

Implementing advance care planning in dementia care: results and insights from a pilot interventional trial

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Abstract

Background: Advance care planning (ACP) is particularly appropriate for persons with dementia (PWD) since it fosters conversation about dementia-specific illness scenarios, addresses inconsistencies between advance directives and patients' observed behaviour, emphasises prospective and relational autonomy, and may be generally consistent to elderly's decision-making needs. However, despite the evidence of its benefits, ACP is yet to become widely used among PWD. In this paper, we present results regarding the feasibility and acceptability of a pilot intervention designed to foster ACP among PWD and their relative and explore future outcome measures in prevision of a randomized controlled trial.

Methods: In order to assess pre-post variations, we used qualitative interviews and four psychometric scales: Hospital Anxiety and Depression Scale, Questionnaire of Psychological Autonomy, Decisional conflict scale, and Zarit burden scale. We added two visual analog scales for perceived control over and perceived involvement in healthcare decisions, as well as two hypothetical scenarios to test concordance between PWD's and surrogate's decisions.

Results: Five main challenges in terms of feasibility were 1) to locate eligible patients, 2) to tailor recruitment procedures to recruitment locations, 3) to adapt inclusion criteria to meet clinical routines, 4) to engage PWD and their relatives in ACP, and 5) to choose outcome criteria that do not burden PWD. Alongside with those expected challenges, we discuss substantial unanticipated gatekeeping by the research ethics committee and healthcare professionals. Despite the setbacks, the intervention was well received by PWD and their relatives that expressed satisfaction with the procedure, especially in regard to the opportunity to discuss a sensitive topic with the help of a facilitator. Relatives' perceived control over healthcare decisions increased, as well as concordance between PWD's preferences and relatives' decision.

Conclusion: Misconceptions about dementia and ACP, both in the patient, relatives, and healthcare providers, combined with structural institutional challenges, have the power to impede research and implementation of ACP in dementia care. For this reason, we advocate for a systemic approach of ACP and for the use of ACP tools and research adapted to PWD cognitive capacities.

Trial registration: This trial was registered in the database clinicaltrials.gov with the number NCT03615027

1 Introduction

The World Health Organization estimates that the global prevalence of dementia among people over the age of 60 years is 6–9% (1). This rate is predicted to double by 2030 and triple by 2050 as a function of population aging (1). One consequence of this is that large parts of the population will have a family member with cognitive, emotional and/or communication impairments.

Taking care of people with dementia (PWD) poses significant challenges for both family and professional caregivers. Cognitive impairments fluctuate and may be difficult to assess (2). Already in the early stages of the disease, decision-making capacity (DMC) may be selectively or temporarily impaired due to exacerbations or acute complications; others PWD retain DMC with respect to many treatment-related decisions, at least during lucid periods, even until the later stages of the disease (3).

Advance directives were developed in the United States in the 1960s in order to enhance adherence to the autonomous preferences of a patient in the event of reduced DMC. Practical experience and research however suggest that advance directives alone are often ineffective as they do not give adequate attention to the complex process of planning care and making decisions for reduced DMC, especially at the end of life (4). This is particularly true in caring for PWD for several reasons. First, questions about validity and authenticity may arise (5). Second, family members often feel unprepared to making decisions about end-of-life care on behalf of their relative even in the presence of advance directives (6–8). Third, in the advanced stages of dementia, conflicts between anticipatorily expressed preferences and current behaviour may occur, thus raising complex questions about the applicability of the advance directives to a given situation (9, 10).

The concept of advance care planning (ACP), understood as a comprehensive process of facilitated documentation and implementation, emerged in the US in the 1990s and has gained momentum over the following decades (11). ACP proved particularly appropriate for PWD since it fosters conversation about dementia-specific illness scenarios, can effectively address inconsistencies between advance directives and the patient's observed behaviour, emphasises prospective and relational autonomy, and may be generally more adapted to decision making styles and needs of elderly people (5, 12). Despite convincing evidence about its benefits (13, 14), ACP is yet to become widely used among patients with dementia (13). Currently, ACP in people with dementia presents specific challenges for its implementation. These include, among others, choosing the right moment to initiate ACP, adapting the existing tools to the patient's cognitive capacity, and designating someone who is responsible for initiating and managing ACP (13).

In Switzerland, several policy documents from public health authorities declare the necessity of ACP for PWD (14, 15). However, we found no specific tools adapted to this particular population with its specific decision-making challenges. For this reason, we aimed to develop a

dementia-specific ACP intervention and conduct a pilot trial to explore its feasibility and acceptability as well as appropriate outcome measures for future effectiveness trials (5).

2 Methods

2.1 Intervention

Our dementia-specific ACP intervention called ADIA (initially conceived as *Alzheimer's Disease-specific Intervention of Advance care planning*) was developed based on the ACP model of the Zurich University Hospital, called ACP Medizinisch Begleitet[®] (16,17). This is an action-centered tool (18) that emphasizes shared decision-making about goals of care (19) and is consistent with the Swiss legal framework as well as the ACP recommendations of the Swiss Federal Public Health Office (20).

The ACP Medizinisch Begleitet[®] tool differentiates three situations of lost decision-making capacity and provides specific anticipatory care directives for each. The first situation is sudden loss of decision-making capacity due to an emergency, for example cardiac arrest or acute respiratory insufficiency, when rapid medical interventions could save the life of the person. In the second situation, people are invited to anticipate situations in which they have lost decision-making incapacity for an uncertain period of time and life-sustaining measures are necessary, for instance after a severe stroke when the patient is in the intensive care unit or a stroke unit. In the third situation, people can document their wishes for situations in which they will permanently lack decision-making capacity, as in the case of long-standing unresponsive wakefulness syndrome (vegetative state) or advanced dementia. For each scenario, people are asked to document the goal of care and treatment categories they wish or do not wish to undergo. For this reason, the tool includes evidence-based decision aids about cardiopulmonary resuscitation, respiratory distress, dialysis, artificial nutrition, place of death, and participation to research.

For the ADIA pilot trial, decision aids and advance directives were forward translated into French (by native French speakers) and backward into German (by native German speakers). Moreover, we added information about dementia and its stages based on documentation issued by Alzheimer Switzerland and the "Goals of Care Framework (21). Since ACP Medizinisch Begleitet[®] is also partially inspired by the latter, the dementia-related decision aids in the Goals of Care Framework were an obvious choice to ensure consistency. Moreover, we included dementia-specific scenarios and decisions: in the third section we included a question whether the authors prioritize comfort-oriented treatment measures as opposed to life-saving ones in a series of scenarios linked to various stages of dementia: being unable to read and understand texts, being unable to participate in conversations, needing constant help, living in a nursing home, having a change in personality, not recognizing any more close relatives, becoming incontinent, passing most of the day in bed, being unable to swallow food, losing alertness or awareness. Another addition addressed the potential inconsistency between the advance directives and future behavioral expressions of will authors could decide whether to give priority to the observed behavior or the advance directive (22). ACP Medizinisch Begleitet[®] decision aids were simplified in order to make them easier to read and understand for PWD (23). Alongside the development of the ADIA tool, two palliative care nurses and a specialized educator, all German-French bilinguals, underwent the ACP Medizinisch Begleitet[®] certification training in Zurich to serve as facilitators in the ADIA pilot intervention.

Using the tools explained above, the facilitators conducted two discussions for ACP facilitation with each participating PWD and a close family caregiver. In the first discussion, facilitators explained the goals and components of the ADIA intervention, prompted patients to reflect upon their values and preferences for healthcare, and discuss them with the caregiver. When no family caregivers participated in the first meeting, patients were encouraged to name a health care surrogate and to invite them to the next meeting. During the second visit, that took place one to two weeks later, participants engaged in documenting PWD's preferences. More important, this conversation aimed also at empowering the surrogate to speak for their relative. If necessary, a third meeting was set up with the participants in order to pursue the conversation and finalize the documentation.

2.2 Goals and outcome measures

The primary goal of this pilot study was to test the feasibility and acceptability of the ADIA tool and its aptitude to support patient autonomy, increase planning decisions and relatives' knowledge of patient preferences. The secondary goal was to explore appropriate outcome measures for a future effectiveness trial. Based on the literature review (24–26) we selected four psychometric scales to test pre-post variations in PWD's and relative's anxiety and depression (Hospital Anxiety and Depression Scale, HADS 26), PWD's autonomy (Questionnaire d'autonomie psychologique, 27), PWD's decisional conflict (Decisional conflict scale, 28) and relative's burden (Zarit Burden scale, 29). We added visual analog scales for perceived control and perceived involvement in healthcare decisions, as well as two hypothetical scenarios to test concordance between PWD and surrogate decisions. In the first scenario we investigated concordance of decisions about the implant of a pacemaker; in the second scenario we tested the concordance of decisions about artificial nutrition. Possible answer for relatives were "PWD accepts", "PWD does not accept", and "I don't know". Possible answers for PWD were: "I accept", "I don't accept", and "I don't know".

Concordance score was calculated by counting the number of answers consistent answers per scenario. An interview guide was developed to qualitatively explore participants' satisfaction with the intervention. More detailed information about the methodology is provided in the clinical trials international database clinicaltrials.gov.

2.3 Recruitment and consent procedure

The ADIA pilot trial aimed to include 20-30 patient-relative dyads. Participants for this study were recruited in a tertiary referral medical centre, in respite day care facilities, and in nursing homes in Western Switzerland. Screening and recruitment procedures and inclusion criteria depended on sites and were adapted all along the study. We discuss these adaptations in the results section.

Eligible patients or their relatives were contacted by an investigator and informed orally about the study procedure. If they agreed to participate in the study, the investigator organised the pre-intervention visit at their home, in the respite facility or in their nursing home. During this meeting, the investigator provided all study participants with written study information and explained any questions, enabling them to make an informed decision about their participation in the study. Given the patients' cognitive impairments, oral and written information were adapted based on the recommendations released by Inclusion Europe and the European Commission on Lifelong Learning Program (31). Participants were informed they could withdraw at any moment.

2.4 Study design

This was a pre-post pilot trial. Table 1 synthetize the study structure and contents.

2.5 Research ethics committee approval and consent to participate

The study protocol was submitted to the local research ethics committee (Commission d'éthique de la recherche du Canton Vaud). All methods were performed in accordance with the relevant guidelines and the Declaration of Helsinki. Written informed consent was obtained by each PWD and relative included in this study.

Even though the research was classified as a low-risk non-invasive clinical trial according to the respective law on human research, particular scrutiny was applied and the IRB process took 4.5 months due to the vulnerability of the study sample. As the IRB had the concern that ACP may cause distress to participants it required formal consent of the patients' primary care physicians, proof of the involvement of a psychiatrist as co-investigator, as well as an emergency response plan to address psychological distress that might emerge during ACP. Based on these adaptations, the study received IRB approval.

3 Results

We present the results in three parts: feasibility (3.1), acceptability (3.2), and outcome measures (3.3).

3.1 Feasibility

Two main challenges in terms of feasibility were to locate eligible patients and to tailor recruitment procedures to locations. At the beginning of the study, two sites were deemed promising in order to locate eligible patients for this study. These were a local memory clinic and an Alzheimer's disease advocacy group. Since we observed during the study high rates of attrition - due to among other factors to competition for research, gatekeeping and ambivalence about engaging in ACP - from screening to completion, we decided to include three other recruitment sites in order to increase the potential of eligible patients: a respite care facility, two nursing homes, and a geriatric unit of a tertiary referral hospital. In addition, we decided to advertise our study in a journal for seniors and to ask colleagues and acquaintances to speak about this study in their networks (word-of-mouth). This adjustment of recruitment sites was approved by the IRB and allowed us to increase the number of study participants. This adjustment of recruitment sites was approved by the IRB and allowed us to increase the number of study participants (see Table 2).

The recruitment procedures were adapted to meet the specificities of the recruitment site. At the hospital, potential participants to the study were screened for inclusion criteria during meetings aiming to coordinate research and patients' inclusion in research protocols. If patients fulfilled the inclusion criteria, their physician informed them about the study. For the Alzheimer's disease advocacy group, in respite care facilities, and in nursing homes, potential participants were identified by a nurse or a social worker that briefly explained the study and asked for patient agreement to meet an investigator. Only people that were favourable to the study were contacted by the investigator to organize a meeting. People that self-identified upon reading the journal advertisement or following the word of mouth were asked to contact one of the

investigators. Inclusion criteria were also adapted to accommodate clinical practice with regard to the dementia aetiology, diagnosis, and assessment of DMC. Table 3 presents initial inclusion criteria and adaptations we made to meet sites requirements. Table 2 depicts screening, inclusion, and number of participants that completed the study following their recruitment location. Figure 1 depicts reasons for attrition and refusal to participate.

It is worth noting that 44 PWD were excluded by their physician without giving any reason. Moreover, six patients introduced to the study by their physician said they were no more interested in participating when the investigator called them. In respite care facilities, the investigators met several potential participants who were eligible and had medically documented dementia but were not fully informed about their diagnosis.

Four proxies asked whether they could benefit from ACP without taking part in the study since they felt the procedure was too long: three of them accepted only after having been informed that the intervention was only available within the pilot trial. One PWD refused to participate due to study length. Framing the study as a research aimed to improve care for PWD was a successful strategy to engage people in the pre-post assessment, possibly because it leveraged empathy in order to help advance research and other people benefit of ACP. Nonetheless, lack of awareness was evidenced by three people saying that they already had advance directives but were unable to recall what kind of document they filled in, when they documented them or where they were stored.

3.2 Acceptability

Nine interviews were conducted during the pre-intervention assessment and 10 during the post-intervention assessment. For pre-intervention assessment participants were asked about reasons to participate in ACP. The main reasons relatives and patients alike brought up for their study participation were difficult experiences with the end of life of a close relative and the need to “make things easy” for the relatives (excerpt 1, 2 and 3, Table 4). Even though the first visit didn’t specifically investigate existing preferences about the end of life (just the existence of advance directives), five participants spontaneously mentioned their wish not to undergo futile care (Excerpt 6 and 7) before this had been discussed with a facilitator. Difficult relations with estranged family members who should be surrogate decision makers was also given as a reason for participating in the study. Four dyads referred to having difficulty communicating about this topic due to the emotional charge of the discussion, either among the couple (excerpt 4) or between them and their children (excerpt 5). This was presented as a reason for participating in ACP or as a reason for not sharing (yet) the decisions with their children. Other reasons to engage in ACP included age, health status, and, for one participant, the hope that participating in this study would result in better treatment of his recently diagnosed Alzheimer’s disease.

Among the elements most appreciated, participants noted the facilitator’s technique – the fact that she was an agreeable person, punctual and flexible in terms of schedule, her way of explaining things (for example by giving examples from her actual experience), thus facilitating discussions that patients would have only reluctantly had with their partners. Four participants also appreciated elements related to the structure of the ACP discussion, such as the opportunity to discuss values before decisions. The mere opportunity to document decisions with the support of a professional was noted as the main element appreciated by four participants.

Several patients referred to ACP’s beneficial impact on the relationship with the relative participating in the discussion. Two participants mentioned that ACP allowed them to engage in a difficult discussion together and learn something more about one another. Three participants noted that documenting preference also results in a relief, either for the patient or for the proxy. Other results noted were that ACP set in motion other advance decisions – such as making decisions about funerals – or encouraged participants’ acquaintances to document their advance directives.

Among the main difficulties underlined was the complexity of the ACP part on medical treatment decisions, for example the lacking clarity of the questions, the use of percentages to indicate the likeliness of survival, and the complicated way in which options about future care were presented. Two patients felt that some formulations were too complicated and needed their relatives to “translate” them.

3.3 Outcomes measures

Six meetings took place with a dyad consisting of a PWD and a relative. In three cases, the PWD was accompanied by two relatives. In the latter case, we asked the one that self-identified as main caregiver to fill in the scales. In all cases this was a woman. Two PWD participated alone. Table 5 displays the socio-demographic characteristics of patients and their main caregivers.

Most patients struggled with the psychometric assessment scales. The Psychological Autonomy Inventory was judged to be long and the PWD did not understand all the questions. Most patients had problems filling in the Decisional Conflict Scale, because they could remember going through the ACP process but could not recall particular steps or decisions apart from being against futile care.

People with dementia therefore had to be assisted by the investigators for filling in questionnaires and scales. Because of the above mentioned difficulties with some scales, we prioritized the HADS, the relatives’ perceived control on healthcare decisions, and the concordance between patient and their relatives’ decisions on specific healthcare scenarios. Despite this adjustment, we observe a large amount of missing data,

particularly in PWD questionnaires (Table 6). Altogether these experiences suggest that scales tend to burden PWD and make them feel uncomfortable. One spouse also reported being hurt by the Zarit burden scale since she felt caring for her partner was not a burden. Several other relatives also found that the study entailed too many questionnaires and scales.

4 Discussion

The challenges we encountered will be presented and discussed following three main axes: 1) engaging PWD and their relatives in ACP, 2) researching how gatekeeping is enacted by professionals, and 3) designing pre-post studies and outcome measures that are appropriate to PWD and their relatives.

4.1 Engage PWD and their relatives in ACP

The encountered difficulties in engaging PWD and their relatives in ACP might be explained in several ways. Firstly, in Western Switzerland there is a lack of awareness about the tools that allow people to anticipate healthcare decisions, such as durable power of attorney and advance directive (32). Shared decision making is not a standard in Switzerland neither, particularly for older PWD (33, 34). Hence, PWD and their relatives might be hesitant whether it is appropriate for them to express the wish of planning ahead for loss of decision-making capacity.

Secondly, taking care of PWD poses a significant challenge to relatives, and care planning for the present and immediate future tends to take precedence over advance care planning (6). This might explain why some relatives were concerned about the length of the study. Yet, prioritizing actual care planning might also conceal a lack of knowledge about the health trajectory of PWD and an understanding of physical health as completely separate from mental health (35). Indeed, in addition to usual barriers to ACP, PWD and their relatives, according to our study, tend to avoid planning ahead for various reasons, including a strong need to stay focused on the present to circumvent acknowledging the certainty of progressive impairment; the patient's and relatives' belief that this acknowledgment would be upsetting their loved ones; the expectation that family members who are closely involved will take care of issues as they arise; and lack of interest because PWD themselves will not have awareness of the decisions being made (35).

Thirdly, it is worth noting that several PWD we met in respite care were not fully aware of their diagnosis. This might suggest that the diagnosis and stages of dementia were not always explained in a timely and sufficient manner nor were they fully understood by the patients and their relatives. Autonomous decisions about future care do, however, require appropriate information to weigh up the pros and cons (6). ACP provides patients and their relatives with an opportunity to obtain more information about the disease, its likely course, expected problems and therapeutic options. Yet, partial information or non-disclosure of the diagnosis disempower patient and their relatives and may prevent them from benefitting from ACP.

4.2 Gatekeeping by professionals

End-of-life-related research, particularly with vulnerable people, presents numerous methodological challenges (35, 36). Whereas most of them were expected, throughout the ADIA pilot study we encountered substantial unanticipated gatekeeping by the research ethics committee and healthcare professionals.

A fundamental assumption that underlies modern clinical research ethics is that certain categories of people are deemed "vulnerable," and that this calls upon a duty to provide special protections (38). In our research, this duty was evidenced by the research ethics committee expressing several concerns about the safety of the intervention for PWD and asking additional physicians to be included as co-investigators in the study. An overly strict application of these rules, however, is a well-known form of overregulation that makes research with vulnerable persons particularly arduous (39) and may prevent this patient population from benefitting of innovative interventions in healthcare. The ethical principle that is violated by such overregulation is the proportionality of risk mitigation and access to benefits.

During the screening for our study, almost half of the patients were excluded by their physicians for several reasons. Often times opinions diverged between professionals with regard to patient decision-making capacity. Indeed, it is not clear whether/how the fluctuation of cognitive impairments impacts decision making capacity (40). Moreover, physicians have diverse appreciation of patient decision making capacity (41). The fact that about half of the patients screened were excluded by the physicians also suggests an assessment of eligibility by adding implicit supplementary criteria regarding severity of other symptoms (36, 42). This gatekeeping practice may conceal paternalistic attitudes since it suggest that physician's assessment is based on what the physician believes would harm PWD and their relatives, on PWD's supposed compliance, and on physician's sense of the patient's interest and attitude (43). At university hospitals, another reason for the physicians to have refused access to their patients may have been a competition between research studies and a prioritization of pharmaceutical trials and biomarker studies over studies of complex communication interventions that do not fit the traditional mainstream logic of medical research.

As mentioned, PWD in respite care facilities were often times not aware of their diagnosis even though they were experiencing cognitive impairments and their professional carers had confirmed their eligibility for the study. This suggests that the diagnosis of dementia and the (neurodegenerative) disorders leading to dementia might not be disclosed in a comprehensible way to PWD. The literature indeed pinpoints difficulties with disclosing the diagnosis (36, 39), assessing patient knowledge about their diagnosis, and providers' fear to initiate the process of information and disclose sensitive information (44).

Gatekeeping has consequences however. Firstly, it may violate the ethical principles of respect of autonomy and of the right to self-determination, beneficence, and justice with regard to a fair distribution of benefits and burdens of research (45). There is a consensus in the literature that, in order to improve ACP, healthcare professionals should be responsible for providing patients and their relatives with opportunities to discuss ACP (46). Goal-oriented care and shared decision making models advocate for a more active role of professionals, patients and their relatives and provide valuable frameworks to broach ACP with people with dementia (19).

Secondly, gatekeeping might result in sampling biases that prevent researchers from validly assessing research outcomes. In this respect, three effective recruitment strategies seem to be systematic screening of patient by a researcher, thoughtful messaging to show the importance of the research study, and seeking the support from clinical champions (36). It will be important in the future to investigate in advance staff's openness to innovative approaches and to collaboratively design the overall study procedure with staff involved in the recruitment procedure.

4.3 Acceptability of the ADIA tool

Several authors described appropriate outcome criteria for assessing ACP (25). Among the most common, we chose to prioritize the HADS (27) for the patients and the Zarit Burden Scale for the relatives (30) since they are used in routine screening in hospital clinic and we thought PWD and their relatives would be familiar with it. Yet, when questioned based on the HADS, PWD found it difficult to remember how they have been feeling in the past two weeks, which raises concern about the appropriateness of this scale for this population and this context (47). The Decisional Conflict Scale (29) is a tool that is widely used to assess ACP effectiveness with patients and their relatives (48). It was, however, difficult for PWD to remember decisions they had made and thus to apply the scale. Those challenges have already been described in the literature but effective strategies to address them in PWD are still missing (49). We conclude that pilot trials following a pre-post design with quantitative outcome measures may not be the most appropriate to PWD and their relatives. Indeed, questionnaires put PWD's cognitive capacities and attention span on strain. On the other hand, the length of the study also posed organisational challenges to proxies.

Visual analogue scales that we used to measure perceived control on and perceived involvement in healthcare decisions, proved much easier for PWD. Well accepted were also the two hypothetical scenarios by which we tested the concordance between PWD decisions and surrogate decision on their behalf. Interviews were also much appreciated. We thus recommend using tools that focus on the current thoughts and feelings of PWD, and on concrete decision. This might imply the need to adapt tools or create new ones. The balance between quantitative outcomes measures and the qualitative assessment of patients and proxies' experience could be improved in a future randomized control trial.

Despite the challenges described above, we found promising results with regard to the acceptability and the usefulness of a dementia-specific intervention of ACP. Proxies expressed satisfaction with the procedure, especially with the opportunity to discuss these issues with the facilitator. High-quality trials demonstrate the potential of ACP understood as a longitudinal conversation to help future surrogates prepare for in the moment decision making (50). These studies evaluated a broader (and more fitting) range of outcomes than prior work, including surrogate preparedness. Our study confirms that finding since it underlies that proxies' perceived control increased and some of them felt that the presence of documents supported their role. Concordance between patient preferences and surrogate decisions changed from 83–100%. In addition, during the Covid-19 epidemic, one daughter reported to her mother's physicians that ACP helped her feel comfortable in making substitute decisions about her mother's treatment.

We advocate to decrease the use of scales in order to assess dementia-specific ACP tools and privilege qualitative interviews, visual analogue scales, and questions based on concrete scenarios to help PWD and their proxies to project the future. Outcomes measures should focus on investigating proxies' preparedness to make decision on the behalf of the PWD since much of the existential burden of healthcare decision will fall on the proxies' shoulders.

5 Conclusion

Misconceptions about dementia and ACP in PWD, their relatives, and health professionals, combined with structural challenges in institutions, have the power to impede research and implementation of ACP in Western Switzerland. For this reason, we advocate for a systemic approach of ACP. Firstly, consistent efforts should be provided at a national level to raise awareness about tools that allow people to plan ahead their healthcare. Secondly, there is an urgent need to increase healthcare providers' awareness and knowledge of ACP in order to allow PWD and their relatives to benefit from it. In order to improve ACP implementation in PWD care, professionals should be trained to facilitate ACP for PWD

and their relatives, and ACP should be included in healthcare routines. In order to ensure that PWD wishes are known and applied, executives should be involved in creating the conditions for ACP and dissemination of decisions that stem from ACP.

List Of Abbreviations

ACP Advance care planning

Covid-19 Corona Virus Disease

DMC Decision-making capacity

PWD People with dementia

Declarations

Ethics approval and consent to participate

This study was approved by the local research ethics committee.

Consent for publication

N/A

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interest

The authors declare no conflict of interest in relationship with this study.

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Authors' contributions

RJJ and ERT conceived, designed, and planned the research. FB and AS were the co-investigators and performed participants screening, the data collection and the data analysis. RJJ acted as sponsor. FB, AS and RJJ wrote the manuscript and ERT contributed with comments.

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Tables

Table 1: Study design and content of the visits

Aim of the visit:	Pre-intervention assessment	Intervention		Post-intervention assessment
		Part I	Part II	
	<i>Leader:</i>	<i>Investigator</i>	<i>ACP Facilitator</i>	<i>Investigator</i>
Information and consent		x		
Eligibility		x		
Sociodemographics		x		x
Perceived control on healthcare decision		x		x
Perceived involvement in healthcare decisions		x		x
Hospital anxiety and depression scale		x		x
Decisional conflict scale (only patients)		x		x
Psychological Autonomy Inventory (only patients)		x		x
Zarit burden scale (only proxies)		x		x
Concordance between patient and proxy decision		x		x
Reflection on value and treatment preferences			x	x
Advance directive documentation			x	

Table 2: People included by location

Location	N eligible	N included	N completed
Memory clinic and Geriatric and rehabilitation unit	81	8	7
Alzheimer's disease advocacy group	-	0	-
Respite day care and nursing homes	20	8	4
Word-of-mouth	2	0	0
Advertisement	2	0	0
Total	105	16	11

Table 3: Inclusion and exclusion criteria

At the beginning	After discussion
Older than 65 years	
Having been diagnosed with an early-stage dementia of Alzheimer’s disease aetiology	PWD of neurodegenerative and/or vascular etiology People with a clinically probable neurocognitive disease People with mild cognitive impairments PWD is informed about the diagnosis by their physician Are excluded: People with fronto-temporal dementia
Retaining full decision-making capacity according to the Montreal Cognitive Assessment (MoCA > 20), the Mini Mental State Examination (MMSE > 20) or Clinical Dementia Rating Scale (CDR < 1.5)	DMC is assessed clinically Are excluded : People with anosognosia
Showing interest in advance care planning or advance directives	
Having the necessary French language skills to engage in conversations	
Having a close family caregiver willingly to participate to this pilot intervention	PWD that have a family caregiver willingly to participate and PWD alone

Table 4: Exemplary excerpts from qualitative data

Topics	Occurrences	Exemplary excerpt
End of life or death of a close one	5	<p>(1) “Well, there was your brother, that became suddenly sick with a brain hemorrhage... he was left four months without speaking, being able to move, walk, nothing... Heu, I was pained by that situation (...) and after all, he had a chemotherapy anyway...” (D1V1, relative)</p> <p>(2) “There was my brother’s wife... so, her son, was on artificial nutrition. It stroke me... » (D6V1, relative)</p>
Difficulty communicating on this topic	4	<p>(3) “You (PWD) don’t like to speak about that... seriously, when we are only the both of us. So... when there’s someone else (the ACP facilitator), it helps...” (D1V1, relative to PWD)</p> <p>(4) “Our children, they are a little bit avoiding this conversation. (...) Yesterday, we said to our son that we would meet you this morning... and suddenly his expression changed, he shuttered us out. We feel that in his opinion speaking about that might bring us all bad luck” (D4V1, relative)</p>
Preference for no futile care	5	<p>(5) “Well, our treatment preference is... no futile care... it (dying) should be quick” (D2V1, PWD)</p> <p>(6) « Relative: Actually, my mother, she always said that she didn’t want futile care to keep her (alive)... ” PWD: Yeah, I told you all that a long time ago.” (D16V1)</p>

Table 5: Sociodemographic characteristics

	Patients (N=11)	Relative (N=9)
Median age	81	62
Women	5 (45%)	9 (100%)
Degree:		
1. Mandatory school	1 (9%)	1 (11%)
2. Certificate of apprenticeship	5 (46%)	3 (33%)
3. Federal certificate	3 (27%)	2 (22%)
4. University or HES or EPFL	2 (18%)	3 (33%)
Patient lives:		
1. Alone	5 (45.5%)	
2. With a relative	5 (45.5%)	
3. In an institution	1 (9%)	
Main caregivers are:		
1. Spouse		6 (66%)
2. Daughter		3 (33%)

Table 6: Outcome measures (means unless said otherwise)

	Pre	Post
Hospital anxiety and depression scale:		
1. Median anxiety (min/max):	16 (12/18)	15 (14/20)
2. ◦ Patient (N=9)	16 (15/18)	18 (14/18)
◦ Proxy (N=9)		
3. Median depression (min/max):	6.5 (3/11)	4.5 (2/11)
4. ◦ Patient (N=9)	8 (3/12)	8 (4/12)
◦ Proxy (N=9)		
Mean Zarit Burden Score (relative only, N=9)	28.28	31.83
Concordance between patient preferences and surrogate decision:		
1. Scenario 1 (N=6)	5 (83%)	6 (100%)
2. Scenario 2 (N=6)	5 (83%)	6 (100%)
Mean relative's perception of being in control from one (no control) to 10 (full control) (N=9)	5.83	8.16
PWD advance directives present, n (%) (N=11)	2 (18%)	10 (90%)
Surrogate decision maker designated, n (%) (N=11)	4 (36%)	9 (81%)

Figures

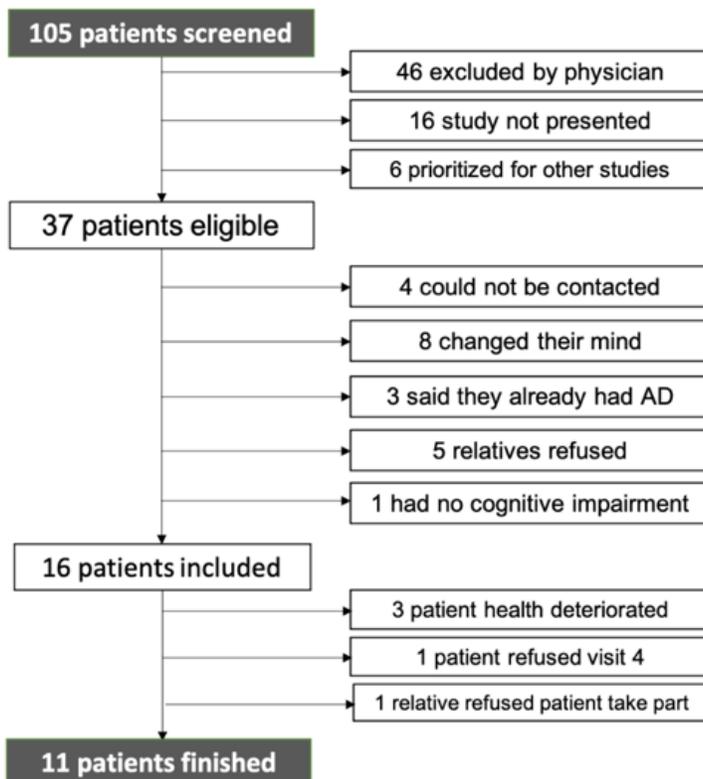


Figure 1

Reasons for attrition from screening to study termination. AD = advance directives.