current circumstances (17).

Recent studies on neuroscience have unveiled staggering facts on the connections between consciousness and brain activity: a state of awareness may in fact still linger even in patients who sustained major brain injuries and damage and have no reaction to external stimuli (18). How should doctors and facilities act in such instances? Thanks to ever-advancing scientific research and discoveries in that realm, this quandary will continue to be investigated by scholars; in fact, if on the one hand an underlying and “latent” state of consciousness may warrant upholding the patient’s right to self-determination under all circumstances, on the other hand it might also make it justifiable to disregard or not fully comply with their decisions at a time when they are in a state of extreme physical and psychological frailty and vulnerability.

In light of all that, we believe that framing a living will cannot in and of itself guarantee patient autonomy when it comes to choosing what forms of treatment to accept or refuse if and when healthy individuals become incapable of making decisions. That is primarily because a “will” cannot possibly encompass each and every clinical scenario that could occur at some point in a person’s future. As a matter of fact, since they are to be used in a clinical setting, DATs need to be as short and clearly stated as possible, thus including clinical situations in a somewhat general and unspecific fashion (19, 20). It is our belief that any given individual and/or patient who decides to frame a living will can never be adequately aware and informed as to the conditions they may be in, if and when a major disease strikes and doctors have to follow through on those decisions. Moreover, advance consent is by its very nature unspecific, since it is impossible to identify beforehand what therapeutic approach may become necessary (21).

A far preferable route is in our view advance care planning (ACP), which documents an advance expression of preference within an already well-established doctor-patient relationship. ACP is well-suited for instance to meet the needs of terminally ill cancer patients, who may grow less and less conscious as a result of palliative care over time (22), or for those with neurodegenerative diseases such as Alzheimer’s, which causes gradual loss of cognitive skills (23), Amyotrophic Lateral Sclerosis, age-related or vascular dementia and the like. Patients suffering from such severely debilitating diseases can express their will through ACP, and the choices thus made will reflect their “current” wishes, being aware of the disease and its likely progression and conclusion. We do not mean to argue that DATs are completely useless. Still, we feel that the patients’ actual desires may be better fulfilled within the framework of a trust-based therapeutic alliance with their doctors, in order to best deal with impending loss of consciousness.

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