



Educational aims

- To understand the importance of discussing end-of-life care preferences with your patients at the appropriate time.
- To become aware of the possible interfering factors of timing, reserve and hope in talking about end-of-life care.

Key points

- Using the Surprise Question may be a useful tool in determining the appropriate moment to discuss this with your patients.
- By talking with your patients about end-of-life care in a timely manner, unnecessary and unwanted treatment can be prevented.
- Constraints of doctors to implement this in their practice can be overcome by implementing a training session as described in this article.
- Collaboration between primary and secondary care on this issue is strongly recommended in order to assure the care continuum maximally.



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Talking about end-of-life care in a timely manner

In 2014, a group of physicians of the Catharina Hospital in Eindhoven (The Netherlands) started a project called “Talking about end-of-life care in a timely manner”. Just like others in the country, the Eindhoven group noticed that regularly, very frail elderly people were admitted to hospital in acute situations without there ever having been conversations about their wishes concerning treatment options at the end of life. The project aimed to prevent unnecessary admissions and treatments for these frail patients by stimulating physicians, patients and informal caregivers to start conversations about end-of-life care together at an earlier stage. The first phase of the project consisted of research: a study of the relevant literature on previous projects on the matter and a small empirical study in the Eindhoven region. This yielded as the most important causes of the delay of these conversations: the factors of timing (when is the right moment?), reserve (because of the potential emotional despair of the patient) and hope (who am I to rob a patient of their hope?).

In the second phase of the project, several approaches were developed to help caregivers, patients and informal caregivers with the planning and execution of conversations about end-of-life care. Meetings were organised for patients and informal caregivers to foster awareness and to provide information. For caregivers, information was provided (*via* symposia and an app) and specifically designed training sessions were developed. The training sessions consist of reflection on the caregivers’ personal choices with regard to end-of-life care (research has shown that caregivers choose less intensive medical treatments at the end of life) and of practising with the known complicating factors of timing, reserve and hope, and the different ways of thinking and talking about death and dying (typology of death and dying).



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How to prevent unnecessary and unintended life-prolonging intensive treatments and intensive care unit admissions <http://ow.ly/nzb130gktnC>

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As medical professionals, to help and cure our patients is our greatest passion. Fortunately, in contrast to a century ago, we now live in an era where medical science has contributed much to treatment options and has improved the prognosis of many diseases greatly. This is, for example, also reflected in many television series around the world where doctors are depicted as heroes saving

patients from virtually every life-threatening illness. This undoubtedly enforces the public’s belief in the possibilities of medical science to cure many diseases. It also responds to a feeling most people around the world have, that one’s health is one of the most important possessions an individual can have.

Nevertheless, we all know that the only certainty when we are born is that we eventually will die too.



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Setting the scene with a real-life case

A 62-year-old male with chronic obstructive pulmonary disease (COPD) of Global Initiative in Chronic Obstructive Lung Disease stage III (forced expiratory volume in 1 s 32% of predicted value) is brought to your emergency department at 02:30 h on a Sunday because of shortness of breath and drowsiness. On admission, he appears subconscious, reacting only to administration of pain stimuli. His blood pressure is 130/85 mmHg, and his pulse rate is 136 beats per min and irregular. His breathing pattern is shallow with a frequency of 10 breaths per min. His central venous pressure is elevated. Auscultation of the chest reveals very soft vesicular breathing sounds, with an enlarged expiration and diffuse wheezing. Normal cardiac tones are heard with no murmurs. Furthermore, he has extensive peripheral oedema. His physical examination is otherwise normal. The results of additional examinations are shown in table 1.

The patient has previously been seen by your colleague in the out-patient pulmonary department of your hospital. He has known the patient for >10 years due to his COPD. During the last 2 years, he developed chronic respiratory failure and he has had three periods of exacerbations of his COPD, treated with oral corticosteroids and antibiotics with acceptable results. His regular medication consists of long-acting β_2 -agonists and long-acting anticholinergic agents together with high-dose inhaled corticosteroids and 10 mg oral prednisolone. Furthermore, he is on long-term oxygen therapy (flow 1.0 L O₂ per min).

A medical history reveals coronary artery bypass surgery 5 years ago because of unstable angina pectoris. Since his operation, the patient has not had any complaints of angina. Furthermore, he was diagnosed with osteoporosis with spontaneous vertebral fractures 2 years ago for which he uses painkillers and osteoporosis medication.

It is concluded that this patient has a severe exacerbation of his COPD with acute-on-chronic respiratory insufficiency. You wonder whether or not this patient should be intubated. What do you do?

Table 1 Additional examinations

Laboratory results	Hb 11.0 mmol·L ⁻¹ Ht 0.58 Leukocytes 11.0 per nL CRP <6 mg·L ⁻¹ Na ⁺ 136 mmol·L ⁻¹ K ⁺ 3.8 mmol·L ⁻¹ Urea 14.0 mmol·L ⁻¹ Creatinine 120 μ mol·L ⁻¹ Glucose 6.0 mmol·L ⁻¹
Arterial blood gas analysis	pH 7.05 P _{CO₂} 86 mm Hg BE +10 mmol·L ⁻¹ P _{O₂} 41 mmHg SaO ₂ 76%
Chest radiography	Overinflation No cardiac enlargement No infiltrates Otherwise, no abnormalities
ECG	Atrial fibrillation Ventricular frequency of 115 per min, right axis Some ST depression in II, III and aVF No Qs Otherwise, no abnormalities

Hb: haemoglobin; Ht: haematocrit; CRP: C-reactive protein; P_{CO₂}: carbon dioxide tension; BE: base excess; P_{O₂}: oxygen tension; SaO₂: arterial oxygen saturation.

Furthermore, the possibilities of medical treatment are certainly not unlimited and most often also come with sometimes serious side-effects. This sometimes confronts doctors and their patients with difficult questions, especially in those cases where the end of the patient's life is approaching.

- Is continuing treatment or starting a new treatment wise?
- Do the possible benefits outweigh the harm for this patient in this situation?
- What is the present and expected quality of life?
- Is this still worthwhile for this patient?

These are all very important questions that are difficult to address for patients and their doctors, and which are therefore often neglected or avoided [1–3]. This might result in continuation of treatments and, in the worst possible cases, unnecessary prolongation of the suffering and dying process of

patients, which is what we, as doctors, having sworn the Hippocratic oath that begins with the statement that we should not do harm to our patients, should strive to prevent. However, in real daily life, we and others have experienced that talking about end-of-life issues in a timely matter with our patients is often neglected. Therefore, we have brought together a group of medical doctors from primary and secondary care, and representatives from patient organisations, to address and tackle this problem. In this article, after setting the scene by presenting a case report, we want to report the results from the Eindhoven group.

Origin of the project: talking about end-of-life care

In 2014, the Catharina Hospital in Eindhoven, a large teaching hospital in the south of the Netherlands,

started a project to make an inventory of cases similar to the one presented in this article, as well as to analyse these cases. Often, they concern frail elderly patients with chronic illnesses or infirmities who present to the emergency department in acute situations. A commonality of these cases concerns the fact that the issue of end-of-life care has not been dealt with or was started too late in the process. Questions concerning the kind of medical care the patient would like to receive in the end stages of the illness or what view they have on the final moments of their life or the kind of wishes they have been addressed too late (or even not at all) in such cases.

A group of physicians, consisting of doctors specialised in treating chronic patients, general practitioners (GPs), pulmonologists, cardiologists, nephrologists and geriatric physicians, as well as a clinical ethicist, referred to as the Eindhoven group in this article, has decided to work together to address this problem. The issue has been acknowledged by local professionals as well as the Dutch Royal Society of Medicine (KNMG). A poll conducted by the KNMG in 2012 showed that 67% of respondents (all members of the KNMG) support the claim that doctors continue to treat patients and do not address the subject of end-of-life care. A second poll found that 57% of respondents (all GPs) admitted they were afraid to talk about end-of-life care with their patients [2]. The respondents acknowledge the importance of addressing end-of-life care but seem to have a certain reserve in talking about it with their patients. Doctors delay the moment to talk about end-of-life care until the (acute) situations arise such as in the case presented above.

Other factors that are mentioned by respondents were: the time it takes to address end-of-life care and the advancement of technological medical possibilities (should every treatment that is possible also be offered?); the high expectations of modern patients of the capabilities of modern medicine, which is also actively promoted by medical institutes, such as the 2015 exhibition of the Royal Society entitled “Beating Cancer” (<http://sse.royalsociety.org/2015/ beating-cancer>); and the prevalent outlook on life of “never giving up”, visible in the campaigns of several cancer organisations such as the Dutch campaign of the KWF to ride a bike up a mountain to collect money for research on cancer, which uses the slogan “Quitting is not an option” (<https://www.kwf.nl/helpjijons/fietsen/Pages/Alpe-d%27HuZes.aspx>).

Similar to the previously mentioned polls conducted throughout the Netherlands, the Eindhoven group also conducted a small qualitative poll amongst doctors in the region of Eindhoven [4]. This yielded similar results: findings included that doctors struggle with timing, and that reserve and not wanting to rob the patient of their hope were important factors in the delay of the conversation about end-of-life care. Timing refers not only to the logistical problems that are caused by a delayed consultation because of an upset patient but also

to the psychological aspect: when is the patient ready for a conversation about end-of-life care? What is the right time? In addition to the aspect of reserve, as in the reserve and caution towards the emotional upsetting of the patient, it was found that the aspect of hope was also problematic; doctors wondered “who am I to rob the patient of their hope?”.

Starting the project

On the basis of these findings, the Eindhoven group developed several ways to tackle the issue. Each had different target audiences, ranging from healthcare professionals (focussing on doctors first) to patients and informal caregivers. The desired effects of these different approaches ranged from establishing an initial awareness of the problem in all the target audiences by providing adequate information, to practising conversational skills in training sessions for healthcare providers. In the next paragraph, we will briefly describe the different approaches and further on dwell on several aspects of the training sessions for healthcare providers.

In order to establish awareness of the issue with healthcare providers as well as patients and informal caregivers, the Eindhoven group developed different approaches for each target audience. Meetings are held for patients and informal caregivers to provide information on end-of-life care and to urge patients and caregivers to address the issue of end-of-life care with their doctors in time. Information is also provided on the benefits of addressing end-of-life care in a timely manner: to prevent unwanted and/or unnecessary care which can potentially result in negative effects for all concerned, such as regret. The meetings also provide the patients and informal caregivers the opportunity to ask questions on issues they are concerned about, such as “do not resuscitate”, euthanasia and the value of living wills. For healthcare providers, an annual symposium is organised that deals with different aspects of the issue, and which is also used to present the Eindhoven group and their work. In addition, guidelines have been created for healthcare providers ranging from GPs to consultants on how to talk about end-of-life care and when. These guidelines consist of agreements made between GPs and consultants on how to deal with end-of-life care and how to work together on this. This called for the use of ICT (information and communication technology) in order to make it possible for all healthcare providers treating the patient to be able to see the agreements made by the patient and a specific healthcare provider at any moment. The guidelines are also present on an app that has been created, which also provides information on the most prevalent obstacles in talking about end-of-life care. Starting points provided in the app include:

- the so-called Surprise Question (as the patient’s doctor, would you be surprised if this patient died

- in the next year? If not, it might be time to talk about end-of-life care)
- medical indicators of overall health
 - medical indicators for specific conditions, such as heart and pulmonary conditions, oncological diagnoses and neurological disorders, and dementia

Last but not least, training sessions have been developed for healthcare providers with the goal of not only creating awareness of the issue but also providing practical tips on how to communicate about end-of-life care. Healthcare providers suffer from reserve in talking about end-of-life care, which indicates that there is a psychological barrier that needs to be overcome [1, 2]. The participants of the training sessions are consultants as well as junior doctors and GPs, and we aim to bring together doctors from both hospitals and primary care practices. This has been a specific aim from the start because of the difficulty of transferring information between hospitals and primary care practices. GPs often lose sight of their patients when they are admitted to hospital for prolonged periods of time and would like to be informed on their patients' welfare during a hospital stay, and consultants benefit from the insight of GPs on how the patient copes with their illness in daily life and their outlook on life. The training sessions deal with issues such as reserve ("reserve" in this context includes the discomfort associated with talking about end-of-life care that brings about the hesitation to address the issue), hope, cooperation and ways of dealing with death. In the following sections, we will dwell on these different aspects: reserve and hope, because these indicate a psychological barrier of the healthcare provider in talking about end-of-life care; and ways of dealing with death, because these provide insights in how to adjust to the specific ways of thinking and communicating of the individual patient.

Reserve

It is often difficult to pinpoint the moment to talk about end-of-life care from a medical perspective, especially when the patient's health is deteriorating slowly. However, most participants of the training sessions indicated that they were able to find the right moment. One of the possible moments is after a patient's recent hospital stay. Besides concerns of delaying the consultation hour, doctors appear to be more daunted by emotional aspects: the expectations of the patient and especially their fear of what may happen. This is a genuine concern: talking about end-of-life care too soon may trigger this fear and may unnecessarily upset the patient. This unwanted possible outcome is what brings about the reserve in doctors, which is supported by the results of the polls mentioned previously. In addition, the

outlook on life shared by many patients about "not giving up" and the vast medical-technological possibilities, together make it hard to break through this psychological barrier of reserve and the fear of robbing the patient of their hope. These factors also contribute to the decision of many doctors to grant patients the treatment options they wish for, even when they would not choose these treatments for themselves. Research in the USA [5, 6] already suggested this, and this has been confirmed by recent Dutch research: doctors choose different treatments for themselves than for their patients [7]. This also applies to nurses. The study by Matlock *et al.* [6] study revealed that there also appears to be a difference between doctors' preferences when they are healthy and their actual choices when ill, so the difference between doctors' and patients' choices in end-of-life care concerns their preferences when healthy. This difference in preferences when healthy is confirmed in the Dutch study by Van Dijk *et al.* [7].

Analysis

These findings provide a useful starting point in reflecting on this pattern and to think about the way in which doctors act.

- Why do doctors make very different treatment decisions than patients?
- Why do doctors refuse intensive medical treatments at the end of life more often than patients?

These questions are asked of the participants in training sessions not only in order to get them thinking about their own preferences but also to get to their underlying beliefs and convictions. An important part of the training sessions is articulating and challenging these underlying beliefs and convictions, by analysing them, and looking at the assumptions and effects they bring about.

This analysis reveals that these beliefs and convictions are not personal but shared across the whole medical profession. They are integrated, prevailing convictions on what constitutes good medical practice, and are built on the concepts of central values such as autonomy and self-determination. These beliefs and values are obtained during medical training [8]. One of the answers provided by participants of the training sessions on why healthcare providers choose different treatment options from patients is that healthcare providers have more experience with the outcome of intensive treatments for vulnerable patients. They have intimate knowledge of the possible side-effects. For instance, they are aware of the outcome measures of resuscitations. When asked for an explanation of this difference between healthcare providers and patients, and the role of the personal

experiences of the healthcare providers, the participants of the training sessions mention the fundamental beliefs regarding self-determination, autonomy and the like. This exposes the way in which these fundamental beliefs are perceived by the participants: autonomy and self-determination are seen as the basis for freedom of choice, which includes a minimal role for influence by others. Freedom of choice then refers to the absence of outside pressure by means of convictions and considerations of others. Although this is a common way to define self-determination and freedom of choice, it is not the only and certainly not an unproblematic way of doing so. Freedom of choice is also possible in an intensive process of listing the pros and cons by the healthcare provider and patient working together. More importantly, to influence is not the same as to force. In other words, such an analysis, such as participants of the training sessions perform, can possibly change the idea healthcare providers have of the role of their own choices and experiences in talking about intensive treatments in end-of-life care situations with their patients. Individual preferences of healthcare providers contain experiential knowledge that deserves a place in talking about end-of-life care in addition to evidence-based knowledge. This neither challenges the patient's freedom of choice nor the healthcare providers own professionalism.

Hope

Likewise, such an analysis is made of the beliefs surrounding the role of hope. Healthcare providers often ask themselves "Who am I to rob the patient of their hope?" when asked about the reserve they have towards talking about end-of-life care. The reserve about robbing the patient of their hope seems to be even more prevalent than the one about self-determination. Hope is apparently seen as a kind of emotional equivalent of self-determination in which the vulnerability of the patient is felt even more. This also explains the reserve. Are you allowed to touch on this subject as a doctor? Hope is often associated with life extension and providing more time. In the training sessions, it is attempted to show participants the role of quality of life in sustaining hope. This helps the patient to disconnect from a combative way of being ("never give up") that only brings about frustration when their condition deteriorates further. Then, there is room to talk about important aspects of end-of-life care, such as preparing for a good way to say goodbye to life and loved ones. The doctor is an important factor in shifting the attention from life extension to quality of life. It is not about the length of life *per se* but about maintaining a good or acceptable quality of life for as long as possible. To summarise, the analyses

Educational questions

- 1) Prognostic factors associated with increased mortality in the intensive care unit of patients admitted with a severe COPD exacerbation are:
 - a) Forced expiratory volume in 1 s
 - b) pH
 - c) Long-term oxygen therapy
 - d) Glasgow coma scale
- 2) Prognostic factors associated with increased short-term mortality of patients admitted to hospital because of a COPD exacerbation are:
 - a) COPD of Global Initiative in Chronic Obstructive Lung Disease stage III
 - b) Long-term oxygen therapy
 - c) Body mass index
 - d) Cardiac failure
- 3) Compared to what physicians recommend to their patients, physicians in western societies tend to choose a therapy for themselves at the end of their lives that is:
 - a) More or less the same as they would recommend to their patients
 - b) Less aggressive as they would recommend to their patients
 - c) More aggressive as they would recommend to their patients
 - d) Not known, as no research has been done in this field yet.
- 4) A recent review showed that the pooled accuracy of the Surprise Question is:
 - a) 85%
 - b) 75%
 - c) 65%
 - d) 55%

conducted in the training sessions are focussed on the underlying beliefs and convictions that bring about reserve in talking about end-of-life care, and help to shift the focus from this reserve to providing new goals for talking about end-of-life care by replacing the hope for life extension with the hope for quality of life.

Ways of dealing with death

The final aspect of the training sessions consists of adjusting to the way in which patients deal with death. It aims to adjust to the patients' need for information, their values, and their way of thinking and communicating. When a doctor is successful in this, patients feel more acknowledged and understood, which helps the communication process. We are all different. We do not have the same outlook on life. The same goes for being ill and the way we think about death and dying. Some people feel threatened when talking about death and dying, and try to avoid the subject; others are comfortable talking and thinking about death, and are clear about their wishes. Just as in conversations about treatment options, patients may have very different needs for information. Some patients are well prepared, having looked up information on the internet, and wondering about all the ins

Suggested answers

- 1) b and d.
- 2) b, c and d.
In a systematic review and meta-analysis, SINGANAYAGAM *et al.* [10] identified different predictors for short-term, long-term and intensive care unit (ICU) mortality in hospitalised patients with a COPD exacerbation. Predictors for short-term mortality were age, male sex, low body mass index, cardiac failure, chronic renal failure, confusion, long-term oxygen therapy, lower limb oedema, COPD of Global Initiative in Chronic Obstructive Lung Disease stage IV, cor pulmonale, acidaemia and elevated plasma troponin level. Predictors for long-term mortality were age, low body mass index, cardiac failure, diabetes mellitus, ischaemic heart disease, malignancy, forced expiratory volume in 1 s, long-term oxygen therapy and arterial oxygen tension on admission. Predictors for ICU mortality were age, low Glasgow Coma Scale score and pH.
- 3) b.
Research in for example the USA and the Netherlands showed that at the end of their own lives, physicians tend to choose less aggressive therapies for themselves compared to what they would recommend to their patients [6, 7, 11].
- 4) b.
In a recent systematic review and meta-analysis of the literature, WHITE *et al.* [12] showed that the pooled accuracy of the Surprise Question in predicting patients nearing the end of life was 74.8% (95% CI 68.6–80.5). Doctors appeared to be more accurate than nurses.

and outs. Others do not want all this technical information but require adequate attention to their fear of the treatment itself. This diversity in needs for information and empathy is also found in the conversations about end-of-life care. In the training sessions, a scientifically substantiated typology of five ways of dealing with death is used:

- 1) Proactive
- 2) Open-minded
- 3) Trusting
- 4) Rational
- 5) Social

This typology by VAN BERKEL and METAAL [9] was developed on the basis of interviews with 1570 Dutch respondents in which the following aspects were addressed: work, beliefs, social network, and ideas about illness, death and care. In the training sessions, the participants practice conversations on end-of-life care with actors playing the role of the five different types of patient. This enables the participants to recognise the different types and to adequately adjust their conversational skills to the needs of the specific patient.

Conflict of interest

None declared.

Patient case continued

In our patient, end-of-life care issues were not previously discussed, or at least, these are not found in his patient record file. To give this patient a chance, he is intubated because initial treatment was unsuccessful. During the next week at the intensive care unit, it appears that he cannot be weaned off the ventilator. His GP is contacted, who tells you that since the patient's wife died 2 years ago, the patient has led an isolated life. He has no family and because of his shortness of breath, he is unable to walk >50 m. He can barely leave his home. His neighbours cooked his meals every day. In conversations with his GP, he had mentioned on several occasions that his life does not have any quality and meaning for him anymore, and that he would not mind if died soon. This was acknowledged by the patient during trials of weaning. After 1 week, an extubation trial is performed with the patient's consent. It is also agreed to not re-intubate him in case of failure. Unfortunately, the trial is unsuccessful and the patient dies several hours thereafter.

Conclusion

The Eindhoven group aims to promote talking about end-of-life care in a timely manner in order to stimulate patients to take control of their end-of-life care and to help physicians to address this issue with their patients in a timely manner. The most important goal of the project is prevention of treating patients out of embarrassment, and of unnecessary intensive care in the final phase and regret in retrospect. In order to prevent these outcomes, doctors and patients need to address the wishes and possibilities in end-of-life care in a timely manner. The training sessions with doctors and meetings with patients and caregivers aim to lower the threshold on both sides that exists because of unease and sensibilities regarding talking about death and dying. The training sessions provide reflective exercises to re-evaluate obstructing convictions on self-determination, freedom of choice and hope, as well as communication exercises to improve adjustment to the communication styles and needs for information of patients. The training sessions and meetings foster an understanding of the urgency of a timely conversation about end-of-life care and aim to help the participants to become more adequate in communicating about this subject.

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