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“Gives peace of mind” – Relatives’ perspectives of end-of-life conversations

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Abstract

Objectives. Planning for end-of-life (EOL) and future treatment and care through advance care planning (ACP) is being increasingly implemented in different healthcare settings, and interest in ACP is growing. Several studies have emphasized the importance of relatives participating in conversations about wishes for EOL and being included in the process. Likewise, research has highlighted how relatives can be a valuable resource in an emergency setting. Although relatives have a significant role, few studies have investigated their perspectives of ACP and EOL conversations. This study explores relatives’ experiences of the benefits and disadvantages of having conversations about wishes for EOL treatment.

Methods. Semi-structured telephone interviews were held with 29 relatives who had participated in a conversation about EOL wishes with a patient and physician 2 years prior in a variety of Danish healthcare settings. The relatives were interviewed between September 2020 and June 2022. Content analysis was performed on the qualitative data.

Results. The interviews revealed two themes: “gives peace of mind” and “enables more openness and common understanding of EOL.” Relatives found that conversations about EOL could help assure that patients were heard and enhance their autonomy. These conversations relieved the relatives of responsibility by clarifying or confirming the patients’ wishes, and they also made the relatives reflect on their own wishes for EOL. Moreover, they helped patients and relatives address other issues regarding EOL and made wishes more visible across settings.

Significance of results. The results indicate that conducting conversations about wishes for EOL treatment and having relatives participate in those conversations were perceived as beneficial for both relatives and patients. Involving relatives in ACP should be prioritized by physicians and healthcare personnel when holding conversations about EOL.

Introduction

Advance care planning (ACP) refers to the process of discussing and making decisions about care and treatment at end-of-life (EOL) before patients lose their capacity to make those decisions (Fan et al. 2019). For individuals who are nearing EOL, ACP helps them define their goals and preferences for future medical treatment and care (Rietjens et al. 2017). It has been shown to improve the quality of life of patients, reduce unwanted hospital admissions, and increase the use of palliative care (Brinkmann-Stoppelenburg et al. 2014; Martin et al. 2016). Furthermore, ACP encourages individuals to discuss their wishes for future treatment and care with their relatives and healthcare providers so that their preferences can be taken into account if they eventually become unable to express them (Rietjens et al. 2017). However, other studies (Jiminez et al. 2018; Korfage et al. 2020) have not found the same evidence regarding the impact and effectiveness of ACP. Nevertheless, despite the contradicting findings ACP is being increasingly implemented in different healthcare settings, and interest in ACP is growing, as evidenced by the increase in laws and public awareness on the topic (Rietjens et al. 2017; Ziebell 2022).

In 2017, via a Delphi study with 109 international experts from several different countries from across the world, a consensus was reached. The experts defined ACP as “the ability enable individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with the family and health-care providers, and to record and review these preferences if appropriate” (Rietjens et al. 2017). The hope with this definition was to provide clarity of ACP and further benefit patients and their relatives by facilitating care to patients in accordance to their preferences and goals (Rietjens et al. 2017).

Usually ACP is incorporated during a conversation about EOL and different ACP tools for clarifying and documenting patients’ wishes have been implemented to various degrees around the world (Andreasen et al. 2019; Hawkes et al. 2020; Hickman et al. 2015). As described by

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Mack and Dosa (2020), The Physician Orders for Life Sustaining Treatment (POLST) paradigm is an effective ACP tool. The POLST form has been implemented in large parts of the U.S. healthcare system (Zive et al. 2019). The form is designed for seriously ill or medically frail patient and should be completed during a conversation between the patient and a healthcare professional and, when possible, a relative or nursing staff. The conversation is based on a process of shared decision-making whereby the patient shares his or her values and wishes for treatment at EOL, and the healthcare professional explains the patient's diagnosis, prognosis, and treatment alternatives including the benefits and burdens of life-sustaining treatment (Hickman et al. 2015; Mack and Dosa 2020).

The literature has described several barriers to initiating ACP conversations that healthcare personnel encounter. These barriers include concerns about causing distress for the patient or diminishing their hope, personal discomfort with talking about death and dying, a lack of experience with such conversations, and limited training in ACP (Myers et al. 2018). In addition, the patient and family could be considered a barrier if they have difficulty understanding or accepting the prognosis (Dias et al. 2023). Nevertheless, several studies have emphasized the benefits of involving relatives in the process (Bollig et al. 2016; Kastbom et al. 2019; Sharp et al. 2018; Tuesen et al. 2022a) and have especially highlighted how relatives can be a valuable resource in an emergency setting to ensure treatment is in accordance with the patient's values and preferences (Cullati et al. 2021; Escher et al. 2021). Furthermore, as shown by Bollig et al. (2016) most patients trust their relatives and the healthcare personnel to make decisions on their behalf, whereas in contrast, most relatives are insecure of the patient's wishes and find decision-making a burden. These findings emphasize the importance of including relatives in EOL conversations.

Despite several studies concluding that relatives are important in the ACP process, few researchers have investigated the perspectives of relatives regarding these conversations and the potential advantages or disadvantages of participating in them. Thus, the aim of this study is to examine relatives' experiences of the positive and negative aspects of participating in conversations about wishes for treatment at EOL.

Method

Study design

Semi-structured telephone interviews were held with 29 relatives who had previously participated in a conversation about wishes for treatment at EOL with a dying or frail relative (a patient or nursing home resident) and a physician based on and with completion of a Danish version of the POLST form. The time interval between the telephone interview and the conversation was 2 years. All telephone interviews were conducted between September 2020 and June 2022.

The 2-year follow-up period was planned based on the assumption that a fair part, but not all, of the patients would die during the period, which would give a nuanced picture of the conversation from both relatives, where the patient would still be alive and relatives, where the patient would be deceased.

Participants and data collection

From 2017 to 2020, a Danish POLST study (Tuesen et al. 2021, 2022b) was carried out to develop a Danish version of the American POLST form and test that form with Danish patients and nursing home residents (hereafter "the patient"). Like the American POLST form, the Danish version contained three topics the patient must decide on: (a) cardiopulmonary resuscitation (CPR), (b) level of medical interventions (full treatment, selected treatment, and palliation only), and (c) artificially administered nutrition (see Supplementary Material 1). Project sites included hospital wards, outpatient clinics, general practices, and nursing homes. Patients were eligible for inclusion in the study if their general practitioner or a hospital physician could respond "no" to the question of whether they, as a healthcare professional, would be surprised if the patient died from advanced disease, frailty, or old age within the next 6–12 months (known as "the Surprise Question") (van Lummel et al. 2022). The study included a total of 120 patients. Aided by the Danish POLST form, the physician and the patient engaged in a conversation about the patient's beliefs, values, diagnosis, prognosis, goals for care, and treatment options (Tuesen et al. 2021). During the conversation, the Danish POLST form was filled in and the wishes registered in the patient's medical records. When possible, a relative would participate in this conversation as well. In the Danish POLST study, the physicians were instructed by the research team to discuss the patients' values, beliefs, and goals before filling in the POLST form (Tuesen et al. 2021, 2022b) and the project material included a list of "helpful prompts and questions" (see Supplementary Material 2) to initiate, conduct, and conclude the conversation (Tuesen et al. 2021). No specific education in conducting the POLST conversations were offered to the healthcare professionals (Tuesen et al. 2021) and no follow-up conversation about wishes for treatment at EOL was scheduled (Tuesen et al. 2021, 2022b). However, follow-up conversations may have taken place outside the study at the wish of either the patient or a physician.

The participants in the current study were relatives who had taken part in those conversations. All relatives were selected by the patients at the time of the Danish POLST study. At the time of participation in the conversation, the relatives were also asked about being contacted 2 years after the conversation for the purpose of participation in an interview about their experiences in regard to the conversation.

All interviews were conducted by telephone by the first author; a female MD and PhD student with experience conducting interviews from prior research, courses on qualitative methods, and under supervision from a senior researcher with extensive experience in qualitative research. Before the interviews, all relatives agreed to be contacted received information sent by post (see Supplementary Material 3) about an upcoming telephone call regarding the interview and information about the project. Additionally, the letter contained contact information and the relatives had the opportunity to decline or ask questions before participating. If no refusal was communicated, the relative was contacted via a phone call to invite them for an interview. If they agreed to participate, the interview was either held during the same call or scheduled for a more convenient time for the relative. Relatives with signs of cognitive impairment or dementia were excluded from the interviews.

The interviews consisted of mostly open-ended questions with follow-up questions (see Supplementary Material 4) to probe the interviewee's responses. The interview guide was based on knowledge from the literature regarding patients' and physicians' experiences of the POLST conversation (Tuesen et al. 2022a) and POLST assessments tools (The POLST Quality and Research Toolkit (PQRsT), 2013). A key point of inquiry in the interview guide was the influence of the conversation on the relative and the patient. No pilot testing of the interview guide was conducted, but the guide was discussed and approved by the last author before initiating the interviews. Furthermore, the first two interviews were listened through and commented by the last author to ensure the quality of the interviews. During the interview period, questions were added continuously on the basis of new findings from the completed interviews. No repeat interviews were conducted. The interviews were digitally recorded and transcribed verbatim by an external professional party. No transcripts were returned to the participants for comment or correction. The data were stored in SharePoint and the Open Patient data Explorative Network (OPEN).

Data analysis

Content analysis was used to assess the data (Graneheim and Lundman 2004). The first and last author coded the data. Analysis of the transcripts took place in multiple phases (Kvale 1994) and the themes identified were derived from the data. In phase 1, the first author read the transcripts of the interviews, coded the units, identified meaning units, and delineated preliminary categories, themes, and sub-themes. In phase 2, the last author read and independently coded 10 of the interviews. The findings of the two authors were subsequently compared, discussed, and revised to ensure agreement on the codes, sub-categories, themes, and sub-themes. After summarizing the findings, the two authors reread all of the interview transcripts to confirm that no category was left out. Validation of the results entailed repeated reading of the interviews in order to question the findings from the interview transcripts as well as multiple discussions with the co-authors. Analysis and coding were supported by the computer program NVivo 2020 (Alfasoft).

Ethics

The project was registered with the Danish Data Protection Agency (Journal No. 20/25136). According to Danish legislation, the study did not require permission from the Regional Committees on Health Research Ethics. To ensure data security, a license agreement was obtained with OPEN (OP1202).

Written informed consent to be contacted 2 years after the POLST conversation was obtained from all participating relatives at the time of the POLST conversation. All relatives were informed of their right to end the interview at any time without reason or consequence. Relatives were also informed that they could decline to answer any question that they were not comfortable with.

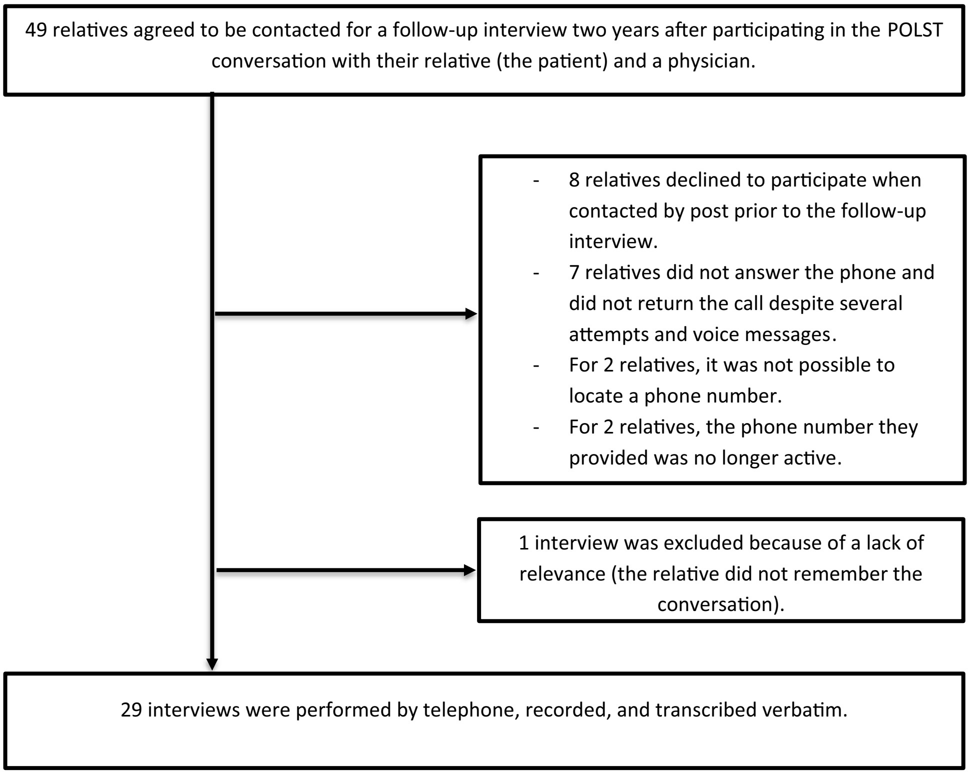
Results

A total of 49 relatives agreed to be contacted 2 years after the POLST study for research investigating their experience of the conversation and whether the patient's wishes were followed. Of these relatives, 29 (59%) participated in the telephone interview. Figure 1 presents the reasons for non-participation.

Table 1 shows the characteristics of the relatives and the sites where the POLST conversations were held (hospital department, general practice, or nursing home). The majority of the interviewed relatives were women, and most patients were included from a hospital setting.

In the 2-year period between the conversations and the interviews, 19 of the 29 patients had died. The duration of the interviews ranged from 7 to 34 min (mean = 16 min).

The analysis revealed two themes: "gives peace of mind" and "enables more openness and common understanding of EOL." In addition, "patient autonomy" and "relative's reflection on the



49 relatives agreed to be contacted for a follow-up interview two years after participating in the POLST conversation with their relative (the patient) and a physician.

- 8 relatives declined to participate when contacted by post prior to the follow-up interview.
- 7 relatives did not answer the phone and did not return the call despite several attempts and voice messages.
- For 2 relatives, it was not possible to locate a phone number.
- For 2 relatives, the phone number they provided was no longer active.

1 interview was excluded because of a lack of relevance (the relative did not remember the conversation).

29 interviews were performed by telephone, recorded, and transcribed verbatim.

Figure 1. Flow diagram of inclusion of the participants.

Table 1. Characteristics of the relatives and description of from which health care setting the patients were included

Characteristics	*N*, (%)
Female	19 (66)
Type of relative	
Partner	14 (48)
Sibling	2 (7)
Child	11 (38)
Nephew/niece	1 (3)
Brother/sister-in-law	1 (3)
Healthcare setting	
Hospital department	
Oncology	7 (24)
Hematology	3 (10)
Neurology	7 (24)
Geriatric	3 (10)
Medical	1 (3)
General practice	3 (10)
Nursing home	5 (17)
Patients died before the interview	19 (66)

Table 2. Themes, sub-themes, categories, and examples of codes

Theme	Sub-themes	Categories	Example of codes
Gives peace of mind	Enabling patients' autonomy	Patient autonomy Avoiding unwanted treatment and conflicts	Meaning for the patient Conflicts between patient and healthcare personnel Use of the form Conflicts in the family/between patient and family members
	Relatives reflections on the conversation	Possibility to disclaim responsibility Clarification and confirming silent understanding Self-reflection among relatives and patients	Knowing wishes beforehand Meaning for the relatives Reasons for participating in the project/conversation Need of the form Own experiences and their significance
Enabling more openness and common understanding of EOL		Preparing for EOL Visibility between health care settings When and who to conduct the conversation Why wanting the conversation	Practical measures in regard of EOL Understanding of disease/prognosis Information of family and relatives Visibility of wishes The significance of the physician

EOL = end-of-life.

conversation" were identified as two sub-themes under "gives peace of mind." Table 2 displays an overview of the codes, categories, themes, and sub-themes.

Gives peace of mind

Enabling patient autonomy

The majority (83%) of the relatives highlighted the importance of allowing the patient to decide what they wanted and wished for regarding treatment at EOL, which enhanced their autonomy. The relatives explained that this aspect was of great significance to most patients, and close to half of the relatives or patients had referred to the POLST form at a later time when encountering new physicians or healthcare personnel.

> But then she [the patient] came back and held the form and said, 'but this is the wish I have. I will not have any more [treatment]. I wish to die now. I don't want to live anymore because this existence is not worth living, and I have written it in this form, and you must respect me. You have to respect it, and that is how it is'. She used it a lot, that document. She had it [the form] present, and she used it. It was really good because it actually gave her peace – a lot of peace of mind. (I. 1)

The relatives felt that the conversations gave the patients the chance to be heard and explain their wishes, which helped them avoid unwanted treatment. In one conversation, the relative learned that the patient felt guilty about not wanting more treatment and was unsure if that decision was fair to their relatives, who wanted to keep them alive. Through this conversation, the patient's erroneous consideration of their family's feelings was revealed and resolved. Furthermore, the conversation helped the patient realize that their wishes were the most important.

A fifth of the relatives highlighted the difficulty of having different opinions within the family and the risk of conflict due to a lack of communication as well as disagreements amongst family members. Again, the conversation and documentation were seen as valuable tools to prevent later conflicts. Because matters had already been decided and recorded, no one could blame others for acting irresponsibly or in discrepancy with the patient's wishes.

> it's really good because then it is he [the patient] who decided. It wasn't me who should make any decisions. It wasn't me who had to take a stand – it was kind of himself (I. 13).

All relatives, who remembered the conversation (24 out of 29), referred to the conversation as a good experience, and none described it as distressing or disheartening for the patient or family members. Half of the relatives acknowledged having a sense of what was coming before meeting with the physician, and the conversation confirmed this feeling while also alleviating worries and helping the patients make their wishes for EOL clear to all relevant parties.

Relatives' reflections on the conversation

Three quarters found that the conversation gave them a feeling of security and assurance that they did not act against the will of the patient, which relieved them of feeling responsible for making decisions on behalf of the patient and possibly feeling guilty for making the wrong decision. Furthermore, they felt happy and safe knowing that they did not act against the patient's wishes, and if an emergency situation occurred, they would not have to decide how to proceed or what the patient might want, as that had already been discussed and decided:

> It's an important thing, and it gives you peace of mind too. When a situation occurs, you know exactly what she [the patient] wants and doesn't want, so I think that's important (I. 25).

Three of the relatives explicitly mentioned a change in perceived quality of life as the patient aged. They admitted to accepting levels of disability and inactivity in the patient which, earlier in the process, they would have regarded as indicative of reduced or even lack of quality of life. This change in perceptions of quality of life affected the relatives' opinions about continuing treatment in the hope of keeping the patient alive longer.

The relatives expressed insecurity about acting in accordance with the patient's wishes in an acute situation if they would be asked what they thought the patients would want. Here as well, the conversation and the POLST form were regarded as important tools to avoid acting on their own needs instead of in line with the patient's wishes.

One third of the relatives emphasized that they felt better equipped to help in situations where the patient felt sad or insecure about the future. After the conversation, they felt able to be more actively supportive rather than merely listening to the patient's concerns. If the patient became uneasy about whether matters were under control, the relative could refer to the conversation and reassure the patient that their wishes had already been discussed and documented.

More than two thirds of the relatives confirmed that they had already known the wishes of their loved one and were therefore not surprised by their preferences during the conversation with the physician. However, not all of the interviewees had discussed EOL with their relatives beforehand, and their knowledge of the patient's wishes derived more from a silent understanding of the patient's way of living or attitude toward other aspects of life.

> …knew and knew… I guessed she had the same opinion as me, which she had… (I. 7)

Regardless of whether the relative or patient had discussed EOL before the POLST conversation, the majority agreed that specifying and documenting the patient's wishes was of great importance. Furthermore, the conversation fostered a common understanding between the relative and patient regarding EOL and the prognosis. For 12 relatives, it also prompted the relative to reflect on and share their own wishes.

Enabling more openness and common understanding of EOL

According to most of the relatives asked (15), the conversation initiated a talk about not only treatment but also other EOL-related matters by extension, including practicalities such as the funeral, finances and living conditions for survivors, and inheritances. Thus, the conversation incentivized the patient to be more open and reflective about their wishes for practical matters as well, which most relatives regarded as equally important.

> Yes, I believe that it (having the conversation) helped open up about the disease and the entire process, yes. (I. 17)

Moreover, the conversation and the POLST form increased awareness of patients nearing EOL and their wishes between healthcare settings, and it simplified the expression of their wishes and discussions of EOL when changing healthcare sectors. However, three relatives also expressed frustrations about the incompatibility of different patient record systems between healthcare settings and the need for the patient themself to draw attention to the form and the documented wishes.

When the relatives were asked if they thought the conversation about EOL was relevant and should be implemented in the Danish healthcare system, most (73%) agreed that it would be beneficial to all parties involved. The relatives believed that the topic was generally difficult to talk about for most people. They also considered it difficult to make reasonable decisions regarding treatment, especially in emergency situations, where they perceived a higher risk of making a decision that conflicted with the wishes of the patient. Therefore, the relatives emphasized the importance of conducting the conversation during a stable period for the patient:

> Yes. I think that it [the conversation] would make things a lot easier for a lot of people and remove many quarrels. That's what I think – because it is often the uncertainty that makes people fall out. I think it would be good having a form like that. It is not everybody who gets to talk about it. (I. 6)

When asked specifically *when* the conversation about EOL should take place, the relatives' answers were more vague and inconsistent. Of the interviewees asked, most (10 relatives) acknowledged sickness, frailty, and age as important factors, and some mentioned an increasing need for help with running the home, moving to a nursing home, or being diagnosed with a fatal disease as events that could prompt the conversation about EOL. However, there was no consensus regarding a specific time at which to initiate the conversation. Four relatives mentioned being young, healthy, or both was a barrier to the conversation and made talking about and deciding these matters a challenging or even impossible task.

Ten of the interviewees also stressed the importance of having a physician conduct the conversation. In most cases, the relatives felt the physician was able to ask questions they were not capable of because of their status as relatives. Furthermore, the physician could inform the patient about treatment options, assess what would be most meaningful for the patient, and guide them through the best care under the given circumstances, as well as having the patient felt heard and understood.

> I can only recommend that there is a physician present (…) who, without influencing the patient's final decision, can give them advice in one way or another, objectively and neutrally. (I. 20)

Discussion

Having a relative participate in the conversation about wishes for treatment at EOL is perceived as beneficial to both the patient and the relative. From this conversation, the relative can better understand the patient's wishes and ensure that those wishes are followed in situations where the patient is not capable of expressing them. The conversation can also relieve the relative of the responsibility to make decisions that they are not sure are in accordance with their loved one's wishes. Additionally, the conversation can make way for discussions and planning of other issues regarding EOL. All relatives referred to the conversation as a good experience, and none described it as distressing or disheartening, which is a reported barrier to initiating ACP for healthcare personnel (Myers et al. 2018).

In a previous study, Kastbom et al. (2020) interviewed family members of nursing home residents and found that most of the relatives had a silent understanding of the patient's wishes regarding EOL and dying. Those wishes had not been explicitly or implicitly communicated but could be deduced from the patient's life, experiences, and values (Kastbom et al. 2020). This finding is in accordance with the current study, as several interviewees admitted that they had not talked with the patient about their wishes beforehand, but they were not surprised by those wishes during the conversation about EOL treatment because they intuitively understood based on the same knowledge described by Kastbom et al. (2020). Still, they all agreed that it was useful to have the conversation and record the wishes explicitly on the form. Such documentation may also prevent relatives from demanding treatment that contradicts the patient's wishes, and it can help remove uncertainty in decision-making on behalf of the patient. These points were expressed by the interviewees in the current study and have been reported by Bollig et al. (2016).

Furthermore, our results showed that the relatives found the conversation valuable in regard to talking about other important matters relating to EOL. This finding is supported by the study by Pollock et al. (2022), who found that ACP conversations could provide an opportunity for a dialogue between the patients and their relatives and help them make decisions for the future.

Most relatives found that the physician made the patient feel heard and understood. They did not emphasize a specific setting – just that it was important for a physician to be present to ask questions, explain options, and give advice regarding treatment. This finding is in line with the research of Heyland et al. (2017), who have determined that the main source of decisional conflict between a patient's values and treatment preferences was a lack of knowledge of the risks, benefits, and alternatives of different treatment options. To avoid this discordance in values and wishes for treatment, patients need help clarifying their underlying values and understanding that the rejection of certain treatment options may be necessary to comply with their values (e.g., quality of life may require sacrificing prolongation of life) (Heyland et al. 2017).

In the research by Tuesen et al. (2021, 2022b), patients were included based on "the Surprise Question," "Would I (a healthcare professional) be surprised if this patient died within the next 12 months?" (van Lummel et al. 2022). As seen in Table 1, 66% of the patients died within a 2-year period, which proves how difficult it is to estimate life expectancy and determine when to conduct the conversation. In this study, we also found that it was difficult to assess the appropriate time to have the conversation about EOL and prepare for death. Fan et al. (2019) have reported that older but healthy adults at a long-term care institution struggled to imagine themselves dying or with a terminal illness, and they consequently found it difficult to think about ACP-related issues and decision-making. This finding supports those of the present study, as most relatives could not easily specify one appropriate time for the ACP conversation, but they mostly agreed that it would be difficult to have that conversation when a person was still young and healthy. The interviewees identified a greater need for help, the onset of a severe disease, and increased frailty and age as important factors in deciding when to have the conversation about EOL, but no standard or fixed time was suggested. However, studies have shown that ACP conversations were initiated significantly later than would be considered optimal (Tros et al. 2022), and patients wished that the conversation had taken place earlier in the process (Kubi et al. 2020). Zwakman et al. (2021) have found that the patient's readiness to talk about EOL can alternate during an ACP conversation, and patients do not need to be ready to talk about all ACP topics when initiating the conversation. Instead of postponing the ACP conversation, it can be modified to suit the needs of the patient at that specific moment (Zwakman et al. 2021) and then resumed another day to cover the topics that have not yet been addressed.

Strengths and limitations

The strengths of this study include the number of interviewees, the diverse representation of relatives in terms of gender and relationship to the patient, and the involvement of different healthcare settings (primary care, nursing homes, and hospital departments). Together, these elements support a nuanced view of the conversation about EOL that conveys its importance independently of the setting or relationship. As an additional strength, the study's findings were validated by two authors, one of whom is highly experienced in qualitative research.

Nevertheless, the results could be influenced by information bias, as relatives who were more positive, had prior experience with illness and death, or even worked within the healthcare system themselves may have been more likely to agree to participate in the interviews. Meanwhile, those who declined to participate might have felt less positive about the EOL conversation and ACP or perhaps lacked the strength to talk about the issue if their loved one was deceased.

During the study by Tuesen et al. (2021, 2022b), the physicians were instructed to discuss the patients' values, beliefs, and goals before filling in the POLST form. However, apart from a list of questions to help initiate the conversation, no education in EOL conversations or conversation script was provided for the physicians. As the conversations were not observed, the quality and structure of the conversations are unknown but probably varied. This may also have influenced the experience of the relatives.

The timeline for the study can be seen as both a strength and a limitation. The interviews were conducted 2 years after the POLST study, which gave the relatives time to reflect on and experience the use of the POLST form (e.g., at a hospital admission or death). At the same time, some relatives admitted that they had forgotten the contents of the conversation, which implies that for some, the 2-year follow-up period could be too long, and important information may have been lost. It is shown that people best remember the things that are distinctive and most meaningful to them personally (Wells 2017), and as dying and death for most will be distinctive experiences, the topic of the interviews may reduce the risk of recall biases. Another response bias may be due to relatives wanting to protect the memory of their loved one's dying and death and therefore mainly focus on the positive aspects (Sinding 2003).

Conclusion

Having relatives participate in the conversation about wishes for treatment at EOL is perceived as beneficial to both patients and relatives. Such participation allows the relative to ensure that their loved one's wishes are respected, and it relieves the relative of a feeling of responsibility and doubt regarding decision-making on the patient's behalf. Moreover, the conversation can help the relative better understand the patient's diagnosis and prognosis, and it seems to facilitate the discussion of other issues regarding EOL that can further prepare the patient and family for EOL and death. When conducting conversations about

EOL, physicians and healthcare personnel should be aware of these benefits and prioritize the inclusion of relatives in ACP conversations.

While the appropriate time or place to conduct the conversation could not be specified, it seems to be an individual matter that depends both on the patients' condition and readiness for the conversation as well as the physician conducting the conversation. Holding the conversation in due time before an emergency situation is considered crucial to effectively make patient-centered decisions. Still, more studies should address the timing and setting of the conversation.

Supplementary material. The supplementary material for this article can be found at https://doi.org/10.1017/S1478951523001633.

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