

Original Article

Cite this article: Boström K, Dojan T, Rosendahl C, Gehrke L, Voltz R, Kremeike K (2024) How do trained palliative care providers experience open desire to die-conversations? An explorative thematic analysis. *Palliative and Supportive Care* 22(4), 681–689. <https://doi.org/10.1017/S1478951522001006>

Received: 9 March 2022

Revised: 13 June 2022

Accepted: 12 July 2022



Key words:

Communication training; Desire to die; Health professional perspective; Suicidality; Thematic analysis

Author for correspondence:

Kathleen Boström,
Department of Palliative Medicine,
University of Cologne,
Faculty of Medicine and University
Hospital, Kerpener Street 62,
50937 Cologne, Germany.
E-mail: kathleen.bostroem@uk-koeln.de

How do trained palliative care providers experience open desire to die-conversations? An explorative thematic analysis

Kathleen Boström, M.S.C.¹ , Thomas Dojan, M.S.C., B.A.¹, Carolin Rosendahl, M.S.C.¹, Leonie Gehrke, M.A.¹, Raymond Voltz, M.D.^{1,2,3,4} and Kerstin Kremeike, Ph.D.¹ 

¹Faculty of Medicine and University Hospital, Department of Palliative Medicine, University of Cologne, Cologne, Germany; ²Faculty of Medicine and University Hospital, Center for Integrated Oncology Aachen Bonn Cologne Duesseldorf (CIO ABCD), University of Cologne, Cologne, Germany; ³Faculty of Medicine and University Hospital, Clinical Trials Center (ZKS), University of Cologne, Cologne, Germany and ⁴Faculty of Medicine and University Hospital, Center for Health Services Research, University of Cologne, Cologne, Germany

Abstract

Objectives. Despite the potential benefits of open communication about possible desires to die for patients receiving palliative care, health professionals tend to avoid such conversations and often interpret desires to die as requests for medical aid in dying. After implementing trainings to foster an open, proactive approach toward desire to die, we requested trained health professionals to lead and document desire to die-conversations with their patients. In this article, we explore how trained health professionals experience an open (proactive) approach to desire to die-conversations with their patients.

Methods. Between April 2018 and March 2020, health professionals recorded their conversation-experiences on documentation sheets by answering seven open questions. A subsample was invited to offer deeper insights through semi-structured qualitative interviews. Interviews and documentation sheets were transcribed verbatim and analyzed thematically, then findings from both sources were compared and synthesized.

Results. Overall, $N = 29$ trained health professionals documented $N = 81$ open desire to die-conversations. A subsample of $n = 13$ health professionals participated in qualitative interviews. Desire to die-conversations after the training were reported as a complex but overall enriching experience, illustrated in seven themes: (1) beneficial (e.g., establishing good rapport) and (2) hindering aspects (e.g., patients' emotional barriers) of desire to die-conversations, (3) follow-up measures, (4) ways of addressing desire to die, as well as (5) patient reactions to it. The interviews offered space for health professionals to talk about (6) content of desire to die-conversation and (7) (self-)reflection (e.g., on patients' biographies or own performance).

Significance of results. As part of an open (proactive) approach, desire to die-conversations hold potential for health professionals' (self-)reflection and a deeper understanding of patient background and needs. They may lead to a strengthened health professional–patient relationship and potentially prevent suicide.

Introduction

Confronted with approaching death due to serious, life-limiting disease or geriatric multimorbidity, patients frequently express a desire to die (Monforte-Royo et al., 2012; Bellido-Pérez et al., 2018; Bornet et al., 2020; Briggs et al., 2021). Recent public discussions tend to see these desires to die only through the narrow lens of (ethically) adequate reactions toward requests for medical aid in dying (MAiD) (Wright et al., 2017). In contrast, we propose a more open approach toward desire to die in palliative care which can take on various forms and is not limited to requesting MAiD (German Guideline Programme in Oncology, 2020). Our broad definition conceptualizes a desire to die as an idiosyncratic and dynamic phenomenon on a continuum of increasing suicidal pressure to act (German Guideline Programme in Oncology, 2020; Kremeike et al., 2021a), including the wish to hasten death (WTHD) and requests for MAiD as only a few of various possible forms of desire to die (Balaguer et al., 2016). While some patients receiving palliative care merely express their acceptance of death or tiredness of life without a WTHD, some harbor latent wishes to die in case of worsening symptoms and only a few may develop acute suicidality (German Guideline Programme in Oncology, 2020; Kremeike et al., 2021a). Our open approach thereby corresponds to other international efforts to re-conceptualize dealing with desire to die or administering MAiD as a “relational care process that occurs over time” (Wright et al., 2017, p. 61). We designed a semi-structured clinical approach for communicatively dealing with desire to die on which we based a training to increase health professionals' self-confidence and capability (Frerich et al., 2020; Kremeike et al., 2020; Voltz et al., 2021).

© The Author(s), 2022. Published by Cambridge University Press. This is an Open Access article, distributed under the terms of the Creative Commons Attribution licence (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted re-use, distribution and reproduction, provided the original article is properly cited.

When it comes to communication about desire to die, a too narrow view among health professionals contributes to widespread insecurity or even reluctance to initiate conversations with patients (Fujioka *et al.*, 2019; Baile *et al.*, 2000). This uncertainty extends to dealing with situations in which patients themselves express a desire to die (Galushko *et al.*, 2016; Kremeike *et al.*, 2021b). There is a long-standing opinion that taboos surrounding the topic of death and dying are still predominant in society, e.g., among health professionals working in curative and palliative care (Wildfeuer *et al.*, 2015; Baile *et al.*, 2000). However, a differing sociological opinion argues that the “death denial” within society is decreasing (Wildfeuer *et al.*, 2015). Potential taboos can come from a widespread misbelief that addressing a desire to die might cause or increase it, which may trigger health professionals to act defensively (Hvidt *et al.*, 2017). A lack of training in communication about desire to die and the fear of being emotionally overwhelmed by such a conversation may lead to an avoidance of the topic altogether (Lenherr *et al.*, 2012; Galushko *et al.*, 2016) — even though patients explicitly wish for their health professionals to address these issues proactively (An *et al.*, 2017; Crespo *et al.*, 2021).

Suicidality research shows evidence for the appropriateness of universal screening for suicidality: a recent meta-analysis of 13 prospective studies clearly stated that it does not pose an iatrogenic risk for patients (DeCou and Schumann, 2018). These findings are recently generalized to the proactive assessment of desire to die in patients receiving palliative care. In a pioneering study, 193 oncological patients were asked upon hospital admission about possible desire to die in form of a short, semi-structured interview. The vast majority of participants did not find it upsetting (94.8%) and deemed it important to talk about these issues (79.3%) (Porta-Sales *et al.*, 2019). Moreover, current evidence we previously published elsewhere suggests a decrease in symptom burden such as depressiveness: in 85 patients with various diagnoses requiring palliative care, moderate to severe depressiveness decreased significantly after an open conversation about desire to die with their health professionals (Voltz *et al.*, 2021).

While effects of desire to die-conversations on patients are increasingly researched, we want to focus on the health professionals’ experience of these conversations: What are the concrete contents of related conversations and what are beneficial or hindering aspects? What do health professionals think of their own role and performance? How do they address desire to die and how do they experience patients’ reaction to it?

In this article, we aim to explore how trained palliative care providers implement and experience conversations about desire to die using an open (proactive) approach (Kremeike *et al.*, 2020).

Methods

Procedure

As part of a larger sequential mixed methods study, health professionals from all palliative care settings were invited to participate in multi-professional trainings (Frerich *et al.*, 2020; Kremeike *et al.*, 2018, 2020). The trained health professionals then selected patients from their palliative care practice to hold a single desire to die-conversation with these patients following our semi-structured clinical approach (Kremeike *et al.*, 2020; Voltz *et al.*, 2021). The clinical approach encourages open desire to die-conversations and can be adapted to the health professionals’ personal communication style. A corresponding booklet was distributed among all trained health professionals for support in planning the conversation (available for reference as a supplement in Kremeike *et al.* (2020)). In the course of this study procedure, qualitative data presented in this article was gathered in two ways:

Health professionals documented their experience of these conversations on desire to die on a documentation sheet with seven open questions (A; see Supplementary material 1). The documentation sheets were explained to them during training, then provided digitally. Health professionals sent back their completed documentation sheets to the research team via fax. A subset of these health professionals was invited to participate in individual semi-structured qualitative interviews (B; see Supplementary material 2). Therewith, the experience of talking about desire to die was explored in more depth. Interviews were conducted by all female members of the research team (KK, CR, LG, and KB) who either held a Master’s (CR, LG, and KB) or doctoral degree (KK) and all underwent interview training. For an overview of the procedure, see Figure 1.

This study was approved by the Ethics Committee of the University Hospital Cologne (Nr. 17-265) and is registered in the German Clinical Trials Register (DRKS00012988). Research was conducted in accordance with the Declaration of Helsinki.

Recruitment

For initial study participation, we recruited a convenience sample of health professionals from all palliative care settings (for details

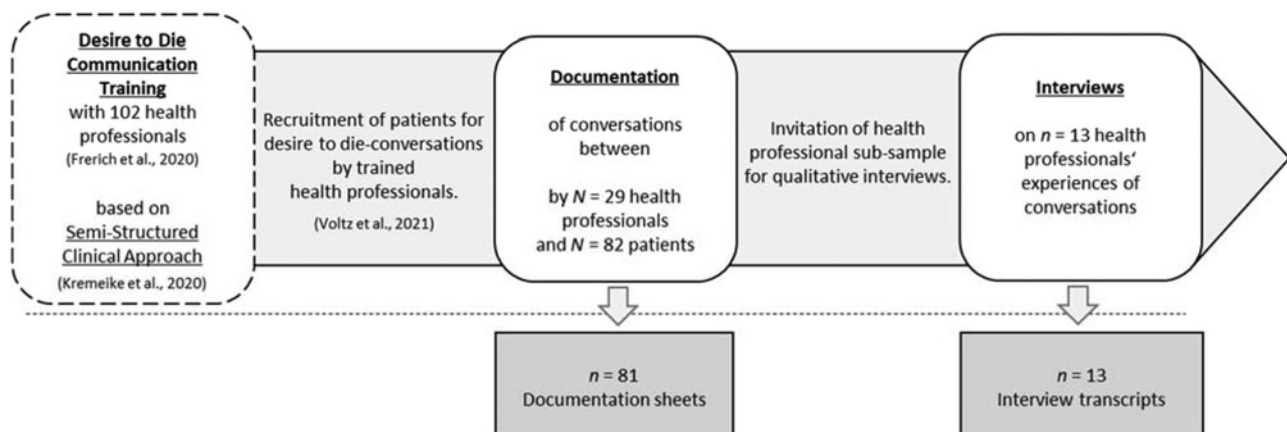


Fig. 1. Study procedure.

on recruitment, refer to Voltz et al. (2021)). For participation in a qualitative interview, an interested subsample of these health professionals was invited, again via convenience sampling. Before study participation, health professionals gave written informed consent for the evaluation of the training course and later, if applicable, for participating in qualitative interviews about their experiences of desire to die-conversations. Due to our sampling strategy, available qualitative data was analyzed after study completion, using an explorative approach without aiming at data saturation. This is common when doing research with palliative patients, as the characteristic frailty as well as drop-out by death of this group of patients runs counter to theoretical sampling approaches (Aktas and Walsh, 2011).

Data collection and analysis

(A) Collection and analysis of desire to die-conversation documentation sheets

Trained health professionals had a desire to die-conversation according to our clinical approach with their selected patients and completed a documentation sheet at their place of work, including the following points of interest:

1. Key data
 - a. Duration of the conversation
 - b. Setting
 - c. Presence or absence of desire to die in the patient
 - d. Proactive (by health professional) or reactive (by patient) addressing desire to die
2. Content
 - a. Type and function of desire to die
 - b. Further (clinical) measures agreed upon
3. Atmosphere of conversation
4. Perception of one's own performance

Content and wording of the documentation sheet was set to fit our semi-structured clinical approach (Kremeike et al., 2020). Therefore, we analyzed the documentation sheets following a concept-driven (deductive) approach (Kuckartz, 2019). During this initial summarizing and structuring analysis, the categories of the clinical approach were used for the construction of main themes.

(B) Collection and analysis of qualitative interview data

A subset of health professionals participated in individual semi-structured interviews where they were asked about their experience of the desire to die-conversation during study participation and in general. Interviews were recorded and transcribed verbatim. To explore beyond the concept-driven findings from the documentation sheets, interview passages were inductively coded using thematic analysis (Braun and Clarke, 2006).

(A and B) Synthesizing data analysis from both sources

Results from documentation sheets and interviews with health professionals were analyzed separately, then themes were compared and synthesized when there was an overlap. Initial coding was done by KB and discussed between three researchers (KB, KK, and TD), initiating ongoing adjustments and consecutive coding until consensus was reached (Campbell et al., 2013). All qualitative data was analyzed using MAXQDA 20 (VERBI

Software, 2019). Coding and explanation of themes was done following quality criteria for thematic analysis (Steinke, 2000).

Results

Sample

Between April 2018 and March 2020, $n = 29$ from the original 102 trained health professionals (28.4%) completed $N = 81$ documentation sheets of desire to die-conversations with their patients. The health professionals were $M = 46$ years of age ($SD = 9.7$), with 26 women and 3 men. Afterward, $n = 13$ interviews were conducted for qualitative evaluation. Health professionals participating in the interviews were 10 women and 3 men. For details on the sample, see Table 1.

The documented desire to die-conversations lasted on average 44 min ($SD = 21.2$). They took place at the patients' home (24/81, 29.6%), palliative care wards (23/81, 28.4%), nursing homes (14/81, 17.3%), hospices (10/81, 12.3%), or elsewhere (10/81, 12.3%; such as via phone, at a walk, or in the hospital cafeteria). The 13 interviews had a mean duration of 41 min ($SD = 20.4$) and took place at health professionals' place of work.

Overview of all themes identified in documentation sheets (A) and qualitative interviews (B) on desire to die-conversations

Overall, seven themes with 29 subthemes were found within the documentation sheets (A) and the qualitative interviews (B). While three shared themes became present in data from documentation sheets as well as the interviews (A and B: "Beneficial Aspects," "Hindering Aspects," and "Follow-Up Measures," see Table 2), two themes were unique to documentation sheets (A: "Ways of Addressing Desire to Die" and "Patients' Reactions to Addressing Desire to Die," see Table 3) and interview data each (B: "Content of Desire to Die-Conversations" and "(Self-)Reflection," see Table 4). For all seven themes and their occurrence within the two data sources, see Figure 2. Given the explorative nature of our study, themes and categories are not meant to be conclusive, but to provide a descriptive account of the data gathered by our convenience sample of health professionals.

Beneficial and hindering aspects of conversations and follow-up measures (themes from A and B)

Regarding beneficial and hindering aspects of their desire to die-conversations, health professionals reported similar aspects both on the documentation sheets (A) as well as within the interviews (B). Leading desire to die-conversations following an open approach was mainly seen as a positive experience by trained health professionals: They reported *beneficial aspects* such as feeling rewarded when they felt an improvement for their patients, e.g., by activating their resources or being able to address their previously unmet communication needs. Patients were reported as being open and showing willingness to cooperate which was deemed a prerequisite for a rewarding conversation. Consequently, health professionals valued a strong relationship with their patients which was sometimes strengthened by talking about desire to die. Some health professionals reported their own self-competence increasing through positive conversation experiences (see Table 2, themes 1.1–1.3 and related quotes).

Table 1. Characteristics of health professionals providing documentation sheets on desire to die-conversations

Characteristic	N (%)		n (%)	
	Sample	29 (100)	Subsample (Interviews)	13 (100)
Profession	Nurses	11 (37.9)	Nurses	2 (15.4)
	Specialist physicians	6 (20.7)	Specialist physicians	2 (15.4)
	Senior physicians	4 (13.8)	Senior physicians	2 (15.4)
	General practitioner	1 (3.4)	General practitioner	1 (7.7)
	Psychologists	2 (6.9)	Psychologists	2 (15.4)
	Social workers	2 (6.9)	Social workers	2 (15.4)
	Others	3 (10.3)	Others	2 (15.4)
All confrontations with desire to die	Never	3 (10.3)	Never	2 (15.4)
	1–3 cases	6 (20.7)	1–3 cases	2 (15.4)
	4–10 cases	2(6.9)	4–10 cases	0 (0.0)
	>10 cases	16 (55.2)	>10 cases	8 (61.5)
	No response	2 (6.9)	No response	1 (7.7)
Experience with desire to die/palliative care ^a	M = 11.6	years	M = 11.0	years
	SD = 10.3		SD = 10.3	

^aVia question: "How many years of experience do you have with desire to die/ palliative care?".

Health professionals reported *hindering aspects* as well which were more present in the documentation sheets than in the interviews: patients who are dismissive or very emotional were reported as demanding. Health professionals themselves sometimes struggled with their own issues regarding the topic, e.g., fearing to be too pushy or insensitive (see Table 2, themes 2.1–2.2 and related quotes).

Within the interviews, health professionals reported in more detail upon what they discussed with their patients regarding *follow-up measures* for the time after the desire to die-conversation. These mainly included facilitating the desired care for the patient, e.g., in a hospice or through a home service. When desire to die-conversations revealed unmet needs or wishes, health professionals informed their patients about or initiated further support and therapeutic measures. This occasionally included starting a process to fulfill a patient's last wish. Most

health professionals used the desire to die-conversation as a starting point for a deepened contact with the patient through further conversations (see Table 2, themes 3.1–3.5 and related quotes).

Ways of addressing desire to die and patients' reactions to it (themes from A: documentation sheets)

For analysis of the theme *Ways of addressing desire to die* from the open-ended questions on the documentation sheet, we deductively applied the categorization for addressing desire to die from our semi-structured clinical approach (Kremeike et al., 2020). These categories present six ways of asking a patient about potential desire to die derived from a Delphi survey with experts conducted previously in our study and published in Kremeike et al. (2020). Health professionals used all six ways of raising the issue of desire to die with their patients. The variety of their phrasings illustrate the

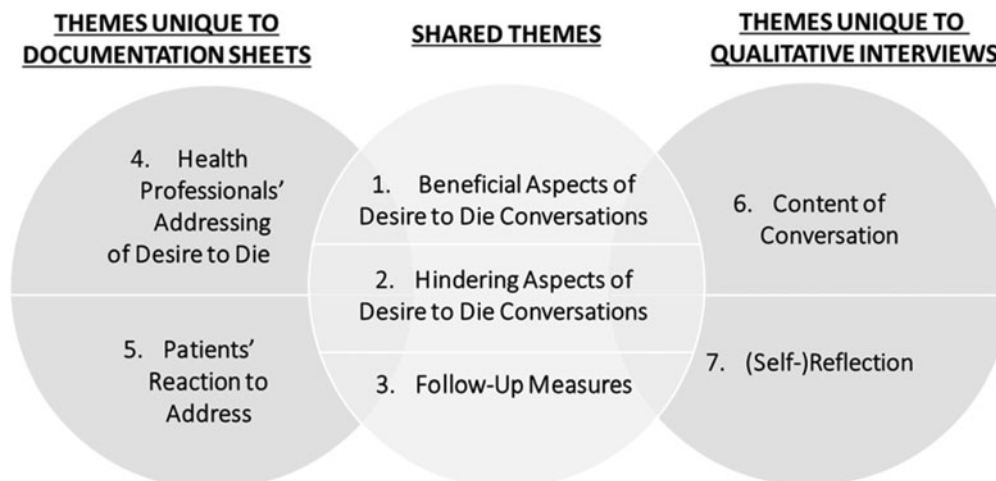


Fig. 2. All themes from both data sources, the documentation sheets and the interviews.

Table 2. Shared themes, their subthemes and exemplary quotes extracted from documentation sheets of desire to die-conversations and qualitative interviews

Themes	Exemplary Quotes
1. Beneficial Aspects during Conversations on Desire to Die	
1.1. Patient Attributes and Resources	<p>“Topics could be discussed openly and without ‘psychological barriers’ in a ‘relaxed’ atmosphere.” (tn87k10, DS*)</p> <p>“The patient is very positive despite her serious illness. She says, she just lets everything happen and that she feels well cared for here.” (tn05k1, DS)</p> <p>“The patient has a stable family network that gives him strength and support.” (tn45k5, DS)</p>
1.2. Perceived Benefit for the Patient	<p>“I felt that the patient experienced the conversation as relieving, since she said to me that she hasn’t been able to talk to someone about it before.” (tn40k4, DS)</p> <p>“During the conversation, the patient revealed that her husband and her brother had committed suicide. For her, it was clear that suicide was only a last resort because it makes her cry to this day every time she thinks about it.” (tn59k6, DS)</p>
1.3 Health Professional Attributes	<p>“So, I find that it is a building block of trust, which also affects me, right. So it is really an additional building block of the doctor-patient relationship if you address [the desire to die].” (tn47k5, QI*)</p> <p>“Well it has, I would almost say – it calmed me down a bit too. I was able to differentiate a bit. I could let things stand as they are. (...) Or, to put it differently: I have found my composure.” (tn53k5, QI)</p>
2. Hindering Aspects during Conversation on Desire to Die	
2.1 Actively/deliberately shaping the course of conversation	<p>“(…)[She] had somewhat dismissed [her desire to die] (...). Maybe we could have gone deeper, but I didn’t think it was appropriate at that moment. It just didn’t fit. That would have seemed too forced to me.” (tn61k6, QI)</p> <p>“The presence of her husband was problematic because she did not want to talk openly in front of him.” (tn40k4, DS)</p>
2.3 Containing Patient Emotions and Concerns regarding Death	<p>“Only a few sentences into the conversation after some questions concerning her general health, the patient started crying, since she is currently under a lot of psychological stress.” (tn40k4, DS)</p> <p>“[The] patient always came back to the thought <How can I endure this pain?> and that she did not want to die as miserably as her husband did.” (tn45k5, DS)</p>
3. Follow-Up Measures	
3.1. Institutional Care	<p>“To feel safer, she wishes to advance her care plan: e.g., organize a care home or hospice care for later.” (tn38k4, DS)</p>
3.2. Care at Home	<p>“I initiated continuing home care through a palliative care team and a team of medical professionals. He decided for home care with a specialized palliative care team.” (tn63k6, DS)</p>
3.3. Follow-Up Conversations	<p>“Every morning, I offer her a cigarette and a talk. She comes daily and tells me about her day. Her best friend is involved in the process to make it easier for her.” (tn49k7, DS)</p>
3.4 Informing about and Initiating Therapeutic Measures	<p>“I explained the legal situation to the patient. For me, it was the first time to do that.” (tn53k5, DS)</p> <p>“So, the first conversation was more like: Okay, what do we do now? I then suggested palliative care to her. (...) So, what are the possibilities? What alternatives to spend your last time are there when the end approaches? (...).” (tn07k1, QI)</p> <p>“Even with psychotherapy and other support options, it was actually very difficult (...); but after six months, she managed to fulfill her last wish. She went to a circus and some kind of play together with her son and grandchildren (...).” (tn38k4, QI)</p>

DS= documentation sheet; QI=, qualitative interview.

variety of their approaches. Some ask more directly about thoughts of not wanting to live anymore while others ask less direct questions, e.g., about wishes, thoughts, and fears regarding the nearing end of life (see Table 3, themes 4.1–4.6 and related quotes).

Correspondingly, *patient reactions to raising the issue of desire to die* were reported as predominantly open, with some confirmations of possible desire to die. Many patients were described to have an emphatic focus on their will to live, while few showed emotional or negative reactions (see Table 3, themes 5.1–5.6 and related quotes).

Content and reflection of desire to die-conversations and beyond (themes from B: interviews)

Findings from the thematic analysis of the qualitative interviews on desire to die-conversations supported and expanded what health professionals had already reported on the documentation sheets. Themes corresponded largely to survey categories, though go beyond that in significant ways. This becomes evident in the two categories, *content of conversation* and *(self-)reflection*. Health professionals used the interviews to talk in depth about how desire to die-conversations could serve to address and explore desire to die. However, these conversations were also

experienced and used as opportunities to more thoroughly engage with their patients’ situation and suffering by giving them room to express themselves. Sometimes, conversations directly led to the activation of resources (see table 4, themes 6.1–6.4 and related quotes).

Furthermore, setting the interview several weeks after the desire to die-conversation gave health professionals space for reflection beyond mere documentation. Most of them were engaged with their patients’ unique personalities and biographies which shaped the desire to die-conversation. They also reflected on themselves, questioning their working style and approaches to desires to die. Some of them were surprised that unconscious expectations regarding their patients (e.g., absence of desire to die) were not met in the conversations. In others, reflection expanded toward conceptual or ethical issues like the term “desire to die” or one’s position regarding MAiD (see Table 4, themes 7.1–7.3 and related quotes).

Discussion

Our study presents how trained health professionals conduct and experience open (proactive) desire to die-conversations. The variety in length, setting, content, and tone of these conversations

Table 3. Themes, subthemes and exemplary quotes unique to the documentation sheets on desire to die-conversations

Themes	Exemplary Quotes
4. Health Professionals Ways of Addressing Desire to Die	
Asking about ...	
4.1. ... wishes, thoughts, and fears regarding the nearing end of life	<i>"Have you ever thought about the end of your life concretely? Do you have any wishes or fears?" (tn28k3, DS*)</i>
4.2. ... fears regarding death and dying	<i>"Last month, you worried about the possibility that you would not survive your gastric tube-operation. How are you feeling about this today?" (tn88k10, DS)</i>
4.3. ... feelings of hopelessness faced with current symptom burden	<i>"With all these therapies you are getting, with all the sorrow, have you ever thought death could come as a relief?" (tn07k1, DS)</i>
4.4. ... thoughts of not wanting to live any more	<i>"Do you sometimes have moments in which living like this feels like a burden?" (tn118,k12, DS)</i>
4.5. ... thoughts of ending one's life prematurely	<i>"Do you sometimes think about ending your life, should pain and breathlessness worsen?" (tn59k6, DS)</i>
4.6. ... desire to die directly	<i>"Do you sometimes wish for your death?" (tn03k6, DS)</i>
5. Patient Reactions to Addressing Desire to Die	
5.1. Confirmative	<i>"She said that she had talked with a friend about seeking assisted suicide in Switzerland. Her friend had then suggested that she speaks to a palliative care physician." (tn64k7, DS)</i>
5.2. Open	<i>"It is good to talk about it, the patient appreciates directness." (tn88k8, DS)</i>
5.3. "Matter-of-fact"	<i>"The patient was very open-minded and sober regarding the topic." (tn107kx, DS)</i>
5.4. Emotional	<i>"She was crying, because she felt understood." (tn53k5, DS)</i>
5.5. Negative	<i>"The topic was rather unpleasant for him." (tn64k7, DS)</i>
5.6. Emphasis on will to live	<i>"Determined rejection of any desire to die. He considers himself an optimist and looks positively at the future and at life."(tn118k12, DS)</i>

*DS=documentation sheet.

mirrors the idiosyncrasy of the existential phenomenon of desire to die (German Guideline Programme in Oncology, 2020; Kreimeike et al., 2022). The findings also reveal how desire to die is embedded in other pressing matters at the end of life: questions regarding isolation, the stress of changing care settings, complex interactions with close ones, as well as physical and psychological symptom burden. Asking about desire to die in an open and respectful manner can serve as a door opener to these topics which are highly relevant to the patient, such as unmet needs behind multi-dimensional suffering (Monforte-Royo et al., 2012; Otte et al., 2017). Where appropriate, this might lead to changes in the care plan, such as care in other institutions or employing volunteer spiritual support.

In our study, all health professionals were trained in an open approach to desire to die and their documented experiences are likely shaped by this training (Frerich et al., 2020; Kreimeike et al., 2020). However, health professionals were free to approach the topic of desire to die in their own style. Contrasting a recent study (Porta-Sales et al., 2019), they did not use a question from a standardized short interview, but delivered insight into their individual phrasings and approaches. Health professionals reported that tailoring the approach to the patients' situation through open questions allows the patients to express even latent desire to die which they have not talked about before. This is in line with delivering person-centered care that has been shown to be beneficial for patients' well-being (Dwamena et al., 2012). By balancing conversations between giving an opportunity to talk without probing too deep for the patient to remain comfortable, health professionals in our study also used techniques described by Strang et al. (2014). This places desire to die-conversations in

the broader context of existential conversations which, despite burdensome aspects, are described as a special honor (Strang et al., 2014).

A high number of health professionals emphasized the positive impact of desire to die-conversations on their relationship with the patient and repeatedly came back for further conversations. Desire to die-conversations here may stand unique in their catalyzing function of addressing existential issues while simultaneously being part of a larger communicative process. Studies on good patient-doctor relationships show that such communication and continuity are essential elements thereof (Ridd et al., 2009). As such, desire to die-conversations may even contribute to suicide prevention by reducing depressiveness (a strong predictor for developing a wish to hasten death) and fostering therapeutic alliance and allowing the patients to report vital information (Rodin et al., 2009; Lewis et al., 2014; Voltz et al., 2021).

However, health professionals also reported on aspects which were hindering to the conversation: both patients' unwillingness to engage on the one side and intense emotions on the other hampered open conversation, a communication challenge known from the literature (Banerjee et al., 2016). Despite some patients displaying a distinctly negative response to the topic of desire to die, most were reported not to take issue with or welcome it. These results strengthen recent research findings (Porta-Sales et al., 2019; Voltz et al., 2021).

Within the qualitative interviews, health professionals used a striking amount of time to reflect on their patients' biography and situation. They displayed a profound knowledge and interest which they used to understand background and function of patients' desire to die. Additionally, they reflected their own role

Table 4. Themes, subthemes and exemplary quotes unique to the qualitative interviews

Themes	Exemplary Quotes
6. Content of Conversation	
6.1. Addressing DD	<i>"We talked about fears. (...) And she told me about her fear of suffocating. To me, this fear of suffocation is really a fear of annihilation. (...) I think she was the one who kind of said: I want this all to be over soon. And in some way, I took that as a form of desire to die."</i> (tn101k11, QI*)
6.2. Exploration of DD	<i>"With her, there was always the ambivalence whether this is a desire to die or something more. The topic came up again and again, even in conversations which were not part of the study. After the conversation (...) it became apparent that (...) she had already entertained the thought of killing herself."</i> (tn86k10, QI)
6.3. Enduring suffering and giving room	<i>"I think he is a person with a need for communication. [We offered] some grief counseling because his wife died and I had the impression (...) that there is still something that he has not processed [yet]."</i> (tn87k10, QI)
6.4. Tying in with resources	<i>"(...) She said she has, four pillars [that support her] (...). [H]er supporting pillars are her friends, also a neighbor and she named us too, her ambulatory palliative care team. Yes, we were one of the supporting pillars. I thought that was beautifully phrased."</i> (tn38k4, QI)
7. (Self)-reflection	
7.1. Reflecting on conceptual topics	<i>"What I still have problems with, is this term: 'desire to die'. (...) A desire always is [for] something positive. A desire may come to pass and (...) – well, I still think it's strange to 'desire' that one were dead. I understand someone doesn't want to endure suffering any longer. (...) But a desire always entails something positive (...)." (tn101k11, QI)</i>
7.2. Reflecting on the patient	7.2.1. Patient interpretation of conversation <i>"(...) We also talked about her former partners and friends and about her son and about what she used to do and about all these things. I simply addressed it [i.e., DD] every now and then [but] without being pushy. [The conversation] just flowed. And I don't think she perceived it as [a conversation about desire to die]."</i> (tn101k11, QI)
	7.2.2. Patient personality and biography <i>"(...) I know that she thinks about things in a differentiated manner and also pays very close attention to every small detail in her own body, to her own feelings, to her dialogue partner (...). I knew that she would reevaluate a lot of things and that she still needs to clarify a lot, such as family history, unresolved conflicts with the son and (...) also a last wish (...)." (tn38k4, QI)</i>
7.3. Reflecting on oneself	7.3.1. One's way of working <i>"I don't want to hurt anyone, of course, and I have to be very, very careful. (...) But IF it is certain, then, of course: Don't dither, but be so direct that (...) the patient really understands what is at stake in that moment."</i> (tnn47k5, QI)
	7.3.2. Expectations and reality <i>"You wouldn't have thought she was capable of that [i.e., holding a DD], because she is such a very positive person (...). In this respect, I found it really interesting to know that this condition [i.e., a DD] has also occurred in patients where one would not necessarily expect it."</i> (tn61k6, QI)

**QI= qualitative interview

and communicative abilities, sometimes taking ethical standpoints. The interviewed health professionals displayed the four key practices captured by the model of mindful communication often found in experienced palliative care leaders (Omilion-Hodges and Swords, 2015): (a) consider your audience, (b) ask questions, listen, repeat, (c) discard scripts, and (d) recognize your role. This communicative style bears positive effects on both patients and health professionals, such as increased clinician well-being, decreased depersonalization, and improved patient care (Omilion-Hodges and Swords, 2015). Either effects of the prior training on desire to die or a pre-existing high level of competence in mindful communication in our interviewed health professionals are conceivable explanations.

Lastly, our results need to be contextualized within the legalization process of MAiD in our country: the German Federal Constitutional Court revoked the legal restriction on (medical) assistance in suicide in February 2020 (Federal Court of Justice, 2020). Up until then, patients with a wish to hasten death often used services provided in neighboring countries (e.g., Switzerland) to legally receive MAiD (Gauthier et al., 2015). Since our study was conducted mainly before February 2020, it is highly possible that today's conversations of desire to die have changed in tone and urgency. First reports from health professionals in Canada suggest a tendency of patients narrowing

conversations towards options of MAiD with new legal opportunities in this regard (Ho et al., 2021). This leaves health professionals feeling restricted in their exploration of background or underlying needs behind a desire to die. To combat these and other reported challenges in communication about desire to die and foster health professional' self-reflection, communication trainings for an open, respectful and proactive approach toward desire to die becomes all the more important (Frerich et al., 2020).

Strengths and Limitations

The interpretation of our results faces several limitations: all information on content of desire to die-conversations is mediated by (a) selected health professionals' perception and memory of the conversations and (b) our questions in the documentation sheets as well as within the interviews. A significant number of trained health professionals did not recruit patients for desire to die-conversations despite high recruitment efforts (e.g., monetary incentives, bi-monthly reminders per phone, and information of health professionals' superiors). Stated reasons were lack of time, no support from superiors and a critical institution-wide attitude concerning conversations about desire to die; problems already reported before (Kremeike et al., 2021b). Consequently, our results do not present a close description of desire to die-

conversations, but an explorative insight into the experience of a convenience sample of health professionals.

It is noteworthy to consider potential effects of the ways health professionals selected patients, lead their conversation and document it. Seeing it as a training exercise in learning to communicate about taboo topics, health professionals might have chosen patients that they considered easy to talk to (Aktas and Walsh, 2011). In our study, no patient reported a serious request for MAiD which can be considered in the context of a potential selection bias through gate-keeping. Additionally, only a highly motivated subsample of all trained health professionals participated in interviews. This might skew results to paint a more positive picture of how desire to die-conversations evolve in general.

Furthermore, health professionals repeatedly remarked on the artificial context of leading a desire to die-conversation within a research project. This unique setting likely had an impact on how these conversations were approached: health professionals could take deliberate time and focus on the topic of desire to die with their patients, yet they had to do so differently than they might otherwise have done (e.g., by planning and documenting their conversation in a fixed time frame). They also reported feeling a role conflict between being a carer and recruiting patients for study participation. Nevertheless, health professionals were free to lead their desire to die-conversations in their own style which is important, given differing requirements, habits and time constraints of different palliative care settings. Thereby, our health professional sample meets the criteria of heterogeneity, making our results generalizable for health professionals trained in dealing with desire to die. Further research might systematically analyze differences between care settings or professions in a larger sample.

Conclusion

When discussing adequate ways of dealing with desire to die, it is important to utilize an open approach that prioritizes the exploration of patients' background and needs and instead of narrowing its focus on requests for MAiD. Health professionals trained in this approach experience conversations about desire to die as mainly positive and use such conversations to negotiate a variety of practical and existential topics. Even in the given context of a study, health professionals experienced desire to die-conversations as a door opener and appreciated their value for (self-)reflection. This insight into health professionals' experience of desire to die-conversations emphasizes the utmost importance of addressing this topic openly, respectfully and with curiosity for the patients' individuality and thereby potentially preventing suicide.

Supplementary material. The supplementary material for this article can be found at <https://doi.org/10.1017/S1478951522001006>.

Acknowledgements. R.V. received grants from the Federal Ministry of Education and Research during the conduct of the study. Grants from the Federal Joint Committee (G-BA) Germany, Innovation Fund; grants from the Federal Ministry of Education and Research; grants from EU – Horizon 2020; grants from Robert Bosch Foundation, Trägerwerk Soziale Dienste in Sachsen GmbH; Association Endlich Palliativ & Hospiz e.V.; grants from the Ministry of Labor, Health and Social Affairs of North Rhine-Westphalia; grants from German Cancer Society, Association of the Scientific Medical Societies, German Cancer Aid; grants from the Ministry of Culture and Science of North Rhine-Westphalia; personal fees from AOK Health Insurance, personal fees from German Cancer Society/National Health Academy (NGA), personal fees from MSD Sharp & Dome, grants from Hertie Foundation, personal fees from Roche Germany outside of submitted work.

Authors' Contribution. K.B. made contributions to study design, recruited participants, conducted the interviews, cleaned and analyzed the data, and wrote the original draft.

T.D. made contributions to data analysis. He revised the paper for important intellectual content and gave approval to the final version published.

C.R. made contributions to study design, recruited participants and conducted the interviews. She revised the paper for important intellectual content and gave approval to the final version published.

L.G. made contributions to study design, recruited participants and conducted the interviews. She revised the paper for important intellectual content and gave approval to the final version published.

R.V. conceived the study design, was the principal investigator and had oversight of the entire study procedure. He revised the paper for important intellectual content and gave approval to the final version published. He is the guarantor.

K.K. conceived the study design, was the operative study manager, conducted the interviews, and made contributions to data analysis. She revised the paper for important intellectual content and gave approval to the final version published.

Funding. This work was granted by the German Federal Ministry of Education and Research (01GY1706).

Conflict of interest. K.B. has nothing to disclose. T.D. has nothing to disclose. C.R. has nothing to disclose. L.G. has nothing to disclose. K.K. has nothing to disclose.

References

- Aktas A and Walsh A (2011) Methodological challenges in supportive and palliative care cancer research. *Supportive Care and Palliative Medicine* 38(3), 406–466. doi: 10.1053/j.seminoncol.2011.03.017
- An E, Wennberg E, Nissim R, *et al.* (2017) Death talk and relief of death-related distress in patients with advanced cancer. *BMJ Supportive & Palliative Care* 10(2), e19. doi:10.1136/bmjspcare-2016-001277
- Baile WF, Buckman R, Lenzi R, *et al.* (2000) SPIKES – A six-step protocol for delivering bad news: Application to the patient with cancer. *Oncologist* 5(4), 302–311. <https://www.ncbi.nlm.nih.gov/pubmed/10964998>
- Balaguer A, Monforte-Royo C, Porta-Sales J, *et al.* (2016) An international consensus definition of the wish to hasten death and its related factors. *PLoS One* 11(1), e0146184. doi:10.1371/journal.pone.0146184
- Banerjee SC, Manna R, Coyle N, *et al.* (2016) Oncology nurses' communication challenges with patients and families: A qualitative study. *Nurse Education in Practice* 16(1), 193–201. doi:10.1016/j.nepr.2015.07.007
- Bellido-Pérez M, Crespo I, Wilson KG, *et al.* (2018) Assessment of the wish to hasten death in patients with advanced cancer: A comparison of 2 different approaches. *Psycho-Oncology* 27(6), 1538–1544. doi:10.1002/pon.4689
- Bornet M-A, Rubli Truchard E, Waerber G, *et al.* (2020) Life worth living: Cross-sectional study on the prevalence and determinants of the wish to die in elderly patients hospitalized in an internal medicine ward. *BMC Geriatrics* 20(1), 348. doi:10.1186/s12877-020-01762-x
- Braun V and Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* 3(2), 77–101.
- Briggs R, Ward M and Kenny RA (2021) The “Wish to Die” in later life: Prevalence, longitudinal course and mortality. Data from TILDA. *Age and Ageing* 50(4), 1321–1328. doi:10.1093/ageing/afab010
- Campbell JL, Quincy C, Osserman J, *et al.* (2013) Coding in-depth semi-structured interviews: Problems of unitization and intercoder reliability and agreement. *Sociological Methods & Research* 42(3), 294–320.
- Crespo I, Monforte-Royo C, Balaguer A, *et al.* (2021) Screening for the desire to die in the first palliative care encounter: A proof-of-concept study. *Journal of Palliative Medicine* 24(4), 570–573. doi:10.1089/jpm.2020.0276
- DeCou CR and Schumann ME (2018) On the iatrogenic risk of assessing suicidality: A meta-analysis. *Suicide and Life-Threatening Behavior* 48(5), 531–543. doi:10.1111/sltb.12368
- Dwamena F, Holmes-Rovner M, Gauden CM, *et al.* (2012) Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database of Systematic Reviews* 12. doi:10.1002/14651858.CD003267.pub2

- Federal Court of Justice** (2020). Judgment of the Second Senate of 26 February 2020. 2 BvR 2347/15, para. (1-343) Available at: http://www.bverfg.de/e/rs20200226_2bvr234715.html.
- Frerich G, Romotzky V, Galushko M, et al.** (2020) Communication about the desire to die: Development and evaluation of a first needs-oriented training concept – A pilot study. *Palliative & Supportive Care* **18**(5), 528–536. doi:10.1017/S1478951520000097
- Fujioka JK, Mirza RM, Klinger CA, et al.** (2019) Medical assistance in dying: Implications for health systems from a scoping review of the literature. *Journal of Health Services Research & Policy* **24**(3), 207–216. doi:10.1177/1355819619834962
- Galushko M, Frerich G, Perrar K, et al.** (2016) Desire for hastened death: How do professionals in specialized palliative care react? *Psycho-Oncology* **25**(5), 536–543.
- Gauthier S, Mausbach J, Reisch T, et al.** (2015) Suicide tourism: A pilot study on the Swiss phenomenon. *Journal of Medical Ethics* **41**(8), 611–617. doi:10.1136/medethics-2014-102091
- German Guideline Programme in Oncology** (2020) Palliative care for patients with incurable cancer 2.1. AWMF-registration number 128/001OL. Available at: <https://www.leitlinienprogramm-onkologie.de/leitlinien/palliativmedizin/> (accessed February 2020).
- Ho A, Norman JS, Joolae S, et al.** (2021) How does medical assistance in dying affect end-of-life care planning discussions? Experiences of Canadian multidisciplinary palliative care providers. *Palliative Care and Social Practice* **15**. doi:10.1177/26323524211045996
- Hvidt EA, Lykkegaard J, Pedersen LB, et al.** (2017) How is defensive medicine understood and experienced in a primary care setting? A qualitative focus group study among Danish general practitioners. *BMJ Open* **7**(12), e019851.
- Kreimeke K, Galushko M, Frerich G, et al.** (2018) The DEsire to DIE in Palliative care: Optimization of Management (DEDIPOM) - A study protocol. *BMC Palliative Care* **17**(1), 30. doi:10.1186/s12904-018-0279-3
- Kreimeke K, Frerich G, Romotzky V, et al.** (2020) The desire to die in palliative care: A sequential mixed methods study to develop a semi-structured clinical approach. *BMC Palliative Care* **19**(49). doi:10.1186/s12904-020-00548-7
- Kreimeke K, Dojan T, Rosendahl C, et al.** (2021a) “Withstanding ambivalence is of particular importance” – Controversies among experts on dealing with desire to die in palliative care. *PLoS One* **16**(9), e0257382. doi:10.1371/journal.pone.0257382
- Kreimeke K, Pralong A, Boström K, et al.** (2021b) “Desire to die’ in palliative care patients-legal framework and recommendations of the national evidence-based guideline on palliative care in Germany. *Annals of Palliative Medicine* **10**(3), 3594–3610. doi:10.21037/apm-20-381
- Kreimeke K, Boström K, Preiser C, et al.** (2022). Desire to die: How does the patients’ chorus sound? *OMEGA Journal of Death and Dying*. 302228221103393. Advance online publication. doi:10.1177/00302228221103393
- Kuckartz U** (2019) Qualitative text analysis: A systematic approach. In Kaiser G & Presmeg N (eds.), *Compendium for Early Career Researchers in Mathematics Education*. Cham: Springer, pp. 181–197.
- Lenherr G, Meyer-Zehnder B, Kressig RW, et al.** (2012) To speak, or not to speak-do clinicians speak about dying and death with geriatric patients at the end of life? *Swiss Medical Weekly* **142**, 1314.
- Lewis DS, Anderson KH and Feuchtinger J** (2014) Suicide prevention in neurology patients: Evidence to guide practice? *The Journal of Neuroscience Nursing: Journal of the American Association of Neuroscience Nurses* **46** (4), 241–248.
- Monforte-Royo C, Villavicencio-Chavez C, Tomas-Sabado J, et al.** (2012) What lies behind the wish to hasten death? A systematic review and meta-ethnography from the perspective of patients [meta-analysis research support, Non-U.S. Gov’t review]. *PLoS One* **7**(5), e37117. doi:10.1371/journal.pone.0037117
- Omilion-Hodges L and Swords N** (2015) Communication that heals: Mindful communication practices from palliative care leaders. *Health Communication* **31**(3), 328–335. doi:10.1080/10410236.2014.953739
- Otte IC, Jung C, Elger B, et al.** (2017) “We need to talk!” barriers to GPs’ communication about the option of physician-assisted suicide and their ethical implications: Results from a qualitative study. *Medicine, Health Care, and Philosophy* **20**(2), 249–256. doi:10.1007/s11019-016-9744-z
- Porta-Sales J, Crespo I, Monforte-Royo C, et al.** (2019) The clinical evaluation of the wish to hasten death is not upsetting for advanced cancer patients: A cross-sectional study. *Palliative Medicine* **33**(6), 570–577. doi:10.1177/0269216318824526
- Ridd M, Shaw A, Lewis G, et al.** (2009) The patient–doctor relationship: A synthesis of the qualitative literature on patients’ perspectives. *British Journal of General Practice* **59**(561), e116–e133. doi:10.3399/bjgp09X420248
- Rodin G, Lo C, Mikulincer M, et al.** (2009) Pathways to distress: The multiple determinants of depression, hopelessness, and the desire for hastened death in metastatic cancer patients. *Social Science and Medicine* **68**(3), 562–569. doi:10.1016/j.socscimed.2008.10.037
- Steinke I** (2000) Gütekriterien qualitativer Forschung. In Flick U, von Kardoff E & Steinke I (eds.), *Qualitative Forschung. Ein Handbuch*. Rowohlt Taschenbuch, pp. 319–331.
- Strang S, Henoeh I, Danielson E, et al.** (2014) Communication about existential issues with patients close to death—Nurses’ reflections on content, process and meaning. *Psycho-Oncology* **23**(5), 562–568. doi:10.1002/pon.3456
- VERBI Software** (2019) MAXQDA 2020. In VERBI Software. Available at: maxqda.com.
- Voltz R, Boström K, Dojan T, et al.** (2021) Is trained communication about desire to die harmful for patients receiving palliative care? A cohort study. *Palliative Medicine*. doi:10.1177/02692163211065671
- Wildfeuer J, Schnell MW and Schulz C** (2015) Talking about dying and death: On new discursive constructions of a formerly postulated taboo. *Discourse & Society* **26**(3), 366–390. doi:10.1177/0957926514564739
- Wright DK, Chirchikova M, Daniel V, et al.** (2017) Engaging with patients who desire death: Interpretation, presence, and constraint. *Canadian Oncology Nursing Journal = Revue canadienne de nursing oncologique* **27**(1), 56–64. doi:10.5737/236880762715664