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End-of-life communication: let's talk about death

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Every year more than half a million people die in the United Kingdom, and most of these deaths occur in hospitals.[1] While some deaths occur suddenly, the majority of deaths are predictable, occurring after a period of chronic illness. All doctors will at some stage be required to care for patients who are dying and communication is the key to doing this well. Sadly, all too often this is not achieved. Indeed, more than half of NHS complaints are associated with care of the dying, many of them focused on information and communication.[2]

Poor communication at the end of life can cause deep distress, both for the patient and their loved ones, and may adversely impact on post-bereavement outcomes. This was highlighted recently by the independent review into the Liverpool Care Pathway (LCP), an integrated care pathway designed to be used in the last days of life, and the subject of intensive media criticism following reports of poor end-of-life care. The independent review identified inadequate communication as responsible for much of the controversy and unhappiness surrounding care of the dying.[3] On the other hand, good communication allows patients and their families to make informed decisions about healthcare, to prepare for the future, and to express and meet their preferences for end-of-life care.

BARRIERS TO END-OF-LIFE COMMUNICATION

Uncertainty about prognosis can make healthcare professionals reluctant to discuss end-of-life care with their patients. This is particularly the case for patients with non-cancer conditions, which are often characterised by relapses and remissions and have a less predictable dying phase. However, most people, if faced with a serious illness and little time to live, would choose to prioritise quality of life over extending the amount of time left,[4] and an inability to accurately predict prognosis should not therefore preclude initiating an honest discussion of the likely outcomes, while acknowledging the uncertainty. Delaying such discussions until the patient is imminently dying makes it much less likely that the patient's preferences for end-of-life care will be met: patients who have late discussions concerning end-of-life care with their physicians are more likely to receive aggressive care close to death.[5]

In cross-cultural surveys most people say they would want to know if they had a serious illness and only a year to live,[6] yet even when prognoses are known to be very poor, doctors tend to delay conversations about dying. One study found that around half of medical oncologists preferred not to discuss resuscitation, advance directives or palliative care, until there were no more treatments available.[7] Doctors may be worried that disclosure of the terminal nature of their illness will deprive patients of hope. However, there is good evidence that the opposite is true: honest discussion of difficult information may enable the patient to feel more empowered about care and decision-making, and enhance rather than diminish hope.[8]

Patients can, of course, continue to have active treatment while being aware of a likely terminal outcome. Indeed, an understanding of the aims of treatment is essential to provide informed consent to receive it. Worryingly, this is not always the case. A recent study in the US showed that 69% of patients with lung cancer (and 81% with colorectal cancer) did not understand that their palliative chemotherapy was unlikely to cure their disease.[9] This misunderstanding was more likely among patients who reported their communication with their physician as most favourable. Does honest end-of-life communication come at the expense of patient satisfaction?

Doctors may feel that discussing bad news will jeopardise their relationships with patients. They are systematically over-optimistic regarding their patients' prognoses, and having a long relationship with a patient was associated with more error, not less.[10] Is this behaviour designed to protect the patient and their family, or the doctor? There is certainly evidence that being truthful about poor

prognoses is stressful for healthcare professionals – in one study giving truthful information about poor prognosis to a (simulated) patient was associated with significantly more stress to the doctor than concealing the information from them.[11]

DEATH AS FAILURE

Underlying all of this is a sense that death is a failure of medicine rather than a natural and essential part of life. Physicians may see death as a personal or professional admission of giving up or having failed; society considers death as something to be avoided at all cost. In fact, the opposite is true: society needs death as much as it needs new life.

Even within the context of a conversation about the end of life, doctors can be reluctant to use the words 'death' and 'dying'. Doctors appear to go to some lengths to avoid these words and instead use euphemisms such as 'time is short' and 'life-threatening illness'.[12] While there may be some patients for whom such language is appropriate, for many others sensitive use of the words 'death' and 'dying' may provide much needed clarity, and consequently avoid harm. It is not uncommon for a patient to express relief when dying is discussed; a lack of clarity can be confusing and stressful for patients.

EDUCATION

Death is necessarily at the centre of palliative care. But for the rest of medicine, and particularly in medical school education, death is very much at the periphery. It is only relatively recently that death and dying have had a place on the medical school curriculum. While palliative care is slowly gaining prominence in UK medical schools, there is a wide variation in terms of training provided. For example, in 2000 the mean number of hours devoted to palliative care teaching in UK medical schools was just 20, with a range from six to 100.[13] In addition, the mode of palliative care teaching varies widely, with lectures and seminars being more common than ward-based learning in many medical schools.

Several studies have shown that junior doctors may be unprepared to provide end-of-life care. A survey of junior doctors and their trainers published in this journal showed that 79% of FY1 doctors had felt out of their depth when caring for dying patients.[14] Around half of those surveyed felt prepared for communicating with dying patients and their relatives, though interestingly more than 70% of their trainers felt the FY1s were not prepared for this task.

Formal palliative care education may have increased over the past few decades, but most medical schools still have a culture that focuses on clerking and signs, discourages contact with dying patients, and does not encourage awareness of the needs of the dying.[15] Medical students describe a lack of meaningful exposure to dying patients. Surprisingly, in one qualitative study less than a quarter of interviewees felt that they had been aware as medical students that as junior doctors they would be caring for patients who would die.[15] If we want to pull death in from the periphery of medicine, we need to start with undergraduate education.

CONCLUSION

Talking about dying with patients is hard, particularly when there has been a long relationship with the patient and the goals of care have changed. But honest conversations, sensitively navigated, will strengthen rather than damage the relationship between doctors and dying patients, allow patients to prioritise and prepare for the future, and reduce suffering in bereavement for those left behind.

Doctors need to be equipped with the appropriate knowledge, skills and attitudes to communicate effectively with patients who are dying. But even these attributes are not enough without the provision of time: time to understand preferences, to build trust, to meet loved ones and to break bad news. End-of-life communication is not an event, but a process, ideally built up over days, weeks or months. In the increasingly time-pressured clinical environment, finding the time for this is likely to become our greatest challenge.

> I think the best physician is the one who has the providence to tell to the patients according to his knowledge the present situation, what has happened before, and what is going to happen in the future.
>
> – Hippocrates

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