The decision to engage in end-of-life discussions: a structured approach for doctors in training

Rory Conn and Philip A Berry

ABSTRACT – Engaging in end-of-life discussions is a major source of anxiety for doctors in training. The authors propose the use of a decision-making model to assist trainees and their clinical supervisors in such situations. Divided into 'patient-centred' and 'physician-centred' components, the model ensures that the following aspects are analysed: patient and family safety, patient and family choice, physician competence and physician comfort. A real but historical end-of-life scenario is presented to a foundation year 1 doctor, and the particular risks of engaging in a discussion are subsequently clarified with reference to each of the model's components.

KEY WORDS: breaking bad news, education, family, independence, resuscitation, supervision, terminal illness

Background

Dealing with ethically complex situations constitutes an inevitable aspect of medical training. In the UK, the curriculum for specialist trainees in internal medicine (doctors who are up to four years beyond obtaining their medical degree) requires trainees to '…contribute to discussions on decisions not to resuscitate [a patient] with patients, carers, family and colleagues appropriately and sensitively ensuring patients' interests are paramount'.[1] However, a questionnaire-based study found that 73% of trainees were required to break bad news while still very junior, and did so alone in 84% of instances.[2] Despite this degree of exposure, evidence suggests that ethical dilemmas raise significant concern with junior doctors and that many lack the requisite skills to deal with discussions surrounding end-of-life scenarios.[3–7] Attempts to resolve ethical dilemmas are commonly, and understandably, postponed, or referred to a senior colleague.[8] Even in a modern consultant-led service, juniors may be wary of intruding on their seniors' time. As a result, they may take on tasks beyond their abilities. The General Medical Council (GMC) instructs all practising doctors to 'recognise and work within the limits of [their] confidence', and the authors would emphasise that in case of doubt, a senior member of the team should be contacted to avoid inappropriate action.

The model presented here provides a structured approach that can be utilised by all members of the team to arrive at an appropriate decision. The assessment of competency is an objective exercise, and therefore dependent on the engagement of the trainers. However, most doctors will recollect instances in which they have had to make a rapid assessment of their own ability before deciding whether to proceed alone. Subjective analysis of ones own strengths and weaknesses also has its place, a reflective approach to continued learning being integral to postgraduate educational programmes. If utilised bilaterally, it is hoped that consideration of the factors listed in the model will allow a comprehensive assessment of a trainee's ability to proceed with end-of-life discussions.

Method

A model previously developed by one of the authors (PB), to aid trainees in deciding whether or not to make clinical management decisions or undertake practical procedures unaided, was adapted for situations in which the need to engage in end-of-life discussions may arise.[9] Components of the model (Fig 1) were developed through informal discussion with trainees and trainers, and personal reflection by the authors. The model was then applied to a real life, but historical, clinical scenario in a retrospective fashion by one of the authors, a junior doctor (RC).

Results

The model

According to the GMC guidelines on Good Medical Practice, 'patient safety and care' should be central to all aspects of clinical skills, team working, patient–physician relationships and reflective learning. This decision-making model is based on this assertion, alongside the four ethical principles that comprise the 'Georgetown mantra' – beneficence, nonmaleficence, autonomy, and justice.[10] The first two factors to be considered are therefore patient centred, concerned with safety and autonomy. The final two concern the doctor's appreciation of their own abilities and their personal comfort.

Patient and family safety

Patient. End-of-life decisions demand absolute certainty, for the decision to palliate, once made, will allow a disease process to advance and death to ensue. Equally, the serious consequences of failing to palliate may be invisible, as suffering may not be evident to medical staff. Therefore, trainees should involve their registrar or consultant to assist in decision making. Prior to

Rory Conn, foundation year 1; **Philip A Berry,** specialist registrar in gastroenterology

St Thomas' Hospital, London

engaging in an end-of-life discussion, the question must be asked – is there any other relevant information, obtainable through examination or further review of the history, of which the trainee is unaware?

Family. Studies have shown that appropriate involvement of relatives in end-of-life decision making is a major factor in determining their overall satisfaction (and therefore psychological safety) during critical illness.[11] Relatives can come away from end-of-life scenarios with a sense of guilt if they have been given the impression that it is entirely up to them to determine whether or not supportive care should be continued. This misinterpretation of 'substituted judgement' (by which relatives are rightly asked to imagine what the patient would want, rather than what they want for the patient) should be avoided.[12] In cases where a terminal prognosis has been reached, supportive and seemingly 'obvious' assurances that the patient will not be abandoned during their terminal decline, and that every effort will be made to ensure comfort, have been shown to reduce

familial distress.[13,14] Additionally the importance of access to spiritual/religious support is increasingly well recognised.[15] Facilitating such involvement of relatives requires confidence and subtlety. The trainee must recognise their limitations in this respect, with the help of those who have greater experience and can evaluate them suitably in advance.

Patient and family choice

Opportunities to exert autonomy at the end of life may be severely diminished, as the senses are dulled and the energy required to make decisions is reduced. All opportunities to declare a preference must be maximised, and one area highlighted in this model is that of choosing who conducts the end-of-life interview. Patients and families are unlikely to request more senior involvement unless the trainee advertises their junior status, or behaves in a way that clearly demonstrates their lack of experience. It is therefore desirable for the trainee to describe their role on the team, and to lay out for the family unit the type of discussion that is required before moving forward. Exploring patient and family choice, rather than just arriving at the bedside and declaring the role (as occurs, say, in the emergency room), may offer an opportunity for specific concerns and fears to be aired.

Physician competence

Competence will have been achieved through observation of seniors during previous discussions. However, every discussion is different, and the sequence of words and responses recalled from those discussions will not necessarily be of relevance to the current scenario. A degree of flexibility is therefore required, whereby the correct principles are utilised according to the specific aspects of the case and in light of the particular personalities and beliefs of the relatives. The ideal elements in a discussion concerning critical illness and end-of-life situations have been established and reviewed.[16,17] Recommendations include adequate planning, sufficient time allocation, and the use of an appropriate physical environment. They also cover the need to personalise delivery and the ability to modulate the pace of disclosure.[18] Potential stumbling blocks in end-of-life discussions include the development of disparity between a physician's and a family's understanding of the disease and its prognosis, and a lack of skill when it comes to discussing palliation, perhaps allowing the negative impression of 'withholding treatment' to dominate in the family's mind.[19]

Physician comfort

It can never be a pleasant task to broach with relatives the imminent death of a patient, however, a doctor's
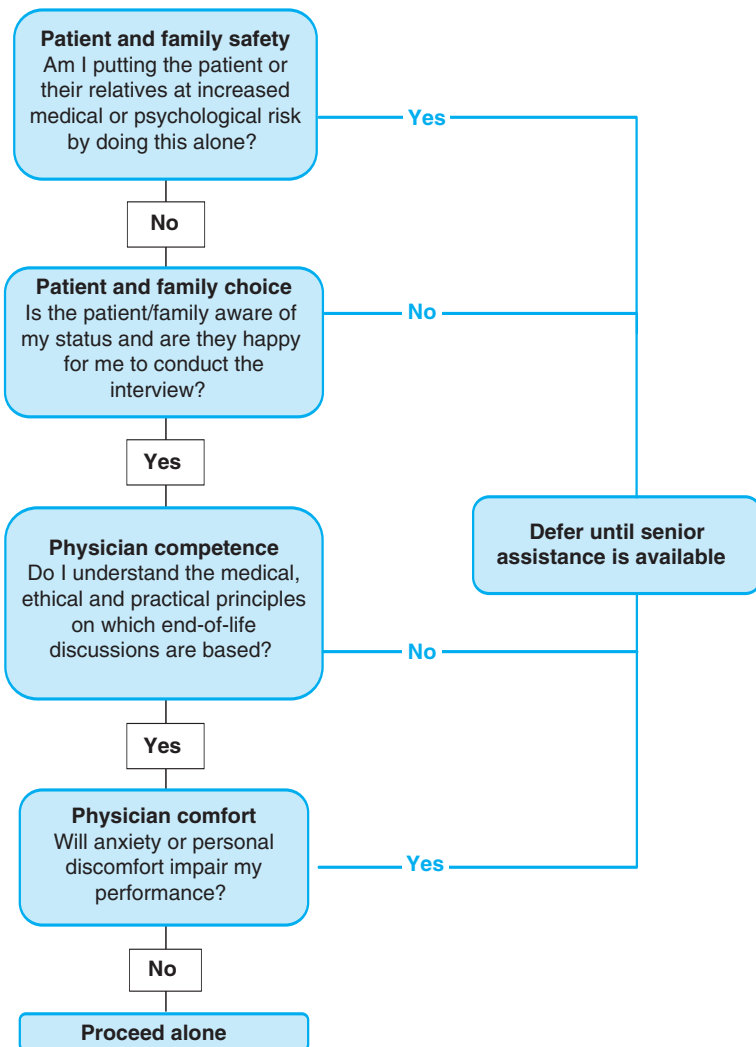

Fig 1. Algorithm to guide decisions by junior doctors when considering engagement in end-of-life discussions.

duty, and a highly rewarding one if done skilfully, is to counsel patients and relatives at this time. To be successful, the doctor needs to project calm, proficiency, sincerity, patience and kindness. A trainee who does not understand why they are having the conversation, or how to start or finish it, will struggle to achieve this profile. Trust will be eroded and the chance of successfully negotiating the task will diminish, with the risk that relatives do not understand the medical rationale for palliation. They may reach the conclusion that appropriate care is being denied for reasons that they cannot agree with (eg bed availability, funding or ageism). Allegations such as this, made by dissatisfied, confused or angry relatives, will result in embarrassment and acute discomfiture.

Scenario

A 75-year-old male patient is admitted with obstructive jaundice, weight loss and early satiety. Over the course of one week, a histological diagnosis of metastatic small cell carcinoma is made. Thus far the patient has been told that there is a serious problem in the liver, and that one of the possibilities is that a tumour is growing there. The patient's family (to whom the patient tends to defer when it comes to decisions and delivery of information) lives some distance from the hospital and has not yet met the medical team face to face. The patient continues to deteriorate, and the on-call foundation year 1 (FY1) doctor is asked to review him on Saturday morning. The last entry in the notes reads, 'Stable. Consider symptomatic Tx only in case of deterioration. Referral to palliative care team'. There is no formal decision regarding resuscitation, and no evidence of a discussion with the patient or his relatives. While the trainee is assessing the patient his son and daughter, who have been called at home by a ward nurse, enter the cubicle. The son asks if his father will need to go to intensive care. The trainee excuses himself, takes the notes and calls the registrar. She is treating a complex patient in the emergency room. Having had the details of the case explained to her, the registrar says, 'They have anticipated this deterioration, undoubtedly made the right call medically, but failed to actually discuss it with anyone. It needs explaining to the family. There's a histological diagnosis, it sounds quite straightforward…he is obviously terminally ill. Look, I'm going to be stuck here for at least an hour. I trust you. Are you happy to sit down with them, go through it, and answer their questions?'

This is a complex situation. The model described can be used by the trainee to self-assess their suitability for the task. Equally, a senior colleague can use the model, over the phone or in person, to prompt the trainee in thinking about their likely strengths and weaknesses and to reassure themselves that proceeding alone is suitable.

Respondent – FY1

Patient and family safety. 'On paper, the information appears to indicate that escalation of care to the high dependency or inten-

sive care unit would not benefit the patient in terms of prognosis or quality of life. In this instance, I would defer speaking to the family and walk to the emergency room with the patient's notes, and results of recent investigations for a further discussion with the registrar to clarify these points. If she was completely tied up, my next port of call would be to ring the on-call consultant directly. My overriding concern would be to ensure that the medical assessment is accurate, and that we would not be running the risk of denying the patient a lifesaving opportunity.'

'I would also worry that my understanding of the treatment options and overall prognosis would be inadequate to answer questions accurately and fully, therefore the patient and family might be put at risk of confusion regarding oncological and palliative care options. Specifically, I do not know what the actual contraindications to potentially life-prolonging chemotherapy are. However, having recognised this knowledge gap I could ask the registrar or consultant specific questions, or even have a quick look at online evidence. This pre-emptive groundwork could go some way to prepare me for all possible questions, and might be sufficient to get me through the interview, however, the first part of the model remains a concern for me.'

Patient and family choice. 'I would already have introduced myself to the family, making my position as one of the members of the on-call team clear, during the initial assessment. I would have stated that I was going to discuss the patient's condition with the most senior doctor available, and that I would return shortly for a further discussion. Therefore it is already clear that I am not the chief decision maker. I imagine that the family's response to this initial prevarication would be a good indicator as to whether they would accept me as the 'doctor in charge' of their father's case. If I detected any antagonism at all, I would warn the registrar that actually a more senior person (either herself or the consultant) might be needed. I would be nervous of asking the family at this point if they preferred the senior, as this question could further undermine trust in my ability to make or convey decisions. In this case I feel that the decision to offer senior assistance should be made by the senior themselves. If the on-call consultant feels that their help is required, they must make themselves available as soon as possible.'

Physician competence. 'I am confident in my ability to communicate diagnoses like this in a compassionate and honest manner, having broken bad news before. My main concern regarding competence is my own vagueness regarding the medical argument for not treating, as mentioned before. Therefore before initiating a discussion with the family I would need to be familiar with the facts concerning survival and quality of life following say, chemotherapy, in patients such as this, and the medical reasons for declining admission to the intensive therapy unit, should the relatives go on to request such escalation. I would also need to understand where the ethical and legal onus of responsibility lies in making this decision. In this situation it would be very important to differentiate what the family members think the patient would want from what they want for the patient – I have heard families ask that their relatives be kept

alive for as long as possible, but this is often before any decent counselling has taken place. I have discussed this before with families, and feel confident in my ability to explore this subject. I am familiar with the logistical aspects of arranging an end-of-life discussion. If the knowledge gap could be addressed, I feel that I would be able to present myself as a competent counsellor in this situation, provided my seniors were in agreement.'

Physician comfort. 'This scenario makes me nervous. The patient is deteriorating quickly and may die during this shift, in a way that was not anticipated by his usual team. I understand the medicine, and am happy that I could quickly find out and communicate the reasons why life-prolonging measures would not be in the patient's best interest, however I would be worried about the family's response. The son has asked about intensive care, therefore the first task will be to draw him back from that expectation. I would anticipate problems in dealing with the expressed emotion and lack of acceptance of the medical decision if he were to insist on intensive care. I am not 100% sure that I would be able to counsel the son and daughter with genuine confidence in this situation, and I know that my own stress might compromise my ability to make, and adhere to, a logical argument. I would also worry that my own anxiety might be sensed by them, reducing their trust in my opinion.'

'In this scenario my own comfort would be dependent on feeling confident about my knowledge of treatment options in rapidly progressive metastatic cancer. By pro-actively imagining what questions might be asked, and seeking answers to these by conferring with my seniors, I should be able to 'arm' myself sufficiently for the interview. More generally, I would hope that the dynamic that I will have developed with the family during my assessments on the ward, and the apparent absence of divergent opinions among family members, would ensure a 'relaxed' interview. The registrar or consultant will not be able to easily assess my comfort with the situation. But, whether it is in person or over the phone, the senior must decide if a trainee sounds suitably composed and not overwhelmed to proceed.'

Conclusion and reflection. 'On this occasion, with the agreement of my senior colleagues, I would agree to proceed alone. Because there is a degree of time pressure, it does seem reasonable for a well-informed if junior member of the team to go ahead unaided. To make the experience more of a training opportunity, it would be ideal if the registrar or consultant could sit in with me to field any tricky questions and give feedback. If I could not get my head around the medical reasons for not treating, and perhaps a few statistics regarding estimated survival with and without treatment, I would have to stand up and say, 'No sorry, I don't think I can do this on my own'.'

Discussion

It is hoped that the proposed model, when applied to similar situations, will provide a foundation for trainees and their seniors on which to base an important decision. If a trainer is uncomfortable with the trainee proceeding alone, the framework's structure should facilitate explanations as to why they feel their input is necessary. The authors propose that medical students are exposed to this model during their training in anticipation of the challenging situations that they will meet within weeks of entering the wards.

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Address for correspondence: Dr PA Berry, St Thomas' Hospital, Westminster Bridge Road, London SE1 7EH. Email: philaberry@hotmail.com