Patients in their last year of life – communication about death, dying and desire to die

Inaugural Dissertation
zur
Erlangung des Doktorgrades
philosophiae doctor (PhD) in Health Sciences
der Medizinischen Fakultät
der Universität zu Köln

vorgelegt von
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Universitäts- und Stadtbibliothek Köln (USB), Köln

2025

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Datum der Mündlichen Prüfung: 30.06.2025

DANKSAGUNG

Ich widme diese Doktorarbeit meinen Eltern: Ingrid und Harald Boström. Sie haben mir das Interesse an der Welt und den Menschen darin vermittelt und ihre liebevolle Unterstützung hat mich beim Schreiben dieser Arbeit stets getragen.

Besonders danken möchte ich meiner Projektleitung, Priv.-Doz. Dr. Kerstin Kremeike, die mich sowohl durch Ihre inhaltliche und methodische Expertise als auch durch persönliche und auflockernde Gespräche durch diese Zeit begleitet hat. Ich bedanke mich ebenfalls bei Herrn Prof. Dr. Voltz für seine stete Förderung und die Betreuung meiner Promotionsarbeit. Dazu möchte ich all meinen Kolleginnen und Kollegen vom Zentrum für Palliativmedizin der Uniklinik Köln danken, durch die die Arbeit in den Projekten immer sowohl Erfüllung als auch Freude bereitete. Mein großer Dank gilt auch meinem Partner Till Freese, der mir stets den Rücken stärkt und mich immer wieder aufgefangen und zu mir selbst zurückgeführt hat.

Nicht zuletzt gilt mein Dank den Patientinnen und Patienten, ihren Zugehörigen sowie den Versorgenden, die mit ihrer Zeit und ihren Erfahrungen diese Studie unterstützt haben.

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- WTHD = wish to hasten death

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Zusammenfassung

Hintergrund

Menschen in ihrem letzten Lebensjahr äußern nicht selten den Wunsch nach einem vorgezogenen Lebensende, meist aufgrund multidimensionalen Leids (körperlich, psychisch, sozial oder spirituell). In der palliativen Versorgung sind Gespräche über Sterben, Tod und Todeswünsche essenziell, um Leid zu explorieren sowie Handlungsoptionen aufzuzeigen. Jedoch stellen solche Gespräche durch unterschiedliche Wertesysteme und gesellschaftliche Tabus häufig kommunikative Herausforderungen dar.

Zielsetzung

Ziel der Arbeit ist die empirische Untersuchung des Erlebens und der Bewertung solcher Gespräche durch Palliativpatient:innen, Angehörige und Versorgende. Die Analyse der Kommunikationsmuster erfolgt anhand des transaktionalen Kommunikationsmodells, um praxisrelevante Erkenntnisse zur Optimierung der Gesprächsführung zu gewinnen.

Methode

Die dreiphasige Mixed-Methods-Studie „Desire to Die in Palliative Care – Optimization of Management (DEDIPOM)“ bildet die Datenbasis. Nach Entwicklung eines Gesprächsleitfadens und Schulungen zum Umgang mit Todeswünschen (Phase 1 und 2) führten geschulte Versorgende leitfadengestützte Gespräche mit Patient:innen (Phase 3). Die Inhalte der dokumentierten Gespräche wurden thematisch analysiert (Paper 1). Mittels qualitativer Framework-Analyse wurden in Interviews mit Patient:innen, Angehörigen und Versorgenden Kommunikationsmuster identifiziert (Paper 2). Alle Ergebnisse wurden im transaktionalen Kommunikationsmodell von Barnlund integriert.

Ergebnisse

Zwischen 2018 und 2020 dokumentierten 29 Versorgende 79 Gespräche über Todeswünsche, von denen 13 Versorgende, 13 Patient:innen und 13 Angehörige an Interviews teilnahmen. Die thematische Analyse (Paper 1) identifizierte förderliche und hinderliche Aspekte und initiierte Maßnahmen. Die Analyse der Interviews (Paper 2) zeigte Unterschiede in Offenheit und Qualität der Gespräche in drei Typen: 1) „Zwischen den Zeilen“ (implizit, subtil), 2) „Aneinander vorbei“ (inkongruent, missverständlich) und 3) „Sachlich-nüchtern“ (direkt, distanziert).

Diskussion und Ausblick

Die Kommunikationtypen und Missverständnisse in den analysierten Todeswunsch-Gesprächen zeigen die Notwendigkeit differenzierter kommunikativer Zugänge auf. Das transaktionale Kommunikationsmodell hilft in der Analyse solcher Gespräche, da es die Ko-Konstruktion von Bedeutung und mögliche Einflussfaktoren betont. Jedoch bleibt es deskriptiv ohne normative Handlungsempfehlungen, so dass Gesprächspartner:innen zur Selbstreflexion angehalten sind.

Summary

Background

People in their last year of life often express the wish for the end of life to come sooner, mostly due to multidimensional suffering (physical, psychological, social or spiritual). In palliative care, conversations about dying, death and desire to die are essential to explore suffering and options for action. However, different value systems and social taboos often present communicative challenges.

Objective

The aim of the present dissertation is an empirical investigation of the experience and evaluation of such conversations by palliative patients, relatives and health professionals. Occurring communication patterns are analyzed using the transactional communication model to gain practical insights for optimizing the conduct of conversations.

Method

The three-phase mixed-methods study “Desire to Die in Palliative Care - Optimization of Management (DEDIPOM)” forms the data basis. Following the development of communication guideline and training on dealing with desire to die (phases 1 and 2), trained health professionals conducted guideline-based conversations with patients (phase 3). The content of the documented conversations was analyzed thematically (Paper 1). Qualitative framework analysis was used in interviews with patient, relatives and health professionals to identify communication patterns (Paper 2). All results were integrated into Barnlund's transactional communication model.

Results

Between 2018 and 2020 29 health professionals documented 79 conversations about desire to die, of which 13 caregivers, 13 patients and 13 relatives took part in interviews. The thematic analysis (Paper 1) identified supportive and obstructive aspects and initiated measures. The analysis of the interviews (Paper 2) showed differences in the openness and quality of the conversations in three types: 1) “Between the lines” (implicit, subtle), 2) ‘past each other’ (incongruent, misleading) and 3) “matter-of-fact” (direct, distanced).

Discussion and outlook

The types of communication and misunderstandings in the analyzed desire to die conversations show the need for differentiated communicative approaches. The transactional communication model helps in the analysis of such conversations, as it emphasizes the co-construction of meaning and possible influencing factors. However, it remains descriptive without normative recommendations for action, so that interlocutors remain encouraged to self-reflect.

1. Introduction

„Wenn Du vor mir stehst und mich ansiehst, was weißt Du von den Schmerzen, die in mir sind und was weiß ich von den Deinen. Und wenn ich mich vor Dir niederwerfen würde und weinen und erzählen, was wüsstest Du von mir mehr als von der Hölle, wenn Dir jemand erzählt, sie ist heiß und fürchterlich. Schon darum sollten wir Menschen voreinander so ehrfürchtig, so nachdenklich, so liebend stehen wie vor dem Eingang zur Hölle...“

“When you stand before me and look me in the eyes, what do you know of the pain that is in me and what do I know of yours. And if I were to prostrate myself before you and weep and tell you, what more would you know of me than of hell, if someone told you that it is hot and terrible. For this reason alone, we humans should stand before each other as reverently, as thoughtfully, as lovingly as before the entrance to hell...”
- Franz Kafka, from a letter to Oskar Pollak (own translation), 08.11.1903[1]

When a person suffers from a disease that is chronic, progressing, terminal or in other ways life-limiting, a medical approach that is merely curative is no longer adequate. These patients have a medical indication for palliative care.[2] The word “palliative” is derived from the Latin word “pallium”, meaning “coat” and also used in the sense of comfortably “coating somebody in” with a blanket or cape. Palliative care is defined as medical treatment aiming to relieve symptoms and improve quality of life without the aim to cure the underlying disease.[2] It can, however, also be used as an accompanying treatment alongside curative therapies in early stages of disease.[3] Palliative care follows a holistic approach that conceptualizes the experience of disease influenced by medical, social, psychological and spiritual factors. Therefore, working in multi-professional teams and including patients’ relatives as best as possible are key ideas of palliative care.[3] As the title of this doctoral thesis suggests, I focus on patients in their last year of life. By the term “last year of life” I do not necessarily refer to the last 12 months of a patients’ life (which can only be correctly defined post mortem), but to the prognosticated last year of life as assessed by the surprise question: “*Would you be surprised if the patient died within the next 12 months?”*[4] If the answer to this question is no, then the indication for palliative care should be considered.[4]

When patients in their last year of life are confronted with high symptom burden and their own impending death, they can develop a desire to die earlier than they naturally would.[5, 6] For patients, a desire to die is most often an expression of their multi-dimensional suffering.[5] In some patients, this desire in its most extreme form can lead to suicidality or the request for (medical) aid in dying.[7] Once expressed to their health professional or a relative, a desire to die can change communication drastically and is frequently met with defense or a loss for words.[8]

This is probably what Kafka attempted to express in the introductory quote: communicating the subjectively felt dimensions of suffering is complex and perhaps prone to never being understood completely by the conversation partner. Especially, communication about desire to die is still perceived as challenging, as it is associated with insecurities and stigmatization.[9] This is the case even though communication about death, dying and desire to die does not harm participants, but can be beneficial for all parties – if conducted in a sensitive, respectful, and open manner.[10]

In this doctoral thesis, I intend to shed light on how patients in their last year of life, their relatives as well as their health professionals can experience communication about death, dying and desire to die. As research on this topic suggests, communication is often perceived less than optimal, sometimes with detrimental effects on all communication participants. Therefore, results from this doctoral thesis will provide a base assessment based on qualitative data to further explore this type of communication.

In a first part, I will describe the contexts in which communication about death, dying and desire to die occurs. Therefore, I will give a brief overview of a) the cultural aspects that influence such communication, b) the legal framework that defines what kind of medical aid in dying may be allowed and what remains prohibited and c) the structures of care in which patients in their last year of life may receive palliative treatment. I will then present a thorough definition of the term desire to die as well as its prevalence and possible backgrounds, functions and meanings. Subsequently, I will approach the topic of communication about desire to die by describing empirical findings and introducing a psychological model of communication which will serve as the basis for my final discussion.

During the second part, I will elaborate upon the aim, methods and basis of data for this doctoral thesis and explain the study during which data was collected and analyzed. Hereafter, I will summarize the two internationally published and peer-reviewed papers on communication about desire to die that form the heart of this thesis.

In the third and last part, I will reconsider the findings from the two papers for a final synthesis and discussion. Therefore, I will first introduce the transactional communication model and briefly differentiate it from older communication models.[11] Using the transactional communication model as a leading framework for the synthesis of findings from paper 1 and 2, I will thereby test its applicability to desire to die communication. In a final discussion, I will weigh the strengths and limitations of this thesis and give an outlook on implications for clinical practice and research before I draw my conclusion.

While writing about the existential topic of communication about death, dying and desire to die, I was naturally lead to reflect upon my own ethical-moral position in relation to end-of-life care or (medical) aid in dying but also on the consequences of "*privileging [of] some voices at the expense of other, less well represented, ones*.".[12] Therefore, I intend to contextualize and critically examine my findings during all stages of the process so as not to fall prey to premature generalizations. The obvious vantage point for the contextualization in question is provided by simply looking at the origin of the data analyzed within this doctoral thesis. As it was collected between 2018 and 2020 from health professionals, patients and relatives living in Germany as German native speakers, it only allows analysis and a tentative generalization on adult, predominantly white Western Middle-European voices from a relatively stable socio-economic background. Voices of immigrants, people of color, of poor or homeless people at the end-of-life as well as those with intellectual disabilities or psychiatric conditions are unfortunately not included within my analysis, so their context needs further attention. To understand what shapes communication about death, dying and desire to die in the specific milieu I can write about, I will examine some of the factors of influence within the Theoretical Background within the next chapter.

2. Theoretical Background

To write about death, dying and desire to die and the ways in which patients, their relatives and health professionals talk about it, it is necessary to first know the context in which desire to die may occur. Therefore, I will give a short outline of the following structural aspects that influence discourse and communication about death, dying and desire to die in patients with chronic or life-limiting diseases in Germany: cultural aspects, legal aspects and structures of care. For a brief overview of current trends in these three context factors that may influence desire to die communication, see figure 1.

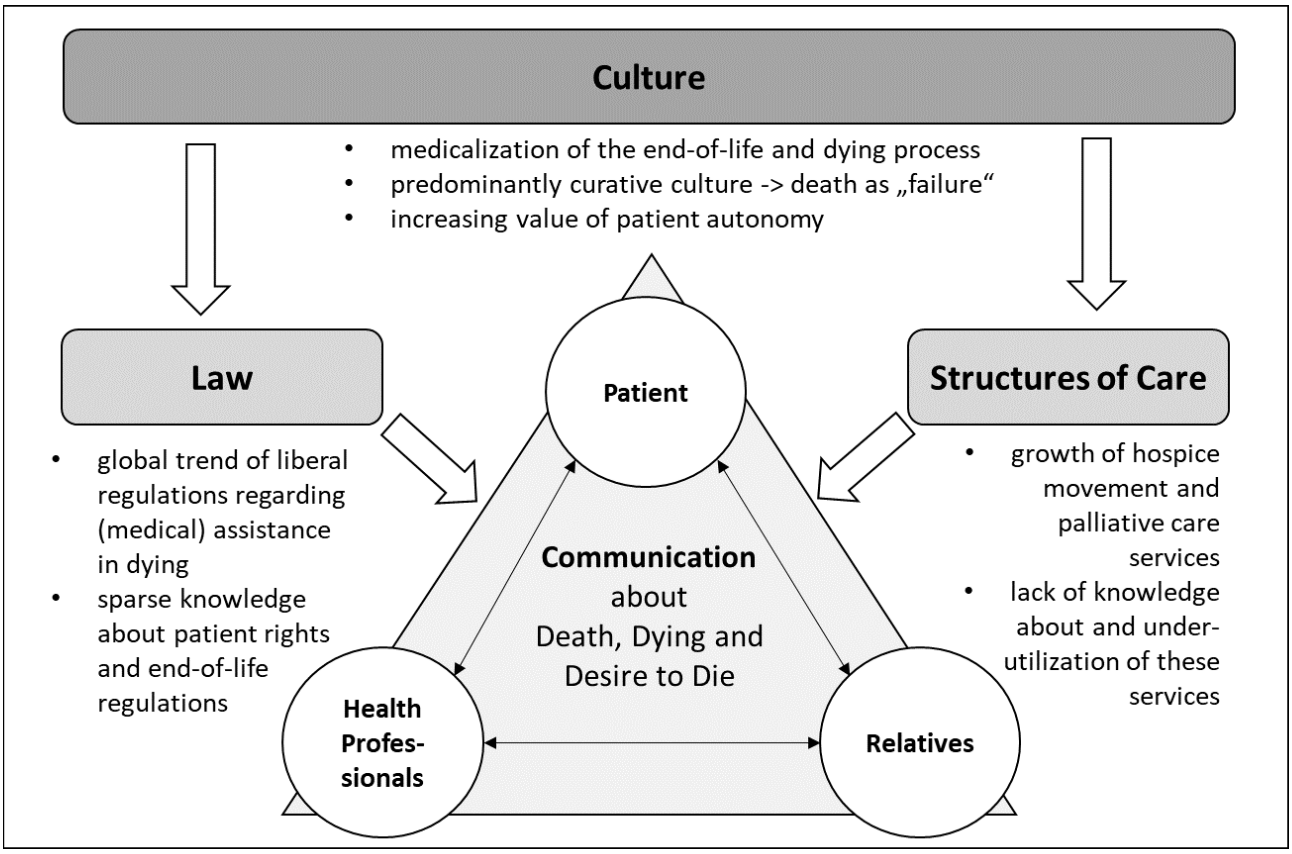

Fig. 1 *A rudimentary overview of current trends in the domains of culture, law and structures of care among the general population that potentially influence communication about death, dying and desire to die between patients, their relatives and health professionals. Own illustration.*

Once these outlines are drawn, I will define the phenomenon of desire to die and report on how it is currently embedded in (medical) communication.

2.1. Framework Conditions of Desire to Die

2.1.1. Culture: Medicalization and the Call for Patient Autonomy

Over the last decades, impressive advances in medical care and therapies as well as hygiene and nutrition increased general life expectancy and health.[13, 14] These developments are accompanied by a medicalization of death and dying, as the *Lancet Report on the Value of Death* points out: the way in which Western society at large understands and integrates death has changed fundamentally. Death comes later in life and is often prolonged, dying moved from the family to health care settings and consequently, skills, traditions, and knowledge within families and communities are getting lost over the course of the process.[15] Within such a mindset, delayed death and every incremental success in the fight against illness and disease count as desirable and worth financing.[16] This medicalization of dying is rooted in a pervasive curative culture in which the care for the dying and terminally ill in form of supportive and palliative care is secondary and death is often perceived as failure.[15] In the everyday practice of medical care at the end-of-life or in terminal illness, this is reflected in aggressive, often unwanted or not indicated overtreatment to the detriment of the patient's quality of life.[17] It is therefore not surprising that a legitimate fear of overtreatment is common in older patients and their relatives and often named in the context of hypothetical desires to die.[18]

These fears persist despite effective ways to alleviate suffering in palliative and hospice care and to honor preferences at the end of life through Advance Care Planning.[19] However, it is not the advances in and support for hospice and palliative care that dominate the public discourse on death and dying. Rather, questions of bodily autonomy, duty of care and dignity are raised in the political debate concerning the legalization as well as the ethically and practically feasible realization of (medically) assisted suicide.[20]

It is therefore important to consider a second trend in our relationship with death and dying, namely the increasing wish for control and autonomy regarding our own life, which naturally extends to organizing our own end-of-life. In line with the self-realization goals of (Western) moral individualism, life and death are increasingly regarded as personal onjects that are at disposal of the personal will.[21] This runs counter to the veritable unknowability of death, eventually forcing every individual to come to terms with their own mortality.

Even with the open debate on what constitutes a good death, there are lines of argument that still suggest a culture of taboo regarding the topic of death and dying, as Wildfeuer et al. (2015) outline.[22] These taboos might be rooted in diverse reasons ranging from religious concerns, prescribing to an overly curative medical culture (as described above) to fundamental convictions of what depth of emotion and existential topics are permitted in conversation.[15] Within many families, but also between health care providers and patients, the fear of death or a tacit mutual understanding of death as medical failure hinders open communication about it.[15]

Current challenges with desires to die of old or terminally ill people must be understood within the tension field of these two modern trends (medicalization of death and dying and focus on autonomy) and deeply rooted cultural or familial taboos still surrounding death, dying and desire to die.

2.1.2. Law: Medical Aid in Dying

In public debate, desire to die is often narrowly understood as the wish for (medical) aid in dying, e.g. by (physician) assisted suicide or termination of life on request (often called euthanasia). Therefore, it is important to have a comprehensive understanding of the proceeding global liberalization in laws and practices concerning (medical) aid in dying such as (physician) assisted suicide and euthanasia. This process can also be understood within the context of the two trends described above.

Internationally, practices of medical assistance in dying are now being legal in 19 jurisdictions.[23] Concrete legal interpretations differ between jurisdictions, with some allowing only for termination of life on request (e.g. Canada and the Netherlands) and others for assisted suicide (e.g. Swiss and Germany).[24]

In Germany, the principal ruling of the federal constitutional court from February 2020 reopened the debate under the notion of a self-determined death.[25] From 2015 on, §217 of the criminal code determined businesslike assistance in suicide as punishable.[26] Despite its initial intention to criminalize for-profit organizations like *Dignitas* or *Sterbehilfe Deutschland*, the §217 was heavily criticized due to the vagueness of the term "businesslike" that potentially targeted physicians who assist in suicide on repeated occasion as well. Resulting from a constitutional complaint by patient representatives and health professionals alike, the federal constitutional court deemed §217 as unlawful. In its ruling, however, it went beyond this statement and instated (assistance in) suicide as part of every individuals' personal right: the right to a self-determined death must be guaranteed to preserve human dignity. This includes the right to commit suicide as well as the right to seek and accept third party help in doing so. This ruling was deemed exceptionally progressive as the federal constitutional court set no range limitation (e.g. severe illness or limited life expectancy) to their decision - a desire to die only needs to be judged as freely accountable, stable and autonomous in order to provide legal grounds for (medical) aid in dying.[25] As current court rulings on cases of (improper) assistance in suicide show, there are greatly divergent perceptions of what constitutes a free, stable and autonomous wish.[27] To counterbalance the potential effects of these exceptional rights, the ruling further emphasized the need for advancements in suicide prevention, encouraged restrictive regulations by the state and specifically stated that assistance in suicide is a question of conscience and that no one (especially no health professionals) can be forced to participate.[25] A first draft is debated in German Parliament at the time of writing (December 2024).[28]

In the debate unfolding after the ruling, arguments were applied according to two central positions: 1. a restrictive approach with a strong focus on preservation of life and concerns that further liberalization will put improper pressure on socio-economically disadvantaged minorities (i.e., nudge them into asking for the comparatively cheaper services of (medical) aid in dying) and 2. a liberal approach focusing on the strengthening and expansion of the personal right to a self-determined death with a skeptical attitude regarding state regulations.[20]

Whereas assistance in suicide is currently lawful, termination of life by request remains criminalized in Germany under §216 of the criminal code.[29] However, even though the handling regarding requests for medical aid in dying are important for patients as well as a matter of principle, one must keep in mind that only a small percentage of patients with a desire to die will ever take advantage of it.[7]

When a patient expresses their desire to die, there are other legal rulings that shape medical decision-making to be kept in mind. Often, patients fear that they will receive treatments that will unnecessarily prolong their life and induce suffering.[30] For any treatment or therapy to be started or maintained, it is necessary to assess both medical indication and patient will (either direct will, will expressed by proxy or will expressed by an advance directive). If one of them is missing, any treatment is considered assault.[7] Similarly, patients are allowed to decide against any kind of treatment, even if there is proper medical indication for it.[7]

Moreover, when a patient is entering the dying phase, certain life-prolonging treatments (e.g. ventilation) that can induce unnecessary suffering are no longer indicated.[7] They should either not be initiated at all or concluded immediately – an act that is considered identical from a legal standpoint due to the sameness of its result, but still often poses an emotional challenge for health professionals. A predominantly curative culture that considers not actively fighting death as a failure (of medical treatment) further discourages the discontinuation of treatment. Thus, contrasting the clear legal and professional recommendations as presented in ethical guidelines, patients at the end of life still often receive unwanted and non-beneficial treatment in acute hospitals.[17]

Patients or relatives often lack knowledge about their rights and medical options at the end of life, while health professionals often hesitate to allow for death as an option due to fear of potential lawsuits.[31] These uncertainties can foster feelings of being at the mercy of a medical machinery in patients and potentially contribute to developing a desire to die.

However, a profound knowledge about this legal framework is often missing from patients as well as health professionals.[32] Therefore, and since assisted suicide is now technically legal in Germany, first policy papers and guiding principles to deal with the rising requests are currently published by renowned medical and palliative care associations and institutions.[33-35]

2.1.3. Structures of Care: Palliative Medicine and the Hospice Movement

Formal structures of care heavily influence how patients and their relatives are cared for and if they feel taken care of. In Germany, palliative care for people with chronic or life-limiting diseases follows two traditions: 1. the hospice movement which sees itself as a citizen movement and has supported 2. advances in palliative medicine as a young and growing medical and research field.

In 1967, Dame Dr. Cicely Saunders, founder of the hospice movement, opened the first hospice (St. Christopher's) in London. During the 1980s, the first German hospice was built at the University Hospital Cologne and the hospice movement started to take hold in Germany. Today, Germany has about 1500 ambulatory hospice services and 250 hospices which take in guests that suffer from life-limiting diseases with a bad prognosis and who are in need of intense palliative care.[36]

Beyond the hospice movement, palliative medicine has been growing as its own field.[3] By now, palliative care delivery is divided into general palliative care and specialized palliative care.[3] Most people at their end of life are cared for in settings of general palliative care such as ambulatory care or hospice services, general hospital wards or residential care homes. When a patient suffers from complex symptomology and does no longer respond to the means of general palliative care, specifically trained palliative care professionals take over. Specialized palliative care is delivered in palliative care wards in hospitals or by specialized ambulatory palliative care teams. In 2024, there were about 350 palliative wards and 403 specialized ambulatory palliative services in Germany.[36]

Patients who express a desire to die often fear to suffer from unbearable symptoms like pain, dyspnea or nausea as their disease worsens in the future.[5] With palliative care, these symptoms are largely treatable. As an option of last resort, palliative sedation can be induced in cases of unbearable suffering that is refractory to treatment.[37]

According to studies, however, most people are not aware of their treatment options at the end-of-life.[38] Additionally, most people do not die at their preferred place of death (at home), but rather at general wards in hospital.[39] There is further evidence that the hospital is the least preferred place of death and both relatives and patients report low satisfaction with hospital end-of-life care.[40]

When we consider care structures as influential factors on desire to die, there are two aspects to keep in mind: As fear of unbearable symptoms is a known background of desire to die, lack of knowledge about means of symptom control through palliative care, but also lack of access to palliative care due to structural inequalities (e.g. rural supply) can potentially foster desire to die – and wishes for assisted suicide.[18, 41] Studies show correlations between better care through improved symptom control and a diminished desire to die.[42]

However, patients express desire to die in all care settings and in all stages of disease.[6] This goes to show that desire to die as a phenomenon may be influenced by factors of care, but is its own complex phenomenon with multiple backgrounds, meanings, and functions.

2.2. Desire to Die: A broad Phenomenon

Within current literature, there are several terms to designate patient wishes for her or his life to end sooner or death to come earlier than it would naturally occur: a wish to die,[43] a death wish,[44] a wish to hasten death,[45] acute or latent suicidality,[46] as well as desire to die.[6] To standardize reporting on desire to die in research and to provide an internationally accepted definition, an international group of researchers proposed the term “wish to hasten death” (WTHD) as a

> *“(…) reaction to suffering, in the context of a life-threatening condition, from which the patient can see no way out other than to accelerate his or her death. This wish may be expressed spontaneously or after being asked about it, but it must be distinguished from the acceptance of impending death or from a wish to die naturally, although preferably soon. (…)”*[45]

In this work, I chose to use the term desire to die, in line with the definition from the *German National Guideline*.[7] Here, a desire to die is conceptualized along a continuum of increasing suicidal pressure. This continuum ranges from mere acceptance of death to a tiredness of life or a wish to hasten death that can culminate in latent or even acute suicidality. Desire to die as a term encompasses more fully the spectrum of thoughts and wishes old or terminally ill persons may have regarding their illness or end of life. In contrast to WTHD, desire to die includes acceptance of death, tiredness of life or vague wishes for peace and quiet and therefore enables us to talk about those patients that long for death without the wish to hasten it. For a depiction of the full continuum of desire to die according to *National Guideline: Palliative Care for Patients with Incurable Cancer*, please see figure 2.[7]

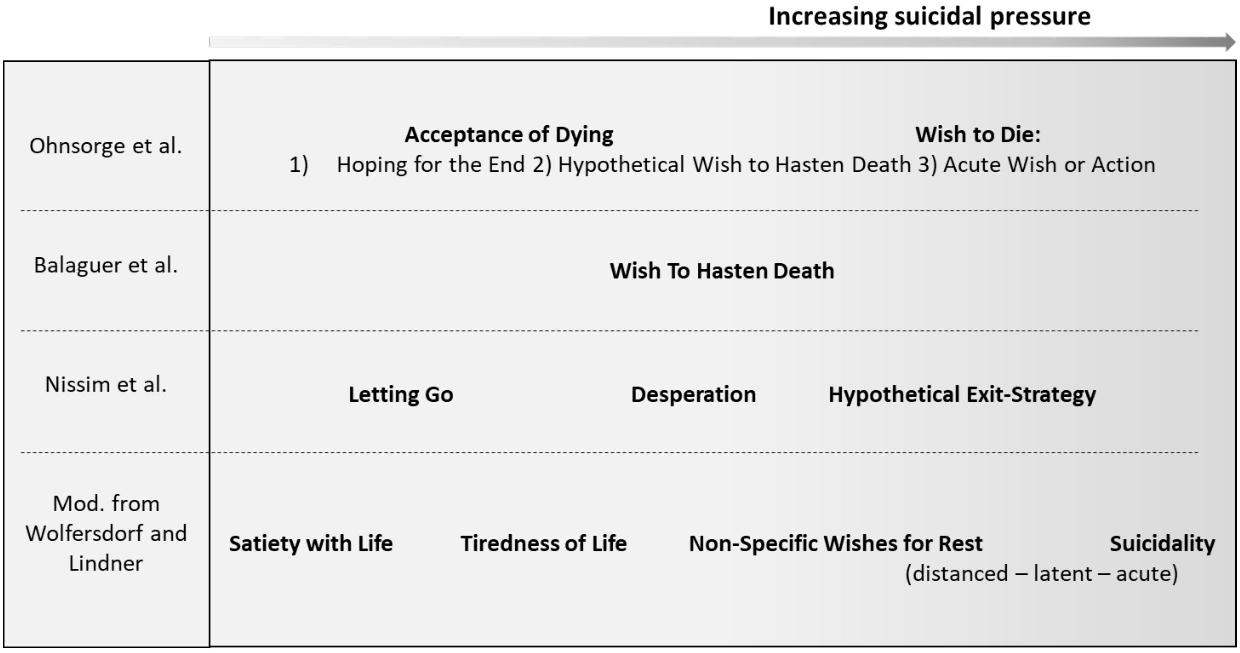

Fig. 2 Different forms of desire to die along a continuum of increasing suicidal pressure. Illustration adapted from the *National Guideline: Palliative Care for Patients with Incurable Cancer (p.417)*.[7]

It is important to acknowledge that even though every suicidal person holds a desire to die, not every desire to die equals suicidality.[7] Within the context of incurable disease, it is sometimes hard to distinguish whether a patient displays an understandable reaction to suffering and impending death (e.g. grief) or whether they display signs of clinical depression. Grieving for a lost future or the loss of (physical) functions as well as temporarily considering (hastened) death can be a natural part of dealing with incurable disease. It is therefore important to clarify diagnostically whether a patient displays the reactions listed above or signs of clinical depression (e.g., some of the same symptoms but markedly coupled with self-devaluation and low self-esteem) which cause burden and can be treated even in late stages of advanced disease.[7] This nuanced understanding of desire to die has the potential to challenge a traditional psychiatric understanding of suicidality. Since up to 90% of people ending their life by suicide can be considered mentally ill,[47] there often is an assumption of causality according to which suicidality occurs only within the context of psychiatric disease (such as depression) or a suicidal crisis.[48] Operating with this kind of psychiatric understanding of suicidality, some clinicians and researchers derive an imperative of suicide prevention at all costs - even for the palliative context.[49] There are, however, more voices advocating for a lively discussion of desire to die and suicidality that is more attentive to non-psychiatric manifestations of suicidality as well as the right to (assisted) suicide in psychiatric patients.[47, 50, 51]

Although studies confirm that desire to die is more prevalent in patients with psychiatric illnesses such as depression or anxiety disorders – and therefore the psychiatric approach remains to be important –, it is also common in healthy older people near the end-of-life.[52, 53] Prevalence varies depending on study and sample: whereas 18.3-44.5% of oncological patients and 12.9% of geriatric patients report a desire to die, up to 22% of patients with multiple sclerosis report suicidal thoughts and 24.5% of those patients seeking assisted suicide in Switzerland are neurological patients according to recent studies.[54-58] Besides underlying diagnoses, the different concepts of desire to die used also account for the variance in desire to die prevalence as assessed in empirical research, as a recent study shows.[59]

A desire to die may vary both intra- and interpersonally with the possibility for a simultaneously existing will to live.[7, 60, 61] The will to live lacks a widely accepted theoretical model.[60] Instead, it is variously described as relating to survival or a wish to continue living, an instinctive force which can be influenced by a global state of well-being, but also as stemming from an internal struggle between life and death.[60] Colosimo et al. (2017) coined the term "double awareness" to make sense of this phenomenon, defining it as *"a person's capacity to be engaged in the world while preparing for impending death"*.[62] As human beings, we are able to experience seemingly paradoxical mental states at the same time: patients despair and hope, they reject company but do not want to be left alone or they request the most aggressive medical treatment while longing for a hastened death. This capacity for double awareness can be applied to make sense of the coexistence of will to live and desire to die.[61]

A common form of describing the desire to die phenomenon is by reporting on its backgrounds, meanings and functions which are equally diverse. Studies report that often a combination of physical factors (e.g. pain, fatigue, dyspnoea and loss of function), psychic or emotional factors (e.g. depression, fear or hopelessness), social factors (e.g. the feeling of being a burden and (fear of) dependency) as well as what Rodriguez-Prat et al. (2017) call "loss of self"[63]: the loss of control, the loss of self-esteem and the subjectively felt loss of dignity over the course of disease progression provide the backgrounds for developing a desire to die. Other studies also name spiritual aspects such as the loss of meaning and a profound lack of a sense of life.[5] As Belar et al. (2024) point out, the experience of time, of being in a state of transience also seems to be a common experiences that influences desires to die.[64] In their model of common pathways of distress, Rodin et al. (2008) found that both depression and hopelessness independently predict the desire for hastened death in terminally ill cancer patients while mediating effects of other psychosocial (self-esteem, spiritual well-being and attachment security) and disease-related (physical symptom burden and age) variables.[65]

Meanings of desire to die are often not easy to pin down or distinguish from its functions. Meanings concern the patients' subjective attempts at making sense of their desire to die that potentially varies in dependency of a person's cultural background or illness narrative.[5] Potential meanings of desires to die according to Ohnsorge et al. (2014) can include

- allowing a life-ending process to take its course,
- to let death put an end to severe suffering,
- a situation that is seen as an unreasonable demand or a life that is experienced as without value,
- to relieve others from the burden of oneself,
- preserve self-determination,
- move on to another reality or be an example to others.[5]

Rodriguez-Prat et al. (2017) identify additional meanings of a desire to die: a cry for help or, perhaps paradoxically, an expression of a will to go on living, but not in this way.[63]

A desire to die is not an affliction that patients suffer under, but a psychological construct that serves several important functions. Perhaps the most important function of desire to die is its potential as a means for communication: while talking about existential topics at the end-of-life is often not easy and sometimes avoided,[66] expressing a desire to die immediately draws attention and thereby opens the conversation for these topics.[67] Often, a desire to die can serve as a last means to regain control. Patients who lose control over their body and their life may find inner support in knowing that at least they are in control of ending their own life.[68] Other functions include shortening the exhausting timeline leading towards inevitable death,[63] or gaining attention and care from health professionals and family.[69]

The desire to die can therefore be described as its own phenomenon, specifically describing the experience of patients with chronic or life-limiting diseases or people near the end-of-life. Whereas there is no therapeutic intervention to date specifically targeting desire to die, interventions like Dignity Therapy or Managing Cancer And Living Meaningfully (CALM) attempt to support patients in their experience of dignity, legacy and positive life review.[70, 71] First results show effectiveness in increasing patients dignity, psychic well-being, and quality of life, but do not measure whether these decrease potential desire to die.[71]

2.3. Communication: Talking about Death, Dying and Desire to Die

As there is no specific therapeutic intervention yet, communication can be seen as the first intervention to be considered before others.[10] Therefore, basic principles of end-of-life communication need to be understood to progress further.

As Gudat, and colleagues (2015) put it, communication can be understood as an *"intersubjective interaction that involves not only an exchange of verbal information but also opens a space where demanding work on relationships is done by people with different biographies and visions"* (p.204).[72] Additionally, they describe communication as an often-ritualized interaction where conversation partners are assigned certain roles.[72]

Communication about desire to die can be situated as one very specific aspect within end-of-life communication. There is not a lot of research that specifically examines conversations about desire to die.[10, 73-76] Drawing from evidence in suicidology research, the updated 2020 *German National Guideline* recommends the proactive approach on desire to die.[7] It states that asking about suicidality does not carry an iatrogenic risk of either causing or increasing latent suicidality in patients. Therefore, by analogy, the same should apply to desire to die.[7] By now, a few studies with samples from patients in their last year of life support these claims: in 2019, Porta-Sales et al. asked $N = 193$ oncological patients about potential desire to die. About 95% of them did not find the question upsetting, regardless of whether they had a desire to die themselves.[73] The same research group published results in a proof-of-concept study according to which assessing the WTHD in the first palliative care encounter using a semi-structured guideline (Assessment of the Frequency and Extent of the Desire to Die (AFEDD)) was assessed as "not bothersome" by 87% of the $N = 30$ participants.[73]

In our own DEDIPOM study, we evaluated effects of an open conversation about desire to die on the wish to hasten death, will to live, hopelessness, depression, fear of death and dying as well as health professional-patient-relationship in $N = 85$ patients in their last year of life.[10] There was no deterioration in any of the outcomes, but a significant improvement in depression two weeks after the conversation. All other outcomes showed positive, albeit not significant trends.

As a four-point strategy, the *German National Guideline* suggests that a desire to die needs to be

1. noticed and identified,
2. understood through an emphatic, sense-making process including the patients relative,
3. accompanied competently (which can mean that merely staying present during patients suffering can suffice) and
4. that only then strategies for suicide prevention should be considered.[7]

These instructions for communication are of course limited to those patients and relatives who are (still) able to communicate their desires to die verbally. In palliative care, illness induced impairments often hinder communication, e.g. when a patient is no longer fully conscious, has a speech impairment or a decline in cognitive abilities.[77] Language barriers pose another challenge that can only partly be solved by instigating an interpreter.[78] For the sake of brevity, this doctoral thesis cannot go into these types of communicative challenges.

More broadly speaking, research on end-of-life communication reveals communication needs, but also challenges. For one, several communication partners need to be considered as a minimum: patients, their relatives and responsible health professionals. Their situation and perspectives are drastically different from each other:

Being a patient with terminal illness means, being personally confronted with the lived experience of their illness and their own impending death. This personal affectedness can lead to patients wishes for communication about death, dying and desire to die. Harding et al. (2013) found that patients receiving palliative care wish for conversations about desire to die.[79] Similarly, of $N = 573$ patients with multiple sclerosis (MS), 35.9% described openly addressing death and dying as "*relevant*".[80] However, patients often do not address challenging subjects themselves due to their own insecurity or in order not to burden others, especially their relatives or loved ones.[81, 82]

Relatives, on the other hand, share a (perhaps conflicted) history with the patient, often have to take on the role of informal caregiver and are affected themselves, e.g. by overburdening and grief.[83] They, too, are reported to be reluctant in talking about death and dying.[81] As patients and their relatives can best be described as a system that influences individual communication behavior by their unique structure, organization, and transactional patterns,[84] relatives fill a special role in communication about end-of-life issues and desire to die.

Lastly, health professionals have the knowledge to offer an understanding of the illness in medical terms and the power to grant treatment.[43, 72] Even though they value open communication about death and dying, many also report own reluctance in addressing end-of-life topics with their patients.[43] Udo et al. (2014) found that health professionals fear emotional overload when addressing desire to die.[8] Other reasons may have to do with the predominantly curative culture in medicine that sees death as failure and therefore complicates open communication about it.[85] A resulting "defensive medicine" is considered to relate to a tendency in health professionals to over-prescribe and over-treat due to fear of being legally charged.[31]

There are, however, established, and effective approaches for health professionals to communicate about end-of-life issues. To build basic trust in conversation, Drecksen et al. (2017) found that the right combination of empathy, authenticity and the necessary distance has proven to be effective.[86] Additionally, Omilion-Hodges and Swords (2015) described successful palliative care providers using a model they termed "mindful communication".[87] The four key components of mindful communication are listed as a) know your audience (e.g. by exploring patient biography), b) ask questions (i.e. applying a proactive and interested approach), c) discard scripts (e.g. by remaining authentic and bringing parts of one's own personality into the conversation), and d) recognize your role (e.g. by reflecting in which professional or personal role you currently act in relation to the patient).[87]

The communicative approach most often named, however, is “person-centered communication” which can be defined as a communicative practice that a) elicits and understands patient perspectives, b) understands patients within their psychosocial and cultural contexts, and c) attempts to reach a shared understanding of patient problems that are followed by treatments concordant with patient values.[88] Studies show that patient-centered communication increases patients’ emotional well-being, their trust in health professionals and their adherence to recommendations.[89, 90] However, person-centered communication is more than just a health professional skill, as patients need to engage in person-centered communication as well.[91]

This example of empirical evidence for the co-creation of communication may pose a challenge for underlaying communication models, as not all of them are equally well-suited to capture this dynamic. There are some established psychological communication models that conceptualize communication in different ways, thereby offering a more or less fitting framework for the empirical findings listed above. Depending on the year of their development and dominant concepts at the time, psychological communication models can be divided in transmission (sender-receiver) models and transactional models that differ in their view on linearity of communication and interdependence of communication partners.[92] We will return to the importance of communication models later in chapter 7, when I explain and discuss in detail the communication model best-suited for making sense of existential communication about death, dying and desire to die.

3. Basis of Data, Methods and Aim

For more than 15 years, the Center for Palliative Medicine at the University Hospital Cologne has conducted research projects to advance understanding of desire to die, illuminated different stakeholders’ perspectives on the phenomenon, and supported health professionals in accompanying patients with a desire to die.[10, 56, 93-98] To meet needs for training in dealing with desire to die reported by health professionals,[95] a first clinical approach and two-day training curriculum was developed.[88,94] Guideline and training were based on an extensive literature search as well as results from expert focus groups. Health professionals who attended one of the two pilot trainings reported increased self-confidence, knowledge, self-reflection on attitudes as well as skills in dealing with desire to die, measured by a questionnaire specially developed for this purpose, but not validated.[94]

Based on these preliminary results, the study “The Desire to Die in Palliative Care – Optimization of Management (DEDIPOM)” was designed to refine the clinical approach and evaluate the effects of conversations about desire to die by trained health professionals on patients in their last year of life. All data examined in this doctoral thesis was gathered within the DEDIPOM study which was funded by the German Federal Ministry of Education and Research and lasted from 5/2017 - 12/2020.

DEDIPOM was a mixed-methods study comprised of three phases:

1. Phase: Refining and consenting the clinical approach

In individual qualitative interviews, *N* = 14 patients in their last year of life were asked about their preferences and experiences in conversations about desire to die. A first version of the clinical approach was updated with this information and then consented in a two-round Delphi survey. From *N* = 377 invited (inter-)national experts, *n* = 210 took part in round 1 and *n* = 200 in round 2.[99, 100]

2. Phase: Training of health professionals

   In 12 two-day trainings, *N* =102 health professionals were trained in dealing with desire to die and on using the clinical approach. Health professionals reported their self-confidence, knowledge, self-reflection on attitudes and skills in quantitative pre-post evaluation questionnaires.[94]

3. Phase: Evaluation of conversations about desire to die

   Of the trained health professionals, *n* = 29 recruited *N* = 173 patients to lead one conversation about desire to die. The effects of this conversation on clinically relevant outcomes were assessed in *N* = 85 of these patients, using validated, quantitative questionnaires.[10] Health professionals documented *N* = 79 of these conversations on provided standardized conversation sheets.[67] For qualitative evaluation of the desire to die conversation, 14 interview triads were conducted with a sub-sample of *n* = 13 patients, *n* = 13 of their relatives and *n* = 13 associated health professionals in individual qualitative interviews.[101]

The procedure and all phases of the study are illustrated in figure 3. For more details on methods and aims, please refer to the study protocol.[96] The DEDIPOM study received a positive voting from the Ethics Committee of the University of Cologne (#17-265) and was registered in the German Clinical Trials Register (*DRKS*00012988).

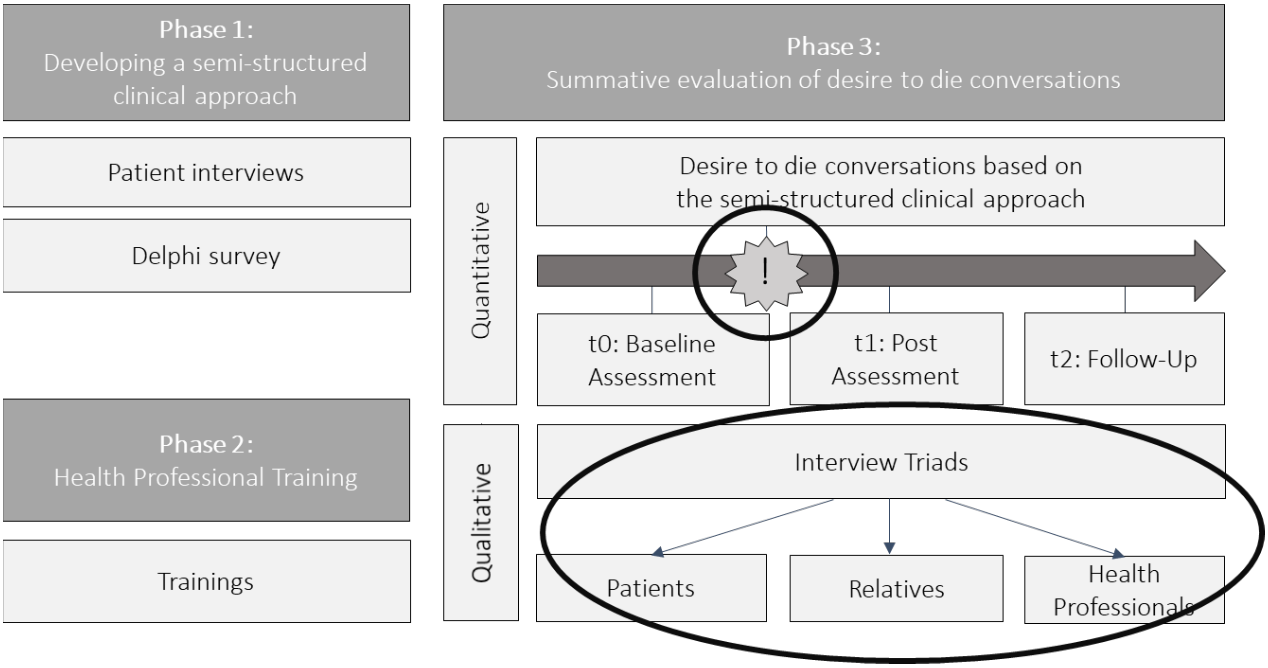

***Fig. 3** Procedure of the three-phase mixed-methods study DEDIPOM. Basis of data examined in this doctoral thesis are circled. Own illustration.*

This doctoral thesis is based on qualitative data from phase 3 which allows to explore desire to die conversations from different perspectives.
To begin, content and structure of desire to die conversations between health professionals and their patients are explored and critically discussed. Paper 1 reports the health professionals' experiences of desire to die conversations documented via open questions answered on a documentation sheet.[67] What are contents of desire to die conversations and how do health professionals realize such a conversation?

Secondly, the experience of such a conversation on desire to die as well as surrounding conversations on death and dying are examined from the perspective of different stakeholders. Paper 2 follows a framework analysis approach that is well-suited to reduce large amounts of qualitative interview data and present inter-relationships between different stakeholders.[101] Following this approach, it is possible to establish a typology of communication from interview triads with patients, relatives, and health professionals about the desire to die conversations. How do communication styles and relationships between these stakeholders influence how communication about death, dying and desire to die is realized, perceived and evaluated? What potential types of communication emerge and what do they reveal about the talking about desire to die in clinical practice?

Both papers follow a qualitative approach that was chosen based on appropriateness to the study subject and the explorative nature of the study's aim.[102] Whereas quantitative methods allow to derive generalizable results usually based by means of data large samples, qualitative methods are well-suited to investigate phenomena that have seen little attention in research as of yet.[102] Another advantage of qualitative methods is their capacity to remain close to the subjective experience of study participants and therefore allow insights into their lived experience.[102]

The aim of this doctoral thesis is to explore patterns of communication about death, dying and desire to die in patients, relatives, and health professionals. The target audience for this doctoral thesis are palliative care providers of all professions and in all settings of care that seek to improve their understanding of communication about this existential topic and their own way of talking about desire to die with their patients and their relatives.
After presenting both paper 1 and 2 for extensive reading, I will continue with a summary of their procedure and findings within the next chapter, before I provide a synthesis of findings within the context of the transactional communication model by Dean C. Barnlund.[11] By applying the transactional model of communication to the empirical findings from paper 1 and 2, I aim to both give these findings a clearly arranged structure as well as test the value of the transactional model of communication for communication about death, dying and desire to die.

4. Synthesis of Findings

In this cumulative doctoral thesis, the content, experience, and personal evaluation of desire to die conversations is presented using a multi-perspective qualitative approach. Integrating textual data from desire to die conversations documented by health professionals (paper 1) and interview triads with a sub-sample of these same health professionals, their patients, and the patients' relatives (paper 2) allows to form a substantial contribution to understanding of communication about, death, dying and desire to die at the end-of-life. The following chapter contains summaries of the findings discussed in both papers before findings are synthesized in a detailed discussion, following the transactional communication model.[11] The original texts of both papers discussed in this cumulative doctoral thesis as they have been accepted for publication can be found at the end of this dissertation.

4.1. Paper 1: Health professionals' implementation of and reflection on desire to die conversations

Primary aim of this paper was the exploration of how health professionals trained in dealing with desire to die both implement and experience conversations about it, using an open (proactive) approach.[67] After taking part in a two-day training on desire to die, health professionals were asked to recruit patients from their practice for an open conversation about desire to die. All in all, N = 29 health professionals held N = 79 of such conversations and documented them on documentation sheets consisting of open questions. A mixed inductive-deductive thematic analysis of open on documentation sheets and relevant parts from qualitative interviews allowed for a grouping of seven themes with 28 sub-themes:[103]

1. *Beneficial Aspects*
2. *Hindering Aspects*
3. *Follow-Up Measures*
4. *Addressing Desire to Die*
5. *Patient Reactions*
6. *Content*
7. *(Self-)Reflection*

These themes shed light on structure, content and personal evaluation of these desire to die conversations from the perspective of health professionals.

As *Beneficial Aspects* for conducting these conversations, both attributes of the patient as well as the health professional played a role: an open, well-composed and reflective attitude from both conversation partners is appreciated. Health professionals also valued the feeling that the conversation was beneficial for the patient, e.g. by bringing emotional relief or initiating changes in care.

Hindering Aspects were reported as well, with health professionals listing challenges with attentively staying on topic if the patient is not as open to it or with navigating the presence of relatives during the conversation. Supporting patients that reacted with strong emotions and concerns which health professionals experienced as barely containable was deemed psychologically taxing.

Desire to die conversations were reported to initiate *Follow-Up Measures* such as devising a care plan, changing care settings, providing information on therapeutic measures, or simply staying available for supportive follow-up conversations.

When health professionals described the content of desire to die conversations, they reported on their ways of *Addressing Desire to Die:* these ranged from direct questions about a present desire to die to questions about symptom burden or wishes, thoughts and fears regarding the end of life and thereby illustrated health professionals' individual communication styles. Most *Patient Reactions* were positive, i.e. open, neutral, or confirming, while only a few showed strongly emotional or defensive reactions.

Further conversation *Content* included the exploration of background, meaning and functions of the desire to die, e.g. having a biographical history with suicidality. Conversations were also used to give patients room to express their wishes and fears or give an account of their personal history. In some conversations, resources could be activated while in others, health professionals simply stayed present and endured the patients' suffering with them. Lastly, health professionals showed a remarkable capability for *(Self-)reflection.* Besides reflecting on the concept of desire to die itself, their own communication practice and their changed expectations regarding desire to die, they also empathized greatly with their patients, e.g. by honoring their biographical achievements.

When considered as a whole, findings from paper 1 indicate the importance of desire to die conversations for three distinct reasons:

1. The open and respectful act of asking about a patients' desire to die serves as a door opener for other existential or practical concerns important to the patient. These can range from patient education regarding their end-of-life options to concrete changes in the care plan but can also simply mean that a patient finds room to express their own illness narrative.
2. This function as a door opener positions desire to die conversations as a catalyst for existential concerns within a larger communicative process. The conversation often served as a kick-off for follow-up questions and a deepened examination of end-of-life concerns. As health professionals report, they experienced this process as a deepening of their patient-relationship.
3. The conscious planning, conducting and documentation of desire to die conversations supported the health professionals in a process of self-reflection. Their profound knowledge and interest in their patients as well as their implementation of the fundamentals of mindful communication shows that the topic of desire to die is well-suited to facilitate increased attention and care.[87]

4.2. Paper 2: Patients', relatives' and health professionals' experiences of conversations about death, dying and desire to die

In this paper, the aim was to explore in what ways patients, relatives, and health professionals experience communication surrounding death, dying and desire to die and whether there is a typology of communicative styles.[101] After having had at least one documented desire to die conversation as described above, a sub-sample of N = 13 patients, N = 13 of their respective health professionals as well as N = 13 of the patients' relatives participated in individual qualitative interviews, forming N = 14 multi-perspective interview triads. Through a framework analysis approach,[104] the communication within the triads was first analyzed along five interpretative themes:

1. *How was the communication perceived?*
2. *Did conversation partners share a reality?*
3. *How was death talked about?*
4. *What communication strategies were used?*

In this analysis, desire to die conversations as well as death talk in general turned out to be interpreted differently dependent on the individual and therefore susceptible to communicative pitfalls. Of all patients, relatives and health professionals, a surprisingly large number offered completely different accounts of the same situations. In a few cases, patients did not remember having a desire to die conversation at all. These might be due to time between conversation and interview, but also different understandings of what constitutes a desire to die conversation or health professionals' way of addressing the topic. Regarding the way participants communicated about death, most patients, relatives and health professionals preferred to talk mainly about concrete matters of end-of-life care. Only in some cases, communication about existential issues like spiritual concerns or fear of death was explicitly demanded by patients.

The almost universal exclusion of relatives from desire to die conversations by patients, but mainly by health professionals, is another main finding of this paper. However, whether or not relatives want or need to be included in desire to die conversations remains debatable. While some relatives themselves did not see it as an option at all, others suffered from the feeling of being left out.

A typology was developed based primarily on the expressions on the theme *Did conversation partners share a reality?* and enriched by the expression of the four other themes. Shared reality proved as a vital concept for analysis because it is both a strong human need and allows to explain certain types of miscommunications.[101] Triads could be grouped into three distinctive types: *Between the Lines*, *Past each other* and *Matter-of-fact* that each require different approaches from health professionals:

1. *Between the Lines:* In type 1 there was a predominant feeling of ambivalence regarding desire to die and related communication needs. In this type, patients were often presented as withdrawn and did not openly talk about their desire to die. This necessitated that health professionals read between the lines more than in the other types. Relatives of this type felt rejected by the patient's reticence and some reported displaying symptoms reminiscent of

complicated grief. Both patients and relatives from this type reported the highest distress, lacked trust in each other's honesty and displayed a low tolerance for emotional disharmony.

Due to its secretive and sometimes mistrustful communication, especially between patients and relatives, type 1 would best benefit from a proactive approach by the health professional. Having a desire to die addressed by a third party can offer relief for the patient and may give hints as to what kind of support might be needed, e.g. psychotherapeutic or family counseling.

2. *Past each other:* The second type stands out through a contradictory finding: all triad members explicitly wish for open conversation about desire to die, yet follow different strategies to achieve it. This matches the high number of situations in which members of this type often seem to talk past each other: they objectively experience the same situation but subjectively remember it completely differently. However, only a few triad members are discontent with the communication in their triad. Patients of this type cast their health professionals and relatives in different roles as conversation partners: one is responsible for talking about existential issues like fear of death, the other for concrete matters of care or funeral planning. Here, too, relatives are seldom personally acquainted with the health professional or part of the conversation about desire to die. When they do meet, the exchange of desired information (e.g. on laws regarding assisted suicide) does not always succeed. Ill-fitting communication styles of this type warrant a more accompanying approach from the health professional. They should remain present and sensitive to potential communication pitfalls as well as routinely check understanding of the information shared.
3. *Matter-of-fact:* Type 3 seems to present the least challenging type for communication. It is characterized by satisfaction with the absence of conversations about desire to die. Most patients and relatives do not wish for talking about death, dying or desire to die. They judge their communicative atmosphere to be open, but in the content of their conversations, only concrete matters of end-of-life care are taken into focus. Health professionals seem content with this situation as well. While most patients of type 3 deny holding a desire to die, few report that they keep it to themselves to not alarm others. The contact between relatives and health professionals remains sparse, but deeper contact is not wished for or seen as an option. In this type, existential questions about death and dying remain dormant and are not addressed, but they also do not (yet) appear as pressing. Although the third type does not report high communication needs yet, their health professionals should remain vigilant to how these may change with a higher burden during illness progression. Additionally, the action-oriented approach focusing solely on concrete matters of care might offer a feeling of control, but can entail a neglect of existential issues regarding death, dying and desire to die.

Integrating findings from the three types with the overarching findings from all triads, paper 2 paints the multi-perspective communication about death, dying and desire to die as a complex, but vital endeavor:

1. To assess communication and support needs and potentially gain further information on the patient, health professionals should invite relatives to offer their point of view.[105]
2. Honoring the fact that there is no fail-safe way to deliver information or assess a situation exactly as it is from only one perspective, health professionals should remain sensitive to potential misjudgments and not act on assumptions. A way of integrating this into practice could be asking patients and relatives about their understanding of facts and situations.[106]
3. As they can require different communicative strategies, health professionals should keep vigilant for typical patterns of communication. However, there should remain an openness for idiosyncratic cases. Staying present in authentic support is fundamental for the possibility of beneficial desire to die conversations.

5. Discussion

Within this chapter, I will elaborate how communication about death, dying and desire to die as a special form of existential communication can be understood within the model of transactional communication. To this end, I will firstly argue the need for psychological models of communication in general. I will then describe the transactional model of communication as proposed by Dean C. Barnlund,[11] in contrast to more commonly applied transmission (sender-receiver) models of communication.[92] By giving a detailed account of the model's flaws and benefits in reference to findings from Paper 1 and Paper 2, I will establish the necessity to understand desire to die conversations as a mutual and ongoing co-creation of meaning by both communicators. The introductory remarks concerning framework conditions of culture, law and structures of care will be incorporated as context factors in this communication model and positioned within recent literature.

A final outlook will critically examine the merit of such a communication model for conversations about death, dying and desire to die.

5.1. Communication in the Last Year of Life – The Need for Psychological Models of Communication

Everyday life offers enough challenges in communication to have spawned a whole genre of advice literature: communication problems within couples, families or in professional contexts. In palliative or hospice care, it appears that communication is prone to be even more challenging. Partly due to cultural taboos (see chapter 2) talking about death and dying is considered uncomfortable or even dangerous.[43] Communication situations like breaking bad news (e.g. diagnosis of terminal disease) or discussing possibilities of end-of-life care are often experienced as borderline traumatic or are simply avoided.[107, 108] Despite its potential for providing relief in patients in their last year of life, health professionals tend to hold back in addressing desire to die or suicidality proactively.[10]

These conversations are an essential part of providing holistic care addressing emotional, physical, spiritual, psychological and social needs as well as enabling prognostic information and shared decision making.[109] Therefore, the existential themes outlined here emphasize the importance of communication in palliative care. According to Ragan (2016), one can even say that "*palliative care is communication (sine qua non)*" (p. 1).[110] Only by means of communication, patient autonomy can be honored by inquiring about patient values, wishes and preferences. A patients' desire to die can tell us about when their sense of living a life worth living is hurt. Therefore, a conversation about potential desire to die can also become a conversation about what kind of life the patient considers worth living. Considering this, ensuring that communication is successful and beneficial to all communication partners becomes a pressing issue.

At this point, it is important to acknowledge that there is not a common standard by which communication is deemed successful or not. Although there are prevailing common sense views of successful communication (e.g. "*She understood me*" or "*He knew what I meant*"), philosophical definitions diverge. For the sake of this dissertation, I follow the definition that "*thought contents must be intersubjectively shareable and (…) speaker thought content and hearer thought content stand in some particular relation.*" [111] (Pagin, 2008, p.11-12)

To this end, visualizing the communication encounter by using a communication model can prove useful to gain insight. Through providing an overview, allowing for detection and adjustment of patterns as well as matching with existing mental models, visualization of information can help readers comprehend influencing factors on what makes communication successful in this sense.[112] I therefore am interested in a model's hermeneutical value: how can a particular model help to find meaning behind a particular communicative process? This finding of meaning has practical value as interpretation of statements is a major part of the psychotherapeutic toolkits. Moreover, gaining theoretical insight can be a first step in changing a personal perception of a matter and thereby gives the opportunity to adjust practical behavior accordingly.

Communication psychology offers different communication models of various degrees of complexity that claim different explanations for successful or unsuccessful communication. For this doctoral thesis, I will apply the transactional model of communication by Barnlund (1970) to the findings from Paper 1 and 2 to visualize and structure the findings and later discuss its usefulness for conceptualizing communication about death, dying and desire to die.[11] Therefore, I will give an overview of the theoretical background and structure of the transactional model of communication, before I test its applicability against findings from Paper 1 and 2. At first, though, I will give reasons for my decision to choose the transactional model of communication by giving a brief introduction to and comparison with the widely known and historically older alternative model of communication: the transmission model.[92]

5.2. Transmission Models of Communication

In an older tradition of communication models, communication is conceptualized as a linear, one-way path in which a sender intentionally communicates something to a perceiver.[92] The sender conveys an information (e.g. a patient states "*I can't go on like this*.") and the receiver (e.g. a health professional) gets the information. When the health professional answers (e.g. with "*Now that's something we don't want to even think about, do we?*"), the process repeats with reversed roles. In transmission models, responsibility for conveying information correctly is with the sender. The receiver inhabits a more passive role. Potential for misunderstanding during the disclosure of information comes as noise, either environmental (e.g. noise from a construction site) or semantic. Semantic noise designates problems in encoding or decoding of the communicated information, e.g. when participants do not understand a symbol or a different meaning of a used word.[92]

However, transmission models are criticized for their implicit power imbalance: the sender always has more information than the receiver and therefore more power.[105] They set the tone and terms for the conversation, while the receiver remains mostly passive. Disclosure of information is seen not unlike exchanging a commodity. There are, of course, real-life differences in the roles of sender and receiver: a health professional as sender does in fact have more knowledge obtained in medical school and is an expert in their field. However, even in a commonsense theory of communication, more factors come to mind that play a role: what prior medical knowledge does the patient as receiver have? What experience knowledge does she or he have as the person with the sick body? How willing to engage with each other are both parties, how responsive are they to the way the other acts and reacts? Considering just a few of these factors helps to make tangible the idea that conversation should be considered as equally created by all parties involved. It is this meaning of "equality" which I apply when I refer to conversation partners as being equal in the rest of my thesis.

When communication is conceptualized as an interaction between equals, this model can be criticized for dismissing the co-creation of meaning within communication. If meaning is not co-created, but information is an exchangeable commodity, just one person is to blame for misunderstandings. In the case above, either the health professional is not open or willing enough to engage with the patients' desire to die, or the patient failed in conveying the real meaning behind her or his sentence due to lacking communication skills. When conceptualized within such a transmission model, most desire to die conversations reported on in Paper 1 and 2 must be dismissed as failures: most patients had no memory of having had a desire to die conversation at all or remembered it vastly differently than their health professional. From a transmission model perspective, the most likely interpretation is the health professional's failure in unambiguously delivering their inquiry about the patients' desire to die.

Conceptualized like this, communication lacks mutuality: sender and receiver are distinct entities with a neutral pathway for disclosure of information in between. The transmission model is an interpersonal model in which communication partners are separate and act in reaction to each other. Thereby, the transmission model allows for clear criteria under what circumstances communication can be considered successful or unsuccessful. Only when the message, as it was intended by the sender, has been understood by the receiver can we consider the exchange of information a success.

Following the line of argumentation from du Pré and Foster (2016),[105] I would consider a rigorously applied transmission model of communication as unhelpful to fully capture communication about existential topics like death, dying and desire to die.

5.3. Transactional Model of Communication

A conceptually very different model of communication is the transactional model proposed by Dean C. Barnlund in 1970.[11] Barnlund’s model allows to answer some of the criticisms applied to the transmission model. Within this model, the power imbalance is bypassed through a model of co-creation. Both sender and receiver create a shared meaning and embody both roles simultaneously in an ongoing process. Thereby, communication is seen as integrated in our social reality as not only a way to understand it, but also to construct it.[92] Instead calling on sender or perceiver, the transaction model refers to both roles as communicators that act simultaneously. It also expands the ultimate goal of communication from exchanging messages to creating relationships and form our self-concepts.[92]

Within this model, openness for interpretation and the way information is perceived is crucial. Therefore, ongoing awareness of feedback cues by both communication partners becomes necessary. However, transactional models still consider the inevitability of noise. Noise can alter how information is perceived, e.g. as external (such as the formerly mentioned construction site) or internal factors (such as fears of engaging with certain topics). Therefore, misunderstandings may arise. Within a transactional model, these are not to be eradicated but rather held in mind and used to gain potentially deeper understanding and connection. Another distinctive feature of the transactional model is its embeddedness in contexts that may account for various forms of noise. These comprise of

1. a physical and psychological context (i.e. the room in which the conversation is held and the psychological conditions both communicators are in),
2. a relational context (i.e. personal common history of the communicators or lack thereof),
3. a social context (i.e. implicit communication norms like who is allowed to speak first) and
4. a cultural context (i.e. various aspects of identity such as race, gender or class).[92]

For a simplified illustration of the transactional model of communication, please refer to figure 4.

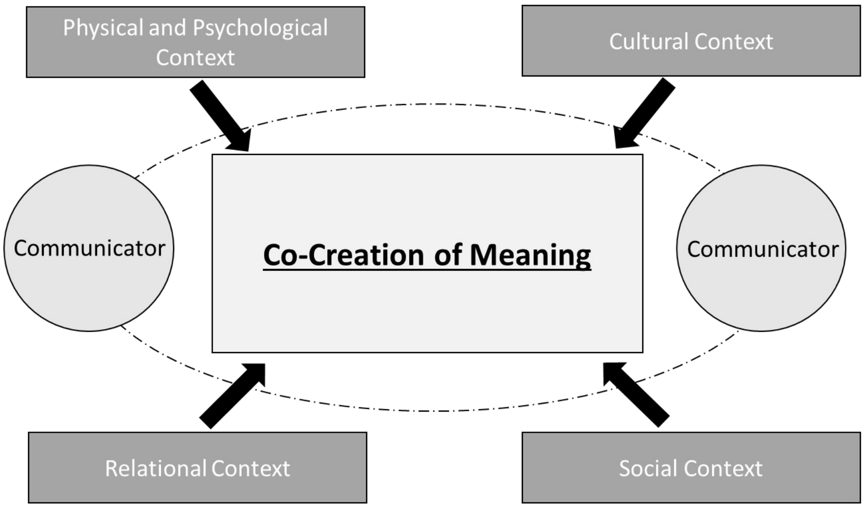

Fig. 4 *The transactional model of communication with four types of context. For the sake of simplicity, context factors are illustrated as separate although they can be related or overlapping. Own illustration.*

Based on these observations on the importance of context in the transactional model, we can state that it is a relational model in which the communication partners are conceptualized as interdependent. Essentially, the transactional model easily takes root in a relationship-centered care paradigm that focuses on emotions, presence and empathy.[105] It is easy to see how this model holds potential for desire to die conversations: some of the obvious implications are picking up on underlying emotions of desire to die, staying present even if conversation topics become challenging topics and showing empathy towards what the patient attempts to convey through a desire to die.

If we reconsider our introductory example (Patient states: "*I can't go on like this.*" - Health professional answers: "*Now that's something we don't want to even think about, do we?*") with a focus on the mutual co-creation of meaning and an interest in the chances inherent to misunderstandings, it looks rather different. The health professionals' answer allows to consider context factors such as their relational history (Do patient and health professional already have a long history of fighting against illness?), the health professionals' cultural context (Has the health professional undergone a professional socialization with a focus on predominantly curative care?) or their potential psychological barriers. Thus, this model provides us with the option to consider more information to interpret the conversation. With its focus on co-creation of meaning and its applicability to relationship-centered care, the transactional model of communication seems useful to serve as a productive lens for analysis of conversations on desire to die. In the following paragraph I will apply the model to findings from Paper 1 and Paper 2.

5.4. What does transactional communication mean in the context of desire to die conversations?

In the following chapter, I will utilize the transactional communication model and its premises as a descriptive means to a) structure and illustrate conversations about death, dying and desire to die as experienced by patients, health professionals and relatives and b) integrate what these three stakeholders evaluate as successful or unsuccessful within these conversations. Therefore, I will first analyze the transactional models' premise of co-creation of meaning in desire to die conversations, then go into the impact of context factors, before I consider the role of misunderstandings in desire to die conversations.

Co-creation of meaning: talking about desire to die as a conversation offer on existential topics

Within the documented desire to die conversations in Paper 1, I interpret the topic of desire to die as a "door opener": an offer to talk about existential topics. By asking about desire to die, a conversational space is opened to consider all end-of-life related subjects that are relevant to the patient. The metaphor of a door opener basically describes a mutual adaptation of the conversation content through communication partners (e.g. health professional and patient): topics are adapted depending on how communication is perceived by both communication partners.[92] This co-creation of meaning can be illustrated through the transactional model in which this change in conversation topics would be described as a process of mutually steering the conversation in a common direction.

A key quote from Paper 1 by a health professional is that their "*conversation just flowed*": the health professional does not even know whether the patient perceives the conversation as a desire to die conversation. In fact, this is not the most important aspect, as conversations are not necessarily seen as a linear exchange of information that follows a set aim. Rather, health professionals seem to accept the back and forth of co-creating the conversation topic. The topic of desire to die often opens the metaphorical door to more factual topics of planning care at the end of life or patients' funeral. This is a commonality with the findings from the interview triads in Paper 2 and will be discussed there.

In their list of what they considered beneficial or hindering for conversation, health professionals explicitly acknowledged the shaping of conversation by situational context (e.g. presence of spouse during conversation) or psychological barriers of the patient. Although they describe this shaping as hindering, a phrase used to describe it is that "*It just didn't fit*". This indicates the interdependence of both communicators, as the intention to send a message is apparently not enough for successful communication: it needs to fit for both communicators, who both simultaneously create the meaning of the conversation.

Considering contexts: How to address desire to die

Psychological and Relational Context

When considering the findings the documented desire to die conversations from Paper 1, the interdependent dynamic of both communicators as proposed by the transactional model becomes apparent in the conversation openings and reactions of patients. Potentially based on their own psychological context and their relational context or history with the patient, health professionals decided on either a direct or less direct approach. They asked about fears and wishes at the end-of-life or more direct about thoughts about ending one's own life prematurely. Psychological context could subsume anything in a diverse range of factors, starting from time pressure, an internal motivation to have a “good” conversation or not being in the mood to talk. Similarly, relational context between health professional and patient is equally diverse (and in our case unknowable) and could include (mutual) sympathy, a longer or shorter time spend together in the treatment of illness as well as previous time spent for relationship building. The health professionals’ initial opening might also be influenced by cultural or social context that sets norms about the appropriateness of speaking about death and dying directly.

In their reaction to these openings, patients were influenced by the exact same contexts as well. Therefore, what could otherwise have been considered failed communication (e.g. a negative reaction that describes the unpleasantness of the topic for the patient) becomes open for interpretation within the transactional model. It is possible that a more subtle conversation opening might prompt more subtle or even evasive responses, as the topic is not clearly named and therefore the patient can choose more freely how to steer the path of conversation towards a different topic. Depending on the influencing factors named above, the opposite might equally be true: a very direct and open approach to the topic of desire to die might cause a more evasive answer, as the approach might not fit the patient and their situation and so, alternative topics are sought out.

Another psychological context factor at play here may be the relevance of desire to die for the study patients. Health professionals eventually documented that according to their perception, only 22% of patients held a desire to die.[10] It is therefore entirely possible that desire to die simply was not the most pressing matter for patients. Due to its capability to incorporate both intra- and interpersonal aspects, but also broader context factors, the transactional model of communication proves highly capable to illustrate the complexities of desire to die conversations.

What we learn about the communication dynamic between patients, health professionals and relatives from the interview triads in Paper 2, provides even more viability for the use of the transactional communication model. As already discussed in the margins, most patients could either not remember the desire to die conversation or remembered it vastly differently than their health professional did. A transactional model considers the entire process of co-creation of meaning and the equal role both participants play. Reading feedback cues from patients, health professionals might have chosen a more careful or subtle approach to the topic desire to die, either by how indirectly they phrase their questions or by broaching related topics instead of inquiring about desire to die itself. In this line, one can argue that health professionals were respectful of their patients’ equal position and allowed for them to co-create the conversation by interpreting and respecting patients’ cues and only going as far as patients themselves were ready to.

Cultural Context

At this point, potential for internal forms of noise due to cultural context must be considered: talking about existential issues like death, dying and desire to die is still considered a taboo topic by many, despite recent developments that suggest a change in attitude.[22, 113]

As detailed above, all participants within the interview triads were shaped by these cultural contexts. Therefore, a more careful approach towards the topic might have been a subconscious decision from both patients and health professionals in equal measure. This underlines the interdependency of conversation partners within the transactional model that might have shaped conversation in a way that it becomes neither too overwhelming for the patients nor too challenging for the health professionals. A recent study with patients, relatives and health professionals emphasizes this delicate balance of relational autonomy with socio-cultural values in which end-of-life situations happen.[114]

Another note from the interviews that picks up on this line of thought is the fact that in most relationships within the triad, death and dying were discussed through a focus on factual topics (e.g. funeral planning). Thereby, these forms of desire to die conversations might illustrate an elegant dance that allows to broach the topic death, dying and desire to die by talking about the tangible instead of the intangible, existential and potentially incomprehensible.[115] This focus on factual topics can be understood and interpreted along the two cultural trends of modernity introduced prior: the medicalization of death and dying and the rising call for greater autonomy in shaping one's own end-of-life.[15, 20, 116]

Social Context

Both papers 1 and 2 provide findings that show the influence of cultural context factors, which tends to overlap with social context: unspoken norms of how to speak about topics. In Paper 1, after exploration of desire to die, the conversation content is reported to focus on concrete measures that follow the conversation. These included the information about and initiation of therapeutic measures as well as the clarification of desired care setting.[67] As per expertise, most health professionals seem to want to alleviate patient suffering by suggesting medical or therapeutic actions, thereby working in accordance with the trend of medicalization of death and dying. This focus in content and language that prioritizes concrete and material topics over existential or immaterial ones is also prevalent in Paper 2. Here, most triad members talk about death more through topics of care and end-of-life planning (e.g. advanced directives or the desired funeral set-up) than potentially existential concerns.[101] I therefore argue that this emphasized aspect of planning is indicative of the wish for autonomy and control over one's own end-of-life. As Joshi et al. (2024) point out, this fluctuation of attention between future planning and reflection of present and past can also be understood within the context of a changed temporality in terminal illness.[117]

Misunderstandings as a chance for interpretation: failed or successful desire to die conversations

We have now analyzed how the co-creation of meaning is present in conversation on death, dying and desire to die and considered various influencing context factors. Another, practical question that can be addressed in such conversations is whether they fulfill their purpose: are these conversations successful?[111]

Not talking about desire to die directly or not remembering the conversation as such could be interpreted as an avoidance of open conversation and harbors risks for potential misunderstandings. However, it can also be seen as a chance for further exploration of additional information. By focusing on related topics instead of desire to die, patients might reveal their wishes and preferences for good end-of-life care and the circumstances under which they would like to continue living until the end.

Another concept within Paper 2 that is heavily drawn upon as an explanation for the misunderstandings mentioned above is shared reality. As the longing for *shared reality* describes a strong human need to experience commonality through communication,[118] the concept of shared reality can be compared to what du Pré and Foster (2016) refer to as shared meaning in a transactional model of communication.[105] Whereas shared meaning as described in the transactional model is always co-created by communicators within a conversation, shared reality is either achieved or not.[118] The question answered by the concept of shared reality – whether communicators perceive their conversation to be about the same topic, thus creating an objectification of subjective realities – is of no fundamental importance within the transactional model of communication.

We can therefore tentatively state that the transactional model of communication does not allow any sort of objective measurement for the “failure” or “success” of a conversation, e.g. whether all communicators (health professionals, patients and relatives) know about a patients’ potential desire to die and acknowledge necessary actions. This can be our first point of criticism for the transactional model of communication on which I will further build my comprehensive critique in chapter 7.6.

A topic that all triad participants commented on is their perception of and reaction to openness (or lack thereof) in desire to die communication. There was an almost unanimous agreement that openness was helpful and should be aimed for. However, attempts at opening up to each other sometimes left ambiguous feelings or emotional overload. In the language of the transactional model of communication, openness can both be considered an unstated social norm as well as a cultural context factor. Therefore, openness can be considered a conviction of one or both participants in conversation, but its realization in communication depends on what both parties make of it in a process of mutual creation.

Some authors go further and criticize openness in conversation as the gold standard, claiming it medicalizes death acceptance, prioritizes direct communication and imposes a medical framework on (palliative) patients that does not fit their needs.[119] In a study by Olson et al. (2021), the authors found that mirroring patients’ language, as well as emotional and verbal cues when approaching topics like death and dying as well as keeping up emotional reflexivity is a more common practice in experienced palliative care practitioners.[119] This matches descriptions of conversations within the interview triads in Paper 2 which could easily be described with the same words that Olson et al. (2021) use: "*a complex interrelationship of patient prognosis, family language patterns, and clinician perspective and goals*" (p.5).[119]

5.5. Considering sample and time of data assessment - a further look at cultural context factors

As has already been established, context factors play an important role in how the conversation about desire to die is co-created by all communicators. However, the cultural context is also reflected through the composition of our study sample and in the time of data assessment. They are not part of the findings relating to conversation content but provide the framework for conversation to happen. Therefore, I devote the following sub-chapter, to contextualize these two aspects with findings from current empirical studies.

Study Sample

Studies repeatedly show that sociodemographic variables like gender, age, migration background as well as diagnosis, health professional background and care setting impact how conversations about death, dying and desire to die are conducted and experienced.[120-122] Within the context of suicide prevention, for example, one study found that women seek more contacts to receive support while men, when attempting to talk about suicidality, often did so through not directly suicide-related and ambiguous topics.[123] This made it harder for men to receive the needed support. Although neither paper 1 nor paper 2 applies a focused analysis along the sociodemographic axes mentioned above, critically examining the study sample allows to spotlight trends regarding gender and health professional background. In both paper 1 and paper 2, it is mostly women who are picked to engage in a desire to die conversation - by mostly female health professionals. This is in line with findings from a study on death talk and gender that found female physicians to spend more time on average on death talk and engage more in social and emotional topics.[124]

Regarding the study sample of health care professionals, the two largest professional groups were nurses (37.9%) and physicians (37.9%). The psycho-social professions are represented by only a small number (24.1%). Other studies show that our sample is representative in the way that nurses are often the ones who are addressed with desires to die, followed by physicians.[125] It is possible that these groups are perceived by patients as those they have the most contact with and those that have the authorization to actually do something other than talk, e.g. prescribe lethal medication.[126] However, these professional groups are those with the least training in end-of-life communication.[127, 128] Studies repeatedly report poor communication skills, especially from physicians.[129] When considering conversations with relatives of patients with a wish for assisted suicide, a Swiss study found that relatives report more contact with providers of assisted suicide than with physicians.[130] This raises the question: who should be responsible for having conversations about desire to die (and medical assistance in dying) in palliative and hospice care? There is a call for a stronger role of psychiatry in these conversations,[131] but I would strongly argue that all groups of the multiprofessional team need to have basic training in communication about death, dying and desire to die. Patients and relatives will approach any team member regardless of training, if they feel safe to do so. As communication is a form of care and a key competence of palliative care, being able to communicate sensibly and effectively is also inscribed into the professional ethos of everybody working in palliative care.[132] Therefore, health professionals are advised against acting purely on their assumptions regarding patients' end-of-life preferences (including a desire to die), especially since evidence suggests that health professionals' assumptions often do not match actual patient preferences.[132] As talking about such existential topics (e.g. end-of-life preferences or suicidality) has repeatedly been shown to not get easier with experience, there is specific need for trainings.[133]

Time of Data Assessment

Data for both paper 1 and 2 was gathered before the ruling of the federal constitutional court from the 26th of February, 2020. During the time in which the desire to die conversations were held, businesslike assistance in suicide was punishable in Germany after §217 of the German criminal code. Anyone who assisted in suicide in a businesslike manner (meaning: for a fee and with the intent of repetition) could face up to 5 years of prison and practicing physicians were threatened to lose their license.[26] In Paper 1, health professionals were trained to use a broad definition of desire to die as basis for an open, calm, and individualized approach towards their conversation. As they reported, this approach was helpful to reduce their own concerns regarding a negative reaction from their patients.

However, when we look at countries with more liberal laws regarding medical aid in dying, there is reason for the assumption that the way of talking about desire to die changes.[76]

As first research from Canada reports, there already are restrictions in the openness of discussions on end-of-life care planning with a new tendency to narrow down the discussion on medical aid in dying.[76]

In those jurisdictions where medical aid in dying is legally authorized, health professionals report a tension between assumptions about patients' rights to be informed about their end-of-life options in conversations and the purpose and possible risks of clinical disclosure.[134] There are different approaches to resolve that tension: The state of Victoria (Australia) where termination of life on request is legal, prohibits health professionals from starting a conversation regarding medical aid in dying to prevent undue influence.[134] In other jurisdictions, health professionals have started to bring up the topic themselves.[134] Yet, these conversations can be associated with intense stress for the health professionals, due to concerns for their own psychological well-being, conflicting belief systems or role conflics.[135] The now legal option of assisted suicide in Germany calls for ethical self-reflection on a personal, institutional, professional as well as societal level.[136] Desire to die conversations will and must change, since every health professional needs to reflect on their answer if a patient asks them for assistance in suicide.

Independent from health professional concerns, patients as well as relatives have already begun claiming their right to this end-of-life option.[126] As the findings of paper 2 show, there often are things left unsaid in communication about death, dying and desire to die and relatives and patients not always share a perspective. Although family members' support needs in the context of (medical) assistance in dying are still understudied, there is first evidence that relatives can be present in the process in the roles of carers, advocates, supporters and performers.[137] This is in line with experiences in Germany that, more often than before, relatives address patients' desire to die and potentially request assisted suicide. Considering findings from paper 2, a supposed merging of wishes from patients and their relatives should be considered with utmost care. Within the triads, many participants both misjudged each other's wishes for communication and support as well as extent of suffering and resilience.[101] Checking for undue influence and repeatedly clarifying the current information status of all participants will become one of the key communication tasks for health professionals when confronted with requests for assisted suicide. In this context, it might be advisable to clearly distinguish what type of conversation is being held: 1. a supporting or therapeutic conversation to explore meanings, background, and functions of a desire to die or 2. an informative conversation about end-of-life options, potentially including assisted suicide.[138, 139]

Now that I have conclusively applied the transactional model of communication with its focus on co-creation of meaning and influencing context factors to conversations on death, dying and desire to die, I can present an illustration on how these conversations can be conceptualized within the model. For this illustration, please refer to figure 5.

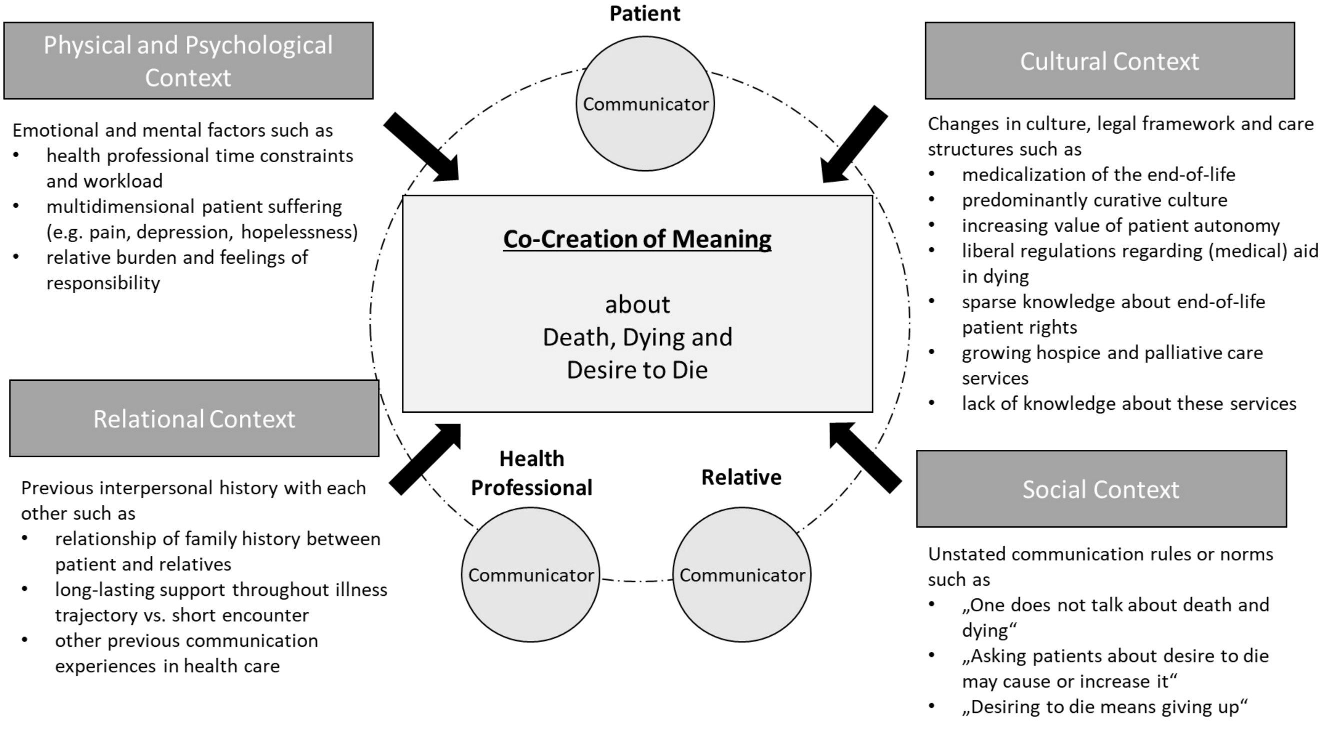

Fig. 5. *Transactional communication model[11] adapted to communication about death, dying and desire to die. Context factors are not meant to be exhaustive.*

5.6. Critical Assessment: What value does the transactional model for desire to die conversations hold?

The transactional model of communication brings important merits when applied to desire to die conversations: focusing on the co-creation of meaning (thereby advocating for the important function of misunderstandings), emphasizing the equal roles of all communicators in this co-creation and specifically stating four context factors that shape conversation. In these regards, the transactional model corresponds satisfyingly with the empirical reality of desire to die communications as assessed in Papers 1 and 2 as well as related research quoted above. However, there are also results from Paper 1 and 2 suggesting that the transactional model might not be sufficient in illustrating what "successful" communication about desire to die should look like, according to Pagin.[111]

When evaluating their desire to die conversation or the atmosphere in which conversations about death and dying takes place, triad participants always considered withdrawal or reticence as negative and hindering. Within a transactional model, this withdrawal provides a possibility for interpretation as just another form of communicative behavior. It seems that the triad participants' evaluation of withdrawal as something negative like rejection (e.g. within Type 1 of the interview triads in paper 2) cannot be illustrated within the transactional model. This is a first hint that there seem to be two dimensions on which to critically value the transactional model:

1. a descriptive dimension (its value in describing what happens during a conversation) and
2. a normative dimension (its value in assessing whether what happens during a conversation should happen like that).

In a related line of reasoning, I already argued that the transactional model of communication does not allow any kind of objective measurement whether communication partners reach shared reality. Since there is empirical evidence that knowledge about patients' preferences, fears and wishes increases the likelihood for delivering patient-centered care, it can be of critical importance whether everyone has the same information.[132] As we see in Paper 2, in 12 out of 13 triads not everyone had the same information, as participants used differing communication styles such as compartmentalization or denial that hindered the emergence of shared reality. Therefore, it becomes necessary to look at possible aspects of critique of the transactional model to allow a complete appreciation of its value in illustrating desire to die conversations.

Critique 1: Inadequate risk assessment?

In a previous paragraph, I discussed the patients' inability or unwillingness to remember the desire to die conversation as such – even though its' contents were documented by their health professionals. From a clinical perspective, this finding can have ambivalent consequences: on the one hand, it may come as a relief for health professionals that patients do not remember these conversations as negative. On the other hand, it can become a serious matter of concern if a patient does not realize that he is asked about potential desire to die and therefore, his desire to die with its associated burden remains latent. The transactional model does not evaluate such outcomes as successful or failed communication but emphasizes the role of co-creation of meaning between both parties. However, this constructivist approach might not suffice to make sense of the possibility of real-world risk through communication that does not follow its intended purpose (i.e. inquiring about desire to die and associated burden). Taking this thought a step further to a literal life-and-death-scenario, the real-world implications of inadequately inquiring about suicidality (which can be an extreme form of desire to die) can be highly dangerous. Studies found that not accepting or undermining patients' suicidal ideation can lead to patients feeling more distressed and less hopeful, while simultaneously reduce the chance of future help-seeking behavior.[140] Moreover, perceived social support – e.g. by empathically asking about suicidality – is a major mediating factor between the impact of stressful life events and suicidality.[141] Despite such results, there are no known reliable study results regarding the effectiveness of inquiry for suicidality on mortality.[142] However, it is likely that sensitive and empathic inquiry about desire to die and suicidality may help to "*uncover patients who make their intent known and are amenable to intervention*".[142]

Critique 2: Perpetuation of communicative taboos?

The line of reasoning followed above brings me to my main critique of the transactional model with its constructivist and relativistic properties: If communication is always conceptualized as co-created and misunderstandings treated exclusively as sources of information instead of indicative of failure, I argue that there is a chance of perpetuating unspoken taboos in language and content. According to the transactional model, taboos (e.g. "*one does not talk openly about death*") are considered as merely one aspect of cultural context among others that shape conversation. On this basis alone, this taboo can be neither challenged nor problematized and its empirically founded real-world implications may prosper unhindered if our communications unfold according to approaches that draw solely upon the transaction model.[143-145]

This raises the question whether there is a lasting value in holding on to communication principles such as 'open communication' as the gold-standard. For avoiding or decreasing burden in patients with desire to die as well as other medical communication, such as the ethics of informed consent before initiating any kind of treatment, it is necessary that certain information is openly and concisely communicated so that it may be understood the way it was meant. The application of the transactional model to conversation strategies and techniques remains uninvolved with such ethical principles of communication, even if it allows the explanation of what was going on where communication failed to meet these principles.

Critical Appraisal

Although it is possible to describe the emergence of social realities, like conversations, quite well with constructivist means, the same constructivist means fail when used to clarify ethical problems. As a model based on constructivist properties, the transactional model of communication cannot assert a criterion outside the construction. Ergo, there is no criterion which can be taken as a binding direction for the construction. Within a model like the transactional model, only the opinions of the constructors involved remain. Those are, due to the assumption of their equal justification, bound to end in a stalemate that cannot change the status quo. I therefore conclude that a constructivist model (like the transactional model) seems suitable for description, but it is not sufficient for a normative orientation because it cannot identify any objectively binding values. In this respect, it cannot easily be translated into practice. At this point, demands from theoretical models and clinical reality come together, perhaps providing a fruitful ground for further development and practical solutions.[146]

Within chapter 8, I attempt to formulate some proposed solutions for communication about death, dying and desire to die in clinical practice and give an outlook on potential directions for further research and theory building.

5.7. Strenghts and Limitations

When deriving insights for communication about death, dying and desire to die from the findings discussed above, various strengths and limitations inherent in the studies from paper 1 and paper 2 should be kept in mind. For the sake of brevity, I will use this sub-chapter to discuss only those limitations and strengths that are not already reported in the respective papers.

When considering the limitations of this doctoral thesis, it becomes apparent that findings from papers 1 and 2 are both limited in different ways by being mediated. As there is no audio-taped or otherwise documented transcript of the desire to die conversation, my analysis is dependent on the accuracy of documentation sheet notes and interview recollection.[67, 101] Beyond limitations already discussed within the respective papers, one can assume that the data of this doctoral thesis is influenced by various biases: in Paper 1, health professionals had undergone a two-day training program on dealing with desire to die. They were therefore sensitized regarding the complexities of desire to die which might have influenced their documentation of conversation in direction of a confirmation bias, i.e. wishing to match what they find in real life conversations to what they learned in trainings.[147] This could be one explanation why health professionals’ documentation of desire to die conversations differed drastically from what patients recalled about those conversations. Another explanation for patients’ differing or lacking memory of these conversations might be recall bias: as most patients did not report a desire to die at that time, their focus in memory recollection might have been on other topics which hindered accurate recall. Although anonymity was assured repeatedly and effects on care were ruled as out of the question, it is still likely that a sensitive topic like desire to die might cause interview participants to answer according to social desireability.[148]

Potential researcher bias cannot be excluded either: although interviewers underwent interview training and supervision during study duration, it cannot be ruled out that a tendency to ask questions more reluctantly or in an abstract manner due to concerns about keeping boundaries or burdening participants might have influenced respective answers.[149] Potential ways of addressing these limitations in further research are discussed in the following chapter.

When considering the strengths of this doctoral thesis, one must consider the data first. The sample of health professionals (*N* = 29 and *n* = 13, respectively) and patients (*N* = 79 and *n* = 13, respectively) provides a large basis of qualitative data for analysis.[67, 101] Health professionals as well as patients are diverse regarding their profession, setting of care, (cared for) diagnosis and age groups. Therefore, a tentative generalization of findings on the population of palliative care providers and patients in their last year of life is viable. As the triad interviews show, relatives, too, seem to have a unique perspective on desire to die communication that often does not coincide with those of patients and health professionals. Although our sample of *n* = 13 relatives is equally diverse in its characteristics (e.g. concerning relation and gender), a larger sample is needed to explore relative experiences and communication needs in-depth. Moreover, as all sampling followed a convenience sampling strategy, it remains unclear whether data saturation has been achieved.[150]

The greatest strength of this doctoral thesis lies in its expansion of knowledge regarding content, experience, and processes of desire to die conversations. Previous research focused on the phenomenon of desire to die with its background, meanings and functions and thereby enabled researchers to define desire to die as a complex phenomenon with varying levels of suicidal pressure to act.[6, 43-46] Regarding conversations about desire to die, the focus of previous research was on its effects, establishing that they are not harmful but have the potential to relieve burden. [10, 73]

Within this doctoral thesis, I shed light on the conversations that produce these effects and gave voice to those participating in these conversations. The analysis of the content and evaluation of conversations about desire to die held by health professionals considered in conjunction with the perception of these conversations by patients, health professionals and relatives allows the tentative drawing of an integrated view of communication about death, dying and desire to die. The reported experiences as well as the multiple perspectives of all three stakeholders allow us to see that meaning-making in conversations about desire to die is not a linear process, but a form of co-creation. By utilizing the transaction model of communication to illustrate conversations about death, dying and desire to die, it becomes apparent that what at first glance looks like a susceptibility for miscommunication and lack of open engagement can give valuable insight. The co-creation of meaning in conversations about death, dying and desire to die is influenced by different context factors, such as patient biography or societal norms of talking about death and dying, and evolves by communication partners sending out and responding to communication cues. However, by applying this constructivist-realist lens to communication, one must keep in mind that they do not consider normative aspects of information transfer in communication and the real-world negative consequences of communicative misunderstandings. Thereby, my doctoral thesis structures and illustrates empirical findings on conversations about death, dying and desire to die through a theoretical model that can be expanded and tested in further research.

6. Implications for Research and Clinical Practice

6.1 Research

Based on the assumptions about methodological strengths and limitations described above, we can derive several implications for further research that enhances quality and reliability of the findings.

Firstly, methods of data assessment can be expanded to strengthen and add to the presented findings. Both the documented desire to die conversations and the interview triads are limited by providing information mediated by a predefined structure. To gain insight into the content process of desire to die conversations unmediated by such structures, audio- or video recordings of conversations from everyday practice would prove useful. The use of audio- or video-recordings would additionally provide the option to perceive and interpret non-verbal cues such as longer silences, tone of voice, facial expression or posture.[151] As conversations about desire to die are still considered extremely personal and existential, recording them by audio or video in a clinical setting might be met with distrust.[152] Recordings should therefore only be conducted with outmost respect for the involved participants.

Secondly, all findings discussed within this thesis are of an explorative nature and derived from qualitative methods. Therefore, they do not provide information on cause and effect behind the researched phenomena, but can raise more questions: In what ways do desire to die conversations impact patients? What communication needs do relatives have concerning desire to die? Can existing communication approaches for health professionals be applied to conversations about desire to die?

The scientific gold standard for approaching causality in research are Randomized Controlled Trials (RCTs).[153] To my knowledge, there are no published RCTs as of yet that consider important questions such as the evaluation of effects of desire to die conversations on patients and health professionals or differences of communication types in desire to die conversations. Therefore, it might seem that a methodically sound RCT could establish the importance of existential conversations at the end-of-life, such as desire to die conversations. However, RCTs have been criticized for claiming a methodical rigor they cannot uphold.[154] As communication usually develops organically and is hard to standardize, it might be necessary to consider other methods to be more adequate and equally meaningful in gaining further insight on communication about desire to die.

Both papers 1 and 2 also raise important aspects that are yet under-researched: Recruitment for the DEDIPOM study stopped one month before the ruling of the Federal Court of Justice and therefore, the data examined in this thesis cannot account for its impact on the content of desire to die conversations. Within Paper 1, there was almost no mention of assisted suicide as content of desire to die conversations - only 1 of 29 health professionals discussed the legal options of assisted suicide. As outlined above (see chapter 2), the ruling of the Federal Court of Justice regarding the impunity of assistance in suicide fundamentally changed the discourse about desire to die in Germany. From clinical experience, a shift in the way patients and relatives, but also health professionals, talk about desire to die is noticeable. This is underlined by first evidence from other jurisdictions in which medical assistance in dying was legalized.[134]. Assessing this impact on patients, relatives and health professionals by conducting a study with similar design as the DEDIPOM study or through in-depth interview studies might give valuable insights into how the content of conversations might have changed.

Another under-researched aspect that becomes apparent in Paper 2 of this thesis is the integration of relatives in desire to die conversations. Further research could identify reasons for non-inclusion of relatives and develop targeted interventions. Thereby, relatives' feeling of being left out could potentially be prevented and patients' worry of burdening their loved ones with their desire to die could be diminished.[101]

Lastly, synthesizing results from Paper 1 and 2 within the transactional model of communication allows to illustrate desire to die communication as well as identify context factors.[11] However, despite its appraisal as an ethically sound model that values all conversation participants as equal,[105] my analysis highlights that it cannot offer any guidance for normative orientation in existential communication on desire to die. To bundle information on desire to die communication, future research might want to consider reusing and expanding such and well-known model as the existing transactional model, e.g. by adding further context factors, considering ethical requirements for medical communication, and emphasizing self-reflection in any transfer on clinical realities.

6.2 Clinical Practice

When examining the findings from paper 1 and 2 from a clinical perspective, one can identify important sources for miscommunication or dissatisfaction with communication. Some of them only apply to conversations on desire to die, others are common in other areas of medical communication. Therefore, it is possible to derive practical tips that are routed in existing medical communication research.

To ensure the relevance of this dissertation for clinical practice, I have compiled a list of its main findings along with tips for their practical implementation (please see table 1).

Source of miscommunication or communication dissatisfaction	**Practical suggestion**
Paper 1	
Patient is uninformed regarding patient rights at the end-of-life or treatment options within palliative and hospice care. →	**Educate patient** verbally but consider potential information overload: add **text material** to read up on after the conversation, invite a **relative** to the talk, back up on how the conversation was understood in the end and **repeat important information**.[106]

Patient is reserved regarding the topics of death, dying or desire to die	→	Know that thoughts regarding these topics are often associated with fear, hopelessness and thoughts of a lost future. Attempt to **apply a dual framework** that incorporates living the best in the present while acknowledging the possibility of death.[155]
Patient reacts very emotional	→	Stay present, **validate and normalize emotions**.[156]
Patient is reserved due to present family member	→	Acknowledge the **impact of family structures** and consider a one-on-one conversation with both patient and relative. Ask what information you are allowed to share, but be aware of the potential for instrumentalization.[155]
Health professional holds back in addressing potentially challenging topics		**Reflect on own biography and professional socialization** to uncover underlying concerns regarding potential patient / relative reactions. Consider potential **effects of counter-transference** from your counterpart.[155]
Paper 2		
Patient and family member do not share the same view on the situation / interpret it differently	→	**Practice impartiality** by validating the psychological necessity for each participants' view. Perhaps foster taking each other's perspectives by using circular questions, e.g.: *"How would your husband describe your current state of mind?"*[157]
Relatives are not included in conversation	→	Keep relatives and their important role in mind: they can provide vital information, but also suffer from their own burden. **Actively attempt to involve relatives in the conversation**, after checking in with the patient.[155]
Conversation lingers on concrete topics and does not address existential concerns	→	Know that concrete topics can be a "safe" way of addressing issues perceived as threatening, e.g. impending death. **Use meta-communication** and gently **provide room** to explore potentially underlying existential topics, e.g.: *"I experience you talking a lot about the specifics of your funeral lately. Do you have any fears or expectations regarding your death?"*[158]
Patients / relative remembers conversation content differently	→	At the end of conversation, **back up how patient / relative understood conversation**, e.g.: *„I take XY*

than health professional	*from our conversation today, does this match what you take from it?"* [106]

Table 1. *Practical suggestions for communication about death, dying and desire to die based on findings from Paper 1 and Paper 2.*

Numerous practical tips and guidelines aim to help with the challenges of communicating about death, dying and desire to die. There are now first evaluated interventions that target communication patterns in the family system of patients at the end-of-life.[159] However, as these sensitive topics hold potential for a drastic real-world impact on patient satisfaction, informed decision-making and overall quality of life, "*high levels of clinician confidence and communication skills*" are key.[160] Therefore, health professionals are advised to not only learn communication techniques based on current best-practice advice or existing communication models alone, but also to engage in self-reflection concerning their own attitude regarding death, dying and desire to die.

6.3 Self-reflection

Although there are valuable suggestions (see table 1) gained, no model can serve as blanket advice for every communication encounter. The complexities of face-to-face and real-time communication encounters may sometimes put health professionals in front of competing priorities, e.g. when the value of accepting a patient's construct of their reality (following the relativist-constructivist idea behind the transactional communication model) clashes with the necessity to make them understand a certain prognosis or treatment options (following the ideal of informed consent).[119] Can we perhaps use the practice of self-reflection to guide us on a way out of this dilemma?

Self-reflection as defined by Brookfield (1987) means "critical reflection" and is comprised of "*two interrelated processes: identifying and challenging assumptions, and imagining and exploring alternatives."* [161]

As a recent meta-ethnographic review points out, there still is a lack bioethical reflection as well as embedded ethics regarding the desire to die in clinical practice.[162] In that sense, increased capability of self-reflection seems highly needed regarding desire to die. How could this look in a concrete example?

In an example, a health professional may be confronted with a situation in which one of their patients requests assisted suicide through an Aid in Dying Agency, because they fear suffering through escalating symptom burden in the expected illness trajectory. In this case, the health professional might already have explained all possible alternatives. It is possible, though, that the patient disregards these alternatives. Perhaps they appear as if they cannot be reached by the health professional's attempt at equipping them with the information to make an informed decision. On the one hand, the transaction model of communication can give impulses to explain how patient and health professional construct meaning in this encounter, e.g. through considering context factors (How is the patient's personal history? How did jargon and time constraints shape the communication encounter?). On the other hand, the health professional needs to be aware of the normative aspect of their encounter: equipping patients with information to make informed decisions is one of the highest standards of medical ethics.[163]

Engaging in critical self-reflection can help the health professional to navigate these competing priorities, as Olson et al. (2021) suggest.[119] Following the two interrelated processes mentioned above, the health professional needs to first identify and challenge assumptions made in the previously imagined conversation encounter. They could see that the requests for assisted suicide might have different meaning for themselves and for the patient: perhaps the health professional works under the (unspoken and unthinking) assumption that assisted suicide is always wrong. Perhaps the patient works on a different (unspoken and unthinking) assumption in which only a death free of even the slightest chance of suffering can be considered a “good death”. Therefore, all information on alternatives delivered by the health professional will not be considered by the patient to begin with.

Being aware of their own attitude towards each of these aspects is a prerequisite for the second part of critical self-reflection: imagining and exploring alternatives. Alternative approaches for delivering information important to the patient can be found e.g. by reacting to clues coming from the patient: picking up their idea of a “good death” or exploring their idea of suffering. Part of utilizing self-reflection can also be the acknowledgement and conscious handling of situations when misunderstandings prevail and there is no solution deemed satisfying by all parties.

In studies on medical students, the awareness of self-reflection is not fully developed.[164] Communicative self-reflection (especially regarding dealing with desire to die) is not yet standard in medical curricula in Germany.[165] For proficient and experienced health professionals, participating in a training as developed in the DEDIPOM study is considered helpful. Besides showing positive changes in participants’ self-confidence, their knowledge about, attitude towards and skills in communication about desire to die, participants’ answers emphasized their enhanced level of self-reflection.[94] By now, this training approach has been integrated into a module for German medical students as well.[166] Granting self-reflection skills in medical curricula (as well as in curricula of nursing and psychosocial professions) the place they deserve would be a start for equipping a new generation of health professionals for the challenges posed by existential communication about death, dying and desire to die.

7. Conclusion

Opening up for honest communication about existential or emotionally touching topics implicates vulnerability and therefore poses a challenge for most people. This is especially true for conversations about death, dying and desire to die – even though talking about these topics is vital to promote good end-of-life care and support. In this doctoral thesis, I explored communication about desire to die between patients in their last year of life, their relatives and health professionals. By analyzing qualitative data from documented desire to die conversations as well as interview triads with all three stakeholders, I was able to establish that a) such communication is embedded within the larger sphere of existential topics surrounding death and dying, serving as a door opener, and b) heavily influenced by pre-existing relationship dynamics, individually learned communication strategies and cultural notions of self-determination and care at the end-of-life. A common understanding or shared reality of what constitutes a desire to die conversation shows to be surprisingly rare, even though meaning was co-created by all conversation participants. Most often, such conversation seems to be restricted to patients and health professionals with relatives being excluded. As three types with varying degrees of shared reality, but also emotional distress and communication satisfaction emerges, it becomes apparent that there is no one-size-fits-all solution to conversations about desire to die. Rather, these conversations seem to be not a single occurrence, but an ongoing process. During this process, health professionals ought to keep a delicate balance: they need to follow the patients' (or relatives') ability, readiness and strategies to discuss desire to die and meet their responsibility to ensure their patients can make self-responsible and informed decisions. This should be accompanied by constantly reflecting on their own potential concerns and biases.

My thesis' findings highlight the absolute importance of remaining open and curious regarding what might be conveyed between the lines. Even though data was not gathered in naturally occurring conversations and therefore, content and atmosphere was mediated, these findings are a first structured exploration into the experience of and patterns in desire to die communication.

Related to what I already discussed in chapters 8.1 and 8.2, future work on my thesis' topic could build on this first exploration. Even though empirical research always poses more questions than it answers, there are a few broad practical considerations for health professionals that directly derive from my doctoral thesis. Based on the conclusions made, health professionals should not act on assumptions or without self-reflection, but always consider taking on multiple perspectives and keep in mind the possibility of misunderstandings – as well as their potential.

To conclude: in palliative and hospice care, we relate to and are constantly in contact with each other through means of communication and medical, psychological, and spiritual care. These means can be messy and it is highly probable that there will never be perfect understanding. Still, it is both practically and ethically important for health professionals to actively reflect on topics like death, dying and desire to die and train their communication skills to adequately accompany those people in their last year of life who might develop a desire to die. Research, too, can benefit from the integration of multi-dimensional perspectives through the utilization of (communication) models for the reduction of complexity – while remaining critical of any model's limitations in depicting reality.

Beyond that, I believe that cultivating an attitude of openness, curiosity, and willingness to engage with patients and their families, to learn from experiences – especially mistakes and miscommunication – is the basis for authentic communication about death, dying and desire to die. As the systemic psychotherapist Steve De Shazer put it: miss-communication and not understanding each other “*constitutes, or even enables conversation. After all, in the case of (total) understanding, there wouldn’t be anything left to say*.” (p.76, translation by author)[167]

8. References

1. Brod M. Franz Kafka, Briefe 1902-1924. Frankfurt: Fischer, 1983, p. 19.
2. World Health Organization (WHO). Palliative care. The essential facts., https://cdn.who.int/media/docs/default-source/integrated-health-services-(ihs)/palliative-care/palliative-care-essential-facts.pdf?sfvrsn=c5fed6dc_1 (2020, accessed 23.12.2023 2023).
3. Kremeike K, Bausewein C, Freytag A, et al. DNVF-Memorandum Versorgungsforschung im letzten Lebensjahr. *Gesundheitswesen* 2022; 84. DOI: 10.1055/a-1889-4705.
4. Downar J, Goldman R, Pinto R, et al. The "surprise question" for predicting death in seriously ill patients: a systematic review and meta-analysis. *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne* 2017; 189: E484-e493. 2017/04/08. DOI: 10.1503/cmaj.160775.
5. Ohnsorge K, Gudat H and Rehmann-Sutter C. What a wish to die can mean: reasons, meanings and functions of wishes to die, reported from 30 qualitative case studies of terminally ill cancer patients in palliative care. *BMC Palliative Care* 2014; 13: 38. DOI: 10.1186/1472-684X-13-38.
6. Kremeike K, Pralong A, Boström K, et al. ‘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* 2021; 10: 3594-3610.
7. Leitlinienprogramm Onkologie DK, Deutsche Gesellschaft für Hämatologie und Medizinische Onkologie, Deutsche Gesellschaft für Palliativmedizin,. Palliativmedizin für Patienten mit einer nicht-heilbaren Krebserkrankung – Langversion 2.2 – September 2020. , https://www.awmf.org/uploads/tx_szleitlinien/128-001OLk_S3_Palliativmedizin_2020-09_02.pdf (2020, accessed 07.11.2023).
8. Udo C, Melin-Johansson C, Henoch I, et al. Surgical nurses' attitudes towards caring for patients dying of cancer - a pilot study of an educational intervention on existential issues. *European journal of cancer care* 2014; 23: 426-440. 2014/01/30. DOI: 10.1111/ecc.12142.
9. Love HA and Morgan PC. You can tell me anything: Disclosure of suicidal thoughts and behaviors in psychotherapy. *Psychotherapy* 2021; 58: 533-543. DOI: 10.1037/pst0000335.
10. Voltz R, Boström K, Dojan T, et al. Is trained communication about desire to die harmful for patients receiving palliative care? A cohort study. *Palliative medicine* 2022; 36: 489-497. 2021/12/24. DOI: 10.1177/02692163211065671.
11. Barnlund DC. A transactional model of communication. *Communication theory*. Routledge, 2017, pp.47-57.
12. Marsh I, Winter R and Marzano L. Representing suicide: Giving voice to a desire to die? *Health (London, England : 1997)* 2022; 26: 10-26. 2021/09/21. DOI: 10.1177/13634593211046843.
13. Vos T, Lim SS, Abbafati C, et al. Global burden of 369 diseases and injuries in 204 countries and territories, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. *The Lancet* 2020; 396: 1204-1222. DOI: 10.1016/S0140-6736(20)30925-9.
14. Plass D, Vos T, Hornberg C, et al. Trends in disease burden in Germany: results, implications and limitations of the Global Burden of Disease study. *Deutsches Arzteblatt international* 2014; 111: 629-638. 2014/10/16. DOI: 10.3238/arztebl.2014.0629.
15. Sallnow L, Smith R, Ahmedzai SH, et al. Report of the Lancet Commission on the Value of Death: bringing death back into life. *The Lancet* 2022; 399: 837-884. DOI: 10.1016/S0140-6736(21)02314-X.
16. Solberg CT, Norheim OF and Barra M. The disvalue of death in the global burden of disease. *Journal of Medical Ethics* 2018; 44: 192-198.
17. Cardona-Morrell M, Kim JCH, Turner RM, et al. Non-beneficial treatments in hospital at the end of life: a systematic review on extent of the problem. *International Journal for Quality in Health Care* 2016; 28: 456-469. DOI: 10.1093/intqhc/mzw060.
18. Motamedi M, Brandenburg C, Bakhit M, et al. Concerns and potential improvements in end-of-life care from the perspectives of older patients and informal caregivers: a scoping review. *BMC Geriatrics* 2021; 21: 729. DOI: 10.1186/s12877-021-02680-2.
19. Jimenez G, Tan WS, Virk AK, et al. Overview of Systematic Reviews of Advance Care Planning: Summary of Evidence and Global Lessons. *Journal of Pain and Symptom Management* 2018; 56: 436-459.e425. DOI: https://doi.org/10.1016/j.jpainsymman.2018.05.016.

20. Birkenstock E. *Option assistierter Suizid. Wann genug ist, entscheide ich*. Zürich: Seismo Verlag, 2022.
21. Prado CG. Moral individualism and elective death. *International Journal of Law and Psychiatry* 2013; 36: 471-476. DOI: https://doi.org/10.1016/j.ijlp.2013.06.003.
22. Wildfeuer J, Schnell MW and Schulz C. Talking about dying and death: On new discursive constructions of a formerly postulated taboo. *Discourse & Society* 2015; 26: 366-390. DOI: 10.1177/0957926514564739.
23. Mroz S, Dierickx S, Deliens L, et al. Assisted dying around the world : a status quaestionis. . *ANNALS OF PALLIATIVE MEDICINE* 2021; 10: 3540–3553. DOI: https://doi.org/10.21037/apm-20-637.
24. Ana W, Claud R, Katherine ES, et al. Comparison of official reporting on assisted suicide and euthanasia across jurisdictions. *BMJ Supportive &amp; Palliative Care* 2022: spcare-2022-003944. DOI: 10.1136/spcare-2022-003944.
25. Bundesverfassungsgericht. Urteil des Zweiten Senats vom 26. Februar 2020 - 2 BvR 2347/15 -, Rn. 1-343,. 2020.
26. § 217 Geschäftsmäßige Förderung der Selbsttötung. Strafgesetzbuch, Besonderer Teil (§§ 80 - 358), 2015.
27. Deutsches Ärzteblatt. Berliner Arzt wegen Unterstützung zum Suizid zu Haftstrafe verurteilt, https://www.aerzteblatt.de/nachrichten/150472/Berliner-Arzt-wegen-Unterstuetzung-zum-Suizid-zu-Haftstrafe-verurteilt (2024, accessed 04.05.2024).
28. aerzteblatt.de. Referentenentwurf zur Suizidprävention vorgelegt, Freitag, 29. November 2024. *Ärzteblatt*, 2024.
29. Tötung auf Verlangen. In: Bundesministerium der Justiz, (ed.). *§ 216*. Strafgesetzbuch.
30. Barmeyer A. Was passiert, wenn ich mich nicht mehr äußern kann? In: Barmeyer A (ed) *Krank, was tun? Vom ersten Symptom über Arztsuche, Lohnfortzahlung bis Kur – ein Wegweiser*. Berlin, Heidelberg: Springer Berlin Heidelberg, 2020, pp.125-136.
31. Sekhar MS and Vyas N. Defensive medicine: a bane to healthcare. *Ann Med Health Sci Res* 2013; 3: 295-296.
32. Schwartz J, Schallenburger M, Batzler Y-N, et al. *Dealing with assisted suicide Attitudes and experiences from members of the German Association for Palliative Medicine Background*. 2024.
33. Ethikkommission für Berufe in der Pflege Niedersachsen. *Konfrontation von Pflege(fach)personen mit Todeswünschen oder Bitten um assistierten Suizid. Wahrnehmungs- und Verhaltenshilfen. Langfassung*. Göttingen: Empfehlung der Ethikkommission für Berufe in der Pflege Niedersachsen,, 2024.
34. Sandra Blumenthal, Luise Farr, Stephan Fuchs, et al. *Der Umgang mit dem Wunsch nach Suizidassistenz in hausärztlichen Praxen. DEGAM S1-Handlungsempfehlung, AWMF-Register-Nr. 053-063*. 2024.
35. Deutsche Gesellschaft für Palliativmedizin e. V. Empfehlungen der Deutschen Gesellschaft für Palliativmedizin (DGP) zum Umgang mit dem Wunsch nach Suizidassistenz in der Hospizarbeit und Palliativversorgung. 2021.
36. Deutscher Hospiz- und Palliativverband e.V. Zahlen zur Hospiz- und Palliativarbeit, https://www.dhpv.de/zahlen_daten_fakten.html (accessed 07.11.2023 2023).
37. Cherny NI. Palliative sedation. *Textbook of palliative medicine and supportive care*. CRC Press, 2021, pp.717-726.
38. Patel P and Lyons L. Examining the knowledge, awareness, and perceptions of palliative care in the general public over time: a scoping literature review. *American Journal of Hospice and Palliative Medicine®* 2020; 37: 481-487.
39. Radbruch L and Payne S. White Paper on standards and norms for hospice and palliative care in Europe: part 1. *European journal of palliative care* 2009; 16: 278-289.
40. Mayland CR, Mulholland H, Gambles M, et al. How well do we currently care for our dying patients in acute hospitals: the views of the bereaved relatives? *BMJ supportive & palliative care* 2017; 7: 316-325. 2017/01/18. DOI: 10.1136/bmjspcare-2014-000810.
41. Batzler YN, Melching H, Schallenburger M, et al. Reasons for wanting assisted suicide—a retrospective evaluation of telephone inquiries. *Deutsches Arzteblatt international* 2023; 120. DOI: 10.3238/arztebl.m2023.0178.

42. Rosenfeld B, Pessin H, Marziliano A, et al. Does desire for hastened death change in terminally ill cancer patients? *Social Science & Medicine* 2014; 111: 35-40. DOI: https://doi.org/10.1016/j.socscimed.2014.03.027.

43. Gudat H, Rehmann-Sutter C and Ohnsorge K. Communication of wishes to die. In: Rehmann-Sutter C, Gudat H and Ohnsorge K (eds) *The Patient's Wish to Die: Research, Ethics, and Palliative Care*. Oxford: Oxford University Press, 2015, pp.204-216.

44. Kessler E-M, Grünewald L and Schäfer T. Depressed older patients with death wishes: Experimental evidence for psychotherapists' age and health bias. *Clinical gerontologist* 2021; 44: 154-159.

45. Balaguer A, Monforte-Royo C, Porta-Sales J, et al. An International Consensus Definition of the Wish to Hasten Death and Its Related Factors. *PLoS ONE* 2016; 11: e0146184. DOI: https://doi.org/10.1371/journal.pone.0146184.

46. Wolfersdorf M. Suizid und Suizidalität aus psychiatrisch-psychotherapeutischer Sicht. *PiD - Psychotherapie im Dialog* 2012; 13: 2-7. DOI: 10.1055/s-0032-1304969.

47. Pollmächer T. Der assistierte Suizid aus psychiatrischer Sicht. *Der Nervenarzt* 2023; 94: 625-630. DOI: 10.1007/s00115-023-01497-1.

48. Levi-Belz Y, Gvion Y and Apter A. Editorial: The Psychology of Suicide: From Research Understandings to Intervention and Treatment. *Frontiers in psychiatry* 2019; 10: 214. 2019/04/26. DOI: 10.3389/fpsyt.2019.00214.

49. Brodsky BS, Spruch-Feiner A and Stanley B. The zero suicide model: Applying evidence-based suicide prevention practices to clinical care. *Frontiers in psychiatry* 2018; 9: 33.

50. Barbara Schneider, Reinhard Lindner, Ina Giegling, et al. Suizidprävention Deutschland. Aktueller Stand und Perspektiven, https://www.naspro.de/dl/Suizidpraevention-Deutschland-2021.pdf (2021, accessed 08.05.2023 2023).

51. Krebs E. Queering the Desire to Die: Access Intimacy as Worldmaking for Survival. *Journal of Homosexuality* 2023; 70: 168-191. DOI: 10.1080/00918369.2022.2103874.

52. Kelly BJ, Pelusi DAN, Burnett PC, et al. The prevalence of psychiatric disorder and the wish to hasten death among terminally ill cancer patients. *Palliative & Supportive Care* 2004; 2: 163-169. 2005/04/04. DOI: 10.1017/S1478951504040222.

53. Rurup ML, Pasman HR, Goedhart J, et al. Understanding why older people develop a wish to die: a qualitative interview study. *Crisis* 2011; 32: 204-216. 2011/09/24. DOI: 10.1027/0227-5910/a000078.

54. Chochinov HM, Wilson KG, Enns M, et al. Desire for death in the terminally ill. *The American journal of psychiatry* 1995; 152: 1185-1191. 1995/08/01. DOI: 10.1176/ajp.152.8.1185.

55. Wilson KG, Dalgleish TL, Chochinov HM, et al. Mental disorders and the desire for death in patients receiving palliative care for cancer. *BMJ supportive & palliative care* 2016; 6: 170-177.

56. Strupp J, Ehmann C, Galushko M, et al. Risk factors for suicidal ideation in patients feeling severely affected by multiple sclerosis. *Journal of palliative medicine* 2016; 19: 523-528.

57. Dürst A-V, Spencer B, Büla C, et al. Wish to Die in Older Patients: Development and Validation of Two Assessment Instruments. *Journal of the American Geriatrics Society* 2020; 68: 1202-1209. DOI: https://doi.org/10.1111/jgs.16392.

58. Fischer S, Huber CA, Furter M, et al. Reasons why people in Switzerland seek assisted suicide: the view of patients and physicians. *Swiss medical weekly* 2009; 139: 333-338. 2009/06/17. DOI: 10.4414/smw.2009.12614.

59. Rodríguez-Prat A, Pergolizzi D, Crespo I, et al. The Wish to Hasten Death in Patients With Life-Limiting Conditions. A Systematic Overview. *Journal of Pain and Symptom Management* 2024; 68: e91-e115. DOI: https://doi.org/10.1016/j.jpainsymman.2024.04.023.

60. Bornet M-A, Bernard M, Jaques C, et al. Assessing the Will to Live: A Scoping Review. *Journal of Pain and Symptom Management* 2021; 61: 845-857.e818. DOI: https://doi.org/10.1016/j.jpainsymman.2020.09.012.

61. Boström K, Dojan T, Hellmich M, et al. The double awareness of the wish to hasten death and the will to live: A secondary analysis of outlier patients from a mixed-methods study. *Palliative medicine* 2024; 38: 1042-1053. DOI: 10.1177/02692163241269689.

62. Colosimo K, Nissim R, Pos A, et al. "Double Awareness" in Psychotherapy for Patients Living With Advanced Cancer. *Journal of Psychotherapy Integration* 2017. DOI: 10.1037/int0000078.

63. Rodríguez-Prat A, Balaguer A, Booth A, et al. Understanding patients' experiences of the wish to hasten death: an updated and expanded systematic review and meta-ethnography. *BMJ Open* 2017; 7: e016659. DOI: 10.1136/bmjopen-2017-016659.
64. Belar A, Arantzamendi M, Larkin P, et al. The state of transience, and its influence on the wish to die of advanced disease patients: insights from a qualitative phenomenological study. *BMC Palliative Care* 2024; 23: 57. DOI: 10.1186/s12904-024-01380-z.
65. Rodin G, Lo C, Mikulincer M, et al. Pathways to distress: the multiple determinants of depression, hopelessness, and the desire for hastened death in metastatic cancer patients. *Social science & medicine (1982)* 2009; 68: 562-569. 2008/12/09. DOI: 10.1016/j.socscimed.2008.10.037.
66. Lutfey K and Maynard DW. Bad news in oncology: How physician and patient talk about death and dying without using those words. *Social Psychology Quarterly* 1998: 321-341.
67. Boström K, Dojan T, Rosendahl C, et al. How do trained palliative care providers experience open desire to die-conversations? An explorative thematic analysis. *Palliative & Supportive Care* 2022: 1-9. 2022/08/09. DOI: 10.1017/S1478951522001006.
68. Rodríguez-Prat A, Wilson DM and Agulles R. Autonomy and control in the wish to die in terminally ill patients: A systematic integrative review. *Palliative & Supportive Care* 2021; 19: 759-766. 2021/07/07. DOI: 10.1017/S1478951521000985.
69. Coyle N and Sculco L. Expressed desire for hastened death in seven patients living with advanced cancer: a phenomenologic inquiry. *Oncology nursing forum* 2004; 31: 699-709. 2004/07/15. DOI: 10.1188/04.Onf.699-709.
70. Rodin G, Lo C, Rydall A, et al. Managing Cancer and Living Meaningfully (CALM): A Randomized Controlled Trial of a Psychological Intervention for Patients With Advanced Cancer. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology* 2018; 36: 2422-2432. 2018/06/30. DOI: 10.1200/jco.2017.77.1097.
71. Xiao J, Chow KM, Liu Y, et al. Effects of dignity therapy on dignity, psychological well-being, and quality of life among palliative care cancer patients: A systematic review and meta-analysis. *Psycho-Oncology* 2019; 28: 1791-1802. https://doi.org/10.1002/pon.5162. DOI: https://doi.org/10.1002/pon.5162.
72. Gudat H, Rehmann-Sutter C and Ohnsorge K. Communication of wishes to die. 2015, pp.203-216.
73. Porta-Sales J, Crespo I, Monforte-Royo C, et al. The clinical evaluation of the wish to hasten death is not upsetting for advanced cancer patients: A cross-sectional study. *Palliative medicine* 2019; 33: 570-577. DOI: 10.1177/0269216318824526.
74. Hudson PL, Schofield P, Kelly B, et al. Responding to desire to die statements from patients with advanced disease: recommendations for health professionals. *Palliative medicine* 2006; 20: 703-710. DOI: 10.1177/0269216306071814.
75. Lindy W, Ben W, Danielle K, et al. Restricting conversations about voluntary assisted dying: implications for clinical practice. *BMJ Supportive &amp; Palliative Care* 2020; 10: 105. DOI: 10.1136/bmjspcare-2019-001887.
76. Ho A, Norman JS, Joolaee S, et al. 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* 2021; 15: 26323524211045996. 2021/09/28. DOI: 10.1177/26323524211045996.
77. Linse K, Aust E, Joos M, et al. Communication Matters—Pitfalls and Promise of Hightech Communication Devices in Palliative Care of Severely Physically Disabled Patients With Amyotrophic Lateral Sclerosis. *Frontiers in Neurology* 2018; 9. Review. DOI: 10.3389/fneur.2018.00603.
78. Periyakoil VS, Neri E and Kraemer H. Patient-Reported Barriers to High-Quality, End-of-Life Care: A Multiethnic, Multilingual, Mixed-Methods Study. *Journal of Palliative Medicine* 2015; 19: 373-379. DOI: 10.1089/jpm.2015.0403.
79. Harding R, Simms V, Calanzani N, et al. If you had less than a year to live, would you want to know? A seven-country European population survey of public preferences for disclosure of poor prognosis. *Psychooncology* 2013; 22: 2298-2305. 2013/03/20. DOI: 10.1002/pon.3283.
80. Buecken R, Galushko M, Golla H, et al. Patients feeling severely affected by multiple sclerosis: How do patients want to communicate about end-of-life issues? *Patient Education and Counseling* 2012; 88: 318-324. DOI: https://doi.org/10.1016/j.pec.2012.03.010.

81. Ekaterina A, Erica W, Rinat N, et al. Death talk and relief of death-related distress in patients with advanced cancer. *BMJ Supportive &amp; Palliative Care* 2020; 10: e19. DOI: 10.1136/bmjspcare-2016-001277.

82. Macmillan Cancer Support. *No regrets: How talking more openly about death could help people die well*. London: Macmillan, 2017.

83. Breen LJ, Aoun SM, O'Connor M, et al. Effect of caregiving at end of life on grief, quality of life and general health: A prospective, longitudinal, comparative study. *Palliative medicine* 2019; 34: 145-154. DOI: 10.1177/0269216319880766.

84. Omilion-Hodges LM and Swords NM. Communication Matters: Exploring the Intersection of Family and Practitioner End of Life Communication. *Behavioral Sciences* 2017; 7: 15.

85. Ranse K, Yates P and Coyer F. End-of-life care in the intensive care setting: A descriptive exploratory qualitative study of nurses' beliefs and practices. *Australian Critical Care* 2012; 25: 4-12. DOI: https://doi.org/10.1016/j.aucc.2011.04.004.

86. Derksen F, Hartman TCO, van Dijk A, et al. Consequences of the presence and absence of empathy during consultations in primary care: A focus group study with patients. *Patient Education and Counseling* 2017; 100: 987-993.

87. Omilion-Hodges LM and Swords NM. Communication that heals: mindful communication practices from palliative care leaders. *Health communication* 2016; 31: 328-335. 2015/09/12. DOI: 10.1080/10410236.2014.953739.

88. Epstein RM and Street RL. Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. *National Cancer Institute; 2007 National Institutes of Health Publication* 2007; 07-6225.

89. Jiang S. Pathway Linking Patient-Centered Communication to Emotional Well-Being: Taking into Account Patient Satisfaction and Emotion Management. *Journal of Health Communication* 2017; 22: 234-242. DOI: 10.1080/10810730.2016.1276986.

90. Saha S and Beach MC. The impact of patient-centered communication on patients' decision making and evaluations of physicians: A randomized study using video vignettes. *Patient Education and Counseling* 2011; 84: 386-392. DOI: https://doi.org/10.1016/j.pec.2011.04.023.

91. Cegala DJ and Post DM. The impact of patients' participation on physicians' patient-centered communication. *Patient Education and Counseling* 2009; 77: 202-208. DOI: https://doi.org/10.1016/j.pec.2009.03.025.

92. Introduction to Communication Studies. *Communication in the Real World*. University of Minnesota,, 2016, pp.2-58.

93. Galushko M, Strupp J, Walisko-Waniek J, et al. Validation of the German version of the Schedule of Attitudes Toward Hastened Death (SAHD-D) with patients in palliative care. *Palliat Support Care* 2015; 13: 713-723. 2014/05/23. DOI: 10.1017/s1478951514000492.

94. Boström K, Dojan T, Frerich G, et al. Umgang mit Todeswünschen in der Palliativversorgung – Evaluation eines Schulungsprogramms. *Zeitschrift für Palliativmedizin* 2022; 23: 198-206. DOI: 10.1055/a-1729-7360.

95. Galushko M, Frerich G, Perrar KM, et al. Desire for hastened death: how do professionals in specialized palliative care react? *Psycho-Oncology* 2016; 25: 536-543. DOI: https://doi.org/10.1002/pon.3959.

96. Kremeike K, Galushko M, Frerich G, et al. The DEsire to DIe in Palliative care: Optimization of Management (DEDIPOM) - a study protocol. *BMC Palliat Care* 2018; 17: 30. 2018/02/21. DOI: 10.1186/s12904-018-0279-3.

97. Voltz R, Galushko M, Walisko J, et al. Issues of "life" and "death" for patients receiving palliative care--comments when confronted with a research tool. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer* 2011; 19: 771-777. 2010/04/28. DOI: 10.1007/s00520-010-0876-z.

98. Frerich G, Romotzky V, Galushko M, et al. Communication about the desire to die: Development and evaluation of a first needs-oriented training concept—A pilot study. *Palliative & Supportive Care* 2020; 18: 528-536.

99. Kremeike K, Frerich G, Romotzky V, et al. The desire to die in palliative care: a sequential mixed methods study to develop a semi-structured clinical approach. *BMC Palliat Care* 2020; 19: 49. 2020/04/18. DOI: 10.1186/s12904-020-00548-7.

100. Kremeike K, Dojan T, Rosendahl C, et al. “Withstanding ambivalence is of particular importance”—Controversies among experts on dealing with desire to die in palliative care. *PLoS ONE* 2021; 16: e0257382. DOI: https://doi.org/10.1371/journal.pone.0257382.
101. Boström K, Dojan T, Thölking T, et al. Talking about desire to die - talking past each other? A framework analysis of interview triads with patients, informal caregivers and health professionals. *BMC Palliative Care* 2024; submitted.
102. Renjith V, Yesodharan R, Noronha JA, et al. Qualitative Methods in Health Care Research. *International journal of preventive medicine* 2021; 12: 20. 2021/06/05. DOI: 10.4103/ijpvm.IJPVM_321_19.
103. Braun V and Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006; 3: 77-101. DOI: 10.1191/1478088706qp063oa.
104. Gale NK, Heath G, Cameron E, et al. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology* 2013; 13: 117. DOI: 10.1186/1471-2288-13-117.
105. du Pré A and Foster E. Transactional Communication. In: Wittenberg E, Ferrel BR, Goldsmith J, et al. (eds) *Textbook of Palliative Care Communication*. Oxford: Oxford University Press, 2016, pp.14-31.
106. Makoul G and van Dulmen S. What Is Effective Doctor–Patient Communication? Review of the Evidence. *Clinical Communication in Medicine*. 2015, pp.30-39.
107. Periyakoil VS, Neri E and Kraemer H. No Easy Talk: A Mixed Methods Study of Doctor Reported Barriers to Conducting Effective End-of-Life Conversations with Diverse Patients. *PLOS ONE* 2015; 10: e0122321. DOI: 10.1371/journal.pone.0122321.
108. Rehmann-Sutter C, Gudat H and Ohnsorge K. Communication of wishes to die. In: Rehmann-Sutter C, Gudat H and Ohnsorge K (eds) *The Patient's Wish to Die: Research, Ethics, and Palliative Care*. Oxford: Oxford University Press, 2015.
109. Olsson MM, Windsor C, Chambers S, et al. A scoping review of end-of-life communication in international palliative care guidelines for acute care settings. *Journal of Pain and Symptom Management* 2021; 62: 425-437. e422.
110. Ragan SL. Overview of Communication. In: Wittenberg E, Ferrel BR, Goldsmith J, et al. (eds) *Textbook of Palliative Care Communication*. Oxford: Oxford University Press, 2016, pp.1-9.
111. Pagin P. What is communicative success? *Canadian Journal of Philosophy* 2008; 38: 85-115.
112. Yi JS, Kang Y-a, Stasko JT, et al. Understanding and characterizing insights: how do people gain insights using information visualization? *Proceedings of the 2008 Workshop on BEyond time and errors: novel evaLuation methods for Information Visualization*. Florence, Italy: Association for Computing Machinery, 2008, p. Article 4.
113. Moreno S, Medina-Rico M, Osorio Clavijo K, et al. End of Life in Patients With Advanced Non-curable Cancer: Patient Considerations Around the Moment of Death. *OMEGA - Journal of Death and Dying*; 0: 00302228231190240. DOI: 10.1177/00302228231190240.
114. Tripodoro VA, Veloso VI, Víbora Martín E, et al. ‘Someone must do it’: multiple views on family’s role in end-of-life care – an international qualitative study. *Palliative care and social practice* 2024; 18: 26323524241260425. DOI: 10.1177/26323524241260425.
115. Anderson WG, Kools S and Lyndon A. Dancing around death: Hospitalist–patient communication about serious illness. *Qualitative Health Research* 2013; 23: 3-13.
116. Rodríguez-Prat A, Monforte-Royo C, Porta-Sales J, et al. Patient Perspectives of Dignity, Autonomy and Control at the End of Life: Systematic Review and Meta-Ethnography. *PLOS ONE* 2016; 11: e0151435. DOI: 10.1371/journal.pone.0151435.
117. Joshi M, Ásgeirsdóttir GH, Bakan M, et al. Dealing With Temporality in Patients With Life-Limiting Disease: An International Qualitative Study. *Qualitative Health Research*; 0: 10497323241263751. DOI: 10.1177/10497323241263751.
118. Hardin CD and Higgins ET. Shared reality: How social verification makes the subjective objective. *Handbook of motivation and cognition, Vol 3: The interpersonal context*. New York, NY, US: The Guilford Press, 1996, pp.28-84.
119. Olson RE, Smith A, Good P, et al. Emotionally reflexive labour in end-of-life communication. *Social Science & Medicine* 2021; 291: 112928.

120. Natasja JHR, Agnes van der H, Pauline SCK, et al. Assistance in dying for older people without a serious medical condition who have a wish to die: a national cross-sectional survey. *Journal of Medical Ethics* 2015; 41: 145. DOI: 10.1136/medethics-2012-101304.

121. Rubli Truchard E, Monod S, Bula CJ, et al. Wish to Die Among Residents of Swiss Long-Term Care Facilities: A Multisite Cross-Sectional Study. *Journal of the American Medical Directors Association* 2022; 23: 1935-1941. DOI: https://doi.org/10.1016/j.jamda.2022.09.001.

122. Anke E, Celia S, Irene H, et al. The wish to die and hastening death in amyotrophic lateral sclerosis: A scoping review. *BMJ Supportive &amp; Palliative Care* 2021; 11: 271. DOI: 10.1136/bmjspcare-2020-002640.

123. Balt E, Mérelle S, van Bergen D, et al. Gender differences in suicide-related communication of young suicide victims. *PLoS One* 2021; 16: e0252028. 2021/05/22. DOI: 10.1371/journal.pone.0252028.

124. Skulason B, Hauksdottir A, Ahcic K, et al. Death talk: gender differences in talking about one's own impending death. *BMC Palliative Care* 2014; 13: 8. DOI: 10.1186/1472-684X-13-8.

125. Wilson M, Ostroff C, Wilson ME, et al. Profiles of intended responses to requests for assisted dying: A cross-sectional study. *International journal of nursing studies* 2021; 124: 104069. 2021/10/01. DOI: 10.1016/j.ijnurstu.2021.104069.

126. Leboul D, Bousquet A, Chassagne A, et al. Understanding why patients request euthanasia when it is illegal: a qualitative study in palliative care units on the personal and practical impact of euthanasia requests. *Palliative care and social practice* 2022; 16: 26323524211066925. 2022/01/18. DOI: 10.1177/26323524211066925.

127. Coyle N, Manna R, Shen M, et al. Discussing Death, Dying, and End-of-Life Goals of Care: A Communication Skills Training Module for Oncology Nurses. *Clinical journal of oncology nursing* 2015; 19: 697-702. 2015/11/20. DOI: 10.1188/15.Cjon.697-702.

128. Harnischfeger N, Rath HM, Alt-Epping B, et al. Effects of a communication training for oncologists on early addressing palliative and end-of-life care in advanced cancer care (PALLI-COM): a randomized, controlled trial. *ESMO Open* 2022; 7: 100623. DOI: https://doi.org/10.1016/j.esmoop.2022.100623.

129. Kee JWY, Khoo HS, Lim I, et al. Communication Skills in Patient-Doctor Interactions: Learning from Patient Complaints. *Health Professions Education* 2018; 4: 97-106. DOI: https://doi.org/10.1016/j.hpe.2017.03.006.

130. Gamondi C, Pott M, Preston N, et al. Swiss families' experiences of interactions with providers during assisted suicide: a secondary data analysis of an interview study. *Journal of palliative medicine* 2020; 23: 506-512.

131. Gopal A. Physician-Assisted Suicide: Considering the Evidence, Existential Distress, and an Emerging Role for Psychiatry. *The journal of the American Academy of Psychiatry and the Law* 2015; 43: 183-190.

132. Kirk TW, Coyle N and Doolittle M. Communication Ethics. In: Wittenberg E, Ferrel BR, Goldsmith J, et al. (eds) *Textbook of Palliative Care Communication*. Oxford: Oxford University Press:, 2016, pp.27-34.

133. Dundas I, Hjeltnes A, Schanche E, et al. Does it get easier over time? Psychologists' experiences of working with suicidal patients. *Death Studies* 2022; 46: 458-466. DOI: 10.1080/07481187.2020.1740831.

134. Brassfield ER and Buchbinder M. Clinical discussion of Medical Aid-in-Dying: minimizing harms and ensuring informed choice. *Patient Education and Counseling* 2021; 104: 671-674. DOI: https://doi.org/10.1016/j.pec.2020.08.029.

135. Otte IC, Jung C, Elger B, et al. "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* 2017; 20: 249-256. DOI: 10.1007/s11019-016-9744-z.

136. Voltz R. Nach Abschaffung des Paragraphen § 217. Wo stehen wir? – Die „Zwei Hände Methode". *Zeitschrift für Palliativmedizin* 2020; 21: 288-291. DOI: 10.1055/a-1269-213.

137. Scheeres-Feitsma TM, van Laarhoven AJJMK, de Vries R, et al. Family involvement in euthanasia or Physician Assisted Suicide and dementia: A systematic review. *Alzheimer's & Dementia* 2023; 19: 3688-3700. DOI: https://doi.org/10.1002/alz.13094.

138. Gamondi C, Fusi-Schmidhauser T, Oriani A, et al. Family members' experiences of assisted dying: A systematic literature review with thematic synthesis. *Palliative medicine* 2019; 33: 1091-1105. DOI: 10.1177/0269216319857630.
139. Kelly B, Handley T, Kissane D, et al. "An indelible mark" the response to participation in euthanasia and physician-assisted suicide among doctors: A review of research findings. *Palliative & Supportive Care* 2020; 18: 82-88. 2019/07/25. DOI: 10.1017/S1478951519000518.
140. Bergen C, Bortolotti L, Temple RK, et al. Implying implausibility and undermining versus accepting peoples' experiences of suicidal ideation and self-harm in Emergency Department psychosocial assessments. *Frontiers in psychiatry* 2023; 14. Original Research. DOI: 10.3389/fpsyt.2023.1197512.
141. Yıldız M. Stressful life events and adolescent suicidality: An investigation of the mediating mechanisms. *Journal of Adolescence* 2020; 82: 32-40. DOI: https://doi.org/10.1016/j.adolescence.2020.05.006.
142. Schreiber J and Culpepper L. Suicidal ideation and behavior in adults, https://medilib.ir/uptodate/show/1708 (2023, accessed 20.05.2024).
143. Rawlings D, Tieman JJ, Sanderson C, et al. Never say die: death euphemisms, misunderstandings and their implications for practice. *International Journal of Palliative Nursing* 2017; 23: 324-330. DOI: 10.12968/ijpn.2017.23.7.324.
144. Chapple A, Ziebland S and Hawton K. Taboo and the different death? Perceptions of those bereaved by suicide or other traumatic death. *Sociology of Health & Illness* 2015; 37: 610-625. DOI: https://doi.org/10.1111/1467-9566.12224.
145. Lenherr G, Meyer-Zehnder B, Kressig RW, et al. To speak, or not to speak – do clinicians speak about dying and death with geriatric patients at the end of life? *Swiss medical weekly* 2012; 142: w13563. DOI: 10.4414/smw.2012.13563.
146. Pfaff H and Schmitt J. The organic turn: coping with pandemic and non-pandemic challenges by integrating evidence-, theory-, experience-, and context-based knowledge in advising health policy. *Frontiers in public health* 2021; 9: 727427.
147. McSweeney B. Fooling ourselves and others: confirmation bias and the trustworthiness of qualitative research – Part 1 (the threats). *Journal of Organizational Change Management* 2021; 34: 1063-1075. DOI: 10.1108/JOCM-04-2021-0117.
148. Bergen N and Labonté R. "Everything Is Perfect, and We Have No Problems": Detecting and Limiting Social Desirability Bias in Qualitative Research. *Qualitative Health Research* 2019; 30: 783-792. DOI: 10.1177/1049732319889354.
149. Sperling D. "Could You Help Me Die?": On the Ethics of Researcher-Participant Relationship and the Limitations of Qualitative Research. *International Journal of Qualitative Methods* 2022; 21: 16094069221105076. DOI: 10.1177/16094069221105076.
150. Fusch Ph D PI and Ness LR. Are we there yet? Data saturation in qualitative research. 2015.
151. Tate A. Death and the treatment imperative: Decision-making in late-stage cancer. *Social Science & Medicine* 2022; 306: 115129. DOI: https://doi.org/10.1016/j.socscimed.2022.115129.
152. Zeynep Turhan CB. Challenges and strategies of translation in a qualitative and sensitive research. 2022.
153. Hariton E and Locascio JJ. Randomised controlled trials - the gold standard for effectiveness research: Study design: randomised controlled trials. *BJOG : an international journal of obstetrics and gynaecology* 2018; 125: 1716. 2018/06/20. DOI: 10.1111/1471-0528.15199.
154. Van Noorden R. Medicine is plagued by untrustworthy clinical trials. How many studies are faked or flawed? *Nature* 2023; 619: 454-458. 2023/07/19. DOI: 10.1038/d41586-023-02299-w.
155. Juliet Jacobsen, Keri Brenner, Joseph A. Greer, et al. When a Patient Is Reluctant To Talk About It: A Dual Framework To Focus on Living Well and Tolerate the Possibility of Dying. *Journal of Palliative Medicine* 2018; 21: 322-327. DOI: 10.1089/jpm.2017.0109.
156. Shenk CE and Fruzzetti AE. The Impact of Validating and Invalidating Responses on Emotional Reactivity. *Journal of Social and Clinical Psychology* 2011; 30: 163-183. DOI: 10.1521/jscp.2011.30.2.163.
157. Feinberg PH. Circular questions: Establishing the relational context. *Family Systems Medicine* 1990; 8: 273.

158. von Below C. “We Just Did Not Get on”. Young Adults’ Experiences of Unsuccessful Psychodynamic Psychotherapy – A Lack of Meta-Communication and Mentalization? *Frontiers in Psychology* 2020; 11. Hypothesis and Theory. DOI: 10.3389/fpsyg.2020.01243.

159. Heier L, Weiß J, Heuser C, et al. Communication patterns in families affected by parental cancer from the healthy parents’ perspective—process evaluation of the complex intervention Family-SCOUT. *Supportive Care in Cancer* 2024; 32. DOI: 10.1007/s00520-024-08705-x.

160. Adams V, Katz NT, Philip JAM, et al. Desire to Die Statements in the Era of Voluntary Assisted Dying: An Audit of Patients Known to a Victorian Consultation-Liaison Palliative Care Service. *American Journal of Hospice and Palliative Medicine®* 2022; 39: 1203-1209. DOI: 10.1177/10499091211069620.

161. Brookfield SD. *Developing critical thinkers: Challenging adults to explore alternative ways of thinking and acting*. Jossey-Bass, 1987.

162. Borges PJ, Hernández-Marrero P and Martins Pereira S. A bioethical perspective on the meanings behind a wish to hasten death: a meta-ethnographic review. *BMC Medical Ethics* 2024; 25: 23. DOI: 10.1186/s12910-024-01018-y.

163. Terry PB. Informed Consent in Clinical Medicine. *Chest* 2007; 131: 563-568. DOI: https://doi.org/10.1378/chest.06-1955.

164. Adams CL, Nestel D and Wolf P. Reflection: A Critical Proficiency Essential to the Effective Development of a High Competence in Communication. *Journal of Veterinary Medical Education* 2006; 33: 58-64. DOI: 10.3138/jvme.33.1.58.

165. Hillienhof A. Ärztliche Kompetenz: Neues Curriculum soll Persönlichkeitsentwicklung unterstützen. *Deutsches Ärzteblatt* 2022; 119: A-726 / B-595.

166. Schallenburger M, Schwartz J, Batzler Y-N, et al. Handling the desire to die– evaluation of an elective course for medical students. *BMC Medical Education* 2024; 24: 279. DOI: 10.1186/s12909-024-05269-6.

167. De Shazer S. *"...Worte waren ursprünglich Zauber". Lösungsorientierte Therapie in Theorie und Praxis*. Dortmund: verlag modernes lernen, 1996.

9. Original Texts of Paper 1 and Paper 2

Paper 1 (accepted and published paper)

Boström, K., Dojan, T., Rosendahl, C., Gehrke, L., Voltz, R. & Kremeike, K. (2022) How do trained palliative care providers experience open desire to die-conversations? An explorative thematic analysis. Palliative and Supportive Care, 1-9. doi:10.1017/S1478951522001006

Paper 2 (accepted and published paper)

Boström K, Dojan T, Thölking T, et al. Talking about desire to die: Talking past each other? A framework analysis of interview triads with patients, informal caregivers, and health professionals. *Palliative and Supportive Care*. 2025;23:e83. doi:10.1017/S1478951524002104

Palliative and Supportive Care

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Original Article

Cite this article: Boström K, Dojan T, Rosendahl C, Gehrke L, Voltz R, Kremeike K (2022). How do trained palliative care providers experience open desire to die-conversations? An explorative thematic analysis. *Palliative and Supportive Care*, 1–9. 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

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

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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).

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 inthis 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

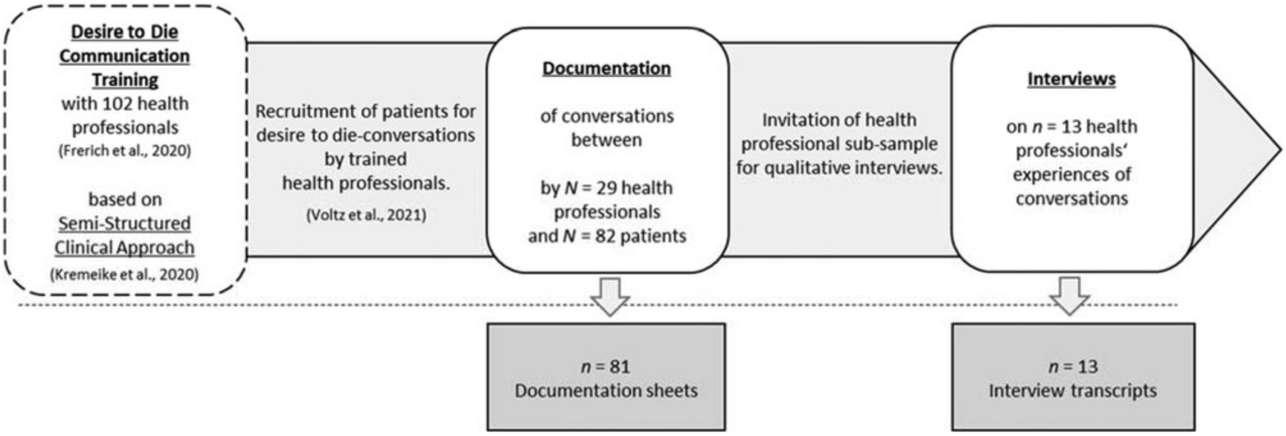

Fig. 1. Study procedure.

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 documentations 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	

[a] Via 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

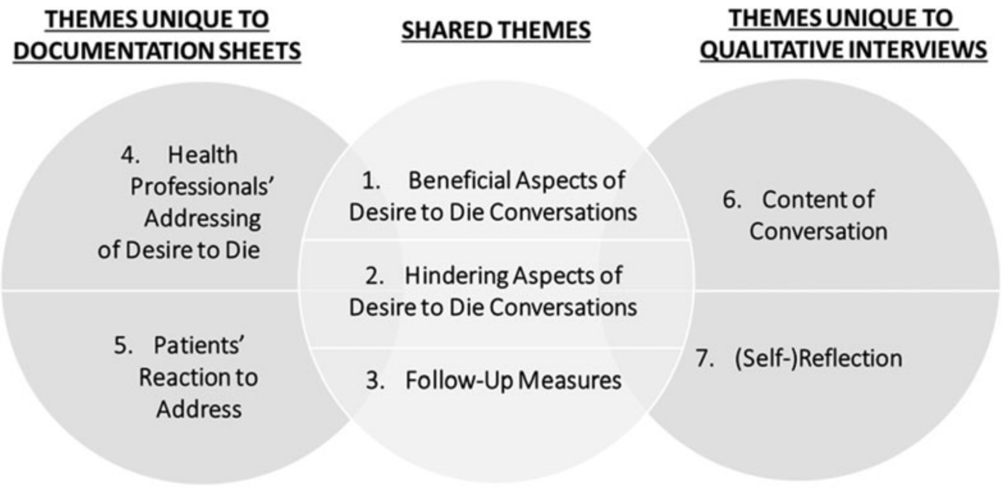

Fig. 2. All themes from both data sources, the documentation sheets and the interviews.

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	*“Topics could be discussed openly and without ‘psychological barriers’ in a ‘relaxed’ atmosphere.” (tn87k10, DS*)* *“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)* *“The patient has a stable family network that gives him strength and support.” (tn45k5, DS)*
1.2. Perceived Benefit for the Patient	*“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)* *“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)*
1.3 Health Professional Attributes	*“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*)* *“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)*
2. Hindering Aspects during Conversation on Desire to Die	
2.1 Actively/deliberately shaping the course of conversation	*“(…)[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)* *“The presence of her husband was problematic because she did not want to talk openly in front of him.” (tn40k4, DS)*
2.3 Containing Patient Emotions and Concerns regarding Death	*“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)* *“[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)*
3. Follow-Up Measures	
3.1. Institutional Care	*“To feel safer, she wishes to advance her care plan: e.g., organize a care home or hospice care for later.” (tn38k4, DS)*
3.2. Care at Home	*“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)*
3.3. Follow-Up Conversations	*“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)*
3.4 Informing about and Initiating Therapeutic Measures	*“I explained the legal situation to the patient. For me, it was the first time to do that.” (tn53k5, DS)* *“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)* *“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)*

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	*"Have you ever thought about the end of your life concretely? Do you have any wishes or fears?" (tn28k3, DS*)*
4.2. … fears regarding death and dying	*"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)*
4.3. … feelings of hopelessness faced with current symptom burden	*"With all these therapies you are getting, with all the sorrow, have you ever thought death could come as a relief?" (tn07k1, DS)*
4.4. … thoughts of not wanting to live any more	*"Do you sometimes have moments in which living like this feels like a burden?" (tn118,k12, DS)*
4.5. … thoughts of ending one's life prematurely	*"Do you sometimes think about ending your life, should pain and breathlessness worsen?" (tn59k6, DS)*
4.6. … desire to die directly	*"Do you sometimes wish for your death?" (tn03k6, DS)*
5. Patient Reactions to Addressing Desire to Die	
5.1. Confirmative	*"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)*
5.2. Open	*"It is good to talk about it, the patient appreciates directness." (tn88k8, DS)*
5.3. "Matter-of-fact"	*"The patient was very open-minded and sober regarding the topic." (tn107kx, DS)*
5.4. Emotional	*"She was crying, because she felt understood." (tn53k5, DS)*
5.5. Negative	*"The topic was rather unpleasant for him." (tn64k7, DS)*
5.6. Emphasis on will to live	*"Determined rejection of any desire to die. He considers himself an optimist and looks positively at the future and at life."(tn118k12, DS)*

*DS= documentation sheet.

mirrors the idiosyncrasy of the existential phenomenon of desire to die (German Guideline Programme in Oncology, 2020; Kremeike 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; Kremeike 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	*"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." (tn101k11, QI*)*
6.2. Exploration of DD	*"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." (tn86k10, QI)*
6.3. Enduring suffering and giving room	*"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]." (tn87k10, QI)*
6.4. Tying in with resources	*"(…) 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." (tn38k4, QI)*
7. (Self-)reflection	
7.1. Reflecting on conceptual topics	*"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)*
7.2. Reflecting on the patient	7.2.1. Patient interpretation of conversation *"(…) 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]." (tn101k11, QI)*
	7.2.2. Patient personality and biography *"(…) 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)*
7.3. Reflecting on oneself	7.3.1. One's way of working *"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." (tnn47k5, QI)*
	7.3.2. Expectations and reality *"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." (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 todays' 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, Waeber 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 semistructured 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, Gaulden 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, Joolaee 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.

Kremeike 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

Kremeike 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

Kremeike 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

Kremeike 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

Kremeike 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 Philosphy* **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, Henoch 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

Documentation Form: Conversations about desire to die

<u>Important</u>: This document serves as a follow-up to conversations with patients about possible desire to die. Please do <u>not</u> fill out this document during the conversation, but only afterwards.

Date:_____________ **Duration:**___________ min

Setting: ____

☐ Initial conversation as part of the study ☐ Follow-up conversation (to the conversation from _____________)

In what context (e.g. spatial or temporal arrangement) **did the conversation take place?**

____

____

____

____

____

Who raised the issue of desire to die?

☐ You as a caregiver ☐ The patient

What specific wording was chosen for this?

____

____

____

____

____

What was the reaction to this (by you or the patient)**?**

____

____

____

____

____

Were there any particular challenges during the interview? ☐ No ☐ Yes, namely:

____

____

____

____

____

Was there anything during the interview that went particularly well? ☐ No ☐ Yes, namely:

____

____

____

____

____

Code:

From their perspective, is there currently a desire to die? ☐ Yes ☐ No

If „Yes“,…

…how was it expressed?

... *how would you categorize it?*

…from your point of view, what are the backgrounds and meanings of the desire to die?

... *what functions do you attribute to the desire to die?*

Specific measures / further action:

If space is limited, please use additional sheets.

If you have any questions, please contact us:
Phone: 0221-478-878 35 or 0152-546 963 45 E-Mail: tw-palliativ@uk-koeln.de

Please fax the completed form to the following number: 0221-478-146 02 30.

Version 3.4 (03.07.2019)

Code:

The data collected is not associated with patient data in accordance with data protection regulations.s

Code:

Semi-structured guideline for qualitative interviews with caregivers

Introduction

Talking together with patients (P) and their caregivers is an essential part of their treatment and support. In the case of patients with serious, incurable diseases, personal topics are often addressed, such as the imminent end of life. Today I would like to talk to you about how you perceive such conversations with patients or their relatives (R).

Entering the communication with P	**I am particularly interested in the conversations about desire to die that you had as part of your study participation. How did you experience these conversations?**
Content	• What is it about when you talk to your P about death wishes? • What aspects of such conversation do you think are challenging / pleasant? • How do you feel during and after having such conversation with P?
Influence	• What has it been like for you, since beginning our study, to approach P directly about desire to die?
Communication about desire to die	**You also had a conversation with P. How did you perceive this conversation - or possible follow-up conversations?**
Self-perception	• How did you experience yourself in this conversation? • How do you think P perceived the conversation? • Did you remember anything in particular from this conversation? • What do you think you did particularly well? What would you have liked to have done better?
Proactive	• Who brought up the subject of wanting to die? What was that like for you?
Relatives	**There may also have been conversations with R in which desire to die were a topic.**
R – CG	• If so, what is it like to talk with R about desires to die? • Does the relationship dynamic allow for a conversation about desire to die?
R –P	• As a CG, how do you experience the topic of desire to die in conversations between P and R?
General	• What is it like for you in general to talk with R about the topic of desire to die? Compared to conversations with P?
Relationship with patient/relatives	**How would you describe your relationship with P?**
CG - P	• What effect did the conversation have on the relationship between you and P?
CG - R	• Why did you choose P for the study? • How do you perceive P's relatives R?

	• How would you describe your relationship with R? • How does the P - R relationship affect your communication with P?
Study participation	
Conversation aid Study	• What role did the guide play for you in the interview? • How did you experience the use of the documentation form? • It is possible that something changed for you privately or professionally as a result of participating in the study. If so, what impact did study participation have on you? • How did your attitude toward proactively addressing death wishes change? • What motivated you to participate in the study?
Interview conclusion	**You have already mentioned many interesting points to me. From my side, this would bring us to the end of the conversation.**
	• Is there anything else you would like to add to the topic? Something that is important to you or something that has not yet been mentioned? • Is there anything else you would like to know or that remained unclear? • How was the interview for you? • What was the reason for you to participate in this interview?
Acknowledgement	**We thank you very much for your participation. The results of the interviews will certainly help to significantly improve the conversations between patients and providers.**

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Original Article

Cite this article: Boström K, Dojan T, Thölking T, Gehrke L, Rosendahl C, Voltz R, Kremeike K (2025) Talking about desire to die: Talking past each other? A framework analysis of interview triads with patients, informal caregivers, and health professionals. *Palliative and Supportive Care* **23**, e83, 1–10. https://doi.org/10.1017/S1478951524002104

Received: 27 May 2024
Revised: 14 October 2024
Accepted: 24 November 2024

Keywords:
Desire to die; palliative care; communication; death talk; framework analysis

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Talking about desire to die: Talking past each other? A framework analysis of interview triads with patients, informal caregivers, and health professionals

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Abstract

Objectives. Up to 40% of seriously ill patients develop a (temporary) desire to die which can lead to requests for assisted dying. Health professionals often feel uncertain about addressing these topics, while informal caregivers may feel guilty and left out. Open and respectful communication proves beneficial. It remains unclear how this communication ideal realizes within the lived experience of all 3 parties. Therefore, we conducted in-depth analysis of communication strategies about desire to die from triangulated perspectives of patients, informal caregivers, and health professionals.

Methods. We conducted semi-structured interviews with purposefully sampled triads consisting of seriously ill patients, their respective informal caregivers and health professionals. Interviews were part of the qualitative evaluation of a 3-phase mixed-methods study on the effects of communication about desire to die on seriously ill patients. We followed a framework analysis approach to build communication types.

Results. From the $N = 13$ patients, 54% suffered from oncological diseases. Health professionals ($N = 13$) were multiprofessional. Informal caregivers ($N = 13$) were partners, children, or another relation. All in all, we conducted $N = 14$ interview triads ($n = 3$ incomplete; $N = 39$ individual interviews).

Four key themes emerged from analysis: (a) how open communication was perceived, (b) whether participants reported shared reality, (c) how they talked about death, and (d) their communication strategies.

Ultimately, 3 communication types were inductively derived at from these key themes. Type 1 “Between the Lines,” type 2 “Past each Other” and type 3 “Matter of Fact” show differing expressions on the key themes, especially on (b) shared reality. Specific type characteristics produce suggestions for health professionals’ communicative practice.

Significance of results. Awareness of typical communication strategies is necessary to foresee potential pitfalls such as loss of information or acting on unchecked assumptions. To reduce distress and increase information flow, health professionals should actively approach informal caregivers for desire to die conversations.

Background

In the face of life-threatening illness, patients frequently develop a desire to die – an existential experience involving physical, psychological, social, and spiritual aspects. Of those, 12–45% of patients express temporal and 10–18% persistent desire to die (Chochinov et al. 1995; Wilson et al. 2016). Different definitions of desire to die are used to capture the complex phenomenon (Balaguer et al. 2016; Kremeike et al. 2021). We apply a broad understanding that allows for a range of forms, backgrounds, meanings, and functions (Kremeike et al. 2021) and a simultaneous will to live (Voltz et al. 2010). As desire to die is prone to change, we propose the conceptualization along a continuum of increasing suicidal pressure: from acceptance of death or satiety of life to latent or even acute suicidality (Kremeike et al. 2021). The latter can also find expression in the wish for hastened death (Balaguer et al. 2016) or suicidality and wishes for assisted dying (Rodin et al. 2009).

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Health professionals are recommended to address desire to die with their patients (German Guideline Programme in Oncology 2020). A proactive approach in an atmosphere of openness, interest, and respect for patients' thoughts, experiences, and (planned) actions is necessary (Kremeike et al. 2021). If carried out by trained health professionals, desire to die conversations do not harm patients but tend to alleviate depressiveness (Porta-Sales et al. 2019; Voltz et al. 2022).

Ideally, palliative care involves strong therapeutic alliances and shared decision-making between health professionals and patients (Kuosmanen et al. 2021; Thomas et al. 2021), with informal caregivers as important stakeholders. This multiperspectivity likely plays a crucial role concerning desire to die conversations in palliative care. While it may enable better care, it also holds potential for conflicts or misunderstandings: divergent understandings of vital information such as the palliative prognosis are common (Jacobsen et al. 2013). Remaining taboos surrounding death and dying can render the topic unspeakable (Collins et al. 2018a) and may foster denial (Gerber et al. 2020). As humans have a fundamental need for shared reality (Echterhoff et al. 2009), failing to create commonality through communication can cause pain and add to the experience of loneliness in terminal illness (Kang 2021).

Severely ill patients wish for end-of-life conversations with their health professionals (Harding et al. 2013). However, they rather speak with informal caregivers than professionals about suicidal ideation (Lindner et al. 2014) and tend not to address challenging topics like desire to die on their own as to not be a burden (Macmillan Cancer Support 2017).

Health professionals report high levels of uncertainty regarding desire to die conversations (Udo et al. 2014). They also fear to trigger latent suicidality by asking related questions (Allan and Allan 2019), even though asking about suicidality holds no iatrogenic risk (DeCou and Schumann 2018). Therefore, there is a need for specific trainings (Galushko et al. 2016). A multiprofessional training on dealing with desire to die showed increasing levels of health professional confidence thereafter (Boström et al. 2022).

Relatives that operate as informal care providers often know a lot about the patients' needs and are potentially vital allies in care provision (Fridriksdottir et al. 2006). At the same time, they require support when the patient they are related to desires to die (Metselaar et al. 2019).

Several questions arise when negotiating the topic of desire to die in these interrelationships: Who is included in conversations about desire to die and to what extent? What are contents and potential communicative strategies when talking about desire to die between patients, health professionals, and informal caregivers? What are potential functions of differences in communication styles? And how can health professionals best approach desire to die conversations with patients and informal caregivers? Taking all these aspects into consideration, we aim to explore in what ways patients, health professionals, and informal caregivers experience desire to die conversations and what communication types emerge within these triads.

Methods

The presented interview data stems from phase 3 of a mixed-methods study aiming to consent a clinical guideline on dealing with desire to die (phase 1), train health professionals in using the guideline (phase 2), and evaluate the effects of a proactive guideline-informed desire to die conversations on severely ill patients, their informal caregivers and health professionals (phase 3) (Kremeike et al. 2018). The study was registered in the German Clinical Trials Register (DRKS00012988; registration date: 27.9.2017).

After the clinical guideline was consented (Kremeike et al. 2020), health professionals participated in a training course based thereon (February 2018–January 2020) (Boström et al. 2022). Trained health professionals recruited suitable patients for an open and proactive conversation on desire to die (April 2018 and March 2020). For an analysis of conversation contents, refer to Boström et al. (2022). Following a quantitative evaluation of the conversation effects on patients (Voltz et al. 2022), a subsample of patients, their health professionals, and a relative were invited by the research team to participate in individual interviews for qualitative evaluation (May 2019–January 2020).

This article presents the results from this qualitative evaluation of desire to die conversations. For contextualization of the presented interview data within our bigger study and the respective sampling process (Kremeike et al. 2018), see Fig. 1.

Sample

Sampling in phase 3 of our mixed-methods study (Voltz et al. 2022) took place in a 2-step process. We quantitatively evaluated our desire to die conversations with a larger patient sample and then conducted qualitative interviews with a subsample of patients, health professionals, and relatives derived thereof.

1. Large patient sample for quantitative evaluation (Voltz et al. 2022): We asked health professionals previously trained in dealing with desire to die in to recruit patients following a convenience sampling strategy. Patients were eligible if they (i) had a life expectancy between 3–12 months (estimated by surprise question (White et al. 2017)), (ii) were aged ≥18 years, and (iii) had sufficient cognitive ability and German language skills (Voltz et al. 2022).
2. Subsample for qualitative evaluation: After completion of in-person quantitative data collection, a selection of patients was chosen based on researcher impressions. Following a purposeful sampling strategy, patients were aimed to represent a variety of ages, genders, diagnoses, and care settings, but also insightful experiences. If patients agreed to participate, they were asked to suggest a relative (a person that plays a significant role in their life regardless of family relationship) for an interview. The patients' health professional was also invited. Interviews were held individually.

To minimize bias, a cover story communicated the study topic to patients and informal caregivers as "end-of-life communication." Each set of associated patient, health professional and relative interviews formed a triad. We use the term "triad" even in cases where 1 member is missing. Complete and incomplete triads were analyzed together, as they included relevant information on the absent party. To all 2-people-relationships within the triads (patient–relative, patient–health professional, and health professional–relative) we refer as "dyads."

Data collection

Interviews were conducted individually at a time and place chosen by each interviewee. Four female researchers (KB, LG, CR, KK) with backgrounds in psychology, nursing, speech therapy, and physiotherapy conducted the interviews following a

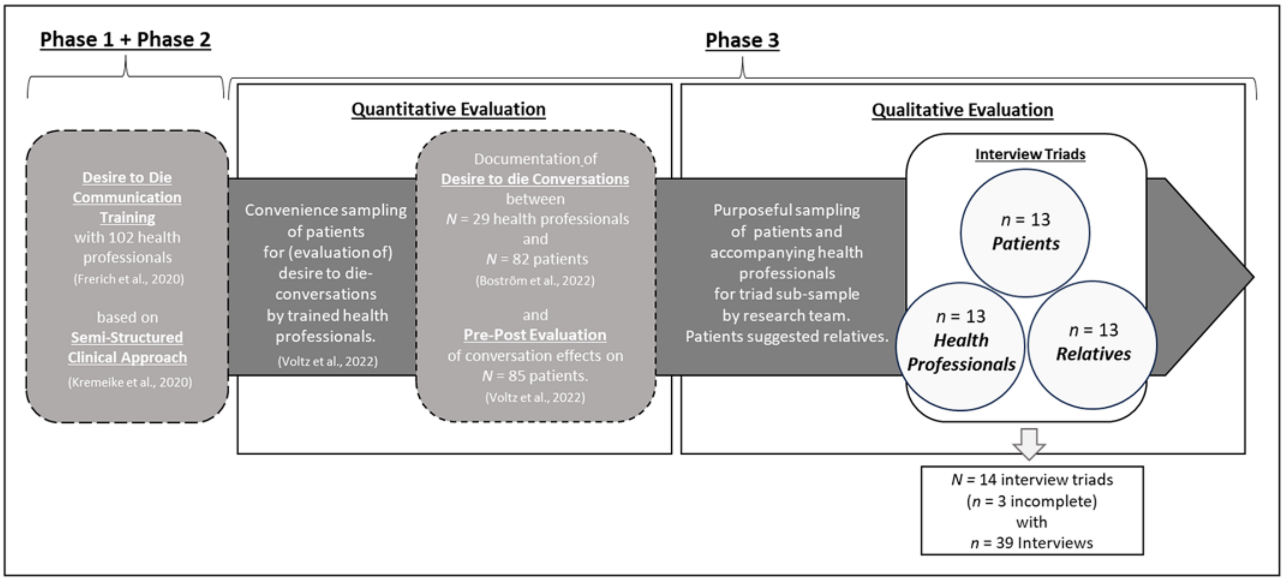

Figure 1. Study procedure with respective sampling strategies for each phase, adapted from Boström et al. (2022).

semi-structured guideline (see Appendix 1). All interviews were audio-recorded and transcribed verbatim. Sociodemographic data was collected using a brief questionnaire.

Data analysis

Three female (KB, KK, TT) and one male researcher (TD) coded, analyzed, and discussed data. KB and TD have backgrounds in psychology, KK is a physiotherapist and social scientist, and TT a physician and ethicist. All steps of data analysis were conducted using the qualitative data analysis software MAXQDA 2020 (VERBI Software 2019).

We chose framework analysis according to Ritchie and Lewis (2005) to analyze the interview triads with the aim of generating a communication typology. This method provides the opportunity to manage large sets of qualitative data as well as a dynamic approach to develop a framework from “both a priori issues and emergent data driven themes” (Parkinson et al. 2016). It follows a structuring as well as interpretative approach and lets researchers relate data to existing theories or phenomena. As participants did not strictly differentiate between desire to die conversations and death talk, we included information on both in our analysis. However, if participants reported on persons other than triad members (e.g. further relatives or patients), this information was excluded. For the entirety of the 6-step data analysis process please see Fig. 2.

Four overarching key themes with 12 subthemes resulted as our final interpretative code system from interpretative analysis in step 5: (1) *How was communication about death and desire to die perceived?*, (2) *Did conversation partners share a reality?*, (3) *By what conversation content was death made understandable?*, and (4) *What strategies are used to communicate about death and desire to die?* (see Table 1).

In step 6, we used specific patterns of expressions on these key themes in each triad to inductively generate 3 communication types (see Fig. 2). Not all key themes proved equally suitable to differentiate between types as some did not sufficiently mark differences (e.g. expressions of *By what conversation content was death made understandable?*). To achieve distinct communication types, we focused on 1 meaningful key theme which varied greatly between triads: *Did conversation partners share a reality?* was used as a basis to cluster by type and other key themes enriched type definitions. We then refined types based on expressed discontent about communication on desire to die from the interpretative triad summaries.

Results

Sample

Of 33 patients asked to participate, 14 triads were interviewed (May 2019– February 2020). Three were incomplete: 1 missed a patient (died before interview date), 1 a relative (withdrew due to overburdening), and 1 a health professional (already interviewed before). Therefore, $N = 39$ individual interviews were conducted in total. On average, patient triad interviews took place 103 ± 73 days after the desire to die conversation. There is a large range of time past between desire to die conversation and interviews, since recruitment for qualitative interview evaluation did only start after quantitative evaluation was completed for most patients. Depending on time of entry into the quantitative evaluation, patients had a longer or shorter period between completing quantitative evaluation and being recruited for qualitative interviews. For triad characteristics, see Table 2.

All health professionals had addressed desire to die with their patient (Boström et al. 2022), but only 4 of the 13 interviewed patients recalled such a conversation (triads 2, 3, 4, 7). Others either did not recall a desire to die conversation at all (triads 5, 10, 8, 9) or remembered it vastly different than their health professional (triads 11, 12, 1, 14, 3). Only in 1 triad the relative was present during the desire to die conversation (triad 1). Informal caregivers and health professionals rarely spoke about desire to die (except triad 1 and 10) and in half of the cases, informal caregivers reported no contact with health professionals at all. Only 2 informal caregivers explicitly wished for more inclusion (triads 4, 6). However, contact between health professionals and informal caregivers might be beneficial: some informal caregivers knew vital information about a patients’ plan for assisted suicide (triads 5, 13)

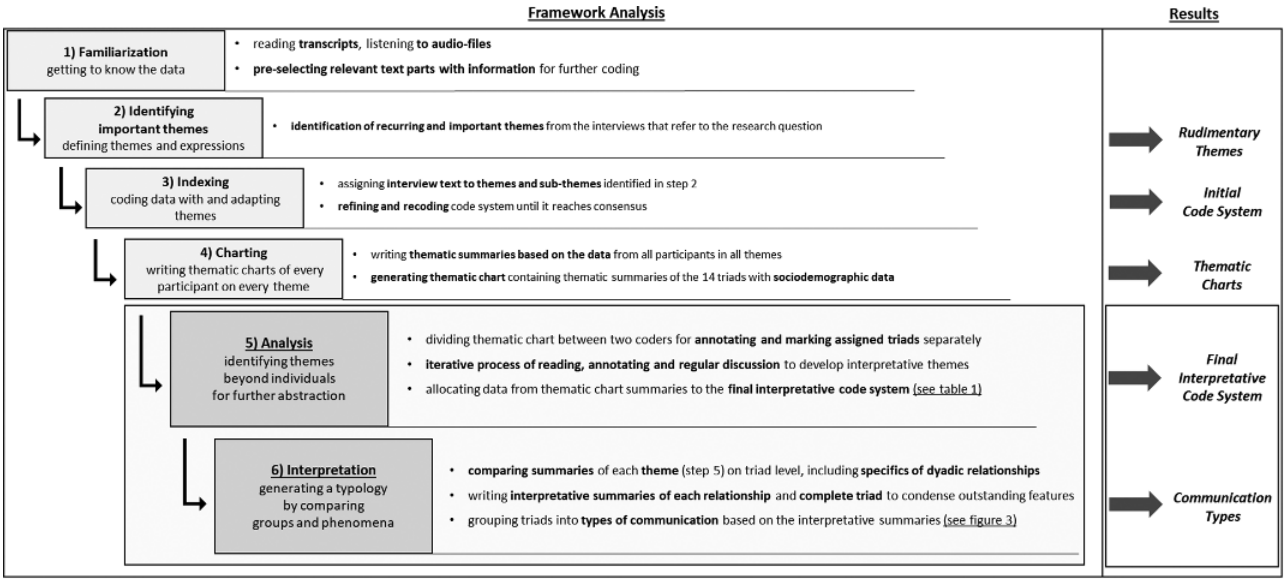

Figure 2. Six step process of framework analysis according to Ritchie and Lewis (2005).
All 6 steps of the Framework Analysis process. Steps 1–4 represent preparing analysis steps with steps 5 and 6 highlighted as their results are reported in this paper. For results of step 5, see table in appendix, for results of step 6, see Figs. 3–5.

Table 1. Interpretative key themes and subthemes (analysis step 5) used as a basis for building typology

Key themes and subthemes	Definition	Quote
1. How was the communication perceived? 1.1 Open and helpful 1.2 Open and ambivalent 1.3 Open and overwhelming 1.4 Withdrawn and hindering	• Talk about death or desire to die was more or less open. • Openness was perceived as helpful, ambivalent, or overwhelming. • Withdrawal was usually considered hindering.	*"It was relieving [to talk about the option of assisted suicide with my son]. As if there was a door that was already open, that I didn't have to push open."* (Patient, Triad 2)
2. Did conversation partners share a reality? 2.1 Shared 2.2 Unshared	• Shared reality: similar perception of communication content, atmosphere and each other. • Unshared reality: unrelated or paradox perceptions of the same situation.	*"He is my partner after all. He knows me inside out. We talk very intensively and often deeply."* (Patient, Triad 4) *"That's very difficult with my wife. She rarely wants to talk about the disease (…). I can't get through to her anymore."* (Relative, Triad 4)
3. How was death talked about? 3.1 Factual topics 3.2 Existential topics	• Factual: e.g. practices like funeral wishes or advance care directives. • Existential: e.g. fears or spiritual convictions. • Both are not mutually exclusive.	*"I asked her if she was not at all afraid of the medical challenges, of pain, of whatever kinds of symptoms and complaints? She said 'No, because you will take care of that.' She was more concerned (…) to have people that accompany her spiritually."* (Health Professional, Triad 12)
4. What communication strategies are used? 4.1 Compartmentalization 4.2 Protecting the other/the self 4.3 Denial 4.4 Acknowledgment	• Topics were compartmentalized between conversation partners. • Information was not shared based on anticipated burden. • The end-of-life situation was not talked about or denied. • All acknowledge desire to die and necessary actions. • Communication strategies are not mutually exclusive.	*"The conversation (…) was okay (…). Except for having to open up too much which I don't like to. (…) You don't have to know everything about me just because I'm dying."* (Patient, Triad 13)

the health professional was not aware of while others reported to suffer from feeling left out by the patient (triads 2, 10).

Types of communication within triads

Triads differed in their expressions on the interpretative key themes (see Table 1), particularly regarding *Did conversation partners share a reality?*. Thereby, we were able to inductively generate 3 types of communication: *Between the Lines, Past Each Other*, and *Matter Of Fact* (see Figs. 3–5) which, to our knowledge, have not been described elsewhere. Their definitions were enriched with additional details from the 4 other key themes. For a complete list of all triad summaries and their expressions on all 4 key themes according to type, see Appendix 2.

> Type 1 – Between the Lines
> *He always says: I'm fine. And when I asked, he said to me: Don't always ask, I feel like shit.* (Relative about patient, triad 6)

Type 1 was found in 5 triads (triads 2, 4, 5, 6, 10). Triad participants **mostly did not share a reality** of the desire to die conversation or death talk. Although often said to be helpful in principle, **openness** about desire to die is experienced as **overwhelming** by members of this type, yet they perceive each other's **withdrawal as**

Table 2. Participant characteristics

		Patients (*n* = 13)	Health professionals (*n* = 13)	Informal caregivers (*n* = 13)
Age (mean + standard deviation)		68 ± 11	47 ± 11	58 ± 14
Gender	Female	10 (77%)	10 (77%)	8 (62%)
	Male	3 (23%)	3 (23%)	5 (38%)
Characteristics		**Diagnosis** - Oncological disease: 7 (54%) - Geriatric multimorbidity: 3 (23%) - Chronic Obstructive Pulmonary Disease (COPD): 2 (15%) - Neurological disease: 1 (8%)	**Profession** - Physician: 5 (39%) - Nurse: 2 (15%) - Social worker: 2 (15%) - Other**: 4 (31%)	**Relation** - Partner: 5 (39%) - Child: 4 (31%) - Friend: 2 (15%) - Other family member: 2 (15%)***
		Desire to die present* - Present: 4 (31%), namely ∘ Acceptance of death ∘ Desire to die ∘ Wish to hasten death Wish for assisted dying - Not present: 9 (69%)	**Address of desire to die** - Proactive (by health professional): 8 (62%) - Reactive (by patient): 5 (38%)	
Education	Baccalaureate	4 (31%)	12 (92%)	6 (46%)
	Higher secondary school	3 (23%)	1 (8%)	5 (38%)
	Lower secondary school	6 (46%)		2 (15%)
Nationality	German	11 (85%)	12 (92%)	12 (92%)
	Other	2 (15%)	1 (8%)	/
	Missing data	/	/	1 (8%)
Duration of interview (minutes)	Mean	49 ± 39	48 ± 20	38 ± 13
	Range	20 − 180	18 − 82	23 − 60
Days between conversation and interview	Mean	98 ± 75	111 ± 75	100 ± 67
	Range	33 − 300	33 − 299	33 − 315
Interview setting		- Home: 7 (54%) - Residential care facility: 4 (31%) - Hospice & Hospital: 1 (8%) each	- Home: 2 (15%) - Work environment: 11 (85%)	- Home: 10 (77%) - Other****: 3 (23%)

* as judged and documented by the health professional
**psychologist, nondenominational chaplain, hospice coordinator, speech therapist;
***daughter in law, niece;
****work environment, research team office

hindering for their communication. Withdrawal conjured accusations regarding their reasons for being withdrawn, hinting at enmeshed social relations. Their communicative **strategies** reflect that: some chose to keep to themselves **to protect the other or themselves** from burden or unwanted consequences. A few **compartmentalize** and constrict flow of information according to assigned roles (e.g. health professional for medical, relative for personal concerns), while others **deny** the severity of the situation. Patients and informal caregivers of this type report the **lowest satisfaction** due to miscommunication and unmet communication needs, e.g. in triad 4 a husband laments how his wife stopped opening up to him while the wife names him as her most intimate familiar. Death talk mainly focuses on **factual** aspects, yet sometimes **existential** matters emerge.

Type 2 – Past Each Other

> *He always tries to be totally helpful and do everything (…). But really with the matter [of the end-of-life], I'm not sure …* (Patient about relative, triad 11)

This type consists of 4 triads (1, 11, 12, 13). Comparing perceptions of desire to die conversations shows a mixed picture. While participants of **some triads report shared reality**, others report **incompatible accounts**. For example, the health professional from triad 1 reported an emotionally challenging educational conversation on the legal possibilities of assisted dying while patient and relative still wrongly believed it to be illegal afterward. Regarding dyadic relations, all **value open communication**, but employ different strategies to achieve it. In their **strategies** to

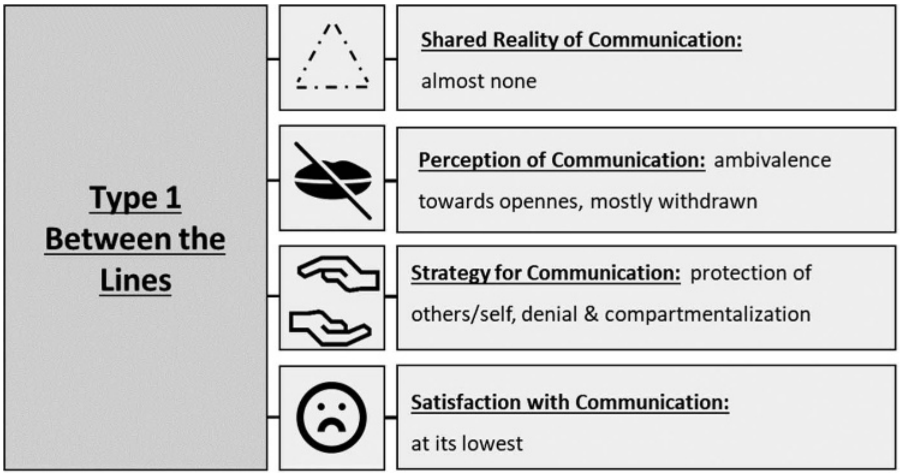

Figure 3. Expressions of key themes in type 1 "between the lines" that describe communication about death and desire to die in the particular triads of patients, health professionals, and informal caregivers.

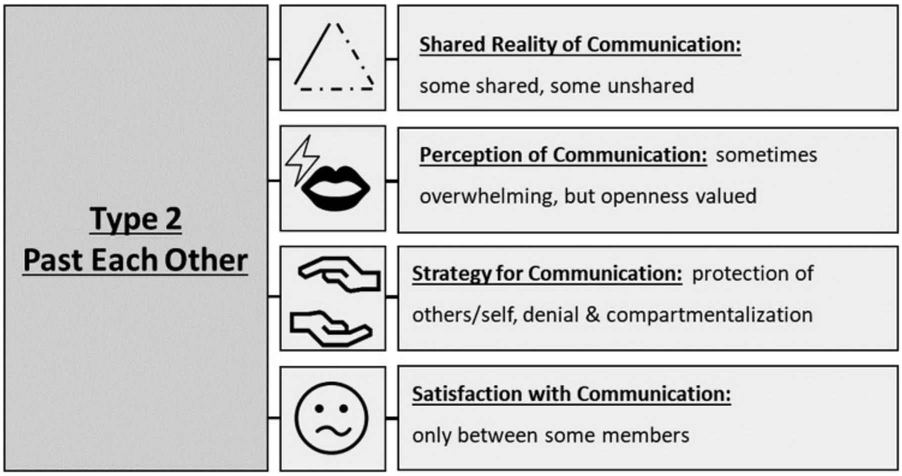

Figure 4. Expressions of key themes in type 2 "past each other" that describe communication about death and desire to die in the particular triads of patients, health professionals and informal caregivers.

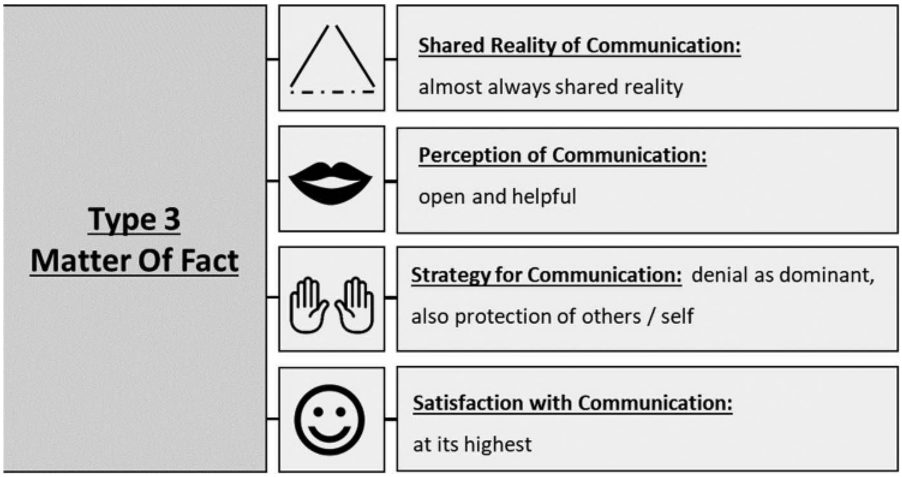

Figure 5. Expressions of key themes in type 3 "matter of fact" that describe communication about death and desire to die in the particular triads of patients, health professionals and informal caregivers.

communicate about desire to die or death, most triads engage to a similar degree in **compartmentalization and protection of the other**. Compartmentalization took place based on topic (e.g. spirituality shared with a partner and medical care in the hands of the oncologist, triad 12). Sometimes, this leads to loss of important information. **Satisfaction varies** between individual triad members. While the focus on **factual** aspects is high, the *Past Each Other*-type often address **existential** matters as well.

Type 3 – Matter of Fact

> *We talked about symptoms of illness, but we didn't talk about death. Of course, [about] health care, you know.* (Health professional about relative, triad 9)

This type contains 5 triads (3, 7, 8, 9, 14). Triad participants **all seem to share a reality** on the desire to die conversation, yet often, there either is no desire to die, or patients and informal caregivers report no further need to talk about it. Conversations were perceived as mostly **open and helpful**. In their communicative **strategies**, some fall back on **compartmentalization** or attempt to **protect others**. However, most triad parties show discrepancies in narratives and sometimes direct accusations, hinting at **denial** in dealing with desire to die (triads 8, 9, 14). Triad participants of the 3rd type report **high satisfaction**. Regarding content, triad participants of the *Matter of fact*-type share a focus on **factual** aspects of end-of-life care characterized by a professional attitude. For this type, death talk equates organizing care, e.g. by initiating advance care planning or funeral planning. Therefore, only health professionals of this type acknowledge that the desire to die conversation might not have been perceived as such. The contact between informal caregivers and health professionals (3 of 5 without contact) is remarkably rare.

Discussion

Talking openly about death and desire to die can offer clarity and emotional relief but also has potential for miscommunication and distress. By exploring such communication in interview triads with patients, health professionals, and informal caregivers, we found 4 interpretative key themes: how *open communication was received*, whether *reality was shared*, what type of *content made death understandable*, and what *communication strategies* were used. From these key themes, we inductively established 3 communication types: *Between the Lines, Past Each Other*, and *Matter of Fact*. Health professionals in are well advised to use different communicative approaches based on the types' characteristics.

What the communication types can teach us

Although the unquestionable detection of our types in clinical praxis is difficult, knowledge about them may increase health professionals' awareness what kind of engagement is required: The *Between the Lines* Type 1 reports high discontent and a communication perceived as withdrawn. Additionally, patients often reported an unexpressed desire to die. They might therefore be the type in highest need of a proactive approach to desire to die by health professionals (Boström et al. 2022; Voltz et al. 2022). It may also enable to initiate adequate psychosocial support. In type 2, *Past Each Other* parties are interested in open communication, but seem to apply diverging strategies. Here, too, informal caregivers are often left out. In this type, an accompanying approach might serve best, to offer stability and guidance as well as prevent transmission errors. On first sight, the *Matter of Fact* approach of Type 3 seems to make for easy communication. Because desire to die barely seems a burdensome topic in Type 3, there is a danger of overlooking concealed or potential desire to die. Health professionals should be sensible toward patients or informal caregivers who put on a façade which might crumble if the burden of disease increases. Overall, 1 hypothesis could be that triads that focus more on facts rather than emotions report more convergent experiences of the desire to die conversations and death talk than triads that focus on emotions rather than facts.

We do not consider it a problem that we did not identify a type with "perfect" communication (i.e. including health professionals, informal caregivers, and patients, perceived as open and satisfying and resulting in correct transmission of information and completely shared reality). Rather, we suggest that even instances of "failed" communication in our results support the notion of communication as always co-constructed and interpretative: people are simultaneously sender and receiver in a process of mutual influence (du Pré and Foster 2016).

Inclusion in desire to die conversations: who speaks to whom about what?

Due to our study design, health professionals addressed desire to die proactively (Voltz et al. 2022). Thereby, we assume they provide a space for patients to talk about topics relevant to them, either **existential** or **factual** (Boström et al. 2022). Although working through existential topics at the end-of-life is advised (Granda-Cameron and Houldin 2012), such a process can only be encouraged, not enforced. In patient-relative-dyads factual topics dominated and death was usually talked about through organizing care – informal caregivers' common communication responsibility (e.g. by keeping track of patient's medical history, diagnosis and prognosis) (Wittenberg et al. 2017). When oneself or a loved one has a life-limiting illness, focusing on factual topics and planning can help experience self-efficacy instead of powerlessness (Nipp et al. 2017; Wittkowski 2015), without risking the emotional vulnerability of addressing existential fears. Informal caregivers' end-of-life responsibilities can also be cause for immense suffering – a suffering health professional should address (Wittenberg et al. 2017).

In our study, however, meaningful contact between health professionals and informal caregivers was almost nonexistent – common at the end-of-life (Lind et al. 2011). For some informal caregivers, exclusion caused frustration or hindered information flow (e.g. triads 5, 14). As health professionals systematically underestimate informal caregivers' needs for information and involvement (Collins et al. 2018b), we suggest to actively offer informal caregivers a part in communication about desire to die.

Perception of desire to die conversations: what is said and what is understood?

A large proportion of triad members reported divergent experiences of desire to die conversations or death talk in general. One cause might be differing inner states and motivations. In communication, the need for **shared reality** is so strong that people often assume others hold the same inner states as they do without checking (Echterhoff et al. 2009). This might explain health professionals assuming a strong impact of the desire to die conversation on their patients, because it had such a strong impact on them.

Divergent perceptions might also stem from the fact that patients often do not want to recall end-of-life conversations, believing they are not as far advanced in their illness (Almack et al. 2012; Granek et al. 2013). Differing memories of conversations between health professionals and patients are also common in high-emotion settings, e.g. breaking bad news (Toutin-Dias et al. 2018). If we consider desire to die conversations a high-emotion setting, health professionals can resort to known communication concepts to account for stress-induced reduced memory capacity. Thereby, they can increase the probability that their words are understood correctly (Hyer and Covello 2017). Paraphrasing contents at the end of conversation, asking for patients understanding and offering follow-up conversations may foster shared reality in desire to die conversations (Makoul and van Dulmen 2015).

Conversation strategies: straight to the point or past each other?

Most triad members valued **open conversation** regarding death, dying and desire to die. Within the literature, too, there often seems to be a general consensus that open conversation about death and dying is advisable (Granda-Cameron and Houldin 2012). As openness can also be perceived as overwhelming, patients, informal caregivers, and health professionals utilize different strategies to deal with it.

One strategy and a well-researched psychic mechanism is **denial**, which protects the self against an unbearable, threatening truth by refusal to believe it (Blumenthal-Barby and Ubel 2018). Denial has an important protective function, but can also be harmful, e.g., when patients decide against their own values (Friedrichs 2014). In our findings, participants who most often denied the situation were the most content (see Type 3), but also appeared as the most emotionally disengaged and left out important information (e.g., a patients' ideas on assisted dying).

A recurring reason for developing a desire to die is the fear of being a burden to others (Gudat et al. 2019; Hatano et al. 2021). In this context, **compartmentalizing** communication and support needs between informal caregivers and health professionals makes sense from a patient perspective. Compartmentalizing information might offer psychological relief; slicing difficult to process information in smaller and easier to digest parts.

Compartmentalization was often used to **protect the other/the self** but is not the same. Often, triad members withheld difficult information or emotions from others based on the assumption that the conversation partner would be overwhelmed or react negatively. This indicates a taboo surrounding palliative care and fear of terminal illnesses (Kirby et al. 2018).

Within triad 1, the patient, health professional and relative all **acknowledged** the existence of the patients' wish for assisted suicide and the need to act. All were present during the desire to die conversation, but vital information was misunderstood, leaving the patient's son frustrated. Despite recommendations to integrate informal caregivers into the conversation (Leitlinienprogramm Onkologie 2020), this illustrates that it is no fail-safe solution. Due to psychological barriers or unfitting assumptions (Almack et al. 2012), miscommunication may appear. Here, too, common communication concepts might mitigate such loss of information (Hyer and Covello 2017; Makoul and van Dulmen 2015).

Strength and limitations

To our knowledge, there is no study from palliative care research that combines perspectives of patients, health professionals, and informal caregivers on the same desire to die conversation. Research on perspectives in palliative care often refers to individuals or dyads (Carrillo et al. 2018; Liljeroos et al. 2021). We suggest that our triadic approach allows a broader insight into desire to die conversations and their surrounding atmosphere. Our sample heterogeneity concerning professions (health professionals), diagnoses (patients), and relations (informal caregivers) also allows a tentative generalization.

However, our findings predate the decision of the German Federal Constitutional Court ruling (medically) assisted dying as legal in February 2020 – 1 month after the last triad interview. The reality of requesting assisted dying may change communication about desire to die, as evidence from Canada suggests (Ho et al. 2021). Moreover, prior study experience may have influenced participants' answers, despite matching semi-structured interview guidelines. Health professionals underwent desire to die training and initiated the conversation, therefore knowing which situation to reflect on. Patients' participation under the cover story of "end-of-life communication" may have primed them toward this topic. Moreover, time past between desire to die conversation and interview participation might have contributed to the fact that patients could not recall such a conversation, therefore potentially limiting interpretability. However, those 4 patients who did not recall the desire to die conversation at all were not those with the highest number of days between conversation and interview. Informal caregivers had no prior knowledge about the study. Since data was conducted at 1 time point, we cannot examine the entire communication process. Future research could address this in multi-perspective qualitative studies over several time points since desire to die changes over time and is influenced by felt interconnectedness and external events (van Wijngaarden et al. 2021).

Conclusions

Desire to die communication is recommended to take place in an atmosphere of respect, interest, and openness (Kremeike et al. 2020; Leitlinienprogramm Onkologie DK 2020). Realizing these recommendations while meeting the psychological complexities of information processing might seem challenging. Yet, our findings allow for a few suggestions for practice. Health professionals should

1. offer to integrate informal caregivers as a resource of information on the patient as well as to assess their potential need for support (see also (Foster et al. 2015)).
2. be aware of own potential misjudgments and not act on assumptions, e.g. by asking their patients' understanding of facts and situations (Makoul and van Dulmen 2015). Here, interest for and openness toward their patients is imperative.
3. be aware of different communicative coping strategies – their own and those of patients and informal caregivers. Staying present in authentic support is key, as communicative misunderstandings will never be fully eradicated.
4. keep balance between acknowledging types of communication and remaining open for individual communication styles.

These recommendations in mind, our findings offer other valuable insight about the nature of communication about death, dying, and desire to die.

Supplementary material. The supplementary material for this article can be found at https://doi.org/10.1017/S1478951524002104.

Data availability statement. The datasets generated and/or analyzed during the current study are not publicly available as participants were assured that their personal data may be viewed only by members of the research team but are available from the corresponding author on reasonable request.

Acknowledgments. Not applicable.

Authors contributions. KB made substantial contributions to design of the work; analysis and interpretation of data and drafted the original manuscript. TD made substantial contributions to the conception analysis and interpretation of data and substantively revised the work. TT made substantial contributions to analysis and interpretation of data and substantively revised the work. LG made substantial contributions the acquisition of data and substantively revised the work. CR made substantial contributions the acquisition of data and substantively revised the work. RV made substantial contributions to the conception and design of the work and substantively revised it. KK made substantial contributions to the conception and design of the work; to acquisition and interpretation of data and substantively revised the work.

All authors approved the submitted version (and any substantially modified version that involves the author's contribution to the study) and agreed both to be personally accountable for the author's own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature.

Funding. This study was funded by the Federal Ministry of Education and Research (01GY1706).

Competing interests. KB, TD, CR, LG, TT, and KK declare no support from any organization for the submitted work; no financial relationships with any organizations that might have an interest in the submitted work in the previous 3 years; no other relationships or activities that could appear to have influenced the submitted work.

RV reports 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; Federal Ministry of Education and Research; EU—Horizon 2020; Robert Bosch Foundation; Trägerwerk Soziale Dienste in Sachsen GmbH; Association Endlich Palliativ & Hospiz e.V.; Ministry of Labor, Health and Social Affairs of North Rhine-Westphalia; German Cancer Society, Association of the Scientific Medical Societies, German Cancer Aid; Ministry of Culture and Science of North Rhine-Westphalia; personal fees from AOK Health Insurance; German Cancer Society/National Health Academy (NGA); MSD Sharp & Dome; Hertie Foundation and Roche Germany.

KB, KK, and RV all give the desire to die trainings mentioned in the article on an honorary basis.

Ethical approval. The Ethics Committee of the University of Cologne (#17-265) approved of this study and all participants gave written informed consent before participation.

Consent for publication. Not applicable.

References

Allan A and Allan MM (2019) Ethical issues when working with terminally ill people who desire to hasten the ends of their lives: A western perspective. *Ethics & Behavior* **30**(1), 28–44. doi:10.1080/10508422.2019.1592683

Almack K, Cox K, Moghaddam N, *et al.* (2012) After you: Conversations between patients and healthcare professionals in planning for end of life care. *BMC Palliative Care* **11**(1), 15. doi:10.1186/1472-684X-11-15

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

Blumenthal-Barby JS and Ubel PA (2018) In defense of "denial": Difficulty knowing when beliefs are unrealistic and whether unrealistic beliefs are bad. *The American Journal of Bioethics* **18**(9), 4–15. doi:10.1080/15265161.2018.1498934

Boström K, Dojan T, Frerich G, *et al.* (2022) Dealing with desire to die in palliative care – evaluation of a training program. *Zeitschrift Für Palliativmedizin* **23**, 1–9. doi:10.1055/a-1729-7360

Carrillo GM, Arias-Rojas M, Carreño SP, *et al.* (2018) Looking for control at the end of life through the bond: A grounded theory on the hospital discharge process in palliative care. *Journal of Hospice & Palliative Nursing* **20**(3), 296-303. doi: 10.1097/NJH.0000000000000447

Chochinov HM, Wilson K and Enns M (1995) Desire for death in the terminally ill. *American Journal of Psychiatry* **152**(8), 1185–1191. doi:10.1176/ajp.152.8.1185

Collins A, McLachlan S-A and Philip J (2018a) Communication about palliative care: A phenomenological study exploring patient views and responses to its discussion. *Palliative Medicine* **32**(1), 133–142. doi:10.1177/0269216317735247

Collins A, McLachlan S-A and Philip J (2018b) How should we talk about palliative care, death and dying? A qualitative study exploring perspectives from caregivers of people with advanced cancer. *Palliative Medicine* **32**(4), 861–869. doi:10.1177/0269216317746584

DeCou CR and Schumann ME (2018) On the iatrogenic risk of assessing suicidality: A meta-Aanalysis. *Suicide and Life-Threatening Behavior* **48**(5), 531–543. doi:10.1111/sltb.12368

du Pré A and Foster E (2016) Transactional Communication. In Wittenberg BRF E, Goldsmith J, *et al.* (eds), *Textbook of Palliative Care Communication*. Oxford: Oxford University Press, 14–31.

Echterhoff G, Higgins ET and Levine JM (2009) Shared reality: Experiencing commonality with others' inner states about the world. *Perspectives on Psychological Science* **4**(5), 496–521. doi:10.1111/j.1745-6924.2009.01161.x

Foster C, Myall M, Scott I, *et al.* (2015) 'You can't say, "what about me?" I'm not the one with cancer': Information and support needs of relatives. *Psycho-Oncology* **24**(6), 705–711. doi:10.1002/pon.3716

Fridriksdottir N, Sigurdardottir V and Gunnarsdottir S (2006) Important needs of families in acute and palliative care settings assessed with the family inventory of needs. *Palliative Medicine* **20**, 425–432. doi:10.1191/0269216306pm1148oa

Friedrichs J (2014) Useful lies: The twisted rationality of denial. *Philosophical Psychology* **27**(2), 212–234. doi:10.1080/09515089.2012.724354

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. doi:10.1002/pon.3959

Gerber K, Lemmon C, Williams S, *et al.* (2020) 'There for me': A qualitative study of family communication and decision-making in end-of-life care for older people. *Progress in Palliative Care* **28**(6), 354–361. doi:10.1080/09699260.2020.1767437

German Guideline Programme in Oncology (2020) Palliative care for patients with incurable cancer 2.1. Available at https://www.leitlinienprogramm-onkologie.de/leitlinien/palliativmedizin/ (accessed 19 February 2020).

Granda-Cameron C and Houldin A (2012) Concept analysis of good death in terminally ill patients. *American Journal of Hospice and Palliative Medicine®* **29**(8), 632–639. doi:10.1177/1049909111434976

Granek L, Krzyzanowska MK, Tozer R, *et al.* (2013) Oncologists' strategies and barriers to effective communication about the end of life. *J Oncol Pract* **9**(4), e129–135. doi:10.1200/jop.2012.000800

Gudat H, Ohnsorge K, Streeck N, *et al.* (2019) How palliative care patients' feelings of being a burden to others can motivate a wish to die. Moral challenges in clinics and families. *Bioethics* **33**(4), 421–430. doi:10.1111/bioe.12590

Harding R, Simms V, Calanzani N, *et al.* (2013) If you had less than a year to live, would you want to know? A seven-country European population survey of public preferences for disclosure of poor prognosis. *Psycho-Oncology* **22**(10), 2298–2305. doi:10.1002/pon.3283

Hatano Y, Morita T, Mori M, *et al.* (2021) Complexity of desire for hastened death in terminally ill cancer patients: A cluster analysis. *Palliative and Supportive Care* **19**(6), 646–655. doi:10.1017/S1478951521000080

Ho A, Norman JS, Joolaee 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**, 1–14. doi:10.1177/26323524211045996

Hyer RN and Covello VT (2017) Breaking bad news in the high-concern, low trust setting: How to get your story heard. *Health Physics* **112**(2), 111–115. doi:10.1097/hp.0000000000000623

Jacobsen J, deLima Thomas J and Jv A (2013) misunderstandings about prognosis: An approach for palliative care consultants when the patient does not seem to understand what was said. *Journal of Palliative Medicine* **16**(1), 91–95. doi:10.1089/jpm.2012.0142

Kang Y (2021) Why are dying individuals stigmatized and socially avoided? Psychological explanations. *Journal of Social Work in End-of-life & Palliative Care* **17**(4), 317–348, doi:10.1080/15524256.2021.1930330

Kirby E, Lwin Z, Kenny K, *et al.* (2018) "It doesn't exist…": Negotiating palliative care from a culturally and linguistically diverse patient and caregiver perspective. *BMC Palliative Care* **17**(1), 90. doi:10.1186/s12904-018-0343-z

Kremeike 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), 1–12. doi:10.1186/s12904-020-00548-7

Kremeike K, Galushko M, Frerich G, *et al.* (2018) The DESIRe to DIe in Palliative care: Optimization of Management (DEDIPOM) - a study protocol. *BMC Palliat Care* **17**(1), 30. doi:10.1186/s12904-018-0279-3

Kremeike K, Pralong A, Boström K, *et al.* (2021) '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

Kuosmanen L, Hupli M, Ahtiluoto S, *et al.* (2021) Patient participation in shared decision-making in palliative care–an integrative review. *Journal of Clinical Nursing* **30**(23-24), 3415–3428. doi:10.1111/jocn.15866

Leitlinienprogramm Onkologie DK (2020) Palliativmedizin für Patienten mit einer nicht-heilbaren Krebserkrankung - Langversion 2.2 - September 2020. Available at https://www.awmf.org/uploads/tx_szleitlinien/128-001OLk_S3_Palliativmedizin_2020-09_02.pdf (accessed 06 January 2021).

Liljeroos M, Milberg P, Krevers B, *et al.* (2021) Dying within dyads: Stress, sense of security and support during palliative home care. *PLoS ONE* **16**(9), e0257274. doi:10.1371/journal.pone.0257274

Lind R, Lorem GF, Nortvedt P, *et al.* (2011) Family members' experiences of "wait and see" as a communication strategy in end-of-life decisions. *Intensive Care Med* **37**(7), 1143–1150. doi:10.1007/s00134-011-2253-x

Lindner R, Foerster R and von Renteln-kruse W (2014) Physical distress and relationship problems: Exploring the psychosocial and intrapsychic world of suicidal geriatric patients. *Z Gerontol Geriatr* **47**(6), 502–507. doi:10.1007/s00391-013-0563-z

Macmillan Cancer Support (2017) *No Regrets: how Talking More Openly about Death Could Help People Die Well*. London: Macmillan.

Makoul G and van Dulmen S (2015) What Is effective doctor–patient communication? Review of the Evidence. In Brown, J Noble LM, Papageorgiou A, *et al.* (eds), *Clinical Communication in Medicine*. Hoboken: John Wiley & Sons, Ltd., 30–39.

Metselaar S, Meynen G, Voskes Y, *et al.* (2019) Evaluating PAD requests in psychiatry: The importance of involving others. *The American Journal of Bioethics* **19**(10), 63–65. doi:10.1080/15265161.2019.1654016

Nipp RD, Greer JA, El-Jawahri A, *et al.* (2017) Coping and prognostic awareness in patients with advanced cancer. *Journal of Clinical Oncology* **35**(22), 2551–2557. doi:10.1200/JCO.2016.71.3404

Parkinson S, Eatough V, Holmes J, *et al.* (2016) Framework analysis: A worked example of a study exploring young people's experiences of depression. *Qualitative Research in Psychology* **13**(2), 109–129. doi:10.1080/14780887.2015.1119228

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

Ritchie J and Lewis J (2005) *Qualitative Research Practice, A Guide for Social Science Students and Researchers*. London: Sage Publications.

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. *SocSciMed* **68**(3), 562–569. doi:10.1016/j.socscimed.2008.10.037

Thomas T, Althouse A, Sigler L, *et al.* (2021) Stronger therapeutic alliance is associated with better quality of life among patients with advanced cancer. *Psycho-Oncology* **30**(7), 1086–1094. doi:10.1002/pon.5648

Toutin-Dias G, Daglius-Dias R and Scalabrini-Neto A (2018) Breaking bad news in the emergency department: A comparative analysis among residents, patients and family members' perceptions. *European Journal of Emergency Medicine: Official Journal of the European Society for Emergency Medicine* **25**(1), 71–76. doi:10.1097/mej.0000000000000404

Udo C, Melin-Johansson C, Henoch I, *et al.* (2014) Surgical nurses' attitudes towards caring for patients dying of cancer – A pilot study of an educational intervention on existential issues. *European Journal of Cancer Care* **23**(4), 426–440. doi:10.1111/ecc.12142

van Wijngaarden E, Merzel M, van den Berg V, *et al.* (2021) Still ready to give up on life? A longitudinal phenomenological study into wishes to die among older adults. *Social Science & Medicine* **284**, 114180. doi:10.1016/j.socscimed.2021.114180

VERBI Software (2019) *Maxqda 2020*. Berlin, Germany: VERBI Software.

Voltz R, Boström K, Dojan T, *et al.* (2022) Is trained communication about desire to die harmful for patients receiving palliative care? A cohort study. *Palliative Medicine* **36**(3), 489–497. doi:10.1177/02692163211065671

Voltz R, Galushko M, Walisko J, *et al.* (2010) Issues of "life" and "death" for patients receiving palliative care-comments when confronted with a research tool. *Supportive Care in Cancer* **19**(6), 771–777. doi:10.1007/s00520-010-0876-z

White N, Kupeli N, Vickerstaff V, *et al.* (2017) How accurate is the 'Surprise Question' at identifying patients at the end of life? A systematic review and meta-analysis. *BMC Medicine* **15**(1), 139. doi:10.1186/s12916-017-0907-4

Wilson KG, Dalgleish TL, Chochinov HM, *et al.* (2016) Mental disorders and the desire for death in patients receiving palliative care for cancer. *BMJ Supportive & Palliative Care* **6**(2), 170. doi:10.1136/bmjspcare-2013-000604

Wittenberg E, Borneman T, Koczywas M, *et al.* (2017) Cancer communication and family caregiver quality of life. *Behavioral Sciences* **7**(1), 12. doi:10.3390/bs7010012

Wittkowski J (2015) Coping and Attitudes toward dying and death in German adults. *OMEGA - Journal of Death and Dying* **72**(4), 316–339. doi:10.1177/0030222815575283

Appendix 1: Interim results (Analysis Step 3) consisting of themes and sub-themes later used for writing thematic summaries

Theme and Sub-Themes	Definition and Quote
1. Content 1.1 Variability in Content 1.2 Background, Functions and Expressions of Desire to die 1.3 Therapy Decisions 1.4 Arranging Patient's End of Life 1.5 Patient's lived Life	**Definition:** The theme contains information about what specific aspects surrounding death and desire to die triad members talk about. Content may vary regarding on the situation and conversation partner. It may range from the desire to die itself to decisions of care, the organization of the end of life and looking back on patient's lived life. **Quote:** *"[W]e talk a lot and [regarding] the topic of death, I would say I already told him a lot, because it always brings about a kind of security for me, when I finally said something out loud. (…) I want to put [this outfit] on and be buried in this place and this saying is very important, just so you know.' I always discussed these kind of things openly. (laughs)" (Patient, Triad 9)*
2. Form 2.1 Initiation of DDC 2.2 DDC and other Contact with relatives 2.3 Recognition of DDC 2.4 Context of DDC	**Definition:** Within this theme, participants give information on the form of DDCs such as under which conditions the conversation began, whether it was recognized as a conversation about desire to die and in which context it was held. Another formal aspect is the inclusion or exclusion of relatives in DDCs. **Quote:** *"But there was a time when she was not doing so well and the diagnosis still had to sink in a bit, where she also said that there were moments when she thought about [her desire to die]. But she also didn't talk to anyone. So I was the first one she expressed it to. Neither to her other doctors nor to her husband, and she also said: 'No, my husband shouldn't know that either.'" (Health professional, Triad 11)*
3. Evaluation 3.1 Facilitating Factors 3.2 Challenges 3.3 Impact 3.4 Evaluation of DDC as Intervention	**Definition:** In this theme, participants report on how they evaluate the DDC and how they engaged in it as well as its impact on the time after. This evaluation regards the particular DDC conducted within study context as well as death talk in general. **Quote:** *I: "How did you personally experience [being confronted with the patients' desire to die]?"* *R: "I had to swallow. I said 'How can he say something like that?' But I have-, I- I was in a situation where you don't know what to answer. No. I can't just say: 'Now give me a break, it'll be alright.' But I also can't say: 'Yes, maybe it would be better for you.' I couldn't have said that. I really couldn't. No, but as I said, he always says: 'I'm fine.' And when I asked, he said to me: 'Don't always ask, I feel like shit.' Yes, with these words." (Informal Caregiver, Triad 6)*

Appendix 2 – Summaries of all triads within the three types

Type 1 – Between the Lines	
„Enmeshed" (2)	
▪ Only health professional-patient and patient-relative spoke about desire to die ▪ Openness as ambivalent, perceived reticence as hindering ▪ Unshared Reality, except health professional-relative ▪ Focus on manifest & material, except health professional ▪ Protecting the Other / the Self, Denial	The patient (female, 65, cancer) is ambivalent about her hypothetical desire to die and manifest will to live. She does not want to alarm her relative (female, 65, friend) or health professional (female, 48, physician) with suicidal thoughts, but feels her suffering is not taken seriously by her relative. The relative offers a divergent perspective, implying that the patient is in denial about the gravity of her illness and refuses meaningful conversation. The relative and health professional never met which aligns with health professionals' strong aversion to enmeshed family dynamics. The health professional describes the relationship with the patient as trusting and open, yet barely reports on content from the desire to die conversation.
"Withdrawn" (4)	
▪ Only health professional-patient spoke about desire to die ▪ Openness as helpful, yet relative perceives reticence ▪ Unshared Reality ▪ Focus on manifest & material, except patient ▪ Compartmentalization, Denial, Protecting the Self / Other	The patient (female, 77, cancer) sometimes harbors thoughts about suicide, but never tells anyone. She denies her emotional distress, but reports meaningful and deep conversations only with her relative (male, 79, husband). Although she esteems her relative, he is only consulted for his medical knowledge. Her relative's perspective diverges: he perceives the patient as withdrawn due to her illness and suspects that she prefers to share existential concerns with her health professional (female, 36, psychologist) instead of him. He barely knows the health professional, but displays distress and wishes to be included. The health professional evaluates the desire to die conversation positively and broadly reflects on the topic from a disengaged professional point of view.
„Transmission errors" (5)	
▪ health professional-patient and patient-relative spoke about desire to die ▪ Openness as helpful, yet relative perceives reticence ▪ Unshared Reality ▪ Focus on manifest & material, except health professional ▪ Compartmentalization, Denial	The patient (female, 77, multimorbid geriatric) appears to be ambivalent or erratic regarding her (previously stated) desire to die but also regarding her memory in general –alcohol abuse may have impaired her cognitive functioning. She denies having a desire to die and does not recall the health professional (female, 44, nurse) at all. The health professionals' perspective diverges: she knows the patient (and her previous desire to die) well and describes their conversation as lively and open. The patient's relative (female, 58, daughter in law) knows about the end of life preferences of the patient, but has never spoken to the health professional about this crucial information. Information is shared selectively due to compartmentalization: the health professional sees herself as responsible for the patient, not the relative.
"Disallowance" (6)	
▪ All spoke about desire to die ▪ Openness as helpful and overwhelming, yet relative perceives reticence ▪ Unshared Reality ▪ Focus on manifest & material ▪ Compartmentalization, Protecting the Self / Other	At time of the interview triads, the patient (male, 64, cancer) had already passed. The patient opened up to the health professional (female, 64, general practitioner) that he harbored a hypothetical desire to die, though kept it to himself. In contrast, from his relative's (female, 76, sister) perspective, the patient appeared uncommunicative and withdrawn. She strongly opposes the possibility that the patient might have harbored a desire to die. The desire to die conversation took place with all parties of the triad. Though everybody agreed to this, the health professional in hindsight regrets having included the relative, whom she deems too protective and believes to be in denial of death. Accordingly, the relative reports that they have not spoken about the patient's (then approaching) death.
„Whose suffering?" (10)	
▪ Only health professional-patient spoke about desire to die	The patient (male, 71, COPD) has not talked with his relative (female, 41, daughter) about death or desire to die. He is ambivalent about his wish to do so: on the one hand, he reports no need to, on the other hand, he

▪ Openness as helpful and overwhelming, yet relative perceives reticence ▪ Unshared Reality ▪ Focus on manifest & material, except health professional ▪ Protecting the Self / Other	reports disappointment that his daughter seems not to take his illness seriously enough. His daughter's perspective diverges: she experiences her father as emotionally withdrawn which causes her intense frustration. Yet, her own fear of addressing the topics that burden him are hindering to her as well. Even though she works in the same institution as the health professional (female, 60, hospice worker), they never talked. The health professional paints yet another picture: despite having to read between the lines, she experienced the desire to die conversation with the patient (mostly about his biography) as successful. The patient does not recall such death talk with his health professional. She also remembers conversations about the patients' depression with the relative, although she admits not having lots of time for her. She believes the patient shields his daughter from his suffering.

Type 2 – Past each Other	
„At cross purposes“ (1)	
▪ All spoke about desire to die ▪ Openness as helpful ▪ Unshared reality by all ▪ Focus on manifest & material, except health professional ▪ Integration of Perspectives	The patient (female, 88, multimorbid geriatric) wants do die and she and her relative (male, 58, son) openly talk about assisted suicide. All parties of the triad value openness and respect regarding the patients' desire to die. There has been a conversation with the entire triad in which the health professional (male, 57, chaplain) offered spiritual support, but also explained the legality of assisted suicide in Germany. However, their perceptions and evaluations of this conversation diverge: The patient does not remember the content of the conversation at all. Her son strongly disliked the spiritual aspects. Both still believe assisted suicide is not legal in Germany, while the health professional was deeply moved by explaining the topic openly to them.
„Rhetoric of fact" (11)	
▪ Only health professional-patient spoke about desire to die ▪ Openness as helpful, relative is ambivalent ▪ Unshared Reality, except health professional-relative ▪ Focus on manifest & material, except health professional ▪ Compartmentalization, Protecting the Other / the Self	The patient (72, female, cancer) does not count a conversation about advance care planning with her health professional (36, female, general practitioner) as death talk. She dismisses death as nothing special and prefers to talk about it only regarding end of life care. Her health professional perceived their conversation as more existential in nature and was surprised by her patients' openness and her hypothetical desire to die – although she went easy on her. Her relative (70, male, husband) is ambivalent about her openness: he values deep conversations and death talk as only fitting for their age, yet is overwhelmed by psychological suffering. The patient admits not being able to talk to him openly. The relative and the health professional are in helpful contact, yet not about desire to die. Both relative and patient compartmentalize serious topics to outside the triad.
"Assigned Roles" (12)	
▪ health professional- patient and patient-relative spoke about desire to die ▪ Openness as helpful ▪ Unshared Reality, except health professional-relative ▪ Focus on manifest & material and personal & existential ▪ Compartmentalization	The patient (57, female, cancer) clearly sees personal and existential topics within her family and not with her health professional (35, female, specialist physician). Her health professional has responsibility for her physical health. She remembers the desire to die conversation to be about preferred place of death. The health professional reports a contrasting account: the patient talked about her spiritual passing into the world of death. Although all value open conversation, the clear assignment of conversational roles aligns with the divergent perspectives of health professional and patient. This triad lacks an interview with a relative (husband), who was reported to only seldomly be present in medical conversations.
„Too overwhelming“ (13)	
▪ health professional- patient and patient-relative spoke about desire to die	The patient (female, 60, cancer) dominates to which extent death talk may happen and with whom. She draws a line along her ambivalence regarding the topic and casts her relative and health professional in

▪ Openness as ambivalent, perceived reticence by health professional ▪ Shared reality by health professional-patient, unshared by health professional- relative ▪ Focus on manifest & material and personal & existential ▪ Compartmentalization, Protecting the other / the self	different roles: it is too intimate to talk about the existential aspects with her health professional (54, female, hospice specialist worker), but her relative (55, male, friend) is deeply involved in funeral or potential plans for assisted suicide plans. Convergently, the health professional perceived her as emotionally shut-off, while her relative welcomes her openness and self-reflection, although it sometimes overwhelms him. The health professional does not recall the sparse contact with the relative.

Type 3 – Matter of Fact	
„Not an issue“ (8)	
▪ Only health professional-patient spoke about desire to die ▪ Openness as helpful by all ▪ Shared Reality, except health professional-patient ▪ Focus on manifest & material ▪ Denial	The patient (76, male, cancer) does not recall a desire to die conversation with his health professional (40, male, specialist physician), but also states no need for one. The health professional describes a desire to die conversation, but only in rather general terms. The patient values open conversations with his relative (72, female, wife) and between her and his health professional. She confirms that perception. Desire to die has never been an issue, all focus on concrete matters of life and care.
„Deeply attached“ (9)	
▪ health professional-patient and patient-relative spoke about desire to die ▪ Openness as helpful, only relative ambivalent ▪ Shared Reality, except health professional-patient ▪ Focus on manifest & material, except health professional ▪ Compartmentalization, Denial, Protecting the Other / the Self	The patient (female, 40, MS) names conversations with her relative (46, male, partner) as her main support. They talk about death mainly in concrete plans for the future, but do not frame it as talking about desire to die – even though her relative recalls such a statement. She values the openness; he is ambivalent about it. However, she also aims to protect him from her burden. The relative and the health professional (31, female, speech therapist) did not talk much yet, as they both see the patient in focus. The health professional talks about the helpful open conversation with the patient, while the patient does not name her health professional as a conversation partner once.
„Concrete support“ (14)	
▪ health professional-patient and patient-relative spoke about desire to die ▪ Openness as helpful, only relative ambivalent ▪ Shared Reality ▪ Focus on manifest & material ▪ Denial, Protecting the Other / the Self	The patient (male, 64, COPD) infrequently harbors a desire to die, considering assisted suicide, palliative sedation or just finding rest. He actively plans for his end-of-life via advance care planning which was also topic of his desire to die conversation with his health professional (48, male, hospice coordinator). The patient did not perceive the desire to die conversation as such, but his health professional suspected that much. They both report a good and easy-going relationship revolving around concrete and manifest topics surrounding end of life care. His relative (53, female, niece) supports the patient with daily life tasks and lends an open ear, even though she knows he holds back with more burdensome topics – which the patient confirms. She has no contact to the health professional, but does not see it as an option either way. Predominantly, all triad members evaluate the open communication intended on concrete matters as helpful. However, whereas the patient considers his niece as a potential help in administering assisted suicide in the future, the health professional and the niece both do not know about these hypothetical plans.
„Division of labor“ (3)	

▪ health professional-patient and patient-relative spoke about desire to die ▪ Openness as helpful ▪ Shared Reality ▪ Focus on manifest & material ▪ Compartmentalization, Protecting the Other / the Self	The patient (female, 69, COPD) does not wish to die, but actively plans a conscious end of life. All members of the triad report that they value and lead open conversations about dying and desire to die, thereby sharing the same perspective regarding the situation. Since the health professional (female, 57, hospice nurse) describes the desire to die conversation as strongly focused on life (rather than death), the patient accordingly barely recalls having spoken about desire to die. The patient consciously compartmentalizes her needs between health professional and relative (female, 43, daughter): her health professional brings emotional security, her relative manages worldly affairs. The health professional and relative never met and do not wish to.
„Professionals“ (7)	
▪ health professional-patient and patient-relative spoke about desire to die ▪ Openness as helpful ▪ Shared Reality ▪ Focus on manifest & material ▪ Compartmentalization, Protecting the Other / the Self	The patient (female, 66, cancer) reports having held a desire to die in the past, though not any longer at time of the interview. When asked by her health professional (has not partaken in the interview triad) about discontinuation of life support measures, she wants her physician to decide in her place. With her family, the patient does not discuss death and dying out of fear of being a burden. Convergently, her relative (female, 35, daughter) states that it is difficult to initiate death talk with her mother, who fends off all attempts. Even as a relative, the daughter (herself a general practitioner) recommends taking a professional distance towards desire to die. Death and dying are experienced as non-negotiable and therefore must be approached “professionally”, thereby withdrawing from being personally affected or responsible for decisions. There was no contact between relative and health professional.

Semi-structured guideline for qualitative patient interviews

Introduction
Conversation between patients (P) and their health professionals (HP) are an essential part of care and support. In the case of patients with severe, incurable diseases, it is likely that very personal topics may be addressed. It is not uncommon for patients' own end-of-life issues to come up. Today I would like to talk to you about how you perceive such conversations.

Beginning of Interview **Communication with Health Professionals** *[Name + Function]*	**I am especially interested in your communication with your HP. How do you experience conversations with your HP?**
Example Content Impact Relative (R)	• How is a typical conversation with HP like? • What are the topics you and HP talk about? • Is there anything that doesn't come up with HP even though you would like to discuss it? • How do you feel during / after a conversation with HP? • You may hear that VG is talking to R. If so, how do you experience the conversations between VG and R?
Communication about Desire to Die	**Some people with incurable illness wish that their life may end sooner or that death may come earlier. Perhaps you talked about this with your HP. If so, how was the conversation for you?**
Proactive Approach Impact Process	• What is it like to talk about desire to die with HP? • Is there something particular you remember from that conversation? • Who approached the topic desire to die? o What was it like to address desire to die with HP? o What was it like to be addressed by HP about desire to die? • What impact does a conversation about desire to die have on you? o If present, did your desire to die change after such a conversation? • Did your treatment change after the conversation?
Relationship with Health Professional	**How would you describe your relationship with HP in general terms?**
VG – P VG – R	o How do you experience HP? (As a HP? As a person?) • What makes HP important to you? • How would you rate your relationship between HP and R?
Communication with Others	**HP may not be the only person with whom you talk about potential desire to die. If there are other people, how do you experience such conversations with them?**
	• What people may that be? (Relatives? Friends? Other HPs?) • What do you notice when you compare these conversations with the ones you have with your HP?
End of Interview	**You already addressed many interesting aspects. From my side we would come to the end of our interview.**
	• Is there something that you would like to add regarding the topic, something, that may be important to you or was not addressed yet? • Is there something you want to know or that remains unclear?

	- How did you experience the interview? - What was your reason for participating in this interview?
If not addressed yet	
	- Own medical history - Familiy medical history (e.g. suicides within the family) - Influencing factors on desire to die (relieving / aggravating) - Background information on relatives
Note of Thanks	**We would like to thank you very much for your participation.** **The results from this interview will contribute to improve conversations between patients and their health professionals.**

Semi-structured guideline for qualitative health professional interviews

Introduction

Conversation between patients (P) and their health professionals (HP) are an essential part of care and support. In the case of patients with severe, incurable diseases, it is likely that very personal topics may be addressed. It is not uncommon for patients' own end-of-life issues to come up. Today I would like to talk to you about how you experience such conversations with patients or their relatives.

Beginning of Interview Communication with Patient	**I am especially interested in your conversations about desire to die that took place while you participated in our study. How did you experience these conversations?**
Content Impact	• What are the contents of desire to die conversations with your patients? • Which aspects of these conversations do you experience as challenging / pleasant? • How do you feel during or after such conversations with your patients? • How do you experience approaching patients potential desire to die proactively since the beginning of the study?
Communication about Desire to Die	**You also had a conversation with P. How did you perceive this conversation or possible follow-up conversations?**
Self Perception Proactive Approach	• How do you experience yourself in such a conversation? • How do you think P experienced the conversation? • Is there something particular you remember from that conversation? • In your opinion: What did you manage particularly well? What would you like to have done better? • Who addressed the topic of desire to die? What was that like for you?
Relatives	**There may also have been conversations with R in which desire to die was an issue.**
R – HP R – P Generell	• If so, how is it like to talk with R about desire to die? • Does the relationship dynamic allow for a conversation about desire to die? • How do you as a HP experience conversations about the topic of desire to die between P and R? • How do you exerience talking about the topic desire to die with R in general? Compared to conversations with P?
Relationship with Patient / Relative	**How would you describe your relationship with the P?**
HP - P HP - R	• What impact did the conversation have on your relationship with P? • Why did you recruit P for the study? • How do you experience the relative of P? • How would you describe your relationship with R? • How does Ps and Rs relationship influence your communication with P?
Study Participation	
Communication	• Which role did the communication guideline play in your

Guideline Study	conversation? • How was using the documentation sheet like? • Perhaps something changed for you - either personally or professionally - since study participation. If so, what impact did the study participation have on you? • How did your attitude regarding proactive desire to die change? Todeswünschen? • What was your motivation to participate in the study?
End of Interview	**You already addressed many interesting aspects. From my side we would come to the end of our interview.**
	• Is there something that you would like to add regarding the topic, something, that may be important to you or was not addressed yet? • Is there something you want to know or that remains unclear? • How did you experience the interview? • What was your reason for participating in this interview?
Note of Thanks	**We would like to thank you very much for your participation.** **The results from this interview will contribute to improve conversations between patients and their health professionals.**

Semi-structured guideline for qualitative relative interviews

Introduction

Conversation between patients (P) and those who care for them are an essential part of care and support. In the case of patients with severe, incurable diseases, it is likely that very personal topics may be addressed. It is not uncommon for patients' own end-of-life issues to come up. As a relative (R), you experience a lot on the side of the patient (P). Perhaps you are also in direct contact with their health professional (HP). In this context, I would like to talk to you today about your perception of consultative and supporting conversations in palliative care.

Beginning of Interview Communication in Care	**I am especially interested in your conversations with HP. Did you have a chance to talk to HP? If so, how do you experience conversations with HP?**
R-HP	• How would you describe your involvement in the treatment of P? • How close or intense would you describe the content between you and HP? • What is it you talk about with HP? • Is there anything that doesn't come up with HP even though you would like to discuss it? • How do you feel during or after conversations with HP? • If you had any Falls es bereits one-to-one conversations with HP: How are they like in comparison to those with P present?
Perspective on HP-P	• How do you experience the conversations between HP and P if you are present?
Communication about Desire to die	**Some people with incurable illness wish that their life may end sooner or that death may come earlier. Perhaps you talked about this with the P or the HP. If so, how do you experience talking about desire to die for you?**
Example	• Do you recall a particular conversation? • What do you think of the HP talking to you or the P about desire to die? • In your opinion, how do these conversations affect P? ○ If present: How do the conversations influence the desire to die?
Perspective on HP-P	• How do you experience the communication between HP and P since study participation in general? • How is it like or would it be like to talk about Ps desire to die with the HP?
R-HP	○ Burden? Own desire to die? • If you ever talked about desire to die with P, how was it like?
R-P	• What do you experience as helpful and what as Was erleben Sie als hilfreich und was als hindering when talking about desire to die? ○ With HP? With *P*? • What is your attitude toward talking about desire to die at all in palliative care?
In general	○ With *P*? With *ZG*?
Relationship	**How would you describe your relationship with HP?**
R-HP	○ How do you experience HP? (As a HP? As a person?) • How would you rate your relationship between HP and R? How do you experience them both together?
Perspective on HP-P	• How would you rate the HPs aptitude for conversations about desire to

R-P	die? - How is your relationship with P?
Communication with Others	**HP may not be the only person with whom you talk about potential desire to die. If there are other people, how do you experience such conversations with them?**
	- What people may that be? (Relatives? Friends? Other HPs?) - What do you notice when you compare these conversations with the ones you have with HP or P?
End of Interview	**You already addressed many interesting aspects. From my side we would come to the end of our interview.**
	- Is there something that you would like to add regarding the topic, something, that may be important to you or was not addressed yet? - Is there something you want to know or that remains unclear? - How did you experience the interview? - What was your reason for participating in this interview?
Note of Thanks	**We would like to thank you very much for your participation.** **The results from this interview will contribute to improve conversations between patients and their health professionals.**

VERSICHERUNG

Hiermit versichere ich an Eides statt, dass ich die vorliegende Dissertationsschrift selbstständig und ohne die Benutzung anderer als der angegebenen Hilfsmittel angefertigt habe. Alle Stellen - einschließlich Tabellen, Karten und Abbildungen-, die wörtlich oder sinngemäß aus veröffentlichten und nicht veröffentlichten anderen Werken im Wortlaut oder dem Sinn nach entnommen sind, sind in jedem Einzelfall als Entlehnung kenntlich gemacht. Ich versichere an Eides statt, dass diese Dissertationsschrift noch keiner anderen Fakultät oder Universität zur Prüfung vorgelegen hat; dass sie - abgesehen von unten angegebenen Teilpublikationen - noch nicht veröffentlicht worden ist sowie, dass ich eine solche Veröffentlichung vor Abschluss der Promotion nicht ohne Genehmigung der / des Vorsitzenden des IPHS-Promotionsausschusses vornehmen werde. Die Bestimmungen dieser Ordnung sind mir bekannt. Die von mir vorgelegte Dissertation ist von Prof. Dr. Raymond Voltz betreut worden.

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Übersicht der Publikationen:

- Boström, K., Dojan, T., Thölking, T., Gehrke, L., Rosendahl, C., Voltz, R. & Kremeike, K. (2024). Talking about desire to die - talking past each other? A framework analysis of interview triads with patients, informal caregivers and health professionals. Palliative & Supportive Care; accepted for publication.
- Boström, K., Dojan, T., Rosendahl, C., Gehrke, L., Voltz, R. & Kremeike, K. (2022) How do trained palliative care providers experience open desire to die-conversations? An explorative thematic analysis. Palliative and Supportive Care, 1-9. doi:10.1017/S1478951522001006

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07.07.2025, Düsseldorf
Kathleen Boström

SCHRIFTLICHE ERKLÄRUNG ZUM GELEISTETEN BEITRAG

Bei der Erstellung der in dieser Arbeit verwendeten Publikationen

- Boström, K., Dojan, T., Thölking, T., Gehrke, L., Rosendahl, C., Voltz, R. & Kremeike, K. (2024). Talking about desire to die - talking past each other? A framework analysis of interview triads with patients, informal caregivers and health professionals. Palliative & Supportive Care; accepted for publication.
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leistete die Doktorandin, Kathleen Boström, folgenden eigenen Beitrag: Die Doktorandin leistete wesentliche Beiträge zum Studiendesign, rekrutierte Teilnehmende und führte einen Großteil der Interviews durch. Sie bereinigte, analysierte und interpretierte die Daten, dabei wandte sie eine von ihr ausgewählte Methode an und schrieb den Entwurf. Sie überarbeitete den Entwurf gemäß den Rückmeldungen der Ko-Autor*innen und übernahm den Prozess der Einreichung und Revision des finalen Manuskripts.
Hierdurch wird bestätigt, dass die Doktorandin einen wesentlichen Beitrag zu den jeweiligen Publikationen geleistet hat.

07.07.2025, Düsseldorf
Kathleen Boström