



UvA-DARE (Digital Academic Repository)

Future care

Advance care planning with older people and their families in general practice

Glaudemans, J.J.

Publication date

2021

[Link to publication](#)

Citation for published version (APA):

Glaudemans, J. J. (2021). *Future care: Advance care planning with older people and their families in general practice*.

General rights

It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations

If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: <https://uba.uva.nl/en/contact>, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

Chapter 3

Experiences with approaches to advance care planning with older people: a qualitative study among Dutch general practitioners.

MD MSc Jolien J. Glaudemans¹, MD PhD Eric P. Moll van Charante²,
MD PhD Jan Wind², MD John J. Oosterink³, Prof. Dick L. Willems¹

1. Section of Medical Ethics, Department of General Practice, Amsterdam Public Health research institute, Amsterdam University Medical Centres, Amsterdam, The Netherlands
2. Department of General Practice, Public Health research institute, Amsterdam University Medical Centers, Amsterdam, the Netherlands
3. Huisartsenpraktijk Kerkelanden, Hilversum, The Netherlands

Author contributions

MD MSc Jolien J. Glaudemans: conceptualization, methodology, investigation, data curation, analysis, writing - original draft, review, and editing, project administration, and funding acquisition.

MD PhD Eric P. Moll van Charante: conceptualization, methodology, analysis, writing – review and editing, and supervision.

MD PhD Jan Wind: analysis, writing – review and editing, and supervision.

MD John J. Oosterink: analysis, writing – review and editing.

Prof. Dick L. Willems: conceptualization, methodology, analysis, writing - review and editing, supervision, project administration, funding acquisition.

Abstract

Objectives: Advance care planning (ACP) with older people needs to be approached differently than ACP with patients with a terminal illness. ACP is still used with only a minority of older patients due to a lack of knowledge regarding appropriate approaches to ACP with older people. General practitioners (GPs) may play a key role in ACP with older people. Therefore, we explored their experiences with and views on approaches to ACP with older patients in daily practice.

Design, setting and participants: A qualitative study among a purposive sample of 19 Dutch GPs based on semi structured interviews.

Results: Approaches to ACP with older patients can be divided into two categories: systematic and ad hoc. Systematic approaches consisted of discussing a fixed combination of topics with community-dwelling older patients who are frail, cognitively impaired or are aged >75 years, and with older patients living in residential care homes during group information meetings, intakes, comprehensive geriatric assessments and periodic assessments. Meetings were aimed at making agreements in anticipation of future care, at providing information and encouraging older people to take further steps in ACP. With ad hoc approaches, respondents discussed only one or two topics related to the near future. Ad hoc ACP was mainly done with deteriorating patients or when patients or family initiated ACP. Systematic and ad hoc approaches were used simultaneously or sequentially and were both used for initiating and following up on ACP. Due to a lack of time and knowledge of other occasions and topics than the ones respondents used, respondents seemed to underuse many occasions and topics.

Conclusions: Awareness of appropriate systematic and ad hoc approaches for ACP, and the focus on providing information and encouraging older people to take further steps in ACP reported in this study can support GPs and improve older patients' access to ACP.

Introduction

Making decisions with older people and their family in acute situations or when someone is unable to fully speak for himself or herself can be difficult, stressful, and can have undesirable consequences such as unwanted care or treatment with high risks of harm.¹⁻³ This scenario may in part be avoided by advance care planning (ACP). ACP enables individuals who have decisional capacity to identify their values, reflect on the meanings and consequences of serious illness scenarios, define goals and preferences for future medical treatment and care, and discuss these issues with family and healthcare providers. ACP addresses individuals' concerns across the physical, psychological, social and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review preferences.⁴ Benefits of ACP have been demonstrated: it can increase compliance with patients' end-of-life wishes, decrease family distress, increase the use of palliative care resources, and can decrease life-sustaining treatment.⁵⁻⁷ ACP can, however, be difficult, time-consuming and require adequate financing, transfer of information and training, and the purpose, form and efficacy of ACP in daily practice are the subject of discussion.^{8,9}

Despite this, ACP has become particularly relevant with the ageing of societies and the increase in multimorbidity and medical possibilities, especially to older people and their family, who are at a higher risk of having to make vital choices and may need to shift their care goals.^{10,11} ACP is receiving growing attention, and the majority of older people would like to have ACP.^{12,13} Nonetheless, it still takes place only with a minority of older people,^{14,15} perhaps because approaches to ACP, both in research and clinical practice, are often focused on end-of-life care for deteriorating patients, or patients with cancer or Alzheimer's disease, instead of older people in general.^{16,17} Consequently, approaches to ACP in the literature are diverse and focused on care at the very end of life, and knowledge of approaches to ACP with older people in general is lacking.^{16,18,19}

In many Western countries, general practitioners (GPs) are considered central professionals in the treatment and care of older people (both community dwelling and those living in residential care homes).²⁰ In the Netherlands, they often closely collaborate with practice nurses. These nurses screen older patients for frailty or cognitive impairment through comprehensive geriatric assessments, provide

proactive support and manage care.²¹ Older people, their family and healthcare professionals feel GPs should have a prominent role in ACP.^{22,23} Despite the lack of knowledge, GPs have experience with ACP with older patients in their daily practices. Therefore, we aimed to explore GPs' experiences with and views on different approaches to ACP with older patients in their daily practices.

Materials and methods

Design, and patient and public involvement

We conducted semi structured interviews with Dutch GPs.²⁴ Besides all authors, of which four are GPs, the following were involved in the development of the research question, method and analysis to foster reflexivity: through advisory committee meetings representatives of three older patients' organisations were involved, and through research meetings GPs from the Department of General Practice, Amsterdam Public Health research institute were involved. In addition, the ethics section of the Amsterdam Public Health research institute, consisting of members with clinical, philosophical and anthropological backgrounds, were involved in the analysis. Unfortunately, as there was a time lag between the interviews and publication, member check of the results with respondents before publication was not feasible. Results of this study will be shared with respondents on publication of the study.

Study population and sampling

We purposively sampled GPs, aiming for variety in sex, age, type of practice organisation, and rural or urban population, by approaching GPs from the Department of General Practice, Academic Medical Centre—University of Amsterdam—Amsterdam Public Health research institute and using the snowball method. To ensure rigour regarding our research question we explored both positive and negative experiences and aimed for variety in the extent of experience with ACP (ranging from 'hardly any' to 'structurally embedded in daily practice') by asking GPs for their experiences with 'conversations with older patients about their wishes and preferences for future care'. One GP did not participate due to lack of time; 19 agreed to participate. All respondents gave oral and written consent. According to the Medical Research Involving Human Subjects Act in the Netherlands (Wet

medisch-wetenschappelijk onderzoek met mensen or WMO), the study did not need an ethics committee's approval.

Data collection

Interviews took place between November 2012 and January 2015. All interviews were performed one-on-one by the first author, who is a GP and trained qualitative researcher, and took place at the respondent's practice or home, or at the Academic Medical Centre. The semi structured interviews were guided by questions based on an interview topic list (box 1, based on previous research by our research group).¹⁶ Because we felt we needed deeper insight into the (non-)necessity and potential goals of ACP with older patients, we refined the topic list after the first three interviews and added a topic concerning how respondents either knew or did not know how they should treat an older patient in an acute situation. Interviews were recorded, transcribed verbatim and rendered anonymous. Each interview started with an open question on the respondent's recollection of positive or negative experiences with ACP with older patients (>65 years). Respondents were encouraged to describe detailed aspects of typical occasions for ACP, for example, which topics they addressed and the roles of those involved in ACP. With each (sub)topic, they were asked about their thoughts, feelings, views and reasons for their approaches. We regarded saturation as being reached when the last three interviews presented no new relevant information.

Data analysis

We used MAXQDA software to thematically analyse the transcripts of the interviews. We used open coding and inductive analysis to identify various aspects of approaches to ACP.²⁵ The first author and two other researchers, IS, physician and trained qualitative researcher, and JO, co-author, GP and trained qualitative researcher, read the first four interviews to become familiar with the material, independently coded these interviews and searched for potential themes. The independent analyses were merged into a final coding scheme, and subthemes were generated based on consensus and in-depth analysis.

Results were regularly compared and discussed with all authors and within the ethics section of the Amsterdam Public Health research institute. The coding scheme was refined and illustrative quotes were selected that related to the research aim.

Box 1 Interview topic list

1. Example of a positive or negative experience with advance care planning (ACP) with an older patient (when the respondent first reported a positive experience, we thereafter discussed a negative experience, and vice versa):
 - a. Timing of ACP, reasons for ACP and occasions.
 - b. Initiative.
 - c. Roles of those involved.
 - d. Topics discussed.
 - e. Follow-up.
 - f. Documentation.
 - g. Transfer of information.
 - h. Spend time.
 2. Experience with acute situations in which respondent did or did not know what choices to make.
 3. Opinion of respondent on ACP with older people.
-

Results

Characteristics of the 19 respondents are described in table 1. Interviews lasted 59 min on average (range 35–77 min). Respondents reported on ACP with community-dwelling patients and patients living in residential care facilities. We identified two categories of respondents' experiences with and views on ACP with older patients: systematic approaches and ad hoc approaches. Systematic approaches in this study, however, seemed to always be influenced by or combined with ad hoc approaches, as the personal situation of a patient influenced ACP greatly. The different approaches were used simultaneously or sequentially and were both used for initiating and following up on ACP. Intervals between a first ACP contact and follow-up varied from weeks to years.

Systematic approaches to ACP

When respondents systematically approached ACP they approached ACP with different patients the same way by discussing a fixed combination of topics with older patients during planned occasions for ACP. Respondents invited community-dwelling patients aged 75–85 years and older, or older patients who were assessed by them or nurses as frail or cognitively impaired, often through a comprehensive

Table 1 Respondents' characteristics

Respondents' characteristics	Number of GPs
Sex	
Male	7
Female	12
Age, years	
<40	8
40-49	4
50-59	6
>60	1
Practice location	
Urban	10
Rural	9
Practice population*	
Older people	
Many	6
Average	10
Few	3
Immigrants	
Many	8
Average	3
Few	8
Socioeconomic status	
Low	5
Average	9
High	5
Appointment in GP practice	
Tenure	8
Temporary	11

*As estimated by the respondents.
GP, general practitioner.

geriatric assessment.²¹ Respondents used 75 years or 85 years as age limits because they felt ACP was more relevant for those individuals given the increased frailty at those ages. Respondents' contracts with health insurers, in which some of them had agreed to include older patients from certain age limits in proactive

care, also contributed to setting these age limits. Respondents did, however, feel younger patients could benefit from ACP, but time constraints kept them from including them.

Systematically approached ACP was initiated during group information meetings and during screening for frailty or cognitive impairment by a practice nurse. These systematic approaches were often aimed at providing information, encouraging patients to think, talk and ask questions about ACP, and inviting them for individual ACP conversations. Respondent 19, for example, organised group information meetings for his patients aged ≥ 75 years, during which he discussed what might be important in this phase of life, and explained about resuscitation, palliative care and euthanasia:

'I come across many patients who are in the last phase of their life and I notice many misconceptions about palliative care, euthanasia and resuscitation exist. This way I can explain about these things to a large group at once. I received so much positive feedback, and many people came to my practice afterwards because they want to discuss their preferences for the discussed topics.'

ACP with residential care home patients was initiated during intakes and (bi)annual scheduled periodic assessments. Respondent 13 explained how ACP took place during intakes:

'We discuss someone's medical history and whatever is relevant currently. We also discuss what someone wants in acute situations. We always discuss resuscitation, and hospital admission. We have a whole list: tube feeding is always mentioned, mental incompetence, if someone has a written statement regarding euthanasia or has any thoughts about it, and if someone already has wishes or preferences regarding their funeral.'

Although respondent 13 felt these intakes were a good occasion for ACP, patients did not always immediately react positively:

'God yes, occasionally I scared people when I asked these questions during an intake. 'Oh, I've never thought about that!' they said. People react differently. When someone did not think about this beforehand, I explain a few things and

give them an information letter which they can take home to read and discuss with their partner and children. And after some time, we make an appointment again to further discuss it.'

When follow-up of ACP was approached systematically, intervals between ACP contacts varied between every 1 year or 2 years to every six months. Although respondents felt follow-up was worthwhile, respondents who did it struggled with the time spent on these contacts.

When systematically approaching ACP, respondents always discussed resuscitation and euthanasia. In the interviews, they also mentioned other combinations of topics they always discussed during these occasions, for example, hospital admission, antibiotic treatment and tube feeding, and palliative care, legal representation, views on life and death, organ donation, place of burial and preferred place of death. Respondents discussed these topics because they were part of a routine and they felt discussing them was necessary to be able to anticipate situations in which the patient would have little time to make a deliberate decision, or the patient would be unable to speak for herself or himself. Reasons respondents reported for not discussing topics when systematically approaching ACP were that the topics were not yet relevant for a patient, they felt resistance to the consequences of discussing certain topics or were unaware of the possibility of discussing certain topics with community-dwelling older people, as respondent 1 illustrated:

'Yes, I realise now I've never made agreements with patients about resuscitation. In fact, I never do this in my practice. I do it with my patients who live in a nursing home, but I've never asked other patients.'

Respondents had negative experiences when they explained many scenarios in detail, as patients had difficulty comprehending them all. In addition, they felt that discussing everything that could happen in the future was not useful, because patients' preferences could change, and such explanations were time-consuming, as respondent 10 illustrated:

'If you want to do it well, it takes a lot of time. All those scenarios are just one tick box on a form, but it is difficult to explain what you really mean. And it might confront people too much if you talk possible future cancer diagnosis

and treatment. So, you need good information provision for patients. It is easier when someone already knows what they want than when there's not much wrong with someone yet.'

Due to the abovementioned reasons and negative experiences respondents used systematic approaches less than they wanted, despite also having positive experiences with and views on systematic approaches to ACP with older patients.

Ad hoc approaches to ACP

All respondents had experience initiating and following up on ACP ad hoc with patients aged 65 years and older, which took place during routine care. Discussed topics depended on the situation. Respondents initiated or followed up ACP ad hoc when patients deteriorated or were likely to deteriorate in the near future. Examples respondents gave of actual deterioration were an accumulation of incidents, such as falling and delirium, and new symptoms or diagnoses, failing therapy, or gradual deterioration due to a chronic, progressive or terminal illness. Examples of patients they felt were likely to deteriorate in the near future were older patients who needed help for everyday activities or needed medical devices, or whose informal caregivers were becoming overburdened. With these patients, respondents wanted to prevent having to acutely organise care when a patient would deteriorate or a family would become overburdened. Respondent 17 illustrated this with this quote about a patient who had Chronic Obstructive Pulmonary Disease and lung cancer and started having cognitive problems but had decisional capacity to discuss preferences:

'[I felt we needed to discuss this] mainly because of her cognitive problems, and how we should deal with her care, the capacity of her daughters and the option of nursing home care. Because I saw her daughters were reaching their limits, or actually had been going across for a long time. I wondered for how long there were going to keep on going like this, also because I know how difficult it is to have to arrange an emergency admission to a nursing home, if necessary.'

Other reasons were, wanting to prevent conflict, feeling that the patient may not want treatment or care, or believing treatment may no longer be appropriate or could even be harmful, for example, when patients or family could not accept a

poor prognosis, when patients were non-compliant with therapy or when they were initially not open to ACP. Respondent 5 explained why she initiated ACP with a patient who was initially not open to ACP:

'He had a feeding tube but want to eat by himself anyway. As a result, he ended up in ICU every 3–4 weeks. But he was fed up; he just wanted to be left alone and hated to be admitted to the ICU. So, we thought 'this is not good care. We're just reacting on the acute deteriorations.' Initially he didn't want to talk, walked away when I visited. But after a couple of tries he started trusting me.'

Patients and family also initiated ACP, by expressing concerns, wishes or preferences, or showed they were open to ACP. Respondent 3 talked about how a patient who had had a stroke was open to ACP:

'He asked why he had to use antihypertensive medication and said he didn't want to use them if they would only prolong life. But, if he would have a higher risk of having another stroke and he would not die but have less quality of life, he wanted to continue using them. When he said 'If it would be over at once it would be fine with me', I asked: 'If you'd have another stroke, would you still want to go to the hospital?' He said he wouldn't want to go. For me it's obvious I should then continue talking about resuscitation as well.'

Topics brought up by patients or family varied from euthanasia, resuscitation, care and preferred place of living and dying to continuation or withdrawal of preventive medication, donation of their body to science, organ donation and place of burial. Patients and/or family brought up these topics because they questioned the benefits of treatments, certain preferences or an unsustainable home situation, and because of the public debate on euthanasia, resuscitation and organ donation. When respondents reported on ad hoc approaches, they generally reported discussing only the initial topic, but sometimes one topic led to another. The discussed topics varied and often concerned scenarios in the near future. Few respondents reported discussing patients' views on life and death, seemingly because of the lack of knowledge regarding reasons to discuss them, and the belief that patients would not expect them to discuss them. When they did discuss this topic, however, they talked about patients' wishes, things that matter most to patients, religion, quality of life, unfinished business, and views on the end of

life and death. In general, respondents had positive experiences with their ad hoc approaches. Because other care often demanded respondents' time, however, respondents reported they used potentially appropriate occasions and topics less than they wanted.

Facilitators of and barriers to ACP independent of the approach

All respondents encountered facilitators of and barriers to ACP with older patients independent of systematic or ad hoc approaches, from which we identified three categories; facilitators and barriers related to respondents themselves, to the organisation of care, and to patients and their families.

Facilitators and barriers related to GPs

First, respondents' beliefs regarding ACP and certain treatments and care options, and which goals they wanted to achieve through ACP, strongly influenced how they practised it. It influenced, for instance, whether they felt explicitly discussing certain topics was necessary, as well as which topics they thought were worth discussing at all. When respondents, for example, felt the likelihood of resuscitation occurring is small they were hesitant to discuss resuscitation. Respondent 10, on the other hand, felt discussing it with older people in general is important:

'People who appear to be in good health can get a heart attack the next day. So (resuscitation) is something that would be good to ask to all people above a certain age.'

Another barrier occurred when respondents felt they could not oversee the consequences of treatment limitations, or felt treatment limitations could pose an extra burden on them, patients or family, as respondent 7 explained:

'Look, if I had chosen the easy way (and the patient was admitted at the hospital) I would have slept better. What if she gets something at home that disables her but doesn't lead to her death, and it would have been able to prevent this by admitting her to the hospital. I can't be 100% sure.'

Other barriers were that respondents assumed they knew or understood what the patient wanted without explicitly discussing a topic, and respondents' lacking knowledge about possibly appropriate topics for ACP with older patients.

Facilitators and barriers related to organisation of care

Approaching ACP systematically, and especially organising group information meetings to initiate ACP, was an important facilitator for ACP with older people, related to organisation of care; inviting patients systematically, making ACP a routine and planning time for it led to an increase in the number of older patients with whom respondents individually had ACP. An important organisational barrier was a lack of time, necessary to discuss and practise ACP in a good way. Respondent 10 explained why taking the time for ACP is important:

'You want to understand why people make certain choices and be able to support those choices. (A living will) is just worth less and I find it less satisfactory.'

Facilitators and barriers related to older patients and/or their families

When patients or family took initiative, were open to ACP, had clear preferences and were on the same page as the respondent regarding those preferences, this facilitated ACP. The opposite, however, led to respondents struggling with how to practise ACP with these patients, and to them being more persistent in their attempts to have ACP, or making decisions regarding ACP themselves instead of together with the patient.

Discussion

Approaches to ACP with older patients can be divided into two categories: systematic and ad hoc. Respondents had positive experiences with both approaches. With systematic approaches, respondents discussed a fixed combination of topics with systematically selected community-dwelling patients and patients living in residential care facilities. These meetings were aimed at providing information, encouraging patients to take further steps in ACP and at making agreements anticipating acute situations and situations in which patients would be unable to speak for themselves. Respondents invited these patients for group information meetings about ACP, or initiated ACP during intakes, periodic assessments or comprehensive geriatric assessments. Resuscitation and euthanasia seemed to be important topics, because respondents who approached ACP systematically always discussed them. Ad hoc approaches consisted of discussing one or two topics,

which were often related to the near future and varied from treatment limitations to care, preferred place of living, and views on life, dying and death. Respondents reported these topics were discussed when patients took the initiative or seemed to be open to ACP, when a patient's situation deteriorated or if respondents felt the provided care was not appropriate. Different systematic and ad hoc approaches complemented each other in the ACP process; they could be used simultaneously or sequentially and were used for both initiating and following up on ACP.

Systematic approaches, often complemented by ad hoc approaches seemed to facilitate ACP with older people, because such approaches made relevant topics accessible to a larger number of older people than sole ad hoc approaches. Respondents, however, underuse them because of the lack of awareness of possible and appropriate occasions and topics, difficulty when discussing many topics in detail, lacking skills for discussing views on life and death, and the lack of time. GPs also differed in what they felt were appropriate and relevant occasions and topics. These differences seemed to be related to what goals they want to achieve with ACP: providing good care according to their personal and professional views, answering patients' questions, or preventing conflict, crisis or care that no longer seems appropriate.

Comparison with existing literature

To the best of our knowledge, this study is the first to report on ACP with older people, including healthy and frail older people and people with cognitive impairment or terminal illness, in the daily practice of primary care. In particular, systematic approaches such as the group information meetings with people aged 75 years or older seem to be interesting new opportunities to make ACP accessible to older people in general. Positive experiences with systematic approaches in this study fit with literature on ACP with specific subgroups such as frail patients and patients with chronic and terminal illness.²⁶⁻²⁹ In addition, literature supports our findings on ad hoc approached occasions for ACP that are related to deterioration or initiative from the patient or family.^{27,28,30} Following up on ACP is generally considered to be important but previous research seems focused on initiating ACP and less on approaches to follow-up discussions. Even though all respondents have different approaches to follow-up of ACP, this study adds to the existing knowledge that all reported occasions can function both as initial and as follow-up for ACP. Literature is also limited on which topics should be discussed, and in what detail,

with older people, in general, and with specific subgroups of older people. Topics for ACP with older people reported in this study, such as patients' views on life and death, and future care scenarios concerning resuscitation, hospital admission, preferred place of living and dying, and palliative care correspond with existing literature on topics for ACP.^{31,32} Other topics reported in this study may be specifically appropriate for ACP with older people, such as care and the patient's wishes regarding organ donation and place of burial, as they have not been addressed previously. Regarding the two latter topics, however, this may also reflect that ACP generally does not address post-death wishes. Although legal representation and views on life and death were only discussed by a few respondents, they seem to be essential topics for ACP.^{33,34} Reasons for respondents to not discuss legal representation might be that family often functions as legal representation without legal representation being explicitly discussed. Respondents that did not discuss views on life and death were mostly not aware of the reasons for discussing it. As reported, euthanasia seems to be an important topic for ACP in the Netherlands, influenced by the enactment of the euthanasia and the active public debate on it. Euthanasia might, however, not be an important topic for ACP in countries where legislation does not permit it. When GPs assumed they knew their patients' preferences without explicitly discussing it, lacked knowledge and skills regarding ACP with older people in this study, and lacked time for it, this made them reluctant towards ACP, which fits with previously known barriers to ACP.^{18,19} In addition, both that healthcare providers' assumptions on patients' preferences often do not correspond with patients' actual preferences, and GPs' reasons for ACP, may indicate supporting patients' autonomy deserves more attention.^{35,36} The influence of what goals GPs wish to achieve with ACP seems, however, underexposed in literature.³⁷ The intention to provide information and encourage older patients to take further steps in ACP and to instantly make agreements in anticipation of future care, has to our knowledge not been reported before and may therefore specifically apply to ACP with older people.

Implications for research and/or practice

For both clinical practice and research, experiences and views studied show that ACP can be made more accessible to older people if aimed at anticipating on acute situations and situations in which patients would be unable to speak for themselves, and at information provision and encouraging older patients to take further steps in ACP. Knowledge of appropriate approaches to ACP with older

people, especially systematic approaches, can add to existing guidelines and tools and thereby support GPs and improve older patients' access to ACP. In addition, GPs' awareness of their assumptions on patients' preferences, and awareness of goals they and their patients wish to achieve through ACP may facilitate ACP. Future research should be directed towards systematic approaches to ACP with older patients, in particular towards investigating which (limited number of) ACP topics are appropriate to discuss as that may prevent patients, family and GPs from being flooded by too many detailed topics. Attention would also be warranted for the follow-up of ACP and the interval between ACP contacts, while maintaining tailored care and preventing too short intervals, as they may pose too great a burden on GPs, patients and family. Other opportunities for research lie in investigating the perspective of older people, family and nurses on ACP with older people, especially systematic approaches. In addition, investigating goals those involved in ACP may wish to achieve may support beneficial effects of ACP.

Strengths and limitations

This study gives an overview of how ACP with older people can be approached. It shows possible occasions for ACP with older people and topics for those occasions. Thereby, it shows how systematically approached ACP can make relevant topics in ACP accessible to all older patients, shows opportunities for improving the current practice of ACP with older patients and may give direction to research on ACP. A strength of the qualitative design of this study is that it gives in-depth insight into reasons for the way respondents practise ACP. However, it also has its limitations. First, the small number of respondents means we have to be cautious when drawing conclusions on which topics are essential in ACP with older people. Second, interviews were conducted only with Dutch GPs. Therefore, resuscitation and euthanasia may indeed be important topics to discuss during ACP with all older people but may also be a consequence of the public debate on these topics in the Netherlands. The fact that four of the authors are GPs is a strength, as both their positive and negative experiences led to a more critical view on the design and analysis of this study. It is, however, also a limitation because it may have led to too one-sided perspective on ACP in different stages of this study. By involving representatives of older patients' organisations and the ethics section of the Amsterdam Public Health research institute we, however, tried to include diverse perspectives on ACP. That the interviewer is a GP may have created less openness towards feelings of insecurity and negative experience. It may, however, also have

created more understanding of difficult situations and thereby increased openness. Our strategy to sample respondents with experience with ACP might have led to respondents with above average interest in palliative care and care for older patients. Thus, it may also have led to a more positive view on ACP. We tried to overcome this bias by exploring a broad range of experiences and views by purposively sampling GPs with different experiences, backgrounds and with experiences in populations with different backgrounds. The risk of bias was further minimised through focusing on positive and on negative experiences with either practising ACP or not practising ACP, elaborate research group discussions and coding.

Declarations

Acknowledgements

The authors thank Ilse Zaal-Schuller for analysing interviews and the advisory committee and all the GPs who participated in this research. Contributors JJG was responsible for the planning of the study, sampling of respondents, and the analysis and writing of the final report. DLW and EMvC provided inputs at all stages. JJO analysed interviews and all authors, including JW, commented on all draft documents and read and approved the final manuscript. DLW had overall responsibility.

Funding

This work was financially supported by The Netherlands Organization for Health Research and Development (ZonMw), project number 839110004.

Disclaimer ZonMw played no role in the design, execution, analysis, and interpretation of data, or writing of the study.

Competing interests

None declared.

Patient consent

Not required.

Provenance and peer review

Not commissioned; externally peer reviewed.

Data sharing statement

This is a qualitative study and therefore the data generated are not suitable for sharing beyond that contained within the report. Further information can be obtained from the corresponding author.

Open access

This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

References

1. Kanzaria HK, Brook RH, Probst MA, Harris D, Berry SH, Hoffman JR. Emergency physician perceptions of shared decision-making. *Acad Emerg Med*. 2015;22(4):399-405.
2. Legare F, Ratte S, Gravel K, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions. *Patient Educ Couns*. 2008;73(3):526-535.
3. Handy CM, Sulmasy DP, Merkel CK, Ury WA. The surrogate's experience in authorizing a do not resuscitate order. *Palliat Support Care*. 2008;6(1):13-19.
4. Sudore RL, Lum HD, You JJ, et al. Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. *J Pain Symptom Manage*. 2017;53(5):821-832 e821.
5. Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. *Palliat Med*. 2014;28(8):1000-1025.
6. Houben CHM, Spruit MA, Groenen MTJ, Wouters EFM, Janssen DJA. Efficacy of advance care planning: a systematic review and meta-analysis. *J Am Med Dir Assoc*. 2014;15(7):477-489.
7. Baidoobonso S. Patient Care Planning Discussions for Patients at the End of Life: An Evidence-Based Analysis. *Ont Health Technol Assess Ser*. 2014;14(19):1-72.
8. Glaudemans JJ, de Jong AE, Onwuteaka Philipsen BD, Wind J, Willems DL. How do Dutch primary care providers overcome barriers to advance care planning with older people? A qualitative study. *Family practice*. 2018.
9. Johnson SK, I. ; Butow, P.N. ; Tattersall, M.H.N. Advance Care Planning: is quality end of life care really that simple? *Internal Medicine Journal*. 2017;Apr;47(4):390-394.
10. Steering group Appropriate end-of-life care (Stuurgroep Passende zorg in de laatste levensfase). Report: not all that can be done should be done. (Rapport: Niet alles wat kan, hoeft.). *Royal Dutch Medical Association (Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst)*. 2014.
11. Dutch Healthcare Council (Raad voor de Volksgezondheid en Zorg). Aging while being able to manage oneself (Redzaam Ouder). 2012.
12. Sharp T, Moran E, Kuhn I, Barclay S. Do the elderly have a voice? Advance care planning discussions with frail and older individuals: a systematic literature review and narrative synthesis. *The British journal of general practice : the journal of the Royal College of General Practitioners*. 2013;63(615):e657-668.
13. De Vleminck A, Batteauw D, Demeyere T, Pype P. Do non-terminally ill adults want to discuss the end of life with their family physician? An explorative mixed-method study on patients' preferences and family physicians' views in Belgium. *Family practice*. 2017.

14. Raijmakers NJ, Rietjens JA, Kouwenhoven PS, et al. Involvement of the Dutch general population in advance care planning: a cross-sectional survey. *Journal of palliative medicine*. 2013;16(9):1055-1061.
15. De Vleminck A, Pardon K, Houttekier D, Van den Block L, Vander Stichele R, Deliens L. The prevalence in the general population of advance directives on euthanasia and discussion of end-of-life wishes: a nationwide survey. *BMC Palliat Care*. 2015;14:71.
16. Glaudemans J, Moll van Charante E, Willems D. Advance care planning in primary care, only for severely ill patients? A structured review. *Family practice*. 2015;32(1):16-26.
17. Janssen DJ, Spruit MA, Schols JM, Wouters EF. A call for high-quality advance care planning in outpatients with severe COPD or chronic heart failure. *Chest*. 2011;139(5):1081-1088.
18. De Vleminck A, Houttekier D, Pardon K, et al. Barriers and facilitators for general practitioners to engage in advance care planning: a systematic review. *Scandinavian journal of primary health care*. 2013;31(4):215-226.
19. De Vleminck A, Pardon K, Beernaert K, et al. Barriers to advance care planning in cancer, heart failure and dementia patients: a focus group study on general practitioners' views and experiences. *PLoS One*. 2014;9(1):e84905.
20. European primary care, 2004/20E. *Health Council of the Netherlands (gezondheidsraad)*, 2004.
21. Welsh TJ, Gordon AL, Gladman JR. Comprehensive geriatric assessment--a guide for the non-specialist. *Int J Clin Pract*. 2014;68(3):290-293.
22. Conroy S, Fade P, Fraser A, Schiff R, Guideline Development G. Advance care planning: concise evidence-based guidelines. *Clinical medicine*. 2009;9(1):76-79.
23. Michiels E, Deschepper R, Van Der Kelen G, et al. The role of general practitioners in continuity of care at the end of life: a qualitative study of terminally ill patients and their next of kin. *Palliat Med*. 2007;21(5):409-415.
24. Murphy E, Dingwall R, Greatbatch D, Parker S, Watson P. Qualitative research methods in health technology assessment: a review of the literature. *Health Technology Assessment*. 1999;2(16):276.
25. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol*. 2013;13:117.
26. O'Callaghan A, Laking G, Frey R, Robinson J, Gott M. Can we predict which hospitalised patients are in their last year of life? A prospective cross-sectional study of the Gold Standards Framework Prognostic Indicator Guidance as a screening tool in the acute hospital setting. *Palliat Med*. 2014;28(8):1046-1052.

27. Thoonsen B, Engels Y, van Rijswijk E, et al. Early identification of palliative care patients in general practice: development of RADboud indicators for Palliative Care Needs (RADPAC). *The British journal of general practice : the journal of the Royal College of General Practitioners*. 2012;62(602):e625-631.
28. Highet G, Crawford D, Murray SA, Boyd K. Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study. *BMJ Support Palliat Care*. 2014;4(3):285-290.
29. Overbeek A, Korlage IJ, Jabbarian LJ, et al. Advance Care Planning in Frail Older Adults: A Cluster Randomized Controlled Trial. *J Am Geriatr Soc*. 2018.
30. Hickey DP, Shriner CJ, Perry SE. Patients' initiation of advance care planning discussions with their family physician. *Fam Med*. 2005;37(8):536.
31. Steinhauer KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *Jama*. 2000;284(19):2476-2482.
32. McMahan RD, Knight SJ, Fried TR, Sudore RL. Advance care planning beyond advance directives: perspectives from patients and surrogates. *J Pain Symptom Manage*. 2013;46(3):355-365.
33. Royal College of Physicians. *ACP definition. Concise guidance to good practice: A series of evidence-based guidelines for clinical management*. . London: RCP 2009 2009.
34. Boyd K, Mason B, Kendall M, et al. Advance care planning for cancer patients in primary care: a feasibility study. *The British journal of general practice : the journal of the Royal College of General Practitioners*. 2010;60(581):e449-458.
35. Johnson SB, Butow PN, Kerridge I, Tattersall MHN. Patient autonomy and advance care planning: a qualitative study of oncologist and palliative care physicians' perspectives. *Support Care Cancer*. 2018;26(2):565-574.
36. Downey L, Au DH, Curtis JR, Engelberg RA. Life-sustaining treatment preferences: matches and mismatches between patients' preferences and clinicians' perceptions. *J Pain Symptom Manage*. 2013;46(1):9-19.
37. De Vleminck A, Pardon K, Beernaert K, Houttekier D, Vander Stichele R, Deliens L. How Do General Practitioners Conceptualise Advance Care Planning in Their Practice? A Qualitative Study. *PLoS One*. 2016;11(4):e0153747.