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Fundamentals of end-of-life communication as part of advance care planning for older people: An interview study with nursing staff

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ABSTRACT

This exploratory interview study investigated nursing staff members' perspectives on the fundamentals of end-of-life communication with older people as part of advance care planning in home care, nursing home, and hospital settings. Separate semi-structured interviews were conducted with 17 nursing staff members about their experiences, opinions, and preferences before, during, and after end-of-life conversations. Overall themes clustering the fundamentals include preconditions such as feeling comfortable talking about the end of life and creating space for open communication. Fundamentals related to the actual conversation—such as using senses and applying associative communication techniques (e.g., using understandable language), following conversation phases, and being aware of interprofessional collaboration—were also considered important. This study emphasizes the importance of moving along with the older person as well as connecting, adapting, and letting go of control over the conversation's outcome. Many fundamentals can be traced back to the basics of nursing and the humanity of conversation.

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Introduction

Nursing staff experience many challenges in end-of-life (EOL) communication with older people in advance care planning (ACP). They often feel uncomfortable talking about death, lack training and guidance on how to engage in EOL communication, and are uncertain about timing, content, roles, and responsibilities.[1] EOL communication as part of ACP (hereafter called EOL communication) includes early and proactive informal (i.e., spontaneous) and formal (i.e., planned in advance) conversations between an older person, a family caregiver, and a healthcare professional about future EOL care, the transition to the EOL phase, and death and dying from a holistic perspective.[2-4] EOL communication prepares older people and their family caregivers to take a proactive role in decision-making about future EOL care[5] and might support them in receiving physical, social, spiritual, and psychological care that aligns with their preferences.[6,7]

According to previous research, EOL communication requires specific fundamentals.[8] In this study, fundamentals are defined as the important aspects of EOL communication such as the prerequisites, competencies, activities, and values involved in preparing for, carrying out, and evaluating holistic and person-centered EOL communication.[9] In a recent scoping review, we identified several fundamentals.[10] The most important fundamental is building a

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trusting relationship between the nursing staff and the older person.[10] This relationship enables nursing staff to sense older people's readiness for EOL communication, estimate the right timing for an EOL conversation, and identify and adjust to the needs of older people.[10] Nursing staff attune EOL communication to the values and needs of older people to approach the communication process in a person-centered manner.

Although some general fundamentals of EOL communication for nursing staff have been identified, a deeper understanding of the content of these fundamentals is needed. Moreover, these identified fundamentals mainly pertain to the hospital setting.[10] Because EOL communication is part of the entire healthcare chain and because initiating EOL communication in the hospital setting is often considered "too late" for older people, the fundamentals of EOL communication in home care and nursing home settings must be understood.[10] Moreover, in the home care setting, older people can readily prepare for (future) EOL decisions before substantial physical and cognitive limitations arise. Therefore, in this study, we aimed to gain an in-depth understanding of the fundamentals of EOL communication with older people as part of ACP in home care, nursing home, and hospital settings from the perspectives of nursing staff. A deeper understanding of the fundamentals for performing EOL communication can support nursing staff in providing open, tailored, effective, and high-quality EOL communication as part of integrated care. Moreover, this understanding can facilitate the development of a theoretical framework to educate nursing staff, guide the design of interventions to support nursing staff in improving and taking a central role in EOL communication, and implement these interventions.

Materials and methods

This study is reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines.[11]

Design and methods

This study adopted an exploratory qualitative design using semi-structured interviews.[12,13]

Working group

The research group consulted an interprofessional working group (n = 16) regarding the interview guide content, participant selection, qualitative analysis approach, and the interpretation of the results. This working group consisted of a patient representative; nursing staff members with different educational levels working in hospital, home care, and nursing home settings; members of a transmural palliative care consultation team; a spiritual caregiver; and other experts in palliative care, geriatric nursing care, and nursing education. The working group gathered three times during the study.

Population and domain

This study was conducted at two healthcare organizations (providing care in multiple healthcare settings) in the south of the Netherlands. Purposive sampling was used to yield maximum variation in the sample of nursing staff regarding educational level, healthcare setting, and years of experience in caring for older people and palliative care. Nursing staff members were invited to participate in the study if they worked as care assistants, certified nursing assistants, licensed vocational nurses, registered nurses, clinical nurse specialists, or nurse practitioners in home care, nursing home, or hospital settings. An inclusion criterion was having spoken (formally or informally) about future EOL care or dying with older people in the six to eight weeks before the interview. Older people were defined as those over 65 years of age and receiving palliative care in home care, nursing home, or hospital settings (e.g., due to frailty or chronic illness).

Data collection

The research team consisted of researchers experienced in qualitative research, interviewing about sensitive topics, and ACP. Semi-structured interviews were performed face-to-face at a location of the participant's choice. Two researchers (FP, nurse scientist and Ph.D. candidate, and JF, senior researcher/lecturer and postdoc) conducted the first six interviews to discuss and adjust the interview approach and content if necessary. One researcher (FP) conducted the remaining interviews. Baseline characteristics (healthcare setting, education level, age, gender, and years of experience with care for older people and palliative care) were collected verbally by FP before the start of the interview. The fundamentals defined within the described themes in the scoping review (e.g., person-centered approach, preparing for EOL communication, carrying out EOL communication, and professional attitude and required skills)[10] were used to create the first draft of the interview guide. The research group, working group, and consultants on the project (two patient representatives and two experts in ACP, palliative care, and qualitative research) discussed the first draft, and after discussion, the final interview guide (Appendix A) was established. The interview guide consists of questions about experiences, opinions, and preferences regarding fundamentals before, during, and after EOL conversations and interprofessional collaboration. Specifically, nursing staff were asked to describe how they engage in EOL communication, what they think are important fundamentals of EOL communication, why they think these fundamentals are important, and how they apply these. FP conducted one pilot interview to become familiar with the interview guide and test its applicability. The interview guide was considered applicable, and the data from the pilot interview were also used in the analysis. Field notes were recorded after each interview.

Recruitment and procedures

Nursing staff from our professional network and the working group were recruited and selected. FP approached the nursing staff members by email or telephone, began the informed consent procedure and scheduled interviews for those who were interested. Candidate interviewees were informed about the research purpose and received the participant information form by email. Participants were encouraged to ask questions about the study at any time. All participants signed an informed consent form before the interview.

Data analysis

The interviews were audio-recorded, transcribed verbatim, and analyzed using the reflexive thematic analysis approach of Braun and Clarke.[14] After every one or two interviews, the interviews were transcribed and analyzed, and the interview approach and content were adjusted when necessary to allow for a deeper exploration and understanding of the research topic. FP transcribed the first five interviews to become familiar with the data. The other interviews were transcribed by an independent professional transcription service. Transcripts and preliminary findings were not returned to the participants.

The analysis was conducted from an essentialist epistemology perspective with an experiential orientation.[15] One-third of the transcripts were coded independently by two researchers (FP and JF) to create an initial overview and to improve reliability. FP analyzed the rest of the data. The coding of each researcher was constantly compared to allow cross-validation in the interpretation. FP and JF initially followed an inductive analysis approach, starting the analysis

from the interview data rather than from the themes developed in the previous scoping review. The analysis of the first seven interviews focused on creating semantic codes to identify the explicit and surface meaning of the data. Subsequently, latent codes were also created to capture underlying ideas, patterns, and assumptions. FP and JF formulated the overall themes and underlying fundamentals. The first fundamentals were formulated after the fourth interview, and the first overall themes were formulated after the tenth interview. After the twelfth interview, the themes had been developed, so we shifted to a deductive analysis approach to work toward saturation. The emphasis on certain questions in the interview guide changed over time as saturation was reached on some topics or additional questions emerged from on previous interviews. Data collection ended when saturation was reached (i.e., the point during data analysis at which additional interviews produced little or no new useful information related to the study objectives).[16] Saturation was cross-checked and discussed after every three or four interviews with a second researcher (JF). The analysis was regularly discussed and adjusted with the research group until a consensus was reached. We also discussed the final analysis with the working group and adjusted it slightly to reach a consensus. Any potential biases or assumptions the researchers made during the data collection and data analysis that were relevant to the description of the fundamentals were noted in memos. Atlas.ti (version 23.2.1) was used to support the analysis.

Ethical issues

The study was conducted according to the principles of the Declaration of Helsinki and the Medical Research Involving Human Subjects Act.[17] The study was approved by the Medical Research Ethics Committee of Zuyd University of Applied Sciences and Zuyderland Medical centre (registration number: Z20230031).

Results

Participants and demographic data

Seventeen individual interviews were conducted between June 2023 and December 2023. One nursing staff member refused to participate for personal reasons. Two nursing staff members refused to participate because of a lack of perceived experience with EOL communication.

The interviews had a mean duration of 64 min (SD = 11 min). The median age of the nursing staff members was 50 years (range: 25–64 years). Most nursing staff members worked as nurses (58.8 %) and in a nursing home (41.2 %) (Table 1). Their median working experience with older people was 23 years (range: 5–40 years).

Table 1
Participant characteristics.

Characteristics (n = 17)	Median (range)
Age (years)	50 (25–64)
Working experience with older people (years)	23 (5–40)
Working experience in palliative care (years)	13 (4–37)
	N (%)
Gender, female	15 (88.2)
Gender, male	2 (11.8)
Education level, master's degree	4 (23.5)
Education level, postgraduate degree	2 (11.8)
Education level, bachelor's degree	4 (23.5)
Education level, vocational education	7 (41.2)
Profession, nurse*	10 (58.8)
Profession, care assistant*	3 (17.6)
Profession, nurse practitioner*	4 (23.5)
Setting, nursing home	7 (41.2)
Setting, hospital	5 (29.4)
Setting, home care	5 (29.4)

* In the Netherlands, nurses (i.e., registered nurses, licensed practical nurses, or licensed vocational nurses) require a vocational education, a bachelor's degree, or a postgraduate degree; nurse practitioners require a master's degree; and care assistants require a vocational education.[32]

Findings

Five overall themes were formulated in which 19 fundamentals were clustered (Fig. 1). The fundamentals described within themes 1 and 2 are related to preconditions, and those in themes 3 and 4 are related to performing the actual conversation. Theme 5 is related to interprofessional collaboration. Supplementary File 1 provides a detailed schematic overview of the fundamentals. Table 2 presents additional quotes.

Theme 1: Feeling comfortable

The most important precondition for engaging in EOL communication is feeling comfortable with this type of communication. Three fundamentals contribute to feeling comfortable: the ability to communicate about the EOL, learning by doing, and establishing a trusting relationship.

Ability to communicate about the EOL

To feel comfortable and safe in EOL communication, nursing staff emphasized the importance of being able to talk about the EOL and other sensitive topics, both personally and professionally. Nursing staff explained that it is essential to be aware of the absence or presence of this ability, as a lack of ability to talk about the EOL themselves can negatively impact conversations.

The ability to talk about the EOL and the awareness of this ability also help nursing staff recognize and anticipate important cues and valuable information from older people. Moreover, nursing staff explained that they must be aware of their values, beliefs, and cultural backgrounds and how these might affect their conversations with older people. They expressed varying opinions about the appropriateness of expressing their emotions during EOL conversations. Many nursing staff members believed that showing emotions could contribute to the humanity and openness of the conversation. However, some considered it unprofessional (see also Table 2, quote 3).

> "I am human too, right? I can also shed a tear if the person has really touched me emotionally. That should simply be possible as well." (Z10: care assistant, nursing home)

Nursing staff indicated that for older people to engage in EOL conversations, they must be physically calm, free of pain, and not restless. Moreover, older people should feel safe and be open to discussing the EOL. Nursing staff also emphasized the importance of observing whether the older person could express themselves freely during the conversation. Nursing staff members observe whether the older person is relaxed and actively participating in the conversation to confirm this observation.

Establishing a trusting relationship

Establishing a trusting relationship facilitates nursing staff members' interpretation of observations, allows them to see older people as humans, and allows for an open and intimate conversation. These factors assist nursing staff in meeting the needs of older people. According to nursing staff, building a relationship requires feeling a

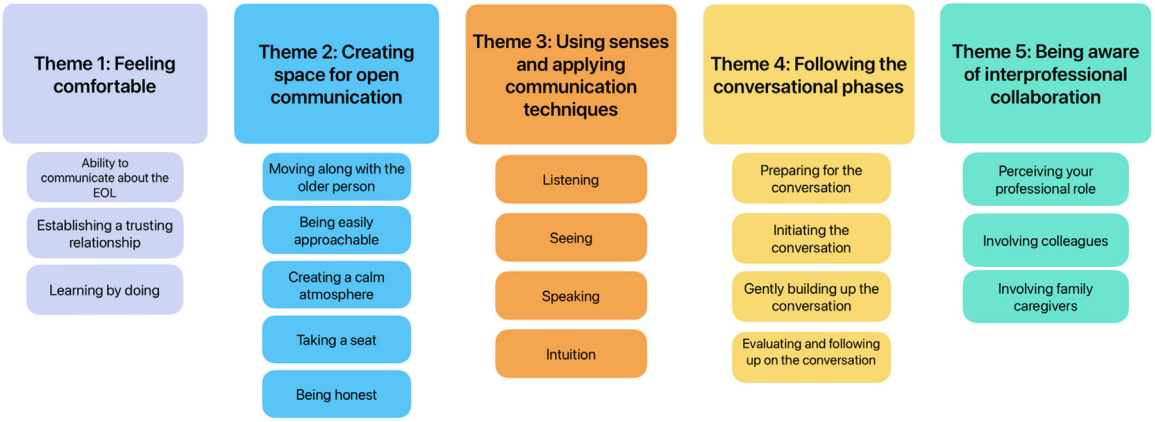

Fig. 1. Overall themes and fundamentals.

mutual connection between them and the older person, which is very person-dependent. The first impression of the older person can already be decisive in feeling this connection. Nursing staff explained that several factors contribute to this feeling, including a shared sense of humor, speaking the same dialect, demonstrating expertise and confidence, and older age, which often reflects greater life experience. In addition, nursing staff explained that in most settings, their professional role allows them to spend time with the older person and quickly strengthen the relationship. In this professional role, nursing staff members share intimate moments with older people, such as assisting with activities of daily living, and they are easily accessible and visible to the older person.

According to nursing staff, there is no specific threshold for establishing a trusting relationship that is sufficient to begin an EOL conversation. This relationship gradually develops as communication progresses. However, nursing staff mentioned that older people provide several indicators: becoming more forthcoming, expressing emotions, displaying interest, demonstrating trust, and initiating conversations with the nursing staff. If a trusting relationship does not develop, nursing staff typically opt to ask another colleague to initiate an EOL conversation with the older person.

> "The patient is also quick to share things on their own or during moments of care. These are certainly intimate moments for the patient, which makes them feel comfortable talking about it. [...] Then I come back the next day to wash someone; then I come back to a family discussion. They often see the same face anyway. Also in the evening or even at night, when people feel uncomfortable or just cannot sleep or just want to talk to someone about it." (Z2: nurse, hospital)

Learning by doing

Nursing staff members with less experience considered possessing communication techniques and awareness of potential conversation topics important, whereas more experienced nursing staff members stressed that knowledge alone is not enough. Nursing staff emphasized that to feel confident in EOL communication, learning by doing is paramount. Most nursing staff members felt that with enough practice, EOL communication could be approached like any other person-centered conversation between two people. They also believed that the conversation should focus on life rather than solely on the EOL.

> "When I started doing the conversations myself [...] I was not really comfortable yet, because I was trying to force a certain issue. [...] Then you are not comfortable, and a patient feels that. [...] Yes, as I slowly drove that structure into the background, I started having completely different conversations and also started talking about life" (Z4: nurse practitioner, hospital)

Theme 2: Creating space for open communication

To have an open conversation about the EOL, it is crucial to create enough space for this conversation. Nursing staff can create space by adjusting their attitude and approach to the conversation and to the older person (i.e. moving along with the older person). Important fundamentals in the attitudes of nursing staff are being easily approachable, calm, honest, and sitting down. This attitude can also help the older person feel comfortable, as described in the previous theme.

Moving along with the older person

kEach EOL conversation differs, and nursing staff adapt their approach to an EOL conversation according to various factors, such as the reason for the conversation and the older person's personality, medical history, prognosis, life experiences, anxiety levels, cognitive ability, and cultural background. In addition, nursing staff consider the older person's emotional and physical condition, level of openness, resistance, facial expressions, and posture, along with the atmosphere in the room, to decide on their approach. Nursing staff indicated that they can get to the heart of a conversation more easily when they do not maintain a fixed structure but rather move along with the older person. The only recurring structure they mentioned were the dimensions of palliative care (i.e., social, psychological, physical, and spiritual). Nursing staff use these dimensions to understand and explain symptoms, identify areas of concern, and take a holistic perspective when interacting with older people.

> "Every conversation is so different. Always so different. What you say to patient A, you cannot say to patient B. No, you cannot. [...] You have to adapt to the person." (Z5: specialized nurse, nursing home)

Being easily approachable

Nursing staff emphasized that empathy, compassion, and respect are key to being easily approachable. They explained that they show empathy by listening carefully, paying attention to the conversation, not being judgmental, not forcing their views, and acknowledging the older person. Compassion can be expressed by being near the older person, placing a hand on their shoulder, holding their hand, or hugging them. Nursing staff explained they showed respect by communicating at an equal level with the older person. To achieve this, they address older people by their first names (with permission), sit

Table 2
Example quotes.

Theme	Fundamental	Example quotes
Feeling comfortable	Ability to communicate about the EOL	1. "I can only have these conversations if I feel comfortable and safe. For me, that is the basis of a good conversation. You must feel comfortable and well so that you can listen to what the resident has to say. I think that is important." (Z12: care assistant, nursing home)
		2. "I am human too, right? I can also shed a tear if the person has really touched me emotionally. That should simply be possible as well." (Z10: care assistant, nursing home)
		3. "I have that kind of conversation with the client, and I have to give the client my full attention. To let him vent. I should not sit there with my own emotion." (Z5: specialized nurse, nursing home)
		4. "If you can handle it [talking about dying] privately, then you can handle it professionally as well. Yes, I think for a lot of people it is really about learning about dying. Learning to be comfortable with it. Learning to see that it is part of life and that you do not need to talk about death, you need to talk about life, and how do you want to fill in the remaining part of your life?" (Z8: nurse, hospital)
	Establishing a trusting relationship	5. "The patient is also quick to share things on their own or during moments of care. These are certainly intimate moments for the patient, which makes them feel comfortable talking about it. [. . .] Then I come back the next day to wash someone; then I come back to a family discussion. They often see the same face anyway. Also in the evening or even at night, when people feel uncomfortable or just cannot sleep or just want to talk to someone about it." (Z2: nurse, hospital)
		6. "The moment you feel that the conversation is going well and that the patient is opening up to you, then you can deepen the conversation, slowly guiding it towards what you want to know about the patient." (Z11: nurse practitioner, hospital)
	Learning by doing	7. "When I started doing the conversations myself [. . .] I was not really comfortable yet because I was trying to force a certain issue. [. . .] Then you are not comfortable, and a patient feels that. [. . .] Yes, as I slowly drove that structure into the background, I started having completely different conversations and also started talking about life." (Z4: nurse practitioner, hospital)
		8. "I think you can still do so many courses and training, which might give you some tools, but if you do not feel things, then I do not think all that training is of any use at all." (Z11: nurse practitioner, hospital)
Creating space for open communication	Moving along with the older person	9. "Every conversation is so different. Always so different. What you say to patient A, you cannot say to patient B. No, you cannot. [. . .] You have to adapt to the person." (Z5: specialized nurse, nursing home)
	Being easily approachable	10. "I also show a piece of myself. That is very important. [. . .] That they feel, 'I know you.'" (Z6: specialized nurse, nursing home)
		11. "I think it requires a big part of your empathy, but I think it also requires you to just be human and not just be the nurse who comes in to perform the technical procedures." (Z8: nurse, hospital)
	Creating a calm atmosphere	12. "I also actually go there and then I have the time and then I have the conversation. But I always try to do that here as well. Even though I am busy I get the feedback back, 'You are always calm'. . .I say, 'Well. . .you should know'. Yes, I seem to radiate that [calmness]. And I do think that is very important." (Z5: specialized nurse, nursing home)
	Taking a seat	13. "I never stand. No. [..] That really is a no-go. I have to be at eye level. [. . .] I am equal to the client. It is very different talking if I stand above and. . .no, you cannot. Even if a client is on the floor, I still get down on my knees." (Z5: specialized nurse, nursing home)
	Being honest	14. "People sometimes say: you are not allowed to tell the patient that he is dying. [. . .] And usually, I come into the room, and you look at the person and they say: 'I am dying, eh'. I say 'yes'. You know, it is not up to me to say 'no' at that moment." (Z8 nurse, hospital)
		15. "I think it is my job to start the conversation about that. How things have been at home, what they expect, how they see themselves in a year's time. [. . .] Sometimes they tell me that '[in a year] I am going to take a nice trip around America with my family'. That is the point for me to jump in and marinate that patient in the idea that life might also be over sometime soon." (Z4: nurse practitioner, hospital)
Using senses and applying communication techniques	Listening	16. "Listen. . . by keeping your mouth shut. Literally. And by simply listening to what the client says. And occasionally summarizing what you have heard. But listening really means listening. Sometimes you can really listen for half an hour and just let the client talk." (Z1: specialized nurse, nursing home)
		17. "You need to take your time and listen carefully to what the patient is telling you and not be busy with the next question in the conversation. That is what you often used to be busy with. The patient tells you a lot, but in your head, you think, 'Oh, I have to ask this', but then you miss the essence of what someone is telling you. [. . .] I think the main thing is not to be too preoccupied with the next question you are going to ask." (Z4: nurse practitioner, hospital)
		18. "Yes, what is important to the patient, what is on his mind [. . .] you try to filter, I think. I do not think you really listen, but you filter what comes up in the conversation, what it does to the patient, what their non-verbal response to it is. And you are trying to address that." (Z4: nurse practitioner, hospital)
	Seeing	19. "When they talk about it [love for loved ones or pets], you can often see a certain sparkle in their eyes. [. . .] So, it is not just listening, it is also looking: what does it do to a patient when they start talking about something? Does someone get sad? Does someone get a smile on their face from what they are telling?" (Z11: nurse, hospital)
		20. "You are looking for confirmation that yes, that is what I see, or this is what the patient is experiencing. [. . .] Maybe the patient does not realize that it makes them more emotional or that someone is very distressed or panicked by a certain idea. [. . .] You also try to hold up a mirror to them in the good sense of 'you say it, but I do not really see from you that it is actually true, is that correct?'" (Z2: nurse, hospital)
	Speaking	21. "You can use 25 sentences for something, but then the essence is often lost. So, it is better to say it concretely with examples of what it is about and what we are talking about. In CPR, for example, I always appoint that the heart is stopped; they are going to press on it to get it back again." (Z3: nurse practitioner, hospital)
		22. "Sometimes it is good to just take a step back and let silence fall so that the client has space to move forward." (Z15: nurse, home care)
		23. "Allow silence in the conversation if they ask a question or they have been emotional. That too is allowed. Just be quiet and see what happens. Especially see what happens. And allow that silence for a

(*continued*)

Table 2 (*Continued*)

Theme	Fundamental	Example quotes
		moment. Or if you are having a conversation and you notice that someone is starting to think. . .and then allow that silence." (Z13: nurse, home care)
	Intuition	24. "This [sensing] is a nursing thing that I can never articulate very well, but we [nursing staff] all feel it." (Z4: nurse practitioner, hospital)
		25. "You cannot hang a protocol on it. It is often an intangible thing. It is a feeling." (Z6: specialized nurse, nursing home)
Following the conversational phases	Preparing for the conversation	26. "The moment I am there, it happens. [. . .] You cannot prepare it because you do not know what the other person's needs are at that moment." (Z13: nurse, home care)
	Initiating the conversation	27. "Most of the time, it is really by chance. Today, for example, I was sitting with Mr. R. in the living room. He started himself: 'I do not remember it all'. Then I have an opening, and then I can engage in a conversation. Then I ask, 'How come, and what do you feel? How do you feel?' In that way, I then continue." (Z10: care assistant, nursing home)
		28. "Yes, or I or the physician will start the conversation with the situation of the last few days or weeks. Yes, what you see. These are the symptoms or the deterioration, the behavior. . . and the family then says: we recognize this, or we also see this or. . . And then, yes, eventually you get to a point where you say, 'what are the expectations and where is this going to go?'." (Z9: nurse nursing home)
	Gently building up the conversation	29. "I try to keep it informal, especially when people find it very difficult to engage in difficult conversations. Then you try to give a certain level of trust through something light-hearted at first, and if you find that it is there and the conversation goes really well, then you just get really far and also really deep sometimes." (Z11: nurse practitioner, hospital)
		30. "Often, they will tell me who they are, what they are struggling with, what their family is like. From there, I can ask more questions. [. . .] And the other time, yes, it is actually like, well, I have been asked by the district nurse, for example, who has indicated that a conversation is needed. And then they start talking from there." (Z7: specialized nurse, home care)
	Evaluating and following up on the conversation	31. "Often, in the room, I ask if everything has been discussed, if the patient has any questions. Whether there is anything else I can do for him. [. . .] And if not, relatively shortly at the end of my shift, I will walk in again later to ask, 'Was the conversation okay? Are you okay?'." (Z8: nurse, hospital)
Being aware of interprofessional collaboration	Perceiving your professional role	32. "It is not entirely clear what I am really allowed to do according to certain guidelines and protocols. It really is a gray area, I think. So, you are a bit more reserved in what you say and what you ask. You also do not want to say things that are not up to me." (Z2: nurse, hospital)
	Involving colleagues	33. "I do that [evaluate] more often with colleagues. It may be that I also have doubts sometimes, and then I evaluate with colleagues, like 'Look, I had this conversation yesterday, I did this and that. What do you think?' Or I do it with the spiritual caregiver." (Z1: specialized nurse, nursing home)
	Involving family caregivers	34. "I think it is nicer to have the conversation with the family so that they are also aware of what the client wants. Because I think it is important that we are all on the same page. But if the client does not want that, or does not have a social network, we can also do it alone." (Z15: nurse, home care)
		35. "What I personally do is try to stay out of. . .disagreements between families. That is something distressing. [. . .] Then I say, you know, [. . .] 'you have to try to resolve that between yourselves'. [. . .] You do try to really focus on that client. I still focus on the first contact then, but I am not going to steer into the whole family dynamic." (Z1: specialized nurse, nursing home)

beside them, give them space and time to share their stories, and adjust their verbal tone to the older person's verbal tone. Other methods contributing to an approachable attitude, are keeping conversations informal, showing their accessibility by having a welcoming attitude, not crossing their arms or turning away from the older person, and making plenty of eye contact. To demonstrate shared interests and similarities with the older person, nursing staff also occasionally share something about themselves in the conversation. Sharing this information is important because it helps nursing staff appear more "human".

> "I think it requires a big part of your empathy, but I think it also requires you to just be human and not just be the nurse who comes in to perform the technical procedures." (Z8: nurse, hospital)

Creating a calm atmosphere

To create a calm atmosphere, nursing staff mentioned that it is essential that they take their time and show they have enough time for the conversation by speaking slowly, limiting the number of people present, enhancing physical silence by closing the door or bed curtain, and minimizing distractions. Nursing staff stated that they aim to maximize privacy and minimize interruptions by telling their colleagues that they will be having an EOL conversation and switching off devices such as phones, iPads, or pagers.

> "I also actually go there and then I have the time and then I have the conversation. But I always try to do that here as well. Even though I am busy, I get the feedback back, 'You are always calm'. . . I say, 'Well. . . you should know'. Yes, I seem to radiate that [calmness]. And I do think that is very important." (Z5: specialized nurse, nursing home)

Taking a seat

Nursing staff explained that sitting down demonstrates that they consider the older person as an equal and encourages conversation. However, nursing staff admitted that they do not always sit down because of time constraints. If they sit down, they usually prefer to sit on a chair or on the older person's bed, typically when the older person is emotional. Some nursing staff members also stated that sitting next to another healthcare professional or a family caregiver during a conversation involving multiple people is essential. This positioning helps the older person to pay attention during the conversation.

> "I never stand. No. [..] That really is a no-go. I have to be at eye level. [. . .] I am equal to the client. It is very different talking if I

stand above, and. . .no, you cannot. Even if a client is on the floor, I still get down on my knees." (Z5: specialized nurse, nursing home)

Being honest

Nursing staff also expressed the importance of direct and honest communication. They apply these concepts to reflect their trustworthiness and because they feel the older person sometimes needs this, for example to put things in perspective or understand the seriousness of a situation. According to nursing staff, EOL conversations are especially direct when the urgency of the conversation is high, such as when acute deterioration occurs. In this case, the older person's specific wishes regarding the last phase of life and death are asked more quickly.

"I think it is my job to start the conversation about that. How things have been at home, what they expect, how they see themselves in a year's time. [. . .] Sometimes they tell me that '[in a year] I am going to take a nice trip around America with my family'. That is the point for me to jump in and marinate that patient in the idea that life might also be over sometime soon." (Z4: nurse practitioner, hospital)

Theme 3: Using senses and applying communication techniques

The foundation of EOL communication involves using one's senses (listening, seeing, and speaking) and associative communication techniques. By contrast, many decisions nursing staff make about their approach are also intuitive.

Listening

Nursing staff indicated that they prioritize active listening and understanding what the older person says over anticipating the next question to maintain the conversation's flow, allowing them to focus completely on the older person.

"You need to take your time and listen carefully to what the patient is telling you and not be busy with the next question in the conversation. That is what you often used to be busy with. The patient tells you a lot, but in your head, you think, 'Oh, I have to ask this', but then you miss the essence of what someone is telling you. [. . .] I think the main thing is not to be too preoccupied with the next question you are going to ask." (Z4: nurse practitioner, hospital)

Nursing staff explained that they listen carefully to what the older person is saying, what is important to them, what they are worried about, and what information is important for the advance care plan. Filtering is essential for this. When nursing staff filter, they are alert to topics that are important to the older person. Nursing staff then emphasize these topics to help deepen the conversation, especially when information the older person shares requires specificity or clarification. If necessary, nursing staff remember information to bring up later conversation, for example, if it is not the right time to discuss a particular topic in-depth. Returning to a previously discussed topic during another conversation is also a good way to show older people that they have been heard, and it contributes to a trusting relationship.

Seeing

Nursing staff pay attention to intonation and non-verbal communication, such as body language, facial expressions, and the look in the eyes of the older person. They use these expressions to recognize agitation, fear, sadness, misunderstanding, and resistance. Nursing staff had difficulty articulating how they identify these signals. However, they reported that they do assess whether the verbal and non-verbal signals of the older person are consistent, and they use previous conversations with the older person as a reference to identify expressions or changes in these expressions.

Nursing staff had less difficulty articulating signals of resistance. When an older person is not ready for an EOL conversation or the conversation is not initiated at the right moment, the older person shows evasive body language (e.g., crossing their arms or turning away from nursing staff); avoids eye contact; gives few, short, slow, or atypical responses; changes the subject; sits or lies restlessly; or verbally expresses not wanting to have the conversation.

Nursing staff also stressed the importance of verifying perceived signals by verbalizing their observations, which can reduce the risk of misinterpretation. However, older people may also be unaware of the signals they are giving, and the nursing staff member may want to make them aware of those. For example, a nursing staff member may say "I have the idea that. . .is this true?". Thus, nursing staff try to deepen the observation, identify its cause, and anticipate it appropriately.

"You are looking for confirmation that yes, that is what I see, or this is what the patient is experiencing. [. . .] Maybe the patient does not realize that it makes them more emotional or that someone is very distressed or panicked by a certain idea. [. . .] You also try to hold up a mirror to them in the good sense of 'you say it, but I do not really see from you that it is actually true, is that correct?'" (Z2: nurse, hospital)

Speaking

For a fluent conversation, nursing staff must use understandable language and take regular pauses between sentences. Nursing staff explained that the older person should understand exactly what the conversation is about to avoid misunderstandings. Therefore, nursing staff avoid using difficult words and speak in concise sentences, explaining information in a short and simple way with examples. Several nursing staff members also reported using the teach-back method, in which the older person is asked to summarize what was discussed in the conversation. This eliminates misunderstandings and allows nursing staff to verify that the information has been conveyed correctly. Moreover, nursing staff explained that they regularly pause and create silence to allow the older person to think or process. This can also help older people to be aware of what they are feeling or thinking during the conversation rather than after the conversation.

"Allow silence in the conversation if they ask a question or they have been emotional. That too is allowed. Just be quiet and see what happens. Especially see what happens. And allow that silence for a moment. Or if you are having a conversation and you notice that someone is starting to think. . .and then allow that silence." (Z13: nurse, home care)

Intuition

Although on the one hand nursing staff are consciously engaged in observing and listening to older people, they also make many decisions about their approach according to their own feelings or intuition. Many nursing staff members reported that their approach to EOL conversations is intangible, as they sense how best to anticipate the older person; they emphasized that EOL communication is often described or approached too theoretically, especially by policy makers.

"You cannot hang a protocol on it. It is often an intangible thing. It is a feeling." (Z6: specialized nurse, nursing home)

Theme 4: Following the conversational phases

Nursing staff generally divide EOL communication into four phases: preparing the conversation, initiating the conversation, gently building up on the conversation, and evaluating and following up the conversation. Nursing staff members' senses, communication techniques, and methods for creating space for open communication, as described in the previous themes, are applied in each phase.

Preparing for the conversation

To prepare for an EOL conversation (especially an informal one), nursing staff mentioned that they must be informed of past EOL communication and understand the reason for the current conversation, who the older person is, and the emotional state of the older person. Nursing staff obtain information by reading patient or client records or through colleagues' verbal communication. However, experienced nursing staff stressed that complete preparation for an EOL conversation is typically not enough because of the dynamic nature of the conversations and the reliance on the older person in those conversations. Some nursing staff members suggested that preparing for an EOL conversation can result in a narrowed perspective of the older person.

"The moment I am there, it happens. [. . .] You cannot prepare it because you do not know what the other person's needs are at that moment." (Z13: nurse, home care)

Initiating the conversation

Nursing staff indicated that an EOL conversation can be initiated in many ways, and this initiation depends on the reason for the conversation. For example, the older person may give a signal (e.g., sadness, worrying, questions about a particular treatment, or deterioration) that nursing staff respond to with an informal conversation. Nursing staff also mentioned that in rare cases, they "spontaneously" approach an older person for an informal EOL conversation.

Sometimes, nursing staff also initiate a formal conversation (e.g., in response to deterioration or admission to a nursing home); they begin with a greeting and describe or ask about the older person's current situation (e.g., "How are you today?"). Thereafter, nursing staff often choose to follow up on what the older person talks about and then to slowly work toward the reason for or goal of the conversation.

"Most of the time, it is really by chance. Today, for example, I was sitting with Mr. R. in the living room. He started himself: 'I do not remember it all'. Then I have an opening, and then I can engage in a conversation. Then I ask, 'How come, and what do you feel? How do you feel?' In that way, I then continue." (Z10: care assistant, nursing home)

Gently building up the conversation

After initiating an EOL conversation, nursing staff rely primarily on the older person's signals and cues. Nursing staff stated that the conversation must be initiated "lightly" (e.g., by posing general questions about the older person) and gradually progress to more "heavy" topics such as death or dying. The speed of this progression depends on the older person's resistance to discussing heavy topics and the relationship between the nursing staff member and the older person. Questions nursing staff use to start the conversation are often related to determining who the older person is, such as "Where are you from?", "What is important to you?", or "What empowers you?". Depending on the older person's answers, nursing staff respond by asking follow-up questions or by expressing some form of acknowledgement. For example, if an older person mentions that being able to go outside is important to him or her, nursing staff might answer "Why is that?". These responses are highly dependent on the older person and the nursing staff member (see also the previous fundamental 'Moving along with the older person').

Nursing staff discuss difficult topics by asking "bridging questions" in response to what the older person says (e.g., if an older person says "I would not let that happen to me [referring to a past experience]" nursing staff would respond with, "What do you mean by that?" or "What does that mean to you?") to add depth to the conversation and gain a deeper understanding of the values and preferences of the older person. More direct questions are sometimes also used, such as, "Have you ever thought about. . .?" or "Have you talked to your general practitioner about. . .?". When appropriate, possible scenarios are discussed to guide the older person to imagine a specific process or situation.

Nursing staff emphasized the importance of highlighting that choices do not need to be made instantly during the conversation and that decisions are not unchangeable. In addition, they explained that they seek balance in the collection of information so that they can provide appropriate care, inform the older person, and let them vent. The specific content of the conversations depends on the older person, who leads the conversation.

"I try to keep it informal, especially when people find it very difficult to engage in difficult conversations. Then you try to give a certain level of trust through something light-hearted at first, and if you find that it is there and the conversation goes really well, then you just get really far and also really deep sometimes." (Z11: nurse practitioner, hospital)

Evaluating and following up on the conversation

Preferably, communication does not end after an EOL conversation. Nursing staff reported that they also evaluate the conversation and follow up with the older person when needed. To evaluate the conversation, nursing staff ask if the older person has any questions about what was discussed, if they have missed any topics in the conversation, and how they experienced the conversation. This follow-up typically occurs immediately after the conversation. If the conversation was difficult, nursing staff may evaluate the conversation later to give the older person time to calm down. If a nursing staff member wants to follow up on the conversation and the older person shares this need, they generally do so on a different day. This is because some topics may not have been addressed during the conversation or the older person's health status may change, necessitating a new conversation. Often, at the end of the conversation, the nursing staff also ask if the older person is willing to have a follow-up conversation. Furthermore, they document the points that were discussed and evaluated, along with any agreements, in the older person's record.

"Often, in the room, I ask if everything has been discussed, if the patient has any questions. Whether there is anything else I can do for him. [. . .] And if not, relatively shortly at the end of my shift, I will walk in again later to ask, 'Was the conversation okay? Are you okay?'" (Z8: nurse, hospital)

Theme 5: Being aware of interprofessional collaboration

Nursing staff believed that EOL communication and the development of an advance care plan is a team effort. This team includes other nursing staff members; other professionals, such as physicians and spiritual caregivers; and family caregivers. Moreover, to

accurately engage in this team effort, nursing staff must be familiar with their own professional role.

Perceiving your professional role

Most nursing staff members had difficulty describing their role in EOL communication, both individually and within the interdisciplinary team. Some nursing staff members had never thought about their role. In addition, many indicated that their healthcare organization did not agree on what roles, authority, and responsibilities they had in ACP. Therefore, nursing staff members' descriptions of their roles varied, although there were some similarities. Many nursing staff members indicated that they saw themselves as someone who coaches, empowers, informs, makes the older person think, and helps structure the older person's thoughts. In addition, nursing staff felt it was important to encourage and support their colleagues in EOL conversations.

Some variations became visible in the role descriptions of nursing staff, highlighting the differences between nurse practitioners, care assistants, and nurses. Nurse practitioners indicated that they almost always engage in formal EOL conversations, whereas care assistants mostly engage in informal conversations. Nurses engage in both formal and informal conversations, but informal conversations occur much more often. Although the reasons, triggers, settings, and attendees typically differ between formal and informal conversations, nursing staff indicated that the fundamentals for these conversations generally did not. Nevertheless, nurse practitioners emphasized discussing treatment preferences more than nurses and care assistants. Care assistants found this topic difficult; they feel that they are not allowed to interfere in conversations about treatment preferences, which mostly occur with nurse practitioners, nurses, and physicians, and thus often only talk about what is important to the older person in the present and the future, and how the older person feels. In addition, nurse practitioners and care assistants typically engage in EOL conversations alone, while nurses sometimes also engage in formal EOL conversations with a physician. Furthermore, home care nurses typically engage in EOL conversations that look further into the future than those performed by nursing staff in hospitals and nursing homes, as the life expectancy of older people in the home care setting is generally longer than that in other settings. In addition, they placed more emphasis on taking the lead in offering additional interprofessional support.

> "It is not entirely clear what I am really allowed to do according to certain guidelines and protocols. It really is a gray area, I think. So, you are a bit more reserved in what you say and what you ask. You also do not want to say things that are not up to me." (Z2: nurse, hospital)

Involving colleagues

Nursing staff explained that they often are curious about the opinions of their colleagues. They want to know if their colleagues think they engaged in the conversation correctly, and they want to reflect on that conversation together. In addition, nursing staff indicated that they sometimes discuss the best approach to a conversation with their colleagues before they meet the older person, such as when resistance from the older person is expected. Moreover, they sometimes choose to engage in an EOL conversation together with a colleague if they expected the conversation to be difficult.

> "I do that [evaluate] more often with colleagues. It may be that I also have doubts sometimes, and then I evaluate with colleagues, like, 'Look, I had this conversation yesterday, I did this and that. What do you think?' Or I do it with the spiritual caregiver." (Z1: specialized nurse, nursing home)

Involving family caregivers

Although nursing staff felt that the older person should take the lead in an EOL conversation, most nursing staff also indicated that family caregivers should be involved. This is especially relevant in formal conversations, as informal conversations often do not involve family caregivers due to their spontaneous nature. Most nursing staff reported that they involve family caregivers in the conversation by asking for additional information (e.g., when the older person is unsure about the answer to a question), by asking for family caregivers' opinions and sometimes allowing family caregivers to vent or express concerns. However, nursing staff explained that the older person must be in the lead and have the final say in the conversation. They indicated that they support older people in having the final say by asking them questions directly.

On the other hand, conversations with family caregivers can be challenging. Some situations may arise in which family caregivers attempt to dominate the conversation, hold an opinion that conflicts with that of the older person, or disagree with other family members. Nursing staff indicated that they aim to minimize their involvement in family conflicts and prioritize the needs of the older person. In cases of disagreement among family members, nursing staff explained that they prefer to communicate exclusively with the primary contact person.

> "I think it is nicer to have the conversation with the family so that they are also aware of what the client wants. Because I think it is important that we are all on the same page. But if the client does not want that, or does not have a social network, we can also do it alone." (Z15: nurse, home care)

Discussion

According to the nursing staff involved in this study, the overall themes containing the fundamentals of EOL communication as part of ACP included preconditions such as feeling comfortable with talking about the EOL and creating space for open communication. The overall themes containing fundamentals related to the actual conversation (e.g., using one's senses and applying associative communication techniques, following the conversational phases, and being aware of interprofessional collaboration) are also important. This study builds on our previous scoping review, in which we identified several fundamentals of EOL communication.[10] The central finding of the scoping review was that building a trusting relationship helps nursing staff attune EOL communication to the values and needs of older people to approach the communication process in a person-centered manner.[10] The present interview study adds more fundamentals, such as the ability to communicate about the EOL, learning by doing, and using intuition, and adds more depth and a richer understanding of these fundamentals. For example, we described how nursing staff can best build a relationship with older people (step by step, and by moving along with them) and how they can attune EOL communication to the values and needs of older people. Moreover, this study elucidates the importance of interdisciplinary collaboration and role clarification; highlights the differences between formal and informal communication, reveals the differences in EOL communication between staff with different education levels working in different healthcare settings; and emphasizes the importance of moving along with, connecting with, and adapting to the older person. The central fundamentals in this study resemble the Nursing Fundamentals of Care Framework of Kitson.[18] This dynamic and multidimensional framework includes three dimensions in which nursing staff and patients work together: establishing a nurse–patient relationship, integrating the fundamentals of care into the patient's care plan, and ensuring that the setting or context in which

care is delivered and coordinated supports person-centered fundamentals of care.[18] This suggests that EOL communication relies its primary fundamentals on the basics of nursing care and is closely related to the professional identity of nursing staff.

All the findings and fundamentals indicate that EOL communication can best be symbolized as a dance in which a nursing staff member gently moves along with the older person, connecting and adapting to the older person's needs and preferences by using their senses and intuition. This dance with the older person is only possible when nursing staff and older people feel comfortable in the conversation and trust each other. Feeling this connection in the conversation and moving along according to each person's preferences is more important than striving for specific goals or structures, such as identifying treatment wishes or completing checklists. The same may be evident for listening. We found that nursing staff prioritize active listening and understanding what the older person says over anticipating the next question to maintain the conversation's flow. Thus, their focus is on the older person. This is in line with other studies.[19,20] Carl Rogers defined active listening as giving one's total and undivided attention to another person and as something that tells the other person that they are interested and concerned. One must listen not only with the ears but also the eyes, mind, heart, and imagination. One must listen to what is happening within oneself as well as what is taking place in the other person. One must listen to the words of the other person as well as the messages within the words.[21] When nursing staff continuously anticipate the next question in a conversation, active listening may no longer be possible.[22] In addition, thinking too much during the conversation, such as about overdue tasks or perceived stress during nursing staff's shifts, makes active listening difficult. Nursing staff may need to learn to let go of their need for control, goals, structures, and thoughts to participate effectively in EOL communication.

Relinquishing control requires sufficient experience and confidence with EOL communication, as some of our results suggest. Nursing staff with less experience in EOL communication indicated that prior knowledge of communication models and frameworks, knowledge of communication techniques, and thorough preparation for the conversation are key to a good EOL conversation. However, more experienced nursing staff stressed that moving along with the older person, feeling a connection with them, and using senses and intuition are more important for engaging in person-centered EOL communication than knowledge of models or frameworks and thorough preparation. Some nursing staff members even suggested that preparing for an EOL conversation can result in a narrowed perspective of the older person. These are in line with those of other studies. For example, in a recent interview study by Felber et al. ,[23] healthcare professionals, patient representatives, and family caregivers highlighted that preparing for the conversation and simultaneously remaining open to the unexpected is essential for communicating about the EOL.[23] They explained that although they felt it is important to come up with a potential agenda for the conversation in advance, it is imperative to remain flexible and to structure the conversation according to the situation of the patients and family caregivers.[23] Nursing staff's explicit need for sufficient knowledge of communication models and thorough preparation may vary. After gaining experience with EOL communication and feeling comfortable with EOL communication, these models may become less important.

Regarding some fundamentals, nursing staff expressed different styles and preferences. For example, some nursing staff members indicated that it is inappropriate to express their emotions during EOL conversations because this feels unprofessional. Other nursing staff members felt that showing emotion could add to the humanity and openness of the conversation and to connecting with the older person. Sinclair et al. identified showing emotion as an important element for healthcare professionals to show their compassion.[24, 25] They explained that a human-to-human connection is only facilitated through the mutual sharing of stories, feelings, and expressions between healthcare professionals and patients.[24] By contrast, Hayward and Tuckey (2011) and Stuart (2022) found that nursing staff regulate and sometimes suppress their emotions in EOL care to protect themselves from depleting their emotional and energetic reservoirs.[26,27] EOL communication is a personalized communication process in which the needs and preferences of older people and nursing staff differ.

Nursing staff members described some differences in the approach of both forms of EOL communication in the conversational phases. For example, informal conversations are typically initiated spontaneously, often in response to cues from the older person, and then developed from there. By contrast, formal conversations are usually scheduled in advance, begin with a defined introduction and goal, and then expand on the topic at hand. Furthermore, nurse practitioners placed more emphasis on discussing treatment preferences than nurses, typically during formal conversations, whereas care assistants often only discussed what is important to the older person and how they feel, typically during informal conversations. Previous research supports the finding that nursing staff often feel uncertain about their roles and responsibilities in EOL communication and emphasizes the importance of nursing staff and other healthcare professionals being aware of their roles and having a shared understanding and division of their roles and responsibilities.[5,28] This understanding could support interprofessional collaboration.[5,28]

Strengths and limitations

This study has several strengths. First, this study is the first to provide a rich understanding of the fundamentals of EOL communication as part of ACP from the perspectives of nursing staff with different education levels working in different healthcare settings. Second, this study builds on our previous scoping review, which helped guide the interviews. Third, an interprofessional working group was involved in all phases of the study, improving its reliability. This study also has several limitations. First, to gain an in-depth understanding of the fundamentals, we purposively selected nursing staff members who recently engaged in EOL communication. In addition, most of these nursing staff members mentioned that they were comfortable and particularly aware of how they engaged in EOL communication. We did not consider factors such as cultural diversity in the composition of the sample. Not including nursing staff who are less comfortable with engaging in EOL communication or who come from different cultural backgrounds may have led to selection bias, as they may have different opinions or experiences regarding the fundamentals.[29-31] Second, the perspectives of other stakeholders in EOL communication were not included in this study.

Future research

This study provides nursing staff with practical recommendations for EOL communication in clinical practice and suggests areas for future research. First, an additional interview study could explore the perspectives of older people, family caregivers, and other members of the interdisciplinary team. Second, further research should be conducted to validate the identified fundamentals, considering nursing staff members' varying personal preferences and levels of experience with EOL communication. Third, the results of this study should be translated to intervention development and nursing education to improve EOL communication in clinical practice.

Conclusions

This study provides a rich understanding of the fundamentals of EOL communication as part of ACP from the perspectives of nursing staff with different education levels working in different healthcare settings. It emphasizes the importance of moving along with the older person, connecting, adapting, and relinquishing control. Nursing staff have different styles and methodologies depending on their experience with EOL communication and personal preferences, and these differences should be considered within this approach. Many fundamentals can be traced back to the basics of nursing and the humanity of a conversation. Our results may facilitate future research, intervention development, and education in EOL communication.

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CRediT authorship contribution statement

Fran B.A.L. Peerboom: Writing – original draft, Visualization, Resources, Project administration, Methodology, Investigation, Formal analysis, Conceptualization. **Jolanda H.H.M. Friesen-Storms:** Writing – review & editing, Methodology, Investigation, Formal analysis, Conceptualization. **Jenny T. van der Steen:** Writing – review & editing, Methodology, Conceptualization. **Daisy J.A. Janssen:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Judith M.M. Meijers:** Writing – review & editing, Supervision, Methodology, Funding acquisition, Formal analysis, Conceptualization.

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