

Emotional cues and concerns of patients with a life limiting, chronic illness during advance care planning conversations in general practice

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Abstract

Objective: To explore a) to what extent patients with serious illness express emotional cues and concerns during advance care planning (ACP) conversations with their general practitioner (GP), b) the content of cues/concerns and c) GPs' responses to cues/concerns.

Methods: Cues/concerns and GPs' responses in 20 conversations were coded using the Verona Codes (VR-CoDES and Verona Codes-P). A qualitative thematic analysis was used to identify overarching themes within the content of the cues/concerns.

Results: A total of 216 cues/concerns were identified (range: 1-28; mean: 13) in 85% of conversations; with 85% of these being cues/implicit expressions of emotions. In 72% of responses, the GP provided space for the patient to elaborate on cues/concerns. The most common theme cues/concerns were expressed about was "the consequences of illness on quality of life and burdening others".

Conclusion: Emotions were mainly communicated implicitly as cues and the content varied greatly. The amount of cues/concerns expressed show that ACP can evoke many emotions.

Practice Implications: GPs should be attentive to implicit expressions of emotions as these provide opportunities to engage patients in tailored ACP conversations. As patients expressed many cues/concerns, GPs are recommended to have recurrent conversations with patients and actively ask about diverse ACP topics.

Abstract 200/200 words

References 48

Keywords: advance care planning, concern, cue, general practice, communication, emotions

1 1. Introduction

2 Advance care planning (ACP) is described as a process of communication that “enables individuals to
3 define goals and preferences for future medical treatment and care, to discuss these goals and
4 preferences with family and health-care providers, and to record and review these preferences if
5 appropriate” [1]. Patients are encouraged to identify a surrogate decision maker (SDM), a family
6 member or loved one who can make decisions about medical care in the best interest of the patient
7 when the patient is no longer able to do so [1]. One of the objectives of ACP is to prepare patients and
8 SDMs to make the best possible in-the-moment care decisions together with their clinicians [2]. Prior
9 research has shown that ACP improved communication between health care professionals and
10 patients and their families as well as communication about goals of care and overall satisfaction with
11 end-of-life (EoL) care [3, 4]. Another benefit of ACP is that it may reduce psychological distress and
12 complicated grief for the patient’s family and that it gives patients a sense of control and relief [5, 6].

13 For patients with chronic, life-limiting illness(es), which are often marked by trajectories of steady
14 illness progression or gradual health decline punctuated by acute deterioration, it is important that
15 ACP is initiated in a timely manner so that sufficient time can be dedicated to conversations about
16 values, goals and preferences [7]. Clinicians play a pivotal role in the ACP process by preparing patients
17 and SDMs to communicate their values and needs for future care [2]. In Belgium, as in many other
18 countries, general practitioners (GPs) are especially suited to encourage and engage the patient in
19 ACP. GPs in Belgium often have a longstanding, trusting relationship with their patients and are usually
20 aware of their patients’ medical and social context [8, 9]. Because of the nature of the longitudinal
21 relationship GPs often have with their patients, GPs are able to provide a continuity of care and have
22 the ability to coordinate care across different settings. In Belgium, the general practice is easily
23 accessible and it is estimated that 95% of residents have a fixed GP [10]. Additionally, 78% of residents
24 visit their GP regularly (with 78% seeing their GP at least once a year) [10]. Like in many countries, the
25 GP is also one of the most involved professional health providers during the last years of life [10]. In
26 reality, ACP is not often initiated in the GP practice by either patients or the GP. A study from 2011 in
27 Belgium and the Netherlands showed that in 34% of non-sudden deaths, a form of ACP was done (most
28 often relating to the forgoing of life-prolonging treatments) [11]. Another study from 2015 reported
29 that 4,4% of a representative sample of the Belgian population had spoken to their GP about their
30 wishes regarding medical treatment at the end of life, and 1,8% had an advance directive on euthanasia
31 [12].

32
33 It is recommended that ACP includes the exploration of personal values and goals for future care. As
34 values and goals differ between individuals, ACP discussions should be tailored to the patient by being
35 sensitive to patients’ emotions and adapting communication to patients’ health literacy,
36 communication style, and personal values [1]. Patients’ emotional talk in medical consultations is often
37 referred to as cues and concerns [13]. A concern is a clear expression of an unpleasant current or
38 recent emotion. The emotion is explicitly verbalized. In contrast, a cue is a verbal or non-verbal hint
39 which suggests an underlying unpleasant emotion [14]. In medical consultations, patients often
40 express their emotions implicitly, as cues [13]. How health care providers respond to these cues and
41 concerns varies from little or no acknowledgement to explicit and empathic responses [15]. These
42 responses may affect patients’ wellbeing and health outcomes [16-21]. The ability to
43 recognize patients’ emotional needs, as well as possessing the skills to empathically respond to these
44 needs, is a key feature of patient-centered care [16]. However, studies on emotional communication

1 in various medical settings show that physicians often fail to pick up or respond to patients' worries
2 and concerns [22].

3 As of late, there has been a discussion about the value of ACP, since there is limited evidence that ACP
4 conversations or AD completions are associated with goal-concordant care [23]. But, as argued by
5 Tishelman and her fellow researchers [24], ACP should be seen as a matter of public health, wherein
6 the preparation of patients, families and health care providers to make "the best possible in the
7 moment" decisions when they later become necessary is central. The true value of ACP lies thus in
8 empowering patients and their families to better communicate about their EoL values and to support
9 them in the exploration of their concerns and emotions regarding EoL care [24]. To our knowledge, a
10 study investigating the prevalence and content of cues and concerns of patients during ACP
11 conversations has not been done before, nor has there been a study investigating GPs' responses to
12 these cues and concerns. This study therefore aims to:

- 13 1) Explore to what extent emotional cues and concerns are expressed by patients during ACP
14 conversations with their GP and to explore who initiated these cues or concerns,
- 15 2) Explore the content of these cues and concerns, and
- 16 3) Investigate how GPs respond to patients' cues and concerns

17

18 **2. Methods**

19 2.1. Design

20 This study was part of a larger clinical trial, i.e. the ACP-GP trial. ACP conversations between patients
21 and their GPs were analyzed with the Verona coding definitions of emotional sequences (VR-CoDES),
22 an observational coding scheme that allows the researcher to code and quantify the cues and concerns
23 of the patients and the responses of the GPs [13, 15]. Then, a qualitative analysis was conducted on
24 the cues and concerns expressed by the patients to study their content.

25 2.2. Sample and setting

26 The ACP-GP trial is a 2-arm cluster-randomized controlled trial, comparing the ACP-GP intervention to
27 usual care of patients with a chronic life-limiting illness. More details about the study design of the
28 ACP-GP intervention can be found elsewhere [25].

29 To be eligible for inclusion in the ACP-GP trial, GPs had to be Dutch speaking and working in Flanders
30 and Brussels, Belgium. Patients had to be > 18 years old and suffer from a chronic, life-limiting illness.
31 Additionally, GPs used the surprise question ("Would I be surprised if this patient were to die within
32 the next 12 to 24 months?", answer: no) to select patients for inclusion in the study. A total of 35 GPs
33 and 95 patients were recruited for the study and 18 GPs and their patients were randomly assigned to
34 the intervention arm of the study.

35 GPs in the intervention arm received a training in conducting ACP conversations, aimed at improving
36 ACP knowledge and communication skills. GPs received a conversation guide (see Appendix) and
37 flowchart to support the ACP conversations. The training consisted of an e-learning module and two
38 interactive, small-group web sessions led by two trainers experienced in primary care and
39 communication. The first web session included discussion of experiences with ACP, fictional case and
40 video examples, reflection questions and discussion of barriers and facilitators to ACP. During the
41 second session, GPs practiced ACP conversations with simulation patients, followed by interactive

1 feedback and discussion. Patients were also encouraged to prepare for the conversations with the
2 help of a workbook. The workbook highlights the importance of ACP at different stages of health and
3 allows the patients to reflect on different ACP topics (see Appendix). The conversation guide for the
4 GP and the workbook for the patients covered similar themes. GPs were asked to conduct at least
5 two ACP conversations with each included patient.

6 2.3. Collected Data

7 We used audio-recordings of ACP conversations between patients and their GPs from the ACP-GP trial
8 [25] that were collected in the intervention group. The ACP conversations took place between October
9 2020 and March 2021, either at the GPs' practice or at the patients' home. In addition to the GP and
10 patient, a trusted person of the patient could participate in the ACP conversations.

11 For this study, only first conversations were considered for analysis as we wanted a homogeneous
12 sample of conversations. Although all GPs in the intervention group (n=18) were instructed to audio-
13 record the conversations, we only received 25 audio recordings of first conversations from 11 GPs.
14 Audio recordings that were of poor quality (n=2) or too hard to understand due to dialect (n=3) were
15 excluded for the analysis, leaving 20 first conversations with 21 patients which were transcribed
16 verbatim and analyzed. All transcripts were pseudonymized.

17 One conversation included a man and his wife, who were both patients with a chronic, life-limiting
18 illness recruited for the study. The conversations lasted between 17 minutes and 59 minutes, with a
19 median duration of 25 minutes. In six conversations a relative or a friend was present to support the
20 patient. The patient and their relative or friend form a patient-unit. Statements expressed by a relative
21 or friend were included in the analyses. From here on, we use "the patients" to refer to the patient-
22 units. Some GPs had more than one patient included in the study, and thus had ACP conversations
23 with multiple patients. A median of 2 conversations led by each GP were analyzed.

24 2.4. Data analysis

25 2.4.1. Identification of cues and concerns and the GP responses

26 To explore the extent of cues and concerns of the patients and the responses of the GPs, the Verona
27 coding definitions of emotional sequences (VR-CoDES) were used. The VR-CoDES is a consensus-based
28 system used to observe medical consultations [14]. First, patients' expressions of negative or
29 unpleasant emotions were coded into cues and concerns. In addition to identifying cues and concerns,
30 we noted whether the patient or the GP initiated the cue or concern (*whether the cue/concern was a*
31 *response to something the GP said or did, or whether the patients expressed the cue/concerns*
32 *unrelated to what the GP had said or done previously*).

33 Second, GP responses to the expressions of negative or unpleasant emotions were coded on two
34 dimensions. First, whether or not the response explicitly referred to the cue or concern (*did the*
35 *response of the GP contain the wording or the key elements of the cue/concerns it refers to or not?*).
36 Second, the response was coded as providing space to the patient for further disclosure of the cue or
37 concern, or as reducing space. For responses that were explicit and provide space, a distinction was
38 made between responses that address the affect and those that address the content of the
39 cue/concern.

1 The cues and concerns, and GP responses, were coded from the transcripts. Two coders (LC, VL) were
2 trained in coding based on the VR-CoDES system by one of the developers of the system. The first
3 seven consultations were coded by consensus. Coding consensus was achieved by focusing on the
4 definitions and the extensive list of examples supplied with the manual, and then on inspection of the
5 current context of the ACP conversation. Subsequently, three consultations were coded separately by
6 the two coders to calculate the interrater reliability (Cohen's Kappa) on the identification of the cues
7 and concerns. The agreement was substantial (Cohen's kappa = 0.63). Discrepancies in the three
8 conversations used for reliability checks were discussed until consensus was reached. If no consensus
9 could be reached between the two coders, a third researcher who also received the training (KP) was
10 consulted. After establishing sufficient interrater reliability, the last ten consultations were coded by
11 LC. The coding of the GP responses was then done by consensus by LC and VL. The cues and concerns
12 of the patients and the responses of the GPs were counted and analyzed quantitatively. The statistical
13 analysis of the coded material was conducted using SPSS (v.27) and Microsoft Excel.

14 2.4.2. Thematic analysis on the cues and concerns

15 To explore the content of the cues and concerns (i.e. the themes that cues or concerns were expressed
16 about) during the ACP conversations, a combination of deductive and inductive thematic analysis was
17 conducted [26]. The cues and concerns previously identified with the VR-CoDES served as the
18 utterances of interest. Transcripts were read line by line and data was coded into an a priori framework
19 of 6 categories, which were the themes of the conversation guide which GPs received to lead the ACP
20 conversations (deductive component) by LC. Any utterance that could not be categorized within the
21 framework was inductively categorized under a new category (LC and ADV). These categories were
22 then modified and refined where necessary to specific themes until a final codebook was created.
23 Finally, quotes were selected and approved by the research team to illustrate the results. Qualitative
24 analysis software (NVivo 12) was used to organize the data.

25 2.5. Ethics

26 Ethical approval for the study was obtained from the Commission for Medical Ethics of the Vrije
27 Universiteit Brussel/UZ Brussel (ref: 2020/068). All GPs, patients, and SDMs in the study were asked
28 for permission to audio-record the ACP conversations. Written informed consent was obtained from
29 each participant. GPs were also instructed to confirm consent verbally with the patient and SDM before
30 recording a conversation.

31

1 3. Results

2 3.1. Sample description and duration of the ACP conversations

3 Table 1 reports sociodemographic and clinical characteristics of the patient sample. The majority
4 (57,1%) of the patients were female. Mean age of the patients was 77 years (range: 58 – 92). Seven
5 patients (33,3%) had an advance directive (AD) prior to the study.

6 **Table 1.** Characteristics of patients (n = 21) and trusted person present during the ACP conversation (n = 6).

	N (%)
Patients (N=21)	
Sex (patients)	
Female	12 (57,1%)
Age (patients)	
<= 65	1 (4,8%)
66 – 75	7 (33,3%)
76 – 85	9 (42,9%)
>= 86	4 (19%)
Highest level of education attained (patients)	
Primary school	2 (9,5%)
Secondary school	17 (81%)
Post-secondary school	2 (9,5%)
Religion (patients)	
Christianity	11 (52,4%)
None	9 (42,9%)
Prefer not to say	1 (4,8%)
Diagnosis (oncological or not oncological) (patients)	
Oncological	6 (28,6%)
Marital status (patients)	
Married, civil union, or domestic partnership	11 (52,4%)
Widow(er)	9 (42,9%)
Divorced or single, never married	1 (4,8%)
Have one or more advance directives**	
Yes	7 (33,3%)
Trusted persons (N=6)	
Sex	
Female	6 (100%)
Relation to the patient (trusted persons)	
Spouse	5 (83,3%)
Friend	1 (16,7%)

7 *20 conversations with 21 patients were analyzed. One conversation included a man and his wife, who were both patients
8 recruited for the study.

9 **Belgium has five types of advance directive: 1) Advance directive to refuse medical interventions; 2) Advance directive for
10 euthanasia in the case of irreversible coma; 3) Directive for funerary arrangements; 4) Directive for organ donation; 5)
11 Testament for donating the body to medical science. Patients could also indicate any other documentation they had
12 completed, such as power of attorney, under an "other" category.

13

14 Characteristics of the GPs can be found in table 2. Of 11 GPs, six were female (54,5%). Five GPs (45,5%)
15 had between zero and five years of experience; two GPs (18,2%) had more than 20 years of experience.

1 No GPs were active as a physician in a palliative home care team. One GP was a coordinating and
 2 advisory physician.

3 **Table 2.** Characteristics of the GPs (n = 11).

Characteristics	N (%)
Sex	
Female	6 (54,5%)
Age	
<= 30	3 (27,3%)
31 – 40	3 (27,3%)
41 – 50	3 (27,3%)
51 – 60	1 (9,1%)
>= 61	1 (9,1%)
Years of experience	
0 – 5	5 (45,5%)
10 – 20	4 (36,4%)
>= 20	2 (18,2%)
Practice	
Group	8 (82,7%)
Solo	1 (9,1%)
Community health center*	1 (9,1%)
Multiple	1 (9,1%)
Coordinating and advisory physician**	
Yes	1 (9,1%)
Palliative home care team	
Yes	0 (0%)

4 *A primary care setting with an interdisciplinary collaboration by at least 3 disciplines: a GP, a nurse and a third discipline at
 5 the primary care level (e.g. social worker). The centers are highly accessible and have a low financial threshold. These centers
 6 are often situated in areas where welfare problems are more common.

7 ** This is a general practitioner, preferably experienced and trained in gerontology and palliative care, who is responsible for
 8 the coordination of medical activities in the nursing home, for the training of nursing home staff, and the development of
 9 (training for) palliative care. They are also responsible for the medical treatment of residents who have no regular general
 10 practitioner.

12 3.2. Prevalence of emotional concerns or cues expressed by patients during ACP conversations

13 **Table 3.** Frequencies and percentages of cues and concerns expressed by the patient during the 17 ACP conversations and
 14 whether the cues and concerns were GP elicited or patient elicited.

	Cue	Concern	Total
Total	183 (84.7%)	33 (15.3%)	216 (100%)
GP elicited	75 (34,7%)	17 (7,9%)	92 (42.6%)
Patient (or relative) elicited	108 (50%)	16 (7,4 %)	124 (57.4%)

15 *Row and column percentages are depicted.

16 In 17 of the 20 recorded conversations the patients expressed cues, concerns, or both. A total of 216
 17 cues/concerns were identified across these 17 conversations (Table 3). Patients mainly expressed their
 18 negative emotions and worries as an implicit cue, rather than an explicit concern (183 cues vs 33
 19 concerns). GPs elicited 42.6% and patients initiated 57.4% of the cues/concerns. During the six
 20 conversations in which a relative of the patient was present, 60 cues/concerns were expressed, of
 21 which 40% by the relatives (21 cues/3 concerns, not shown in the table). The number of cues/concerns
 22 in a conversation ranged from one to 28, with a mean of 13. In eight conversations, no concerns were

1 expressed, only cues. See table A1 in Appendix for the descriptive statistics of the cues/concerns
 2 expressed in the 17 ACP conversations. In three of the 20 conversations, no cues or concerns were
 3 identified. These conversations were between 20 and 24 minutes long. See table A2 in Appendix for
 4 the description of the conversations.

5 3.3. Content of the cues and concerns expressed by patients and their relatives during an ACP
 6 conversation

7 **Table 4.** Overview of the themes and the amount of cues and concerns per theme, in 17 ACP conversations

	Cues N	Concerns N	Total N(%)
Consequences of illness on QoL and burdening other	54	12	66 (30,6%)
Severity of illness, now and in the future	36	12	48 (22,2%)
Being tired of life*	34	5	39 (18,1%)
Previous experiences with HC professionals	32	1	33 (15,3%)
Reluctance and doubt about engaging in ACP*	12	0	12 (5,6%)
The burden of surrogate decision making	9	1	10 (4,6%)
Establishing specific goals for medical EoL care	3	2	5 (2,3%)
Not wanting to receive detailed information	3	0	3 (1,4%)
Total	183	33	216 (100%)

8 * Themes that were not included in the conversation guide for GPs

9 When analyzing the content of the cues/concerns, we identified eight themes about which
 10 cues/concerns were expressed (see table 4). Being tired of life” and “ambivalent feelings towards ACP”
 11 were added to the codebook, in addition to six themes that were part of the conversations guide that
 12 the GPs received. The majority (30,6%) of all cues/concerns were expressed about “the consequences
 13 of illness on quality of life (QoL) and burdening others”. The least amount of cues/concerns were
 14 expressed about “not wanting to receive detailed information on diagnosis and prognosis” (1,4%) and
 15 “establishing specific goals for EoL care” (2,3%). It is important to note that the content of the cues
 16 and concerns was often interwoven and it is more useful not to perceive these themes as fully
 17 independent entities.

18 1. The consequences of illness on quality of life and burdening others

19 A number of patients expressed cues/concerns about the consequences of their illness that (in the
 20 future may) diminish their QoL. A diminished quality of life was defined by some as no longer being
 21 able to live an active live, for others it meant a decrease in meaningful social contacts, losing the ability
 22 to structure their daily life because of uncertainty about the flare-up of illness symptoms, not being
 23 able to live at home, or a decreasing independence. When a GP asked his patient what worried him
 24 the most about the future, the patient answered “*That I’ll become dependent. For example, that I
 25 would end up in a wheelchair. And well, that I can’t make do on my own anymore, that I would need
 26 help. That’s what I’m most worried about*” (Patient D).

27 Additionally, some patients expressed cues or concerns that centered around the role of family in their
 28 care (a few patients expressed disappointment in their family for not helping more), and more
 29 specifically not wanting to be a burden to their relatives or others. Patient I explained how he felt
 30 conflicted about his wife’s help: “*I was in tremendous pain (at night). My wife is at my side right away,
 31 because then she won’t sleep all night. (...) And then you start to think, it can’t keep going like this, that
 32 my wife always has to shoulder this. But I also know that I’ll hurt her if I tell her that*”.

1 2. The severity of illness, now and in the future

2 The cues/concerns patients expressed about their current health often centered around general health
3 problems and their impact on QoL, not seeing an improvement after treatment, or fear of having a
4 stroke or heart attack as a result of their health condition. Patient S: *“Well, um, let’s say the moment
5 that something happens, let’s say a stroke or something, or, or, to say nothing of my kidneys. Let’s go
6 with a stroke, ‘What can I still do then, and what can I not do anymore?’, ‘How will they have to help
7 me?’. And so, that keeps mulling around in my head. I’m a little afraid of that”*. A few patients asked
8 their GP for reassurance about their current health status (e.g., *“Is it that serious already?”*). Some
9 patients also expressed uncertainties and worries about their future health and the course of their
10 disease, and related to that, the organization of their care (if their significant other was no longer able
11 to provide care if their symptoms worsened).

12 3. Being tired of life

13 Some patients expressed cues/concerns about experiencing a lack of meaningfulness. Some patients
14 expressed negative emotions about existential themes (e.g. feeling existential dread: *“what am I still
15 doing here?”*, no longer finding joy in life and having no perspective or feeling worthless). Patient J: *“I
16 don’t enjoy living anymore, you know. And I think that I, uh... I should have died a long time ago. (...)
17 It’s sad, I think it’s pitiful that I’m not interested in anything anymore. Not in traveling, and in what
18 happens or being more afraid. I don’t feel any joy in living anymore, that’s what I mean”*. Other patients
19 also expressed feeling lonely. This included feeling that they are on their own, a lack of meaningful
20 social interactions, and feeling misunderstood, like patient E: *“My family, they don’t understand. They
21 don’t know I’m this sick. They think my voice sounds good, and until now I’m mentally well, but my
22 body...”*. A few patients also looked back on their life and expressed disappointment with how it had
23 turned out.

24 4. Previous experiences with healthcare professionals not being supportive

25 Some patients had seen relatives or friends suffer at their end of life, often unnecessarily in the eyes
26 of the patient. A number of patients had to make a decision about the (non-) treatment of a relative,
27 and had not felt supported by the treating physician. The wife of a patient explained how she had felt
28 when she had to make a decision about the treatment of her mother: *“I had to make a decision, against
29 the doctors wishes. My mother had a heart attack. (...) Then I had to go up against the doctors and say
30 no. The doctor said, ‘Do you realize what you’re doing?’ And you carry that with you for the rest of your
31 life. It’s like I murdered my mother. I don’t want that (referring to not wanting to make difficult
32 decisions for a loved one without having talked them through)”* (wife of patient I). These experiences
33 encouraged the patients to talk about ACP. Most patients wanted to avoid having to suffer at the end
34 of life, or wanted to protect their relatives from having to make difficult decisions without having
35 discussed their wishes.

36 5. Reluctance and doubt about engaging in ACP

37 For a few patients, participation in a study about ACP triggered (difficult) emotions. A small number of
38 patients talked about feeling distressed when they had to think or talk about ACP (e.g. a patient not
39 being able to sleep after discussing the workbook with his wife). Although all patients had consented
40 to participate and agreed to have a conversation about ACP with their GP, a few patients were still
41 very reluctant to talk about ACP. These patients also expressed uncertainty about which decisions to

1 make about their future care and documenting these in an AD, and doubting whether or not their
2 decisions would stay consistent over time.

3 6. The burden of surrogate decision making

4 A few patients expressed cues/concerns that it would be difficult to ask someone to take on this role
5 as they expected that it would be a burden for their children to make future care decisions. Another
6 expressed cue/concern was that the patient did not want to put too much of burden on the shoulders
7 of the GP, but still wanted the GP to be their SDM. When this theme was discussed, some patients
8 reflected about what kind of decisions their children or partners would make for them and if these
9 would align with their own preferences.

10 7. Establishing specific goals for medical EoL care

11 Specific medical end-of-life decisions were discussed by a small amount of patients during the ACP
12 conversations. Mostly, patients expressed not wanting to suffer at the end of life. One patient
13 specifically asked to not perform a CT scan because she was afraid of it. Another patient, when asked
14 by the GP what she meant when saying she wanted “to be treated well”, responded: *“That they don’t*
15 *mess with me, ‘we’re still going to operate on you’, but that I can say it’s not necessary. Do you*
16 *understand?”* (patient L).

17 8. Not wanting to receive detailed information about diagnosis and treatment options

18 One patient expressed a cue/concern about being scared of becoming overwhelmed and feeling
19 panicked when receiving too much information about their health or treatment and requested to be
20 spared of the details concerning their health or treatment. The patient gave the GP permission to fully
21 inform the patient’s spouse about their health and treatment.

1 3.4. GPs' responses to patients' emotional expressions during ACP conversations

2 **Table 5.** Frequency of the GPs' responses to cues and concerns and examples

Response type	Definition	Frequencies	Percentages	Example of responses to their respective cue/concern
Provide space		155	72%	
Non-explicit provide space	The health provider does not refer explicitly to the cue/concern and provides space for further disclosure	66	31%	<i>Patient: I don't know either. I was doing better then. I've gotten a lot worse in the last 14 days</i> GP: You sense that?
Explicit provide space for content	The health provider refers explicitly to the content of the cue/concern and provides space for further disclosure	50	23%	<i>Patient: Yes. If the pain goes away, those dark thoughts also go away.</i> GP: You've actually thought about it, but you're saying: 'my thoughts did begin to change a little the last few days'?
Explicit provide space for affect	The health provider refers explicitly to the affect of the cue/concern and provides space for further disclosure	39	18%	<i>Patient: I'm keeping, I'm holding her back in her activities, because I can do almost nothing anymore and she's still very active.</i> GP: Yes, you feel like you're a burden on that 'buddy'?
Reduce space		61	28%	
Non-explicit reduce space	The health provider does not refer explicitly to the cue/concern and reduces space for further disclosure	37	17%	<i>Patient: I would, um, I would feel it's really unfortunate for (my husband). That's another thing entirely.</i> GP: And, suppose you were not conscious anymore?
Explicit reduce space	The health provider refers explicitly to the cue/concern and reduces space for further disclosure	24	11%	<i>Patient: I'll be bothered by that (referring to urinary catheter). I think I'm nervous.</i> GP: But, on the other hand, you won't have the feeling anymore that you have to urinate every five minutes. And it'll indeed also be dry there.

3

4 An overview of the GPs' responses to cues and concerns according to the VR-CoDES and examples of
 5 responses are presented in table 5. The GPs provided space to the patient or relative for further
 6 disclosure of the cue/concern in 72% of responses. The most common response was to explicitly
 7 provide space to elaborate on the cue/concern (explicit provide space for content: 23%, explicit
 8 provide space for affect: 18%). The least common response was to explicitly reduce space (11%).

1 4. Discussion and conclusion

3 4.1. Discussion

4 This study provides insight into the cues and concerns expressed by patients with a serious illness
5 during ACP conversations with their GP, the content of these emotional expressions and how the GP
6 responds to them.

7 The frequency of expressed emotional cues or concerns by patients and their relatives in this study, a
8 mean of 13 per conversation, is high compared to other studies of healthcare communication using
9 VR-CoDES, such as in cancer care or older persons' home care visits, where the reported mean of
10 cues/concerns was around 3 or 4 [27, 28]. The topic of ACP seems to evoke many emotions and worries
11 in patients and their relatives. As cues and concerns are expressed with high frequency, it may be
12 challenging for GPs to offer an in-depth response to each one within the duration of a single
13 consultation.

14 Patients expressed a high number of cues compared to low numbers of concerns in this study. This
15 observation is in accordance with other studies that have found that patients and relatives are inclined
16 to express emotions implicitly, as subtle cues, rather than as explicit expressions of emotions [29]. One
17 explanation may be that patients find ACP topics sensitive and are uncomfortable making concerns
18 about these topics explicit. We know from previous studies that patients believe it is a GP's
19 responsibility to initiate ACP while GPs might have the expectations that patients will address these
20 issues [30], which often leads to missed opportunities to address ACP in practice. Previous research
21 has demonstrated that it is difficult for people to articulate their stance toward end-of-life topics [31].
22 The fact that the patients in this study rarely initiated communication about emotional concerns and
23 had a tendency to indirectly express these concerns as hints, implies that cues/concerns must be
24 actively explored in order to successfully create opportunities for individualized ACP conversations
25 [32]. This also means that GPs need the right skills for helping the patient understand and translate
26 these subtle cues into core, underlying concerns and communication training efforts should pay
27 adequate attention to this. Given that some patients expressed reluctance or doubt about conducting
28 ACP, patients' readiness to engage in ACP have to be taken into account. This readiness to engage in
29 ACP is a spectrum [31]; GPs should be attentive and be able to adapt their communication style to the
30 needs of every patient.

31 Current ACP discussions are mainly focused on EOL care decisions [33]. However, the qualitative results
32 of this paper show that the topics considered, were much broader than only EOL care decisions. For
33 example, not a single patient expressed a cue or concern about establishing specific goals for medical
34 EOL care or completing ADs. However, quite a few patients expressed cues/concerns related to being
35 tired of life and experiencing existential dread, or were feeling depressed or lonely. This theme went
36 beyond on the context of the conversation guide for GPs and workbook for patients, showing that GPs
37 should be attentive to patients' emotional expressions, since these contain hints to what really matters
38 to the patient. Little research has been done on existential loneliness in the context of ACP
39 conversations. It has however been shown that this is an important issue in the care for terminally ill
40 people [34,35], hence more research is warranted. To address important existential problems,
41 professionals have been reporting a need for more support and training [36].

42 Patients indicate that they would like to discuss non-acute care needs with their GP, but often feel that
43 the GP does not have enough time [37]. Hence, studies have found that patients rarely introduce

1 discussion of non-acute care or non-physical needs, and that GPs also do not initiate such
2 conversations [38, 39]. It is encouraging that patients in this study were able to hint or talk about
3 psychosocial or existential themes, when the GP explicitly and consciously provided the time and space
4 to discuss these themes. This also fits the idea that ACP is a matter of public health which is becoming
5 more common. The focus is shifting to ACP as a social process, instead of a medical process, in which
6 stakeholders (patients, families and health care professionals) are engaged in an ongoing series of
7 conversations about EoL wishes, preferences, values and potential care goals [40]. The question “what
8 matters to you” should lie at the core of the conversations rather than focusing on EOL care decisions
9 [33].

10 Lastly, our results show that GPs responded to the cues and concerns with a reaction that provided
11 space for the patient to elaborate on the (hidden) concern in three out of four responses, which is
12 comparable to other studies using the VR-CoDES in different settings (e.g. studies in cancer care: [41,
13 42]; or studies in family practice: [43]). Literature indicates that being attentive to patients’ emotions
14 and providing empathic reactions can be associated with positive patient outcomes, such as reduced
15 distress [44, 45]. Patients who feel heard and understood are more satisfied with the health care they
16 receive [16].

17 This is the first study to explore and provide a description of patients’ and their relatives’ emotional
18 cues and concerns during ACP conversations and about what (i.e. which themes) these cues and
19 concerns are actually expressed. This study gives us information on the GPs’ responses to the
20 emotional concerns and on how the communication between the GPs and patients unfolded during
21 the ACP conversations. Other valid coding schemes for studying communication in medical encounters
22 exists such as the Empathic Communication Coding Scheme [46], however, the VR-CoDES provide a
23 valid framework with a with the ability to also study implicit emotions (cues) which was considered as
24 a strength given the known barriers for patients to initiate and discuss ACP [30]. A first limitation of
25 this study is that data analysis was based on audio recorded conversations. We therefore lack
26 information on the non-verbal communication of the patients, relatives and their GPs. Non-verbal
27 aspects are an important part of communication; however, research has shown that communication
28 ratings using audio and video are highly correlated and that the loss of information is limited [47].
29 Additionally, audio-recording may have less influence on the communication unfolding between the
30 patient and the provider [48]. Secondly, the GPs in this study received a training on facilitating and
31 responding to discussions about EoL care and EoL values. Although the training didn’t necessarily prime
32 the recognition and responding to patients’ cues and concerns, a greater responsiveness to implicit or
33 explicit expression of emotions can be expected. Similarly, patients in this study also had access to a
34 workbook that stimulated patients to reflect on different ACP topics in advance, which might have
35 influenced the discussions. A final limitation of this study is that the majority of the observational
36 coding of the cues and concerns with the VR-CoDES was done by a single coder, this possibly poses a
37 limitation for the reliability of the coding.

38 4.2. Conclusion

39 Emotions during ACP conversations were mainly communicated implicitly as cues. The amount of
40 cues/concerns expressed show that ACP topics evoke many emotions in patients. The content of the
41 cues/concerns also varied greatly. Cues and concerns were mostly expressed about the consequences
42 of illness on quality of life and on burdening others, the severity of illness, and being tired of life. GPs

1 were mostly attentive to the cues and concerns that the patients expressed and mainly provided space
2 for the patient to elaborate on them.

3 4.3. Practice implications

4 It is recommended that GPs are attentive to patients' cues and concerns during ACP conversations.
5 These emotions point to what matters to the patient in last phase of life and provide opportunities to
6 engage patients in tailored ACP conversations. As patients express mostly cues and less concerns, GPs
7 should be attentive to implicit expressions of emotions. The content analysis revealed that patients
8 express cues and concerns about a wide variety of themes; even more themes than we anticipated on
9 in the workbook for the patients and conversation guide for the GPs. The GP should keep these themes
10 in mind during ACP conversations with their patients and if possible, actively ask about them. Lastly,
11 since patients expressed a lot of cues and concerns during the ACP conversations, GPs are
12 recommended to have recurrent ACP conversations with their patients and GPs should make time for
13 these discussions.

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17 **Conflict of interests**

18 The authors declare no competing interests.

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24

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5. References

1. Rietjens JAC, Sudore RL, Connolly M, van Delden J, A Drickamer M, Droger M, van der Heide A, Heyland DK, Houttekier D, Janssen DJA, Orsi L, Payne S, Seymour J, Jox RJ, Korfage IJ, European Association for Palliative Care. Definition and recommendations for advance care planning: an international consensus supported by the European association for palliative care. *Lancet Oncol.* 2017;18:e543–51. [https://doi.org/10.1016/S1470-2045\(17\)30582-X](https://doi.org/10.1016/S1470-2045(17)30582-X).
2. Sudore RL, Fried TR. Redefining the "planning" in advance care planning: preparing for end-of-life decision making. *Ann. Intern. Med.* 2010;153:256–61. <https://doi.org/10.7326/0003-4819-153-4-201008170-00008>.
3. Jimenez G, Tan WS, Virk AK, Low CK, Car J, Hau Yan Ho A. Overview of Systematic Reviews of Advance Care Planning: Summary of Evidence and Global Lessons. *J Pain Symptom Manage* 2018;56:436-459.e25. <https://doi.org/10.1016/j.jpainsymman.2018.05.016>.
4. Brinkman-Stoppelenburg A, Rietjens JAC, van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. *Palliat Med* 2014;28:1000–25. doi:10.1177/0269216314526272
5. McMahan RD, Tellez I, Sudore RL. Deconstructing the Complexities of Advance Care Planning Outcomes: What Do We Know and Where Do We Go? A Scoping Review. *J Am Geriatr Soc* 2021;69;234-244. doi: 10.1111/jgs.16801.
6. Murray L, Butow PN. Advance care planning in motor neuron disease: a systematic review. *Pall Supp Care* 2016;14:411–32. doi:10.1017/S1478951515001066
7. Stevens, J., Pype, P., Eecloo, K. *et al.* Facilitating advance care planning in the general practice setting for patients with a chronic, life-limiting illness: protocol for a phase-III cluster-randomized controlled trial and process evaluation of the ACP-GP intervention. *BMC Palliat Care* **20**, 97 (2021). <https://doi.org/10.1186/s12904-021-00796-1>
8. Munday D, Dale J, Murray S. Choice and place of death: Individual preferences, uncertainty, and the availability of care. *J R Soc Med* 2007;100:211 – 15. <https://doi.org/10.1177%2F014107680710000509>.

9. Michiels E, Deschepper R, Van Der Kelen G, Bernheim JL, Mortier F, Vander Stichele R, Deliens L. 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;21:409–15. <https://doi.org/10.1177%2F0269216307078503>.
10. De Vleminck A, Batteuw 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* 2018;35:495–502. <https://doi.org/10.1093/fampra/cmx125>
11. Meeussen K, Van den Block L, Echteld M, Bossuyt M, Bilsen J, Van Casteren V, Abarshi E, Donker G, Onwuteaka-Philipsen B, Deliens L. Advance Care Planning in Belgium and The Netherlands: A Nationwide Retrospective Study Via Sentinel Networks of General Practitioners 2011;42:565-577. <https://doi.org/10.1016/j.jpainsymman.2011.01.011>.
12. 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. <https://doi.org/10.1186/s12904-015-0068-1>.
13. Zimmermann C, Del Piccolo L, Bensing J, Bergvik S, De Haes H, Eide H, Fletcher I, Goss C, Heaven C, Humphris G, Kim YM, Langewitz W, Meeuwesen L, Nuebling M, Rimondini M, Salmon P, van Dulmen S, Wissow L, Zandbelt L, Finset A. Coding patient emotional cues and concerns in medical consultations: the Verona coding definitions of emotional sequences (VR-CoDES). *Patient Educ Couns* 2011;82:141-8. <https://doi.org/10.1016/j.pec.2010.03.017>.
14. Zimmermann C, Del Piccolo L, Finset A. Cues and concerns by patients in medical consultations: a literature review. *Psychol Bull* 2007;133:438–463. <https://doi.apa.org/doi/10.1037/0033-2909.133.3.438>.
15. Del Piccolo L, de Haes H, Heaven C, Jansen J, Verheul W, Bensing J, Bergvik S, Deveugele M, Eide H, Fletcher I, Goss C, Humphris G, Kim YM, Lngewitz W, Mazz MA, Mjaaland T, Moretti F,

- Nübling M, Rimondini M, Salmon P, Sibbern T, Skre I, van Dulmen S, Wissow L, Young B, Zandbelt L, Zimmerman C, Finset A. Development of the Verona coding definitions of emotional sequences to code health providers' responses (VR-coDES-p) to patient cues and concerns. *Patient Educ Couns* 2011;82:149–155. <https://doi.org/10.1016/j.pec.2010.02.024>.
16. Street Jr RL, Makoul NK, Epstein RM. How does communication heal? Pathways linking clinician-patient communication to health outcomes, *Patient Educ Couns* 2009;74:295–301. <https://doi.org/10.1016/j.pec.2008.11.015>
17. Street Jr RL. How clinician-patient communication contributes to health improvement: modeling pathways from talk to outcome, *Patient Educ Couns*. 2013;92:286–291. <https://doi.org/10.1016/j.pec.2013.05.004>
18. Fogarty LA, Curbow BA, Wingard JR, McDonnell K, Somerfield MR. Can 40 Seconds of Compassion Reduce Patient Anxiety?. *J. Clin. Oncol.* 1999;17:371–371. <https://doi.org/10.1200/jco.1999.17.1.371>.
19. Uitterhoeve R, Bensing J, Grol R, de Mulder P, Van Achterberg T. The effect of communication skills training on patient outcomes in cancer care: a systematic review of the literature. *Eur J Cancer Care* 2010;19:442-457. <https://doi.org/10.1111/j.1365-2354.2009.01082.x>.
20. Roter DL, Frankel RM, Hall JA, Sluyter D. The expression of emotion through nonverbal behavior In medical visits: mechanisms and outcomes. *J Gen Intern Med.* 2006;21:S28–34. <https://doi.org/10.1111/j.1525-1497.2006.00306.x>.
21. Fiscella K, Meldrum S, Franks P, Shields CG, Duberstein P, McDaniel SH, Epstein RM. Patient Trust Is It Related to Patient-Centered Behavior of Primary Care Physicians. *Med Care.* 2004;42: 1049-1055. <https://doi.org/10.1097/00005650-200411000-00003>.
22. Finset A. “I am worried, Doctor!” Emotions in the doctor-patient relationship. *Patient Educ Couns* 2012;88: 359-363. <https://doi.org/10.1016/j.pec.2012.06.022>.

23. Sean Morrison R. Advance Directives/Care Planning: Clear, Simple, and Wrong. *J Palliat Med* 2020;23;878-879. doi: 10.1089/jpm.2020.0272.
24. Tishelman C, Eneslätt M, Menkin EE, Van Den Block, L. Tishelman et al's Response to Morrison: Advance Directives/Care Planning: Clear, Simple, and Wrong. *J. Palliat. Med.* 2021;24. <https://doi.org/10.1089/jpm.2020.0540>
25. Stevens, J, Pype, P, Eecloo K, Deliens L, Pardon K & De Vleminck A. Facilitating advance care planning in the general practice setting for patients with a chronic, life-limiting illness: protocol for a phase-III cluster-randomized controlled trial and process evaluation of the ACP-GP intervention. *BMC Palliat Care* 2021;20:97. <https://doi.org/10.1186/s12904-021-00796-1>
26. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* 2006;3(2):77-101. doi:10.1191/1478088706qp063oa
27. Heyn L, Finset A, Eide H, Ruland CM. Effects of an interactive tailored patient assessment on patient-clinician communication in cancer care. *Psycho-Oncol.* 2013;22:89–96. <https://doi.org/10.1002/pon.2064>.
28. Hafskjold L, Sundling V, Eide H. Nursing staff's responses to thematic content of patients' expressed worries: observing communication in home care visits. *BMC Health Serv Res* 2018;18:597. <https://doi.org/10.1186/s12913-018-3390-5>
29. Suchman AL, Markakis K, Beckman HB, Frankel R. A model of empathic communication in the medical interview, *JAMA* 1997;277:678–682. doi:10.1001/jama.1997.03540320082047.
30. De Vleminck A, Houttekier D, Pardon K, et al. Barriers and facilitators for general practitioners to engage in advance care planning: a systematic review. *Scand J Prim Health Care.* 2013;31(4):215–26. <https://doi.org/10.3109/02813432.2013.854590>.
31. Zwakman M, Milota MM, van der Heide A, Jabbarian LJ, Korfage IJ, Rietjens JAC, van Delden JJM, Kars MC. Unraveling patients' readiness in advance care planning

conversations: a qualitative study as part of the ACTION Study. *Support Care Cancer*. 2021 Jun;29(6):2917-2929. doi: 10.1007/s00520-020-05799-x.

32. Ahluwalia SC, Levin JR, Lorenz KA, Gordon HS. Missed opportunities for advance care planning communication during outpatient clinic visits. *J Gen Intern Med*. 2012 Apr;27(4):445-51. doi: 10.1007/s11606-011-1917-0. Epub 2011 Oct 25. PMID: 22038469; PMCID: PMC3304032
33. Abel J, Kellehear A, Millington Sanders C, Taubert M, Kingston H. Advance care planning re-imagined: a needed shift for COVID times and beyond. *Palliat Care Soc Pract* 2020;14:2632352420934491. <https://doi.org/10.1177%2F2632352420934491>
34. Cartwright C, Onwuteaka-Philipsen BD, Williams G, et al. Physician discussions with terminally ill patients: a cross-national comparison. *Palliative Medicine*. 2007;21(4):295-303. doi:[10.1177/0269216307079063](https://doi.org/10.1177/0269216307079063)
35. Sand L, Strang P. Existential loneliness in a palliative home care setting. *J Palliat Med*. 2006 Dec;9(6):1376-87. doi: 10.1089/jpm.2006.9.1376.
36. Sundström M, Blomqvist K, Edberg AK, Rämgård M. The context of care matters: Older people's existential loneliness from the perspective of healthcare professionals-A multiple case study. *Int J Older People Nurs*. 2019 Sep;14(3):e12234. doi: 10.1111/opn.12234.
37. Beernaert K, Deliens L, Vleminck A, Devroey D, Pardon K, Van den Block L, Cohen J. Early identification of palliative care needs by family physicians: A qualitative study of barriers and facilitators from the perspective of family physicians, community nurses, and patients. *Palliat. Med*. 2014;28:480–490. <https://doi.org/10.1177%2F0269216314522318>.
38. Deschepper R, Bernheim JL, Vander SR, et al. Truth-telling at the end of life: a pilot study on the perspective of patients and professional caregivers. *Patient Educ Couns* 2008;71: 52–56. <https://doi.org/10.1016/j.pec.2007.11.015>.

39. White C, McMullan D, Doyle J. "Now that you mention it, doctor ...": symptom reporting and the need for systematic questioning in a specialist palliative care unit. *J Palliat Med* 2009;12:447–450. <https://doi.org/10.1089/jpm.2008.0272>.
40. Prince-Paul M, DiFranco E. Upstreaming and normalizing advance care planning conversations—A public health approach. *Behav. Sci.* 2017;7:18. <https://doi.org/10.3390/bs7020018>
41. Mellblom AV, Finset A, Korsvold L, Loge JH, Ruud E, Lie HC. Emotional concerns in follow-up consultations between paediatric oncologists and adolescent survivors: a video-based observational study. *Psycho-Oncol.* 2014;23:1365-72. <https://doi.org/10.1002/pon.3568>.
42. Korsvold L, Mellblom AV, Finset A, Ruud E, Lie HC. A content analysis of emotional concerns expressed at the time of receiving a cancer diagnosis: An observational study of consultations with adolescent and young adult patients and their family members. *Eur J Oncol Nurs.* 2017;26:1-8. <https://doi.org/10.1016/j.ejon.2016.10.005>.
43. Aelbrecht K, De Maesschalck S, Willems S, Deveugele M, Pype P. How family physicians respond to unpleasant emotions of ethnic minority patients. *Patient Educ Couns* 2017;100:1867-1873. <https://doi.org/10.1016/j.pec.2017.04.001>.
44. Duric V, Butow P, Sharpe L, Lobb E, Meiser B, Barratt A, Tucker K. Reducing psychological distress in genetic counseling consultations for breast cancer, *J. Genet. Couns.* 2011;12:243–264. <https://doi.org/10.1023/A:1023284219871>.
45. Sep MSC, van Osch M, van Vliet LM, Smets EMA, Bensing JM. The power of clinicians' affective communication: how reassurance about nonabandonment can reduce patients' physiological arousal and increase information recall in bad news consultations. An experimental study using analogue patients. *Patient Educ Couns.* 2014;95 :45e52. <http://dx.doi.org/10.1016/j.pec.2013.12.022>

46. Bylund CL, Makoul G. Examining empathy in medical encounters: an observational study using the empathic communication coding system. *Health Commun.* 2005;18(2):123-40. doi: 10.1207/s15327027hc1802_2. PMID: 16083407.
47. Williams K, Herman R, Bontempo D. Comparing audio and video data for rating communication. *West J Nurs Res.* 2013;35:1060–73. <https://doi.org/10.1177%2F0193945913484813>.
48. Henry SG, Jerant A, Iosif AM, Feldman MD, Cipri C, Kravitz RL. Analysis of threats to research validity introduced by audio recording clinic visits: selection bias, Hawthorne effect, both, or neither?. *Patient Educ Couns* 2015;98:849–56. <https://doi.org/10.1016/j.pec.2015.03.006>.

Appendix

Table A1. Descriptive statistics of the cues and concerns expressed during the 17 ACP conversations.

Descriptive statistics	<i>N</i>
Average amount of cues and/or concerns	13
Cues	11
Concerns	1,6
Min amount of either cues or concerns	1
Min amount of cues	0
Min amount of concerns	0
Max amount of cues and/or concerns	28
Cues	25
Concerns	5
Distribution of amount of cues	
0 - 5	5
6 - 10	4
11 - 15	6
16 - 20	2
> 20	2
Distribution of amount of concerns	
0	8
1 - 3	5
4 - 5	4

Table A2. Description of conversations.

Patient gender	Patient age	Relatives/trusted person present	Physician gender	Duration of conversation	Number of cues and concerns
Female	59	/	Female	34:24	17
Female	67	/	Female	55:55	22
Female	85	/	Male	23:58	0
Male	75	Wife	Male	21:58	3
Female	90	/	Male	17:51	20
Male/Female	85/87	/	Male	22:40	1
Female	69	/	Male	28:36	12
Male	76	Wife	Male	19:17	7
Male	82	Wife	Female	58:39	23
Male	93	/	Female	28:31	17
Female	85	/	Female	23:45	1
Female	83	/	Female	38:35	9
Male	76	/	Female	23:15	0
Female	78	/	Male	23:25	11
Female	67	/	Male	27:52	7
Male		/	Male	23:24	10
Male		Wife	Male	31:02	7
Male		/	Female	59:14	28
Male	76	Wife	Female	27:21	18
Female	83	Friend	Female	20:01	0

GP Conversation guide

Preparation
Does the GP have the necessary information on hand, e.g. about the patient's current health status, earlier ACP conversations, advance directives previously completed? Does the GP have information about the role of family members or close persons in the patient's care?
Have other health providers been consulted?
Has sufficient time been allotted for the conversation?
Introduce the topic
Listen to the patient's story and encourage the patient to openly talk about their worries, wishes, and values. Begin with what the patient wants to talk about before exploring other themes.
Example question: "What was your impression of the workbook? Which themes were most important to you?"
The ACP conversation
1. Values, norms, and quality of life. Example question: "What does 'good health care' mean to you?"
2. Experiences with serious illness or death of loved ones or close persons.
3. Worries and uncertainties regarding current and future health. Example question: "When you think about your health in the future, what worries you the most?"
4. Trusted person and surrogate decision maker. Example question: "If you were to become seriously ill and someone had to make a medical decision for you, who would you trust to do this? What makes you choose this person?"
5. Information preferences. Example question: "To what extent would you like to inform your family members about your health situation?"
6. Goals of care. Example question: "In the past, you told me that (e.g., not being hospitalized) is important to you. Is that still the case?"
7. Advance directives.
Summarizing and documenting the conversation; planning and follow-up.
Example question: "Today we talked about (topic of conversation). Would it be alright with you if in the next conversation, we talk about (e.g., topics patient may not have had time for)?"
How to respond if patient is not open to talking about ACP

Workbook “My wishes for future care”

Introductory text
<ol style="list-style-type: none">1. Introducing ACP as a theme that can be helpful to patients in different stages of their illness trajectory2. Defining ACP as thinking about, talking about, and documenting wishes for care3. Explaining how the workbook can be used to help patients think about and discuss ACP
Open questions
<ol style="list-style-type: none">1. What is important for you to live well?2. What is most important to you regarding your physical and mental health?3. Do you have experiences with serious illness or death of someone close to you? Is there anything you would or would not want, based on that experience?4. Do you have any questions or concerns about your current health?5. When you think about the future, are there things you are worried about, health-related or otherwise?
Scale questions: <i>How would you like to make decisions about your care, now or in the future?</i> (patients indicate a preference between two ends of a scale by placing a mark along the scale)
<ol style="list-style-type: none">1. I would like to know: Only the essential minimum of information about my diagnosis and treatment ←→ Every detail about my diagnosis and treatment)2. During my treatment, I would like: For those close to me not to be informed of my health situation (Diagnosis, prognosis, treatment) ←→ For those close to me to be completely informed of my health situation3. During my treatment, I would like: For doctors to only provide information and recommendations about treatment ←→ For doctors to make the final decision about my treatment4. During my treatment, I would like: For my family to not have any input in decisions about my treatment ←→ For my family to make the final decision about my treatment
Talking about it/surrogate decision maker
<ol style="list-style-type: none">1. If you would like to talk about your wishes, with whom would you want to talk about them? [Checkboxes for e.g. spouse/partner, son/daughter/children]2. Can you think of someone who could make medical decisions for you, if you were no longer able to do so yourself?3. Do you have any other thoughts, questions, or concerns about your current or future health care that you would like to discuss?4. I have discussed this workbook with: [Table for name, relation to this person, and date of conversations]