38 Communication with the Dying

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> You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.
>
> Cicely Saunders (1918 – 2005)

Abstract: Despite the steady development of palliative and hospice care in Germany over the last 30 years, many doctors feel insecure and insufficiently trained for such conversations and try to avoid them.

SPIKES can be used as a guide for breaking bad news about diagnosis and prognosis. For the prognosis of survival time, the "surprise question" is recommended ("Would I be surprised if the patient died in the next week/month/year?").

Even with a short prognosis, it is very important to get to know and take into account the patient's individual priorities and preferences when setting treatment goals and planning treatment. This applies in particular to patients with a different cultural or spiritual background.

Special communication strategies are required for patients who, in an unrealistic hope of survival, desperately demand ever new attempts at therapy and with patients who wish to die.

In addition to communication with the patient, support for relatives is also an important issue in palliative care. Conflicts can also arise here, e.g. if relatives want to prevent the patient from receiving appropriate information or aggressively demand therapeutic measures that are no longer indicated from the doctor's point of view. Here too, an appreciative approach, but also an indication of boundaries, can facilitate a joint treatment strategy that is supported by everyone.

38.1 Introduction

In 1969, a new book attracted a great deal of attention in the USA: Kübler-Ross published her interviews with the dying (Kübler-Ross 2001). She had noticed that in the hospital where she worked, hardly anyone spoke to the seriously ill or dying patients. Many doctors were full of compassion and wanted to help these patients but had no idea what these patients actually wanted. Kübler-Ross's interviews showed what the severely ill patients were feeling, but the publication of the interviews was seen as a breach of taboo at that time. One should not talk to the dying, and certainly not in public.

A self-experiment by a Canadian doctor shortly after the opening of the first palliative care clinic in Montreal (Buckingham et al. 1976) showed just as impressively how far this exclusion of the dying also went in terms of communication behavior. He had been admitted undercover to the surgical oncology department of the hospital as a patient with a tumor disease, with a carefully prepared medical history and falsified examination findings. In his field notes, he describes how the doctors only entered the room in groups and no longer dared to speak to him alone, and how eye contact to him became increasingly rare and talking times shorter. The discomfort of the staff, both the assistant doctors and the nurses, in communicating with him as a supposedly terminally ill patient were evident.

Almost 40 years have passed since this impressive attempt. But what has changed? There is an increasing number of communication courses for doctors, and in the recently developed national catalog of learning objectives for medical students, the doctor as communicator is presented as one of the essential six role functions of the doctor. Last but not least, the development of palliative care both as a specialized medical field and as a general competence of medical personnel has brought about a slow rethinking process.

This is also to be seen in the context of a social development in which taboos are slowly being taken out of death and dying, which are increasingly being perceived as a public issue. In recent years, a number of films have been produced, such as "The Bucket List" ("Das Beste kommt zum Schluss") or "Stopped on Track" ("Halt auf freier Strecke"), which have achieved high viewing figures.

In November 2013, the ARD (German TV channel) themed week featured a large number of reports on the subject of death and dying, which were well received by the public.

Nevertheless, even today there are still enough reports from patients and relatives complaining about a lack of communication, a lack of understanding and an inability to deal with this topic among doctors and other healthcare professionals. In communication seminars, doctors report that they feel insecure and inadequately trained for informed consent discussions, and it is not uncommon for doctors to try to avoid such discussions.

Thus, there is a lack of information and training opportunities for communication with the seriously ill and dying in order to improve the care of these persons in this extremely distressing life situation.

38.2 Diagnosis and prognosis

Receiving a diagnosis of a life-threatening and life-limiting illness is a severe blow for the patient, which can plunge them into an existential crisis. The diagnosis of a tumor disease, for example, means that many of the patient's life plans can no longer be realized. The goals that have perhaps been always postponed for a later period of life are suddenly unattainable. Time is suddenly a scarce and precious commodity that must be managed well. The major impact on the patient is most severe when communicating the diagnosis, but new medical findings on disease progression can also occur later in the course of the disease, when a significantly worse prognosis has to be communicated to the patient. While a tumor diagnosis, for example, may in many cases initially include options for cure or at least prolonged survival, the diagnosis of a recurrence or metastases can suddenly lead to a significantly worse prognosis for the remaining life span.

Communicating such a diagnosis of a life-threatening disease or limited prognosis is thus distressing for the doctor. The uncertainty of how the patient will react, whether they will burst into tears or even become aggressive, causes anxiety and can lead to doctors to avoid such conversations or at least wanting to keep them as brief and detached as possible.

Guidelines such as SPIKES (Baile et al. 2000) (see Table 38.1) or NURSE (Name - Understand - Respect - Support - Explore) (Back et al. 2005) offer help in breaking bad news. However, these guidelines should not be taken as a rigid scheme, but rather as a loose framework for any individual conversation.

It is important in such conversations, even more than in other situations, to take breaks, recognize the patient's feelings and, if necessary, endure them. Doctors are often afraid that patients will fall into deep despair or even burst into tears during the conversation. They fear that they will not be able to bring the patient out of this despair and that they themselves may be overwhelmed by their feelings.

Although it can certainly happen that patients start to cry during such a conversation, the majority will return to a less emotional level after less than a minute and, for example, ask the doctor what to do next.

However, too much information about possible next steps and measures is not necessary in this conversation and may even be counterproductive. The patient will only be able to comprehend and retain a small part of the information offered anyway. The doctor should also not assume that the patient will fully accept the information offered on diagnosis and prognosis. The communication of information on diagnosis and prognosis is not a one-off event (with one good informed consent discussion), but rather a continuous process, with a series of discussions and time in between for the patient to reflect. In these discussions, the doctor should always check back with the patient about the patient's current level of knowledge and the amount of information he or she wants or can tolerate at the moment.

Setting	• Conversation at eye level, • Avoiding rooms that create distance or disturbances, • Clarification of the participation of other persons in the discussion (family members, team members)
Perception	• Open questions to assess the level of knowledge and patient perception: • "What do you know about your illness so far?". "Have you already been told anything about the results?" • Misunderstandings can be eliminated.
Invitation	• Establish willingness of the patient to accept new information. • "Should we talk about this now?" "Should I describe all the results to you in detail, or just outline the most important results?"
Knowledge	• Breaking the bad news, • Introduction with a warning shot: "I'm very sorry, but I am bringing bad news today" • Comprehensible and clear terminology, offer illustrations, • Structure information in units, allow questions, • Avoid phrases: "There's nothing more we can do for you."
Empathy, Emotions	• Exploring emotions, reacting empathetically, • Name emotions, provide space for emotions
Summary	• Summarizing and planning, be specific, write down, outline, • Consider patient preferences

Tab. 38.1: SPIKES – guidance for breaking bad news
(from Baile et al. 2000)

When communicating with seriously ill and dying people, estimating the remaining life span is a very challenging and ethically sensitive issue. The question "How much time is left?" contains very different facets that are essential for the life and care context of the individual patient.

Patients in advanced stages of a cancer disease often want to know how long they have left to live (Hagerty et al. 2005). They want to know how much time they have left to express their wishes for end-of-life care, consider how urgent it is to draw up an advance directive or a power of attorney or they want to settle outstanding financial and personal matters ("last things") (Stone, Lund 2007). Despite the desire for information, there is some ambivalence. Patients do ask about it and obviously want to hear their prognosis, but because of the high existential significance, it is then difficult to realize the certainty of the suddenly so short remaining time, as Chochinov put it: "We want to be told, but we do not want to know." (Chochinov et al. 2000).

This is probably the most tangible benefit of a reliable prognosis: giving patients the opportunity to live their lives effectively and make personal decisions. Saying the unsaid, settling personal matters or fulfilling last wishes can be of great importance for seriously ill people. In this way, communicating the prognosis contributes to patient-centered palliative care (Christakis 1999). Dealing honestly and sincerely with the question of prognosis is thus one of the central tasks of palliative care. Contrary to frequent fears, the knowledge of one's own prognosis and the feeling of being prepared for dying can alleviate patients' fears (Hagerty et al. 2005, Tattersall et al. 2002).

The professional caregivers assessment of survival time also plays an important role in therapeutic decisions.

However, the clinical impression of doctors leads to a very inaccurate assessment in 80% of cancer patients. In most cases the remaining lifespan is assessed too optimistically and is overestimated up to fivefold (Christakis 1999, Stiel et al. 2010).

Two measurement instruments are predominant in German-speaking countries: the Palliative Prognostic Index (PPI) and the Palliative Prognostic Score (PaP-S) (Stiel, Radbruch 2014). However, it is not clear whether the informative value of these instruments is sufficient for the assessment of individual patients, or whether the value of the instruments lies more in the description of patient groups in research (Stiel et al. 2010).

Given the questionable validity of the existing prognostic instruments for individual patients, a different approach is thus recommended in clinical practice. The "surprise question" can at least provide a clear warning for both longer and shorter periods of time as to which patients may have a much shorter survival time than expected, allowing communication and care planning to be adapted accordingly. The practitioner asks themselves the question: "Would I be surprised if the patient died in the next year/week/hours?". If this question is answered with "No, this would be no surprise", there is a high probability that the patient will actually die within this period (Pattison, Romer 2001). The surprise question can also be used for non-cancer diseases (Murray, Boyd 2011, White et al. 2017), for example with a sensitivity of 24.8% and a specificity of 93.4% in patients with renal insufficiency requiring dialysis (Pang et al. 2013). It allows the practitioner communication and care planning that is tailored to the patient's prognosis.

If the patient really wants an answer to the question about the remaining period of time, it is advisable to describe time periods (e.g. "I'm afraid it is rather a matter of a few days or a few weeks, and not months"). The formulation of defined points in time (e.g. "I estimate there are still 3 weeks to go.") carries the risk that this point in time is taken very literally and is very likely to be incorrect. If the remaining period is shorter, the patient may not have been able to fulfill last things that were important to them. But even if the period is longer than initially estimated, the patient and their relatives may become dissatisfied because they have prepared themselves for the supposedly imminent end of life and said goodbye to each other, but the end has not happened yet.

When discussing the prognosis, caregivers are advised to openly discuss the fact that this is an estimate. It can be helpful to discuss your own uncertainty in the sense of: "However, I have often been wrong about such prognoses, so I can't tell you exactly".

38.3 Priorities and preferences

Palliative care for severely ill and dying patients is not about achieving objectively defined goals, as in other areas of medicine (e.g. in internal medicine the adjustment of blood pressure into the normal range, or low complication rates after surgery). In contrast, the focus of palliative care is on maintaining the patient's individual quality of life to the greatest extent possible. This is complicated by the vagueness of the concept of quality of life, which is primarily defined by the patients themselves. There is a large number of different instruments for the assessment of health-related quality of life. However, these questionnaires and scales can only ever capture specific facets of quality of life, namely those covered by the items of the questionnaire.

The Schedule for the Evaluation of the Individual Quality of Life (SEIQoL) (Neudert et al. 2001, O'Boyle et al. 1995) has been recommended as a comprehensive measure of individual quality of life in seriously ill patients. The SEIQoL starts with the patient first naming the five areas that they consider most important for their quality of life, and what percentage each area contributes to their quality of life. They then indicate the extent to which they feel restricted in each of these five areas. From this, an overall quality of life score can be calculated. Interestingly enough, in the case of seriously ill patients, quite often it is not symptoms such as pain or shortness of breath or other health-related issues that are named by patients in first place, but above all family and interpersonal relationships are valued for quality of life.

In everyday clinical practice, the instrument is not necessarily suitable for the care of dying patients, as considerable cognitive skills are required to assess the areas and the impairment percentages. However, experience with this quality-of-life instrument emphasize that patients' priorities are not always in the medical field. Of course, suffering patients greatly value if they no longer have to suffer from pain, shortness of breath or nausea. However, some patients are prepared to accept a higher level of residual discomfort, if this for example allows them to spend the final stage of their lives in their familiar home environment with their family.

From the patient's perspective, the possible treatment options are also evaluated according to individual goals. For example, chemotherapy or radiotherapy may well be worthwhile from the patient's perspective, even if the expected prolongation of life is only a few weeks or months, if, for example, an important family celebration is expected during this time (e.g. silver wedding anniversary or grandchild's first communion).

For palliative care planning it is therefore necessary to understand the patient's individual priorities and preferences, or at least to involve the patient in the care planning and ask them whether the proposed treatment plan fits their personal goals.

The values expressed by the patient and the decisions the patient derives from those values, for example to reject treatment measures, should be respected by the care team, even if they do not coincide with the team's own values or the optimal procedure from the medical point of view. Patients do have a right to make "irrational" decisions.

Patients also have the right not to come to a decision on the available treatment options, or at least not to want to make a decision right now. In this situation, the patient should not be pressed into making a decision, even if valuable time may be wasted from the point of view of the care team. Patients may feel ambivalent about upcoming decisions and may need more time to evaluate the pros and cons of each option. Care teams often find it hard to cope with ambivalence and prefer clear-cut decisions that lead to defined action pathways. However, the patient's preferences to not decide now should be respected and the decision postponed.

Overall, sufficient time should be allowed for discussions with patients and relatives, and the topics of discussion should be kept as open and broad as possible. Only then can patients also feel their way towards topics that are of great importance to them, but which they are only able or willing to bring up very cautiously in conversation.

E 38.1		Depression	Comment
01		[Doctor and medical student enter the room for the ward round, after greeting the student explains that the patient had just practiced on the bicycle ergometer before the ward round]	
02	P	What I've noticed now: I can cycle better than I can walk, being on my way.	Patient opens discussion
03	D	Yes, how is walking going at all?	Break / relevance in everyday life
04	P	Walking is fine. A very slight limp, I can demonstrate if you like.	
05	D	You don't have to now... but we can definitely / I'll just watch you when we meet in the corridor.	Focus: „Now ward round“
06	P	Yes, I'm hardly ever there.	Transition
07	D	[laughs]	Waiting
08	P	I avoid it a bit because I'm ... the depression strikes after all	Problem of the patient
09	D	...	Waiting
10	P	So I like to be there / I'm happy when I have the room to myself.	Eye contact from P to D
11	D	So why don't you want to go out into the corridor?	Query / interest
12	P	Depressed and then - I'd rather not meet or see others or have conversations	Problem theme
13	D	Is the depression easier to bear when you are here or does it not occur here at all?	
14	P	Yes, they do occur here too, but it's easier then. And what I've noticed is that I no longer have control over my lower jaw, saliva runs	Indicates with both index fingers the corners of the mouth and runs his

		out of the corner of my mouth here	fingers along the lower lip, swallows, wipes of lower jaw
15	D	I haven't even noticed that yet.	D follows flow of the discussion
16	P	So I always have to be careful...	
17	D	Hmm - that you don't drool.	
18	P	That I'm not drooling.	Patient repeats very softly
19	D	How does your depression manifest itself, Mr. X?	Query on fundamental problem
20	P	Yes, I think about my future, what I can still do and what I can no longer do,	
21	D	Hmm	
22	P	And how things will go on like this [uh] and how my wife will have to manage on her own	Eye contact from P to D

This is followed by a discussion about the thoughts (giving up hobbies such as mountain biking or canoeing) and burdening distress (loss of appetite, weight loss) that the patient is experiencing.

The consultation, which was originally very focused on the patient's physical condition, suddenly turns into an in-depth conversation about depression, grief and coping with the illness. The doctor first waited to see what the patient actually wanted to say (lines 7, 9 and 11) and then responded to the patient’s carefully probing responses. When he offers a withdrawal to the physical condition, she asks again about the depression, signaling genuine interest, so that the patient is then able to discuss the psychological problems.

38.4 Cultural setting and spirituality

Individual priorities and preferences are shaped not least by the patient's cultural background (§ 28). For example, the value of self-determination is often rated significantly lower in other than Western European or North American cultures. In a cultural setting in African or Asian countries, it is quite conceivable that decisions are made by relatives or family elders rather than by the patient. The patients themselves may well agree to this. In Africa, there is even a separate word for this collective form of decision-making: ubuntu.

However, even in these cultures it cannot always be assumed that the patient wishes to forego self-determined, informed decision-making in favor of extended decision-making by the family. Patients with a migration background can also adapt very quickly to the cultural framework of their new home country. In the second and third generation, corresponding values may have been internalized from childhood.

This can lead, for example, to a patient with a Turkish migration background whose wife (who has lived in Germany for 20 years but rarely leaves the house and hardly speaks German) prefers more traditional Turkish values, while the children (born and raised in Germany, visiting a German school, and with German friends) represent Western European values and norms, while the patient (who works for a large German company on the assembly line, with many German and Turkish work colleagues) oscillates between the two extremes. According to the differences in values, it may well be that three different communication goals and communication strategies have to be used with the people involved.

In general, therefore, it cannot be assumed that patients with a migration background and their relatives agree with the values explicitly or implicitly put forward by the healthcare team.

Just as with different cultural values, the physician may also be confronted with spiritual issues in discussions with the seriously ill or dying (Box 38.1).

Box 38.1 Discussion about near-death during ward round (palliative care ward, University Hospital Aachen)

During the ward round on the palliative care ward, I saw a postcard on a patient's bedside table with a picture by Hieronymus Bosch: "Ascent to the heavenly paradise", depicting a tunnel of light, similar to what is often described by people after a near-death experience. When I look at the picture, the husband says that this image is very comforting for the patient, as one knows from these depictions roughly what will happen when she dies. And he asks what I would think of that?

How do I deal with such a question as a doctor? Do I refer to the pastoral counselor as an expert for such issues? Or do I dare to give a personal answer and engage in a conversation about the patient's feelings, which resonate in the background with the husband’s question? In this case, this led indeed to a conversation about her fear of death, and the patient was able to ask questions about dying that she had not dared to ask before.

Unfortunately, doctors are now often only seen as experts for the body, both by the doctors themselves and by the patients they treat and their relatives. Patients only tell the doctor about their physical complaints and little else because they assume that the doctor does not want to hear anything else. Patients occasionally launch a trial balloon, a cautious question that goes beyond the physical dimension. If the doctor responds, the patient can feel their way forward and, as their confidence grows, address questions and problems beyond the purely somatic level.

This openness to issues outside the physical dimension is important - especially in crisis situations such as life-threatening illnesses - because it can make it easier to understand why a patient refuses or wants to demand certain treatment measures. Cultural and spiritual values and beliefs shape the ideas of what health or a dignified life are. In palliative medicine, for example, the idea of a "good death" is strongly influenced by one's own spiritual background.

The doctor must have at least a basic knowledge of cultural and spiritual aspects of palliative care in order to plan medical treatment appropriately. This includes, for example, rules and rituals from other cultures and religious communities. As a doctor, I must at least recognize special codes. During a visit to a palliative care unit in India, we discussed why the relatives were so angry after the death of a patient: they had asked repeatedly whether they should give the dying person a drink of water. With severe swallowing problems and the provision of good mouth care, the staff had answered in the negative. However, in this region it is an important Hindu custom to give a dying person water, so that he will not become thirsty on the way beyond. This is also used as a code between patients and relatives that it is now time to die. The negative response by the staff was therefore understood by the family to signify that death was still a long way off. The disappointment was all the greater when she died in the night.

In Islam, trust in the fate determined by God can lead to a fatalistic attitude (no matter what the patient decides, whether he lives or dies, only God decides, see Box 38.2). Certain rituals may be important for dying muslims. For example, the patient, sensing that the end is near, may say the Islamic creed but then choose not to speak anymore because no other words should pass his lips after the profession of faith. After death, a number of activities are needed, for example a ritual ablution (usually performed by a muslim undertaker). Sometimes the relatives do not want the deceased to be touched by non-Muslims, so that the nursing staff cannot even remove wound dressings or parenteral lines.

Box 38.2 Interview with Islamic nurse in West Africa (Hands-on-Care, Brikama, Gambia)

Nurse1: (The relatives) don't appreciate it when you tell them "This patient is going to die". It is actually not accepted in Islam because it is God who knows who will make it and who will not make it. You as an individual cannot say that this one is going to die. That is not accepted.
Interviewer: Yes, I've heard that before. So in Islam - this is difficult for me to understand - it's like this: No matter what examination findings or lab results you have, you are never certain, and only God can know?
Nurse1: Exactly. A chronic illness and dying are two different things. You treat someone who has been sick for so long that everyone is discouraged, and that person suddenly gets better and is walking around again. God has sickness at his command, and God has death at his command. Therefore, God decides who lives and who dies, not the doctors. This is the belief that all Muslims have. With all the findings, with all the vocabulary, with all the specialists, hold that up to them and they will say: that is rubbish.

Patients from other cultural backgrounds may also have traditional religions, often with a strong emphasis on magical thinking, instead of or in combination with a monotheistic religion (Box 38.3).

Box 38.3	Interview with an Islamic nurse in West Africa (Hands-on-Care, Bri-kama, Gambia)

Nurse 2: So when a patient is in the dying phase, in the terminal stage, it is better for people who are still conscious to go to the mosque and pray that it comes easily, gently and quickly. Others may hallucinate or reveal something from the past. And this is all associated with witchcraft. This person, this patient was involved in witchcraft. That is not good. It doesn't give a good name to the family you come from. Even if you die, others will hear that, and they will look at your family the same way, they will stigmatize them and also associate the rest of the family with witchcraft. So that's not good. As medical staff, when it happens in the hospital, we try to keep the patient safe. We send the family out of the room. They sit outside and wait. We all wait for God. (...) Whatever (the patient) says then, we will try to keep him safe, somewhere where nobody can hear him, and nobody can pass on what (the patient) has revealed.

The following "spiritual anamnesis" with the acronym HOPE can be used as a guide for everyday life (Table 38.2) (Anandarajah, Hight 2001, Okon 2005).

Sources of hope	What gives you hope (or strength or comfort or peace) in the time of illness?
Organized religion	Are you a part/member of religious or spiritual community? Does it help you? How?
Personal spirituality and practice	What aspects of your spiritual beliefs do you find most helpful and meaningful personally?
Effect on treatment and end of life issues	How do your beliefs affect the kind of medical care you would like me to provide over the next few days/weeks/months?

Tab. 38.2: HOPE guidance for communication on spirituality (Okon 2005)

38.5 Handling hope

Ideally, after providing appropriate information about diagnosis and prognosis, realistic treatment goals for the remaining life span can be defined together with the patient and all available treatment options can be considered according to the patient's priorities and preferences, but also according to the expected benefits and potential side effects and risks of the specific treatment options.

In communication with the patient and relatives, it is emphasized that the change to a palliative care goal does not mean that all hope must be abandoned, but that hope can now be found in realistic and achievable care goals, such as maintaining the highest possible quality of life for the remaining life span.

However, this ideal form of doctor-patient communication is not always possible. Some patients do not want to accept the sudden limitation of their lifespan due to a life-limiting diagnosis. According to the Kübler-Ross model (2001), this should not be seen as a lack of understanding, lack of discernment or unreasonableness, but as one kind of typical coping with the disease (stage of denial, refuse to acknowledge). The urgent demand for new chemotherapy or radiotherapy trials can be an expression of this coping style.

The attempt to switch to realistic palliative care goals is categorically rejected by patients and relatives in this situation ("Do you want to just let me die now?").

In this setting, decision making requires critically reflection on one's own motivation as a healthcare provider. Treatment options such as fourth or fifth-line chemotherapy should not be offered by doctors out of a sense of helplessness in the face of pressure from the patient or relatives. Treatment options should only be offered to the patient if they have a medical indication for this patient. The introduction of interdisciplinary tumor boards and the shift of decision making from individual oncologists to these boards has certainly contributed to alleviation of such pressure to act in healthcare teams.

When communicating with patients and relatives, it is particularly important to recognize and respect this great desire for curative treatment, as an expression of the will to survive, and to communicate this back to the patient. Patients certainly have a right to hold on to unrealistic hopes. In individual cases, it may make sense to discuss and even initiate therapeutic trials that the healthcare team considers to have little chances of success, if this can build a bridge of trust between healthcare team and patient, with the longer-term goal that later on uncomfortable decisions can be transported over this bridge.

A practical strategy for communicating with patients and relatives who are pinning their hopes on unrealistic treatment goals is to talk about "Plan B". In the discussion, the patient's hopes and goals are accepted, but then he is asked about his alternative Plan B ("But what will you do if this therapy is not possible / does not respond? Do you have a plan B?"). In most cases, the patient will be willing to talk and think about the potential alternatives for a short period of time. After a few minutes the doctor will then end the Plan B discussion looping back to the patient’s preferences ("But I understood that you actually had completely different hopes"). The conversation about Plan B can then be resumed later, in subsequent meetings.

38.6 Handling death wishes

Death wishes can be very different in nature, ranging from the acceptance of death from rapid progression of the disease to the maximum form of suicidal ideation. The explicitly expressed wish for assisted suicide is not rare in everyday clinical practice and represents a particular challenge and burden for the entire healthcare team (Nauck et al. 2014, Jansky et al. 2017).

In systematic literature reviews (Hudson et al. 2006, Borges et al. 2024), the most common reasons identified for the wish for hastened death were being a burden on others, loss of autonomy, physical symptoms, depression and hopelessness as well as existential anxiety and fear of the future.

Contrary to the idea that the wish for hastened death necessarily means a direct request for assisted suicide or euthanasia, these patients' wishes appear to have primarily multifaceted communicative functions (Stiel et al. 2010).

In our own study (Pestinger et al. 2015), it was not so much the patient's current suffering that was perceived as unbearable, but rather the suffering that was anticipated with further progression of the disease. The remaining lifetime is balanced against these anticipated images of suffering. Anticipated suffering causes anxiety and creates insecurity, while claiming control over the time of death creates security for the patient.

Patients want to be able to express their wishes and give voice to their thoughts. They want their thoughts and feelings to be accepted. However, by expressing their wish to die, they also implicitly raise the question of alternative ways of treating their suffering, e.g. with palliative care interventions.

The wish to die should not be seen as absolute and exclusive, but can certainly be an expression of ambivalence, in which two hopes - hope for an imminent end to life and hope for more life - exist side by side.

For our department, we have formulated six steps for communication about wishes for hastened death.

Adressing the issue	• Expression of suicidal thoughts or requests for assisted suicide should always be taken seriously. • Questions should be asked about the motives and the suffering behind the wish for hastened death. • If patients make allusions to a wish for hastened death or suicidal ideation, it can be helpful to clearly address the implied content ("Did I understand you correctly that you are thinking about suicide?").
Additional information	• What kind of wish for hastened death (acceptance of death, ending life-sustaining therapies, suicidal ideation) • Time dimension (general consideration, hypothetical plan if the situation becomes unbearable, concrete plan) • Most severe problem or symptom (“What is bothering you most?”)
Respecting the decision	• Acknowlegement of the patient's suffering and distress • Respecting the patient’s decision, even if it seems to be opposed to one’s own values
Offering alternatives	• Requests for assisted dying can be rejected, without abandoning the patient, if alternatives are being offered. • Anticipated suffering may be alleviated with information on palliative care, including options such as palliative sedation for refractory suffering. • Patients have a right to forgo or discontinue any sustaining therapy, including mechanical ventilation. • Voluntarily stopping eating and drinking is an option that does not require any assistance from other persons and can be controlled completely by the patient.

Building a trusting relationship	• A one-off discussion will not provide any change in the wish for hastened death. The first talk should thus only be the starting point of building a trusting relationship with the patient. • This should be expressed clearly to the patient („we will not leave you alone with this issue“) • Open issues at the end of the discussion have to be endured, for example when patients repeat their request for assisted dying.
Debriefing and reflection	• Talking to patients about wishes for hastened death can be challenging for healthcare professionals • Debriefing is necessary to reflect on the challenges and to alleviate distress • Ideally debriefing should be done before subsequent discussions with the patient • This can be done as informal discussions with team members, moral case deliberations, supervision or ethical consultations.

Tab. 38.3: Six steps for communication on wishes for hastened death
(Ethics Comitee of the University Hospital Bonn)

38.7 Communication with family members and significant others

In palliative care, communication with the patient's relatives sometimes seems more difficult than with the patients themselves. Dealing with aggressive relatives or relatives who constantly demand additional medical interventions for the patient, even if the patient does not want them anymore, may be challenging. Box 38.4 is a typical example of a spouse who wants to prevent the patient from being adequately informed in order to protect him from the burden of knowledge.

It is not easy for the palliative care physician to balance the options in this situation. On one hand, the patient is our primary partner in the treatment, and their needs (such as informed consent) are paramount. On the other hand, the spouse is part of the family system, which for most patients is their major resource for resilience, and supporting the needs of family members and significant others (even in bereavement) is itself part of the definition of palliative care (Radbruch et al. 2020.

Box 38.4 Case study from the palliative care ward

The doctor on the palliative care ward wants to see the patient with pancreatic cancer who has just been admitted. The patient's wife intercepts him at the door and tells him that he should not talk to the patient about the tumor disease or prognosis during the admission interview, as the patient knows nothing about it. He would not be able to cope with that knowledge.

One possible approach here, for example, would be reframing: not to understand the wife as an obstacle that needs to be overcome, but to respect her position and value her as an expert ("Thank you for this information. You've known your husband for a long time and I need to get to know him first, so this kind of information is very important to me"). The doctor could then address his dilemma that may arise from the wife's request ("I would like to do as you wish. But what do I do if your husband asks me directly to tell him honestly about diagnosis and prognosis. Then I can't lie to him!"). This may help to overcome the blockade of the spouse.

In other situations, such as conflicts among family members or between relatives and patients, structured family talks may be useful, with all relevant family members and significant others as well as several members of the healthcare team, and with the goal to consent a joint strategy for the patient’s further care.

38.8 Communication with team members

Communication with the dying is not only the responsibility of the doctor, but also involves other professions of the healthcare team. On a palliative care ward or in an inpatient hospice, this includes the nursing staff, social workers, psychologists, physiotherapists, spiritual caregivers, volunteers and possibly other professional groups such as dieticians. It is not uncommon for important topics to be discussed with the nurse in the morning while washing. Depending on the problem constellation, chaplains, social workers or psychologists can take on specific aspects of communication, but all staff must be willing to participate in open and trusting communication.

In specialized palliative care services (palliative care units, inpatient hospices, specialized outpatient palliative care teams (SAPV)), interdisciplinary team meetings are an essential part of the daily routine. During the meeting, information is gathered from the perspective of the various professions and treatment is planned jointly. In particular, discussing stressful situations in the meeting can provide important relief for individual team members.

In some cases, conflicts may come up in the team when discussing the optimal treatment plan. In such cases, it is often helpful to clarify the values of the individual conflicting parties behind the point at issue. Conflicts can thus also be used to clarify and perhaps also develop the shared values in the team, and do not just have to be seen as an evil to be avoided.

38.9 Conclusions

There are many difficult situations when communicating with the severely ill and dying, from communicating the diagnosis and prognosis to conflicts with relatives and the wishes for hastened death. Doctors need solid basic training for these situations. In Germany, palliative medicine has been a compulsory subject in medical studies since 2009 and has been implemented at all universities. At our own university, communication training includes simulated patients in role plays, with one medical student in the role of the doctor, a further 5-6 students as observers and a member of staff from clinical practice as a moderator. The positive feedback from the students confirms the effectiveness of such role plays.

Similarly, many places offer communication seminars for doctors on this topic. Such communication training is at least as important for the implementation of palliative care as sufficient knowledge of medications for pain and symptom control.

However, in clinical practice the implementation of learned skills can be difficult because there is not enough space or time. Talking medicine needs better reimbursement, because only then will good communication with dying patients and their relatives be possible across the board in all out- und inpatient settings as the basis for appropriate palliative care.

Further information on communication with the seriously ill and dying, as well as on symptom control and other aspects of palliative care, can be found in the S3 guideline on palliative medicine in the oncological guidelines program of the Association of Scientific Medical Societies and in the textbook on palliative medicine (Aulbert, Nauck and Radbruch (eds.), Schattauer Verlag, 3rd edition 2011, Deutsche Gesellschaft für Palliativmedizin 2019).

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Further references on doctor-patient communication can be found in other topic-specific chapters and in the complete bibliography of the handbook.

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