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'Too late or too soon': The ethics of advance care planning in dementia setting

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# **“Too late or too soon”: the ethics of advance care planning in dementia setting**

**Marta Perin, Luca Ghirotto, Ludovica De Panfilis**

## **ABSTRACT**

Advance care planning (ACP) is considered a pivotal aid in the decision-making process, especially for many people living with dementia, who inevitably will lose the capacity to make decisions at the End of Life. In Italy, ACP has been recently regulated by Law 219/2017, leading to the investigation of how physicians deal with ACP in dementia. In order to comprehend the perception of physicians who provide care for patients with dementia regarding ACP and to describe their difficulties and needs, this study presents the results of a qualitative research performed within a Local Health Authority in northern Italy. Data were collected by semi-structured interviews with 11 physicians dealing with patients with dementia and were analyzed using Interpretative Phenomenological Analysis. Four superordinate themes were identified, describing both the difficulties and challenges perceived by physicians in performing a shared ACP in their daily activities. This study proves that physicians experience the difficulty to synchronize the times required by shared ACP with more rapid development of dementia. Results also suggest that further trainings about communication on ACP are urgently required to ease the implementation of shared ACP. A broader involvement of institutions and other professionals is also important in spreading ACP among healthcare institutions.

## **Keywords**

Advance Care Planning, Dementia, Physician, End of Life Care, Decision-making Process

## BACKGROUND

Due to the exponential increasing worldwide number of people living with dementia, the ethical aspect related to the healthcare assistance in dementia setting are becoming a central priority of global public health.<sup>1</sup>

Regarding rights, the autonomy and dignity of the person in the management of End of Life treatment choices, such as, among others, decisions regarding artificial nutrition, location of care, and provision of palliative care, are usually challenging topics for both patients and physicians, becoming even more complex in dementia context for two main reason. First, dementia quickly affects a patient's cognitive skills, substantially reducing his/her continuous and active participation in the decision-making process about present and future healthcare treatment.<sup>2,3</sup> Second, the terminal stage of dementia is not always easy to identify,<sup>4</sup> and consequently patient with dementia are at the highest risk to receive suboptimal care at the End of Life, including overly aggressive treatments, low palliative care referrals, and poor pain and symptom management.<sup>5</sup>

In this regard, Advance Care Planning (ACP) with these patients has been proven to be a pivotal aid in the decision-making process,<sup>6</sup> ensuring that the patient's medical care is

<sup>1</sup> World Health Organization and Alzheimer's Disease International. (2012), Dementia: a public health priority, Retrieved from: [https://www.who.int/mental\\_health/publications/dementia\\_report\\_2012/en/](https://www.who.int/mental_health/publications/dementia_report_2012/en/).

<sup>2</sup> Defanti, C., Tiezzi, A., Gasparini, M., Congedo, M., Tiraboschi, P., Tarquini, and then '...' Primavera, A. (2007). Bioethics and Palliative Care in Neurology Study Group of the Italian Society of Neurology (2007): Ethical questions in the treatment of subjects with dementia. Part I. Respecting autonomy: awareness, competence and behavioural disorders. *Neurol Sci.* 2007, 28(4), pp. 216-31.

<sup>3</sup> Fetherston, A.A., Rowley, G., & Allan, C.L. (2018). Challenges in end-of-life dementia care. *Evidence-Based Mental Health*, Volume 21, pp.107-111.

<sup>4</sup> Tjia, J., Dharmawardene, M., & Givens, J.L. (2018). Advance Directives among Nursing Home resident with mild, Moderate and Advanced Dementia. *J Palliat Med*, Jan;21(1), pp. 16-21.

<sup>5</sup> Lichtner, V., Dowding, D., Allcock, N., Keady, J., Sampson, E.L., Briggs, and then '...' Closs, S.J. (2016). The assessment and management of pain in patients with dementia in hospital settings: a multi-case exploratory study from a decision making perspective. *BMC Health Serv Res*, Aug 24; 16(1), p. 427.

<sup>6</sup> World Health Organization. (2018). Towards a dementia plan: a WHO guide. Geneva: Retrieved from: <https://apps.who.int/iris/bitstream/handle/10665/272642/9789241514132-ng.pdf?sequence=1&isAllowed=y>.

adjusted with the patients' values and goals discussed in advance, including specific medical treatments, and individualized medical treatment plans especially at, but not limited to, the End of Life.

ACP has been defined as a continuous process that should change with a patient's mutable health states, becoming more specific about medical care and treatment preferences when needed.<sup>7</sup> ACP might end with Advance Directives (ADs), a written document drafted by a competent person allowing a person to express his/her wishes about medical treatment at the End of Life after the person becomes incompetent. Although ADs are widely considered a useful tool to respect patient's values and preferences,<sup>8,9,10</sup> an increasing number of studies has shown that completion of ADs alone does not decrease the stress of surrogates' decision-making, prevent conflicts, or prepare patients to identify and share their values to surrogates and physicians. On the contrary, has been proved that a specific ACP activity beyond ADs may better prepare patients and their surrogate, even if it is still particularly challenging, especially for patients' care givers and physicians also in dementia setting.<sup>11,12</sup>

The 219/2017 Italian Law on Informed Consent, Advance directives and Advance Care Planning legally recognizing the value of a shared decision-making process for a

<sup>7</sup> Sudore, R.L., Lum, H.D., You, J.J., Hanson, L.C., Meier, D.E., Pantilat, S.Z., and then '...' Heyland D.K. (2017). Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. *J Pain Symptom Manage*, May;53(5), pp. 821-832.

<sup>8</sup> McMahan, R.D., Knight, S.J., Fried, T.R., & Sudore R.L. (2013). Advance Care Planning Beyond Advance Directives: Perspectives from Patients and Surrogates. *J Pain Symptom Manage*. 2013 Sep;46(3), pp. 355-65.

<sup>9</sup> Porteri, C. (2018). Advance directives as a tool to respect patient's values and preferences: discussion on the case of Alzheimer's disease. *BMC Med Ethics*. 19(1), 9, pp.2-8.

<sup>10</sup> DeLima, T.J., Sanchez-Reilly, S., Bernacki, R., O'Neill, L., Morrison, L.J., Kapo, J., Periyakoil, V.S., & Carey, E.C. (2018). Advance care planning in cognitively impaired older adults. *J Am Geriatr Soc*, 66(8), pp. 1469-1474.

<sup>11</sup> Vandervoort, A., Houttekier, D., Vander Stichele, R., van der Steen, J.T., & Van den Block L. (2014). Quality of Dying in Nursing Home Residents Dying with Dementia: Does Advanced Care Planning Matter? A Nationwide Postmortem Study. *PLoS One*. 9(3), pp.1-8.

<sup>12</sup> Sellars, M., Chung, O., Nolte, L., Tong, A., Pond, D., Fetherstonhaugh, D., McInerney, F., Sinclair, C., & Detering, K. M. (2019). Perspectives of people with dementia and carers on advance care planning and end-of-life care: A systematic review and thematic synthesis of qualitative studies. *Palliative Medicine*. 33(3), pp. 274-290.

chronic and debilitating pathology or a pathology characterized by an unstoppable evolution with a poor prognosis, such as dementia.<sup>13</sup>

In Italy, dementia affect approximately 600.000 people, becoming, since 2014, the fifth leading cause of death.<sup>14,15</sup> The perspective of Italian physicians about the implementation of ACP after 219/2017 law within dementia setting can add a broader understanding of their challenges and experience, to concur at enhancing the ACP and doctor-patient-surrogate relationship when difficult decisions have to be made.

For that reason, this study aims both to comprehend the perception of physicians who provide care for patients with dementia regarding ACP, as adopted by the Italian Law 219/2017, and to describe their difficulties and needs in implementing ACP for patients with dementia.

## METHODS

### Study design

We followed the Interpretative Phenomenological Analysis (IPA) methodological indications. According to Smith et al., IPA aims to explore how participants are making sense of their personal and social world. IPA can reveal the participants' lived experience along with their perceptions and understandings of a particular experience.<sup>16</sup>

The design is a phenomenologically oriented qualitative study through semi-structured

<sup>13</sup> Ciliberti, R., Gorini, I., Gazzaniga, V., De Stefano, F., & Gulino, M. (2018). The Italian law on informed consent and advance directives: New rules of conduct for the autonomy of doctors and patients in end-of-life care. *J Crit Care*, 48, pp. 178-182.

<sup>14</sup> Di Carlo A., Baldereschi, M., Amaducci, L., Lepore, V., Bracco, L., Maggi, S., and then '...' ILSA Working Group. (2002). Incidence of dementia, Alzheimer's disease, and vascular dementia in Italy. The ILSA Study. *J Am Geriatr Soc*, 50(1): pp. 41-8.

<sup>15</sup> Istat (2018), Report: *La salute mentale nelle varie fasi della vita, anni 2015-2017*, Accessed June 12, 2019 from <https://www.istat.it/it/archivio/219807>

<sup>16</sup> Smith, J.A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. SAGE 2009.

interviews. We followed the Criteria for Reporting Qualitative Research (COREQ) to communicate the research we conducted.<sup>17</sup>

### **Participants and setting**

We conducted the study at a provincial Local Health Authority in northern Italy 10 months after the entry into force of the Law 219/2017. It is the first Italian law on End of Life, and it was approved after fervent public and political debate lasting almost twenty years. It regulates not only advance directives but also several rights citizens have regarding healthcare issues, including the right to be fully informed, the right to withhold consent to lifesaving treatments, and the right to express preferences and wishes through advance care planning. To date, few studies investigated the Italian Law impact on the Italian medical culture. According to Maffoni et al.<sup>18</sup>, the law represents a useful instrument to guide healthcare professionals (HPs), and especially doctors, in carrying out the daily work, while safeguarding the patient from the caregiver's will.

We conveniently selected departments and services whose heads were already known by the researchers at the time of the study and where it was more likely that eligible participants were working. Research settings were the neurology, geriatrics, long-term care, physical and rehabilitative medicine and respiratory wards of the main provincial Hospital; the emergency department and palliative care unit, and the Centers for Cognitive Disorders and Dementia. As to purposeful sampling, participants had to have similar experience and meet the following inclusion criteria

- Being a practiced doctor (with at least 5 years of working experience);

<sup>17</sup> Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007, 19 (6), pp. 349 – 357.

<sup>18</sup> Maffoni M, Argentero P, Giorgi I, Giardini A. (2020) Healthcare professionals' perceptions about the Italian law on advance directives. *Nurs Ethics*, 27(3):796-808. doi:10.1177/0969733019878831.

- Having assisted dementia patients for at least 3 years before the Law went into effect;
- Caring for dementia patients at the time of the interview;
- Willing to participate and sign the informed consent.

The heads of each department or service were informed by LDP, the principal investigator (PI), on the objectives of the study. She then asked for collaboration which included recommending suitable participants.

After obtaining access to the field and the lists of possible HPs, the PI e-mails the information and requests for participation. The invited participants were then contacted by telephone by the PI who, after obtaining consent, agreed on the place and times for participating in the study. All participants provided signed informed consent.

The study was approved by the Ethics Committee of the Local Health Authority of Reggio Emilia (AVEN) (Protocol n° 2018/0124618, 09/11/2018).

### **Procedure/Data collection**

A topic guide for the semi-structured interview was developed by the PI and a member of the research team, MP. The PI is the head of the Bioethics unit, while MP holds a master's degree in Philosophical Sciences and was previously trained in qualitative research. At the time of the research project, she was a trainee at the Bioethics Unit of the Health Authority.

The main topics addressed were as follows:

- physicians' perceptions about difficulties in dealing with patients with dementia, with particular reference to the experiences of
  - communication of the diagnosis;
  - assisting the patients during advanced stages of illness;

- proposing the use of vital supports;
- sharing choices; and
- respecting patient's autonomy
- Physicians' perceptions about ACP, as established by the recent Italian Law 219/2017, with particular regard to its possibility to preserve the dignity of the patient in an advanced stage of incompetence.

We used open-ended, semi-structured interviews because of their flexible structure. We preplanned some exemplifying questions that are reported in Table 1.

MP conducted the semi-structured interviews at a place and time in agreement with the participants.

Field notes were also made during and after the interviews. No repeat interviews were carried out, and transcripts were not returned to the participants for comment or correction.

PLEASE INSERT HERE Table 1 – Interview topic guide

## **Data Analysis**

The interviews were audio-recorded and then were verbatim transcribed. According to IPA,<sup>19</sup> we followed these analytical stages: a) each transcript was extensively read by MP who conducted the interviews, before initial notes were made; b) the meaning units were first identified and associated with a subtheme by MP who then c) moved to the other interviews repeating the first analysis; d) super ordinate themes were finally identified by MP and corroborated through discussion among the authors (LDP and LG, head of the Qualitative Research Unit). Finally, MP with LG made the connections

<sup>19</sup> Smith, J.A., Flowers, P., & Larkin, M. op. cit. note 24.



between the different emerged themes by giving a representative sense of the participants' experience. Interviews were coded by MP, but no description of the coding tree and any specific software were used to manage the data. Participants also did not provide feedback on the findings.

## **RESULTS**

Not all the 19 heads of the selected wards and departments accepted to participate in the study. Particularly, we did not receive a reply from the respiratory ward while heads of the Physical and Rehabilitative Medicine department and Palliative Care Unit asserted that they have not managed patients with dementia for a long time. There was great interest from geriatricians attending the Centres for Cognitive Disorders and Dementia to participate in the study.

13 physicians were contacted, two of them refused to participate. The final sample consisted of two male and nine female physicians (mean age = 50 years): two palliative physicians, two neurologists, one geriatrician working in the long-term care department, and six geriatricians attending the Centre for Cognitive Disorders and Dementia. The interviews lasted a mean of 34' (range: 21' to 52'). We show the final sample characteristics in Table 2.

PLEASE INSERT HERE Table 2 – Participants' characteristics

Four themes (and related subthemes) presents an integrated picture of what the physicians experience regarding ACP:

1. Shaping the healthcare relationship in the dementia setting: moving with uncertainty and difficulties;
2. Role of family members in dementia care;
3. Ethics vs pragmatism: making the right decision at the right time;
4. What physicians need to improve ACP in the Italian context.

Those core themes entail subthemes that report the recurrent meanings our analysis identified. Themes and subthemes are summarized in Table 3.

PLEASE INSERT HERE Table 3 – Themes and subthemes

### **Shaping the healthcare relationship in the dementia setting: moving with uncertainty and difficulties**

Dealing with this kind of disease is not without difficulties. Dementia affects the patient-doctor healthcare relationship. This theme interprets the difficulties faced by the participants and how they manage the possibility to share an ACP with patients who quickly lose cognitive and relational skills.

#### *Struggling with the rapid loss of critical thinking*

Caring for a patient with dementia is a very problematic process to build and, mostly, maintain with the disease's development. Due to the progressive and rapid deterioration of the cognitive ability, critical thinking and judgment, participants identify the patient's needs as well as preferences over healthcare assistance as an increasingly more complicated process, especially regarding healthcare treatments at the End of Life:

*In my opinion, dementia is a very particular clinical setting compared to other pathologies where sharing decision can be a more straightforward process because, at least in the early stages, they do not affect patients' cognitive ability. I believe that, in the dementia setting, we have additional problems because, when a person has a deficit in his/her insight and do not have a proper consciousness of illness, this becomes a big obstacle for us. We have to move with much more uncertainty and with more difficulties (COD.4).*

Physicians are worried to arrive “too late” when it is no longer possible for them to directly share anything with the patients because their competences and functioning are already too impaired:

*The difficulty in dementia care can be that you realize the situation too late, and, therefore, when there is the diagnosis, the risk is that the patient is no longer capable of following a specific speech or of making competent choices (COD. 2).*

Again, due to the peculiar development of dementia, the anticipation of shared ACP in the initial phases of the disease, when the patient can still process and understand what they are talking about, is desirable:

*With our patients, we should do everything in the first moment in order to be sure they still can choose appropriately, because, as time passes, their ability to choose decreases (COD. 8).*

Additionally:

*If we could develop an ACP in the early stage of the disease (...), it would be an adequate response to improve care (COD. 5).*

*Emotional weight of an early discussion on future care treatments*

Discussing future treatments at the very beginning of the care path triggers emotional concerns. Participants find it difficult to start an ACP when the patients themselves do not require it:

*I find it challenging to identify a still competent patient with which to start such a speech. I do not know if it is due to my lack of preparation in the field, but I find it hard to. I have never had any patient who has covertly asked me, who has faced the problem before (COD.2).*

Participants are not prepared to face possible reactions the patients may express in front of an open discussion on dementia and its evolution. Feeling uncomfortable about this issue is a recurrent theme in the participants' experience:

*Telling a patient that dementia is going to end in this way seems to me something grievous. (...) These patients can live 10 years...how can I tell them that, after 10 years, they are going to die like this? (COD.8).*

This feeling increases when they have to deal with young patients or those who can still understand the critical consequence that dementia will have for them and their families. Moreover, physicians are worried that deciding too early about something that can happen many years later can call into question the validity of the precedent expressed will, when not periodically revised:

*This disease can last up to 8, 9 years, and, in the meanwhile, the patient's life changes. The problem is that, at a certain point, if you ask him again the same question, you do not know if the answer they give you is because they understood what you are asking or if their mind has changed but without relating it to any reason (COD.11).*

#### *Taking care of the fragility of the patient*

A mutual understanding between the patients and their professional caregivers, closeness and intimacy as well as continuity and constancy in the relationship are perceived as necessary aspects that should be considered to dissect sensitive matters implied in the shared ACP. Besides, a specific communication, based on sensitivity and empathy, as well as on the capacity to balance certain and uncertain information, is an essential aspect to take care of the fragility of the patient:

*We have to evaluate carefully, use much sensitivity, try to use a language selecting each time the topics, also choosing the opportune moments to introduce them... but the idea is to arrive to understand what the person wants for himself, to make that the path of care can be coherent with what the person expresses (COD.4).*

Additionally:

*It is the person in charge of the patient that must do this thing, no matter who he/she is. What matters is that he/she will be the one that's going to follow the patient, the one who is going to answer every time the patient needs something (COD.3).*

## **Role of family members in dementia care**

This theme collects participants' perception about family members and caregivers' involvement in the decision-making process. Family members and/or patient's caregivers are important, as well as problematic, in the decision-making process, especially at the End of Life.

The family members and patients' caregiver are a support for participants to take appropriate decisions:

*Planning and sharing a care path with a person who probably, after a few seconds, has already forgotten everything, is problematic. That is why I do this part of my work with the family member who brings the patient to the visit. This is a huge limit (COD.9).*

In a dementia setting, a family member is essential to piece together patients' past biography and previous will as well as desires if expressed:

*The role of the family, the role of the caregiver, is an inevitable reference for us (...) because he is often the guardian of patient's desire and indications that the person could express, even in a completely informal way, such as something they had discussed together (COD.4).*

Supporting family members in taking care of their loved ones is an essential part of patient's care that also makes the decision-making process at the End of Life more comfortable:

*If we establish a good relationship with caregivers, there are no particular problems. They must be supported a lot: if you decide to interrupt artificial nutrition or anything else, there must be a great relationship with them (COD.11).*

Anticipation regards here also involving family members from the initial stage of the ACP process to make decisions at the End of Life more manageable:

*In the advanced stage of the illness, it is almost a rule that the patients begin to eat less, so it is essential to talk about it with family members in time, let them understand that, eventually, the use of artificial nutrition is not indicated (COD.1).*

Nonetheless, involving family members is ambivalent as they may become an obstacle in making the most appropriate decision, especially when they ask for disproportionate intervention at the End of Life:

*When we arrived at the critical moment, the family members were not ready to let him go. I had to move the patient to the hospital, and my colleagues had to follow the family's decision, but without getting positive outcomes. (...) Although there was continuous communication, it was not enough structured in dedicated moments (COD.9).*

Provide family members with the right tools to understand who they must take care of is, therefore, essential. The alliance between physicians and family members is a valuable tool to promote ACP also in the dementia context, overcoming the hardness of a direct discussion between physicians and patients.

### **Ethics vs pragmatism: make the right decisions at the right time**

This theme underlines the aspects that structurally hinder the ethical meaning of a shared decision-making process with patients with dementia. The ethical issues especially raise from the communication of the diagnosis, interventions at the End of Life, and efficacy of ACP in the dementia context.

#### *Communication of the diagnosis: between prudence and paternalism*

Participants deem the diagnosis communication as one of the challenging aspects of the care. Three geriatricians working at the Centre for Dementia (who face the communication of diagnosis more directly and frequently than other professionals) and one neurologist described how communication of the diagnosis is often characterized by an ethical conflict regarding how and how much they should reveal to their patient about his/her clinical situation.

*The first difficulty is the communication of the diagnosis, which is an ethical right of the patient, and, yet, there is always that moral concern regarding how much the patient can understand the nuances that this diagnosis leads (COD.5).*

Participants identify two different situations that usually complicate the communication of the diagnosis: the first develops when the patient, already markedly declined, can no longer understand and reprocess the information (which is the most common situation):

*Patients who are already in a moderate-advanced phase of dementia can have important difficulties in understanding, (...) so they tend to forget what they are told,*



*and, therefore, they have less chance of reworking the information because a lot of information is already gone (COD.7).*

In the second case, the patient is still competent and can understand his/her situation, but he/she is afraid and confused. A challenge in understanding and respecting the patient's desire to not being informed also emerged. Participants assume a different attitude toward "truth-telling" about the communication of the diagnosis:

*I do not want to frighten him, because the patient does not even have the perception of time and put in front of him such a catastrophic future... (COD.9).*

Other participants live this moment with a more profound concern regarding the risk that endorsing patient's fears and family request about "do not tell the truth" finally hide a paternalistic attitude:

*Many times, there are situations in which, almost in the unsaid, the patient asks you not to be informed. He/she prefers to have a generalized communication like "there is some memory disorder" rather than being given the label. On the other hand, this colludes a bit with the paternalistic attitude of the doctor who, following this choice, puts himself in a condition of hegemony, managing the case (COD.5).*

#### *Looking for the right moment to intervene at the End of Life*

End of Life represents a very challenging moment for the participants. First, they have many practical difficulties in obtaining a reliable prognosis because the *terminal stadium of dementia* result in a vegetative condition, and it is impossible to define how

*long it will last* (COD 5). It is difficult for the participants to make the right decision at the right time here. The responsibility about something that the patients cannot directly express their wills can be overwhelming.

*Sometime, when you have to intervene, you risk intervening too soon or, on the contrary, you can be too late, and at that point the patient is already suffering, you've already lost some time* (COD.11).

In addition, as mentioned by a geriatrician, the trustee, a new figure introduced by Law 219/2017, is hardly reliable:

*The problem is that she will name her husband as trustee (...) but he does not see her how she is now, or he does not want to see her because he is scared. So, making decisions with a trustee like this can be complicated: here, you can intervene too soon* (COD.11).

#### *Questioning the efficacy of ACP in the dementia context*

Knowing in advance the patient's system of values is useful and allows physicians to solve challenging ethical situations at the End of Life. Four participants recognized the role of talking about values and treatment preferences, considering the complexity of the situation, instead of focusing on the single problem about the End of Life choice.

*Having already formalized what was the system of values of that patient (...) would help everyone to make the most suitable choices* (COD5).

Other participants confirmed that is hard to manage the time required by a shared ACP and time of dementia's evolution:

*It was a prolonged path. (...) A stimulus presentation session lasted over an hour, and you could not get much information. So when we arrived to discuss artificial nutrition, (...), he was no longer able to express his will, (...) So, there is the possibility that you start a shared path of care, but when you get to your goal, the patient is no longer there to give you a proper answer (COD.5).*

### **What physicians need to improve ACP in the Italian context**

This theme interprets what participants need to improve a shared ACP in their daily practice. Its implementation is at its very auroral stage and a lot of work still needs to be done, especially regarding sharing information and promoting a culture of patient's rights among both different HPs and at the institutional level.

#### *Richness of team working: a special role for nurses and general practitioners*

The shared ACP does not rely in an exclusive relationship between the patient and his/her doctor but is described as *authentic team working* (COD.4). Consequently, nurses could play a central role in starting and carrying on a shared ACP. First, they are a direct reference point in supporting a family's concern, uncertainties and doubt when their loved one progressively deteriorates; second, they can also support physicians in the clarification of the current situation, as narrated by one participant:

*The role of the nurse was fundamental because when a decision was finally taken, it causes other consequences, and many new doubts and uncertainties can arise within the*

*family, doubts that do not occur only during the visit, but mostly in the outpatient check-up and during the home visit. The nurse could have that role of answering the question (COD.5).*

In the terminal stage, the need for a strong alliance between the doctor and nurse is significant to accompany the patient and his/her family to the *exitus*:

*So, the nurse helped me and this morning he called me telling me that the patient had died. He was the one who managed the situation, because he was there, taking care of the family during the last days (COD.9).*

A unique role is also recognized to the general practitioner:

*It would be better if there is the possibility, with the general practitioner (...) of outlining a path and understanding (...) what are the expectations and the reality behind the context around the patient (COD.10).*

*Beyond legality: the need to promote a culture of rights*

Since the enactment of Law 219/2017, most participants manifest familiarity with the content of the law. However, 7/11 participants blurred the outline between shared ACP and AD; while ADs are perceived as a very new tool to improve patient self-determination, shared ACP is widely considered as a written form of the doctor-patient collaboration that, if well established, it was done already before (COD. 6). However, 6 participants referred to it with terms such as “building, try, beginning”, suggesting that

shared ACP is for them a process still under construction in dementia setting, and that, *there is still much work to do (COD.3).*

Shared ACP in a dementia setting is *a challenge which required physicians to not be afraid to try it (COD.5)*: it means that physicians find it useful to start perceiving shared ACP as a practice that affects daily life and not only exceptional conditions. Physicians have to adapt to a world that is increasingly moving in the path of patient self-determination, in which the rights of patients with dementia are also included.

*In my opinion It is very important that a cultural change takes place beyond the law. That is, to encourage a change of mentality and this will help us work better, always taking into consideration what is the point of view of the patient (COD.4).*

Two participants, in particular, were concerned about the risk of overly influencing the communication, directing, even involuntarily, the choices of patients and family members:

*Especially in cases where the verbal expression is severely compromised, you are harnessing the communication with meanings that are yours, that belongs to you more than they belong to the patient. So, you are trying to infer a will that finally is not necessarily the one of the patients (COD.5).*

Thus, discussing about ACP in the dementia setting discloses the need, all participants reported, of a specific training, especially concerning how to communicate with the patient. Developing ACP implicates an authentic co-building of meanings:

*I believe that it is important that we will be trained on how to deal with the topic, on how to support dialogue, on how to provide all the information correctly, (...) without letting too much transpire what is your opinion (COD.7).*

## **DISCUSSION**

To our knowledge, this is the first qualitative analysis addressing the topic of ACP in an Italian dementia setting after enactment of the Italian law 219/2017.

Analysis of the interviews revealed a quite homogeneous landscape about the perception of difficulties and concerns that interviewed physicians face for efficient and effective implementation of ACP within their practical reality with patients with dementia. The findings mainly confirmed that the provision of high-quality care for patients living with dementia and their families is mostly hindered by the difficulty of timing required by ACP and time allowed by the more rapid development of dementia.

Our findings confirmed that the future lack of decision-making capacity, impossibility of ongoing evaluation and patient-doctor communication represent specific barriers to initiate ACP by physicians.<sup>20</sup> Presumption regarding the capacity of the person with dementia represent an ethical and moral concern that deeply influence physicians' perceptions on the effectiveness of patient involvement in ACP, confirming the need to recognize and increase the role of the family in the decision-making processes and promote ACP in the initial stage of dementia.<sup>21</sup>

<sup>20</sup> De Vleminck, A., Pardon, K., Beernaert, K., Deschepper, R., Houttekier, D., Van Audenhove C., and then '...', Vander Stichele, R. (2014). Barriers to Advance Care Planning in Cancer, Heart Failure and Dementia Patients: A Focus Group Study on General Practitioners' Views and Experiences. *PLoS One*, 9(1), pp.1-9.

<sup>21</sup> Ruth, P., Albers, G., Gilissen, J., De Lepeleire, J., Steyaert, J., Van Mechelen, and then '...', Van den Block, L. (2018). Advance care planning in dementia: recommendations for healthcare professionals. *BMC Palliat Care*, 17: 88, pp. 1-17.

According to several studies, the best time to discuss ACP with dementia patients is soon after the diagnosis.<sup>22,23,24,25</sup> However, many concerns still affect participant opinion about timely, End of Life shared decision-making. This is in line with many studies proving barriers and facilitators faced by HPs (with particular regard to general practitioners), patients and their caregivers related to ACP with people with dementia, such as the difficulties with determining an optimal timing for ACP, due to the lack of crucial moments to initiate ACP, the patient's lack of awareness of their diagnosis and prognosis,<sup>26</sup> and the limited engagement in ACP by people with early-stage dementia regarding their initiative.<sup>27,28</sup>

Our findings also revealed that physicians perceive the family member as necessary in helping to identify patient's wishes and care preferences. Denning et al. suggest that families facing with dementia may benefit not only from early and ongoing emotional support, but also from a practical help in the end of life decision making process.<sup>29</sup> However, dealing with family members is not always an easy path. As underlined by several studies, and confirmed by our study, most of the time the incipient role of the family member in ACP can hide ideologies, assumptions, and social structures such as

<sup>22</sup> Ibid.

<sup>23</sup> Beck, E.R., McIlpatrick, S., Hasson, F. & Leavey, G. (2017). Health care professionals' perspectives of advance care planning for people with dementia living in long-term care settings: A narrative review of the literature. *Dementia (London)*, 16(4), pp. 486-512.

<sup>24</sup> Mitchell, S.L., Kiely D.K. & Hamel, M.B. (2004). Dying with Advance Dementia in the nursing home. [Arch Intern Med](#), 164(3), pp. 321-326.

<sup>25</sup> Poppe, M., Burleigh, S. & Banerjee, S. (2013). Qualitative evaluation of advanced care planning in early dementia (ACP-ED). *PLoS One*, 10;8(4).

<sup>26</sup> Tilburgs, B., Vernooij-Dassen, M., Koopmans, R., Van Gennip, H., Engels, Y., & Perry, M. (2018). Barriers and facilitators for GPs in dementia advance care planning: A systematic integrative review. *PLoS One*. 20;13(6).

<sup>27</sup> Poppe, M., Burleigh et al., op. cit. note 33.

<sup>28</sup> De Boer, M.E., Dröes, R.M., Jonker, C., Eefsting, & J.A., Hertogh, C. (2012), Thoughts on the Future: The Perspectives of Elderly People with Early-Stage Alzheimer's Disease and the Implications for Advance Care Planning. *AJOB Primary Research*, 3(1), pp. 14-22.

<sup>29</sup> Denning, K.H., King, M., Jones, L., Vickestaff, V. & Sampson E.L. (2016). Advance Care Planning in Dementia: Do Family Carers Know the Treatment Preferences of People with Early Dementia?, *PLoS One*, 11(7).

ageism and paternalism, that also act as barriers to effective engagement of patients in the decision-making process.<sup>30,31,32</sup>

## **PRACTICAL IMPLICATIONS**

Our findings highlighted that advanced and special training is needed to help physicians in communicating with dementia patients and their families, due to the emotional and ethical burden of such communication process.

Moreover, ACP interventions can help in managing the illness' development and the end of life choices.

Finally, further research on the initial stages of dementia is needed to develop physicians' attitudes towards personalized end of life care.

## **CONCLUSION**

A high quality of dementia care requires a wide variety of skills that are not already profoundly spread in the Italian context, and many concerns and uncertainties still affect the effective implementation of shared ACP in dementia care. We can conclude that, even if shared ACP is perceived as a useful tool to improve a patient's quality of life, this opinion is based more on an abstract and theoretical level than on real practical knowledge. Italian physicians dealing with patients with dementia often lack specific communication and ethical skills necessary to start and carry on the complexities of End

<sup>30</sup> Sullivan, S.S. & Dickerson, S.S. (2016). Facing Death: A Critical Analysis of Advance Care Planning in the United States. *ANS Adv Nurs Sci*, 39(4), pp. 320-332.

<sup>31</sup> Cembrani, F., Asioli, F., Bianchetti, A., Ferrannini, L., Mossello, E., Scapati, F., & Trabucchi, M., (2018). La Pianificazione Condivisa delle Cure e l'autodeterminazione della persona anziana affetta da patologie psicogeriatriche, Associazione Italiana di Psicogeriatrici, retrieve from: <https://www.sicp.it/documenti/altri/2018/10/il-documento-dellassociazione-italiana-di-psicogeriatrici-sulla-pianificazione-condivisa-della-cura/>.

<sup>32</sup> Groves K., (2006). Justified paternalism: the nature of beneficence in the care of dementia patients. *Penn Bioeth*, 2(2), pp. 17-20.



of Life care planning. Further training and an educational course about specific communication are urgently required to ease the implementation of ACP, as well as a broader involvement of institutions and other professionals.

### **Strengths and limitations of the study**

The different kinds of interviewed participants represent a significant and homogeneous sample.

Because IPA needs a uniform sample size, the population was limited to the physicians who are supposed to meet patients with dementia. Given the important role of nurses in ACP, the nursing responsibilities in collecting patient's information will have been investigated in this study; however, this issue deserves further specific investigation.

Finally, the findings are limited to the local reality of Reggio Emilia and may not reflect the national level. However, it is reasonable to assume that the experience is not uncommon for other physicians who are involved in dementia care. It is also reasonable to assume that Italy presents different cultural realities that can deeply affect the provision of dementia care. Further investigations on this cultural aspect are expected.

## **Table 1—Interview topic guide**

### **Perception about difficulties in dealing with patients with dementia**

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**Exemplifying questions:**

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- Could you please tell me about the patients you usually meet? Could you please tell me what is your experience in assisting them?
  - Regarding the patients in an advanced stage of illness, what is important to them? What is the communication about?
  - According to your experience, how do you feel you meet the patients' needs?
  - Have you ever faced issues related to End of Life choices?
  - Could you please tell me examples about cases you felt difficult to manage?
- 

### **Perception about shared ACP with patients suffering from dementia, as established by the recent Italian Law 219/2017, particularly regarding the possibility of preserving the dignity of the patient in an advanced stage of incompetence**

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**Exemplifying questions:**

- 
- What is your knowledge about Law 219/2017?
  - Could you please tell me your opinion about ACP?
  - Considering your daily clinical practice, have you ever performed a shared ACP? If yes, what were the effects on the relationship with the patient? If not, could you please tell when you think proposing a shared ACP to these patients is suggestable?
  - In your opinion, in relation to ACP, are there any critical aspects that need to be improved?
  - According to your experience, do physicians and nurses have a different role or tasks in the process of a shared ACP with patients with dementia?
-

**Table 2 - Participants' characteristics**

<b>Participants (code)</b>	<b>Age</b>	<b>Gender</b>	<b>Medical specialization</b>	<b>Work experience (years)</b>	<b>Department</b>	<b>ACP before the Italian Law (Yes/No)</b>	<b>End of Life care provision (Yes/No) - Frequency</b>
1	41	M	Palliative care	10	Primary care	No	Yes - Monthly
2	60	F	Palliative care	25	Primary care	No	Yes - Monthly
3	41	F	Neurology	9	Neurology	No	Yes - Occasionally
4	53	F	Geriatrics	20	Centre for Cognitive Disorders and Dementia	No	Yes - Occasionally
5	39	M	Geriatrics	13	Centre for Cognitive Disorders and Dementia	No	Yes - Occasionally
6	38	F	Neurology	13	Neurology	No	Yes - Monthly
7	54	F	Geriatrics	18	Centre for Cognitive Disorders and Dementia	No	Yes - Occasionally
8	61	F	Geriatrics	30	Centre for Cognitive Disorders and Dementia	No	Yes - Occasionally
9	55	F	Geriatrics	30	Centre for Cognitive Disorders and Dementia	No	Yes - Occasionally
10	40	F	Geriatrics	12	Long-term care	No	Yes - Occasionally
11	55	F	Geriatrics	25	Centre for Cognitive Disorders and Dementia	No	Yes - Monthly

**Table 3 —Themes and subthemes**

	Themes	Subthemes
1	<i>Shaping the healthcare relationship in the dementia setting: moving with uncertainty and difficulties</i>	<ul style="list-style-type: none"> <li>- Struggling with the rapid loss of critical thinking</li> <li>- The emotional weight of an early discussion on future care treatments</li> <li>- Taking care of the fragility of the patient</li> </ul>
2	<i>Role of family members in dementia care</i>	
3	<i>Ethics vs pragmatism: taking the right decision at the right time</i>	<ul style="list-style-type: none"> <li>- Communication of the diagnosis: between prudence and paternalism</li> <li>- Looking for the right moment to intervene at the End of Life</li> <li>- Questioning the efficacy of ACP in the dementia context</li> </ul>
4	<i>What physicians need to improve ACP in the Italian context</i>	<ul style="list-style-type: none"> <li>- The richness of team-working: a special role for nurses and general practitioners</li> <li>- Go beyond legality: the need to promote a culture of rights</li> </ul>