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Qualitative Research

# Preventing unwanted situations and gaining trust: a qualitative study of older people and families' experiences with advance care planning in the daily practice of primary care

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## Abstract

**Background:** Using advance care planning (ACP) to anticipate future decisions can increase compliance with people's end-of-life wishes, decrease inappropriate life-sustaining treatment and reduce stress, anxiety and depression. Despite this, only a minority of older people engage in ACP, partly because care professionals lack knowledge of approaches towards ACP with older people and their families.

**Objective:** To explore older people's and their families' experiences with ACP in primary care.

**Methods:** We conducted qualitative, semi-structured, face-to-face interviews with 22 older people (aged >70 years, v/m: 11/11), with experience in ACP, and eight of their family members (aged 40–79 years, f/m: 7/1). Transcripts were inductively analysed using a grounded theory approach.

**Results:** We distinguished three main themes. (i) Openness and trust: Respondents were more open to ACP if they wanted to prevent specific future situations and less open if they lacked trust or had negative thoughts regarding general practitioners' (GPs') time for and interest in ACP. Engaging in ACP appeared to increase trust. (ii) Timing and topics: ACP was not initiated too early. Quality of ACP seemed to improve if respondents' views on their current life and future, a few specific future care scenarios and expectations and responsibilities regarding ACP were discussed. (iii) Roles of family: Quality of ACP appeared to improve if family was involved in ACP.

**Conclusions:** Quality and accessibility of ACP may improve if GPs and nurses involve family, explain GPs' interest in ACP and discuss future situations older people may want to prevent, and views on their current life and future.

**Key Words:** Aging, caregivers, geriatrics, medical ethics, palliative care/end-of-life care, primary care.

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## Background

Using advance care planning (ACP) (see [Box 1](#), definition of ACP) to anticipate future decisions can increase compliance with people's end-of-life wishes, can decrease inappropriate life-sustaining

treatment and can reduce stress, anxiety and depression (1–4). ACP can, however, also be difficult and time consuming. In addition, the purpose, form and efficacy of ACP are the subjects of discussion (5–8). Nonetheless, because of ageing of societies, multimorbidity,

**Key messages**

- Older people's wish to prevent future situations makes them open to ACP.
- Trust appears to play an important role in ACP.
- Discussing responsibilities and expectations and involving family is crucial.

**Box 1. Definition of ACP**

'ACP is 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. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness. This process may include choosing and preparing another trusted person or persons to make medical decisions in the event the person can no longer make his or her own decisions.' (24)

increasing medical possibilities and decreasing continuity among health care providers, ACP is becoming more and more relevant (9,10).

Older people, in general, may especially benefit from ACP because they have a higher risk of having to make vital and acute choices in the upcoming years and may want to shift their care goals from prolonging life to quality of life. Even though many older people would like to have ACP with a health care provider, ACP currently mainly focuses on people with a limited life expectancy and takes place with a minority of older people (11–16). In addition, the quality of ACP varies greatly, and literature is unclear as to how best to approach ACP with older people, regardless of their health condition (15).

GPs and nurses are central in the care of older people in primary care in most developed countries and seem well suited for ACP with older people (7,17,18). Because knowledge of experiences and views of older people and their informal caregivers—referred to as family in this article—regarding ACP in the daily practice of primary care is limited, exploring those was the aim of this study.

**Methods****Design**

A qualitative approach using in-depth face-to-face interviews was most appropriate for our exploratory aim, taking into account that discussing ACP experiences may be a sensitive and personal matter, and knowledge on older people's and families' experiences is limited. We developed an interview guide (see Table 1) based on a literature (6,15,19). To get a better understanding of what ACP with older people in general can and should consist of, and because the term ACP is not commonly used in the Netherlands, we deliberately explained ACP in a broad and inclusive way. Besides using 'advance care planning' and the Dutch translation 'vroegtijdige zorgplanning', we called it 'talking about future care' and illustrated it with the commonly used definition (see Box 1) and examples of topics that may be discussed during ACP (19).

**Study population and sampling**

We contacted GPs and nurses by e-mail, telephone or face-to-face, through representatives of national and regional elderly and

**Table 1.** Interview guide

## Questions for the older person

1. Can you describe what your life looks like at the moment?
2. How do you look at your future?
3. Can you tell me about the conversation you had with your GP/nurse about future care? (*With all questions, the interviewer asked for thoughts, feelings and reasons for these thoughts and feelings and if they had suggestions for improvement.*)
  - Questions to encourage respondents to talk in more detail about ACP:
    - a. Who started the conversation? Can you tell me why this conversation took place? Do you know if there was a reason for it?
    - b. What did you discuss? Did you discuss all that you wanted to discuss or not? Were there any topics that you did not feel free to discuss?
    - c. Who were present at the conversation?
    - d. Do you know if the conversation was documented? What happened with the documentation?
    - e. Can you tell me if this conversation had or has consequences or effects? Do you feel a need for this kind of conversation or not? Would you miss anything if you would not have had this conversation?
4. Have you had conversations like this before? Can you tell me about it?<sup>a</sup>
5. Do you feel your personal beliefs/religion/cultural background influence the way you feel/think/talk about your future? And your financial situation? And education?

## Questions for (a) family member(s)

1. How did you experience these conversations about future care?
2. How did you experience (not) being present during these conversations?
3. Do you feel it would have been better to (not) be present during these conversations?
4. Did you talk much during these conversations? Did you make any decisions?
5. What do you think/feel about the reason and occasion for this conversation?
6. What do you think/feel about the discussed topics?

<sup>a</sup>The interview guide was refined during the course of the interviews by adding this question.

palliative care provider networks, the network of our research group and by using the snowball method. We asked the GPs and nurses to include in this study older patients with whom they had practiced ACP within the last 3 months. We chose this period as we noticed in the first interviews that, if older people had engaged in ACP more than 3 months before the interview, their recollection of ACP became more difficult. We purposively sampled older patients to ensure variety in sex, age, cognitive impairment, religious background, educational level, place of residence in a rural or urban region, ACP approach used and family presence during ACP. We contacted respondents by telephone for informed consent and only included them if they were able to give informed consent. We asked respondents if

one or more family member(s) had been present during ACP and, if they were, to invite them for the interview. Two family members who had not been present during ACP were present during the interview at their request. Written consent of all respondents was obtained before interviews started.

### Data collection

Interviews took place between March 2016 and May 2017. JG, a trained qualitative researcher and GP, conducted all interviews at the place of the respondent's choice. Interviews were audio recorded, transcribed verbatim and anonymized. We regarded saturation as being reached when the last four interviews presented no new relevant information.

### Data analysis

All authors were involved in the iterative analysis, for which we used field note review and open coding, supported by Maxqda software, to modify the interview guide and to improve trustworthiness of conceptual categories within respondents' experiences with ACP. Additionally, two trained qualitative researchers of our department read the first three interviews, independently coded these interviews, searched for categories and together with JG merged the independent analyses into a consensus code scheme. Identified conceptual categories included openness to ACP, needs for ACP, timing, topics, roles of care providers and family involved in ACP, factors influencing ACP and consequences of ACP. Thereafter, we analysed the interviews in depth, generating three main and multiple subthemes and selected illustrative quotes. Standards for reporting qualitative research was followed to design and report the qualitative data (20).

## Results

We interviewed 30 respondents: 22 older people, including three couples that participated in ACP for both partners and eight other family members (see Table 2). Interviews lasted on average 71 minutes (range 47–100 minutes). We described respondents' experiences and views in three categories: openness to ACP and trust, timing and topics for ACP, and roles of family in ACP.

### Openness to ACP and trust

Respondents appeared to be open to ACP if they felt a need to arrange important matters in order to prevent unwanted future situations: they made specific preferences known to their care provider or reported they wanted explanations and help to make choices and document preferences. Future situations respondents wanted to prevent concerned wanting to prevent suffering, ending up in a nursing home or burdening family with having to make choices for them in the future. If older people had negative experiences with illness at the end-of-life, experienced a low quality of life or had negative views regarding their future, they seemed more inclined to engage in ACP. Respondent 27, for example, wanted ACP to prevent that she would suffer like her late husband, who had died after being sick, confused and in a lot of pain for a long time:

R27: No [my daughter and I] regularly discuss how it went with my husband... well... I say, 'I never want to experience that.' That was so horrible.' [Woman with many physically limiting complaints, aged 80–89]

Older people's positive views on their current and future situation, on the other hand, seemed to make them less open to ACP.

Respondent 28, for example, did not experience a need for ACP yet because of his current good health situation:

R28: 'Well! (Laughs out loud) Then I think to myself like, well yes, if you're healthy, then you think 'What's this I have here? I'm not interested in this at all. [...] It's just, I'm still too active, you know? I think, if I get an accident, and you're home all day, then you'll think 'well, let's get things arranged.'" [Vital man, aged 70–79]

Second, lacking trust or negative previous experiences with ACP, with a GP or nurse could be a reason to be less open to ACP. Respondent 1, a man aged 81–89, for example, said that making euthanasia preferences known to his GP was useless because his deceased wife's euthanasia request had not been followed in the past. In addition, negative thoughts regarding GPs' time or interest in ACP appeared to make respondents less open to ACP. Respondent 5, daughter of Respondent 4, a woman aged 70–79 with cognitive problems, illustrated this:

R5: 'Those [ACP] agreements will not be kept.' [...] JG: 'And does your GP know you want to continue living [in your own home]?' R5: 'No, because she does not give a shit.' [Woman, family of R4, aged 40–49]

If respondents had ACP with a nurse, they often had no ACP with their GP, and their thoughts about GPs' lack of interest and time for ACP often persisted. This appeared to be due to nurses confirming GPs' lack of time and to respondents not recalling the nurse contradicting these thoughts. Respondents 23 and 24, a couple, for example, had ACP with a nurse but did not feel they could initiate it with their GP:

R23: 'Because I don't think it means anything to him... 'That's up to you' or so, he would say...' [...] R24: Oh no... No, I don't see it happening, but I would not mind it.' R23: 'He does not have time for it.' R24: 'No, I mean... I feel sorry for those people... they have this enormous time pressure if you ask me... That's very unfortunate...., yes.' [Man, aged 80–89, woman aged 91–100]

Third, respondents appeared to be less open to ACP if they felt that predicting what their preferences would be in the future was difficult as Respondent 24 illustrated:

R24: 'It does not make a difference if we talk about it, because when it comes to it, I wonder what I would have wanted a year before... if that is still the same... it could just as well be something different.' [Woman aged 91–100]

### Timing and topics for ACP

Even though most respondents were satisfied about the timing of ACP, some felt ACP could have taken place 5 or 10 years earlier than it did, early in their 70s or 80s. Some respondents felt too many topics were discussed, and not all topics discussed during ACP had been relevant yet. Recollection of the discussed topics appeared to be easier for respondents if they had access to documentation of ACP or if family had been present during ACP. If respondents remembered a nurse or GP had explicitly explained reasons for ACP, such as the respondent being frail or deteriorating, respondents did not feel it had been too confronting and acknowledged these were reasons for ACP. However, if respondents could not recollect that reasons for ACP had been discussed, they questioned if ACP had any value. Few respondents reported discussing who would be responsible for documentation and follow-up of ACP, where documentation should be saved, to which other care providers' documentation would be transferred and how binding agreements are made. When respondents initiated ACP,

**Table 2.** Characteristics of respondents: older people and their family interviewed in 2016 and 2017

	Older people	Family <sup>a</sup>
Sex		
Female/male	11/11	7/1
Age		
40–49 years		2
50–59 years		2
60–69 years		1
70–79 years	6	3
80–89 years	12	
>90 years	4	
Highest educational level achieved <sup>b</sup>		
Primary education	8	2
Secondary education	8	2
Tertiary education	5	2
Missing	1	2
Religious background		
Practicing/religious	9	
Not actively religious	12	3
Missing	1	5
Cultural background		
Western	22	8
Non-Western	0	0
Place of residence		
Rural/urban	12/10	
Time between ACP and interview		
<1 month	7	
1–3 months	10	
3–6 months	3	
>6 months	2	
Family		
present during ACP	11	
not present during ACP	11	
ACP with		
GP/GP trainee	7/1	2
Nurse	11	5
Both (sequentially)	3	1

<sup>a</sup>Including family that was present during the interview the International Standard Classification of Education (ISCED) but did not participate in ACP for themselves. <sup>b</sup>ISCED levels of education.

resuscitation and/or euthanasia preferences were discussed. When nurses initiated ACP, care and place of care were discussed, and when GPs initiated it topics varied. Sometimes legal representation was explicitly discussed, and some respondents reported that their GP or nurse had telephone numbers of their family. Some reported drawing up legal representation in a living will with a civil-law notary. If respondents had wanted to discuss additional topics, this concerned not only resuscitation, hospital admission and organ donation but also how they viewed their current life and future. They felt these latter topics were important because they felt their preferences followed from such discussions as Respondent 29 explained:

R29: ‘Yes... In practice something you just have not thought of will happen. So I think you should talk about what the general message of your thoughts is over specifying it. [...] If you know each other a little, and you know if you’re in a direction of ‘no euthanasia, no resuscitation’ that you would also say ‘no intensive care.’ [Vital man aged 80–89]

Respondents were generally positive about the topics discussed. However, if respondents felt discussed future care scenarios were

unrealistic or unappealing, they felt frustrated, especially if GPs or nurses kept pressing on discussing it. Nonetheless, most respondents felt that discussing these topics was a part of standard care. They were positive about the attention they received during these conversations, felt heard and more at ease and felt they could trust their GP or nurse more after the ACP discussion, as Respondent 21 illustrated:

R21: ‘I also want to have a bond of trust. [...] [My doctor] now knows what I’m like a little, you know? Yes. And once I have faith, I have faith.’ [Vital woman aged 70–79]

Respondents also reported being happy about knowing better about what to do in case of an emergency. Respondents 15 and 16, a couple aged 70–79, for example, felt more at ease because they now knew they could count on their GP and the GP after-hours service in case of an emergency and would not have to go to the hospital.

### Roles of family in ACP

Family involvement varied from only being present during ACP to keeping overview or making decisions for older respondents with cognitive impairments, as Respondents 25 (a man aged 80–89 with dementia) and 26 (his wife, aged 70–79) illustrated:

R26: ‘Actually it went the way it goes right now. I have to correct some things. [...] The decisions, that’s something I do more. Because I have the overview.’ [...] R25: ‘She can oversee that better, yes.’

If family was present during ACP, both older respondents and family valued it, as Respondents 12 (Woman aged 90–99) and 13 (woman aged 50–59 and cousin of R12) illustrated:

R12: ‘I can’t remember all of that. [...] They listen with me.’  
R13: ‘I wanted to be there, also because we accompany our aunt medically. In this way, you know how one thing relates to something else... We felt like we better keep the overview and prevent confusion about what a doctor has said.’

Also, it appeared to make recalling the meeting easier. If family had not been present, respondents differed in whether they wanted family to be present during ACP. Respondents felt, for example, it would burden their family too much or felt they could talk more freely without family present as Respondent 21 explained:

R21: ‘If [my daughter] would be there? Well, I would constantly think ‘Does mom say it in the right way and can you say something like this.’ [...] So I thought ‘No, it’s private...’ [Vital woman aged 70–79]

Respondents 2 and 3, on the other hand, felt a need for engaging family in ACP because legally representing each other would become more difficult:

R2: ‘Ten years ago I would make decisions more calm and well-balanced than I would now, if anything happens to [R3] and I get called. And if we are ten years further, the panic threshold will be even lower. So if we old folks have to refer to each other, will that be safe? I wonder. I think we’d then better burden the younger generation.’ [Man aged 70–79]

When family was not present during ACP, some respondents afterwards talked about their preferences with their family. Others did not because they assumed that their family knew what they wanted without explicitly discussing it, or had forgotten what was discussed.

## Conclusions

This study on experiences of older people regardless of their health condition and their family with ACP in the daily practice of primary care gives more insight into older people's openness to ACP and sheds new light on the role of trust in ACP: Our finding that older people appear open to ACP if they wish to prevent certain future care scenarios is supported by previous literature (11,12,21–23). The importance of gaining trust in the GP or nurse one has ACP with, gaining a sense of being heard and feeling better prepared for the future appears to be important for both older people and family but seems underexposed in both literature and clinical practice (8,22,24,25). Older people and their family's lacking trust, or negative thoughts regarding GPs' time and interest in ACP, appeared to make them less open to ACP. This makes it plausible that a vicious circle exists in which people, who lack trust in their care providers, will be less open to it and will less likely gain trust by participating in it (12). A lack of clarity about who is responsible for documentation, transfer and follow-up, and what can be expected from ACP, seemed to leave older people and their families with the belief that their wishes would be granted. This may indicate that ACP could lead to false expectations, would make increased trust through ACP unjustified, and that these topics should be a part of ACP (26). Our study confirms that ACP with older people in primary care needs to be aimed more on discussing views on older people's current life and future than ACP with people with a life-threatening illness (19,23,24,27–30). This raises the question if GPs can sufficiently understand older people's preferences if they do not engage in ACP themselves. Because, in addition, trust in GPs appeared not to increase if ACP took place with a nurse only, we feel GPs involvement in ACP may be crucial for good care for older people. Lastly, our findings support previous literature on the importance of families' involvement in ACP (27,31).

## Strengths and limitations

The main strength of this study is that it is, to our knowledge, the first to explore older people and their families' experiences with and views on ACP in the daily practice of primary care. However, in interpreting the results, note that older people and families who were not open to ACP are underrepresented. To minimize this bias, we encouraged respondents to speak openly about their positive and negative experiences and views. The presence of both older people and families during 11 of the interviews provided valuable insights into the actual practice of ACP, but it may also be a limitation because respondents might not have felt free to speak openly about each other's' roles.

## Recommendations for research and clinical practice

Both for research and clinical practice, gaining trust in care providers through ACP is crucial. This may be achieved if ACP starts with discussing how older people view their current life and future, if there are future situations they want to prevent, and by ensuring adequate information about GPs' reasons and responsibilities for ACP and consequences of ACP. Results of this study may motivate and support GPs to take more initiative in ACP than currently appears to be the case, create more openness of older people towards ACP and involve family in ACP. Future research evaluating the effect of ACP should use qualitative methods because reasons for and added values

of ACP are versatile and difficult to grasp using only quantitative methods. Future research should also focus on documentation and the transfer of discussions on people's general preferences because current living wills and the transfer of documentation are merely focused on future care scenarios and may be less suited to support memory or decision-making in acute situations.

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Ethical approval: according to the Medical Ethics Review Committee, our research is not subject to the Medical Research Involving Human Subject Act (WMO) because participants in our study were not subject to procedures and were not required to follow rules of behaviour.

Conflict of interest: none.

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