

How to talk about dying? The development of an evidence-based model for communication with patients in their last days of life and their family caregivers

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ABSTRACT

Objective: To help healthcare professionals (HCP) act with more confidence when communicating about approaching death, we sought to develop a communication model for HCP to facilitate conversations with dying patients and family caregivers (FC) in nonemergency situations.

Methods: We used a four-phase integrative approach: (1) creation of a preliminary model based on a systematic literature review and expert knowledge, (2) review of the model draft by international palliative care experts, (3) review by key stakeholders, and (4) final appraisal by communication experts.

Results: After the clinical recognition of dying, the communication model provides a structure and practical communication aids for navigating the conversation based on three phases. It describes the content and relational level as core dimensions of effective conversations about approaching death and highlights the importance of HCP self-awareness and self-care when caring for the dying.

Conclusion: Based on systematic involvement of key stakeholders, the model supports clinicians navigating challenging conversations about approaching death with dying patients and their FC successfully and with more confidence.

Innovation: This study expands the theoretical basis for communication about approaching death and offers a pragmatic model for educational interventions and clinical use.

1. Introduction

During serious and life-limiting illnesses, conversations between healthcare professionals and patients and their family caregivers may be held to, among other things, explain prognosis, assess illness understanding, establish advance care directives, or identify values and wishes [1-5]. Most of these conversations are encouraged earlier in the course of serious illness to guide decision-making and patient care [6]. As illness progresses and the end of life nears, one conversation is essential: that of conveying that death is approaching.

Conversations about and in the context of approaching death are one

of the most challenging communication scenarios that healthcare professionals (HCP) may face. Because of their possible impact on all persons involved these conversations remain a demanding task even though caring for dying patients and their family caregivers (FC) is an integral part of the clinical work of HCP [7-10]. However, conversations about approaching dying and death itself rarely belong to their training. Many uncertainties remain such as how to initiate and structure these conversations, what to say and how to respond to demanding emotions. As a result, conversations tend to be avoided [5,11] and patients and their FC remain unprepared when death occurs, which can have long-lasting impact on all involved [12-15].

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Healthcare professionals experience a variety of barriers to discussions with seriously ill patients and their family caregivers about their end-of-life care [16]. Among these barriers, HCP report uncertainty regarding prognosis, the fear of negative psychological impact, and the feeling of being left unprepared for these conversations by inadequate training. Nursing and medical students raise concerns about their ability to cope with distressing emotions, dealing with emotional responses, and not knowing what to say [17]. Nonetheless, HCP are expected to address dying and approaching death in an honest, needs-oriented way with patients and FCs in a timely manner [9,16].

Recognizing when a person is entering the last days of life is a clinical task grounded on interprofessional collaboration that all too often is missed, or the diagnosis comes too late [18-20]. Yet a timely discussion about approaching death has beneficial effects for patients and their FC [21,22]. Patients for whom approaching death is recognized and acknowledged are perceived as receiving more appropriate care during the last days of life [21,23]. Improperly preparing patients and families for death can have detrimental effects for the patient at the time of death, and for the FCs as they grieve [12]. FCs who have missed the moment of death often report more difficulties adjusting to grief [13,14]. In summary, providing patients and families the opportunity to say goodbye has been associated with better outcomes as opposed to developing depression or complicated grief after death [15]. Despite these numerous reasons favoring communication about approaching death, these conversations still cause a high emotional burden for HCP [24-26].

HCP may experience a lack of satisfaction, increased stress and heightened risk of burnout, or illness when dealing with dying patients [27]. Caring for and communicating with dying patients and their family members can lead HCP to face different emotions, thoughts, and behavior that over time can become more difficult to manage. Exposure to these situations without examining one's own reactions and preconceptions may lead to burnout with the potential for a longer-term negative impact on the working and personal lives of health professionals [22,28-31]. In addition, conversations about approaching death can be challenging not only on a professional but also on a personal level. Over two decades ago, Rousseau [32] considered four assumptions about why care of the dying is hard for physicians that still seem valid today: physicians' inference of failure to prevent dying and death, the inevitability of death and confrontation with one own's mortality, systemic constraints for palliative care such as economic disincentives and time pressure, and a paucity of appropriate education and role models in daily practice. Even though the challenging nature of conversations about approaching death on different levels is well known, HCP still are rarely taught how to handle fear and uncertainty around the dying process and how to communicate about approaching death.

Although a growing body of frameworks and strategies for end-of-life communication exists [3,33], opportunities for and exposure to conversations explicitly about approaching death with patients in their last days of life and their family caregivers remain almost nonexistent during medical and nursing education [34,35]. To be able to better provide appropriate training, we developed a theoretical model for communicating about approaching death in nonemergency situations, during which communication and dialogue may still evolve, with patients in the last four to seven days of life and their family caregivers [36,37].

2. Methods

2.1. Development of the model

We developed the communication model in four phases. In phase 1, the basis of the model was established by identifying core elements of existing frameworks about end-of-life communication through a review of the literature and expert knowledge. In phases 2 and 3, the elements of conversations about approaching death identified in phase 1 were

presented to international experts and then to key stakeholders. After obtaining and integrating their feedback, in phase 4 the model was developed further by the project team and presented for approval to different national experts in health care communication.

Details about participants in the four phases of the model's development as well as the recruitment process where applicable, the process of data collection, and our analysis are as follows (Fig. 1).

2.1.1. Phase 1: Drafting the preliminary model (V1)

We conducted a systematic review of the literature about the content, development, and outcomes of end-of-life communication strategies. The review focused on guidelines, tools, frameworks, and models employed in communication skills training for HCP. Studies published in English since 2000 were retrieved from four electronic databases (MEDLINE, CINAHL, PsycInfo, and Embase), as well as from unpublished interventional studies identified from the International Clinical Trials Registry Platform (ICTRP) and the Cochrane Central Register of Controlled Trials (CENTRAL). In parallel, a manual search of references from relevant articles identified other potentially important publications. We searched for national guidelines, statements, and standards on the Internet. We included communication strategies directed to health professionals and trainees, who comprise physicians, nurses, and medical and nursing students that provide services to patients in advanced stages of disease who are approaching the end of life.

The review was registered prospectively [38]. Articles were screened using "Rayyan" [39], a tool for systematic literature reviews.

2.1.2. Phase 2: Review by international palliative care (PC) experts (V2)

The second phase focused on identifying aspects missing from V1, verifying what was already included, and ensuring comprehensibility. Two senior researchers (SCZ, SE) presented the preliminary model to an international group of palliative care professionals from the EU iLIVE-project (iliveproject.eu, a project focusing on best care for the dying person). Ten international experts (Table 1), who were contacted by email and received no financial remuneration for participating, attended a one-hour feedback session that took place on site in Bergen, Norway; we recorded the session audio.

The experts were first asked what aspects of communication about approaching death with a patient in the last days of life and their FC they thought were important and we compared their responses with the V1 model. We then presented the preliminary model to the experts and they were asked to check it for completeness and comprehensibility. Field notes during the meeting (three pages of notes) as well as Post-it notes written by the participants during the first part of the meeting and email comments from after the meeting (two participants) informed the development of the communication model V2.

2.1.3. Phase 3: Feedback from key stakeholders (V3)

In phase 3, we held five focus groups with representative members of

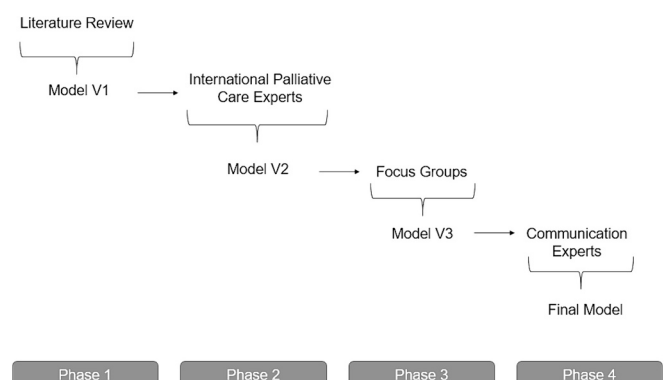


Fig. 1. Communication model development process.

Table 1
Demographic characteristics of international palliative care experts.

Characteristics	PC experts
Gender	
• Female	8
• Male	2
Age	
• 18–34	0
• 35–54	4
• 55–65+	6
Country of Origin	
• Argentina	1
• Iceland	2
• New Zealand	1
• Norway	1
• Spain	1
• Sweden	1
• The Netherlands	3
Specialty (several possible)	
• Epidemiology	1
• Oncology	2
• Psychology	1
• Specialized palliative care	5
• Spiritual care	1
Total	10

main partners or stakeholders in end-of-life conversations, identified during phase 1 and 2, to better understand the essentials of communicating with patients and FC about approaching death. Participants of the different focus groups were 1) medical students, 2) physicians and 3) nurses from different medical wards and outpatient teams considered to have high exposure to end-of-life care and therefore more experience in communication with dying patients, 4) bereaved FC whose family members had died at the palliative care unit of a Swiss university

Table 2
Demographic characteristics of key stakeholders.

Characteristics	Medical students	Physicians	Nurses	Bereaved family caregivers	Patient representatives
Gender					
• Female	5	3	5	4	6
• Male	1	3	0	1	2
Age					
• 18–34	6	1	2	1	0
• 35–54	0	4	2	2	4
• 55–65+	0	1	1	2	4
Competency Level					
• Medical student 4th year	1	–	–	–	–
• Medical student 5th year	5	–	–	–	–
• Assistant Physician	–	1	–	–	–
• Head Physician	–	3	–	–	–
• Senior/ Chief Physician	–	2	–	–	–
• Nurse expert	–	–	4	–	–
• Advance Practice Nurse	–	–	1	–	–
Setting					
• University Hospital	–	3	3	5	8
• Public (Center) Hospital	–	1	0	0	–
• Private Hospital	–	2	1	0	–
• Outpatient	–	0	2	0	–
Specialty					
• Oncology	–	2	0	–	–
• Internal Medicine	–	1	1	–	–
• Intensive Care	–	1	0	–	–
• Specialized Palliative Care	–	2	2	–	–
• Pneumology / thoracic surgery	–	0	1	–	–
• Neurology/ Stroke Unit	–	0	1	–	–
Role/ Relationship (several possible)					
• Stepdaughter–/son	–	–	–	1	–
• Spouse	–	–	–	4	–
• Relative (any)	–	–	–	5	6
• Patient	–	–	–	0	1
• Professional (nurse, coach)	–	–	–	0	3
Total	6	6	5	5	8

hospital within twelve weeks of the interview, and 5) patient representatives who were members of the patient council of the same university hospital. The focus groups were conducted between November 2019 and February 2020 and all participants lived in Switzerland. A total of 30 persons (23 females, 7 males) took part with at least five participants and a maximum of eight per focus group (Table 2).

Audio recorded in each focus group was anonymized and transcribed verbatim with the support of a qualitative data analysis software package [40], and field notes were taken during focus groups and analyses. We employed reflexive thematic analysis [41,42] to code data inductively, and grouped codes into thematic clusters. The complete design of the focus groups, the analysis process, and its results are reported elsewhere [43]. The identified themes served as a basis for developing the subsequent version of the model (V3). We integrated feedback and field notes into mind maps during all stages of model development (Appendix 1).

2.1.4. Phase 4: Final appraisal by national communication experts

In the final phase, the model was presented to the advisory board of the study, a group of three senior experts in health care communication who have worked clinically, conducted research and engaged in communication trainings with a background in medical oncology, oncology nursing, and psycho-oncology for many years in Switzerland. One expert attended a one-hour online video discussion (due to the Corona pandemic), and two of them shared their thoughts on the model separately in a telephone session and via email. Audio from the video conference was recorded and field notes were taken. At the end of phase 4, leading project members (SE, SCZ, SJF, TG) analyzed the statements of the experts about the content and comprehensibility of the model to make final adjustments to the model and test its completeness. The final version of the model was presented to the wider research group and was approved.

3. Results

3.1. Findings from the development process

3.1.1. Phase 1: Results from the literature review

The systematic literature review identified 8979 records, of which 270 full texts were assessed for eligibility; 30 articles finally were selected for in-depth analyses (Fig. 2).

The review identified no communication strategies or guidelines focused specifically on patients in the last days of life and/or their family caregivers. Some were developed for conversations about serious illness and end-of-life issues in general or delivering bad news, e.g., the Serious Illness Conversation Guide (SICG) [44-46], Vitaltalk [47], and the SPIKES protocol for breaking bad news in oncology [48]. Further models, frameworks, guides, and programs have been developed for more general communication in palliative care such as a physician's guide to talking about end-of-life care [49], the SAGE & THYME communication skills model [50], and the ACA training program [51]. Other articles described more specific palliative care communication curricula such as NephroTalk [52], which provides guidance to nephrologists for delivering serious news. Essential components of all communication models highlighted prognostic aspects such as information needs if the illness progresses, and sources of support in the event of further deterioration and for the bereavement phase. On a skills level, relational aspects for discussion of serious topics such as exploring understanding of the current situation and encouraging the sharing of wishes and preferences were broadly recommended. The review also identified the need for specific attention to different conversation partners: the patient; family caregivers and friends; healthcare professionals, especially physicians and nurses; and HCP in training such as medical

students. Finally, the importance of self-care strategies, such as debriefing for professionals when dealing with dying and death were identified [53] (Table 3).

Based on these elements, an initial version of the communication model was developed (Fig. 3). The model encompassed aspects of a philosophy of care when dealing with existential issues, as well as procedural elements such as self-awareness and self-care, identifying patient needs and preferences and addressing a shared care plan. The HCP (oneself) and the patients and FC (others) were placed in the middle of the model. Furthermore, a medical starting point was indicated: the diagnosis of dying, which is the clinical trigger for HCP to initiate the conversation (at the latest).

3.1.2. Phase 2: Review by international palliative care experts

The international group of palliative care experts raised concerns regarding the complexity of the first version. They doubted that the model structure and process were self-explanatory.

Taking into account the target group of medical students or junior

Table 3

Core aspects derived from reviewed literature.

Nr.	Derived criteria	Main reference sources
I	Diagnosing Dying (Awareness of Death and Dying)	[19,20,37,54,55],
II	Reflection (Self-Awareness and Self-Care of HCP)	[24,26,28,53,56,57]
III	Exploration (Understand and Relate) and Shared Decision Making (Definition of an Action Plan)	[44,47,48,52,58]
IV	Communication Strategies/Guides	[49-51,59,60]
V	Professional Role	[61,62]
VI	Philosophy of Care	[53,63]

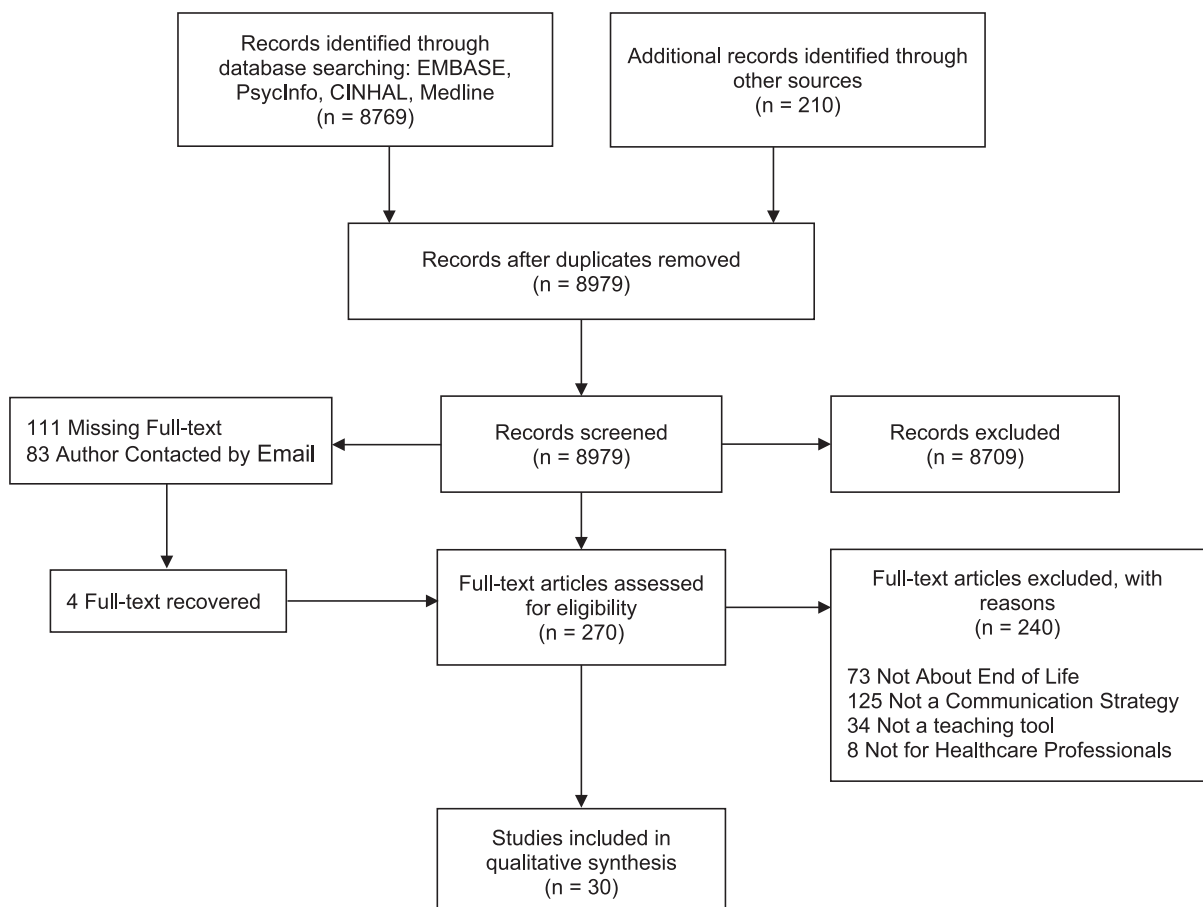


Fig. 2. Prisma chart systematic review.

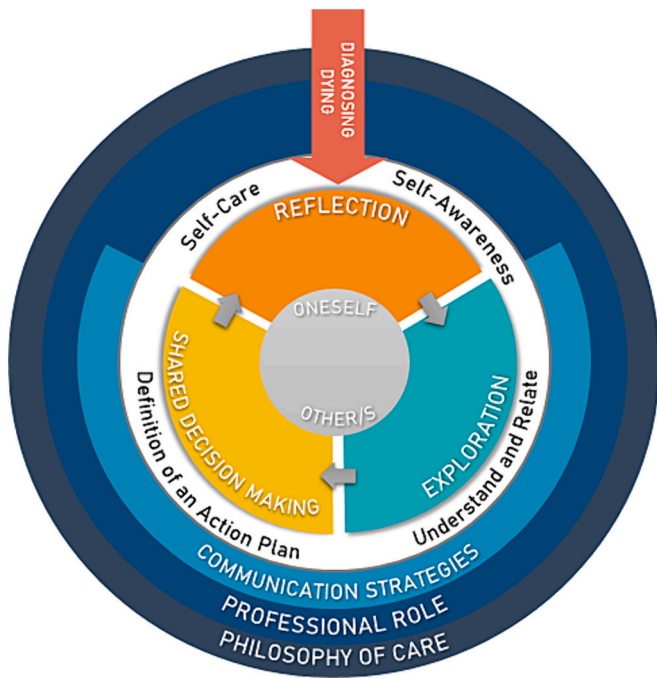


Fig. 3. Model version 1.

physicians, the international experts considered the following aspects of the model to be essential: a) communication strategies (e.g. for dealing with emotions, nonverbal communication, empathy, answering difficult questions, and silence), b) assessment and exploration (e.g. involving what patients and family caregivers want to hear, patient and FC perspectives, exploring major concerns, evaluating and discussing symptoms and conveying information about the dying phase), c) reflection upon setting (e.g. the moment, space, FC who are present, the professional role (e.g. being a mediator between patient and FCs, and decision making and planning (e.g. realistic responses while maintaining hope), and finally d) self-awareness (e.g. preparing a plan, knowing the objective, having a strategy, being aware of patient and FC situations), and self-care (e.g. dealing with one’s own emotions and experiences, and professional training). As a result, communication strategies were taken into account for further developing the structure of the model. The other main themes that arose such as assessment and exploration, reflection on the setting, professional role, decision-making, self-awareness and self-care were integrated into the model’s contents.

To better illustrate the communication process, the model was

represented as an arrow (model version 2, see Fig. 4). To further make the model more self-explanatory and useful for learning, the different aspects of the process were described in detail (A.3), adding different phases: what is happening BEFORE “the patient’s door” (outside), DURING (inside) the conversation, and AFTERwards (outside), taking into account aspects such as self-awareness, the reflection of one’s professional role, and philosophy of care that are present throughout the whole process (see A.3 for the operationalization of the different steps).

3.1.3. Phase 3: Feedback from key stakeholders

Across the five focus groups, four main themes were identified that were considered as being essential for communication about approaching death: 1) embracing care within medical expertise, 2) preparing the conversation while remaining open to the unexpected, 3) recognizing and reflecting on HCP emotions and reactions, and 4) establishing a meaningful connection with others. The themes and subthemes that emerged from the focus groups are reported and discussed in detail elsewhere [43]. All of the themes identified as essential aspects of communication about approaching death became a basis for further development of the model and were integrated either as new or complementary components regarding content, structure, and process.

New aspects of the communication process generated by the focus groups included seeing conversations not as a one-time, linear event (respecting the limited energy of severely ill patients), but more as a circular process that allows changing structure and content depending on the patient’s situation. Highlighted as well were relational aspects of conversation including respect and need for intimacy. The focus group of medical students, junior physicians, and nurses supported this recommendation as being essential as a core educational goal. Other elements suggested for successful teaching and implementation in clinical practice were: 1) the provision of communication aids for HCP that could include specific wording and sentences, 2) training on the job with structured feedback as guided discovery in practice and supervised learning situations, 3) role modeling for learning from each other as well as senior professionals, and 4) role-plays encouraging self-reflection and peer learning.

For model version 3, the phases *before*, *during*, and *after* the conversation were kept but placed within a more circular structure (Fig. 5). A clearer distinction between the *relational* and *content* levels was emphasized by using different colors (see A.4 for the operationalization of the different steps).

3.1.4. Phase 4: Critical appraisal by national communication experts

The main input from the national communication experts concerned drawing a clearer distinction between relational aspects and content and structure of the communication process. In other words, relational

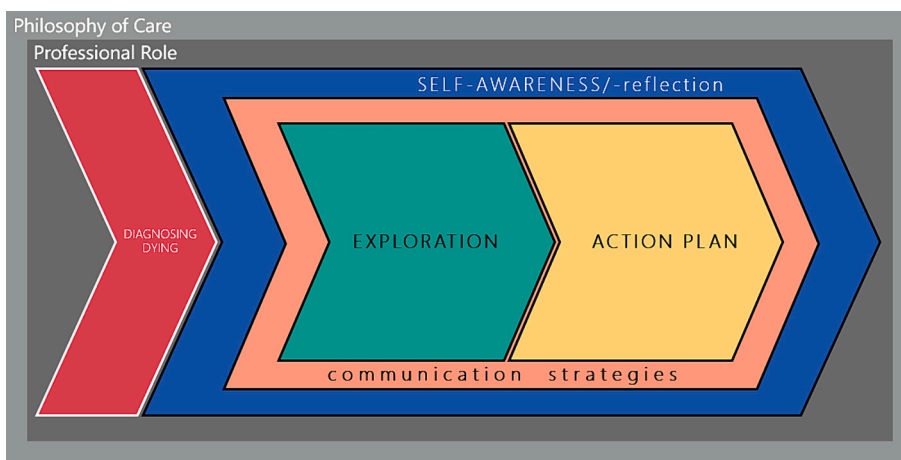


Fig. 4. Model V2.

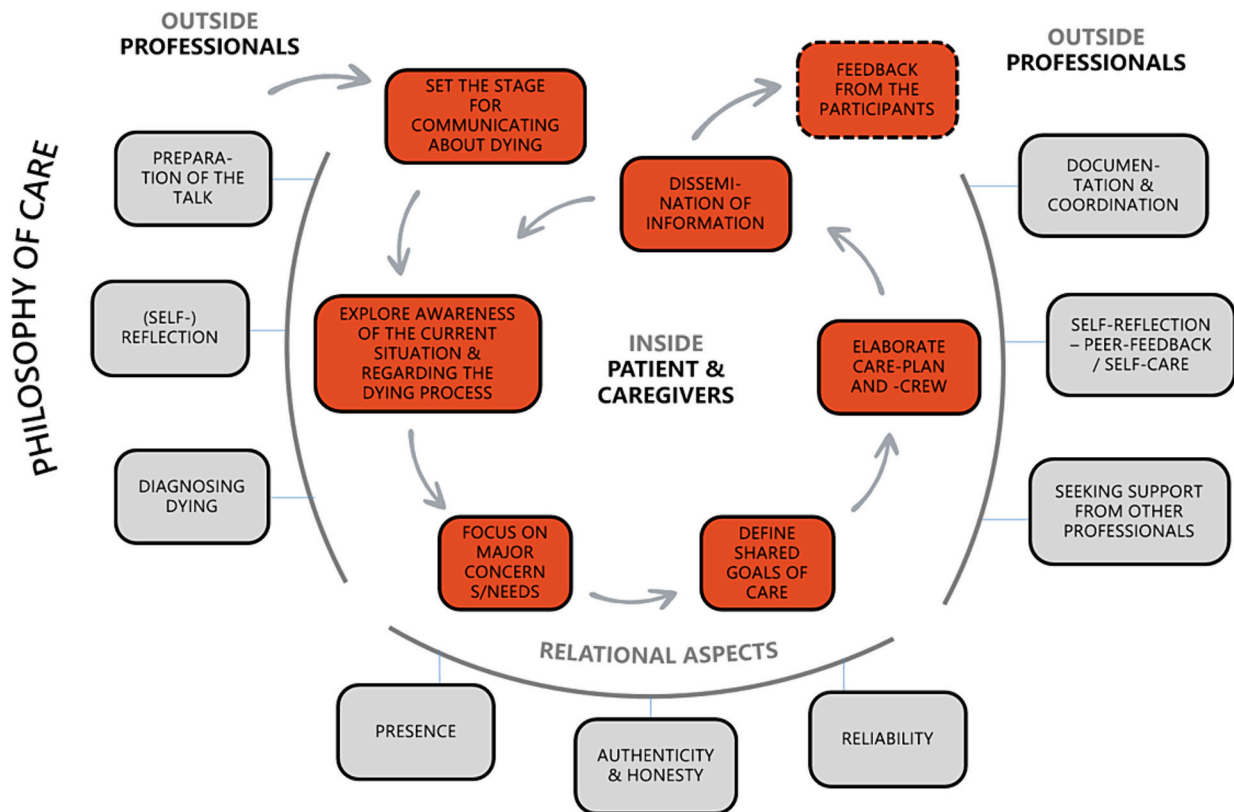


Fig. 5. Model V3.

aspects should point out the different target groups or partners involved in the conversation.

The final model (Fig. 6a, b) highlighted the relational aspect of the conversation by integrating the health care professional as a professional (my role) and person (my emotions) as well as the dying patient and FC with their roles and personal histories and emotions. The philosophy of care was reintroduced through the attitude of the health care professional who is supporting the patient and FC during an exceptional phase of life rather than primarily treating a disease. We also extended the conversation with important elements such as information about the situation from other professionals that shape the conversation but take place before and after it.

3.2. The communication model for talking about dying (TAD)

The final communication model (Fig. 6a, b) is structured by three phases: before (diagnosing dying, preparation), during (actually talking about dying), and after the conversation (postprocessing and debriefing). It also distinguishes between two core dimensions of effective conversations about approaching death: 1) the *content* of the different phases of the conversation and 2) *relational competencies* regarding a) empathic, authentic, and trustworthy communication with the patient and FC and b) the self-reflection and self-care of HCP regarding topics such as dying and death. Reflection on the attitudes and feelings of HCP towards death as a professional and as an individual are central to the model.

In terms of its *content level*, the conversation follows seven steps (Fig. 6b): 1) opening, 2) exploring the patient's self-estimation in terms of deterioration and naming the situation as "dying within the next few days", 3) assessing patient wishes and needs such as support for FC and the place of care, 4) defining common goals of care such as time for rest and silence, 5) co-creation of a care plan that includes who should be informed and presence of FC at the bedside during the night, 6) summarizing what has been discussed, and finally 7) asking open questions

about the need for further information and emotional support. See A.2 for further specific recommendations for each of the steps).

The model highlights the importance of postprocessing and debriefing *after* these conversations in order to reflect on one's own actions and emotions, and learn from specific situations but also to organize further care within the interprofessional team. The debriefing can be a formal or informal encounter to discuss the situation, in a structured or unstructured way, in teams or individually. When talking about dying, debriefing within the professional team is often particularly useful if the conversation is perceived as difficult, and it may be more effective if led by a senior member of the team. For debriefings that may require discussions about the organization, or when hierarchical structures appear to be too rigid for junior staff to find this type of support within their teams, seeking the help of an external person could be effective. An external perspective can help break down barriers and encourage more open communication, as well as provide important support when it may be needed the most. To organize further care, conversations with the extended team can help coordinate different tasks.

The process of communication may be interrupted or stopped at any time and may need to be restarted later, either because the patient or family may need more time to adjust to the discussions or because of a lack of energy or cultural barriers.

The *relational dimension* is built on the perspective of the health care professional and merits specific attention. It encompasses two central themes: a) the essentials of empathic communication with patients and their FC about imminent death, and b) self-awareness of and reflection on one's own attitudes and feelings towards dying and death as a professional and as an individual before, during, and after the conversation (Table 4). During the development process of the model, HCP self-awareness and self-reflection were highlighted by stakeholders as crucial elements before, during, and after the conversation. Consequently, for each of the phases key questions for HCP to reflect upon the relational dimension of the interaction have been identified (Table 4).

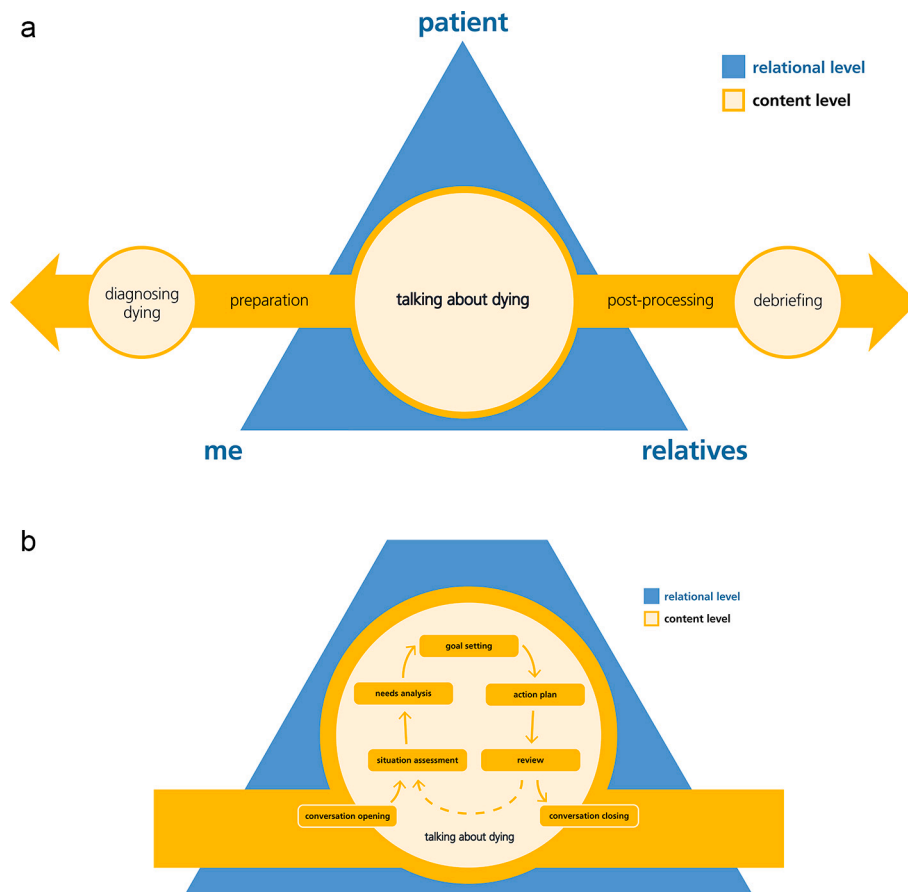


Fig. 6. a: Overview of the Model for Talking about Dying (TAD). b: Inner circle - Overview of the seven steps of the conversation.

Table 4
Operationalization of the relational level.

The relational level (triangle)		
Reflection <i>before</i> the conversation:	Reflection <i>during</i> the conversation (bird's eye view):	Reflection <i>after</i> the conversation:
How well do I know the attitude towards dying and death of ...	What is happening right now (in the interaction)? How ...	What are my responsibilities or tasks ...
<ul style="list-style-type: none"> the dying patient? the FC? myself? 	<ul style="list-style-type: none"> is the dying patient feeling? are the FC feeling? am I feeling? 	<ul style="list-style-type: none"> towards the dying patient? towards the FC? towards myself?

Accompanying and supporting patients and FC before, during, and after dying is a unique situation that will always be remembered by family caregivers, and also by many professionals. It is important that professionals and students learn to feel *for* the people affected without feeling *like* them, or like, them suffer (sympathize rather than pity). To be able to distinguish between the emotions of other people involved and their own, the model emphasizes that professionals should be aware of their own loss history and attitude towards death.

4. Discussion and conclusion

4.1. Discussion

Talking about approaching death with a patient and family caregivers in the last days of life remains a challenging task for all healthcare professionals. Based on a systematic literature review and input from

international experts and key stakeholders, we believe this is the first communication model specifically developed for this time and situation.

This communication model expands on a growing body of frameworks and strategies for the general task of end-of-life communication [3]. Most of the models, frameworks, guidelines, and programs are from Anglo-Saxon countries (Table 3) and not specifically covering conversation challenges with dying patients and their FC. They cover similar aspects of the conversation by following a comparable structure including (1) setting up, preparing, and initiating the conversation, (2) assessing of patient perspective on or perception of illness, (3) clarifying and sharing prognosis, (4) exploring patient preferences, key topics, and goals, (5) anticipating and planning care, and (6) closing and documenting the conversation. By structuring the themes we identified and providing specific steps and communications aids, our model integrates these aspects while focusing on concrete themes and the needs persons who are dying and those caring for them.

Even though existing end-of-life communication strategies refer to end-of-life topics (e.g., [48,49]), they often do not explicitly recommend at what stage of the patient's journey this communication should start and which aspects regarding the end-of-life should be addressed, in particular last wishes, a treatment plan for the last days of life, and preferred place of death. The model therefore recommends initiating conversations about approaching death with the patient and caregivers as part of routine care once dying has been recognized [1,64].

To support acting with more confidence during such conversations, the model contains specific communication aids to be used by healthcare professionals with sensitivity to heterogeneous beliefs, cultural backgrounds, and levels of openness when discussing dying and death. Justifiably, programs that provide standardized communication aids for empathic and compassionate communication have been questioned [53]. Conversations during the last days of life can hardly be

standardized, and they require not only excellent communication skills but also human connection. HCP are required to find a balance between clinical objectivity, connection, and personal feelings [24]. Consequently, the communication model operationalizes two aspects of human relationships: 1) authenticity, honesty, and trustworthiness, which are essential for establishing real communication [65] in a situation such as this, and 2) concrete ideas about practicing self-awareness and self-care before, during, and after end-of-life conversations. Particularly bearing in mind the risks of burnout and compassion fatigue among healthcare professionals, the importance of competence in dealing with dying and death must not be underestimated [28,66]. Consequently, educational interventions based on the model contain not only communication skills training for the actual conversation but provide important occasions for personal reflection and professional development in terms of compassionate care. This is why a workshop based on the model “Talking about dying,” which contains an e-learning module, role-plays, and reflective practices, has been developed [67].

4.2. Limitations and strengths

Having found no clear and entirely applicable guidelines for developing communication models in healthcare, we followed a stepwise approach that began with a systematic review of the literature and obtaining the views of different national and international experts and stakeholders. However, the focus groups were undertaken at a single university site in the German-speaking part of Switzerland, and the numbers of patient representatives involved could have been increased; reproducibility was not fully ensured by this process. And though the model starts with the recognition of dying, by focusing on communication it does not directly engage clinical management. Guidance on the recognition of dying can be found in other sources (e.g., [20]).

A wealth of data shaped the model through its various stages. Throughout, stakeholders and potential partners in this type of conversation were involved, along with the primary target group of the communication model: medical students and junior clinicians. Finally, a qualitative study verified the content of the model [43]. Although the model was developed and validated for communication during a patient’s last few days of life, it also could be applicable to earlier end-of-life discussions.

4.3. Innovation

This is the first model of communication about death with dying patients and their FC developed with stakeholders across disciplines. This model adds to an existing body of specific communication aids and complements end-of-life communication strategies that were developed mainly in Anglo-Saxon countries (see, e.g. [60,68]). Building on existing models and recommendations for communicating effectively during the last days of life [69], it provides a both pragmatic and careful model for this often challenging and unaddressed communication task. With a sound theoretical foundation, based on research and practice, the model may substantially contribute to the existing body of knowledge about end-of-life communication [3,70].

Rather uncommon for a communication model, it addresses not only a structure for the conversation content but also other essential aspects of communication that may affect its quality: the neglected tasks of self-reflection and self-care, which are essential when dealing with existential topics such as dying and death. The model proposes not only *how* to communicate *what*, but also *when* and by *whom*. Healthcare professionals need to be aware of and be able to reflect upon their own emotions, and to care for their own needs as human beings. This is important in all healthcare encounters, but it becomes even more relevant in the context of death and dying.

When applied and discussed in training, but also in clinical practice, the model might also contribute to the professional and personal development of HCP by promoting learning from each others’

experiences and reducing concerns and anxiety when dealing with dying and death, ultimately making the end of life less of a taboo in medicine. A better understanding of and appropriate communication about imminent death will ease the experience of death for both family and professional caregivers who are involved. This model may of course be adapted and continuously modified as it is used in various care settings and cultures, and through additional interprofessional perspectives.

4.4. Conclusion

Healthcare professionals, patients, family caregivers, and professionals in training such as medical students hesitate to talk about dying and death when death is imminent. If conversations about death do not begin when the end of life is near, opportunities to say goodbye and provide the best care for the dying may be forever lost. In developing this communication model, we learned that in general—and particularly when death is near and all are vulnerable—those providing health care need not only clinical expertise but also thoughtful communication skills to build trustworthy, authentic, human partnerships. By offering practical advice on what to say about dying and death *and* how to say it, we believe this model will allow healthcare professionals to open these conversations with greater confidence and master this difficult but meaningful clinical task. The model contributes to medical and nursing education and, even more at the bedside, to compassionate care for dying patients and their caregivers.

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Ethical approval

The Bernese Cantonal Ethic Commission reviewed the study (REQ-2019-00977) and considered that the study could be performed without formal ethical approval.

CRediT authorship contribution statement

Sibylle J. Felber: Writing – review & editing, Writing – original draft, Visualization, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Sofia C. Zambrano:** Writing – review & editing, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Tommaso Guffi:** Writing – review & editing, Project administration, Investigation, Formal analysis, Data curation, Conceptualization. **Felix M. Schmitz:** Writing – review & editing, Visualization, Methodology, Conceptualization. **Beate G. Brem:** Writing – review & editing, Methodology, Conceptualization. **Kai P. Schnabel:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Sissel Guttormsen:** Writing – review & editing, Validation, Supervision, Resources, Methodology, Funding acquisition, Conceptualization. **Steffen Eychmüller:** Writing – review & editing, Visualization, Validation, Supervision, Resources, Methodology, Investigation, Formal analysis, Data curation, Conceptualization.

Declaration of competing interest

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Appendix A. Supplementary data

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References

- Bernacki RE, Block SD, American College of Physicians High Value Care Task Force. 'Communication about serious illness care goals: a review and synthesis of best practices. *JAMA Intern Med* 2014;174(12):1994–2003. <https://doi.org/10.1001/jamainternmed.2014.5271>.
- Clayton JM, et al. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *Med J Aust* 2007;186(S12):S77–105. <https://doi.org/10.5694/j.1326-5377.2007.tb01100.x>.
- Chen W, Chung JOK, Lam KKW, Molassiotis A. End-of-life communication strategies for healthcare professionals: a scoping review. *Palliat Med* 2023;37(1): 61–74. <https://doi.org/10.1177/02692163221133670>.
- Anderson RJ, Bloch S, Armstrong M, Stone PC, Low JT. Communication between healthcare professionals and relatives of patients approaching the end-of-life: a systematic review of qualitative evidence. *Palliat Med* 2019;33(8):926–41. <https://doi.org/10.1177/0269216319852007>.
- Knutzen KE, et al. Actual and missed opportunities for end-of-life care discussions with oncology patients: a qualitative study. *JAMA Netw Open* 2021;4(6): e2113193. <https://doi.org/10.1001/jamanetworkopen.2021.13193>.
- Krones Tanja, et al. Advance care planning for the severely ill in the hospital: a randomized trial. *BMJ Support Palliat Care* 2022;12(e3):e411. <https://doi.org/10.1136/bmjspcare-2017-001489>.
- Scholz B, et al. Clinicians' accounts of communication with patients in end-of-life care contexts: a systematic review. *Patient Educ Couns* 2020;103(10):1913–21. <https://doi.org/10.1016/j.pec.2020.06.033>.
- Pfeifer M, Head BA. Which critical communication skills are essential for interdisciplinary end-of-life discussions? *AMA J Ethics* 2018;20(8):E724–31. <https://doi.org/10.1001/amajethics.2018.724>.
- Galushko M, Romotzky V, Voltz R. Challenges in end-of-life communication. *Curr Opin Support Palliat Care* 2012;6(3):355–64. <https://doi.org/10.1097/SPC.0b013e328356ab72>.
- Flugelman Moshe Y. How to talk with the family of a dying patient: anger to understanding, rage to compassion, loss to acceptance. *BMJ Support Palliat Care* 2021;11(4):418. <https://doi.org/10.1136/bmjspcare-2021-002971>.
- Elia F, Vergano M, Di Meglio L. The patient who fell off a skyscraper. *Intensive Care Med* 2018;44(10):1770. <https://doi.org/10.1007/s00134-018-5089-9>.
- Abbott CH, Prigerson HG, Maciejewski PK. The influence of patients' quality of life at the end of life on bereaved caregivers' suicidal ideation. *Journal of Pain and Symptom Management* 2014;48(3):459–64. <https://doi.org/10.1016/j.jpainsymman.2013.09.011>.
- Stajduhar KI, Martin W, Cairns M. What makes grief difficult? Perspectives from bereaved family caregivers and healthcare providers of advanced cancer patients. *Palliat Support Care* 2010;8(3):277–89. <https://doi.org/10.1017/S1478951510000076>.
- Wright AA, Keating NL, Balboni TA, Matulonis UA, Block SD, Prigerson HG. Place of death: correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health. *J Clin Oncol* 2010;28(29):4457–64. <https://doi.org/10.1200/JCO.2009.26.3863>.
- Otani H, et al. Meaningful communication before death, but not present at the time of death itself, is associated with better outcomes on measures of depression and complicated grief among bereaved family members of cancer patients. *J Pain Symptom Manage* 2017;54(3):273–9. <https://doi.org/10.1016/j.jpainsymman.2017.07.010>.
- Brighton LJ, Bristowe K. Communication in palliative care: talking about the end of life, before the end of life. *Postgrad Med J* 2016;92(1090):466–70. <https://doi.org/10.1136/postgradmedj-2015-133368>.
- Gillett K, O'Neill B, Bloomfield JG. Factors influencing the development of end-of-life communication skills: a focus group study of nursing and medical students. *Nurse Educ Today* 2016;36:395–400. <https://doi.org/10.1016/j.nedt.2015.10.015>.
- Qama E, Diviani N, Grignoli N, Rubinelli S. Health professionals' view on the role of hope and communication challenges with patients in palliative care: a systematic narrative review. *Patient Educ Couns* 2022;105(6):1470–87. <https://doi.org/10.1016/j.pec.2021.09.025>.
- National Clinical Guideline Centre (UK). Care of Dying Adults in the Last Days of Life. (NICE Guideline, No. 31.). London: National Institute for Health and Care Excellence (NICE) [Online]. Available: <https://www.ncbi.nlm.nih.gov/books/NBK356012/>; 2015.
- Domeisen Benedetti F, et al. International palliative care experts' view on phenomena indicating the last hours and days of life. *Support Care Cancer* 2013;21(6):1509–17. <https://doi.org/10.1007/s00520-012-1677-3>.
- Lundquist G, Rasmussen BH, Axelsson B. Information of imminent death or not: does it make a difference? *J Clin Oncol* 2011;29(29):3927–31. <https://doi.org/10.1200/JCO.2011.34.6247>.
- Olsson MM, Windsor C, Chambers S, Green TL. A scoping review of end-of-life communication in international palliative care guidelines for acute care settings. *J Pain Symptom Manage* 2021;62(2). <https://doi.org/10.1016/j.jpainsymman.2020.11.032>. pp. 425–437.e2.
- Coyle N, et al. Discussing death, dying, and end-of-life goals of care: a communication skills training module for oncology nurses. *Clin J Oncol Nurs* 2015; 19(6):697–702. <https://doi.org/10.1188/15.CJON.697-702>.
- Zambrano SC, Chur-Hansen A, Crawford GB. On the emotional connection of medical specialists dealing with death and dying: a qualitative study of oncologists, surgeons, intensive care specialists and palliative medicine specialists. *BMJ Support Palliat Care* 2012;2(3):270–5. <https://doi.org/10.1136/bmjspcare-2012-000208>.
- Eychmüller S, Forster M, Gudat H, Lütolf UM, Borasio GD. Undergraduate palliative care teaching in Swiss medical faculties: a nationwide survey and improved learning objectives. *BMC Med Educ* 2015;15:213. <https://doi.org/10.1186/s12909-015-0485-0>.
- Cripe L, Frankel RM. Understanding what influences oncology clinicians' communicating with dying patients: awareness of one's own mortality may be one key. *Patient Educ Couns* 2016;99(3):307–9. <https://doi.org/10.1016/j.pec.2016.02.001>.
- Granek L, Nakash O, Cohen M, Ben-David M, Ariad S. Oncologists' communication about end of life: the relationship among secondary traumatic stress, compassion satisfaction, and approach and avoidance communication. *Psycho-Oncology* 2017; 26(11):1980–6. <https://doi.org/10.1002/pon.4289>.
- Kearney MK, Weininger RB, Vachon MLS, Harrison RL, Mount BM. Self-care of physicians caring for patients at the end of life: "being connected... A key to my survival". *JAMA* 2009;301(11):1155–64. E1. <https://doi.org/10.1001/jama.2009.352>.
- Hewison A, Lord L, Bailey C. "It's been quite a challenge": redesigning end-of-life care in acute hospitals. *Palliat Support Care* 2015;13(3):609–18. <https://doi.org/10.1017/S1478951514000170>.
- Rodenbach RA, Rodenbach KE, Tejana MA, Epstein RM. Relationships between personal attitudes about death and communication with terminally ill patients: how oncology clinicians grapple with mortality. *Patient Educ Couns* 2016;99(3): 356–63. <https://doi.org/10.1016/j.pec.2015.10.010>.
- Zambrano SC, Chur-Hansen A, Crawford GB. The experiences, coping mechanisms, and impact of death and dying on palliative medicine specialists. *Palliat Support Care* 2014;12(4):309–16. <https://doi.org/10.1017/S1478951513000138>.
- Rousseau P. Caring for the dying: why is it so hard for physicians? *West J Med* 2001;175(4):284–5. <https://doi.org/10.1136/ewj.175.4.284>.
- Ekberg S, et al. Communicating with patients and families about illness progression and end of life: a review of studies using direct observation of clinical practice. *BMC Palliat Care* 2021;20(1):186. <https://doi.org/10.1186/s12904-021-00876-2>.
- Hawkins A, Tredgett K. Use of high-fidelity simulation to improve communication skills regarding death and dying: a qualitative study. *BMJ Support Palliat Care* 2016;6(4):474–8. <https://doi.org/10.1136/bmjspcare-2015-001081>.
- Powazki R, et al. The Care of the Actively Dying in an Academic Medical Center: a survey of registered nurses 'Professional Capability and Comfort'. *Am J Hosp Palliat Care* 2014;31(6):619–27. <https://doi.org/10.1177/1049909113505194>.
- palliative ch. *Betreuung sterbender Menschen und ihrer Angehörigen. Version Fachpersonen*. 2024.
- Rajmakers N, et al. Quality indicators for care of cancer patients in their last days of life: literature update and experts' evaluation. *J Palliat Med* 2012;15(3):308–16. <https://doi.org/10.1089/jpm.2011.0393>.
- Zambrano Ramos S, Guffi T, Felber S. Communication about dying and death: a systematic review of the content, development and outcomes of end of life communication strategies such as guidelines, tools, frameworks and models employed for health professional communication skills training. In: PROSPERO 2019 CRD42019138634; 2024 [Online]. Available: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019138634.
- Ouzzani M, Hammady H, Fedorowicz Z, Elmagarmid A. Rayyan—a web and mobile app for systematic reviews. *Syst Rev* 2016;5(1):210. <https://doi.org/10.1186/s13643-016-0384-4>.
- QSR International Pty Ltd. NVivo (Version 12) [Online]. Available: <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>.
- Braun V, Clarke V. *Thematic analysis: A practical guide*. SAGE Publications Ltd; 2021.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3(2):77–101. <https://doi.org/10.1191/1478088706qp0630a>.
- Felber SJ, et al. Talking about dying and death: essentials of communicating about imminent death from the perspective of major stakeholders. *Palliat Support Care* 2023. <https://doi.org/10.1017/S1478951523001621>. Published online 2023:1-10.

- [44] Ariadne Labs. Serious Illness Conversation Guide. Accessed: Nov. 29, 2023. [Online]. Available: <https://www.ariadnelabs.org/serious-illness-care/for-clinicians/>; 2023.
- [45] Bernacki R, et al. Development of the serious illness care program: a randomised controlled trial of a palliative care communication intervention. *BMJ Open* 2015;5(10):e009032. <https://doi.org/10.1136/bmjopen-2015-009032>.
- [46] Bernacki R, et al. Effect of the Serious Illness Care Program in Outpatient Oncology: A Cluster Randomized Clinical Trial. *JAMA Intern Med* 2019;179(6):751–9. <https://doi.org/10.1001/jamainternmed.2019.0077>.
- [47] Arnold RM, Back AL, Baile WF, Edwards KA, Tulsky JA. The Oncotalk/Vitaltalk model. In: *Oxford textbook of communication in oncology and palliative care*. Oxford: Oxford University Press; 2017. p. 363–8 [Online]. Available: <https://doi.org/10.1093/med/9780198736134.003.0056>.
- [48] Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist* 2000;5(4):302–11. <https://doi.org/10.1634/theoncologist.5-4-302>.
- [49] Balaban RB. A physician's guide to talking about end-of-life care. *J Gen Intern Med* 2000;15(3):195–200. <https://doi.org/10.1046/j.1525-1497.2000.07228.x>.
- [50] Griffiths J, Wilson C, Ewing G, Connolly M, Grande G. Improving communication with palliative care cancer patients at home - a pilot study of SAGE & THYME communication skills model. *Eur J Oncol Nurs* 2015;19(5):465–72. <https://doi.org/10.1016/j.ejon.2015.02.005>.
- [51] Slort W, Blankenstein AH, Wanrooij BS, van der Horst HE, Deliens L. The ACA training programme to improve communication between general practitioners and their palliative care patients: development and applicability. *BMC Palliat Care* 2012;11(1):9. <https://doi.org/10.1186/1472-684X-11-9>.
- [52] Schell JO, et al. NephroTalk: evaluation of a palliative care communication curriculum for nephrology fellows. *J Pain Symptom Manage* 2018;56(5):767–773. e2. <https://doi.org/10.1016/j.jpainsymman.2018.08.002>.
- [53] Gardner C. Medicine's uncanny valley: the problem of standardising empathy. *Lancet* 2015;386(9998):1032–3. [https://doi.org/10.1016/S0140-6736\(15\)00161-0](https://doi.org/10.1016/S0140-6736(15)00161-0).
- [54] Houttekier D, Witkamp FE, van Zuylen L, van der Rijt CCD, van der Heide A. Is physician awareness of impending death in hospital related to better communication and medical care? *J Palliat Med* 2014;17(11):1238–43. <https://doi.org/10.1089/jpm.2014.0203>.
- [55] White N, et al. How do palliative care doctors recognise imminently dying patients? A judgement analysis'. *BMJ Open* 2018;8(11):e024996. <https://doi.org/10.1136/bmjopen-2018-024996>.
- [56] Sanchez-Reilly S, et al. Caring for oneself to care for others: physicians and their self-care. *J Support Oncol* 2013;11(2):75–81. <https://doi.org/10.12788/j.suponc.0003>.
- [57] *When professionals weep: Emotional and countertransference responses in end-of-life care*. In *When professionals weep: Emotional and countertransference responses in end-of-life care*. New York, NY, US: Routledge/Taylor & Francis Group; 2006. pp. xii, 303.
- [58] National Coalition for Hospice and Palliative Care. National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care. 4th ed. 2018. Accessed: Nov. 29, 2023. [Online]. Available: <https://www.nationalcoalitionhpc.org/ncp>.
- [59] Childers JW, Back AL, Tulsky JA, Arnold RM. REMAP: a framework for goals of care conversations. *J Oncol Pract* 2017;13(10):e844–50. <https://doi.org/10.1200/JOP.2016.018796>.
- [60] Wittenberg E, Ferrell BR, Goldsmith J, Smith T, Ragan SL, Handzo G. *Textbook of palliative care communication*. Oxford University Press; 2015.
- [61] MacLeod RD. On reflection: doctors learning to care for people who are dying. *Soc Sci Med* 2001;52(11):1719–27. [https://doi.org/10.1016/S0277-9536\(00\)00289-6](https://doi.org/10.1016/S0277-9536(00)00289-6).
- [62] Barclay S, et al. An important but stressful part of their future work: medical students' attitudes to palliative care throughout their course. *J Pain Symptom Manage* 2015;49(2):231–42. <https://doi.org/10.1016/j.jpainsymman.2014.06.004>.
- [63] Blinderman CD, Billings JA. Comfort Care for Patients Dying in the hospital. *N Engl J Med* 2015;373(26):2549–61. <https://doi.org/10.1056/NEJMra1411746>.
- [64] Tulsky JA, et al. A research agenda for communication between health care professionals and patients living with serious illness. *JAMA Intern Med* 2017;177(9):1361–6. <https://doi.org/10.1001/jamainternmed.2017.2005>.
- [65] Windover AK, Boissy A, Rice TW, Gilligan T, Velez VJ, Merlino J. The REDE model of healthcare communication: optimizing relationship as a therapeutic agent. *J Patient Exp* 2014;1(1):8–13. <https://doi.org/10.1177/237437431400100103>.
- [66] Buonaccorso L, et al. Self-care as a method to cope with suffering and death: a participatory action-research aimed at quality improvement. *Front Psychol* 2022;13:769702. <https://doi.org/10.3389/fpsyg.2022.769702>.
- [67] Guttormsen S, Schnabel K. 'New Module «STERBEN: Über das Sterben sprechen»', DocCom.Deutsch. Die Lernplattform für Kommunikation im Gesundheitswesen. Accessed: Feb 15, 2023. [Online]. Available: <https://doccom.iml.unibe.ch/>; 2024.
- [68] *Oxford textbook of communication in oncology and palliative care*. In: Kissane DW, Bultz BD, Butow PN, Bylund CL, Noble S, Wilkinson S, editors. *Oxford textbooks in palliative medicine*. 2nd ed. Oxford: Oxford University Press; 2017.
- [69] National Institute for Health and Care Excellence (NICE). Care of the dying adults in the last days of life (NG 31) [Online]. Available: <https://www.nice.org.uk/guidance/ng31>; 2015.
- [70] Gonella S, Campagna S, Dimonte V. A situation-specific theory of end-of-life communication in nursing homes. *Int J Environ Res Public Health* 2023;20(1):869. <https://doi.org/10.3390/ijerph20010869>.