Physicians' Views on the Usefulness and Feasibility of Identifying and Disclosing Patients' Last Phase of Life and their Experiences with Using the Surprise Question: A Focus Group Study

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Abstract

Background: Accurate assessment that a patient is in the last phase of life is a prerequisite for timely initiation of palliative care in patients with a life-limiting disease, such as advanced cancer or advanced organ failure. Several palliative care quality standards recommend the surprise question to identify those patients.

Methods: Physicians' views of identifying and disclosing the last phase of life and their experiences with using the surprise question for patients with advanced cancer or chronic obstructive pulmonary disease (COPD) were explored in a qualitative focus group study. Data were analyzed using thematic analysis.

Results: Fifteen medical specialists and general practitioners participated in two focus groups. Themes discussed in the focus groups were: prediction and disclosure of the imminence of death. Participants thought prediction of imminent death, within one year, was important. The surprise question was considered a useful prognostic tool; its use is facilitated by its simplicity but hampered by its subjective character. The medical specialist was considered mainly responsible for prognosticating and gradual disclosing a patient's imminent death. Physicians' reluctance to disclose the imminence of death to a patient was related to the uncertainty around prognostication, concerns about depriving patients of hope or affecting the physician–patient relationship, or about a lack of time or of palliative care services.

Conclusions: Physicians consider the assessment of patients' imminent death important and support the use of the surprise question. However, they experience uncertainty and other barriers in disclosing imminent death. Future studies should examine patients' preferences for those discussions.

Trial registration: not applicable.

Background

In the last phase of life, goals of care need to be realigned with patients' needs and preferences. Furthermore, patients may experience multiple symptoms for which they need palliative treatment.[1,2] Timely initiation of advance care planning, a process of discussing patient's preferences and goals for medical treatment and care in the last phase of life, is essential for providing adequate patient care.[3]

Accurate assessment that a patient is in the last phase of life is a prerequisite for timely initiation of palliative care .[4] Various international frameworks use a life expectancy of one year or less as a criterion to start palliative care. However, the identification of the last phase of life is hampered by variance in disease trajectories. Patients with cancer may undergo significant functional decline in the last months or weeks before death, whereas patients with organ failure, such as chronic obstructive pulmonary disease (COPD), may experience multiple acute exacerbations with ultimate physical decline during a period of one to several years.[5] The surprise question (SQ) – *Would you be surprised if this patient were to die in the next year?* – is recommended as a screening tool to identify patients with life-limiting diseases who may be in the last phase of life.[6] The SQ has been adopted in several quality standards worldwide to

facilitate palliative care and advance care planning, such as the Gold Standards Framework and the Netherlands Quality Framework for Palliative Care.[7,8] Studies about the SQ have mainly focused on its accuracy to predict imminent death, especially in patients with cancer or end-stage renal failure, and to a lesser extent on physicians' experiences with and appreciation of using the SQ for patients with different disease trajectories.[6,9] We therefore set up a focus group study with physicians to: (1) investigate their views on the usefulness and feasibility of identifying and disclosing patients' last phase of life, and (2) assess their experiences with using the SQ.

Methods

Sample

We recruited physicians attending patients with cancer or COPD in the last phase of life. Written invitations were sent to the multidisciplinary oncology boards of eight hospitals to recruit one or two representatives from each hospital. Further, we invited pulmonologists, specialists in the elderly care, and general practitioners (GPs), using the snowball method.

Data collection and analysis

Two focus group meetings were held, each lasting 120 minutes. Prior to the meetings, participants were requested to fill out an online survey, which included ten open- and closed-ended questions about their perspectives on identifying patients' last phase of life and use of the SQ (Box 1). The results from the survey were discussed during the focus groups. Furthermore, the focus group discussions were facilitated by using a set of statements on prognostication and the surprise question (Box 2). One moderator (CCDvdR) and two observers (CO and AvdH) attended both meetings, which were audio-recorded and transcribed.

Two researchers (CO and IvB) read and manually coded the transcripts independently, using the principles of grounded theory.[10] From those codes, themes and subthemes were derived by the two researchers. Disagreements could be resolved by discussion. Theme-related quotes from the focus group meetings to illustrate the findings were selected by one researcher (CO) and approved by the study team. All data were analyzed anonymously. The validity of the findings was tested though member checks by sending a summary of the findings to all participants for review. Under Dutch Law, studies like this are waived from review by ethics committee. We considered participants' agreement to partake in the focus groups as consent for the study.

Results

15 of the 16 physicians who completed the online survey (Table 1) participated in one of the two focus group meetings: 7 oncologists, 3 GPs, 2 specialists in elderly care, 2 pulmonologists, and 1 pain specialist. All participants attended patients with cancer and nine participants also attended patients with COPD.

Table 1
Participants' characteristics and answers to the online survey

	Participants (N = 16)
1. The surprise question is a good and useful method to facilitate prognostication of the last phase of life. 2. Prognostication of the last phase of life is the task of the treating medical specialist. 3. The accurate estimation of the patient's life expectancy is mainly a matter of clinical experience. 4. After prognosticating the final phase of life, the medical specialist must transfer the management of the care to the general practitioner. 5. The application of prognostic tool for the last phase of life makes discussion about that phase easier for the physician. 6. The application of a prognostic tool to identify the last phase of life makes care impersonal. 7. Prognostication of the last phase of life should be delayed in most situations in order to maintain hope for the patient.	
Participants:	7
Medical oncologist	3
Pulmonologist	3
General practitioner	2
Specialist in the elderly care	1
Pain specialist	
Which patients do you attend?	16
Patients with cancer	9
Patients with COPD	
Do you think it is generally useful to identify a patient's last phase of life?	15
Yes	1
No	

*Open-ended questions, answers by participants are indicated by the number of participants that mentioned those answers.

Figure. Themes framework

	Participants (N = 16)
Can you generally predict when a patient with cancer has one year or less to live?	9
Yes	1
No	6
Sometimes	
On which clinical factors do you base your prediction in patients with cancer?*	12
Performance status (condition)	10
Course of disease	6
Antitumor therapy and response	5
Tumor-specific prognosis based on literature	2
Weight loss	2
Co-morbidity	2
Age	1
Hospital (re)admissions	
Can you generally predict when a patient with COPD has one year or less to live? (N = 9)	0
Yes	0
No	9
Sometimes	

*Open-ended questions, answers by participants are indicated by the number of participants that mentioned those answers.

Figure. Themes framework

	Participants (N = 16)
On which clinical factors do you base your prediction in patients with COPD?*	6
Performance status (condition)	5
Incidence of exacerbations	2
Weight loss	2
Pulmonary function test results	2
Hypercapnia	2
Hospital (re)admissions	1
Prognosis based on literature	1
Co-morbidity	1
Presence of anxiety	
Are you acquainted with the surprise question?	15
Yes	1
No	
What are the benefits of the surprise question?*	8
Creates awareness	5
Simple	3
Induces proactivity	
What are the disadvantages of the surprise question?*	6
Subjective	4
Difficult to answer	2
Not incorporated in clinical practice	1
None	
Do you use other prognostic tools to identify the last phase of life in the clinical practice?	15
Yes	1
No	
*Open-ended questions, answers by participants are indicated by the number of participants that mentioned those answers.	
Figure. Themes framework	

We identified two themes and seven subthemes from the discussions (Figure).

Theme 1: Prediction of the imminence of death

According to the participating physicians, prediction of the imminence of death is important, its main purpose being to enable timely provision of tailored palliative care to patients. By identifying patients who have a limited life expectancy, physicians and care teams can facilitate the proactive evaluation of medical treatment and care in relation to patients' preferences for the last phase of life.

Well, yes, predicting imminent death forces you as a treatment team to not only look at the next available treatment line, but to critically look at its benefits for a patient who may not have long to live. It is important for physicians to do so because patients might only be focused on that next treatment line. (Participant 5, medical oncologist *)*

When predicting imminent death in patients with cancer or COPD, participants rely mainly on their clinical experience and on their knowledge regarding the patient's disease stage or tumor type. In an open-ended question in the online survey, participants mentioned several clinical factors or symptoms they use to identify a patient's last phase of life. Those factors are for example performance status for patients with cancer, and acute exacerbations for patients with COPD (Table). Some participants found it difficult to predict imminent death for patients with tumor types for which multiple lines of systemic therapy are available (e.g. breast cancer), because imminence of death may only become evident in case of an acute deterioration after exhausting those treatment lines. Participants who attended patients with cancer as well as patients with COPD found it more difficult to predict imminent death in patients with COPD than in patients with cancer, although for some types of cancer it can be particularly difficult as well.

I think the years of experience have made me better in prognostication, even in situations where the trajectory is different from what we expected. It is never easy and never 100% though. (Participant 15, medical oncologist *)*

With breast cancer, it remains difficult because people can live another 10 years with only a few skeletal metastases. (Participant 13, medical oncologist *)*

Most participants thought the SQ is a useful tool to support the identification of patients' last phase of life. They are typically triggered to use the SQ when they notice significant deterioration of a patient's condition. Facilitators for the use of the SQ are that it is a simple question, clearly formulated, and directly raises awareness about a patient's imminent death. Additionally, the SQ is recognizable and, therefore, applicable for patients with various chronic diseases. Physicians base their response to the SQ on a combination of intuition, and patient and disease characteristics.

You do have a certain idea of a patient and you wonder, "I am curious if he will make it". It is a gut feeling, whether you will say yes or no. (Participant 12, general practitioner *)*

Well, we have been discussing the surprise question extensively at the department this afternoon. I think that the surprise question itself, however subjective it may be, is not so bad in all its simplicity. (Participant 8, anesthesiologist *)*

Participants were not acquainted with other tools than the surprise question to predict death. Participants' opinions were divided on whether it is preferable to use one's own subjective clinical judgement or an objective prognostic tool that combines clinical factors. They thought a prognostic tool may give more accurate predictions than subjective judgement, but a tool would probably also require extra time and effort to complete. All participants disagreed with a statement that use of a prognostic tool would make care impersonal and distant.

If you would have tools to estimate it [imminent death] more reliably, that would help. However, I am very curious if that is possible. (Participant 15, medical oncologist *)*

Theme 2: Disclosure of the imminence of death

All participants thought that acknowledgment of a patient's imminent death is important for the initiation of a discussion with patients about their preferences and needs for medical care in the last phase of life. Most participants thought it is useful and feasible to start this discussion early, that is, about one year before a patient's expected death. This timing may then provide patients and relatives with sufficient time to prepare for the last stage of life and make all necessary arrangements. Some participants, however, thought that one year might be too early to initiate those discussions; they preferred to open such a discussion in the period 'during which palliative care is actually required', the period 'during which maintaining quality of life outweighs prolonging life', or on the last 6 months of life. Physicians should disclose information about a patient's imminent death gradually, preferably during multiple conversations, because that gives the patient the opportunity to process the information and to think about preferences for care. Some participants link the timing of those discussions to a significant deterioration of the patient's disease (e.g. progression of metastases or acute COPD exacerbation), or to the discussion of preferences about resuscitation. Other participants thought that disclosing the imminence of death during those moments may increase the patient's anxiety or panic.

The period of one year has something arbitrary. A trajectory of 1 year is maybe meaningful because the patient can get used to the last phase and make necessary arrangements. (Participant 1, pulmonologist *)*

The last phase of life is an artificial border you draw for yourself. That border, whether 6 months or 1 year, has a different value for each patient. (Participant 3, medical oncologist *)*

It is much harder for patients with COPD who are in acute situations admitted to the hospital, but feel perfectly fine when they are discharged and at home. It is then more difficult to talk about such serious topics [such as death]. My experience with COPD patients is that there is a lot of fear and panic. (Participant 11, pulmonologist *)*

All participants agreed that the treating physician should be responsible for prognostication and disclosure of a patient's imminent death. Although the GP could also play a role, the medical specialist knows best when active treatment options for the patient are exhausted, and thus has more insight whether or not the patient's death is imminent. Participating GPs emphasized that the medical specialist should inform the GP early about the exhaustion of treatments and the imminence of death. Thereafter, the GP should gradually take more responsibility in the further exploring and realizing patients' preferences for end-of-life care.

*I appreciate clear prognostication from the medical specialist. For example, if the medical specialist says that there are no more treatments available for the patient, because it is difficult for me to remain knowledgeable of all treatment options. (*Participant 4, general practitioner *)*

Participants mentioned several barriers for the disclosure of the imminence of death to patients. First, some participants were concerned about a false prediction of imminent death. They found the SQ to be subjective and difficult to answer. Wrong predictions can emotionally harm patients who strictly hang on to those predictions. A few participants mentioned that they had become more reluctant with their predictions due to experiences with patients whose diseases had followed another course than expected

*In all those years, I have sent five people home and said, "You will die within a few days". All five people were still alive after a year. So you can make huge mistakes. (*Participant 2, medical oncologist *)*

Second, participants feared that full disclosure of the imminence of death might deprive the patient of hope, especially in patients for whom it is important to maintain hope until the end. Additionally, they were concerned that discussion of the imminence of death may trigger fear in patients or let patients think that the physician is giving up on them. Therefore, they believed that their answer to the SQ should not be disclosed to the patient, unless it is clear that the patient appreciates such disclosure and can cope with it.

*Of course, there are always several sides to take into account. Look, you are talking about hope. You also regularly see that people have false hope until the very last chemotherapy, because both the doctor and the patient do not want to talk about the patient's imminent death. (*Participant 8, pain specialist *)*

*I do not want to invoke a lot of fear because of my answer to the surprise question. I do not want to take away hope from patients by telling them they have one year to live, while that could be five years. (*Participant 2, medical oncologist *)*

Third, some participants found it difficult to accept imminent death of patients with whom they have an established and good physician–patient relationship, or fear that discussions about patients' imminent death may affect that relationship. On the other hand, a good physician–patient relationship sometimes makes it easier to initiate the discussion about imminent death.

*The more you have a relationship with a patient, the more you don't want to see the end coming. That is a major pitfall. (*Participant 15, medical oncologist *)*

Lastly, participants felt reluctant to use the SQ and to discuss the imminence of death due to concerns about a lack of palliative care services in their clinical practices. Not all hospitals have specialized palliative care teams that can support patients in the last phase of life. Additionally, lack of time during an outpatient consultation makes the initiation of those discussions difficult.

*However, the most difficult thing is to start that conversation [about the last phase of life]. I do not think it gets easier. That is also because I do not have a checklist for it and I have [limited] time at the outpatient clinic. (*Participant 5, medical oncologist *)*

Discussion

In this focus group study we found that physicians consider it important and useful to prognosticate a patient's imminent death. In doing so, physicians are enabled to timely assess patients' preferences for medical treatment and care in the last phase of life. The simply formulated SQ is considered as a useful prognostic tool to facilitate prognostication. However, the assumed subjective character of the SQ makes its use uncertain.[11,12] Clinical experience with patient and disease-related clinical factors are also facilitators of prognostication. Some studies have indeed found that clinical experience is associated with more accurate predictions of the imminence of death, but other studies found no such associations.[13–15]

We found that physicians supported the disclosure of imminent death when this was expected within a year or less, as recommended in quality standards for palliative care [7,8], but they also stressed the importance of a gradual disclosure. Furthermore, the primary responsible physician, typically the treating medical specialist, should initiate the communication about imminent death to patients. However, apart from linking those discussions to moments of significant deterioration in patient's health, little is known about the best way in which imminent death and patient's wishes and preferences may be discussed. Generally, physicians find the disclosure of imminent death difficult, as also supported by previous evidence.[16] Physicians may find it difficult to initiate such discussions due to uncertainty about prognostication and unknown consequences for patients. They are especially uncertain about predicting death in patients with COPD, which is due to the fact that organ failure often has a rather fluctuating disease trajectory. Moreover, physicians may be better in predicting death in a late stage of disease.[17,18] Other barriers to initiate discussions about the imminence of death are concerns about depriving patients of hope, concerns about affecting the physician–patient relationship, having insufficient time for a complex conversation, or lacking palliative care services to provide proactive medical treatment and care in response to the assessment and disclosure of a patient's limited life expectancy. Future studies may explore patients' preferences for discussing imminent death to better align these perceived barriers and difficulties.

Key strengths of our study were the inclusion of a multidisciplinary group of medical specialists and GPs and the participation of physicians who care for patients with two different diseases. The list of statements that was used during the focus groups was a good method to facilitate the discussion and to

code the themes structurally. However, several limitations should also be mentioned. First, most participants had affinity with palliative care, which may have caused some level of bias in discussed experiences and views. Second, the number of participating pulmonologists was rather low. Therefore, this study might not have reached data saturation for use of the SQ in pulmonology.

Conclusions

Our findings reveal that physicians consider prognostication as important because it helps them to think about treatment preferences for their patients. However, despite this perceived importance, doctors are also afraid to open the discussion with patients, because of prognostic uncertainty and unknown consequences for patients, deprivation of hope, physician–patient relationship, lack of time or palliative care services. Furthermore, physicians support the use of the surprise question the SQ, which should be used more routinely and focus on identifying patients in their last phase of life rather than accurately predicting death. Future studies could explore patients' preferences for disclosing the imminence of death.

Abbreviations

COPD
chronic obstructive pulmonary disease
GP
general practitioner
SQ
surprise question

Declarations

Ethics approval and consent to participate

Under Dutch Law, studies like this are waived from review by ethics committee.

Consent for publication

Not applicable.

Availability of data and materials

The datasets, i.e. focus group transcripts in Dutch, analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

CR reports grants from The Netherlands Organization for Health Research and Development, during the conduct of the study. The co-authors declare that they have no competing interests.

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Authors' contributions

AH, CR, and CO designed the study. CR moderated the focus groups. CO and IB coded and analyzed the data. AH and CR checked the coding and data analysis. CO wrote the first draft of the paper. All authors revised the paper and approved the final version.

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Tables

Box 1. Questions of online survey

1. What is your function?

2. Which patients do you attend?

3. Do you think it is generally useful to identify a patient's last phase of life?

4. Can you generally predict when a patient with cancer has one year or less to live?

5. If yes, on which clinical factors do you base your prediction.

6. Can you generally predict when a patient with chronic obstructive pulmonary disease has one year or less to live?

7. If yes, on which clinical factors do you base your prediction.

8. Are you acquainted with the surprise question?

9. What are the benefits and disadvantages of the surprise question?

10. Do you use other prognostic tools to identify the last phase of life in the clinical practice?

Box 2. Statements presented during the focus groups

1. The surprise question is a good and useful method to facilitate prognostication of the last phase of life.

2. Prognostication of the last phase of life is the task of the treating medical specialist.

3. The accurate estimation of the patient's life expectancy is mainly a matter of clinical experience.

4. After prognosticating the final phase of life, the medical specialist must transfer the management of the care to the general practitioner.

5. The application of prognostic tool for the last phase of life makes discussion about that phase easier for the physician.

6. The application of a prognostic tool to identify the last phase of life makes care impersonal.

7. Prognostication of the last phase of life should be delayed in most situations in order to maintain hope for the patient.

Figures

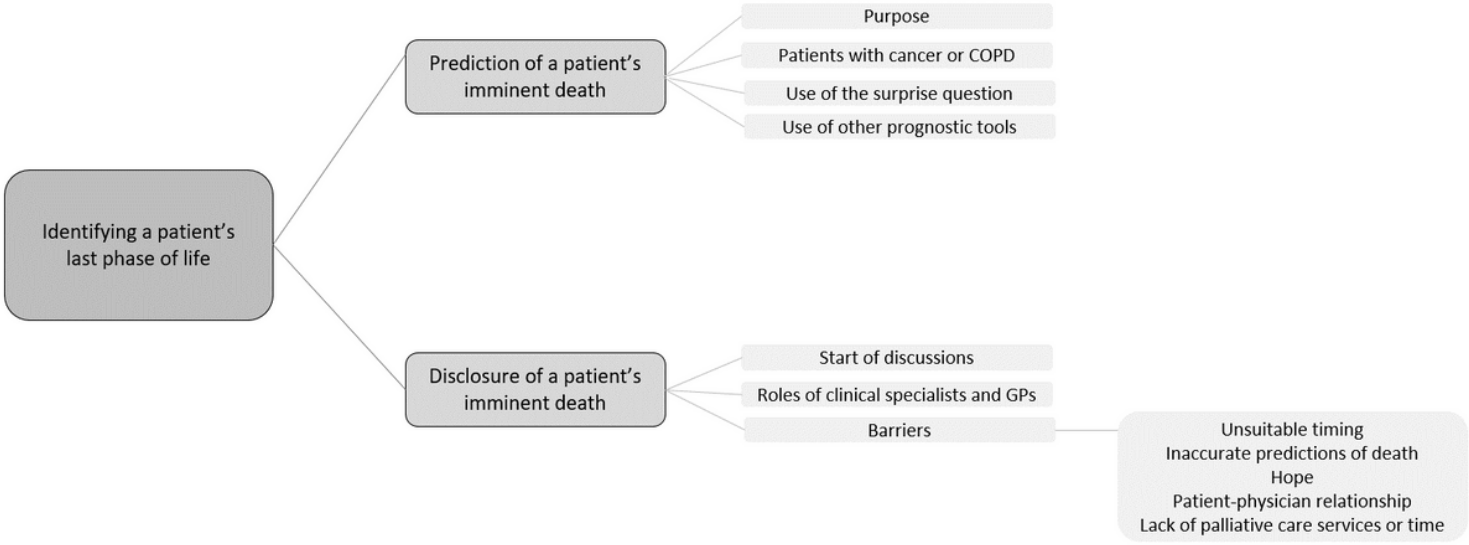

Figure 1

Themes framework