

## Communication challenges in end-of-life decisions

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### Summary

With the progress in healthcare over recent decades and a growing life expectancy, discussions and decisions regarding end-of-life issues have become increasingly important. Especially in intensive care and emergency medicine there is a growing need of decision making for optimised end-of-life care. Prolonging life and preventing death is considered to be the highest principle of healthcare professionals; however, in some cases alleviation of suffering is a more appropriate goal. This article discusses communication challenges in end-of-life decision making and outlines strategies from an area of growing interest and research.

**Keywords:** end-of-life, medical futility, advance care planning, breaking bad news

### Introduction

With the progress in healthcare over recent decades and a growing life expectancy, discussions and decisions regarding end-of-life (EOL) issues have become increasingly important. Especially in intensive care and emergency medicine there is a growing need of decision making for optimised EOL care [1].

Prolonging life and preventing death is considered to be the highest principle of healthcare professionals, however, in some cases alleviation of suffering is a more appropriate goal.

This article discusses communication challenges in EOL decision making and outlines strategies from an area of growing interest and research.

### Discussion of end-of-life aspects with patients – with good communication skills

To assess patients' goals of care and establish a corresponding treatment, discussions with patients or their caregivers are essential. Still, in many patients with palliative diseases (e.g., metastatic cancer or neurodegenerative disorders), in which the relief of suffering is the primary goal of care, EOL discussions do not occur [2, 3]. The reasons for this are manifold. First, communication in the EOL setting is often perceived as a challenge as physicians frequently

have to talk about conditions for which prognoses or outcome are uncertain [4]. Difficulties may arise if patients' understanding of the disease is unrealistic or confidence in treatment is too optimistic [5, 6].

Another barrier which hampers EOL discussions is the physician's concern about a negative impact on patients' or caregivers' emotional well-being, such as giving up hope [7]. However, studies have shown that addressing patients' preferences and goals of care in EOL discussions are associated with greater satisfaction with communication and decision making [2]. Also, talking about prognosis and death is not necessarily perceived as stressful [2, 8]. A lack of communication skills constitutes a barrier for EOL conversations, with many physicians feeling unprepared or inexperienced [9, 10]. Communication training for physicians is often inadequate or simply not available [11, 12].

Especially in intensive care unit (ICU) or emergency settings, EOL discussions are often in conflict with busy daily routine and time constraints, impeding the chance to discuss patients' values and needs [13–16]. A recent study from Basel found that treating physicians significantly altered patient choices regarding their preferred care in the case of a cardiac arrest, raising the question of patient autonomy [17].

Breaking bad news (BBN) to a patient or patient's relatives represents an important but challenging task for physicians. It may change a patient's life and view of their future, as bad news in EOL situations is most often the disclosure of incurable diseases, palliative treatment or the fact that patients may not return to their life at home but require advanced care.

To convey the bad news, healthcare professionals should make arrangements such as choosing an appropriate room or the avoidance of interruptions. Research has shown that patients prefer to receive bad news in person with enough time for questions [18]. The request for the optimal amount of information however may vary by age, health literacy or among different cultures. Hence, it is important for BBN discussions to ascertain patients' individual preferences. Proficient delivery with the help of specific communication strategies such as BAD can reduce patients' or relatives' burden. BAD is an acronym, standing for "Break bad news", "Acknowledge the reaction" and "Discuss the near

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future". Developed in the area of oncology research alongside SPIKES (Setting up the interview, Assessing the patient's perception, Obtaining the patient's invitation, Giving knowledge and information to the patient, Addressing the patient's emotions with empathic responses, Strategy and summary) [19], BAD is regarded as one of the most established communication strategies for BBN today. Table 1 illustrates the different steps of the BAD strategy.

The BAD strategy, as well as SPIKES, focusses on patients' emotions evoked by the bad news. To address these emotions, physicians may use patient-centred communication techniques summarised in the acronym NURSE (naming, understanding, respecting, supporting and exploring). During BBN, naming and/or mirroring patients' emotions as well as understanding statements are especially helpful tools to show compassion towards the patient (table 1). Research has shown that in BBN conversations emotional opportunities are often missed [20]. However, addressing emotions may improve patients' or relatives' long-term adjustment to the bad news and its consequences.

Although sometimes done with good intentions, physicians should avoid premature reassurances (e.g., "It is not that bad...", "Everything is going to be fine") [21, 22]. First, if patients' emotions are not addressed adequately, premature reassurance may be perceived by patients as not respecting their worries and fears. Also, the prognosis of a patient's disease is sometimes difficult to predict and, thus, "premature reassurance" can be perceived as misleading information in the event of deterioration.

**Table 1:** BAD and NURSE communication strategies for the disclosure of bad news.

<b>BAD</b>
<b>Break bad news</b>
Do I have all the necessary information? (e.g., medical results, circumstances in which the patient was brought to hospital)
What kind of information does the patient already have (e.g., already informed about diagnoses? Does the patient know the purpose of the conversation?)
Announcement of bad news with a "warning shot" (e.g., "I am afraid, I do not have good news for you..." or "I am sorry, but I have to inform you...")
KISS – "Keep it short and simple", concise wording of news (e.g., "we have found malignant cells in your biopsy, which means that you have cancer"; "your father has died")
<b>Acknowledge the reaction</b>
Wait (at least three seconds; maintain eye contact)
Address patient's emotions (NURSE, see below)
Avoid premature reassurance (e.g., "everything is going to be okay")
Respond to patient's questions
<b>Discuss the near future</b>
Give information that the patient requires now
What are the concrete next steps?
Amend bad news with good news (if possible)
Make follow-up appointment
<b>NURSE</b>
Naming (e.g., "this must come as a shock...", "I have the impression that...")
Understanding (e.g., "this is absolutely understandable...", "I have no idea, how sad this must be for you")
Respecting (e.g., "I admire that you are so active despite your illness")
Supporting (e.g., "Do you need any information/help?", "here is my phone number, in case you have further questions")
Exploring (e.g., "I wonder what you are thinking about...", "would you like to tell me what you are thinking about...?")

At the end of a BBN conversation, physicians should inform the patient or relative about the next steps. Often, it is advisable to make a follow-up appointment to discuss more detailed treatment plans, as patients' capacity to absorb information is limited after the disclosure of bad news.

Over past decades, the use of intensive care at the end of life has increased steadily. Especially in the case of EOL decisions, such as withdrawal of therapy, relatives experience a high amount of psychological stress, which can affect their well-being. Studies report that up to two third of relatives of patients dying in the ICU show psychological sequelae such as depression, anxiety, complicated grief or post-traumatic stress disorder [23–27].

A study by Lautrette et al. has shown that proactive communication can reduce the risk of developing depression or symptoms of a post-traumatic stress disorder in relatives of ICU patients [28]. The study used a structured communication strategy summarised by the mnemonic VALUE (table 2). This strategy recommends to value and appreciate statements of family members, acknowledge their emotions, as well as to listen and ask questions to understand who the patient was as a person. These steps help the physician to adopt an empathic attitude and to build rapport with the family members during an EOL discussion. Eliciting questions enables physicians to engage family members in the discussion, help them to voice concerns and clear up misconceptions.

The VALUE communication strategy led to EOL conversations in which caregivers had more opportunities to voice concerns and emotions. Also, caregivers were more likely to agree to realistic goals of care, experienced less decisional conflict and, most importantly, experienced less psychological burden.

In conclusion, with a growing need of EOL care, communication with dying patients or their relatives will become increasingly important as a core competence for all caregivers. Today, most people die in hospitals even though the majority of patients would prefer to spend their final days at home [31]. This highlights the need for training in communication skills in EOL settings to help explore and respect patients' preferences in these crucial situations and to make medically meaningful but also patient-centred decisions.

## Advance care planning

Patient autonomy and participation in EOL decision-making are valued as high quality of care [32]. Therefore, the awareness of patients' preferences regarding future medical treatments should be a central element of care for patients, especially in patients with advanced illness. A timely initiation of advance care planning (ACP) gives patients

**Table 2:** The VALUE communication strategy.

<b>VALUE</b>
Value and appreciate family statements
Acknowledge family emotions
Listen to the family and ask questions
Understand patient as a person
Elicit family questions

Adapted from Curtis [29, 30]

the opportunity to receive their preferred care early on [33]. General practitioners are often in the unique position of having a long-term relationship with their patients and relatives, which constitute a good basis for the early start of ACP [34]. Still, the occurrence of ACP in the general practice setting remains low [35, 36].

If a patient's preference is unknown or a patient is not able to express his or her treatment preference, the patient's next of kin often act as surrogate decision-makers, potentially increasing their emotional burden.

Advanced directives (AD), as a set of instructions, may convey a patient's wishes to family members and/or healthcare professionals [37]. ADs may also designate a patient's next of kin as surrogate decision-makers in case the patient is incapacitated. Recent surveys showed that about 28% of the Swiss population above 55 years of age had completed an AD [3, 38]. However, many advanced directives only focus on specific intensive care treatments such as cardiopulmonary resuscitation or intubation, and do not properly address other components of care. Also, ADs often do not provide enough clarity about the goals of care, limiting their usability in clinical settings [39, 40]. ACP was originally developed to overcome such shortcomings by allowing patients to state preferences of care and to document potential treatment plans pre-emptively [33, 41].

Literature has shown that ACP not only improves care towards the end of life, but also reduces stress and depression in surviving relatives and helps physicians make end-of-life decisions in accordance with patients' preferences [33]. Over past years, different treatment plans have emerged, such as Physician Orders for Scope of Treatment (POLST), Medical Orders for Scope of Treatment (MOLST) or Recommended Summary Plan for Emergency Care and Treatment (ReSPECT), which combine discussions about resuscitation with other goals of emergency care [42, 43].

To facilitate such ACP discussions, physicians may use decision aids. Decision aids are tools that illustrate medical information and provide a better understanding for lay people. Patients with a low health literacy and difficulties in processing medical information especially benefit from these interventions, enabling them to participate in the decision-making regarding their own care. Recent research has shown that decision aids increase patient knowledge and reduce patients' decisional conflicts, as patients show higher clarity about which goals of care are the most important to them [44, 45]. For example, videos explaining the nature and outcome of cardiac arrests have been used to increase patient knowledge and were associated with patients' preferences towards less invasive treatments in the event of clinical deterioration [46]. A variety of other examples of decision aids are listed in the decision aid inventory of the Ottawa Hospital Research Institute. Table 3 presents a selection of decision aids targeting end-of-life decisions.

### Medical futility

As a result of a considerable increase in medical interventions available to patients over past decades, physicians

regularly encounter situations in which a treatment is considered medically futile for a specific patient. A recent study on patients in the ICU found that more than 10% of patients received treatment perceived as futile by their treating clinicians [47]. In the context of EOL care, medical futility often refers to interventions that might prolong life, but in which the chance of a benefit for the patient is extremely small and by far outweighed by the potential risks, harms and suffering [47–49]. Such situations are challenging for clinicians and the clinical team, who know the potential burden and distress resulting from a futile intervention for patients and relatives [50, 51]. Several factors contribute to the difficulty in decision making in such situations. First, although physicians may agree to the overall concept of medical futility, this concept is difficult to apply in clinical practice, as the clinical course of the illness and the outcome of interventions are sometimes difficult to foresee [52–54]. This is particularly true for EOL care. Second, judgment of futility is often based on a clinical impression [50]. This incorporates objective medical data from the patient history and subjective data from patient's currently perceived and future expected quality of life, as well as potential benefits and harm associated with the treatment [55–57]. Interpretation of these different variables may contribute to the ambiguity regarding futility for an individual patient [53, 54]. Disclosing that a specific treatment is considered futile and that EOL should be adapted accordingly can be challenging [56]. Even though patients and physicians may agree on the overall treatment goals, an overestimation of the chance of positive outcomes due to misconceptions and lack of knowledge on the patients' side contributes to difficulties in reaching consensus on a specific treatment.

Cardiopulmonary resuscitation (CPR) for in-hospital cardiac arrests is one of the treatments in which medical futility is important to consider [58]. CPR was originally developed to resuscitate healthy patients who suffered from a sudden cardiac arrest. Nowadays, however, CPR is commonly offered to all patients as an intervention, regardless of the underlying reason for the cardiac arrest. Prognosis of in-hospital cardiac arrest (IHCA) is poor, with a survival rate of less than 20% [59]. Further, many IHCA survivors are dependent on long-term care or suffer from permanent brain injury after CPR [60]. For about two decades, the Pre-arrest Morbidity (PAM) index [61] and Prognosis after Resuscitation (PAR) score [62] were the most commonly used clinical risk scores to evaluate prognosis after CPR for IHCA. Although these scores did show sufficient validity in several studies [58, 61, 63], optimal cut-off values differed depending on clinical and sociodemographic characteristics of the respective patient population [64]. Recently, the Good Outcome Following Attempted Resuscitation (GO-FAR) score has been developed and validated in large samples of patients [65–69]. Also, a modified version has been proposed: The Prediction of Outcome for In-Hospital Cardiac Arrest (PIHCA) score [70]. These scores incorporate clinical conditions that are associated with poor outcome such as metastatic cancer, advanced renal failure or sepsis. The authors developed a multivariate prediction model based on a meta-analysis including patients who suffered from an in-hospital cardiac arrest and calculated cut-off scores suggesting the chance of neurologically intact survival, such as “very low” (0.9% of pa-

**Table 3:** Collection of decision aids for end-of-life decisions.

Title	Author/developer	Year	Health condition / topic	Type	Content	Language	Link
A Decision Aid to Prepare Patients and Their Families For Shared Decision-Making About Cardio-Pulmonary Resuscitation (CPR)	Jennifer Kryworuchko	2012	Cardiopulmonary resuscitation	Video	Video explaining cardiac arrest and cardiopulmonary resuscitation and its prognosis	English	<a href="https://vimeo.com">https://vimeo.com</a> <a href="https://decisionaid.ohri.ca">https://decisionaid.ohri.ca</a>
Cardiopulmonary resuscitation: a decision aid for patients and their families	Chris Frank	2009	Cardiopulmonary resuscitation	Written material	Giving information about Cardiopulmonary resuscitation / life support and its outcome giving information regarding advanced directives	English	<a href="https://thecarenet.ca/">https://thecarenet.ca/</a> <a href="https://decisionaid.ohri.ca">https://decisionaid.ohri.ca</a>
Advance Care Planning: Should I Receive CPR and Life Support?	Healthwise	2016	Cardiopulmonary resuscitation End of life issues	Written material	Giving information about cardiopulmonary resuscitation / life support and its outcome giving information regarding DNR orders	English	<a href="https://decisionaid.ohri.ca">https://decisionaid.ohri.ca</a>
Autopsy: Should I have an autopsy done on my loved one?	Healthwise	2016	Autopsy of next of kin after death	Written material	Giving information about autopsy (indications and considerations)	English	<a href="https://decisionaid.ohri.ca">https://decisionaid.ohri.ca</a>
Understanding the Options: Planning care for critically ill patients in the Intensive Care Unit.	Jennifer Kryworuchko	2015	Life prolonging / palliative care	Written material	Information/considerations about life prolonging / palliative care; scaling questions to determine patient's preferences and goals of care	English	<a href="https://decisionaid.ohri.ca">https://decisionaid.ohri.ca</a>
Advance Care Planning: Should I stop treatment that prolongs my life?	Healthwise	2016	Life prolonging / palliative care	Written material	Giving information about life prolonging and palliative care, considerations	English	<a href="https://decisionaid.ohri.ca">https://decisionaid.ohri.ca</a>
Advance Care Planning: Should I have artificial hydration and nutrition	Healthwise	2016	Artificial Hydration and Nutrition	Written material	Giving information regarding hydration/ nutrition explaining advantages and disadvantages of artificial hydration/ nutrition	English	<a href="https://decisionaid.ohri.ca">https://decisionaid.ohri.ca</a>
Advance Care Planning: Should I stop kidney dialysis?	Healthwise	2016	Chronic kidney failure / Dialysis	Written material	Giving information about dialysis, explaining advantages/disadvantages of stopping dialysis	English	<a href="https://decisionaid.ohri.ca">https://decisionaid.ohri.ca</a>
Kidney Failure: Should I Start Dialysis?	Healthwise	2016	Chronic kidney failure / dialysis	Written material	Giving information about chronic kidney failure and dialysis	English	<a href="https://decisionaid.ohri.ca">https://decisionaid.ohri.ca</a>
Breathing with a Ventilator: Stop or Stay On?	EBSCO Health	2019	Patients dependent on a ventilator	Written material	Information about staying or removing from a ventilator (advantages and risks)	English	<a href="https://decisionaid.ohri.ca">https://decisionaid.ohri.ca</a>
When you need extra care, should you receive it at home or in a facility?	Mary Ann Murray	2010	Patients dependent on care	Written material	Information about care at home vs. in a facility; scaling questions to determine patient's preferences	English	<a href="https://decisionaid.ohri.ca">https://decisionaid.ohri.ca</a>
Prepare for your care	The Regents of the University of California	2020	Advance directive	Website	Interactive website offering information regarding end-of-life decision making	English	
Entscheidungshilfe Herz-Lungen-Wiederbelebung	Advance care planning medizinisch begleitet ®	2017	Cardiopulmonary resuscitation	Written material	Information about cardiac arrest / cardiopulmonary resuscitation; Cates plot illustrating risk of death / hypoxic encephalopathy	German	<a href="https://www.pallnetz.ch">https://www.pallnetz.ch</a>

DNR = do-not-resuscitate

tients have a good neurological outcome), “low” (1.7%), “average” (9.4%) and “above average” (27.5%) (the GOFAR score can be accessed under <https://www.gofar-calc.com/>). For patients with a very low and low chance of functional survival CPR attempts may be considered futile [48].

Both scores show promising predictive values regarding implementation in clinical practice.

Especially in cases of uncertainty, these clinical risk scores may be a useful additional tool for physicians to assess medical futility, foster decision making in EOL, and to facilitate conversations with patients and their next of kin. This could further support patients and their next of kin in making informed EOL decisions aligned with their personal values and treatment goals.

## Conclusion

With an aging society, decision making and adequate communication in EOL decisions are becoming increasingly important. Incorporating individuals’ needs and preferences is crucial. Although there are potential barriers to conducting EOL discussions, it is worth taking the time and effort to optimise EOL conversations. Proactive communication can not only ease patients’ and relatives’ psychological burden but can also prevent them from developing long-term mental health issues.

## Disclosure statement

No financial support and no other potential conflict of interest relevant to this article was reported.

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