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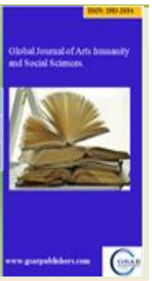

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Advance Care Planning: Timing and Person's Decision-Making Capacity

By

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Abstract
The Authors, after clarifying the difference between advance care planning (ACP) and advance treatment directives (ATD), go into the merits of the ACP timeline by discussing two topical situations: the timing of its start and the evaluation of the decision-making capacity of the person affected by mild dementia. Although there is no good quality guideline of ACP accredited at international level, the Authors suggest the need of trialing new approaches to ACP with a personalized timeline, while respecting some recommendations relating to its starting point.

KEYWORDS: advance (shared) care planning (ACP or SCP), treatment directives, dementia, timing, decision-making capacity, decision support.

Introduction

Although quite simple in terms of its legal framework, the topic under discussion here is an extraordinarily complex subject, especially in the setting of psychogeriatric care. The OECD Report *'Care Needed: Improving the Lives of People With Dementia'* (2018) [1] highlighted the insufficient access to palliative care for people with dementia in all OECD countries, and how advance treatment directives (ATD) still represent a little-used tool [2] that only reaches 4% of patients in England and 2% in Wales. Conversely, in New Zealand, all people followed with a home care plan are informed of the existence of this new opportunity [2]. Even if interest in this recent new frontier of care is increasing [3], as highlighted by recent literature and as confirmed by the recommendations provided by 107 experts from a 33 countries taskforce nominated by The European Association for Palliative Care (EAPC) [4], despite "[…] our text analysis denoted a wide range of research and policy gaps in ACP for people with dementia" [4]. This might happen for a whole series of reasons: because advance care planning (hereinafter ACP) renews and exacerbates the discussion on the scope of individual self-determination, on the myth of rational autonomy, on its cognitive (rational and affective) presuppositions, on the professional duties of the doctor and, more generally, on the re-establishment of the fundamentals of care after the decline of medical paternalism. Today, it should be evident to everyone that the extraordinary success of informed consent has not resolved either the asymmetries or the decisional solitudes that emerge every time a difficult clinical decision must be taken, and every time the different moral perspectives of modern multiculturalism come into conflict. For example, despite Italy has given full recognition to the ACP, difficulties, doubts, concerns and suspicions continue to persist in the professional world, with the consequence that this clinical practice is substantially underused, especially in the setting of psychogeriatric care, as it is also the case at the international level [5].

Advance Treatment Directives (DAT) and Advance Care Planning (ACP): Legal Framework

The legal framework of advance treatment declarations (DAT) and advance care planning (ACP) is relatively simple [6]: in Italy, articles 4 and 5 of Law no. 219/2017 (*'Rules on informed consent* *and advance treatment directives'*) recognize them, indicating, for the latter, the possibility of using it in the event that the person is affected by "a chronic and disabling pathology or one characterized by unstoppable evolution with an inauspicious prognosis", so as to constrain the actions of the doctor and the healthcare team to comply with it if the patient finds himself in a condition of not being able to express his consent or in a condition of incapacity". In any case, before starting the process of formalizing the ACP, the law provides that the patient must be preliminarily informed "on the possible evolution of the current pathology" and on what "he can realistically expect in terms of quality of life, on the clinical possibilities of intervention and on palliative care" in order to express "his consent with respect to what the doctor proposes [...] and his intentions for the future". This can be done either in writing (documenting the person's will in the medical record) or, if the person's physical conditions do not allow it, through video recording or the use of devices that allow the person to communicate his will. Even when formalized, the ACP can be reviewed and updated in relation to "the progressive evolution of the disease, at the request of the patient or at the suggestion of the doctor", with the opportunity to also indicate a trustee, that is, the person chosen directly by the interested party without particular bureaucratic formalities, provided that he or she is of age and capable of understanding and willing, with the task of mediating, interpreting, updating and realizing the desires, preferences and wishes of the suffering person. This is how the ACP, like the DAT, represents the logical extension of the principle of informed consent which finds its legal foundation in articles 2, 13 and 32 of the Italian Constitution, conditioning the actions of the doctor who cannot implement the ACP without the knowledge of the patient, who is however recognized as having the right to refuse it and/or modify it in all phases of life, even in the terminal phase. The binding nature of both the DAT and the ACP is not, however, absolute but relative because the Italian law provides for the possibility of disregarding them "in whole or in part, by the doctor himself, in agreement with the trustee, if they appear clearly incongruous or do not correspond to the current clinical condition of the patient or if there are therapies that were not foreseeable at the time of signing, capable of offering concrete possibilities of improving living conditions" (art. 4, paragraph 5).

Some coincidental opportunities to renew the debate, not only in Italy …

In Italy, three types of coincidence have motivated us to address the issue of ACP in the setting of psychogeriatric care: (a) the guidelines (GL) '*Diagnosis and treatment of dementia and Mild Cognitive Impairment*' approved in 2024 by the *Istituto Superiore di Sanità* (National Institute of health); (b) the joint document approved in 2024 by the Italian Society of Geriatrics and Gerontology (SIGG) and the Italian Society of Palliative Care (SICP) on the end of life of older adults in residential health care facilities; and, (c) the clinical trial that is currently being carried out in residential facilities of two Italian regions to (essentially) introduce a new tool (the MacCAT-T), aimed at standardizing the robustness of the decision in patients with mild-moderate dementia.

The GL approved by the Italian National Institute of Health is a document of over 500 pages. For what concerns us, it is Question 10 ('*Involvement of the person with dementia in the decision-making process*'), the part of the GL that must be examined to understand if and which operational recommendations have been concretely provided regarding the ACP. The GL discusses it at length from page 187 to page 196 with evident inaccuracies that are not only lexical and incomprehensible gaps: the technical terminology to which the GL refers is not precise and appropriate because the advance treatment directives (DAT) and the advance care planning (ACP) are different and non-overlapping legal categories. The GL say nothing about the timing of the ACP, the methods of access to this process and the chain of responsibility that it requires, although they admit that "*the collection of advance treatment directives should be as transparent and standardised as possible in order to maximise their level of sharing*"; all this with the aim of "*ensuring that the wishes of the person with dementia can be understood by all those who will have to take them into account*".

The weak argumentative development is then followed by some recommendations: the Recommendation n. 61 invites clinicians to offer people with dementia the opportunity to express, in their advance directives, their personal wishes, preferences, opinions/beliefs and values regarding their future care and any refusals; the Recommendation n. 62, which invites clinicians themselves to explain to the person with dementia that they will have the opportunity to review and modify the decisions made; and the Recommendation n. 63, which encourages professionals to offer at each check-up the opportunity to modify and review any decision previously made. The general impression that one gets is that the topic has been treated with a good dose of superficiality, by formulating some generic recommendations of little practical impact.

The Joint Document approved by SIGG and SICP on the end of life of older adults in residential care is much more detailed. The topic is addressed in Paragraph 3 of this Document ('*Shared care planning to improve end-of-life care*') where it is recalled that ACP has a strong ethical-legal and deontological basis respecting the right of the persons to be listened to and involved, to receive all the information that concerns them, to not give up their choices even in the final phase of existence, to self-determine, to have the people close to them put in the condition to be able to assist them in the best way and to choose the most appropriate place and context of care. Then to indicate the Format of ACP and the guidelines dictated by the European Association for Palliative Care (EAPC) in 2017, while admitting that it is a dynamic and personalized process, which struggles to be forced into the general rules of standardization that often trivialize complexity. A non-simple process that "contains some dimensions of complexity" starting from the "need to outline and trace the patient's values regarding the good of health" and "to express in an understandable way and clearly trace the diagnostic paths and treatments for each individual health objective and their alternatives” with all the risk-benefit profiles of the different treatment options.

Then, the ACP is not a single act but a dynamic and personalized process that, starting from the reference values of the person, requires mutual respectful recognition, the construction of shared meanings, adequate times and spaces and the sharing of autonomy and individual responsibilities: not only the legal ones but, above all, the human and moral ones. ACP presupposes the choice of the start and its timing. On this issue the Joint Document does not say much, leaving the criteria for the choice of the start undetermined (it must be said that there is no unanimous consensus on a scientific level on this issue).

In line with the SIGG-SICP Joint Document, a trial is being conducted in two Italian Regions (Veneto and Trentino-Alto Adige) to test the decision-making robustness of demented people hospitalized in 11 residential care institutions regarding life-saving treatments. Older adults eligible for this trial are demented people with an MMSE score between 17 and 23/30, with respect to whom, using the MacCat-T, the decision-making competence regarding the possible initiation of artificial nutrition for the correction of dysphagia will be assessed. The study enrols people with dementia who may already be incapable [7]: the MMSE is not, in fact, a validated psychometric test to measure a person's ability to make a free and conscious decision [8]. Then, it could happen that incompetent people are enrolled to express their will regarding possible treatments… We will see what the results of this experiment will be in a near future.

Timeline of shared care planning (ACP): operational indications for its start and for the evaluation of the person's decision-making capacity

As all scientific evidence confirms, ACP is a powerful tool that can and should be used in all care settings [9], despite its widespread underuse in the cohort of demented people [10] especially because cognitive decline is often considered a (prejudicial) barrier to starting ACP [11]. Berrio and Levesque [12] have provided a long list of factors that can interfere with the quality of the ACP process in its clinical use; Harrison Dening [13], more recently, has expanded it to include the incurability of the disease, the interferences exerted by the progressive impairment, the poor knowledge on the trajectory of the cognitive disorder, the lack of confidence of clinicians in the validity of the tool, their poor preparation and the failure to identify a case manager capable of taking charge of the needs of the person and his family in the different phases of the disease. Nonetheless, it is beyond question that the ACP is a tool that guarantees good quality of care even in the psychogeriatric setting as long as its use is personalized, flexible, pragmatic and as much as possible adapted to the situation and context of the person [14]. For all these reasons, dementia should be considered part of the public health agenda in all countries [15], with a holistic approach that must start from the moment of diagnosis until the end of life [16]. Although there is not yet a good quality guideline tested in clinical practice [11], there are many suggested recommendations that should be followed in the ACP when the person is affected by dementia [17]. Our reflection will focus on two complex and still debated issues: when to start the ACP and how to evaluate the person's decision-making capacity.

The start of the process is a very delicate moment regarding which there are different opinions, with some even suggesting starting it before the diagnosis or any cognitive decline [18]. This idea does not convince us because planning our future treatment decisions in advance, when we do not yet know what disease we might be affected by, and what its trajectory would be, runs the risk of outlining hypothetical and not always real scenarios. Certainly, it is of fundamental importance to know whether the person, before the diagnosis, has or has not formalized his or her possible treatment decisions to begin dealing with his or her biographical structure and reference values. In our view, the start of the ACP should be subsequent to the communication of the clinical diagnosis, keeping in mind that the person can always refuse it, with the possibility of delegating others to receive it [19]. If the person does not want to know, it is useless to think about ACP, having to accept the idea that adaptation to any disease always requires a period, which is difficult to standardize because it varies from person to person. This phase of adaptation requires always being accompanied by the clinician who must know what its phases are, and the ways in which it can be dealt with them. Once the diagnosis has been communicated in truthful terms but without interrupting hope, especially in the case of dementia, it is necessary, right from the start, to make a strong alliance with the person and their family members, because the incurability of the disease is not synonymous of absence of therapies if the goal is to slow down the progression of the cognitive deficit: promoting and supporting the patient's compliance is always an unavoidable need, as confirmed by all scientific evidences [20]. Already at this stage, it is good practice to ask the person to indicate their trustee, that is, the person they trust who will accompany them along the path of the disease, supporting them in making their decisions; of this appointment, which by Italian law does not have to comply with particular bureaucratic formalities other than its acceptance, it is always good practice to give formal confirmation in the clinical documentation. As a rule, the demented person never asks to begin the process aimed at formalizing the ACP which must be promoted by those responsible for the care without any rush but without running the risk of having to deal with the cognitive decline and the subsequent incapacity of the person. Among the most dangerous obstacles that can negatively affect the quality of the process, the lack of awareness of the natural trajectory of the disease [21], the concerns about the person's ability to engage in ACP [22] and those regarding the time for a good quality conversation [23], and – finally - believing in the absence of an actual benefit perceived by the person with dementia [24]. The linearity of the ACP timeline is thus influenced by many variables, including the experience of healthcare professionals, their attitude towards the progression of the dementia process, the relationship of trust with patients, cultural differences (in China talking about death is still a taboo, unlike in European countries) and economic inequalities [25]. In any case, the approach must be as personalized as possible and must be based on the real situation of the patient and his context, always keeping in mind that the linearity of cognitive decline is presumed and not always predictable. In this field, haste is always a bad advisor since life expectancy is not short, as documented by the most recent scientific evidence: in men from 5.7 to 2.2 years and in women from 8 to 4.5 years, respectively if under-65 or over-85 [26]. The timing of the start of ACP is thus a difficult choice that cannot be trivialized by anticipating it too much or postponing it without reason with the risk of having to deal with the person's subsequent inability to make their decision. A precise rule does not exist, nor can it be otherwise because ACP is a personalized, fluid and dynamic process, which aims to explore, document and share a person's preferences on their care decisions when they will no longer be able to express their choices freely and above all consciously [27]. Since there is no consensus on when is actually the best time to start ACP, finding a balance between early diagnosis and the degree of cognitive impairment is often a complex issue. Our recommendation is to always start ACP after communicating the diagnosis, and after the person has been described the trajectory of the disease, including what can really be expected from the proposed treatment and what the future care needs may be, eventually requiring the implementation of life-saving treatments that the person will no longer be able to accept/refuse.

There is also no international agreement on the professional called to activate the ACP: some evidence suggests that it should be the family doctor for his constant interaction with patients and their families; others indicate the nurse as the most suitable professional to lead these discussions; others identify it in the specialist doctor in charge of the person. Personally, we are inclined to support the latter option, which must always be implemented by involving the person's family doctor to ensure the continuity and coherence of the communication process [28].

The start of the ACP is however always conditioned by the decision-making capacity (hereinafter DMC) [29] of the person, which could be interfered by the cognitive deficit, even if the person affected by dementia must never be considered and treated as incapable. A good rule is to assume the full mental capacity of the person [30], to accept that dementia is always a fluctuating condition [31] and to recognize that, when explored, this should be done with regard to a particular task, and not in general terms [32]. At the international level, there has been much discussion about the need to explore it with a neuropsychological test using available tools such as the MacArthur Competence Assessment Tool, the Vignette method [33] or the flow chart guide by Church et al. [34]. Our idea is that the test evaluation of the DMC should be limited to situations of doubt, especially when there is disagreement between health professionals and/or the person's family members or when decisions can have serious consequences for the person's life. A good rule is to subject it to do this examination in the case of a therapeutic refusal, as almost always happens, but also in other circumstances, keeping in mind that cognitive deficits often limit the ability to understand, retain and weigh the different treatment options [35], and those fluctuations in attention and memory that exist in all forms of dementia [36]. This does not mean admitting or taking for granted that the diagnosis of dementia always makes the person incapable of making a free and conscious decision [37]: this is an unfortunately widespread ageist stigma that must be countered. The theoretical aspects of DMC and the tools for its evaluation have been widely studied thanks to the MacArthur network [38] and the studies of Marson et al. [39] on the ability of people with Alzheimer Disease to consent to the treatment plan. Assuming that the evaluation of DMC only pertains to the clinical domain, what is still missing in this field is a shared system for its standardization along that continuum that fits into the classic dimensions of understanding, appreciating, ability to choose and reasoning. Even admitting that capacity at a certain point migrates into incapacity, DMC is never a fixed point because there is not always a clear line of demarcation capable of distinguishing people with full capacity from those who have definitively lost it [40]. This approach is, in fact, dangerous as it can lead to under- or over-protection of individuals with reduced capacity (individuals with *marginal capacity* [41]) who must always be offered support in the decision. However, even the most qualified evaluation standards do not consider or underestimate all those ‘other’ aspects (emotional and affective) that have their regulatory centre in the subcortical structures. In fact, every human choice is not the result of cortical structures alone, since the effects (inhibitory and/or activating) of perceptive, semantic and conceptual stimuli [42] and the role played by emotions in decision making have long been known [43]. Research confirms, in fact, that emotions are a powerful and pervasive engine of judgment and decision-making processes, since it is now admitted that they are able to influence risky decisions [43], reduce cognitive fixation [44] and improve attention [45]. On the contrary, when decisions produce a conflict or a feeling of anger, emotions can compromise cognitive processing, since it is recognized that emotional discomfort can lead us to reformulate difficult problems through the shift in coherence [46]. Discussing the growing recognition of the role of emotions in the decision-making process, Keltner and Lerner proposed a model of choice supporting the idea that emotions improve or worsen judgment, observing that the decision-making process depends on the interaction between cognitive mechanisms and motivational aspects that cannot be ignored in every clinical situation, especially in dementia [47].

Conclusions

Although there is still no good quality guideline validated at international level for ACP, there are some useful recommendations that can be used in clinical practice. Our discussion focused on two of them: when it is appropriate to start the process and how the person's ability to make a free and informed decision can be assessed. What we have repeatedly emphasized is that ACP is not an act but a dynamic and prospective process that must be personalized as much as possible in relation to the person's situation; it thus escapes the general principles of standardization that, very often, run the risk of trivializing complexity. We must believe in the positive effects of ACP and invest, even if randomized clinical studies are needed to better support the results [48]. This must be done by considering the end of life of each person as an integral and constituent part of the care relationship, without resorting to improper delegations that dry up responsibilities: especially those of an ethical and human nature that are not a corollary but the main aspect of the care relationship, even (perhaps especially) in the field of dementia.

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