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

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TITLE PAGE**Title**

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

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29 **Data sharing statement**

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

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

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 occasions and topics for 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 occasions and topics for 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

Occasions and topics for ACP with older patients can be divided into two categories of approaches: 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, and with older patients living in residential care homes during group information meetings, intakes, comprehensive geriatric assessments, and periodic assessments. Meetings were not only aimed at making agreements in anticipation on future care, but also at providing information and encouraging patients to take further steps in ACP. With ad-hoc approaches, respondents discussed only one or two topics related to the near

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3 future. Ad-hoc ACP was mainly done with deteriorating patients or when patients or family-
4 initiated ACP. Due to a lack of time for and knowledge of other occasions and topics that the
5 ones respondents used, respondents seemed to underuse other appropriate occasions and
6 topics. The different approaches could be used simultaneously or sequentially, and were all
7 used both for initiating and following up on ACP.
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16 **Conclusions**

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18 Awareness of appropriate occasions and topics (i.e., systematic and ad-hoc approaches) for
19 ACP reported in this study can support GPs and improve older patients' access to ACP.
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25 **Keywords**

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28 Advance care planning, primary care, geriatric medicine
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ARTICLE SUMMARY

Strengths and limitations of this study

- The study design facilitated in-depth insights into general practitioners' (GPs') experiences with and views on occasions and topics for ACP with older people in the daily practice of primary care.
- As we selected respondents with experience with ACP with older people, a limitation of this study is respondents may have an above-average interest in palliative care and care for older patients, and a positive view on ACP.
- By purposively sampling respondents aiming for variety in extent of experience with ACP with older patients, and interviewing them about positive and negative experiences with and views on ACP we minimized this limitation.

ARTICLE

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

INTRODUCTION

Making decisions with older people and their family in acute situations or when someone is unable to fully speak for him 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 be avoided by advance care planning (ACP). ACP enables individuals who have decisional capacity to identify their values, reflect upon 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 health-care 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]

Although the form and precise effects of ACP in daily practice are subject of discussion, benefits of ACP have been demonstrated: it increases compliance with patients' end-of-life wishes and the use of palliative care resources, decreases life-sustaining treatment, stress, anxiety, and depression amongst bereaved family, and prevents hospitalization.[5-10]

With the ageing of societies and the increase in multi-morbidity and medical possibilities, ACP has become particularly relevant, 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.[11, 12] ACP is receiving growing attention, and the majority of older people would like to have ACP.[13, 14] Nonetheless, it still takes place only with a minority of older people,[15, 16] perhaps because approaches to ACP, both in research and clinical practice, are often

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3 focused on end-of-life care for deteriorating patients, or patients with cancer or Alzheimer's
4 disease, instead of older people in general.[17, 18] Consequently, occasions and topics for
5 ACP in the literature are diverse and focused on care at the very end of life, and knowledge
6 on occasions and topics for ACP with older people in general is lacking.[17, 19, 20]
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11 In many western countries, general practitioners (GPs) are considered central professionals
12 in the treatment and care of older people (both community dwelling and those living in
13 residential care homes).[21] In the Netherlands, they often closely collaborate with practice
14 nurses. These nurses screen older patients on frailty or cognitive impairment through
15 comprehensive geriatric assessments, provide proactive support and manage care. [22]
16
17 Older people, their family, and healthcare professionals feel GPs should have a prominent
18 role in ACP.[23, 24] Despite the lack of knowledge, GPs have experience with ACP with
19 older patients in their daily practices. Therefore, we aimed to explore GPs' experiences with
20 and views on different occasions and topics for ACP with older patients in their daily
21 practices.
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35 **MATERIALS AND METHODS**

36 **Study population and sampling**

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38 We conducted semi-structured interviews with Dutch GPs.[25] We purposively sampled GPs,
39 aiming for variety in sex, age, type of practice organization, and rural or urban population, by
40 approaching GPs from the Department of General Practice, Academic Medical Centre –
41 University of Amsterdam - Amsterdam Public Health research institute and using the
42 snowball method. To explore both positive and negative experiences, we aimed for variety in
43 extent of experience with ACP (ranging from 'hardly any' to 'structurally embedded in daily
44 practice') by asking GPs for their experiences with 'conversations with older patients about
45 their wishes and preferences on future care' and variety in positive and negative
46 experiences. One GP did not participate due to lack of time; 19 agreed to participate. All
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respondents gave oral and written consent. According to the Medical Research Involving Human Subjects Act (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 by the first author, who is a GP and trained qualitative researcher, and took place one-on-one 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 (Table I, based on previous research by our research group).[17] 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 what choice to make in acute situations. 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.

Table I. Interview topic list

1. Example of a positive or negative experience with 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.

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 occasions and topics for ACP. [26] The first author and two other researchers, I.S., physician and trained qualitative researcher, and J.O., 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 research group consisting of members with clinical, philosophical and anthropologic backgrounds. The coding scheme was refined and illustrative quotes were selected that related to the research aim.

Patient and Public Involvement

Besides all authors, of which four are GPs, representatives of three older patients' organisations, being members of this studies' advisory committee of this study, were involved in the development of the research questions and methods. As respondents of this study were GPs, patients were not involved in the recruitment and conduct of the study. GPs from the Department of General Practice, Academic Medical Centre – University of Amsterdam -

Amsterdam Public Health research institute, we also involved in the development of the research questions and methods via research meetings of the department. Results will be shared with respondents upon publication of the study.

RESULTS

Characteristics of the 19 respondents are described in Table II.

Table II. Respondents' characteristics

Respondents' characteristics	Number of GPs
Sex	
Male	7
Female	12
Age	
<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

Interviews lasted 59 minutes on average (range 35 - 77). Respondents reported on ACP with community-dwelling patients and patients living in residential care facilities. We identified two

1
2
3 categories of respondents' experiences with and views on occasions and topics for ACP with
4 older patients: systematic approaches and ad-hoc approaches. The different approaches
5 could, however, be used simultaneously or sequentially, and were all used for initiating and
6 following up on ACP. Intervals between a first ACP contact and follow-up varied from weeks
7 to years.
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15 **Systematic approaches to ACP**

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17 When respondents systematically approached ACP they discussed the same combination of
18 topics with older patients they invited for planned occasions for ACP. Respondents invited
19 community-dwelling patients aged 75 or 85 years and older, or older patients who were
20 assessed by them or nurses as frail or cognitively impaired, often through a comprehensive
21 geriatric assessment.[22] Respondents used 75 or 85 as age limits because they felt ACP
22 was more relevant for those individuals given the increased frailty at those ages.
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29 Respondents' contracts with health insurers, in which some of them had agreed to include
30 older patients from certain age limits in proactive care, also contributed to setting these age
31 limits. Respondents did, however, feel younger patients could benefit from ACP, but time
32 constraints kept them from including them. Systematic approached ACP was initiated during
33 group information meetings and during screening on frailty or cognitive impairment by a
34 practice nurse. These systematic approaches were often aimed at providing information,
35 encouraging patients to think, talk and ask questions about ACP and inviting them for
36 individual ACP conversations. Respondent 19, for example, organised group information
37 meetings for his patients aged ≥ 75 , during which he discussed what might be important in
38 this phase of life, and explained about resuscitation, palliative care and euthanasia:
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49 I come across many patients who are in the last phase of their life and I notice many
50 misconceptions about palliative care, euthanasia and resuscitation exist. This way I
51 can explain about these things to a large group at once. I received so much positive
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3 feedback, and many people came to my practice afterwards because they want to
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5 discuss their preferences on the discussed topics.
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7 ACP with residential-care-home patients was initiated during intakes and (bi-) annual
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9 scheduled periodic assessments. Respondent 13 explained how ACP took place during
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11 intakes:
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14 We discuss someone's medical history and whatever is relevant currently. We also
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16 discuss what someone wants in acute situations. We always discuss resuscitation,
17
18 and hospital admission. We have a whole list: tube feeding is always mentioned,
19
20 mental incompetence, if someone has a written statement regarding euthanasia or
21
22 has any thoughts about it, and if someone already has wishes or preferences
23
24 regarding their funeral.
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27 Although respondent 13 felt these intakes were a good occasion for ACP, patients did not
28
29 always immediately react positively:
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32 God yes, occasionally I scared people when I asked these questions during an
33
34 intake. 'Oh, I've never thought about that!' they said. People react differently. When
35
36 someone did not think about this beforehand, I explain a few things and give them an
37
38 information letter which they can take home to read and discuss with their partner and
39
40 children. And after some time we make an appointment again to further discuss it.
41

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43 When follow-up of ACP was approached systematically, intervals between ACP contacts
44
45 varied between every one or two years to every half year. Although respondents felt follow-
46
47 up was worthwhile, respondents who did it struggled with the time spent on these contacts.
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50 When systematically approaching ACP, respondents always discussed resuscitation and
51
52 euthanasia. In the interviews, they also mentioned other combinations of topics they always
53
54 discussed during these occasions, for example, hospital admission, antibiotic treatment and
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56 tube feeding, but also palliative care, legal representation, views on life and death, organ
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3 donation, place of burial and preferred place of death. Respondents discussed these topics
4 because they were part of a routine and they felt discussing them was necessary to be able
5 to anticipate situations in which the patient would have little time to make a deliberate
6 decision, or the patient would be unable to speak for her- or himself. Reasons respondents
7 reported for not discussing topics when systematically approaching ACP were that the topics
8 were not yet relevant for a patient, they felt resistance to the consequences of discussing
9 certain topics, or were unaware of the possibility of discussing certain topics with community-
10 dwelling older people, as respondent 1 illustrated:

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

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

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35 If you want to do it well, it takes a lot of time. All those scenarios are just one tick box
36 on a form, but it is difficult to explain what you really mean. And it might confront
37 people too much if you talk possible future cancer diagnosis and treatment. So, you
38 need good information provision for patients. It is easier when someone already
39 knows what they want than when there's not much wrong with someone yet.

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

52 53 **Ad-hoc approaches to ACP**

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55 All respondents had experience initiating and following up on ACP ad-hoc, which took place

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3 during routine care and during planned occasions. Discussed topics depended on the
4 situation. Respondents initiated or followed up ACP ad-hoc when patients deteriorated or
5 were likely to deteriorate in the near future. Examples respondents gave of actual
6 deterioration were an accumulation of incidents, such as falling and delirium, but also new
7 symptoms or diagnoses, failing therapy, or gradual deterioration due to a chronic,
8 progressive or terminal illness. Examples of patients they felt were likely to deteriorate in the
9 near future were older patients who needed help for everyday activities or need medical
10 devices, or whose informal caregivers were becoming overburdened. With these patients
11 respondents wanted to prevent having to acutely organise care when a patient would
12 deteriorate or a family would become overburdened. Respondent 17 illustrated this with this
13 quote about a female patient in her early 80s who had COPD and lung cancer and started
14 having cognitive problems:
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27 [I felt we needed to discuss this] mainly because of her cognitive problems, and how
28 we should deal with her care, the capacity of her daughters and the option of nursing
29 home care. Because I saw her daughters were reaching their limits, or actually had
30 been going across for a long time. I wondered for how long there were going to keep
31 on going like this, also because I know how difficult it is to have to arrange an
32 emergency admission to a nursing home, if necessary.
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40 Other reasons were, wanting to prevent conflict, feeling that the patient may not want
41 treatment or care, or believing treatment may no longer be appropriate or could even be
42 harmful, for example, when patients or family could not accept a poor prognosis, when
43 patients were non-compliant with therapy or when they were initially not open to ACP.
44 Respondent 5 explained why she initiated ACP with an older patient who was initially not
45 open to ACP:
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52 He had a feeding tube but want to eat by himself anyway. As a result, he ended up in
53 ICU every 3-4 weeks. But he was fed up; he just wanted to be left alone and hated to
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3 be admitted to the ICU. So, we thought 'this is not good care. We're just reacting on
4 the acute deteriorations.' Initially he didn't want to talk, walked away when I visited.
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6 But after a couple of tries he started trusting me.
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9 Patients and family also initiated ACP, by expressing concerns, wishes or preferences, or
10 showed they were open to ACP. Respondent 3 talked about how an 83-year-old male
11 patient, who had had a stroke, was open to ACP:
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16 He asked why he had to use antihypertensive medication and said he didn't want to
17 use them if they would only prolong life. But, if he would have a higher risk of having
18 another stroke and he would not die but have less quality of life, he wanted to
19 continue using them. When he said 'If it would be over at once it would be fine with
20 me', I asked: "If you'd have another stroke, would you still want to go to the hospital?"
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22 He said he wouldn't want to go. For me it's obvious I should then continue talking
23 about resuscitation as well.
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31 Topics brought up by patients or family varied from euthanasia, resuscitation, care and
32 preferred place of living and dying to continuation or withdrawal of preventive medication,
33 donation of their body to science, organ donation and place of burial. Patients and/or family
34 brought up these topics because they questioned the benefits of treatments, certain
35 preferences, or an unsustainable home situation, but also because of the public debate on
36 euthanasia, resuscitation and organ donation. When respondents used ad-hoc approaches,
37 they generally discussed only the initial topic, but sometimes one topic led to another. The
38 discussed topics varied and often concerned scenarios in the near future. Few respondents
39 reported discussing patients' views on life and death, seemingly because of the lack of
40 knowledge regarding reasons to discuss them, and the belief that patients would not expect
41 them to discuss them. When they did discuss this topic, however, they talked about patients'
42 wishes, things that matter most to patients, religion, quality of life, unfinished business, and
43 views on the end of life and death. In general, respondents had positive experiences with
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3 their ad-hoc approaches. Because other care often demanded respondents' time, however,
4 approaching ACP ad-hoc seemed to lead to an underuse of potentially appropriate occasions
5 and topics.
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10 **Facilitators of and barriers to ACP independent of the approach**

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

25 First, respondents' beliefs regarding ACP and certain treatments and care options, and which
26 goals they wanted to achieve through ACP, strongly influenced how they practiced it. It
27 influenced, for instance, whether they felt explicitly discussing certain topics was necessary,
28 as well as which topics they thought were worth discussing at all. When respondents, for
29 example, felt the likelihood of resuscitation occurring is small they were hesitant to discuss
30 resuscitation. Respondent 10, on the other hand, felt discussing it with older people in
31 general is important:
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40 'People who appear to be in good health can get a heart attack the next day. So
41 [resuscitation] is something that would be good to ask to all people above a certain
42 age.'
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46 Another barrier occurred when respondents felt they could not oversee the consequences of
47 treatment limitations, or felt treatment limitations could pose an extra burden on them,
48 patients or family, as respondent 7 explained:
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53 'Look, if I had chosen the easy way [and the patient was admitted at the hospital] I
54 would have slept better. What if she gets something at home that disables her but
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3 doesn't lead to her death, and it would have been able to prevent this by admitting
4 her to the hospital. I can't be 100% sure.'

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7 Other barriers were that respondents assumed they knew or understood what the patient
8 wanted without explicitly discussing a topic, and respondents' lacking knowledge about
9 possibly appropriate topics for ACP with older patients.
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15 Facilitators and barriers related to organisation of care

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17 Approaching ACP systematically, and especially organising group information meetings to
18 initiate ACP, was an important facilitator for ACP with older people, related to organisation of
19 care; inviting patients systematically, making ACP a routine and planning time for it led to an
20 increase in the number of older patients with whom respondents individually had ACP. An
21 important organisational barrier was a lack of time, necessary to discuss and practice ACP in
22 a good way. Respondent 10 explained why taking the time for ACP is important:
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29 'You want to understand why people make certain choices and be able to support
30 those choices. Such [living will] is just worth less and I find it less satisfactory if I don't
31 get to hear the reasons for certain choices because of a lack of time.'
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37 Facilitators and barriers related to older patients and/ or their families

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

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3 Occasions and topics for ACP with older patients can be divided into two categories of
4 approaches: systematic and ad-hoc. Respondents had positive experiences with both
5 approaches. With systematic approaches, respondents discussed a fixed combination of
6 topics with systematically selected community-dwelling patients and patients living in
7 residential care facilities. These meetings were aimed at providing information, encouraging
8 patients to take further steps in ACP and at making agreements in anticipating on acute
9 situations and situations in which patients would be unable to speak for themselves.
10 Respondents invited these patients for group information meetings about ACP, or initiated
11 ACP during intakes, periodic assessments or comprehensive geriatric assessments.
12 Resuscitation and euthanasia seemed to be important topics, because respondents who
13 approached ACP systematically always discussed them. Ad-hoc approaches consisted of
14 discussing one or two topics, which were often related to the near future and concerned
15 treatment limitations, care, views on life, dying and death. Respondents discussed these
16 topics when patients took the initiative or seemed to be open to ACP, when a patient's
17 situation deteriorated, or if respondents felt the provided care was not appropriate. Different
18 systematic and ad-hoc approaches seemed to complement each other in the ACP process;
19 they could be used simultaneously or sequentially, and were used for both initiating and
20 following up on ACP.
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39 Systematic approaches seemed to facilitate ACP with older people, because such
40 approaches made relevant topics accessible to a large number of older people.

41 Respondents, however, underuse them because of the lack of awareness of possible and
42 appropriate occasions and topics, difficulty when discussing many topics in detail, lacking
43 skills for discussing views on life and death, and the lack of time. GPs also differed in what
44 they felt were appropriate and relevant occasions and topics. These differences seemed to
45 be related to what goals they want to achieve with ACP: providing good care according to
46 their personal and professional views, answering patients' questions, or preventing conflict,
47 crisis, or care that no longer seems appropriate.
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Comparison with existing literature

To the best of our knowledge, this study is the first to report on ACP with older people, including healthy but also 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 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.[27-30] 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.[28, 29, 31] 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. The 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 seem warranted and correspond with existing literature on topics for ACP.[32] [33] Other topics reported in this study, such as care and the patient's wishes after death, have, however, not been addressed previously. Although legal representation and views on life and death were only discussed by a few respondents, they seem to be essential topics for ACP. [34, 35] Reasons for respondents not discussing 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

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3 the Netherlands, influenced by the enactment of the euthanasia and the active public debate
4 on it. Euthanasia might, however, not be an important topic for ACP in countries where
5 legislation does not permit it. The lack of knowledge and skills regarding ACP with older
6 people in this study, as well the lack of time for it, fit with previously known barriers to
7 ACP.[19, 20] The influence of what goals GPs wish to achieve with ACP seems, however,
8 underexposed in literature.
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18 **Implications for research and/or practice**

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21 For both clinical practice and research, experiences and views in study show that ACP can
22 be made more accessible to older people if not only aimed at anticipating on acute situations
23 and situations in which patients would be unable to speak for themselves, but also at
24 information provision and encouraging older patients to take further steps in ACP.
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26 Knowledge of appropriate occasions and topics for ACP with older people, especially when
27 systematically approached, can add to existing guidelines and tools and thereby support GPs
28 and improve older patients' access to ACP. Future research should be directed toward
29 systematic approaches to ACP with older patients, in particular toward investigating which
30 (limited number of) ACP topics are appropriate to discuss as that may prevent patients,
31 family and GPs from being flooded by too many detailed topics. Attention would also be
32 warranted for the follow-up of ACP and the interval between ACP contacts, while maintaining
33 tailored care and preventing too short intervals, because they may pose too great a burden
34 on GPs, patients and family. Other opportunities for research lie in investigating the
35 perspective of older people, family and nurses on ACP with older people, especially
36 systematic approaches, but also on ways to overcome barriers. In addition, investigating
37 goals those involved in ACP may wish to achieve may support beneficial effects of ACP.
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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 practice 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 with only 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 the interviewer is a GP is a limitation because it may have created less openness toward 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 minimized through focusing not only on positive but also on negative experiences with either practicing ACP or not practicing ACP, elaborate research group discussions and coding.

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Competing interest statement

The authors report no competing interests.

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Author contributions

JG was responsible for the planning of the study, sampling of respondents, and the analysis and writing the final report. DW and EM provided input at all stages. JO analysed interviews and all authors commented on all draft documents and read and approved the final manuscript. DW had overall responsibility.

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

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ABSTRACT

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

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, and with older patients living in residential care homes during group information meetings, intakes, comprehensive geriatric assessments, and periodic assessments. Meetings were not only aimed at making agreements in anticipation of future care, but also at providing information and encouraging older people to take further steps in ACP. With ad-hoc

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3 approaches, respondents discussed only one or two topics related to the near future. Ad-hoc
4 ACP was mainly done with deteriorating patients or when patients or family-initiated ACP.
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6 Systematic and ad-hoc approaches were used simultaneously or sequentially and were both
7
8 used for initiating and following up on ACP. Due to a lack of time and knowledge of other
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10 occasions and topics than the ones respondents used, respondents seemed to underuse
11
12 many occasions and topics.
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18 **Conclusions**

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20 Awareness of appropriate systematic and ad-hoc approaches for ACP, and the focus on
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22 providing information and encouraging older people to take further steps in ACP reported in
23
24 this study can support GPs and improve older patients' access to ACP.
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32 **Keywords**

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35 Advance care planning, primary care, geriatric medicine
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ARTICLE SUMMARY

Strengths and limitations of this study

- The study design facilitated in-depth insights into general practitioners' (GPs') experiences with and views on approaches to ACP with older people in the daily practice of primary care.
- As we (purposely) selected respondents with experience with ACP with older people, a limitation of this study is respondents may have an above-average interest in palliative care and care for older patients, and a positive view on ACP.
- By purposively sampling respondents aiming for variety in extent of experience with ACP with older patients and interviewing them about positive and negative experiences with and views on ACP we minimized this limitation.

ARTICLE

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

INTRODUCTION

Making decisions with older people and their family in acute situations or when someone is unable to fully speak for him 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 upon 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 health-care 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] Thereby, it may improve end-of-life care, lead to a reduction of intensive treatment at the end-of-life and decrease family distress. Benefits of ACP have been demonstrated: it can increase compliance with patients' end-of-life wishes and increase the use of palliative care resources, and can decrease life-sustaining treatment.[5-7] ACP can, however, be difficult, time consuming and requires 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 multi-morbidity 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

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3 people,[14, 15] perhaps because approaches to ACP, both in research and clinical practice,
4 are often focused on end-of-life care for deteriorating patients, or patients with cancer or
5 Alzheimer's disease, instead of older people in general.[16, 17] Consequently, approaches
6 to ACP in the literature are diverse and focused on care at the very end of life, and
7 knowledge of approaches to ACP with older people in general is lacking.[16, 18, 19]
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13 In many western countries, general practitioners (GPs) are considered central professionals
14 in the treatment and care of older people (both community dwelling and those living in
15 residential care homes).[20] In the Netherlands, they often closely collaborate with practice
16 nurses. These nurses screen older patients for frailty or cognitive impairment through
17 comprehensive geriatric assessments, provide proactive support and manage care. [21]
18 Older people, their family, and healthcare professionals feel GPs should have a prominent
19 role in ACP.[22, 23] Despite the lack of knowledge, GPs have experience with ACP with
20 older patients in their daily practices. Therefore, we aimed to explore GPs' experiences with
21 and views on different approaches to ACP with older patients in their daily practices.
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35 **MATERIALS AND METHODS**

36 **Design, Patient and Public Involvement**

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38 We conducted semi-structured interviews with Dutch GPs.[24] Besides all authors, of which
39 four are GPs, the following were involved in the development of the research question,
40 method and analysis to foster reflexivity: through advisory committee meetings
41 representatives of three older patients' organisations were involved, and through research
42 meetings GPs from the Department of General Practice, Amsterdam Public Health research
43 institute were involved. In addition, the Ethics Section of the Amsterdam Public Health
44 research institute, consisting of members with clinical, philosophical and anthropologic
45 backgrounds, were involved in the analysis. Unfortunately, as there was a time lag between
46 the interviews and publication, member check of the results with respondents before
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3 publication was not feasible. Results of this study will be shared with respondents upon
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5 publication of the study.
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8 9 **Study population and sampling**

10 We purposively sampled GPs, aiming for variety in sex, age, type of practice organization,
11 and rural or urban population, by approaching GPs from the Department of General Practice,
12 Academic Medical Centre – University of Amsterdam - Amsterdam Public Health research
13 institute and using the snowball method. To ensure rigor regarding our research question we
14 explored both positive and negative experiences and aimed for variety in extent of
15 experience with ACP (ranging from 'hardly any' to 'structurally embedded in daily practice')
16 by asking GPs for their experiences with 'conversations with older patients about their wishes
17 and preferences for future care'. One GP did not participate due to lack of time; 19 agreed to
18 participate. All respondents gave oral and written consent. According to the Medical
19 Research Involving Human Subjects Act in the Netherlands (WMO), the study did not need
20 an ethics committee's approval.
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34 **Data collection**

35 Interviews took place between November 2012 and January 2015. All interviews were
36 performed by the first author, who is a GP and trained qualitative researcher, and took place
37 one-on-one at the respondent's practice or home, or at the Academic Medical Centre. The
38 semi-structured interviews were guided by questions based on an interview topic list (Table I,
39 based on previous research by our research group).[16] Because we felt we needed deeper
40 insight into the (non)necessity and potential goals of ACP with older patients, we refined the
41 topic list after the first three interviews and added a topic concerning how respondents either
42 knew or did not know how they should treat an older patient in an acute situation. Interviews
43 were recorded, transcribed verbatim and rendered anonymous. Each interview started with
44 an open question on the respondent's recollection of positive or negative experiences with
45 ACP with older patients (>65 years). Respondents were encouraged to describe detailed
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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.

Table I. Interview topic list

1. Example of a positive or negative experience with 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.

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, I.S., physician and trained qualitative researcher, and J.O., 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.

RESULTS

Characteristics of the 19 respondents are described in Table II.

Table II. Respondents' characteristics

Respondents' characteristics	Number of GPs
Sex	
Male	7
Female	12
Age	
<40	8
40-49	4
50-59	6
>60	1
Practice location	
Urban	10
Rural	9
Practice population* people	
Older	
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

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3 * *As estimated by the respondents*
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5 Interviews lasted 59 minutes on average (range 35 - 77). Respondents reported on ACP with
6 community-dwelling patients and patients living in residential care facilities. We identified two
7 categories of respondents' experiences with and views on ACP with older patients:
8 systematic approaches and ad-hoc approaches. Systematic approaches in this study,
9 however, seemed to always be influenced by or combined with ad-hoc approaches, as the
10 personal situation of a patient influenced ACP greatly. The different approaches were used
11 simultaneously or sequentially and were both used for initiating and following up on ACP.
12 Intervals between a first ACP contact and follow-up varied from weeks to years.
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24 **Systematic approaches to ACP**

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26 When respondents systematically approached ACP they approached ACP with different
27 patients the same way by discussing a fixed combination of topics with older patients during
28 planned occasions for ACP. Respondents invited community-dwelling patients aged 75 or 85
29 years and older, or older patients who were assessed by them or nurses as frail or
30 cognitively impaired, often through a comprehensive geriatric assessment.[21] Respondents
31 used 75 or 85 as age limits because they felt ACP was more relevant for those individuals
32 given the increased frailty at those ages. Respondents' contracts with health insurers, in
33 which some of them had agreed to include older patients from certain age limits in proactive
34 care, also contributed to setting these age limits. Respondents did, however, feel younger
35 patients could benefit from ACP, but time constraints kept them from including them.
36 Systematic approached ACP was initiated during group information meetings and during
37 screening for frailty or cognitive impairment by a practice nurse. These systematic
38 approaches were often aimed at providing information, encouraging patients to think, talk
39 and ask questions about ACP and inviting them for individual ACP conversations.
40 Respondent 19, for example, organised group information meetings for his patients aged
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3 ≥75, during which he discussed what might be important in this phase of life, and explained
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5 about resuscitation, palliative care and euthanasia:

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7 I come across many patients who are in the last phase of their life and I notice many
8
9 misconceptions about palliative care, euthanasia and resuscitation exist. This way I
10
11 can explain about these things to a large group at once. I received so much positive
12
13 feedback, and many people came to my practice afterwards because they want to
14
15 discuss their preferences for the discussed topics.
16

17
18 ACP with residential-care-home patients was initiated during intakes and (bi-) annual
19
20 scheduled periodic assessments. Respondent 13 explained how ACP took place during
21
22 intakes:
23

24
25 We discuss someone's medical history and whatever is relevant currently. We also
26
27 discuss what someone wants in acute situations. We always discuss resuscitation,
28
29 and hospital admission. We have a whole list: tube feeding is always mentioned,
30
31 mental incompetence, if someone has a written statement regarding euthanasia or
32
33 has any thoughts about it, and if someone already has wishes or preferences
34
35 regarding their funeral.
36

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38 Although respondent 13 felt these intakes were a good occasion for ACP, patients did not
39
40 always immediately react positively:
41

42
43 God yes, occasionally I scared people when I asked these questions during an
44
45 intake. 'Oh, I've never thought about that!' they said. People react differently. When
46
47 someone did not think about this beforehand, I explain a few things and give them an
48
49 information letter which they can take home to read and discuss with their partner and
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51 children. And after some time, we make an appointment again to further discuss it.
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3 When follow-up of ACP was approached systematically, intervals between ACP contacts
4 varied between every one or two years to every half year. Although respondents felt follow-
5 up was worthwhile, respondents who did it struggled with the time spent on these contacts.
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9 When systematically approaching ACP, respondents always discussed resuscitation and
10 euthanasia. In the interviews, they also mentioned other combinations of topics they always
11 discussed during these occasions, for example, hospital admission, antibiotic treatment and
12 tube feeding, but also palliative care, legal representation, views on life and death, organ
13 donation, place of burial and preferred place of death. Respondents discussed these topics
14 because they were part of a routine and they felt discussing them was necessary to be able
15 to anticipate situations in which the patient would have little time to make a deliberate
16 decision, or the patient would be unable to speak for her- or himself. Reasons respondents
17 reported for not discussing topics when systematically approaching ACP were that the topics
18 were not yet relevant for a patient, they felt resistance to the consequences of discussing
19 certain topics, or were unaware of the possibility of discussing certain topics with community-
20 dwelling older people, as respondent 1 illustrated:
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34 'Yes, I realize now I've never made agreements with patients about resuscitation. In
35 fact, I never do this in my practice. I do it with my patients who live in a nursing home,
36 but I've never asked other patients.'
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41 Respondents had negative experiences when they explained many scenarios in detail, as
42 patients had difficulty comprehending them all. In addition, they felt that discussing
43 everything that could happen in the future was not useful, because patients' preferences
44 could change, and such explanations were time-consuming, as respondent 10 illustrated:
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49 If you want to do it well, it takes a lot of time. All those scenarios are just one tick box
50 on a form, but it is difficult to explain what you really mean. And it might confront
51 people too much if you talk possible future cancer diagnosis and treatment. So, you
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3 need good information provision for patients. It is easier when someone already
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5 knows what they want than when there's not much wrong with someone yet.
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7 Due to the above mentioned reasons and negative experiences respondents used
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9 systematic approaches less than they wanted, despite also having positive experiences with
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11 and views on systematic approaches to ACP with older patients.
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14 15 **Ad-hoc approaches to ACP**

16 All respondents had experience initiating and following up on ACP ad-hoc with patients aged
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18 65 and older, which took place during routine care. Discussed topics depended on the
19
20 situation. Respondents initiated or followed up ACP ad-hoc when patients deteriorated or
21
22 were likely to deteriorate in the near future. Examples respondents gave of actual
23
24 deterioration were an accumulation of incidents, such as falling and delirium, but also new
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26 symptoms or diagnoses, failing therapy, or gradual deterioration due to a chronic,
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28 progressive or terminal illness. Examples of patients they felt were likely to deteriorate in the
29
30 near future were older patients who needed help for everyday activities or needed medical
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32 devices, or whose informal caregivers were becoming overburdened. With these patient's
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34 respondents wanted to prevent having to acutely organise care when a patient would
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36 deteriorate or a family would become overburdened. Respondent 17 illustrated this with this
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38 quote about a patient who had COPD and lung cancer and started having cognitive problems
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40 but had decisional capacity to discuss preferences:
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44 [I felt we needed to discuss this] mainly because of her cognitive problems, and how
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46 we should deal with her care, the capacity of her daughters and the option of nursing
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48 home care. Because I saw her daughters were reaching their limits, or actually had
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50 been going across for a long time. I wondered for how long there were going to keep
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52 on going like this, also because I know how difficult it is to have to arrange an
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54 emergency admission to a nursing home, if necessary.
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3 Other reasons were, wanting to prevent conflict, feeling that the patient may not want
4 treatment or care, or believing treatment may no longer be appropriate or could even be
5 harmful, for example, when patients or family could not accept a poor prognosis, when
6 patients were non-compliant with therapy or when they were initially not open to ACP.
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10 Respondent 5 explained why she initiated ACP with a patient who was initially not open to
11 ACP:
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15 He had a feeding tube but want to eat by himself anyway. As a result, he ended up in
16 ICU every 3-4 weeks. But he was fed up; he just wanted to be left alone and hated to
17 be admitted to the ICU. So, we thought 'this is not good care. We're just reacting on
18 the acute deteriorations.' Initially he didn't want to talk, walked away when I visited.
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22 But after a couple of tries he started trusting me.
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26 Patients and family also initiated ACP, by expressing concerns, wishes or preferences, or
27 showed they were open to ACP. Respondent 3 talked about how a patient who had had a
28 stroke was open to ACP:
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32 He asked why he had to use antihypertensive medication and said he didn't want to
33 use them if they would only prolong life. But, if he would have a higher risk of having
34 another stroke and he would not die but have less quality of life, he wanted to
35 continue using them. When he said 'If it would be over at once it would be fine with
36 me', I asked: "If you'd have another stroke, would you still want to go to the hospital?"
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40 He said he wouldn't want to go. For me it's obvious I should then continue talking
41 about resuscitation as well.
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46 Topics brought up by patients or family varied from euthanasia, resuscitation, care and
47 preferred place of living and dying to continuation or withdrawal of preventive medication,
48 donation of their body to science, organ donation and place of burial. Patients and/or family
49 brought up these topics because they questioned the benefits of treatments, certain
50 preferences, or an unsustainable home situation, but also because of the public debate on
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3 euthanasia, resuscitation and organ donation. When respondents reported on ad-hoc
4 approaches, they generally reported discussed only the initial topic, but sometimes one topic
5 led to another. The discussed topics varied and often concerned scenarios in the near future.
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7 Few respondents reported discussing patients' views on life and death, seemingly because
8 of the lack of knowledge regarding reasons to discuss them, and the belief that patients
9 would not expect them to discuss them. When they did discuss this topic, however, they
10 talked about patients' wishes, things that matter most to patients, religion, quality of life,
11 unfinished business, and views on the end of life and death. In general, respondents had
12 positive experiences with their ad-hoc approaches. Because other care often demanded
13 respondents' time, however, respondents reported they used potentially appropriate
14 occasions and topics less that they wanted.
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27 **Facilitators of and barriers to ACP independent of the approach**

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

41 First, respondents' beliefs regarding ACP and certain treatments and care options, and which
42 goals they wanted to achieve through ACP, strongly influenced how they practiced it. It
43 influenced, for instance, whether they felt explicitly discussing certain topics was necessary,
44 as well as which topics they thought were worth discussing at all. When respondents, for
45 example, felt the likelihood of resuscitation occurring is small they were hesitant to discuss
46 resuscitation. Respondent 10, on the other hand, felt discussing it with older people in
47 general is important:
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3 'People who appear to be in good health can get a heart attack the next day. So
4 [resuscitation] is something that would be good to ask to all people above a certain
5 age.'
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9 Another barrier occurred when respondents felt they could not oversee the consequences of
10 treatment limitations, or felt treatment limitations could pose an extra burden on them,
11 patients or family, as respondent 7 explained:
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16 'Look, if I had chosen the easy way [and the patient was admitted at the hospital] I
17 would have slept better. What if she gets something at home that disables her but
18 doesn't lead to her death, and it would have been able to prevent this by admitting
19 her to the hospital. I can't be 100% sure.'
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25 Other barriers were that respondents assumed they knew or understood what the patient
26 wanted without explicitly discussing a topic, and respondents' lacking knowledge about
27 possibly appropriate topics for ACP with older patients.
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32 Facilitators and barriers related to organisation of care

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34 Approaching ACP systematically, and especially organising group information meetings to
35 initiate ACP, was an important facilitator for ACP with older people, related to organisation of
36 care; inviting patients systematically, making ACP a routine and planning time for it led to an
37 increase in the number of older patients with whom respondents individually had ACP. An
38 important organisational barrier was a lack of time, necessary to discuss and practice ACP in
39 a good way. Respondent 10 explained why taking the time for ACP is important:
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45 'You want to understand why people make certain choices and be able to support
46 those choices. Such [living will] is just worth less and I find it less satisfactory if I don't
47 get to hear the reasons for certain choices because of a lack of time.'
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54 Facilitators and barriers related to older patients and/ or their families
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3 When patients or family took initiative, were open to ACP, had clear preferences and were on
4 the same page as the respondent regarding those preferences, this facilitated ACP. The
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6 opposite, however, led to respondents struggling with how to practice ACP with these
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8 patients, but also to them being more persistent in their attempts to have ACP, or making
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10 decisions regarding ACP themselves instead of together with the patient.
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16 **DISCUSSION**

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19 Approaches to ACP with older patients can be divided into two categories: systematic and
20
21 ad-hoc. Respondents had positive experiences with both approaches. With systematic
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23 approaches, respondents discussed a fixed combination of topics with systematically
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25 selected community-dwelling patients and patients living in residential care facilities. These
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27 meetings were aimed at providing information, encouraging patients to take further steps in
28
29 ACP and at making agreements anticipating acute situations and situations in which patients
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31 would be unable to speak for themselves. Respondents invited these patients for group
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33 information meetings about ACP, or initiated ACP during intakes, periodic assessments or
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35 comprehensive geriatric assessments. Resuscitation and euthanasia seemed to be important
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37 topics, because respondents who approached ACP systematically always discussed them.
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39 Ad-hoc approaches consisted of discussing one or two topics, which were often related to
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41 the near future and varied from treatment limitations to care, preferred place of living, and
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43 views on life, dying and death. Respondents reported these topics were discussed when
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45 patients took the initiative or seemed to be open to ACP, when a patient's situation
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47 deteriorated, or if respondents felt the provided care was not appropriate. Different
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49 systematic and ad-hoc approaches complemented each other in the ACP process; they
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51 could be used simultaneously or sequentially and were used for both initiating and following
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53 up on ACP.
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3 Systematic approaches, often complemented by ad-hoc approaches seemed to facilitate
4 ACP with older people, because such approaches made relevant topics accessible to a
5 larger number of older people than sole ad-hoc approaches. Respondents, however,
6 underuse them because of the lack of awareness of possible and appropriate occasions and
7 topics, difficulty when discussing many topics in detail, lacking skills for discussing views on
8 life and death, and the lack of time. GPs also differed in what they felt were appropriate and
9 relevant occasions and topics. These differences seemed to be related to what goals they
10 want to achieve with ACP: providing good care according to their personal and professional
11 views, answering patients' questions, or preventing conflict, crisis, or care that no longer
12 seems appropriate.
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24 **Comparison with existing literature**

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27 To the best of our knowledge, this study is the first to report on ACP with older people,
28 including healthy but also frail older people and people with cognitive impairment or terminal
29 illness, in the daily practice of primary care. In particular, systematic approaches such as the
30 group information meetings with people aged 75 or older seem to be interesting new
31 opportunities to make ACP accessible to older people in general. Positive experiences with
32 systematic approaches in this study fit with literature on ACP with specific subgroups such as
33 frail patients and patients with chronic and terminal illness.[26-29] In addition, literature
34 supports our findings on ad-hoc-approached occasions for ACP that are related to
35 deterioration or initiative from the patient or family.[27, 28, 30] Following up on ACP is
36 generally considered to be important but previous research seems focused on initiating ACP
37 and less on approaches to follow-up discussions. Even though all respondents have different
38 approaches to follow-up of ACP, this study adds to the existing knowledge that all reported
39 occasions can function both as initial and as follow-up for ACP. Literature is also limited on
40 which topics should be discussed, and in what detail, with older people in general and with
41 specific subgroups of older people. Topics for ACP with older people reported in this study,
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3 such as patients' views on life and death, and future care scenarios concerning resuscitation,
4 hospital admission, preferred place of living and dying, and palliative care correspond with
5 existing literature on topics for ACP.[31] [32] Other topics reported in this study may be
6 specifically appropriate for ACP with older people, such as care and the patient's wishes
7 regarding organ donation and place of burial, , as they have not been addressed previously.
8 Regarding the two latter topics, however, this may also reflect that ACP generally does not
9 address post death wishes. Although legal representation and views on life and death were
10 only discussed by a few respondents, they seem to be essential topics for ACP. [33, 34]
11 Reasons for respondents to not discuss legal representation might be that family often
12 functions as legal representation without legal representation being explicitly discussed.
13 Respondents that did not discuss views on life and death were mostly not aware of the
14 reasons for discussing it. As reported, euthanasia seems to be an important topic for ACP in
15 the Netherlands, influenced by the enactment of the euthanasia and the active public debate
16 on it. Euthanasia might, however, not be an important topic for ACP in countries where
17 legislation does not permit it. When GPs assumed they knew their patients' preferences
18 without explicitly discussing it, lacked knowledge and skills regarding ACP with older people
19 in this study, and lacked time for it, this made them reluctant toward ACP, which fits with
20 previously known barriers to ACP.[18, 19] In addition, both that healthcare providers'
21 assumptions on patients' preferences often do not correspond with patients' actual
22 preferences, and GPs' reasons for ACP, may indicate supporting patients' autonomy
23 deserves more attention. [35, 36] The influence of what goals GPs wish to achieve with ACP
24 seems, however, underexposed in literature. The intention to provide information and
25 encourage patients older people to take further steps in ACP and not only to instantly make
26 agreements in anticipation of future care, has to our knowledge not been reported before and
27 may therefor specifically apply for ACP with older people.
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56 **Implications for research and/or practice**

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3 For both clinical practice and research, experiences and views in study show that ACP can
4 be made more accessible to older people if not only aimed at anticipating on acute situations
5 and situations in which patients would be unable to speak for themselves, but also at
6 information provision and encouraging older patients to take further steps in ACP.
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10 Knowledge of appropriate approaches to ACP with older people, especially systematic
11 approaches, can add to existing guidelines and tools and thereby support GPs and improve
12 older patients' access to ACP. In addition, GPs awareness of their assumptions on patients'
13 preferences, and awareness of goals they and their patients wish to achieve through ACP
14 may facilitate ACP. Future research should be directed toward systematic approaches to
15 ACP with older patients, in particular toward investigating which (limited number of) ACP
16 topics are appropriate to discuss as that may prevent patients, family and GPs from being
17 flooded by too many detailed topics. Attention would also be warranted for the follow-up of
18 ACP and the interval between ACP contacts, while maintaining tailored care and preventing
19 too short intervals, as they may pose too great a burden on GPs, patients and family. Other
20 opportunities for research lie in investigating the perspective of older people, family and
21 nurses on ACP with older people, especially systematic approaches, but also on ways to
22 overcome barriers. In addition, investigating goals those involved in ACP may wish to
23 achieve may support beneficial effects of ACP.
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40 **Strengths and limitations**

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42 This study gives an overview of how ACP with older people can be approached. It shows
43 possible occasions for ACP with older people and topics for those occasions. Thereby, it
44 shows how systematically approached ACP can make relevant topics in ACP accessible to
45 all older patients, shows opportunities for improving the current practice of ACP with older
46 patients and may give direction to research on ACP. A strength of the qualitative design of
47 this study is that it gives in-depth insight into reasons for the way respondents practice ACP.
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49 However, it also has its limitations. First, the small number of respondents means we have to
50 be cautious when drawing conclusions on which topics are essential in ACP with older
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3 people. Second, interviews were conducted with only Dutch GPs. Therefore, resuscitation
4 and euthanasia may indeed be important topics to discuss during ACP with all older people
5 but may also be a consequence of the public debate on these topics in the Netherlands. The
6 fact that four of the authors are GPs is a strength, as both their positive and negative
7 experiences led to a more critical view on the design and analysis of this study. It is,
8 however, also a limitation because it may have led to a too one-sided perspective on ACP in
9 different stages of this study. By involving representatives of older patients' organisations
10 and the Ethics section of the Amsterdam Public Health research institute we, however, tried
11 to include diverse perspectives on ACP. That the interviewer is a GP may have created less
12 openness toward feelings of insecurity and negative experience. It may, however, also have
13 created more understanding of difficult situations and thereby increased openness. Our
14 strategy to sample respondents with experience with ACP might have led to respondents
15 with above average interest in palliative care and care for older patients. Thus, it may also
16 have led to a more positive view on ACP. We tried to overcome this bias by exploring a
17 broad range of experiences and views by purposively sampling GPs with different
18 experiences, backgrounds and with experiences in populations with different backgrounds.
19 The risk of bias was further minimized through focusing not only on positive but also on
20 negative experiences with either practicing ACP or not practicing ACP, elaborate research
21 group discussions and coding.
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44
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46 advisory committee and all the GPs who participated in this research.
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50 **Competing interest statement**

51
52 The authors report no competing interests.
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Author contributions

JG was responsible for the planning of the study, sampling of respondents, and the analysis and writing the final report. DW and EM provided input at all stages. JO analysed interviews and all authors, including JW, commented on all draft documents and read and approved the final manuscript. DW had overall responsibility.

Data Sharing Statement

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

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