Advance directives in capacity-affecting diseases: The medico-legal perspective

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Abstract. Advanced directives (ADs) and the activation of additional instruments of legal representation in health, in various neuropsychiatric and geriatric settings, nowadays are the tools to support the entitled subject decision-making in healthcare. However, even after Italian Law n. 219/2017 on informed consent and advanced treatment directives, many controversial aspects remain with respect to the entitled subject's autonomy and thus to the full application of the law. The temporal dissonance between care planning and health intervention was one of the main cons, while the entitled subject reference compared to caregivers and practitioners was the main pro. In terms of practical application, the lack of knowledge and practice of ADs by citizens on the one hand, and the poor reference and valorisation to ADs by healthcare professionals on the other, were discussed. No less the frequent reference by the healthcare practitioners to the family members or surrogates in the health choices for the subjects with neuro-psychiatric diseases, or in geriatric setting, results critical, in particular when deviating from settled ADs. Furthermore, the figure of the trustee, as a simple reference for the ADs, is compared to the function of the health guardian, endowed with specific powers of representation; the latter often belatedly and improperly involved in health choices. Some insights from daily consulting activities are proposed for clinical practice, particularly with respect to contingent choices, while highlighting the need to use the appropriate tools provided by law. The regularly updated ADs together with the health guardian function, despite some limitations, fully respond to the need to guarantee clinically, legally, and ethically the entitled person's autonomy and the balancing of rights. (www.actabiomedica.it)

Key words: advance directives, shared care planning, law 219/2017, decision-making, informed consent, geriatric, neurologic disorders, psychiatry, dementia

Introduction

With regard to future incapacitating pathological conditions, and in the case of a chronic, progressively incapacitating pathology and/or with an unfavourable prognosis, there are some instruments that could support the informed choice of the subject: the Advance Directive (AD) in the first situation and the Shared Care Planning (SCP) in the second one, formalised in Italy by the Law n. 219 of

22 December 2017 (1,2). About these instruments, some critical issues are certainly the changing of the interests, the temporal discrepancy between regulated situation and regulatory act, and the poor flexibility. Even, their uniqueness as a means of translating the will and empowering the entitled person has also been emphasised, placing the autonomy of the person at the centre of the entire system (3,4). Like a testamentary will, despite having as its object non-patrimonial and non-disposable assets *par excellence*, the entitled person represents in codified form personal interests, certainly hypothetical, but derived from its own abstraction process. This focuses on an undoubtedly greater referability to the subject, if compared to the best interests inferred by family members, health professionals or even by the magistrate. The issue is that the capacity to self-determine and predetermine one's own health towards the advanced directives appears even more complicated than in the case of informed consent. In fact, there may be an exceptionally long or indefinite time between consciously given advanced directives and its implementation, when the person may be incompetent. Also, the choice is made without a real emotional experience background, neutrally prefiguring oneself in a hypothetical pathological situation, outlining in the future what the person currently wants about personal well-being (5,6). Meanwhile, the same pathological condition that leads the person to predispose ADs, and its influence over family and social *milieu*, may already influence the choice and/or decision-making ability (7). In certain pathological contexts, such as the neuro-psychiatric ones, and in the more nuanced contexts of residential homes for the elderly, the reference to these instruments to trace the subject's will in health choices would be even more imperative and would best enable respect for the dignity of the person. The purpose of this brief narrative review is to examine and critically discuss the context and the legal instruments for responding legitimately to these situations, with related complexities in the application of daily practice. Through discussion, particularly in these multi-layered pathological or frailty contexts, it is also possible to provide healthcare providers with some practical insights.

Contextualisation in pathological frameworks

Some authors have recently addressed the issue of self-determination in health according to Italian Law 219/2017 in subjects with dementia and psychiatric disorders by further investigating it from the perspective of the healthcare professional (8). The discussion focused on the heterogeneous impairment of will, judgement, and conscience, and thus the balancing of personal and social interests, to validly support health decision making, and the following complexity of practical application in the polymorphous neuropsychiatric field. The topic is also of interest in relation to other equally elusive and sensitive areas, such as the geriatric one, where one is often faced with an unclear nosographic framework, hence diagnosis and prognosis, but rather with a syndromic set of wide-ranging and *multidimensional* impairment, also and above all mental (9). Common, in fact, is the non-linear and changeable over time course, even with respect to a gradual decline in the long term, sometimes with extremely poor predictivity, high subjectivity, and multifactorial (10). Here, the complexity of the patient's calibrated health decision-making capacity, even of its eventual ascertainment, and then of its legal translation becomes apparent, together with ADs' greater changeability (11). In comparison with the same reference of testamentary practice or the subject's capacity assessments in UK and German system, often specifically with respect to the contingent purpose, we are faced with the diversity of the clinical assessment from the forensic one, also considering patient simulation, and therefore it is necessary a specific training of the assessor (12,13). It is therefore not only a matter of early diagnosis, which is more relevant in dementias or disorders with an unfavourable prognosis, even on genetic basis, but in general of the early provision of appropriate and full information and of legally recognised instruments both as procedures (AD and SCP) and as subjects involved (see the trustee to recall ADs or legal representatives for health) (14). When in fact the subject shows clear clinical-instrumental impairment of decision-making abilities, those instruments could make the overall health management easier, having predetermined a kind of outline of desired and undesired acts/treatments. Then, entitled subject's early ADs disclosure and drafting aimed precisely on favouring the subject's autonomy. Moreover, the presence of predetermined and illustrated options in the ADs in particularly complex cases of divergent interests would allow the tutelary judge to make an assessment based on clear references to the wishes of the entitled person (15). Those references are especially so in the welfare and residential care context, nursing homes, in territorial psychiatric care, and in palliative care where health management complexity is at its highest, looking at life-support treatments, nutrition, hydration, palliation and deep sedation, up to the extreme eventuality of assisted suicide, this latter in the absence of a specific regulation in Italy. Moreover, the function of the trustee with respect to the ADs is a reference subject, witnessing the documented interest of the subject, rather than of a legally authorised bearer of the interest *tout court*, nor the trustee could have a *creative* role further from ADs (16). It is in these areas in particular that the person expresses own wishes, which are also dictated by the social, health and family implications linked to the pathological condition, the future cognitive and/or volitional changes, and the disability. Preferences and choices that are legitimate and their formalisation in the ADs desirable as powered instruments for the person. Advanced directive allows for discussion with family members to reach a shared decision, for the appointment of a trustee to facilitate compliance, and for updates/amendments to reflect changes in the beneficiary's interests or therapeutic options.

Legal representativeness and legal value of advance directives

At first, it is relevant to compare the trustee linked with ADs to the function of guardianship for health purposes (17). The trustee is a mere reference for the registered ADs, not being authorised to legally represent the subject in case of new instances not included in ADs. On the contrary, the guardianship for health purposes validly supports the entitled subject in the decision-making, as being appointed by the Court. It should also be pointed out that this function is to integrate and support the choices of the entitled person, who for numerous factors may have difficulties in the information and decision-making process. Precisely because of its non-substitutive and representative nature, compare to those that ruled the subject partially or totally incompetent, it certainly and appropriately remains a limited function. And in the complexity of the pathological fields analysed, this limitation could be relevant and could explains why it is still too little practiced. First, the difficulty in the finding of those who perform the function -ending up appointing a lawyer for hundreds of subjects -, and the length of the appointment process, precisely because it is activated too late. Especially in geriatric settings and homes for the elderly, the health guardianship process is started when the need becomes so compelling, when the person is in no way capable of taking care of him/herself, with profoundly serious consequences from a legal and ethical point of view. In fact, it suggests a critical previous care and assistance compared with person's informed choices. More questionable, and disrespectful, is the only involvement of a family member by health providers to infer patients' best interests, as the interests are necessarily subjective (21,22). Moreover, the same mechanism of specific powers delegation to the health guardian for health needs, enumerating in a list those activities on which is authorised, tends to be stiff. Then, the function of the health guardian could be combined with what is formalised and regularly updated in the ADs and, despite the rigidities described, fully respond to the need to guarantee the autonomy of choice of the entitled person and to provide legitimate support. It is therefore necessary, first of all, to anticipate the information phase, when the subject could have a better awareness, willingness and understanding, and to use these tools, which are not yet well explored and known by health professionals (18–20). The use of simple description by practitioners of family members information in clinical records, without the clear specification on entitled subject involvement, the signature by the entitled subject, the disclosure of what risks have been explained, and which comments have been made, result as far critical. It becomes necessary to adhere to the standard, taking care to train people on how to use these instruments, based first on timely and unbiased information on future health needs, on which the choice must be long matured. Subsequently, educate healthcare professionals on asking whether there are any provisions and further on the legal value of the entitled subject directives, as binding wills, but also as the absolute reference of personal autonomy (23). The archive of registered ADs is, moreover, easily accessible to the clinician via digital identity on the Health Ministry gateway. On a par with a testamentary deed, advanced directives are formalised acts, and they are recognized as public deeds if performed with a notary, so representing a strong bind. Disregarding them appears extremely problematic, unless they take over obvious inconsistencies, variations or in the case of new care options not previously foreseen (24). Thereby, to assert *a priori*, even in the light of the document type, that they are not mandatory, does not agree with us (25). And over these dispositions, family members or health providers have no typical legal power for variations. Finally, anticipating judicial practices for the appointment of the health guardianship that can validly and more widely support and represent the subject's best interests and all interests at stake is advisable, compared to the simple referencing role of the trustee, certainly with the involvement of the caregivers. Here, it is not a question of judicializing health choices, but of more broadly guaranteeing respect for the entitled subject, which necessarily lays on lawful representation. The topic could also be observed in a negative way, i.e. in case of disregarded ADs, especially by health professionals, and in comparison, with breach of informed consent, on which there is also more experience and casuistry. With respect to a complaint of violated informed consent, the patient/user is required to attach and prove the alternative will and the plausible consequences of informing and consenting differently (26). Instead, the burden would be on the health care provider to demonstrate the licit reason for the deviation in the face of a defined will and reference for future health care decisions in the ADs.

Ad hoc clinical assessment of capacity

In the same situation of elderly persons or persons with known pathologies affecting their decision-making capacity, the comparison with the notarial pathway in case of the deed of will, may be fruitful. In fact, if the notary observes and/or appreciates certain outward manifestations in the testator that might suggest a condition of incapacity, usually requires an evaluation over mental capacity, to rule out challenges with the validity of the act. Then, in case of psychiatric, neurological, and/or geriatric diseases, in the absence of legally authorised figures and/or advance directives, a similar *point* assessment may be feasible and reasonable to prove the capacity, both in nursing homes and hospitals, thus providing a reference to the health professional (27). This assessment can be conducted by adequately trained physicians like neurologists/psychiatrics or geriatricians, to ensure a better understanding of the subject's needs and better protection of interests at stake. In detail, a brief clinical assessment, with the support of some means already used for clinical and forensic purposes (Mini-Mental State Examination, MacArthur Competence Assessment Tool, etc), could be an option to define decision-making capacity in the *hic et nunc* and on the specific treatment/act (28,29). See the case of choosing on parenteral nutrition, diagnostic or therapeutic invasive procedures, implantation of permanent devices, transfusions, off-label drugs. Emergency situations, considering the life-threatening ones, are exceptions because healthcare provider intervention is required to safeguard the subject, obviously if there are no ADs, otherwise again indication in the subject ADs for emergency situations, e.g. avoiding life-support equipment, remains binding (30).

Conclusion

The arrangement of AD and the initiation also of additional instruments of legal representation such as health guardianship, in various neuro-psychiatric and geriatric settings, to date meet the need for legal and ethical rigorousness in health choices. A *point* clinical assessment of the entitled subject decision-making in those settings could be a viable mechanism to support his/her *specific* choice in health, even encouraging proper representative instruments. Today, the question of accurate and widespread information to health professionals and citizens on the function and value of advance treatment directives remains open. Doctrinal discussion can be useful to support education and information campaigns at various levels and in various social contexts, to promote their conscious use.

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