Brief Report

Optimizing Approaches in Advance Care Planning in Dementia as Perceived by General Practitioners

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Abstract

Context. Feasible, person-centered advance care planning (ACP) approaches for persons with dementia and their care partners are needed, and the optimal approach may differ depending on the situation. Two contrasting approaches involve a highly scripted medical order-setting approach to decide on specific treatments in advance, vs a flexible goal-eliciting, more psychosocially-oriented coping-based approach.

Objectives. To distinguish situations in which either approach is preferred in dementia from the perspective of general practitioners.

Methods. We interviewed 13 practitioners participating in the CONT-END program in the Netherlands. Seven were trained in the order-setting approach and six in the goal-eliciting approach for an ACP trial. Twelve other practitioners participated in a video vignette study showing the two approaches, and we triangulated findings. Inductive qualitative content analyses of interviews aimed at elucidating for whom and when an approach was preferred.

Results. Four attributes distinguished situations in which either approach is preferred: understanding, trust, readiness, and momentum. For the order-setting approach, understanding, trust, and readiness of person and care partner were prerequisites for momentum (time right to express preferences), when not triggered for urgent medical reasons. In contrast, the goal-eliciting approach would help understand the person, foster trust, and create readiness from a first conversation. Without a clear trigger, however, momentum would need to be created.

Conclusion. Skill in employing various approaches to ACP conversations, each with specific benefits, could help tailor ACP to the individual and their situation. Further theoretical and empirical research, including in other populations and settings, may inform person-centered ACP. J Pain Symptom Manage 2026;000:1−8.

Key Words

Communication strategy, Advance medical planning, Goals of care, Dementia, General practice

Key Message

Both an order-setting and a goal-eliciting approach to ACP can be appropriate, but either is perceived as superior depending on the situation of the persons involved, which is underpinned by contrasts within the attributes Understanding, Trust, Readiness, and Momentum. Further theoretical clarification and research could enhance person-centered ACP training programs.

This work has been presented at the Gerontological Society of America (GSA) Annual Scientific Meeting, Boston, November 12, 2025.

A preprint of a shorter version of this article has been posted at MedRxiv https://doi.org/10.1101/2025.06.06.25329142

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Accepted for publication: 21 April 2026.

0885-3924/$ - see front matter

https://doi.org/10.1016/j.jpainsymman.2026.04.618

Introduction

Advance care planning (ACP) is increasingly being conceptualized as a communication process on future care, which may or may not result in formal documentation.[1] However, exactly what ACP entails and its benefits remain unclear,[2] further complicated by overlap between ACP and "goals of care discussions," "end-of-life communication," and "future care planning."[3–5]

Some feel that ACP should result in decisions about medical treatment at the end of life. However, particularly in dementia, a broader approach addressing psychosocial or spiritual care preferences may fit as well. For example, in a study on community-dwelling people with young-onset dementia, social rather than medical issues predominated in defining a good life.[6] Further, as dementia advances, coping with cognitive decline and decreasing ability to engage in ACP typically requires care partners step in.[7] However, with dementia, expanding ACP to cover more aspects of care and of quality of life threatens its feasibility. Indeed, critics have expressed concerns that defining the ideal of ACP with dementia to include 25 elements as agreed to by a panel of experts from 33 countries, "runs the risk of setting up healthcare professionals for failure, or alienating them, potentially jeopardizing the whole process."[8] The panel estimated that a median of four conversations would be needed to address all elements at least once, which could appear paralyzing to healthcare professionals with limited experience.[9] One approach to avoid discouraging healthcare professionals is to define what is "good enough."[10] Another option would be to prioritize the elements of ACP for the particular situation in a person-centered manner and leave the remaining elements for later conversations.

Refined approaches for varying situations have not been examined, nor is there suitable theory to aid selection of elements appropriate for particular situations. From the literature, two prominent approaches are: 1) a highly scripted medical order-setting approach to specify treatment preferences, and 2) a flexible goal-eliciting approach that is more psychosocially-oriented, coping-based. Understanding the benefits and drawbacks of these contrasting approaches help shape a balanced, efficient, and feasible ACP process.

ACP preferably starts soon after dementia diagnosis, when the person often can still be involved.[7,8] At that time, needs other than purely medical needs may be salient. General practitioners (GPs) often bear responsibility for initiating conversations or probing readiness for ACP and to continue these conversations as part of ongoing support. We therefore aimed to assess attributes that distinguish situations in which GPs perceive that an order-setting or goal-eliciting approach would be preferred as a step toward realistic, tailored ACP approaches for individuals with dementia and their care partners.

Methods

We conducted qualitative interviews as part of the innovative CONT-END program (Attempts to Control the End of Life in People with Dementia: Two-level Approach to Examine Controversies). CONT-END included two studies on ACP in dementia. In the CONT-END cluster-randomized controlled trial (cRCT), we randomized GP practices and trained GPs to deliver ACP for people with dementia using either the order-setting or the goal-eliciting approach.[11] In the CONT-END vignette study, we interviewed GPs who had watched animated videos illustrating the two approaches.[12] Therefore, in both studies, interviewees were exposed to the two approaches, and we could ask them to compare the approaches.

The Two Approaches

Because the order-setting approach targeted decision-making, theory used both in developing the training as part of the trial and in building the vignettes was based on a model for shared decision-making: the revised three-talk model of Elwyn et al.[13,14] The model comprises three steps: "team talk, option talk, and decision talk." The goal-eliciting approach was based on the PREPARED framework[15] "for discussing ACP and end-of-life issues with patients with advanced life-limiting illnesses and their families." Items included, for example, "Elicit patient preferences" including their goals and values, "Acknowledge emotions and concerns," and "Realistic hope should be fostered."

The Two Studies

In the CONT-END cRCT, we sought to assess the effects of the two ACP approaches on two outcomes: 1) well-being of persons with dementia and 2) their care partners' evaluations of decision-making and communication with physicians. We trained GPs in ACP conversations, and we offered supportive materials, such as a question prompt list for the dyads of persons with dementia and their care partner.[16] GPs, nurse practitioners (NPs), often along with their general-practice-based assistant practitioners ("POH") who specialized in care for older adults with chronic disease, were trained in small groups in one approach. They attended two three-hour training sessions a few months apart between February 2022 and February 2024. This was followed by an e-learning that included a digital conversation with an avatar of a person with dementia providing feedback on choices in the conversation.[17] The two in-person sessions included theory explained by a physician-trainer familiar with the respective

approach, and practicing conversations with a team of professional actors roleplaying a person with dementia and care partner. They were specialized in acting in medical settings and GPs themselves.

After the training, we conducted an interview study nested in the cRCT. Between February 2023 and June 2024, we invited practitioners to an interview with XJ (female psychologist, PhD candidate, also leading the vignette study), WT (female MD, ACP researcher, PhD candidate), or JWB (female GP, associate professor). In semistructured interviews, we asked about their experiences with the trained approach, explained the other approach, and asked them to what extent either approach would fit with the persons with dementia and their care partners (Supplement, Interview Guide 1). If needed, in particular with the goal-eliciting approach, the explanation was supported by showing visuals used in the training, such as a poster about the PREPARED model.

In the CONT-END vignette study, conducted between July 2020 and January 2021 in the Netherlands, we recruited 50 physicians after announcements in various networks, including 12 GPs. They viewed video vignettes that explained the two ACP approaches in randomized order. The study focused on acceptability of the approaches (along with acceptability of technology and euthanasia)[12] the first question being "Do you consider this an acceptable type of care for people with dementia?" (in what situation, etc.). We also asked, "Which of the two ACP options would you prefer" (please explain; Supplement, Semistructured Interview Guide 2). The interviews in the vignette study were conducted by XJ and a senior female psychologist and contained closed and open-ended questions (Supplement, Interview Guide 2).

Analyses

Two investigators (JTS, CONT-END's PI, methodologist, and XJ) conducted an inductive content analysis to further conceptualize the approaches and how they differed,[18] triangulating data from interviews in the two studies. They started with coding three cRCT interview transcripts independently and then discussed and adapted codes, after which XJ coded the remaining transcripts. To answer the research question, we selectively assigned codes to instances when a particular approach was being preferred. Through comparison of codes for each approach and subsequent coding, we assigned codes to essential characteristics (attributes) where the preference for an approach typically differed. Where possible, we avoided assigning the same code to multiple attributes to clearly demarcate attributes and the contrasts within the attributes. Codes were then compared with the already available vignette study codes. We selected the codes that were relevant to address our research question (i.e., differentiating the approaches) and discussed and revised codes originally assigned to combine between the two studies. The combined codes were further adapted by JTS and discussed until all were agreed upon.

To expose key contrasts underlying the conceptualized ACP approaches, codes preferably contained direction (e.g., whether an approach was easy vs difficult) and meaning (e.g., whether readiness was required vs created through ACP). A key contrast was consistent when the directions within and between the two studies were the same. A limited number of key contrasts were then placed within broad attributes. We finally verified whether patterns of codes differed by the trained approach in the cRCT because exposure to one approach dominated in that study.

Ethics

The Medical Ethics Committee-Leiden, The Hague, Delft CONT-END approved an amendment to the cRCT (NL71865.058.20) on 8 December 2022 to examine the two approaches in qualitative interviews rather than in underpowered quantitative analyses. They approved the vignette study (NL72354.058.19) on 10 April 2020.

Results

We interviewed 25 practitioners in total. Most interviewees were recruited from the urbanized west of the Netherlands. In the cRCT, all invitees agreed, and we conducted 6 interviews with 7 practitioners trained in the order-setting approach (4 GPs, 1 NP, and 2 assistant practitioners) and 4 interviews with 6 practitioners trained in the goal-eliciting approach (3 GPs, 1 NP, and 2 assistant practitioners). Three were duo interviews with GP and either NP (1) or their assistant practitioner (2 interviews). Ten interviewees in the cRCT were female, and 3 were male. Median age was 54.5 years (range: 35−57), and median experience in their function was 12.5 years (range: 1−29). Their 10 practices enrolled a median of 2 dyads (person with dementia and care partner). One practice enrolled none, 2 enrolled 1, 4 enrolled 2, 2 enrolled 4, and 1 enrolled 6 dyads. In the vignette study, 12 other GPs participated (6 males, 6 females). Their median age was 30 (range: 26−32), and median experience in dementia care was 2.5 (range: 1−7) years.

Table 1 shows codes assigned to situations (whom and when), by approach (order-setting or goal-eliciting), and by study (interviews in the context of the cRCT or vignette study). Fifty codes in the cRCT interviews referred to the ACP approaches; exactly 25 referred to either approach. After excluding 11 general codes expressing general appreciation or time needed, and merging 2 with other codes, 37 codes remained.

Table 1

Codes by Approach and Study Source as the Basis for Key Contrasts Within the Attributes[a]

Attribute and Key Contrast Within[a]	Approach Code Refers to		Code Available in Study		Attribute and Key Contrast Within[a]	Approach Code Refers to		Code Available in Study	
	Order-Setting	Goal-Eliciting	cRCT	Vignette		Order-Setting	Goal-Eliciting	cRCT	Vignette
Understanding									
Understanding: required (*from* the person; 4 codes, 1 of which shared[b])					Understanding: facilitated (*for* the person) and offered (to physician; 7 codes)				
This approach requires cognitive capacity	x	x	x x	x	This approach is easier for people with dementia	x	x x	x	x
It is too difficult and complex for the person	x		x	-	It is dementia specific, different from usual		x	x	-
Some are unable to express preferences about concrete treatment orders	x		x	x	It is person-centred, with positive goals, it improves quality of life		x	x	x
Understanding needed to take initiative, both with and without dementia[b]	x		x	-	It is person-centred, helps individualize care		x	x	x
					Understanding person's background helps understanding their choices		x	x	x
					Understanding person's background and choices supports judgments		x	x	x
					Understanding person's background and choices helps physician on call to take the right decisions		x	x	x
Readiness									
Readiness present (person, or also care partner; 6 codes, 1 of which shared[b])					Readiness fostered (physician, actively to person, or also care partner; 4 codes)				
Suitable if the person has decided already	x		x	x	This approach is suitable for persons who have not considered preferences yet		x	x	-
In the case the person takes the initiative for a conversation	x		x	x	Helps to open up, also when people are not ready		x	x	-
In the case the person brings preferences up	x		x	-	This approach is suitable for the first conversation, before starting the other approach		x	x	-
In the case family wants concrete treatment orders	x		x	-	This approach first, next the other approach would be more proactive		x	x	-
Understanding needed to take initiative, both with and without dementia[b]	x		x	-					
Suitable for persons with a direct communication style	x		x	-					

(*Continued*)

Table 1
Continued

Attribute and Key Contrast Within[a]	Approach Code Refers to		Code Available in Study		Attribute and Key Contrast Within[a]	Approach Code Refers to		Code Available in Study	
	Order-Setting	Goal-Eliciting	cRCT	Vignette		Order-Setting	Goal-Eliciting	cRCT	Vignette
Trust									
	Trust needed (4 + 1 codes[c])					Trust established (3 codes)			
Need to trust the family to speak on the person's behalf; rather speak person	x	x	-	x	Improves the relationships with the person		x	x	x
A relationship of trust is a prerequisite for this approach	x		x	x	Establishes relationship before medical issues arise in the early phase of dementia		x	x	x
This approach could confront the person with taboo issues; cause anxiety, distress, add to burden	x		x	x	This is not a confrontational approach		x	x	x
The approach can expose disagreement as there may be different perceptions on what is the right decision	x		x	x					
Risk of family overruling the person when they disagree	x		x	x					
Momentum									
	Momentum present (to clarify) (6 + 2 codes[c])					Momentum generated (time taken for meaning) (4 codes)			
Clarify preferences when still able to respect the person's treatment wishes and their life view	x	x	x	x	The approach addresses the most meaningful topics		x	x	-
Could be urgent for medical reasons	x		x	x	General care goals can be established in nonurgent situations		x	x	x
When clarity is needed, this is the way to provide it	x		x	x	Risk of departing from the subject.		x	x	x
When scenario is different, treatment orders do not apply	x		x	x	Not actionable in an acute situation		x	x	x
Caution treatment orders established (too) quickly, change with changing preferences	x		x	x					
When concrete treatment orders are being preferred	x		x	x					
Easier to start the conversation because it clearer what should be addressed	x		-	x					
Professional should take initiative for this default approach that should be conducted regardless of also doing the other approach	x		-	x					

[a]**Attribute** is defined as essential characteristic in which the preference for an approach typically differed. Attributes comprise key contrast that cover direction and meaning of the differences in the situations in which either approach is being preferred.
[b]Coded both under understanding: required, and under readiness present. The table, therefore, shows 41 codes because one of 40 unique codes was assigned to two attributes.
[c]Number of codes expressed as number of 37 (26 single codes in the cRCT and vignette study, 11 single codes in cRCT only), *plus* 3 additional single codes in the vignette study only, totalling 40 unique codes.

Three codes from the vignette study were added, all referring to the order-setting approach, resulting in 40 single codes in total. Of the 37 codes assigned in the cRCT interviews, 26 were also identified in the vignette study. Eleven codes remained unique to the cRCT, eight of which concerned "readiness"; four for each approach.

The codes in Table 1 are organized by attributes that comprise key contrasts (direction) of the approaches: "understanding"; "readiness"; "trust"; and "momentum" explained in Table 2. For example, the person understanding decisions was a requirement for the order-setting approach, whereas the goal-eliciting approach allows the practitioner to better understand the person. For the order-setting approach, understanding, trust, and readiness were prerequisites for momentum (time right to express preferences), unless urgent medical decisions were needed. In contrast, the goal-eliciting approach would actively help understand the person, foster trust, and create readiness from a first conversation. Without a clear trigger, however, momentum would need to be created.

Momentum could be conceptualized as situations that bring the other attributes and the two approaches together. For example, momentum can refer to timeliness of the physician and person understanding each other, which benefits from, or creates readiness and a relationship of trust needed to engage in ACP effectively.

Of the 40 single codes, 36 could be consistently linked to a single approach, while four applied to both approaches (one or two codes for each of four attributes, except readiness, for which the contrast was consistent). For "understanding" the contrast was inconsistent, as there were different directions in and within the two studies. Some interviewees found one approach easier or less demanding regarding cognitive capacity; others felt this was true for the other approach. Codes and contrasts (directions) did not differ by trained approach in the cRCT.

Table 2

An Analysis of Perceived Fit of Two Conceptualized ACP Approaches With Situations (Relating to the Person, Care Partner, and Physician Involved, and to Circumstances)

Attribute	Two Contrasting Approaches			
	ACP—Order-Setting Approach		ACP—Goal-Eliciting Approach	
	Key Contrast	Description of Findings	Key Contrast	Description of Findings
Understanding	Understanding required (from person)	Understanding of the decisions at stake by the person is conditional for applying this approach or for the person to initiate a conversation, while some persons with dementia are not capable.	Understanding facilitated (for person) and offered (to physician)	Understanding of the person is offered to the physician, and the physician's better understanding of the whole person, background, and where they come from helps them in guiding person-centred decision-making.
Readiness	Readiness present (person, or also care partner)	Related to understanding is the condition that the person or also the care partner is ready for ACP in a more general sense. This is most obvious through them asking for concrete treatment orders themselves or taking initiative for an ACP conversation. Direct asking was perceived as a style of communication related to personality or to regional culture.	Readiness fostered (physician, actively to person, or also care partner)	Creating or probing readiness is a mechanism of how this approach can work. In that sense, it is the most proactive approach and may be suitable before moving to the other approach, for which readiness would be a requirement.
Trust	Trust needed	There should be trust from both sides that the relationship is not being damaged through discussing sensitive topics and the sharing of potentially confronting information. Relevance of trust is increased because families may be divided among themselves about the best treatment, or they may overshadow the wishes of the person.	Trust established	A relationship of trust with the person is established or facilitated through this approach, through taking time to get to know the person in an early phase of dementia, with no need for confrontational decision-making about medical decisions.
Momentum	Momentum present (time right to express preferences)	The moment is right for the person to clarify their preferences as routine at a particular time, urgent, or a preferred moment. A Caution is changing preferences or scenarios not anticipated.	Momentum generated (time taken for meaning)	The moment is created when there is time to understand what is meaningful for the person. A caution is topics addressed too broad and not actionable.

Discussion

We refined a medical order-setting vs a goal-eliciting, more psychosocially oriented approach to ACP in dementia as these can be typified by contrasts within four attributes: Understanding, Trust, Readiness, and Momentum. For the order-setting approach, the first three attributes are prerequisites for optimal momentum in nonurgent situations. In contrast, the goal-eliciting approach can serve to create all of the four attributes, from a first conversation.

A systematic review on preferences of older people concluded that the "ACP approach should be selected carefully to match the person's health and psychosocial status."[19] The attributes in either approach address the person's health and psychological and social situation, but with different emphases. Both approaches are acceptable in multiple countries, including the U.S.,[20,21] and elements of both approaches were recommended in an international Delphi study.[8] However, which is superior for a particular conversation depends on the situation or the persons involved. The goal-eliciting approach may be especially suitable for a first conversation initiated by a professional who is uncertain about capacity, or openness to engage in decision-making, or openness to discuss sensitive topics. In an interview study with Dutch GPs, building trust and addressing nonmedical issues soon after diagnosis facilitated ACP.[22] Starting with the more scripted order-setting approach may fit in case of high health literacy and may be indicated whenever health declines rapidly.

Interviewees felt the order-setting approach was more confronting, or triggering of distressing family dynamics, and it is less flexible when preferences change. However, there is also the benefit of actionable preferences established when the person is still able to express their preferences, which may be helpful to proxies when the person with dementia is clearly not decisional, particularly in acute situations. In other situations, if there are no clear medical treatment preferences yet, combining the two approaches, starting with the goal-eliciting approach and in a next conversation adopting the order-setting approach was considered best—"the most proactive" overall approach. Because there was no consensus which approach was easier, such a combined approach, when a series of conversations is feasible, could address the elements of optimal ACP in dementia.[8]

A strength of this small study is that it was conducted in the context of a unique trial with separate arms for the two approaches. We trained GPs in one approach to apply directly in their practice. Despite the interviewees' limited understanding of the other approach, the real-life cRCT delivered more unique codes than the vignette study, particularly related to readiness (8 of 11 unique codes). Training and actually conducting ACP possibly triggers more thinking about the person's readiness. Also, the GPs in the vignette study were young and less experienced. Therefore, another strength was methodological triangulation of data from two studies, exposing commonalities and differences, which added to richness of the total data used. The two analysts had different relationships to the topic: JTS conceptualized approaches, XJ interviewed in both studies, which helped in-depth discussion of codes.

Our study suggests that a combined approach, training skills in employing various approaches to ACP conversations, each with specific benefits, can help tailor ACP to the individual and their specific situation. Further theoretical and empirical research to define and operationalize the attributes for training and evaluation purposes is needed, which may include other populations and settings to inform person-centered ACP interventions. Truly person-centered conversations and their timing should effectively and efficiently fit with the individual and their care partner.

Disclosures and Acknowledgments

The authors thank Dr. Marieke Perry, MD, PhD and Dr. Jentie Kraamer, MD for providing training in the two approaches, Dr. Bram Tilburgs, RN, PhD and Dr. Mandy Visser, PhD for their contributions to the cluster-randomized controlled trial, Prof. Wilco P. Achterberg, MD, PhD and Dr. Hanneke Smaling, PhD for their contributions to the vignette study, and the participating practitioners for their contributions to the data collected in this study. We are grateful for suggestions to clarify the text from Dr. M. Nienke Slagboom, PhD, and Prof. David R. Mehr, MD, MS. This work was supported by the European Research Council (Consolidator grant number 771483 awarded to JT van der Steen). The financial sponsor did not play a role in any of the aspects of this study. We declare there is no conflict of interest.

Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.jpainsymman.2026.04.618.

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