Perspective and Debate

Care for the person, protection of health and respect for the will of the patient in Italy: support administration as a tool to jointly promote health and respect for autonomy in incompetent patients

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Significance for public health

The concept of health includes not only the physical, but also the psychosocial dimension in accordance with the will of people. The reference to the personal concept of quality of life, values, ethical and religious opinions of each subject are key components underlying the decision-making process concerning a given patient in a given clinical condition: the concept of health does not only exist in the abstract, but must be measured in relation to the specific patient in the specific situation. The authors analyse the Italian debate about the possible designation in advance of the support administrator on the part of the beneficiary in anticipation of a potential situation of incapacity, as a tool to enforce advance care directives, to show how beneficence and respect for autonomy are both essential elements in the choices of the legal system aimed at promoting the health and the wellbeing of its citizens.

Abstract

In Italy, advance health care directives are a subject of considerable debate in both legal theory and practice. This debate focuses in particular not only on the appropriateness of approving ad hoc statutory regulations but also on the extent to which similar advance indications of a person’s wishes are applicable under the existing legal system, albeit in the absence of a law regulating them. The authors of this paper consider, in particular, guidelines relating to the possible use of the mechanism of support administration (amministrazione di sostegno) (Law No. 6/2004) as a procedure to be used for the legal recognition of advance health care directives, particularly in the light of the legal provision for the possible designation in advance of a support administrator by a beneficiary in anticipation of an eventual situation of incapacity. This underlines how the concept of health does not only exist in the abstract, but must be measured in relation to the particular patient in the particular situation and how beneficence and respect for autonomy are both essential elements in the choices aimed at promoting the health and the wellbeing of its citizens.

Introduction

The long process of discussion of Bill No. 2350 (16th Legislature) – containing provisions regarding therapeutic alliance, informed consen and advance health care directives – hasn’t put an end to the Italian debate in legal theory and practice with regard to the scope of applicability of these early manifestations of intention under the existing legal system, and in particular within the sphere of the mechanism for support administration introduced by Law No. 6 of 9 January 2004.

This law has introduced a flexible instrument, able to adapt to the needs of fragile subjects, to protecting them as well as to promote their residual skills, unlike the traditional legal measures to protect individuals, interdizione and inabilitazione, very often disproportionate to the subject’s need for protection.

After all the new measure rests on a philosophy opposite to the one which is at the bottom of the old system of protection and it is mainly characterized by the ability of the administrator to provide support to a wide range of possible beneficiaries; by flexibility according to the specific needs of the beneficiary; by continuous monitoring of the work by the probate judge; by the simplicity of the procedure.

Support administration, compared to interdizione – that entails the subject’s inability to perform valid acts, that are placed in the name and behalf of the subject by a guardian appointed by the court – and to inabilitazione – that allows the subject to make autonomously only acts of ordinary administration – was introduced in Italian legal system with the intent to protect, with the least possible limitation of their ability to act, persons who are wholly or partially deprived of their autonomy in the performance of their daily activities, by means of interventions of temporary or permanent support. On the one hand this measure, established as an instrument of assistance for a person who, as the result of an illness or of a physical or mental impairment, is unable, even partially or temporarily, to provide for his own interest, offers protection to situations that would not be included in the previous protection measures, reaching the subjects whose condition is not severe enough or stable enough to justify a measure of interdizione but nevertheless in a condition as to require a form of protection; on the other hand, the actual implementation of this new measure is supported by a very active role on the part of the health and social care services directly involved in the care and assistance to the person when aware of facts making appropriate support administration: health and social care services managers are in fact required to bring a court action or inform in any case the public prosecutor.

This provision reinforces the intention of offering effective protection to those who even if in a condition of frailty and weakness would risk remain without protection, implementing the principles of fundamental equality and solidarity of Italian Constitution, through the acknowledgment of the active role of the health and social services in ensuring the activation for fragile persons of the new support mechanism provided by the Legislature.
The purpose of this mechanism does not end with the *cura patrimonii* of the beneficiary, having as its main objective the promotion of the individual; thus, the broad scope of application is clear from the letter of the regulations that govern it, in particular from article 404, para. 4 of the Civil Code, which states that whenever the need arises, the probate judge shall adopt urgent measures, if necessary of his own motion, for the care of the person concerned and to safeguard and administer his assets, and from article 408, para. 1 of the Civil Code, which establishes that the choice of the support administrator is made with exclusive regard to the care and best interests of the beneficiary. Nonetheless, reference to generic concept of *interests* (article 404, Civil Code), to *needs* (article 410, para. 1, Civil Code), and to *moral interests* (article 44, Civil Code implementing provisions) of the beneficiary contained in the law confirm the relevance of support administration even in the context of health protection.

**Support administration and health protection**

The relationship between support administration and care for the person is confirmed in a number of court rulings which recognise the effectiveness of the mechanism for the representation of individuals also in the sphere of decision-making related to health care. Grounded in proper respect for the beneficiary, in such cases empowerment of the support administrator to express consent to health care constitutes an instrument for the care or rather for the safeguard of the health of an individual incapable of taking decisions regarding his own state of health.

The relationship between support administration and care for the person is further confirmed by a ruling by the Supreme Court which in fact reaffirmed that the power to care for a disabled person shall likewise be exercised by the person who has been appointed as support administrator, as the appointment must contain an indication of the acts that the administrator is empowered to perform in order to protect the interests – including the personal interests – of the beneficiary.

Such powers may not be exercised – in accordance with the rationale of the provision itself – if not to protect the beneficiary, while at the same time acknowledging this person’s own wishes: the intention of the legislator is specifically to safeguard, with the least possible limitation of their ability to act, persons who are wholly or partially deprived of their autonomy in carrying out their daily activities, through interventions providing temporary or permanent support.

Article 410 of the Civil Code (*Duties of a support administrator*) states that, in the performance of his duties, a support administrator must take into account the needs and wishes of the beneficiary and must promptly notify the beneficiary with regard to the acts to be performed.

Thus, article 407, para. 2 (*Proceedings*) of the Civil Code states that the probate judge must personally consult the individual to whom the proceedings refer, where necessary, in the place in which the individual is to be found, and must take his needs and demands into account, in line with the best interests and needs of the individual.

Even the *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine* of the Council of Europe states in article 6, para. 3 (*Protection of persons not able to consent*) that ‘...where, according to law, an adult does not have the capacity to consent to an intervention because of a mental disability, a disease or for similar reasons, the intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided for by law. The individual concerned shall as far as possible take part in the authorisation procedure. The regulations under consideration, as well as procedures for application of the provision, confirm that decisions of a personal nature, including those relating to health, must wherever possible be the result of an agreement between the beneficiary and the administrator: in the case of incapacity of the beneficiary the administrator must in any case ensure that his own choices respect the personal dignity of the individual concerned and possibly take into account any wishes previously expressed. Respect for the personal integrity of the individual concerned therefore constitutes the fundamental principle in the exercise of the powers attributed to the administrator, in the context of the individual’s assets and even more so in the personal sphere, since life choices must respect the standard value system of the beneficiary and the identity of this person.

The relationship between care for the individual, protection of health and respect for the personal integrity of the beneficiary reflects that global notion of health which includes a subjective dimension where the views expressed by the patient himself assume importance: the concept of health does not exist only in the abstract, but must be measured against the particular person whose health is being considered.

If within this context the dialogue between the support administrator and the beneficiary constitutes a fundamental tool, in cases where the individual concerned is incapable it is necessary to verify the operational space and above all the instruments that will enable the support administrator to operate while respecting the personal integrity of the beneficiary.

An important aspect is the provision contained in the law with regard to the possibility that it is the same individual concerned who designates his own support administrator, in anticipation of his own potential future incapacity, by means of a certified public or private deed (article 408, para. 1), giving due consideration to the autonomy of the individual concerned by means of the identification of a person of trust who will be obliged to act while taking into account his needs and wishes.

**Advance health care directives and support administration**

Legal theory has for some time debated whether it is possible to enhance such precautionary designation by means of additional decisions such as advance health care directives, namely indications regarding health treatment or the choice of the place of care, and whether such advance expressions of wishes should be effective.

The legislator neither provides indications in this regard nor specifies whether, in order to ascertain the wishes of the beneficiary, the administrator must base himself exclusively on actually having heard these wishes or rather – as in cases where the beneficiary is no longer capable of any communication as a result of his infirmity – even by a mere examination of documents and written statements, of evidence given by those who knew him or spent time with him and, naturally, any previous personal acquaintance.

In this connection it has been underlined that the fact that the intentions of the legislator *ex lege* No. 6 of 2004 go beyond that of providing a set of specific rules governing advance health care directives, is clearly evident given that the contents of the deed for the precautionary designation of the support administrator are expressly limited to the mere indication of the legal name of the administrator.

If there is an awareness that it would be possible for an individual to lay down the operating procedures that a support administrator may follow and, consequently, that a probate judge would be assigned the task of verifying any wishes expressed in advance by the beneficiary – in the context of the appointment and the conferment of powers to a...
support administrator to promote care for the person concerned – this situation can serve as a vehicle for an understanding of the system under consideration that would effectively respect the autonomy of the beneficiary, and would be easier to implement precisely in instances where the individual concerned would have drawn up a testament for support including the choice of the support administrator and the simultaneous communication of statements in advance of treatment; nonetheless the effectiveness of these developments remains to be ascertained.

There are some authors, who point out in this regard that choices concerning the beneficiary must be made with an eye to existing assessments, taking into account all the circumstances of the case, without, however, the indications provided ex ante by the person concerned being considered absolutely decisive. Instead these indications would constitute one of the elements to reconstruct the actual wishes of the person concerned, but with the final decision nonetheless being referred back to the support administrator and, evidently, to a judge.

The potential of the system under consideration as an effective instrument to promote the autonomy of the individual concerned may therefore become effective only through the intervention of the probate judge. With regard to the choice of a support administrator, the prospective designation by the individual concerned will gain relevance only at the moment of the appointment to be made by the probate judge in the light of the conditions envisaged by the law, on the understanding that it is only for serious reasons that the judge may diverge from the choice made by the person concerned.

With regard to the additional contents of the deed for the designation of the support administrator, which are not specifically considered by the legislation in question, any enactment in the act for the appointment of the support administrator of any such advance directives – with consequent implications of these directives on the support administrator as well – is left to the probate judge.

In a recent judgment, the Supreme Court considered the possibility of supplementing the act for the designation in advance of the support administrator by the beneficiary, with the intentions of the subject and hence the suitability of this act to convey the advance health care directives, while specifying that the state of incapacity is a constituent element in the provision of support: the judicial intervention cannot be simultaneous with the manifestation of the subject’s need for protection, therefore reflecting the incapacity or infirmity from which this need arises and which, according to the relevant regulatory framework, represents a prerequisite of the system itself and not merely its effects. In the case in question the Court turned down the request of a woman who had undergone heart surgery, with a concurrent declaration of his incapacity, and healthy individuals who request the appointment of a support administrator with the intention of letting their own wishes be expressed in the act, wherever intervention is rendered necessary, only if he can evaluate the existence of serious reasons.

Earlier court rulings on this subject had stressed the connection between the provision of support and advance health care directives by stating that the text of article 408 of the Civil Code makes unequivocal reference to the mechanism for the planning of one’s life and that the designation may be accompanied by a series of duties assigned to a substitute in order to render effective, at a time of incapacity, wishes that were expressed in a state of awareness and explicitly affirming that the regulatory provision of the precautionary designation of a support administrator on the part of the beneficiary in the light of the rationale of the mechanism itself means that it can be affirmed that support administration is, currently, the most appropriate mechanism for the expression of advance health care directives issued in the event of incapacity thereby Thus in the view of the judges it is this legal provision which enables the concrete implementation of the system of protection set out at the level of substantive law in articles 2, 13 and 32 of the Italian Constitution, while the instruments through which one could express one’s wishes remain those of a public or authenticated private deed, referred to, in fact, by article 408, para. 2 of the Civil Code.

The above-mentioned decision of the Supreme Court occurs in a context of disagreement in legal theory and practice with regard to the appointment now for later of a support administrator between those who maintain that the appointment now for later is a prerequisite for the appointment of a support administrator, which is an absolute requisite for the administration of support, as judicial proceedings can only be actual and concurrent with the needs for which the support measure is being requested and those, who in contrast hold that a now for later appointment is possible, deeming that a literal, restrictive interpretation of the legislation would render meaningless the innovative scope of Law No. 6 of 2004, preventing the rapid protection of an individual in the event, for example, of a sudden infirmity happening to this person, by asserting that the requirement that the state of incapacity should exist is a pre-requisite in order to bring about the effects of the protection measures, and not a prerequisite for its institution.

The debate regarding the legitimacy of now for later appointments of support administrators cannot however ignore the diversity of situations that are potentially affected and subject to the rulings that have been referred to, such as cases of individuals affected by irreversible, progressive diseases, who have consciously expressed their own wishes with regard to treatment which, in view of the likely progression of the disease and its future implications, might concern them; individuals who anticipate finding themselves in future, following a planned surgical intervention, in a situation of incapacity, and healthy individuals who request the appointment of a support administrator with the intention of letting their own wishes be known and respected, in anticipation of a future possible state of incapacity.

Particularly significant in this regard is a verdict of the Court of Trieste concerning a request for the appointment of a support administrator, designated by the plaintiff, an individual with a heart condition who had undergone heart surgery, with a concurrent declaration of his own choices with regard to health care.

The Court of Trieste first of all deemed that there must be an existing state of incapacity in order to allow a support administrator to be appointed, pointing out that otherwise one would run the risk of not even being able to imagine the limit on support administrations that would be opened, now, for all individuals, healthy or ill, for every future and uncertain eventuality involving any incapacity on the part of the individual to manage each and every kind of interest regarding health or assets, undermining the rationale and purpose of a measure of protection such as support administration.

On the other hand, the Court of Trieste granted the request, since in the case in question the description of the applicant’s documented health condition made it possible to consider that although the condition of incapacity does not exist, it has nonetheless affected the plain-
tiff sufficiently frequently in the past to lead him to deem likely, and not merely as an abstract possibility, a recurrence of the condition of incapacity to express his consent or his refusal of health care and any therapeutic treatment. The plaintiff is therefore affected by a disease which in all likelihood exposes him to the probability (and not merely the possibility, as with any other individual) of having (or more correctly of having once again) a condition of total incapacity, for which it is necessary to take, without any hesitation or procedural delay, decisions in relation to care, treatment and interventions regarding his health.

This would also exclude the risk of increasing the backlog of applications by healthy persons, in anticipation of their future, hypothetical incapacity.

These pronouncements highlight a tendency to recognize the rationale of support administration as an instrument for the promotion of the individual and the wishes of the person concerned, pointing out that the support administrator and the probate judge have the delicate task, in the case of an individual who is incapable of expressing his own decisions independently, of going ahead with the reconstruction of the wishes of the patient with regard to the choice of health care, a duty made easier by the communication of advance health care directives on the part of the individual concerned.

The manifest need to guarantee the implementation of choices in compliance with the convictions of the individual concerned arises after all in the context of a transition from the perspective of the search and reconstruction of a consent which is legitimate in terms of civil law to the direct application of constitutional rules regarding personal freedom; a perspective according to which self-determination in terms of health care, free from the logic of contractual consent, constitutes an expression of the individual’s absolute rights.

In this context there is also room for discussion on the validity to be assigned to any advance health care directives contained in the act of designation of the support administrator by the beneficiary, but not acknowledged in the appointment by the probate judge.

Some persons hold the view that any advance health care directives possibly included in the act of designation would constitute the main source on which to draw information regarding the wishes of the person to whom the protection measure applies and would acquire the same importance as the needs and wishes expressed by the beneficiary throughout the course of the support administration, even in the light of article 410, para 2 of the Civil Code (Duties of the support administrator), according to which in case of dispute, of harmful choices or acts or negligence in pursuing the interests or in satisfying the needs or requests of the beneficiary, the latter, the public prosecutor or other subjects set out in article 406 may appeal to the probate judge, who shall adopt by means of a reasoned act the appropriate provisions: this is a solution that can also be extended, in the view of these Authors, to cases in which the wishes expressed in advance by the subject are contained in a separate act.

Thus the Court of Modena, commencing from the aforementioned article 408, para. 2 of the Civil Code, highlights how this provision in the Code enables the individual concerned to give advance directives and even deems it difficult to refute the conclusion that the intervention by the legislator designed to introduce and regulate these advance care directives is absolutely superficial, point out that there are already the substantive law (articles 2, 13 and 32 of the Constitution), the instrument through which to express one’s own wishes (precisely, a public or authenticated private deed, article 408, second paragraph) and finally the legal provision to which to have recourse (support administration, Law No. 6 of 2004).

With regard to the formal requirements of such advance health care directives, in relation to the case of a woman hospitalised in a cardiac surgery intensive care unit in a medically induced coma, who had previously designated her support administrator while at the same time expressing directives rejecting specific forms of health care, the Court of Modena observed that, although it is true that the form of these directives was not equivalent, in the case in point, to a public act or to an authenticated private deed as required by the legislation, it is also true that the documents during the preliminary investigation stage made it possible to verify that these directives, as shown in the form countersigned by witnesses, constitute an expression of the specific wish of a person in full possession of her faculties, with the consequence of a due protection of this wish and, specifically, of that self-awareness of personal dignity as formed by the person during her life through her rational inquiries, her emotional experiences and the established outcomes of the development of her philosophical and religious views.

The acknowledgment of the role of the support administrator in the reconstruction of the wishes of the patient is in line with these judgments: this activity may be made easier by the situation whereby the beneficiary, in the past, expressly declared his consent or otherwise to specific therapeutic treatments, yet the administrator may also be assigned the task of communicating the presumed wish of the beneficiary, where the latter is actually unable to do so personally, in cases where the lifestyle, the personality and the ethical, religious, cultural and philosophical convictions of the beneficiary suggest the direction that the beneficiary would have chosen with regard to an individual choice of care.

Others, in contrast, point out that the validity of any advance health care directives that appear in the act of designation would be subject to the sensitivity of the probate judge and therefore the support administrator, and call into question whether such indications communicated by the patient constitute a legal commitment on the part of the support administrator who, in reality, is merely required to abide by the powers and the duties indicated, first and foremost, in the provision of the probate judge that assigns him the role — and it is not certain that the judge will reproduce, in the provision, the wishes of the patient.

Others also point out that the possible designation in advance of a support administrator by the individual concerned, albeit widened in its content with the possible concurrent communication of advance health care directives, is not equal in effect to a living will: support administration can be considered a complementary mechanism, but not a substitute for a living will.

According to a number of authors, the recognition of support administration as the most appropriate mechanism for the expression of advance health care directives by means of the procedures that have been mentioned may even end up depriving any form of advance directive of its value and sanctions the principle of judicialisation of a procedure to exercise self-determination in health matters, making a jurisdictional phase necessary in order to render effective a right which is already regulated under Italian legal system and ultimately implying that the perfect agreement between the powers of the administrator and the advance directives of the beneficiary ends up depriving one of the two instruments of any meaning: either the former is superfluous or the latter is ineffective. Although these authors therefore call into question the a priori, and across-the-board usefulness of the intervention of the support administrator between healthcare staff and the patient (whose wishes are already stated in his advance health care directives), they do not exclude the possibility that in cases where new scientific discoveries, on-going experiments or new prospects yet unknown and therefore not envisaged by the beneficiary in his choice, render these directives inapplicable, it might therefore be useful with a view to taking the best care of the patients’ interests to appoint a support administrator who can contribute to build anew his wishes in his relationship with attending practitioners and to identify the treatments to be performed; an appointment which is not to be made in advance, but only at a time when conditions arise which render topical the usefulness of the appointment of the support administrator.

Even in relation to this scenario, the Court of Genoa, holding an
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Even in Italy there is a need to address the issue of ownership and the criteria for deciding when the patient becomes incompetent, in compliance with fundamental ethical principles of respect for autonomy and beneficence: advance care directives can serve to enhance patient’s autonomy but, beyond respect for autonomy... advance directives may also contribute to the patient’s good... indeed, by means of advance directives, patients are entitled to refuse treatments when they consider that they would be more harmful than helpful.

This need is clearly present also in Recommendation of the Council of Europe’s Committee of Ministers 2009 (11) on principles concerning continuing powers of attorney and advance directives for incapacity that aims to promote self-determination for capable adults in the event of their future incapacity, by means of continuing powers of attorney and advance directives (Principle 1, Promotion of self-determination) and that provides that the attorney, as far as possible, informs and consults the granter on an on-going basis. The attorney, as far as possible, ascertains and takes account of the past and present wishes and feeling of the granter and gives them due respect.

Although it emerges from recent jurisprudence that it is possible to find in Italian legal system the prerequisites and the instruments required for the recognition of previously expressed wishes, even by means of the mechanism of support administration, there are some authors, who, while acknowledging that there is no lacuna in absolute terms from a legislative point of view, do not exclude the appropriateness of a legislative intervention that would establish a connection with the mechanism for support administration by setting out the formal, substantive requirements for these advance manifestations of wishes to be valid and identifying the subject who is legally obliged to interact with healthcare staff so as to respect the wishes of the individual concerned.

Acknowledgement, therefore, of the possibility of enhancing the value of the system of support administration by means of a mechanism based on a prior nomination in terms of the implementation of earlier decisions regarding treatment, does not exclude the fact that it is preferable to lay down a systematic discipline on the subject which guarantees full implementation of the principle of self-determination in the field of health care, particularly in the light of the imperfect overlap between the institution in question and the so-called living will. For some authors, even the need for the directives and for the designation of a fiduciary to be conveyed in a notarial act or in a stronger form seems inappropriate: the absence of directives regarding property and assets, the connection with the sphere of very personal rights and the fact that the directives can be revoked or modified at any time result surely in unfair burdensome formalities, making it seem preferable that these directives are grouped in an original and signed statement or declared by word of mouth to the health care staff and put in writing by them. An ad hoc regulatory framework, as wished for by many, for advance health care directives, may therefore take its place in the legal system, while being assimilated within existing principles, regulations and institutions, and providing an element of certainty for the healthcare staff involved as well as a certified guarantee of the more strongly felt focus on the protection of the complete individual and on respect for his wishes.

Conclusions

The enhancement of patient autonomy, and the growing developments in medical treatments and technologies, which may allow physical survival for years, but which, in some circumstances, could be no longer of real benefit for the patient, and becoming futile, explain why the debate about advance care directives has become increasingly important in most European countries during the last few years.

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