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Shared care planning in people with cognitive disorders and dementia: a survey among patients and caregivers in Italy

Corinna Porteri[1*], Giulia Ienco[1], Edda Mariaelisa Turla[1], Mariassunta Piccinni[2] and Patrizio Pasqualetti[3]

Abstract

Background There is wide convergence in the positions of scientific societies, patient associations and public bodies regarding the advisability of advance care planning (ACP) in cognitive disorders and dementia to respect the specificity of the person. Nevertheless, planning in advance for dementia represents a unique challenge. In Italy, law n. 219/2017 introduced ACP for the first time at the regulatory level, under the name of shared care planning (SCP). Few surveys on the law implementation have been conducted in Italy, but none have specifically involved patients with cognitive disorders and their caregivers. To contribute filling the gap, we conducted a survey among patients and caregivers attending a memory clinic to investigate what their knowledge, attitudes and experiences were regarding SCP.

Methods We developed two semi-structured questionnaires for patients and caregivers organized into the following sections: (i) knowledge of the law; (ii) general attitude on SCP; (iii) experience about SCP; (iv) attitude about realizing a SCP; (v) advance directives. Participation in the survey was offered to consecutive patients discharged from the memory clinic during 26 target weeks and to their caregivers. The interviews were conducted on the occasion of the last scheduled visit to the facility; telephone interview was also provided. Information was collected by means of an online platform (Google Forms). Descriptive and basic inferential analysis was performed by means of SPSS (IBM). The analysis of the open-ended questions was also conducted with the support of the Voyant Tools.

Results Sixty-six patient and 65 caregiver interviews were collected. No participant reported that a doctor has ever talked to the patient about SCP. The large majority of patients (85%) and almost all caregivers (95%) agree/absolutely agree with the opportunity for patients to realize SCP. Almost all participants agree/absolutely agree with the usefulness for the patients of indicating a trusted person to act on their behalf (91% patients and 95% caregivers). Forty-three (65%) patients and 48 (74%) caregivers believe it would be good to start SCP with the patient when the time is right. Among them, 20 caregivers and 12 patients believe it is already time to talk about SCP.

Conclusions Study results showed patients' and caregivers' interest in the SCP process and, at the same time, their mixed attitude when SCP is referred specifically to themselves or their loved ones. This indicates the need to introduce the discourse on SCP into clinical practice while remaining very sensitive to the individual patient's pace and wishes, including his/her possible refusal to talk about SCP.

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*Correspondence:
Corinna Porteri
cporteri@fatebenefratelli.eu

Full list of author information is available at the end of the article

Keywords Law n. 219/2017, Informed consent, Shared care planning, Advance care planning, Advance directives, Cognitive disorder, Dementia

Introduction

Dementia is a leading cause of disability and dependency among older people globally; it has an impact on memory, cognitive abilities and behaviour, interfering with the individual's ability to carry out daily activities [1]. While a number of pathological processes may underlie dementia, the most common is Alzheimer's disease that counts for 60–80% of the cases. The course of dementia can vary from person to person, but is on average long (from 4 to 8 years after a diagnosis) [2] and presents a progressive worsening of symptoms and decision-making capacity [3], with an initial phase in which the individual is able to understand and communicate his/her own desires and interests.

Advance care planning (ACP) is an instrument for respecting the specificity of the individual, i.e. his/her physical, psychic, moral, relational individuality and conscious choices [4]; it is a tool that responds to the need to plan the treatment path especially in all situations in which the patient is initially able to relate directly to the health-care staff and later reaches a condition of inability to express him/herself in a free and conscious way [5].

According, ACP seems to be an ideal tool in the context of dementia to implement care that respects the wishes and wills conveyed by the person before the severe stage of the disease hinders their communication. The provision of ACP is even more relevant in the current situation of increased opportunity for early diagnosis, where the possibility of planning in advance is one of the greatest benefits of making diagnosis [6]. In fact, although the development of disease-modifying therapies is a very active area of research and there are medicines that can help treat symptoms, there's currently no cure for Alzheimer's disease and other dementias.

There is wide convergence in the positions of scientific societies, patient associations and public bodies regarding the advisability of ACP in dementia to respect the specificity of the person and his/her choices [1, 7–12]. In addition, studies on ACP have provided evidence, although of variable quality, on its benefits for the person, family and society and showed that ACP is associated with positive outcomes, such as decreased hospitalizations and increased concordance between care received and prior wishes [11, 13, 14].

Nevertheless, planning in advance for dementia represents a unique challenge [15] and a number of critical issues affect the implementation of ACP in the reality of health-care. A first critical issue is that, despite the increased possibilities for early diagnosis, many patients are diagnosed too late in the course of the disease such that they are no longer deemed capable of deciding on treatment. Moreover, even when the diagnosis is timely, the communication of the same is not always clear and truthful, due to the physicians' desire to protect the patient from negative psychological reactions [16]. In the absence of a genuine diagnosis disclosure, it is not possible to initiate a comprehensive conversation on treatment and care. Fear of causing stress and anxiety for people with dementia and carers has also been identified as a barrier to ACP implementation [14].

A further issue is the identification of the right time at which to start the planning process, in order to avoid planning either too early or too late, when the patient's competence is already impaired [8, 12, 14, 17–20]. Subject's competence in appreciating the clinical situation and deciding on treatment and care, including the choice of a trusted person, is in fact a problematic aspect in the ACP process concerning people with cognitive disorders [21–23].

The potential conflict between "critical interests" (i.e. interests that give our lives as a whole meaning and significance) that the person may have communicated in advance and the patient's actual interests, which some authors interpret as a then-self vs. now-self conflict, further complicates the picture of advance treatment decisions in the context of dementia [24–27].

In Italy, law n. 219/2017 provides for a comprehensive discipline on informed consent to medical treatments, advance directives (AD) and ACP. The law aims to protect the person's right to life, health, dignity and self-determination at all times of life, even when the individual is temporarily or no longer able to decide and express choices about health-care [28, 29]. It promotes the person's autonomy and a shift of the patient-physician relationship toward a patient-centred approach [30–32]. The person's preferences and wills are valued, and the goal of the therapeutic relationship is the patient's health, understood as the best physical, psychological and relational well-being achievable by the individual taking into consideration both medical criteria and the person's individuality [33, 34]. According to the provisions of the law, the therapeutic relationship should be marked by continuous, two-way communication where the patient/physician communication time is expressly defined as care time [32]. To realize a beneficial care, law n. 219/2017 also gives high value to the involvement of the patient's family and social relations [34].

The law introduced ACP for the first time at the regulatory level under the name of shared care planning (SCP) to emphasise the collaborative nature of the process.

Article 5 "Shared care planning" allows patients suffering from a chronic and disabling disease or disease characterized by an inevitable progression with unfavourable prognosis to collaboratively define a care plan with their physicians. The shared plan can be updated according to the evolution of the patient's needs while health-care providers are obliged to comply with it if the patient becomes unable to give consent or enters a state of incapacity. The Italian law also provides for AD, that is another way to plan in advance: Article 4 "Advance directives" states the citizen's right to express wills and provide instructions on medical treatments in anticipation of a possible future incapacity for self-determination. Regulations on SCP and AD also include the individual's right to appoint a trusted person (in the Italian law "persona di fiducia"/ "fiduciario") with power of representation with health-care professionals and organizations [35]. Even though advance planning was already a way of operating in best clinical practice [36], the introduction of SCP as a legal tool and the adoption of an organic law regulating the doctor-patient relationship should constitute no less an impulse towards a wide implementation of SCP in clinical care.

Few years after the entry into force of the law on January 31st, 2018, it is important, as law n. 219/2017 itself requires in Article 8, to collect data on its implementation. This should be done from different perspectives, also taking into account the diversity of medical conditions and the patients' views, in order to have a picture of the situation as a first step to eventually improve it. Although few surveys on the law implementation have been conducted in Italy [17, 30, 37–43], none have specifically involved people with cognitive disorders and their caregivers. To contribute to filling the gap, we conducted a survey among patients and caregivers attending a memory clinic to answer the question: what are the knowledge, attitudes and experiences regarding SCP as regulated by law n. 219/2017 of people with cognitive disorders/dementia and their caregivers?

Methods

Study design

A cross-sectional study was carried out by means of a questionnaire among patients and caregivers attending the MAC-memory clinic of the IRCCS Fatebenefratelli aiming to investigate their knowledge, attitudes and experiences regarding SCP as regulated by law n. 219/2017.

The survey was conducted over a period of 26 weeks between April and November 2022.

The IRCCS Fatebenefratelli Ethics committee approved the study protocol (opinion n. 18/2022).

Participants

Participation in the survey was offered to consecutive patients who were discharged from the MAC-memory clinic of the IRCCS Fatebenefratelli during the target weeks and to their caregivers. The IRCCS Fatebenefratelli is a scientific institute for research and care in the field of psychiatric and cognitive disorders, including dementia. The MAC-memory clinic provides rehabilitation for people suffering from cognitive disorders/dementia. The typical intervention consists of 15 sessions two or three times a week organised in a quite flexible manner to meet the patients' needs. Based on their clinical condition, patients can repeat the rehabilitation intervention over the years.

The number of participants was not planned in advance according to a formal sample size calculation based on specific hypotheses to be tested. The use of an available convenience sample is allowed in observational studies and the "confidence intervals indicate the statistical precision that was ultimately obtained" [44].

Materials

Two semi-structured questionnaires for patients and caregivers [available as Additional files] were developed for the present study (CP wrote the first draft, PP made essential contribution). The patient questionnaire consisted of a total of 40 questions – 29 closed and 11 open; the caregiver questionnaire consisted of a total of 47 questions – 35 closed and 12 open. The open-ended questions were intended to deepen the answers to some closed questions by asking the participants their motivation (i.e.: why? how?). According to the answer given to some questions, some of the following ones could be skipped. Our participants responded to a maximum of 24 questions. The questions could always be repeated or partially rephrased according to the participants' needs in order to facilitate their full understanding.

The questionnaires were organized into the following sections: (i) knowledge of the law; (ii) general attitude on SCP; (iii) experience about SCP; (iv) attitude about realizing a SCP; (v) AD.

Essential information related to patients and caregivers was also collected: age, gender and education for both; plus MMSE, CDR, past experience with the memory clinic for patients, and type of relationship with the patient for caregivers.

The first version of the questionnaire was submitted to three neurologists with expertise in cognitive disorders/dementia and experienced connoisseur of law n. 219/2017 to gather their comments on the content and wording of the questions. The reviewers made some suggestions on the language of the questions to enhance clarity. The final questionnaire was transferred to an online platform and used in the survey after testing the functionality of the platform.

Procedures

To avoid changes in the ordinary behaviour of doctors and health-care team with regard to SCP, care was taken not to make the survey known within the service. Based on essential information about the study, the memory clinic coordinator notified the research team of the potential participants. Subjects judged not to be in a condition to participate in the survey or not interested in being involved in the study were not reported.

The interviews were conducted in the offices of the Bioethics Unit by two researchers (EMT and GI) on the occasion of the last scheduled visit to the facility. Based on the preference of the participants, telephone interviews were also provided. Initial information about the study was provided to patients and caregivers together, while the collection of consent and the interview were conducted separately (except for the very few cases in which the patient preferred the presence of the caregiver throughout the process); in telephone interviews the caregiver was informed and interviewed first. No formal assessment of the subjects' competence to participate in the study was made, but the researchers took care of asking the participants to repeat essential information about the study and their rights as research participants to ensure a prior comprehension. Given the nature of the study and conceiving the consent itself as a process, a more complete evaluation of the specific competence, i.e. the ability to understand the questions and answer them coherently, was made during the interview. The caregivers' request not to interview the patients was always accepted in order not to create uncomfortable or stressful situations. Research subjects gave free and voluntary consent to participation; they were free to withdraw at any time.

Table 1 Participants' socio-demographic and clinical features

	Patients *n* = 66	**Caregivers** *n* = 65
Age, years (range)	76.9 ± 6.4 (60 to 89)	63.9 ± 11.9 (40 to 84)
Gender, female	29 (44%)	48 (74%)
Education, years (range)	8 (1–17)	11 (5 to 17)
Mini Mental State Exam. (range)	27 (18–30)	
Clinical Dementia Rating (range)	0.5 (0.5–3)	
Past experience with the clinic, yes	44 (67%)	

Figures denote mean + SD or median (min-max) or n (%)

Data analysis

Information was collected via an online platform (Google Forms) that allows the data to be imported by a statistical package (SPSS, IBM) to perform basic statistical analysis (frequency distributions, bar chart representation). We reported absolute frequencies when the number of cases on which the analysis is carried out is small. Indeed, the use of percentages, also for descriptive purposes, is not recommended for small sample sizes. As appropriate for small samples, confidence intervals were computed by means of Wilson's procedure. The analysis of the open-ended questions was also conducted with the support of the Voyant Tools, an open-source web-based text reading and analysis environment, which allows to identify the most recurring words in the participants' responses. CP, GI and PP executed the data analysis. [The dataset with closed responses to the questionnaire is available as additional file].

Results

Ninety-five patients were referred to the research team as potential study participants. Twenty-one of them did not participate in the survey; the main reason (16) was that the caregiver judged the patient not to be in a condition to participate. A total of 74 interviews were conducted; 8 interviews (sometimes interrupted after the first few questions) were not considered in the analysis because the patient showed confusion and/or did not fully understand the questions. Sixty-six patient interviews were analysed.

Twenty-four patients attended the memory clinic without caregivers. Six caregivers refused to participate, three of them because of lack of time. Sixty-five caregiver interviews were analysed.

The average time to complete the interview was 15 minutes for both patients and caregivers [min 8 max 35 for patients, min 5 max 25 for caregivers].

Participants' socio-demographic and clinical features are reported in Table 1.

Knowledge of the law

Thirty patients (45%; Wilson's 95% CI: 34-57%) and 43 caregivers (66%; Wilson's 95% CI: 54-76%) have heard about law n. 219/2017, mainly through the media (28 patients and 40 caregivers). Only 7 patients and 1 caregiver judged their knowledge of the law as good or very good. The large majority (21 patients and 28 caregivers) judged their knowledge as poor or very poor. The other participants neither poor nor good. In patients, being aware of the law was correlated with a higher MMSE score (Spearman's rho = 0.260, $p = 0.035$). This was the only statistically significant correlation in our study.

General attitude on SCP

We asked participants their view about the possibility given to patients to start SCP with the physician/health-care team, i.e. the possibility to plan together the possible future stages of care; and their view regarding the usefulness for the patients of appointing a trusted person to act on their behalf in the event of future inability to express oneself and to relate directly with the health-care personnel. Patients' and caregivers' view on SCP and trusted person are reported in Fig. 1.

The words most used by participants to say why they agree/absolutely agree with the possibility of SCP were decision/to decide (13pt, 17cg), choice/to choose (7pt, 8cg), and, for caregivers, will (11). The adjective most used by caregivers in relation to SCP was fair (19), followed by useful (11) that was also the adjective most used by patients (9).

To explain why participants agree/absolutely agree with the appointment of a trusted person the most frequently recurring words in caregivers were again will, decision/to decide, and fair (19, 17, 16 respectively). Among patients guarantee/protection (14), calm (11), will (9), and fair (9) were the key words. Guarantee/protection and calm also returned in caregivers (11 and 4 respectively).

Experience about SCP

Regarding participants' experience with SCP, almost all patients and caregivers (94%; Wilson's 95% CI: 86-98% and 92%; Wilson's 95% CI: 83-96% respectively) reported that no physician has ever spoken with the patient about SCP, neither for the cognitive disorder, nor for any other illness; the remaining participants do not know/do not remember. Subsequent questions concerning the experience with SCP discourse were therefore not proposed to any participant.

Attitude about realizing SCP

Exploring participants' attitude about realizing SCP, we asked whether for the disorder for which the patient attended the memory clinic they believe it would be good to start SCP when the time is right: 43 (65%; Wilson's 95% CI: 53-76%) patients and 48 (74%; Wilson's 95% CI: 62-83%) caregivers believe this is good; while 16 patients and 8 caregivers do not (3 of whom believe that the right time has already passed); the remaining participants do not know.

Patients who believe this would be good (43), think that SCP may improve their relationship with physicians/health-care team (29 agree and 7 absolutely agree); may help them to cope better with their disorder and care path (32 agree and 6 absolutely agree); and may ease the burden of care decisions for family members and caregivers (28 agree and 5 absolutely agree). In the open responses on why and how the above would happen, the key word was trust (20) used to qualify the doctor-patient relationship, while knowing (13) was generally seen as a reason for calm.

Caregivers who believe SCP would be good for the patient at the right time (48), think that SCP may improve their relationship as caregivers with physicians/health-care team (35 agree and 7 absolutely agree); may help the patient to cope better with his/her disorder and care path (29 agree, 2 absolutely agree); and may ease the burden of care decisions for family members and caregivers (25 agree and 14 absolutely agree). While the words in the open-ended responses on why and how the above should happen have a rather low frequency, there is a quite clear indication that knowing and planning in advance can provide significant support for both patients and caregivers.

The large majority of patients (38) would involve family members/friends in the planning, half of them would involve their children (29), one third spouse/partner (19).

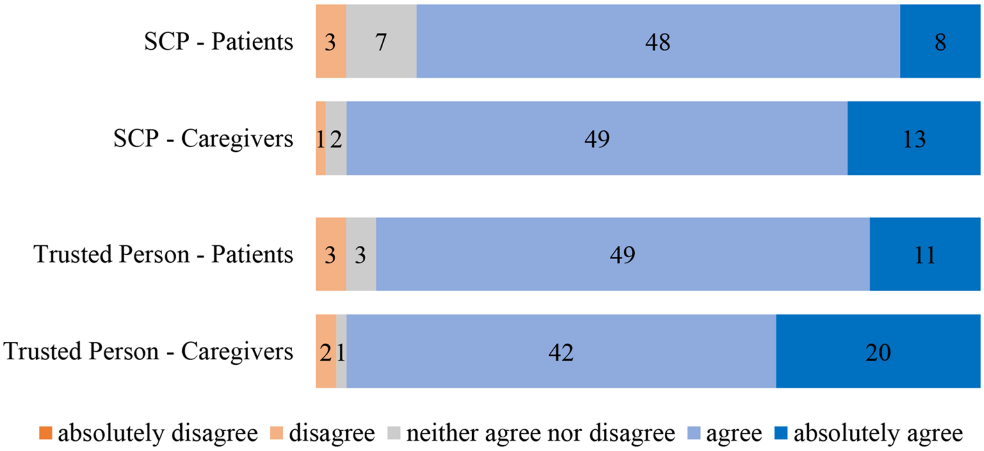

Fig. 1 Participants' view on the possibility to start SCP and the usefulness of appointing a trusted person

Almost all patients (39) would appoint a trusted person to act on their behalf in the event of future inability to express oneself and directly relate with health-care personnel, 2 excluded this and 2 do not know. The preferred trusted person would be daughter/son (27), spouse/partner (18), friend (5).

For their part, caregivers think it would be appropriate to involve family members/friends in care planning (46), and 45 of them would be happy to participate in SCP with their loved ones (only one does not know). In case the patient wishes to designate a trusted person almost all caregivers would be ready to take on the role (46).

Twenty caregivers believe that for the disorder for which their loved one attends the memory clinic it is already time to talk about SCP with doctors, 22 believe it is not time, 5 do not know and 1 prefers not to answer. Among all of them, 7 think it is already too late and 2 have doubts about their loved ones' capacity to realize SCP.

Referring to their own situation, 12 patients believe it is already time to talk about SCP with doctors, 20 believe it is not and 11 do not know. Although without statistical evidence, there is a tendency to answer yes in patients already known to the service (about 1/3) compared to new patients (1/5). Table 2 shows patients' and caregivers' attitude about realizing SCP.

Advance directives

The last section of the questionnaire concerned AD, which is another way of expressing care preferences in advance provided for in law n. 219/2017. Forty-one (63%; Wilson's 95% CI: 51-74%) caregivers and 23 (35%; Wilson's 95% CI: 25-47%) patients heard about AD. No caregiver wrote AD, while two patients did it.

Discussion

We conducted a survey among patients and caregivers attending a memory clinic to investigate what their knowledge, attitudes and experiences were regarding SCP. Sixty-six valid patient interviews and 65 caregiver interviews were collected and analysed.

Knowledge of the law

About half of the patients and two thirds of the caregivers were aware of the existence of the law, although most judged their knowledge as poor. The percentage of caregivers aware of the law is almost in line with the one (70%) found in a survey involving the general Italian population [39]. However, for our study, it was not necessary to have a good knowledge of the law or even to be aware that it had been enacted in order to fully understand and answer the interview questions.

General attitude on SCP

The large majority of patients (85%) and almost all caregivers (95%) agree/absolutely agree with the opportunity

Table 2 Patients' and caregivers' attitude about realizing SCP

Patients				**Caregivers**			
	***n* of respondents**	***n* of response Yes**	**% of Yes (Wilson 95% CI)**		***n* of respondents**	***n* of response Yes**	**% of Yes (Wilson 95% CI)**
For the disorder for which you attend our facility, do you think it would be good to initiate shared care planning when the time is right?	66	43	65% (53-76%)	For the disorder for which your family member attends our facility, do you think it would be good to initiate shared care planning when the time is right?	65	48	74% (62-83%)
Do you think you would involve some family members/friends in the planning?	43	38	88% (76-95%)	Would you be happy to participate in shared care planning with your family member?	46	45	98% (89-100%)
Do you think you would appoint a trusted person who could make decisions on your behalf in the event that you were unable to express yourself/relate directly with the health-care professionals in the future?	43	39	91% (78-96%)	If your family member wanted to appoint a trusted person in shared care planning, would you be willing to act as a trusted person?	48	46	96% (86-99%)
For the disorder for which you attend our facility, do you think the time has already come to talk about shared care planning with physicians?	43	12	28% (17-43%)	For the disorder for which your family member attends our facility, do you think the time has already come to talk about shared care planning with physicians?	48	20	42% (29-56%)

for patients to realize SCP with the physician/health-care team. Participants mainly regarded SCP as a way for the patient of making decisions and choices and expressing will, that is a way of asserting oneself and being an active subject in the care pathway. SCP is considered both fair, as a tool for respecting the patient's autonomy, and useful. This is framed within a doctor-patient relationship described through the interviews as asymmetrical in which the doctor is both perceived as the person who decides and recognised as having expertise that patients and caregivers feel they do not have, but in which participants believe the patient should count more.

Experience about SCP

A first result of the study is that no patient or carer reported that a doctor has ever talked to the patient about SCP, and therefore none of the participants have direct experience of SCP either as a patient or as a caregiver. Contrary to what might be expected, this is not related to the persons' degree of cognitive impairment and/or disability nor to whether or not they had previously attended the memory clinic. The result may appear quite surprising, although it should be considered that ACP is estimated to occur with only 3-39% of people with dementia internationally [45]. One possible explanation for the participants' response, which in any case may only be valid for individuals not too far along the disease trajectory, could be that the physician, while not explicitly mentioning advance planning, gradually introduced care planning into daily practice of care without the patient and caregiver recognising it as SCP. This would indeed be reasonable and would achieve the goal of planning together while conducting the process at the pace of the person with cognitive disorders, i.e. respecting the patient's time for accepting the clinical condition and drawing up the care pathway. This, although not ideal, seems to be consistent with an interpretation of SCP as a process that can also start with discussing current care [11] and shared decision making. This would appear also in accordance with the preference for informal approaches to planning found in people affected by dementia and their family carers [19, 20]. A different explanation might be that physicians struggle to recognise the right time - not too early but also not too late - when to start talking about SCP. This is indeed a crucial and difficult issue, as this may differ from person to person and situation to situation [8, 17]. In Italy the scenario may be made even more complicated by legal uncertainty about how to interpret the concept of capacity [46]: in fact, while law n. 219/2017 is intended to ensure the exercise of the right to therapeutic self-determination also to persons lacking legal or natural capacity, some criticisms concern the wording of the law, characterised by a mixed use of terms referring to capacity and their interpretability and may make its implementation in the complex reality of clinical practice challenging [47]. Although recognizing the right time may be difficult, a timely initiation of ACP has been found to be a facilitator [18, 20] and it has been argued that physicians should start ACP discussion "as soon as the diagnosis is made, when the patient can still be actively involved" [12] as "it always seems early until it is too late" [48]. In addition, it should be noted that decisional capacity in people with cognitive disorders is a gradual process [49] and that capacity to engage and decide may fluctuate over time and also depend upon what support are provided to facilitate complex decision. Minimum requirements for ACP in dementia may therefore be set and ACP be adapted to the patient's decisional capacity with the aim of achieving the greatest possible inclusiveness [11].

Attitude about realizing SCP

Against a largely positive view on SCP in general terms, the percentage of participants who believe that, for the disorder for which the patient attended the memory clinic, it would be good to start SCP at the right time decreases by 20 percentage points for both patients and caregivers, although they are still the majority. Among the participants who think it would be good to start planning with the patient when the time is right, only about one third of the patients and less than half of the caregivers think the time to talk about SCP has already come. This variability in participants' responses indicate how different it is for patients and caregivers to discuss SCP in general terms on the one hand and to apply SCP to themselves on the other, which could be traced back to the difference between rational reasoning and reasoning in which emotions play an important role. This crucial issue must be taken into great consideration in the ACP proposal, which must be tailored to the individual patient [14, 18] and remain optional so that if people with cognitive disorders do not wish to discuss it, they should be free not to [49]. In this case, it might be considered as an option for the patient to delegate family members who know his/her preferences, values and life view to engage in ACP. In our study, the significant number of caregivers who think it is already too late for their loved one to plan care further complicates the picture and again emphasises the importance of finding the right moment to introduce the planning discourse, before it is no longer possible for the person to interact consciously. The favourable attitude toward ACP and the complexity of the same in cognitive disorders have been found in two Italian studies prior to law n. 219/2017 showing that the majority of nursing home residents (with some degree of lack of self-sufficiency) and their family members considered ACP to be a good idea [50], and that the majority of citizens (in the same geographical area of our survey) were in favour of ACP completion for hypothetical patients suffering from Alzheimer's disease, although those who were caregivers of someone diagnosed with Alzheimer's disease were less willing [51], maybe for fear of causing emotional distress to themselves and the patient or because of an increased awareness of the complexity of SCP in dementia. International studies found that, in general, people with dementia and their carers believe ACP is relevant to people with dementia and it should be completed early in the illness trajectory [45].

Participants who believe it would be good to start planning with the patients when the time is right consider SCP a valuable tool to improve the relationship with the health-care team, to cope better with the disorder and to ease the burden for family members. Interestingly, to qualify the type of doctor-patient relationship resulting from the implementation of SCP, the word most used by patients was trust, that is also a key word and concept in the text of the law to qualify the kind of relationship between patient and doctor that the norm promotes and values beyond the technical aspects of care and treatment [33]. Moreover, despite the mentioned physicians' desire to protect patients by avoiding full communication about the disorder or talking about ACP, a number of patients showed that they associate knowing and understanding with a state of greater tranquillity. Health-care providers' misconception about the willingness of elderly patients and family to discuss ACP has been reported [52] and studies found that ACP is acceptable for people with dementia and their caregivers, although engaging in ACP conversations may not be comfortable especially for caregivers. Education and training for health-care professionals are key to promote and optimize ACP [14, 45]. The offer and implementation of ACP also requires an organisation of services that may still be lacking, at least in Italy, given the relative novelty of the law.

Trust-based relationships

The concept of relationship is key in law n. 219/2017: the law values not only the relationship between the patient and the doctor/health-care team, to the point of requiring health-care facilities to ensure staff training in relationship and communication skills, but also the relationship between the patient and his/her family and friendship community. In our survey both patients and caregivers showed to highly appreciate the opportunity to involve family and friends in the care planning and the patient's right to appoint a trusted person with power of representation: in particular the appointment of a trusted person is regarded as a form of guarantee and protection and, again, as a reason for calm.

In the context of cognitive disorders, the importance of considering family and trust-based relationships in ACP has been emphasized in the mentioned international consensus definition of ACP in dementia [11] as well as by the European working group of people with dementia involved in qualitative research on how to adapt ACP definition to dementia [49]: the support of family and trust-based relationships, although not unique to dementia, has been considered to be particularly relevant in planning for dementia especially because of their extensive personal knowledge of the patient. Studies have also indicated the involvement of all stakeholders as a facilitator for ACP and recommended it [18, 20]. In Italy, physicians working in the field of psychiatric and cognitive disorders showed to understand the key role of the patient's relationships as regulated by law n. 219/2017 and want more education about the issue [46].

Advance directives

Finally, two patients said they had written AD: this could be for physicians an opportunity to promote for them SCP instead of AD. In fact, especially if AD were written when the subject was healthy or without the crucial involvement of the physician, SCP would have the benefit of realizing greater concreteness and adherence to the patient's specific clinical situation.

Limitations

The study has been conducted in one single memory clinic and therefore the survey provides preliminary results that we found interesting but in no way claim to be representative of other health facilities on the Italian territory. At the same time, some trends in participants' responses that might be of interest would have required a higher numerosity to achieve strong statistical evidence. For a broader and more informative picture of the situation regarding attitude and experience of people with cognitive disorders and their caregiver on SCP, the promotion of similar surveys in other Italian health-care facilities would be advisable.

Conclusions

Our study showed the interest that patients and caregivers have in the SCP process. This is set in a context in which SCP seems to be uncommon and calls for a cultural change involving both education and training of health-care professionals and citizens' empowerment in relation to health [48, 53]. At the same time, survey results showed participants' mixed attitude when SCP is referred specifically to themselves or their loved ones.

This indicates the need for physicians to introduce the discourse on SCP into clinical practice while remaining very sensitive to patients' pace and wishes, including their possible refusal to talk about SCP.

Abbreviations

ACP	Advance Care Planning
AD	Advance Directives

IRCCS	Italian Institute for Research and Care
SCP	Shared Care Planning

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12910-024-01150-9.

Supplementary Material 1

Supplementary Material 2

Supplementary Material 3

Supplementary Material 4

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Author contributions

CP, bioethicist, conceived and led the project, and wrote the draft of the manuscript. GI and EMT assisted in the management of the project and conducted the interviews. MP contributed to the study with legal expertise. PP managed the methodological and statistical aspects of the study. All authors contributed to the discussion of the results and to the final version of the manuscript. All authors read and approved the final manuscript.

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Data availability

The questionnaire used for the survey is available as supplementary material in the original Italian version and English translation. The dataset with closed responses to the questionnaire is available as supplementary material.

Declarations

Ethics approval and consent to participate

All methods were carried out in accordance with relevant guidelines and regulations. The study protocol was approved by the Comitato etico IRCCS Centro San Giovanni di Dio Fatebenefratelli di Brescia – opinion n. 18/2022. Informed consent was obtained from all subjects for study participation.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

Author details
[1]Bioethics Unit, IRCCS Istituto Centro San Giovanni di Dio Fatebenefratelli, Via Pilastroni, 4, Brescia 25125, Italy
[2]Department of Political Science, Law and International Studies – SPGI, Università di Padova, Padua, Italy
[3]Department of Public Health and Infectious Diseases, Section of Medical Statistics, Sapienza Università di Roma, Rome, Italy

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