

RESEARCH ARTICLE

Consensus definition of advance care planning in dementia: A 33-country Delphi study

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Abstract

INTRODUCTION: Existing advance care planning (ACP) definitional frameworks apply to individuals with decision-making capacity. We aimed to conceptualize ACP for dementia in terms of its definition and issues that deserve particular attention.

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Presentations: The design and preliminary findings of this work have been presented at the online European Association for Palliative Care 17th World Congress October 6 to 8, 2021, and an abstract was published as: van der Steen JT. Developing guidance in addressing the challenges of advance care planning in dementia: An EAPC Delphi study. *Palliative Medicine* 2021;35(1S):14.

The findings were presented at the 8th International Conference on Advance Care Planning (ACP-i), Singapore, May 24 to 27, 2023.

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METHODS: Delphi study with phases: (A) adaptation of a generic ACP framework by a task force of the European Association for Palliative Care (EAPC); (B) four online surveys by 107 experts from 33 countries, September 2021 to June 2022; (C) approval by the EAPC board.

RESULTS: ACP in dementia was defined as a communication process adapted to the person's capacity, which includes, and is continued with, family if available. We identified pragmatic boundaries regarding participation and time (i.e., current or end-of-life care). Three interrelated issues that deserve particular attention were capacity, family, and engagement and communication.

DISCUSSION: A communication and relationship-centered definitional framework of ACP in dementia evolved through international consensus supporting inclusiveness of persons with dementia and their family.

KEYWORDS

advance care planning, conceptualization, decision-making, dementia, palliative care

Highlights

- This article offers a consensus definitional framework of advance care planning in dementia.
- The definition covers all stages of capacity and includes family caregivers.
- Particularly important are (1) capacity, (2) family, (3) engagement, and communication.
- Fluctuating capacity was visualized in relation to roles and engaging stakeholders.

1 | BACKGROUND

Conversations about future care preferences such as in the context of advance care planning (ACP) support person-centered caregiving. ACP is an evolving concept; it increasingly emphasizes the importance of ongoing conversations between patients, relatives, and health care professionals.¹ It is also increasingly understood as a tool to promote well-being rather than just to reduce harm.² ACP essentially involves discussing and, if appropriate, documenting desired future care; however, available consensus definitions focus on medical care. One international Delphi study, focused mostly in the United States, defined ACP as “a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care” and its goal to “help ensure that people receive medical care that is consistent with their values, goals, and preferences during serious and chronic illness.”³ Another international Delphi panel, focused mostly in Europe, included care more generally, defining the goal of ACP as enabling “individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health care providers, and to record and review these preferences if appropriate.”⁴

Both international definitions apply only to ACP in individuals who are able to participate in decision-making and aim to enable

people to make autonomous decisions throughout the ACP process. However, Sallnow et al.,² in their report of the Lancet Commission on the Value of Death, prioritized developing relational frameworks and models to include collective decision-making. This may be more reflective of countries that prioritize community and family, whereas much research on ACP is conducted in high-income countries.

Research on ACP provides evidence for its benefits for the person, family, and society.^{5,6} A conventional view of ACP as focused only on the documentation of medical treatment has been criticized.⁷ However, the concept of ACP has evolved to include preparation for medical decision making and communication to iteratively articulate preferences for future care and treatment, while also offering room for collective decision making.

About one in four persons in Western countries will develop dementia,⁸ and several studies have shown positive effects of ACP with commonly a strong role for family of persons with dementia. For example, reviews^{9–11} conclude that ACP can result in receiving care concordant with preferences and fewer burdensome treatments. Moreover, the communication process of ACP could help individuals anticipate an uncertain course of inevitable cognitive and physical decline and prepare family for a central role in decision-making when the patient can no longer be involved.^{12,13}

Therefore, ACP in dementia requires a flexible, pragmatic approach that is adapted to the individual and their social context. Such an approach may serve as a model to define ACP inclusive of persons with declining capacity more generally. Therefore, to provide the foundation of such an approach, we aimed to conceptualize ACP in dementia in terms of its definition and issues that deserve particular attention in conducting ACP for persons with dementia and their family.

2 | METHODS

In March 2019, the European Association for Palliative Care (EAPC) board approved a highly diverse task force on ACP in dementia (Table 1) with two aims: to conduct a Delphi study to (1) achieve consensus on a conceptualization of ACP in dementia; and (2) to provide recommendations for practice, policy, and research. In this article we report on the first aim, which involved developing a conceptualization (a definitional framework) specifically for ACP in dementia. The Delphi study comprised three phases: (A) preparing the conceptualization; (B) recruiting panelists and data collection; and (C) EAPC board review. The reporting follows the Guidance on Conducting and REporting DELphi Studies (CREDES) in palliative care.¹⁴

2.1 | Protocol ethics review and registration

The Medical Research Ethics Committee Leiden-Den Haag-Delft reviewed the study protocol and, on September 2, 2021 (reference N21.105), declared the study exempt from the Dutch Medical Research Involving Human Subjects Act (WMO). Invitees were provided with an information letter and a consent form for download. Participants then consented by marking a box on the introductory pages in the first survey round. They were free to withdraw at any time. Confidentiality and data protection measures were taken as appropriate. The protocol of the Delphi study was registered at OSF¹⁵ and in a trial registry (NL9720),¹⁶ both on September 7, 2021.

2.2 | Preparing the conceptualization (phase A)

The task force adapted the prior generic consensus conceptualization of ACP⁴ (phase A in Section S1 and Section S2). The 43 elements (an extended and an abbreviated definition, 27 recommendations, and 14 elements of evaluation) were adapted to apply to dementia. The adaptations were informed by the task force member's expert understanding and by a total of 24 published review articles identified from 3 meta-reviews^{11,17,18} in the protocol¹⁵). Subsequently, four core team task force members (JTvdS, MN, LVdB, IJK) mapped the proposed adaptations to the 43 elements from the generic conceptualization⁴ as "retain as is," "revise," or "delete," and three researchers also independently classified the adaptations as (1) "substantial revision" defined

RESEARCH IN CONTEXT

- 1. Systematic review:** Adaptations to a generic advance care planning (ACP) definitional framework were informed by meta-reviews on ACP in dementia. Subsequently, in a systematic, transparent manner, a Delphi panel of experts from Western and non-Western countries evaluated the adapted content and generated new content in four survey rounds.
- 2. Interpretation:** The resulting communication and relationship-centered definitional framework evolved through consensus, offers a definition and three issues of particular importance in ACP in dementia unique in its focus on a communication process that continues independent of the level of capacity, and beyond documenting specific current or end-of-life treatment preferences. It should promote inclusiveness of persons with dementia and their family caregivers.
- 3. Future directions:** The inclusive conceptualization of what ACP in dementia is, provides a much-needed basis for research and policy. In addition, areas of ambiguity were identified and the methodology may serve as a template to conceptualize ACP with other specific conditions.

as two or more changes; (2) a "specification"—defined as greater precision or detail; (3) an "addition"—of new information or element; or (4) adapted style or phrasing only. This preparatory work was discussed in multiple meetings and communications of the full task force and the core team from March 2019 to November 2020.

Next, the core team analyzed the agreed-upon and classified adaptations for dementia to identify themes. The themes informed (three) issues that deserve attention because they are specific, or of particular importance in the case of ACP in dementia. The full task force discussed these themes and labeled them. Subsequently, for each theme, the task force formed subgroups, each reaching out to other experts as necessary for a refined description of the themes to form a definitional framework along with the adapted generic definition. We recognized contexts with less than ideal ACP situations in practice in the case of dementia, possibly warranting a pragmatic approach. Therefore, in addition, we formulated clear boundaries on what is ACP and when it is not ACP to be evaluated by the panel. Based on the panelists' feedback, we revised the statements for re-evaluation, for example, by softening or adding nuances to also achieve a consensus on what is, pragmatically, still ACP in dementia, and what it is not. For example, we started with brief and clear statements such as "If it becomes too difficult to involve the person with dementia due to diminished capacity, it is still ACP if..." As another example, we revised the initial statement "If preferences for current care and treatment are discussed but not future care and treatment, it is still ACP" to "ACP includes exploring preferences

for future care but it may be helpful to start with discussing current care.”

2.3 | Recruiting panelists and data collection (phase B)

From our research and clinical networks and PubMed, we identified candidates for a diverse Delphi panel of experts in dementia care and/or ACP research, practice, and policy, aiming at diversity regarding this expertise, continent of residence, and profession. On September 30, 2021, we invited the candidates to an online survey, anticipating four or five Delphi rounds and aiming to recruit about 100 participants. Self-reported characteristics of the panelists were collected in the first survey round. At request, starting with the second round was allowed if the timing of the first survey round was inconvenient. We then separately sent them the section with self-reported characteristics of the respondents included in the first survey round.

In the survey, we informed the panel of our broad definitions (Section S3) for the persons involved such as family, which includes friends, and for capacity needed to play a role in the ACP process. Over 9 months, four online survey rounds with interim analyses and feedback were conducted with data collected up to June 29, 2022 (Section S2). Surveys were built in Castor Electronic Data Capture Amsterdam featuring a user-friendly layout showing a menu with sections, completed sections and items, and color illustrations. We programmed warnings of incomplete entries, avoiding mandated data entry that risks early termination of completing the survey. We piloted the surveys with local colleague researchers. We sent up to two reminders to panelists who had not completed the survey nearing closure. Reminders were personal emails from the task force chair after we discovered that the first reminder sent in bulk was often not received or was identified as spam. Invitations to participate in the Delphi were stopped if potential participants did not respond to the first two Delphi survey requests.

2.4 | Evaluation Criteria for (dis)agreement and consensus

We used previously developed conservative criteria for consensus, based on median, dispersion (IQR, interquartile range) and percent agreement^{12,19} (see the criteria in footnotes to Tables). Agreement response options with statements were (with the numbers added to show the distance and emphasize symmetry) “(1) strongly disagree,” “(2) moderately disagree,” “(3) neither agree nor disagree,” “(4) moderately agree,” and “(5) strongly agree.” Regarding themes we identified as covering issues specific to or of particular importance for ACP in dementia; we also asked the panelists to rate “How important are the three issues for advance care planning in dementia?” on a scale from 0, not important, to 10, very important. We required a minimum mean of 8. We also asked if any important issues were missing. In round 1,

we referred to “distinct” (e.g., “ACP is distinct for persons with dementia which is importantly a result of changing mental “capacity” of the person with dementia”). The term “distinct” was misunderstood by some panelists. Therefore, in the next rounds, we replaced “distinct” with “specific.” We also asked panelists to rate descriptions of the issues in the survey (asking, for example, “the text below adequately summarizes the issue of capacity”).

After the first round, subsequent Delphi rounds were conducted to achieve consensus. In these rounds we proposed revisions from the previous rounds along with a summary of the panelists’ comments and the panelist’s previous rating in the invitation email with a link to the survey environment.

2.5 | Planned survey content and analyses

Descriptive analyses quantified evaluations. Open-ended comments were summarized and analyzed by multiple authors to inspire revisions (shown in the Sections S4-S7). Pre-planned subgroup analyses of consensus included subgroups of physicians, experts with expertise in ACP in dementia specifically, and those with personal experience with dementia. The Supplement shows that the exact content was developed in-between rounds, based on the panelists’ feedback. The issues specific to dementia were presented in round 1 and in round 3 again to allow more time for the subgroups to revise the content.

2.6 | EAPC Board review (phase C)

The EAPC Board of Directors reviewed and approved the article.

3 | RESULTS

3.1 | Adapting the conceptualization for dementia

Of 43 elements of the generic conceptualization of ACP for dementia, the task force retained 10 as is, revised 32, and 1 was deleted in preparatory phase A. Most adaptations concerned additions of new information or elements (12 of 32), or specifications (11 of 32 offered greater precision or more detail). Eight of 32 elements contained more revisions and were classified as substantial revisions. These included the extended and abbreviated definition that were also adapted for style and phrasing. One revision concerned phrasing adaptation only. Analyzing the adaptations, these covered the themes of capacity, family, and engagement and communication that emerged as three issues specific or of particular importance to ACP in dementia.

3.2 | The task force and panel

The response rate to the online survey was 63.3% (107/163; Figure 1). Most Delphi panelists (58.9%, $n = 63$ from 17 countries) were from

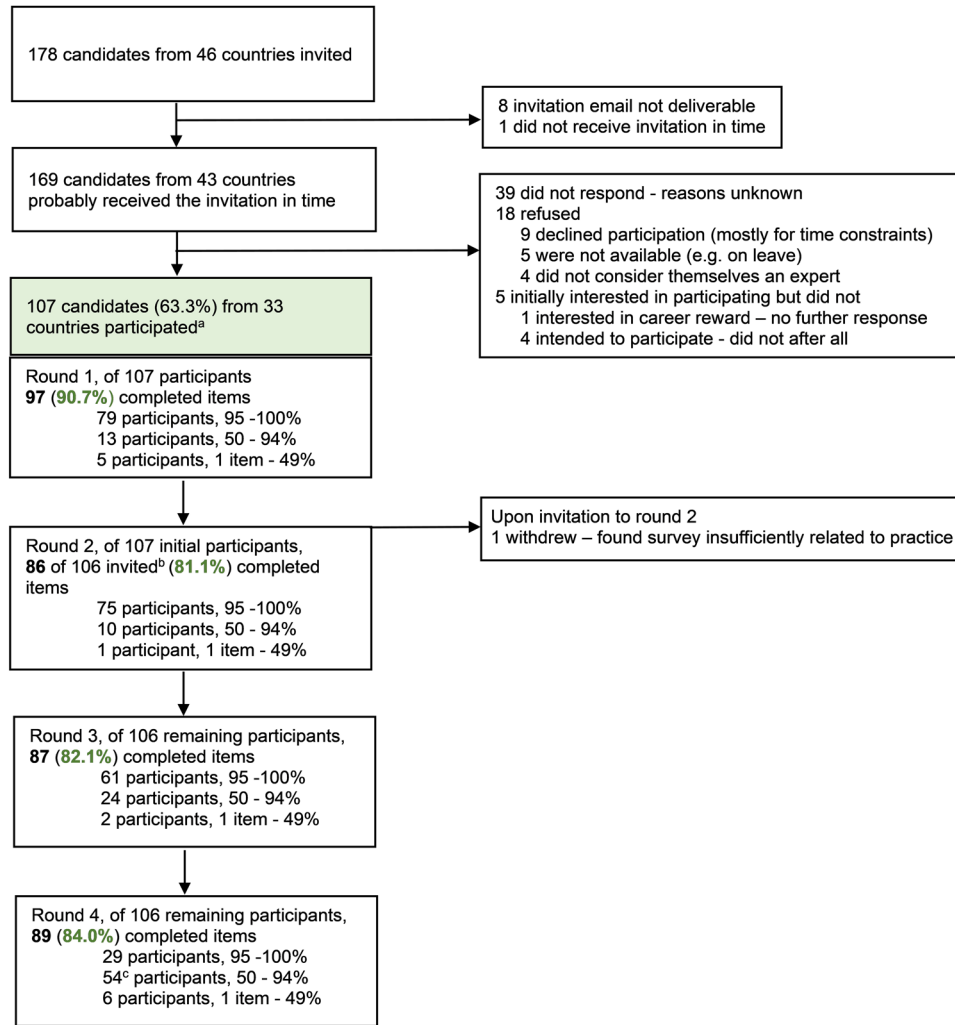


FIGURE 1 Flow chart participation Delphi expert panel and response per survey round. ^aParticipants were defined as those who provided informed consent and completed survey items upon the first or the second invitation (no third invitation was sent to non-respondents). Overall response rate: 107 of 169 (63.3%) participated. Of the 107 (initial) participants, 11 (10.3%) completed a single round, 8 (7.48%) completed 2 rounds, 22 (20.6%) completed 3 rounds, and 66 (61.7%) completed all rounds. ^bWe forgot to send an invite to one of the participants. ^cOf 54 participants who completed 50% to 94%, 39 completed 92%, which was the maximum percentage when missing a hidden item beneath a long list of possible outcomes for evaluation.

Europe and the Americas (18.7%, including $n = 3$ of 20 from the Southern and Middle Americas), and almost a quarter (22.4%, $n = 24$) was from 12 other countries (Table 1). Almost half were physicians or active researchers. Mean professional experience was 24.4 (SD 11.8) years. About three-quarters had experience with ACP in populations other than dementia or personal experience. Characteristics of the task force were similar except for more nurses (half, versus a fifth of the panelists) and task force members had somewhat greater expertise and professional experience.

3.3 | The definition of advance care planning

A consensus of the extended definition was decided on during the first survey round, and the abbreviated definition was decided on in the

second survey round. The final extended definition adapted for dementia is presented in Table 2 (compared to the generic definition shown in Section S4). Essentially it was defined as a communication process adapted to capacity and continued with family.

The extended definition achieved a consensus with high agreement immediately. The median agreement rating of the extended definition was 5 (IQR 1, ranging 4 to 5), and 85.3% (23 moderately and 58 strongly of 95) agreed. The abbreviated definition was supplemented again with parts of the extended definition on values and goals based on the panelist' feedback (shown in Section S4 along with the refined protocol in Section S2). The abbreviated definition also achieved a consensus with high agreement, median rating 5 (IQR 1, ranging 4 to 5), and 89.3% (17 moderately and 50 strongly of 75) agreed. There was also high consensus for the extended and abbreviated definitions among all subgroups of medical

TABLE 1 Task force and panelists' characteristics.

	Task force (n = 14) ^a	Panel (n = 107)	
	n or mean (SD)	n	% or mean (SD)
Continent of residence (panelists: 33 countries), %			
Europe (EuroVoc; ^b 18 countries; panelists only: 17)			
Western Europe (7)	7	35	32.7
Southern Europe (3)	2	15	14.0
Northern Europe (4)	0	7	6.5
Eastern and Central Europe (4; panelists only: 3)	2	6	5.6
Americas (4 countries)			
Northern Americas (2)	1	17	15.9
Southern and Middle Americas (2)	0	3	2.8
Asia (6 countries)	1	11	10.3
Australasia (2 countries)	0	6	5.6
Middle East (2 countries)	0	3	2.8
Africa (2 countries)	0	2	1.9
Alternating between continents (4 countries, all with other participants)	0	2	1.9
Gender, %			
woman	11	74	69.2
man	3	33	30.8
other	0	0	0
prefer not to say	0	0	0
Age, mean number of years (SD)	55.0 (8.3)	104	52.0 (12.1)
Professional experience, mean number of years (SD)	29.9 (10.0)	103	24.4 (11.8)
Profession (more possible), %			
medical	4	53	49.5
physician	4	52	48.6
physician assistant or nurse practitioner	0	1	0.9
nurse (any level)	7	21	19.6
psychologist	2	12	11.2
ethicist	1	9	8.4
policy/administration	2	8	7.5
social worker	0	5	4.7
epidemiologist	2	4	3.7
spiritual counselor	0	3	2.8
other, for example, sociologist, occupational therapist, lawyer, economist	3	12	11.2
Researcher, past, and recent activity, %			
very active researcher (leading research and publishing extensively)	12	53	49.5
researcher but not particularly active (contributing to research and some publications)	2	35	32.7
PhD student or early career researcher	0	13	12.1
not a researcher	0	6	5.6
Specific expertise in ACP in dementia, %			
yes, ACP in dementia specifically	11	60	57.7
no, ACP, or dementia, or both but not combined	3	44	42.3

(Continues)

TABLE 1 (Continued)

	Task force (<i>n</i> = 14) ^a	Panel (<i>n</i> = 107)	
	<i>n</i> or mean (SD)	<i>n</i>	% or mean (SD)
Expertise in ACP in other populations or the general population, %^c			
yes	11	66	75.9
no such experience	3	21	24.1
Personally experienced a family member or friend, %			
having advanced dementia at the end of their life, yes	12	72	70.6
no such experience	2	30	29.4

Roles: two chairs who are also core team and subgroup member, two core group and subgroup member, one core group member only, four subgroup members, four regular members, and one EAPC link person.

^aWe started the task force with 15 members but lost one member who died in phase 1. Data on *n* = 14 are complete. Task force roles included chair (*n* = 2) who were also core team and subgroup member, other core team and subgroup member (*n* = 2), subgroup member (*n* = 7), subgroup member and EAPC link person (*n* = 1), or member with no special task (*n* = 2).

^bEuroVoc multilingual thesaurus maintained by the Publications Office of the European Union.

^c*n* = 87; refers to experience through practice, research, or policy asked in fourth round, whereas all other characteristics were asked in the first round, which allowed for following up on any missing responses.

TABLE 2 The consensus definition of ACP in dementia.

Extended final definition Presented in round 1	Abbreviated final definition After round 2
<p>Advance care planning (ACP) in dementia is a process of communication about future care and treatment preferences that covers preparation for and negotiating, or also arranging of or deciding about future care and treatment with the person with dementia, family, and the health care team, preferably with ongoing conversations and documentation. It enables persons with dementia, in a manner adapted to their decisional capacity, to be supported by health care providers and family to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future care and medical treatment, and to discuss these with family and health care providers. ACP addresses concerns of the person with dementia and the family across the physical, psychological, social, and spiritual domains. It encourages persons with dementia to identify a personal representative and to record and regularly review any preferences, so that their preferences can be considered in continued conversations between family and health care providers should the person with dementia at some point be unable to make their own decisions.</p>	<p>Modified based on feedback in round 2 about parts of the extended definition; “values and goals” additionally to be retained in the abbreviated definition</p> <p>ACP is a process of communication about future care and treatment preferences, values and goals with the person with dementia, family, and the health care team, preferably with ongoing conversations and documentation. This process is continued when the person with dementia becomes unable to make their own decisions.</p>

professionals, specific expertise in ACP in dementia, and personal experience.

Table 3 shows agreement with statements that sought to operationalize the definition, clarifying its boundaries, and Section S5 details the process of achieving consensus. There were statements about who can participate and in which setting, considering the person's awareness of their dementia and capacity. Furthermore, the “in advance” time window could refer to also address both current care and end of life. Multiple iterations were needed for all but a statement about ACP if there is no family. There were some differences in the three preplanned

subgroup analyses in (just) achieving a consensus or not, but there were no clear patterns of differences.

3.4 | Conceptualization of issues that deserve particular attention in ACP in dementia

Consensus was reached in two Delphi iterations (included in survey rounds 1 and 3) on the three issues of capacity, family, and engagement and communication that are specific or of particular importance

TABLE 3 Specification and clarification of the ACP in dementia definition in terms of inclusiveness and minimum requirements.

Specification, final statements that achieved a consensus	Agreement (all high) ^b
Participation	
(a) ACP can start outside the health care setting with the person and family having conversations or documenting preferences ^{c2} (the round 2 statement, revised)	Median 5, IQR 1 (4-5), 81.0% (16 moderately and 52 strongly of 84) agreed
(b) If the person with dementia does not acknowledge the diagnosis or progression of dementia after having been explained again, while not ideal, ACP can be conducted in the form of eliciting values without reference to the dementia (the round 3 statement, revised twice)	Median 5, IQR 1 (4-5), 87.7% (23 moderately and 48 strongly of 81) agreed
(c) If, due to diminished capacity, the person with dementia is hardly or not capable of engaging in ACP, it is still ACP if started with family who is able to serve as a proxy and if previous wishes are clearly known to the family through previous communication or responses to experiences ^{c2,3} (the round 2 statement, revised)	Median 5, IQR 1 (4-5), 84.9% (27 moderately and 46 strongly of 86) agreed
(d) If, due to diminished capacity, the person with dementia is hardly or not capable of engaging in ACP, and if family are largely unaware of the person's preferences, values or life view, while less than ideal, still some form of care planning with health care professionals (such as best interest planning, proxy planning, or goals of care discussions) should be started (the round 3 statement, revised twice)	Median 5, IQR 1 (4-5), 94.1% (23 moderately and 57 strongly of 85) agreed
(e) If there is no family, it is ACP if the person with dementia is capable of engaging in at least one ACP conversation with health care professionals ^{c1,4} (statement newly introduced in round 2 – no revision needed)	Median 5, IQR 1 (4-5), 85.9% (28 moderately and 45 strongly of 85) agreed
In advance time window	
(f) ACP includes exploring preferences for future care but it may be helpful to start with discussing current care ^{c5} (the round 2 statement, revised)	Median 5, IQR 1 (4-5), 86.0% (19 moderately and 55 strongly of 86) agreed
(g) Preferably, ACP discussions about future care and treatment preferences also refer to the end of life, but it is not a requirement ^{c1,5} (the round 2 statement, revised)	Median 5, IQR 1 (4-5), 83.7% (14 moderately and 58 strongly of 86) agreed

^aThe Table in S5 shows the initial and revised statements and details the feedback of the panel, subsequent revisions and the process of achieving consensus.

^bCriteria for consensus (defined as high or very high (dis) agreement): very high agreement, a median of 5 and an IQR of 0 and $\geq 80\%$ scoring a 4 or 5; high agreement, a median of 5 and an IQR ≤ 1 and $\geq 80\%$ scoring a 4 or 5; moderate agreement, a median of 4-5 and an IQR ≤ 2 and $\geq 60\%$ scoring a 4 or 5; low agreement, a median of 4-5, and an IQR ≤ 2 or $\geq 60\%$ scoring a 4 or 5; no agreement, a median 4-5 otherwise or a median > 2 and < 4 . For consensus on disagreement, reverse median with the same IQR requirements and disagreement percentages.^{12,19}

^cNo consensus within subgroup of medical panellists^{c1}; of non-medical panellists^{c2}; those with specific expertise in ACP in dementia^{c3}; those with no specific expertise in ACP in dementia^{c4}; those with no personal experience.^{c5}

to ACP with dementia beyond the generic ACP framework. Consensus on the visualization of connections between the specific issues took three iterations (Figure 2, and Section S7 also showing the process of achieving a consensus in detail).

Table 4 presents the three issues and their descriptions; each reached a consensus in one or two iterations. We expanded the description of the issue of “family” to clarify the importance of family, friends, and a support network in the case of dementia. We presented the expanded description of the “family” issue again to the panel, despite the consensus reached in the first round. Sections S5 and S6 show that the panel raised several difficulties and dilemmas with family involved in ACP for people with and without dementia. No additional issues appeared from the panelists' feedback. Various dispersed subgroup differences appeared with capacity and family, and engagement and communication reached a consensus among all six subgroups.

Figure 2 visualizes interrelationships between the three issues that were decided in consensus in survey round 3 to be specific to or of particular importance for ACP in dementia. Section S7 shows the summaries of the extensive comments the panel provided over three iterations. All elements of the figure (i.e., shape, line type, color, shading text, reach of axis) have been revised to optimize its meaning based on the comments, and the explanatory text was refined and expanded. The main changes involved: (1) more clearly showing the role the person with dementia plays through enlarging the area for the person and (2) adding conversations before diagnosis that can be outside health care settings for which in round 2, we decided to present two versions, starting with and without a health care professional. Figure 2 shows the final version that achieved a consensus in survey round 3 after implementing minor changes based on the panelists' feedback regarding the third version. We also explained “specific” meaning: “of particular importance.” There was high agreement with the statement “I feel

TABLE 4 Three issues specific or of particular importance in dementia and its evaluations.

Issue	The description of the issue that achieved a consensus ^a
<p>Capacity</p> <p><i>Specific to dementia.</i> No consensus, moderate agreement in round 1 (median 4, IQR 1, 82.0% agreed). Consensus, high agreement in round 3 (median 5, IQR 1, 83.5% agreed)^{b1,3}</p> <p><i>Importance to ACP in dementia.</i> Accepted as important in round 1. Mean 8.18 (SD 1.78; n = 93)</p> <p><i>Description (right column).</i> Consensus with high agreement in round 1 (median 5, IQR 1, 96.7% agreed)^{b2,5}</p>	<p><u>Consensus with high agreement in round 1</u></p> <p>Having decision-making capacity generally means to be able to:</p> <ol style="list-style-type: none"> understand the potential consequences of the various options involved in the decision to be taken; apply this understanding to one's own situation; evaluate the consequences of the options in light of one's own values and commitments; and communicate a choice (Grisso and Appelbaum, 1998; Kim, 2010; Alzheimer Europe, 2020). <p>With dementia, capacity to discuss and decide about future health care ("anticipatory decision-making capacity") changes during a period that ACP should continue. Understanding of the situation and alternative treatment, appreciating, reasoning, and communicating a decision are affected, which has legal implications in terms of assessing competency for decision making. However, also in the case of dementia, capacity is not a dichotomy and should be assumed unless there are indications that it should be examined (Stuart & Thielke, 2018; Alzheimer Europe, 2020). Loss of capacity is not an irreversible characteristic of a person, but it refers to capacity regarding a particular type of decision in a particular situation. With dementia, capacity to engage and decide, as in the context of ACP, may fluctuate over time and depend upon what supports are provided to facilitate complex decisions. These may include: clarification of the purpose of ACP, availability of healthcare professionals' time to support decision making, and managing the emotions invoked by such conversations, such as anxiety (Van den Block, 2019; Kato et al., 2021).</p>
<p>Family</p> <p><i>Specific to dementia.</i> No consensus, moderate agreement in round 1 (median 4, IQR 1, 78.9% agreed). Consensus, high agreement in round 3 (median 5, IQR 1, 88.6% agreed)^{c1,3,5}</p> <p><i>Importance to ACP in dementia.</i> Accepted as important in round 3 with mean 8.77 (SD 1.08; n = 82. Not accepted in round 1 (mean 7.99; SD 1.73; n = 93)</p> <p><i>Description (right column).</i> Consensus with high agreement in round 1 (median 5, IQR 1, 90.4% agreed). Revised text, consensus with high agreement also in round 3 (median 5, IQR 1, 96.4% agreed).</p>	<p><u>Consensus with high agreement in round 1 and round 3</u></p> <p>Family of a person with dementia, if available, are often faced with a challenging caregiver role, typically changing over time. Declining capacity of the person with dementia may necessitate shifting engagement and communication in ACP from the person to the family. This may involve ethical dilemmas in decision making on behalf of the person with dementia, for example, around balancing their own versus the interests of the person with dementia.</p> <p>Family caring for a person with dementia runs a substantial risk of high burden with modest rewarding reciprocity. Therefore, the family needs support in providing care for the person with dementia; their relationships need to be valued as important for the person's identity, and both the person and the family in their role in ACP need to be supported from the beginning, reassuring that decisions can be taken together.</p>
<p>Engagement and communication</p> <p><i>Specific to dementia.</i> Consensus, high agreement in round 1 (median 5, IQR 1, 91.0% agreed)</p> <p><i>Importance to ACP in dementia.</i> Accepted as important in round 1 with mean 8.16 (SD 1.85; n = 91)</p> <p><i>Description (right column).</i> No consensus, moderate agreement in round 1 (median 5, IQR 1, 79.5% agreed). Consensus, high agreement in round 3 (median 5, IQR 1, 90.4% agreed)</p>	<p><u>Consensus with high agreement in round 3. Moderate agreement in round 1</u></p> <p>"Engagement and communication" as a third issue specific to ACP in dementia relates to the other two issues. That is, engagement and communication change as a result of decline in capacity and other conditions related to the dementia such as aphasia. These in turn change roles and level of involvement of family.</p> <p>A conducive environment facilitates an active role in ACP conversations (Visser et al., 2022; Dooley et al., 2015). The person with dementia should be engaged in direct communication to the extent possible if the person agrees. To facilitate engagement of the person with dementia, we need to adjust communication strategies, both how we address the person, and how we interpret what the person wants to convey. Even with limited engagement, expressions of approval of care and treatment with uncertainty about the extent to which the approval is indeed an informed approval, entail a form of engagement.</p> <p>In principle, the person with dementia should decide on whether to involve the family. However, input from family and healthcare professionals about known preferences and values of the person can be considered; and communications through observations of the whole of behaviour are important and need consideration as well because a person's preferences may change over time (Sulmasy & Snyder, 2010).</p>

^aAll references were shown to the Delphi study panelists with author name and year; they are included in Section S6.

^bCriteria for consensus (defined as high or very high (dis)agreement): very high agreement, a median of 5 and an IQR of 0 and $\geq 80\%$ scoring a 4 or 5; high agreement, a median 5 and an IQR ≤ 1 and $\geq 80\%$ scoring a 4 or 5; moderate agreement, a median of 4-5 and an IQR ≤ 2 and $\geq 60\%$ scoring a 4 or 5; low agreement, a median of 4-5, and an (IQR ≤ 2 or $\geq 60\%$ scoring a 4 or 5); no agreement, a median 4-5 otherwise or a median > 2 and < 4 . For consensus on disagreement, reverse median with the same IQR requirements and disagreement percentages.^{12,19} No consensus was achieved in the last iterations within the subgroup of medical panellists;^{b1} non-medical panellists;^{b2} those with specific expertise in ACP in dementia;^{b3} those with personal experience;^{b4} no personal experience^{b5}.

^cFamily specific for dementia: high agreement after replacing ratings of four participants with their round 1 rating, as they commented on a typo that was in round 3 only (missing the word "of" in the statement: "ACP is specific for persons with dementia which is importantly a result a changing role of family"). Apparently, they rated the statement rather than evaluating the content of the issue it referred to, downgrading their round 3 rating for this. With the round 3 ratings included as is, the result would have been: median 4, IQR 1, 85.0% agreed.

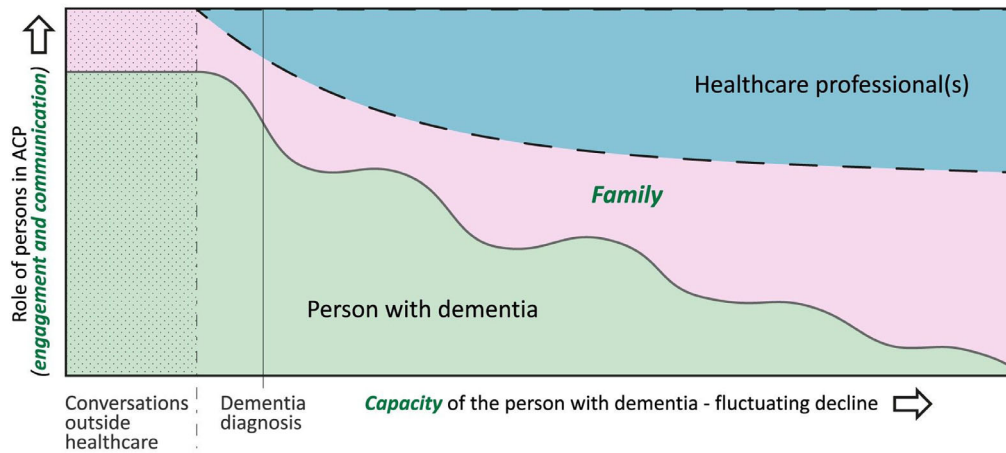


FIGURE 2 Relating the three issues specific to dementia and change over time. The figure shows how three dementia-specific issues (green text) that are of particular importance in the case of dementia in ACP may relate and change with dementia progression during the ACP process. It indicates an ideal model of the engagement in ACP of the person with dementia as long as possible given an unavoidable decline in capacity, along with engagement of the family who is available and involved in the ideal situation, and health care professional(s) with whom the person has trusting relationships. Shaded green indicates conversations outside health care. The green area shows the typical declining contribution and fluctuating active role played (Y axis) of the person with dementia due to decline in capacity (X axis), and the other areas show how this may influence active roles played in ACP by family and health care professional(s). Disclaimer: there are many other factors that influence roles in ACP, while the model cannot show its complexities or detail.

that the revised figure appropriately relates three dementia-specific issues in ACP" (median 5, IQR 1, 94.0% agreement—21 moderately agreed, and 57 of 83 strongly agreed). Consensus was reached within all subgroups alike. In addition, the statement "The initiation of ACP (that is, the exploration of the individual's experiences, knowledge, personal values, and concerns) can occur in healthcare settings and non-healthcare settings" initially reached moderate consensus (median of 5, IQR 2, 74.7% agreed; 15 moderately agreed, and 43 of 79 strongly agreed). However, it reached a high consensus when it was followed by: "However, the benefit of ACP performed in a healthcare or social care settings such as residential care, is that it promotes continuity of information accumulating through ACP conversations and offers opportunities to support navigating complexities around ACP in dementia" (median of 5, IQR 1, 83.5% agreed; 20 moderately agreed, and 46 of 79 strongly agreed).

4 | DISCUSSION

This study represents the first international Delphi panel consensus on a definition of ACP in dementia. ACP in dementia was conceptualized with input from experts worldwide in terms of its definition and three issues that deserve particular attention. This relationship-centered definitional framework has a unique focus on the communication process that continues even after decision-making capacity is diminished or lost by the person with dementia. We went beyond the reach of available definitions that apply up to loss of capacity conceived as a dichotomy, visualizing continuous, fluctuating engagement in ACP along the disease trajectory.

Pragmatic boundaries of ACP in dementia were articulated also in scenarios of the person and knowledgeable family not actively participating and in terms of the time window of current versus future care and end of life. This could lower barriers to initiate ACP, increase applicability of ACP in dementia, and open a path to conceptualize ACP in persons at risk of, for example, mild cognitive impairment, or with limited stable capacity (e.g., intellectual disability). This next step promotes the desired inclusiveness of persons with dementia in ACP. Our endeavor points to most of the generic ACP conceptualization being applicable to dementia, with adaptations often representing additions and refinement that support important issues that deserve particular emphasis.

The experts were thinking of a process focused on eliciting values without pressure, and without jumping to premature conclusions such as deciding about future treatment or documenting preferences without adequate conversation. This would ensure the best possible alignment with the values, wishes, and preferences of the individual concerned. Such conversations may be encouraged to start outside health care settings, but health care professionals have a duty to offer it. In fact, an existing living will could be a starting point of conversations. Yet, in view of a person's fluctuating or declining capacity, tailored and non-verbal communications, such as observations of behaviors, are informative and need to be considered to support autonomy and keep the person engaged as long as possible.

Our findings add to a debate on the usefulness of advance decisions versus in-the-moment decisions.⁷ ACP conversations may contribute, but in itself are not sufficient to improve goal-concordant care²⁰; more is needed to improve care, for example, at an institutional and regional level. Overexpectations of what ACP can achieve without

health care reform and dismissal of the benefits of ACP may not do justice to persons and families wishing to express what is important to them and prepare for the future. Otherwise, people need to await guidance by clinicians in an emergency situation without the benefit of preparation. The consensus on a broader public health approach to ACP allowing for conversations starting outside health care settings speaks to this. The involvement of many stakeholders each with their preferences and style and potential changes in individuals' health over a relatively short time add to the complexity of ACP, well known in palliative care. Palliative care is not just about the end of life, and neither is ACP (as part of palliative care¹²), given that both can start years before life ends. ACP may open ways for individuals with dementia or intellectual disabilities to express their strong desire to live and guide medical decision-making. The panel agreed that addressing future care is essential to ACP, but also that addressing current or end-of-life care could be helpful. Misconceptions about an ACP focus only on end of life, and how to combat these, need future work.

Family support and family representing the person is not unique to dementia, yet the panel considered aspects of family involvement to be particularly relevant with dementia. More guidance beyond our conceptualization and local legislation is needed as to the exact ideal or preferred role of family in ACP. Conversations about providing good care for a person with declining capacities elicit key dilemmas involving previous and current perspectives of multiple stakeholders.¹⁷ Health care professionals should support family, asking them about and preparing them for their role in ACP, anticipating emotional losses, ensuring that they reflect on their own needs and preferences while advocating for the person, and keeping an eye on how the person's personality or their coping style may change. Additional research is also needed for people who may be unbefriended, socially isolated, and do not have family to act in a supportive role.

4.1 | Strengths, weaknesses, and next steps

We recruited a diverse panel of experts who contributed extensively. Future work may also consider views of persons with dementia more directly. We did not include patient representatives in our Delphi study to avoid competing views with (a majority of) professionals. Although over half of the panel was from Europe, the qualitative comments allowed for incorporating all views when preparing revisions for the next round. We refrained from additional, unplanned subgroup analyses comparing consensus among panelists from, for example, Europe versus from elsewhere, as we did not have a particular hypothesis of how country of residence would affect consensus among experts on conceptualization of ACP. Rather, it may affect practical or implementation issues and additional research may be needed of the new definitional framework in each context.

Despite more rounds and a longer survey, the response was not lower than in previous EAPC Delphi studies. We triggered abundant feedback by offering thought-providing statements. The conservative criteria for consensus, room for up to four iterations, and ample opportunity for comments which the panel made use of, were all instrumental

in clarifying the definitional framework including its boundaries and acceptable pragmatic alternatives.

We departed from a generic definitional framework, and our work may in turn be used as a template, adapting it for more generic approaches in ACP with conditions in which there is no or diminishing capacity or for specific conditions such as intellectual disability. We could then move on to examine approaches to extend the current ACP definition for people without capacity more generally.

5 | CONCLUSIONS

A relationship-centered definitional framework of ACP in dementia evolved in consensus with experts from Western and non-Western countries, which should promote inclusiveness of persons with dementia and their family caregivers. It should promote ACP in dementia and call for action. Not offering ACP may deny persons an opportunity or the right to have a say in their care, which might also lead to uncertainty and feelings of guilt in family. The conceptualization comprises capacity, family, and engagement and communication. These three issues of particular importance with dementia should form the basis for actionable recommendations for practice, policy, and research and can also support education.

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CONFLICT OF INTEREST STATEMENT

None; the authors declare there is no conflict of interest.

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CONSENT STATEMENT

All human subjects provided informed consent.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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