

# Advance Directives: regarding the recovery of subjectivity between independence and self-narration

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**Abstract:** After 41 years from the approval of the first living will law in 1976 in California, on December 22<sup>nd</sup> 2017 the bill on “Rules on informed consent and advance directives” has been approved in Italy.

The applicability of the law highlights a lack of a univocal methodology regarding the recovery process of the patient’s subjective dimension under a testamentary will; so, it seemed useful to highlight the passages that occur between the drafting and the use of an advance directive in an existential phenomenological perspective. Is the individual who freely drafts an A.D., choosing to decide now for the future, the same person for which the provisions were outlined? The goal of this paper is to offer an ethical reading of the ontological issue that illness can raise.

**Keywords:** identity; otherness; end-of-life; bioethics; phenomenology.

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ISSN 2533-0675

JPC © 2018

DOI: 10.17605/OSF.IO/7BA84

[journalpc.org](http://journalpc.org)

## **1. Preamble**

**T**he following paper has as its source reference Article 4 of the Italian Law No. 219/2017, by the title “Advance Directives” (Disposizioni anticipate di trattamento - DAT):

### Subsection 1

“Every individual who is of age and capable of understanding and wanting may, through anticipated treatment agreements, express his or her will on healthcare matters, such as consent or refusal towards certain tests or therapeutic choices and individual medical treatments and may also choose an individual, to his or her trust, as a “trustee” to represent the individual in the relationship with the physician and with future health facilities, in the event of any future incapacity of self-determination.”

### Subsection 2

“The trustee must be a person of age and capable of understanding and willing. The acceptance of the nominee by the trustee takes place through the signing of the DAT or by a subsequent act, which is attached to the DAT. The trustee may renounce his or her nominee through a written document, which will be communicated to the settlor.”

### Subsections 3 and 4

“The trustee may be revoked at any time by the settlor, in the same manner as for appointment and without obligation to state reasons”; and “in the event that the DAT does not contain the indications of the trustee

or if he has renounced or died or has become incapacitated, the DAT will remain effective on the settlor's will.”

#### Subsection 5

“Without prejudice to subsection 6 of article 1, the physician is required to comply with the advance directives, which may be completely or partially terminated by the physician himself if they appear to be incongruous or do not correspond with the current clinical condition of the patient, in other words if there are therapies that are not in the written act, that are able to offer certain opportunities to improve living conditions. In the event of a conflict between the trustee and the physician, one proceeds in accordance to subsection 3 of article 3.”

#### Subsection 6

“Advance directives must be drawn up by a public act or by a private authenticated writing, handed over by the settlor to his or her state's civil office of residence, which records it in a special register or towards health facilities where, then, the conditions of subsection 7 apply. They are excused from registration duty, stamp duty and any other kind of tax. In the event that the patient's physical conditions do not allow it, advance directives can be expressed through video recording or devices that allow the person with disabilities to communicate. With the same forms that are renewable, editable and revocable at any time. In cases where emergency and urgency reasons prevent the DAT from being revoked in the forms provided for earlier periods, they may be revoked by a verbal statement collected or recorded by a physician, with the assistance of two witnesses.”

## Subsection 7

“Regions that adopt telematic procedures for managing the clinical record or the electronic health records or other data management methods of the person enrolled in the National Health Service may, by their own act, regulate the copies of advance directives, including the indication set by the trustee, and their insertion into the database, leaving the settlor, however, the freedom to choose whether to make a copy or to indicate where they are available.”

The bill clarifies, by regulating them, the basic principles of the arraignment of the pre-treatment statement by which the declarant expresses his/her will in relation to advance directives in the event of the loss of mental capacity.

It is an important step for Italy that is expressing itself legally on issues of great ethical and civil impact. World-class pioneers regarding biological wills have been: the United States, since 1975, with their Living Will, when the debate on the “right to die” began; in 2005, France, with Law 370 on the rights of the sick and the end-of-life, following which the Code de la Santé Publique had to be changed; Germany, where the biological will has its practical application but there is still no specific regulation in this regard; the Netherlands, where the law on interception of life on demand and suicide assistance was introduced, Law No. 194; England, with the Mental Capacity Act of 2007, which establishes a legal framework for patients who are incapable of making decisions independently, thus protected by early declarations of will; Spain, with Law No. 41 of 2002, which establishes the autonomy of the person by clarifying rights and obligations in the field of clinical information and by instituting the Instructions Previas (anticipated directives); and Denmark, with

Law No. 546 of 2005, which entitles the patient to write a biological will, with the possibility of refusing treatment in the case of illnesses or terminal illness.

Considering the legislative situation in the international scene among pioneer end-of-life countries, the legitimacy of the advance directive (in Italian DAT, *disposizione anticipate di trattamento*) is constitutive of the same: to extend the patient's autonomy in the future, to keep in mind their own will in moments where they lack decision-making ability, and to provide objective support for doctors and family members in the deliberations of previously recorded wills.

If we imagine that we are faced with a specific situation that finds an individual in a condition of signing a directive, is it possible to apply a practical reasoning to understand how certain choices lead to certain consequences, whilst dwelling on the subject who is experiencing an advance directive? Practical knowledge of this kind is based on a far from precise scientific and juridical reasoning and, instead, is characterized as contingent knowledge in continuous redefinition.

That being said, the most suited philosophical approach to this practicability of knowledge is phenomenological, because of the study of overcoming the subject/object dualism in the knowledge process and in the reconsideration of the subject's role in the knowledge of those objects. For better or for worse, experiential knowledge is not enough if the main goal is to reach 'personal' subjective, in other words the core of uniqueness that submits to a certain will and tells us who we are. Therefore, explanation and comprehension are not separate, but two complementary processes and in the advance directive's cases, this complementary

relationship is necessary, because the subject of action is the object in question as well.

The developments that define the space within which we move is clearly already ethical through the problematization on what the best way is for a thoughtful understanding of human's dimension of existence in illness, linking topics related to identity, otherness, end-of-life, bioethics, and phenomenology.

## **2. The issue of autonomy as requirement for consent**

**W**hat drives a man to draw up a directive will? Avoiding the unnecessary difference between those who draft an advance directive despite not suffering from a degenerative pathology or are in a condition of progressive loss of the ability to understand and want, but who are using their right to apply a law, and those who instead chose to draw a will autonomously due to an unfortunate disease or in the full awareness of being near the end of one's existence, what is the philosophical element that unites both agents?

I believe that, in both cases, we are dealing with autonomy, in other words, an individual's ability to consciously regulate in full self-possession even in the perspective of an existential time that seems to deny the possibility of deciding freely of one's own life.

The composition of one's specificity must be personal, free, original and ensured in all ages of life as a natural and social autopoietic exercise.

In bioethical terms, autonomy should be understood both as the patient's right to choose therapeutic treatments and as a supreme principle to authentically evaluate a moral choice, because doing the right thing isn't necessary to act well, one must choose autonomously without constraints (what Kant would define as moral conscience, autonomous and ruling itself). Now, if we consider both the exceptions in the testamentary context of an advance directive, in what sense should an individual's autonomy be considered, as the beginning or the end?

We should probably talk about autonomy as a process of critical judgment regarding what concerns us as free people who are able to self-assert one's self in relation to the surrounding world that concerns us closely and which we cannot overlook. Placing autonomy upstream of a choice or dwelling on the consequences that a choice can have, is an issue that should be treated individually for each single case.

In line with this reasoning Ricoeur refers to autonomy in *Oneself as another* as a path that leads a subject to be oneself starting from the recognition of an objective regulation that must be adopted as a moral law (self-respect) to become an ethical perspective (self-esteem) when that regulation is combined with a human desire. The goal is to harmonize the Kantian and Aristotelian spirit to enquire the autonomy of autonomy: "In the distinction between perspective and norm one will easily recognize the opposition of two traditions, an Aristotelian one, in which ethics are characterized by a teleological perspective, and a Kantian tradition, in which morality is defined by the regulations' obligation, therefore from a deontological point of view. [...] The two traditions will establish a relationship that is both, at the same time, subordinate and complementary" (Ricoeur 2015, pp. 264-5). "As a matter of fact, one's will is

nothing other than practical reason, common in principle to all rational beings; it's empirically determined by one's sensitive inclinations because of its finite constitution. What follows is that the connection between the notion of good will and the notion of an action accomplished by duty is so close that the two expressions become substitutable one another" (Ricoeur 2015, p. 305).

But between the ideal plane and the sensitive plane, the idea of remaining true to oneself presents a double problem of pretence: on one hand, to say that we will maintain faith for something set in the future would be like arbitrarily assuming that an individual's way of thinking won't experience variations, which can't be established for sure; on the other hand, considering a testamentary disposition as an anticipation of carrying out an act, which will not reflect an individual at the moment in which something occurs, would mean to be committed to something an individual can't guarantee. From this dialectic Ricoeur concludes that an individual isn't faithful to oneself, but to another so that every commitment is, actually, a reply. Instead of the moral of autonomy, we should speak of a morality of availability, or the decentralization of oneself towards another individual for a prospective of mutual reliance: as a rupture of solipsism and inevitable practicality of human relationships that cannot be reduced to general models.

The autonomy Ricoeur values seems achievable only through something else other than the subject mentioned, as to affirm that it exists only within a relationship that involves something other than oneself and that fulfils its own free expressed will in which the responsibility to act externally, in response to the subject, overcomes and precedes one's freedom, will and the ethical possibility prevails over an ontological one.

Ricoeur elaborates a concept that emphasizes the conflicting aspects of human experience that are, overall, inclined towards the achievement of an agreement, without defining it. Therefore, human experience is the opening of one individual to another other than himself, which leads him back to himself. In retrospect of the Hegelian recognition topic, Ricoeur's whole philosophy moves towards the subject's conception whose identity is not an immediate factor, self-determined by one's ego, but the result of a dialectic between oneself and another. From the other, oneself returns home as awareness.

“Is it not in my most authentic identity that I ask to be recognized?” (Ricoeur 2005, p. 5); this is what Ricoeur state in the preface of *The Course of Recognition*. “And if fortunately, I happen to be [recognized], should I not address my gratitude to all of those who, in one way or the another, have recognized my identity by recognizing me?” (Ricoeur 2005, p. 5).

Therefore, the derived intersubjectivity would be necessary for one's autonomy and would be placed side to side to the principle of responsibility that another individual offers as a solution to the understanding of that announced autonomy in the form of a disposition.

The individual that signs an advance directive, if is considered so, is a morale subject of a therapeutic action and even if he was considered passive before, becomes active. To not reduce the advance directive to a mere legal exercise means abandoning the idea that one can only talk about a list of requests to apply (or not) practically, and to consider such a will as an exercise of responsibility, or a response to a request for assistance transmitted in a document that was born as a communication document. King claims: “Advance directives cannot be reduced to a set of requirements. The decisions that directives encompass are inherently

difficult and inherently painful, and the burdens of interpreting and implementing them can be borne better but never cast aside. [...] Dying by directive can become more than just a legal exercise” (King 1991, p. 198).

Even though it has often been agreed to only consider the autonomy of the individual that signs an advance directive, regulation 219 recalls that the medical doctor’s autonomy, who operates in agreement with his individual freedom and the professional code of ethics, must be considered as well. The fact that the advance directives can be ignored falls within the normal nature of science’s evolution and its progress in order to improve itself in the interest of life and its related well-being. If, at the time of an active testamentary disposition, science is able to offer a breakthrough in the evolution of a degenerative and disabling pathology, it seems good to ignore a will that is anachronistic, not at the time when it was recorded, but with the respect to improve and change a procedure, at that time, unknown. Once again, the physician is invited to value and respect the will expressed, almost as to give attention to the patient as an individual who’s speaking for his or her health and who acts for his or her own wellbeing.

To perceive the gap that separates common power from the domination that characterizes the ethical primacy of living together on the constraints connected to legal, political and social systems, or as Ricoeur would say “to seek the adaptation between what seems the best to us for the combination of our life and the choices that dictate our practices in the incessant work of interpreting actions and oneself” (Ricoeur 2015, p. 274).

### **3. Self-determination in illness**

Only an autonomous subject, in full possession of all his decisional faculties, or conscious of the meaning of his actions and free from constraints, can self-determine himself by extending his autonomy even in during the stages of a disease, through free informed consent. From the structure of informed consent, as a prerequisite for each therapeutic treatment, one can deduce the existence of the right of self-determination concerning the choice of medical care.

The suggestion to therapeutic self-determinations, today, can establish a sort of connection between what is licit and illicit: self-determination, that is, with respect to one's own health. Only a subject withholding his or her rights can decide the content of the right itself in relation to his or her projections and to the idea that the individual has of him or herself.

Delimiting the boundaries of medical care is complex because of the concrete aspect of medical treatments that physically affect man's integrity; that is why the consent or dissent is legitimate and lawful even in cases of the incapacity to want, if expressed in advance and regulated.

Article 9 of the Oviedo Convention expresses the wishes previously stated in these terms: "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."

An early disagreement of a particular treatment should be taken into account by the physician but cannot bind him. Legally, no one is

forced to cure himself or herself, but there is a duty to do so; refusing care cannot be considered as an asset itself but must be necessarily brought to the benefit of the person concerned as respect towards human beings to which each medical treatment refers.

The hypothesis that during the evolution of a disease the subject's possibility of self-determination may diminish, until it disappears, constitutes what I think should be considered as one of the reasons why the advance directives represent a valid protection of an individual's free expression of his or her will, when and if it's possible to develop an ethical and valid method of recovery of the individual's subjectivity. In my opinion, this task could be assured only by a philosophy that has a familiarity with dealing with issues regarding meanings, that can be treated hermeneutically and phenomenologically.

Despite any identification with a type of project or any type efficiency, man is also his own inadequacy: in other words, the absence from his own will and power of something and the feeling of not fitting into a plan. In the advance directive's case this impossibility is beaten overtime: an individual can decide for his or her own body for a future possible occurrence in which the possibility to choose isn't possible, even if that implies that the individual signing the disposition is the same that benefits of the situation.

How do we go from a mere individual to the individual that each of us is?

In *Oneself as another*, Ricoeur states that: "Owning a body is what people do, or more accurately what people are [...] bodies are identifiable and ri-identifiable as the same" (Ricoeur 2015, p. 110). He continues:

“The odd state of one own’s body depends on a wider problem that has the ontological status of our being at stake and that comes to life from corporeity’s way” (Ricoeur 2015, pp. 135-6).

What should be addressed is “the thing of chi”, meaning the subject’s character that Ricoeur refers to, that: “assures the numeric, qualitative identity, the uninterrupted continuity in change and, finally, the stability in time, which defines uniformity” (Ricoeur 2015, p. 211). It’s about shifting the issue from ‘who am I?’ to ‘what am I?’. The specific sense of an advance directive for an individual is for him or her to appeal to this exclusive deposition, to its very essence traced in the flow of the ages of life and that is always the same as itself as it comes together. Only within this kind of reasoning psychic degenerations of an individual who singed a disposition would not invalidate the sense that certain choices have maintained over time. Investigating the subject’s identity in its selfness means placing the individual within his own value system and own interpretation of the meaning that life as, as long as the ‘what’ of that subject can be retraced as an intention in the world: a being-able-to or being-able-to-act.

Jongsma and van de Vathorst claim: “When cognitive capacities decline, and reflection upon their preferences and values is not possible anymore, we cannot simply argue that this person has developed a new preference or has changed his earlier values. [...] The possibility of being mistaken in hindsight, with a former anticipatory decision, is no reason to disregard the moral authority of this decision” (Jongsma 2015, p. 174).

The guide that accompanies our moral choices, based on what is said about the Advance Directive, forces us to talk about human beings, falling into the sensitivity of our lives.

Enabling someone's choice for someone else means bringing us back to the subjective dimension of every individual's life who cares for another's life, guaranteeing their authenticity (that is, being more like themselves).

#### **4. The role of an individual as guarantor of the subjective will's statement**

**B**efore understanding how an advance directive can be effectively interpreted and therefore applicable, it is necessary, as we have seen, to perform a phenomenological operation and observe how the guarantor participates in a personal process that mainly concerns the life of the settlor (and not only).

As a rule, the patients communicate their will directly to the physicians. However, when losing the ability to make decisions regarding health matters, the decision must be taken and communicated in other ways. This is the advance directives' function. In the absence of this document, another 'part' may be called upon, chosen by the patient, and responsible of deciding for the patient's health decisions.

But how does the other present himself and how can one understand his revelation?

“The other is the following: proximity as non-indifference in difference, as responsibility” (Lévinas 2002, p. 45), with these intense words that Lévinas reverses the priority in the relationship between the subject and the other individual. The structure in the subjectivity’s constructing process starts from the other and moves towards the subject involved. And if, once constituted, one’s self can freely move towards the other, it’s from this other individual that the “I” is ordered; and that is what implies the impossibility of a mutual indifference, not the fear of the other, but for the other, until the subject finds itself in the other’s place in an irreplaceable way. This is what happens between trustee and guarantor, in that very particular situation that leads to “putting oneself into someone else’s skin” (Lévinas 2002, p. 22). The subject’s self (“I”) in these terms is literally challenged by the other’s face, by his or her gaze; and it is considered one’s self because of the other’s review.

The otherness of which Lévinas speaks is already present as a concept in the body itself, to present itself again in an inter-relational form between bodies: “Bodies already from a relation, simultaneously, before words from into a dialogue. My own birth cannot be part of my direct experience, only others can tell me about it. My death cannot be a part of it either: it is handed over to others who can bear witness” (Lévinas 2002, p. 24).

And what if we consider those extreme cases of life between the beginning and the end, when the Other’s testimony is significantly relevant for that ‘self-disposition’ to be recovered in its entirety?

If the self’s true essence is relational and not self-centred, the relationship that the subject can establish with another goes beyond the boundaries of one’s limited awareness and opens to greater experience.

What the other's existence seems to ask the subject involved is to consider in him, or her, a lasting humanity of which one becomes responsible. In this ethical dimension the trustee's role is that of a custodian committed to a certain humanity. This alterity is not a threat, but the discovery of the other a person that determines the subject involved through the choices he makes, having been, in turn, recognized by him.

## **5. Advance directives and narrated identity**

**W**ith experience considered as a phenomenological conception, it is very important to know phenomena for what they are and to catch them in their essence, by going to the things themselves, which means to follow the hidden profile of things and going beyond their appearance. This means that in phenomenology everything has a way of appearing beyond that of simply appearing. The principle of fidelity to things, in the phenomenological perspective, is therefore intricately linked to their transcendence. But the knowledge of a phenomenon and that of an individual are two distinct processes from natural sciences, which move from the datum of objects to seek general laws, and from the human sciences, in which prevailed experience is gained through an inner experience.

The inner experience of an illness, which is the experience a patient lives, does not only reflect a set of biological and psychophysiological developments, it also assumes that one considers the significance that physical suffering has developed. All clinical practices should act by the meaning of the experiences of subjective realities, especially in the spe-

cific case of an advance directive. The verbal and written narrative of the dispositions, as well as a prosperous one-to-one autobiographical writing activity, calls to a co-construction of the patient's history and of its most intimate reality. Everything is connected: the patient's history, the value systems that manage that history, the trustee, the family and the medical team. The aim is to get to share the same story involving the therapeutic process, finding each other in every different role.

In addition, we can include Morin's complexity theory, which identifies a substantial error in sciences' dominant thought that consists in having believed that what is not quantifiable and formalizable does not exist or is nothing but reality's foam.

It would be more correct to say that there is a complex, situational and multidimensional way of thinking, because not all the events can be traced back to simple rules of linear causality; so, we must learn to reason in a complex way, which involves the ability to relate to illness by a thought that welcomes the general and the particular.

And what better subject than philosophy to do so?

## **6. Conclusions**

**T**he results of my research concern focus on the contribution that a philosophical vision can offer to end-of-life issues such as the use of a willing disposition for a free citizen. Considering the integrity of human life in its whole, especially in the stage of illness, when the logic between one's self and the world has lost rationality, means pre-

forming an ontological work that reduces being to its essence. In the case regarding the advance directives, linked with a very strong philosophical tradition belonging to the 20<sup>th</sup> century, I think that a person's substantial self-identity cannot change through the transformations of time because, as Ricoeur would say, identity is not closed process and determined once and for all; it is an overcoming dialect between sameness and ipseity. An individual must learn to know himself as a subject in constant tension and openness, compared to the multiple possibilities of becoming himself in the relationship with Others.

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