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How international experts would define advance care planning: a content analysis

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Abstract: Planning for future medical treatment, and care, referred to as advance care planning (ACP), has evolved to a focus on conversations that explore values and preferences in a broad sense. Given diverse practices internationally, we examined how international experts would define ACP themselves and whether this differs by medical profession. In an explorative study embedded in a Delphi study on ACP in dementia, experts in ACP in persons with dementia and other diseases reported at baseline how they would define ACP “in one sentence, off the top of your head”. We analyzed the text of the reported definitions with content analysis, created codes to identify small definition elements, then merged them into categories. We assessed phrasing from a patient, healthcare professional, or neutral perspective. Almost half (45%) of 87 experts from 30 countries phrased ACP from a patient perspective (29% neutral, 26% professional). Codes (n=131) were merged into 19 categories. Five categories appeared in more than half of the definitions: ‘Choosing between options’, ‘Care and treatment’, ‘Planning for the future’, ‘Individual person’ and ‘Having conversations’. Other categories, including ‘End of life’ and ‘Documentation’ were mentioned by a minority of experts. The categories and perspectives did not appreciably differ between physicians and other professionals. In conclusion, international experts from 30 countries typically defined ACP as person-centered conversations to choose future care and treatment, without focusing on end of life or documentation. Future research should evaluate the extent to which such conceptualization of ACP is present within clinical programs and practice recommendations and our work may serve as a starting point to monitor changes over time. Registration: World Health Organization Clinical Trial Registry Platform (NL9720).

Keywords: Advance care planning (ACP); conceptualization; palliative care; person-centered care; shared decision making

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Introduction

Considering a growing number of patients with chronic disease worldwide (1), advance care planning (ACP) is gaining relevance (2). The coronavirus disease 2019 (COVID-19) pandemic has reinforced the urgency for the pressing concern to clarify individual treatment goals, (un)acceptable outcomes and concrete preferences such as regarding mechanical ventilation in frail or chronically ill people; it has resulted in planning for future care being re-imaged in a broader light (3-5).

Traditionally, stating preferences for future care in critical medical situations has been understood as writing down these preferences in eligible legal documents, i.e., advance directives (6). From 1994, leaders in the field increasingly used the term “advance care planning” to describe a new notion where planning for future care is understood primarily as a process of communication, with written advance directives as “only one component of the broader activity of ACP” (7,8), as a process that “may involve the preparation of a written advance directive” (9), as a “cornerstone” of the process (10) or as “one piece of information to be used at the time of decision making” (8). Since then, there has been a paradigm shift from a “legal transactional approach” to “a communications approach”, to help honor patients medical wishes over the life course (6,11) and avoid risking a “set it and forget it” mentality (12). Adopting a person-centered or relationship-centered perspective and elements of shared-decision making, ACP is considered to be an ongoing process of communication, a continuum of care planning which may refer to periods of years rather than being confined just to the end of life (11,13,14).

There may be cultural differences in what aspects of ACP are emphasized, such as family playing an important role in Asian countries (2,15). In Western countries and non-Western countries, research is accumulating that ACP is effective to some extent (16,17). However, there is heterogeneity as to how exactly ACP is being defined and what it should contain or consist of. This is complicated by, ACP in and of itself having various explicit and underlying goals, not limited to achieving goal-concordant care but also relationship-focused goals (18). Moreover, there are highly heterogeneous models of ACP practices across the globe. Physicians often

lead ACP conversations and are usually responsible for treatment, with a role for non-physician ACP facilitators being common in English-speaking countries but few nurses perceiving such role in, for example, Asian countries (19) or when specialized physicians are on the staff of nursing homes (20). Roles and perceptions of non-physicians on ACP might differ from those of physicians. Therefore, we aimed to examine how individual international experts currently define ACP and whether this differs between physicians and other professionals.

Methods

Study design

This explorative study was embedded in the first round of a Delphi study (2021–2022) on ACP in dementia conducted by the European Association for Palliative Care (EAPC) (21,22) registered at the World Health Organization Clinical Trial Registry Platform (NL9720; 7 September 2021). The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The Medical Ethics Committee Leiden-Den Haag-Delft reviewed the study protocol (23) and declared the study was exempt from the Dutch Medical Research Involving Human Subjects Act (WMO) on 2 September 2021 (reference N21.105). Informed consent was obtained from all individual participants.

Population

We purposively identified potential candidates for a panel with variation in medical *vs.* non-medical professions and geographical area [details on sampling can be found elsewhere as a supplement (22)]. Individuals self-identified they were an English-speaking expert in ACP in persons with dementia, ACP in persons with other diseases or in general without necessarily requiring expertise in ACP in dementia specifically, or in an expert in dementia care. Their expertise included expertise based on research, clinical practice and policy. The panel was recruited by an international taskforce installed by the EAPC. Potential candidates were sought from the taskforce networks

including national and international organizations, conferences and research, groups for dementia care, and for palliative care. Because the majority of identified candidates was from Western countries, we next reviewed the list of expert panelists in previous Delphi studies on ACP and on palliative care in dementia, and from dementia-related organizations' websites. Finally, we searched PubMed targeting authors from Africa, Asia other than Japan, and the South and Central Americas (22). Potential candidates were sent an invitation email with a link to an information letter and a consent form for download. Participants then consented by marking a box on the introductory pages of the first survey. For non-responders, we sent a maximum of two reminders.

Data collection

Data was collected in online surveys with the first round which was open between 30 September and 22 October 2021. Because we deemed understanding how the panel would frame ACP relevant to begin with, in the first survey, at baseline and prior to completing any other Delphi study items and without any prompts, and without any subsequent feedback or consensus procedures, the participants were asked: "How would you define ACP in general, in one sentence, off the top of your head?". Participants were allowed ample room for responses of up to 4,196 characters allowing for an extremely long sentence if participants felt this was needed. They were also asked what ACP is called in their country. If participants from the same country provided different terms for ACP, we reached out to EAPC member organizations and members in those countries and our networks in other countries to confirm ACP terms. We also collected participants' characteristics including age, gender, county of origin, and professional background.

Data analysis

We used content analysis of the responses and created codes and categories using inductive open coding and the constant comparison method (24). All answers were labeled independently by two researchers in Excel software (authors E.J.d.W., intern and medical resident, and M.V., postdoctoral fellow in communication sciences, both with an understanding of ACP from the literature) with consensus meetings after every 20 definitions (four meetings in total). First, responses were divided into meaningful

text and labeled with a code representing the meaning, a synonym, or conjugated form of the words. This resulted in a code tree. Final codes were linked to categories (authors E.J.d.W., M.V., J.T.v.d.S., PhD methodologist and ACP researcher). We omitted categories that held a single code and were deemed irrelevant to ACP.

Next, we analyzed the perspective from which the participants defined ACP, including from the patient, the healthcare professional, or a neutral (no particular) perspective. This was determined in four consensus meetings by authors E.J.d.W. and M.V. independently. The perspective was assigned by evaluating the main verb (e.g., 'guiding', this was labeled as a professional's perspective whereas 'choosing' was labeled a patient perspective). When the verb was unrelatable to either perspective, we assigned a neutral perspective. The content analysis was imported from Excel after transposing ID and data, and verified in SPSS software (IBM version 28.0.1.0, 2021) by J.T.v.d.S. before merging into a single dataset linked to participants' characteristics.

We described the text data in terms of word counts as a potential indicator of the richness of the experts' responses and to verify whether its length differed between native and non-native English speakers, and between physician and non-physicians. We compared definition categories between physicians *vs.* non-physicians using Chi-square tests. We also compared the perspective patterns in these subgroups, using the hierarchical gamma statistics with responses ordered patient, neutral, healthcare perspective. The analysis by profession was part of the analytic plan of the protocol of the original Delphi study (23) and relevant to this embedded study. We have attempted to also explore whether the definition categories and perspectives differed by experts from different continents, Western countries and non-Western countries subgroups not part of the original protocol. No specific patterns emerged, but we refrained from further analyses and reporting because we deemed the subgroups too small for meaningful interpretation of differences. We verified whether length of the provided definitions differed for the professional subgroups, comparing word count with an independent *t*-test because possible differences between subgroups in length could necessitate adjustment of the comparisons of frequencies of categories for length of the provided definitions. The analyses were inductive and explorative (without a priori hypotheses). We adjusted for multiple comparisons and set the level of significance to $P < 0.01$.

Table 1 Participants (n=87)

Characteristics	% or mean [SD]	N
Gender		
Woman	66	57
Man	34	30
Other/prefer not to say	0	0
Age (years)	51 [12]	86
English in country of residence		
An official language	46	40
Not an official language	54	47
Continent of residence		
Europe	54	47
Americas	21	18
Asia	10	9
Middle East	3	3
Africa	2	2
Australia and New Zealand	7	6
Alternating between two continents	2	2
Reside in their country of origin		
Yes, in same country	91	75
No, reside in different country now	9	7
Experience		
Years of professional experience	24 [12]	84
Expertise in ACP (more possible)	–	85–87
Research	72	62/86
Clinical practice	60	52/86
Policy/administration	20	17/85
Other (e.g., ethics, teaching)	8	7/87
None [†]	8	7/87
Expertise in ACP patient groups		
ACP in dementia	60	51
ACP in patients with other diseases [†] or in general	32	27
Dementia care experience only [†]	8	7

Table 1 (continued)**Table 1** (continued)

Characteristics	% or mean [SD]	N
Professional background (more possible)	–	87
Physician [§]	47	41
Nurse (any level)	18	16
Psychologist	11	10
Ethicist	10	9
Policy/administration	8	7
Social worker	6	5
Epidemiologist	5	4
Spiritual counsellor	3	3
Other (e.g., pharmacist, jurist, sociologist)	10	9

[†], of 21 experts who reported a variety of other diseases and populations, 9 included cancer—2 cancer only, 7 combined mostly with chronic diseases or specific populations such as older adults; [‡], these 7 participants had dementia care experience with no particular experience in ACP. However, their definitions contributed to codes also assigned to definitions of those with ACP expertise (3 or more such experts); therefore, even if the definitions of these 7 participants are omitted from analyses, the resulting categories are the same; [§], there were no physician assistants or nurse practitioners in this sample. SD, standard deviation; ACP, advance care planning.

Results

Participant characteristics

The response rate of the Delphi study was 63% (107/169) (21,22). Eighty-seven of the 107 expert participants (81%) from 30 countries provided an ACP definition; for 54%, English was not a national language, and also 54% lived in Europe. Mean age was 51 [standard deviation (SD): 12] years; 66% were women; 47% were physicians (*Table 1*). Most (60%) had expertise in ACP in dementia, 32% in ACP in persons with other diseases, and 8% had dementia care expertise.

The ACP terms, descriptives and perspectives

Table 2 presents 17 examples of terms used for ACP in

Table 2 Examples of terms used for advance care planning[†]

Both English and non-English speaking countries
Advance care planning
English-speaking countries only
End-of-life care planning
Future care planning
Goals of care discussions
Goals of care planning
Non-English speaking countries translated into English
Advance decision planning
Advance medical care planning
Advance treatment coordination
Conversation in advance
Instructions/wishes before someone dies
Making a living will to provide advance healthcare plans
Planning ahead of treatment
Planning care in advance
Planning for the future
Serious illness conversation
Shared care planning

[†], in alphabetical order; data from 33 countries (21); detailed data available upon request.

English and non-English speaking countries. A mean number of 27 (SD: 14, range 4–75) words was used to define ACP excluding lead words such as “ACP is ...” [English-speaking country mean 26 (SD: 12); non-English speaking country mean 27 (SD: 15)]. Forty-five percent of participants defined ACP from the patient perspective, 26% from the healthcare professional perspective, and 29% from a neutral perspective (*Table 1*).

ACP definition categories

We identified 131 codes (*Figure 1*). *Table 3* shows example definitions provided by respondents and the categories assigned of a total of 19 definitional categories (*Table 4*).

Five categories that appeared in at least half of the definitions were: ‘Choosing between options’ (80%); ‘Care and treatment’ (78%); ‘Planning for the future’ (71%); ‘Individual person’ (68%); and ‘Having conversations’ (55%) (*Figure 1*). All but one definition comprised one or more

of these top-five categories; one expert who defined ACP without any of these five categories defined it as “a process that supports people at any stage of health in the end-of-life”.

Further, between half and a quarter of experts referred to the categories of ‘Process’ (43%) and ‘(Losing) capacity’ (37%), ‘(Declining) health’ (29%) and ‘Meaning of life’ (28%) (*Table 4*). Less than a quarter of participants contributed to categories such as ‘Documenting’ (24%) and ‘End of life’ (17%) and categories related to legal issues and other stakeholders involved. Medical care was a code that formed a small part of ‘Care and treatment’ (of 68 in this category, medical care was referred to explicitly 15 times).

Subgroups of physicians and other professionals

The definitional perspectives patterns and the content of the definitions did not differ significantly by profession except for a trend of physicians less often referring to the individual patient (56% *vs.* 78%; $P=0.03$). Also, the physicians used fewer words but the difference was not significant beyond possible indication of a trend [mean 24 (SD: 11), range: 5–51 *vs.* mean 29 (SD: 16), range: 4–75; $P=0.05$]. ‘Choosing between options’ was the most common category in both groups, but for experts who were not physicians, ‘Individual person’ ranked second while this ranked fourth in physicians, for whom ‘Care and treatment’ ranked second.

Discussion

This novel study of 87 international experts from 30 countries shows that they defined ACP most commonly in terms of choosing options, care and treatment, planning and preparation for the future for the individual patient by having conversations. Less common was a focus on ‘End of life’, ‘Documentation’ and medical issues as a small part of the category of ‘Care and treatment’. Almost half of respondents defined ACP from the patient perspective. Our findings did not appreciably differ between physicians and non-physicians.

With the evolution of ACP over time, the ACP definitions by the international panel appear to be adhering to recent consensus definitions; particularly focusing on the individual patient and on communication as a guiding principle, as well as the importance of ACP as a process over time. Capacity loss as a dichotomy does not dominate and less focus is being placed on documentation and end-of-life treatment preferences.

Step 1: codes as part of the text formulated by the panelists, no order	Step 2: merged codes	Step 3: categories [†] [number]
Approach; strategy	Approach	Choosing between options [1]
Choice; choosing; decide; decision-making; when decision arises	Decisions	
Aim; future goals of care; expressing hopes and aims in life	Goals	
Care options; (treatment) options; possibilities	Options	
Wishes; will and preferences	Preferences	
Caring-related; care values	Care	Care and treatment [2]
Treatment; therapy	Treatment	
Medical care	Medical	
Anticipate	Anticipate	Planning for the future [3]
In advance; long term; in prevision; future (steps); for later in life; in a situation in the future you cannot tell them	Future	
Formulate a plan; making plans; plans; planning	Planning	
Being prepared; preparation	Preparing	
Individual; patient; person; one; you; client	Individual	Individual person [4]
Address; conversations; communicate; express; state; talk	Communicate	Having conversations [5]
Engaging in discussions; discuss; making agreements	Discuss	
Involve; engaged; involved	Engaging	
Shared information	Shared information	
Ongoing; process	Process	Process [6]
Unable to make decisions; incapacitated; times in which they might not have the decision capacity; at a time in which a person has become incapacitated; become unable to speak for themselves; inability	Losing capacity	(Losing) capacity [7]
Make their decisions; their own care; themselves; direct own care	Autonomy	
Illness trajectory; chronic diseases; serious illness	Disease	(Declining) health [8]
Health	Health	
Progressive nature	Progressive	
Comfort and compassion	Comfort and compassion	Meaning of life [9]
Quality of life; what's important to you; values; well-being; what you value	Meaning of life	
Enable	Enable	Guiding [10]
Guide; instruct	Guide	
Help; support	Help	
Information; informed	Inform	
Need; necessary	Need	
Directive; statement	Directive	
Register; documentation; documenting; record; document; notes; legal documents	Registering	Documenting [11]
Care partner; family; relatives; loved ones; patient relative; their carers; those close to them; close family and friends; family member	Relatives	Relatives [12]
Reflect; reflection; consideration; psychological	Considering	Thinking [13]
End of life; end-of-life period	End-of-life	End of life [14]
Prolongation of a life	Prolongation	
Care team; work with a team; in close cooperation	Care team	Professionals [15]
Healthcare professional; physician; healthcare provider	Professionals	
Allowed; documentation that allows; allowing patients to [...]; process which allows people	Allowed, allows	Allowing, formal, legal [16]
Formal method; legal matters; legal document; legal professionals	Legal	
Legal representative; proxy; surrogate	Representative	Representative [17]
Difficult	Difficult	Challenging [18]
Issues; problem	Issues	
ACP is completed in a consultation	Completed	Completing now [19]
Current; for this moment; now	Current	

Figure 1 From advance care planning codes to categories. [†], categories are listed in order of frequency. Category names represent the combined codes in that category. For example, the category “Care and treatment [2]” covers care codes and treatment codes including medical care and treatment; participants may have mentioned care and/or treatment individually or both. In particular, care-related and care values was referred to 59 times, treatment and therapy 24 times, and medical care 15 times. ACP, advance care planning.

Table 3 Example definitions by panelists and categories

Definition	Panelist background	Code [†] category [number]
"A voluntary process of information-sharing, reflection and discussion, commonly supported by a health or care professional, about a person's priorities and preferences for future care in circumstances where they would be unable to speak for oneself"	Residing in English-speaking country	Choosing between options [1]
		Care and treatment [2]
	Policy/administration	Planning for the future [3]
		Individual person [4]
		Having conversations [5]
		Process [6]
		(Losing) capacity [7]
		Guiding [10]
		Thinking [13]
		Professionals [15]
"A systemic, structured, comprehensive process of identifying, reflecting on, discussing and preparing future treatment and care decisions"	Residing in non-English speaking country	Choosing between options [1]
		Care and treatment [2]
	Physician	Planning for the future [3]
		Having conversations [5]
		Process [6]
"Identifying future priorities and preferences for care and treatment at the end of life in an ongoing conversation with the person (when able), and if they choose, with those close to them (the family) to support decision making and/or to act as a proxy at points the person loses capacity to indicate future wishes"	Residing in English-speaking country	Choosing between options [1]
		Care and treatment [2]
	Nurse	Planning for the future [3]
		Individual person [4]
		Having conversations [5]
		Process [6]
		(Losing) capacity [7]
		Guiding [10]
		Relatives [12]
		End of life [14]
Allowing, formal, legal [16]		
"A formal method to support a persons preferences at the end of life and is usually documented within their medical notes and completed in consultation with a family member or legal representative"	Residing in English-speaking country	Choosing between options [1]
		Care and treatment [2]
	Nurse	Individual person [4]
		Guiding [10]
		Documenting [11]
		Relatives [12]
		End of life [14]
		Allowing, formal, legal [16]
		Representative [17]
Completing now [19]		

[†], the category numbers align with those listed in Figure 1 and Table 4.

Table 4 ACP definition perspectives and categories

ACP definitions	Total	Profession		P value
		Physicians (n=41)	Any other (n=46)	
Definition perspectives, % [n]				0.16
From the patient perspective	45 [39]	39 [16]	50 [23]	
From a neutral perspective	29 [25]	27 [11]	30 [14]	
From the professional perspective	26 [23]	34 [14]	20 [9]	
Definition categories [category numbers] [†] , % [n]				
Choosing between options [1]	80 [70]	78 [32]	83 [38]	0.59
Care and treatment [2]	78 [68]	83 [34]	74 [34]	0.31
Planning for the future [3]	71 [62]	78 [32]	65 [30]	0.19
Individual person [4]	68 [59]	56 [23]	78 [36]	0.03
Having conversations [5]	55 [48]	54 [22]	57 [26]	0.79
Process [6]	43 [37]	41 [17]	43 [20]	0.85
(Losing) capacity [7]	37 [32]	37 [15]	37 [17]	0.97
(Declining) health [8]	29 [25]	32 [13]	26 [12]	0.56
Meaning of life [9]	28 [24]	27 [11]	28 [13]	0.88
Guiding [10]	24 [21]	27 [11]	22 [10]	0.58
Documenting [11]	24 [21]	17 [7]	30 [14]	0.15
Relatives [12]	22 [19]	20 [8]	24 [11]	0.62
Thinking [13]	20 [17]	20 [8]	20 [9]	>0.99
End of life [14]	17 [15]	15 [6]	20 [9]	0.54
Professionals [15]	16 [14]	12 [5]	20 [9]	0.35
Allowing, formal, legal [16]	9 [8]	7 [3]	11 [5]	0.57
Representative [17]	8 [7]	5 [2]	11 [5]	0.31
Challenging [18]	7 [6]	10 [4]	4 [2]	0.32
Completing now [19]	5 [4]	0 [0]	9 [4]	0.053

[†], listed in order of frequency reported. ACP, advance care planning.

The current study with panelists from over 30 countries suggests globally diffusing ACP conceptualizations in terms of conversations that occur over time. Prior Delphi panels sampled from fewer countries over 7 years ago began the evolution of ACP to its current broader context (13,14). As in the prior definitions, our international expert panel recognized a possible need for documentation of medical preferences, though a focus on preparing people for lack of capacity was somewhat less prominent than in prior definitions. Further, the perspective of the patient underscored by non-physicians might indicate a movement

towards a more flexible agenda of the conversations in experts with non-medical professional background.

Implications

These findings have implications for research, policy, and clinical care. Planning for future care up to around 1994 (7) had been confined to signing written forms (i.e., advance directives), and to end-of-life care. Since then, the new notion of ACP has evolved from end-of-life treatments documented in legal forms to a process based on

conversations over time that enable individuals to articulate treatment preferences for health crises and issues beyond the medical domain and regardless of prognosis. Our results indicate that this evolving concept is being increasingly and consistently adopted by experts worldwide. At the same time, many questions remain, including what tasks, actions, or content constitute ACP and which professions can and should contribute to it. Future qualitative research may explore the meaning of choice in different cultures. Continued research is needed to monitor how ACP is being defined across the globe but also how this may affect research studies and outcome assessment as well as clinical programs and programs funding ACP conversations.

Strengths and limitations

The response rate was high with a panel of experts from diverse professions, English and non-English-speaking countries, and Western and non-Western countries. The experts typically provided rich data with a well-phrased definition in a single long sentence. There were some limitations. We could not include experts from all countries while there may be cultural-specific ACP conceptualizations (25). In addition, the subsequent parent Delphi study was about ACP in dementia and most of the experts had dementia expertise, potentially decreasing the generalizability of our definition findings. However, they probably considered ACP in general as requested, given that capacity was not prominent in their definitions while later on they agreed to capacity being one of three issues of particular importance in dementia (21). There was no discussion amongst the participants; a subsequent discursive exchange may have led to a change of some of the responses. Due to the sample size, we were unable to assess our findings by geographic region, but exploratory initial analyses indicated no obvious differential patterns. Finally, the majority of the sample identified as researchers. Future research may include more clinical and social care professionals who may be more naïve to the international literature on ACP, but this requires considering in more detail how differences in language, meaning and barriers may impact the result.

Conclusions

Self-reported definitions of ACP from international ACP experts from 30 countries demonstrate an evolution of planning from a sole focus of documenting preferences for

end-of-life treatment to person-centered conversations to help plan for the future in a process over time and the life course, regardless of medical prognosis. Further research should monitor any stabilizing, continued or superimposed shifts in the use of ACP definitions over time, the potential effect of different professional roles collaborating in ACP, and how this may affect research studies, ACP measurement, and clinical programs.

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Footnote

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Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was

conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was reviewed by the Medical Ethics Committee Leiden-Den Haag-Delft and was exempt from the Dutch Medical Research Involving Human Subjects Act (WMO) on 2 September 2021 (reference N21.105). Informed consent was obtained from all individual participants.

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