

# Do patients need to know they are terminally ill?

**Emily Collis** and **Katherine Sleeman** say that decision making can be ethically sound only with a fully informed patient, but **Leslie Blackhall** thinks the concept of “terminal illness” is not clearly defined and that prognoses can never be certain

**Emily Collis** consultant in palliative medicine, Pembroke Palliative Care Centre, Central London Community Healthcare Trust, St Charles' Hospital, London W10 6DZ, UK [emily.collis@clch.nhs.uk](mailto:emily.collis@clch.nhs.uk)

**Katherine E Sleeman** clinical lecturer in palliative medicine, Cicely Saunders Institute, King's College London, London, UK

**YES** Patients have the right to make informed decisions about their healthcare.

Informed consent, and the process of balancing risks and benefits of treatment, is a fundamental ethical principle.<sup>1</sup> This principle is no less relevant for a patient with terminal illness, for whom an awareness of the incurable and life limiting nature of their underlying condition is essential to decision making.

## Knowledge gives power

Decision making in terminal illness extends from the medical treatments and supportive care to decisions around advance planning of care, finances, guardianship, power of attorney, and voicing preferences for place of death. Worryingly, such decisions are not always fully informed. A recent study showed that 69% of 710 US patients with incurable lung cancer (and 81% of 483 patients with

colorectal cancer) who received palliative chemotherapy were not aware that this was unlikely to cure the cancer.<sup>2</sup> On the other hand, being given the opportunity to express a preference for place of death and having increased awareness of dying were associated with achieving death at home for patients with cancer.<sup>3</sup> Accurate information enables patients to make informed, realistic choices and helps them to get their preferred care.

The central premise of informed consent is autonomy, which needs to be balanced with non-maleficence. It is difficult to argue that you can do more harm by communicating honestly and sensitively with a patient about their condition than by failing to communicate, depriving the patient of autonomy. Calman proposed that poor quality of life occurs when experience does not meet hopes, and so the role of doctors is to provide information to help gradually bridge this gap.<sup>4</sup> In England, the doctors' regulatory body, the General Medical Council, states that information should be withheld from terminally ill patients only

**Accurate information enables patients to make informed, realistic choices and helps them to get their preferred care**



**Leslie J Blackhall** section head, Palliative Care, University of Virginia School of Medicine, Charlottesville, VA, USA [LB9X@hscmail.mcc.virginia.edu](mailto:LB9X@hscmail.mcc.virginia.edu)

**NO** Patients do not need to be told that they are terminally ill. However, this does not mean we should pretend we can cure them of incurable illnesses or that we should withhold prognostic information from those who want it. But insisting on prognostic disclosure to facilitate “patient choice” about end of life care is a failed model for medical decision making that creates more suffering than it relieves.

## What does terminal mean?

The choice model has outlived its usefulness for two main reasons. Firstly, disclosing a “terminal” prognosis is impossible because we do not have a clear definition. Even palliative care physicians do not have a universally accepted definition for this, or for related terms such as dying or end of life.<sup>1</sup>

Does telling someone that they are terminally ill mean telling them how long they have to live (hard to know for any individual)?<sup>2</sup> Does it mean telling them that they will eventually die (true for all of us)? Does it mean telling them there is “nothing we can do” (never true)? Are patients

terminally ill when they first develop incurable cancer, even if they might live many years before dying of that illness? Are they terminally ill only when their functional status starts to decline and they develop more symptoms, or only when they are bedbound and unconscious? This lack of precision is not just a semantic problem; it indicates an underlying failure of the medical profession and wider culture at large to consider how the fact of human mortality should be accounted for in the practice of medicine.

## False choices

The second problem with the case for prognostic disclosure is the claim that patients need this information to make choices about their care, especially artificial life support. The way these choices are usually framed, however, further reveals our confusion about the role of medicine in caring for patients with life limiting (meaning progressive, incurable) illnesses. The underlying assumption is that patients have a choice between therapy that will prolong life and therapy directed at comfort.

But this assumption is largely an artefact of the unusual cases (mostly of patients in a persistent vegetative state) that have captured the attention of the media, bioethicists, and the

## This week's poll asks:

“Do patients need to know they are terminally ill?”

Head to Head:

• Yes • *BMJ* 2013;346:f2589

• No • *BMJ* 2013;346:f2560

• **Vote now on [bmj.com](http://bmj.com)**

## [bmj.com](http://bmj.com)

• Research: Exploring preferences for place of death with terminally ill patients (*BMJ* 2009;339:b2391)



if it is thought that giving information will cause serious harm, specified as “more than becoming upset.” If information is withheld, the reasons must be justified, documented, and reconsidered at a later date.<sup>5</sup>

### Good communication

Therefore, the key consideration for doctors is not whether patients are informed that their disease is incurable, but how this information is communicated.<sup>6</sup> Patients should be given the information they want or need in a way they can understand.<sup>5</sup> This should be ascertained through ongoing dialogue, and sensitivity to patients’ beliefs, culture, and preferences regarding this information is essential. Ideally these conversations would occur throughout the course of the illness, enabling patients to come to terms with the situation in their own time.<sup>6</sup>

Patient who are aware that their illness is terminal may request more specific information about prognosis. The definition of a terminal illness is simply one that is incurable and life limiting, covering many malignant and non-malignant conditions. From a clinical perspective the term “terminal illness” does not convey a specific prognosis, but in the UK from a legal perspective it

is defined as “a progressive disease from which death may reasonably be expected within six months.”<sup>7</sup> Because prognosis can never be completely accurate, it should be discussed with patients only if they request information, and the uncertainty of the estimate acknowledged. It can be more helpful to provide a framework (for example, describing prognosis as likely to be measured in months, weeks, or days), rather than a specific prediction.<sup>8</sup> However, the uncertainty about prognosis should not obscure the clarity that the illness is progressive and incurable.

### Maintaining hope

Relatives may ask that clinical information is withheld from the patient or delivered to them instead because they fear that the patient will be unable to cope with the news or lose hope. The GMC states clearly that no one can make decisions on behalf of patients who have capacity, and that unless a patient refuses information, withholding information at the request of a relative is not ethically justifiable.<sup>5</sup> It may be helpful to inform relatives of this clear ethical position but give reassurance that if patients state that they do not want information, this will be respected. On the other hand, collusion with relatives

in withholding information may lead to feelings of isolation and anxiety in the patient, potentially triggering complex bereavement problems for the family.<sup>8</sup>

The loss of hope is often cited as an argument against full disclosure to terminally ill patients. However, hope and terminal illness are not mutually exclusive. In contrast, tempering the diagnosis of terminal illness with unrealistic, or false, hope can create false expectations.<sup>9</sup> A clinician sensitively delivering information that an illness is incurable and life limiting does not preclude the patient and family from having hope: to live to witness a specific occasion, for a peaceful death, or that there may be a cure that is beyond the realms of current scientific understanding. Therefore, the challenge for doctors is to communicate honestly with terminally ill patients in such a way that allows hope to be maintained.<sup>9</sup> Breaking bad news is challenging in any context, but the consequences of neglecting this duty may directly affect the trust between doctor and patient, the patient’s autonomy, and ultimately his or her quality of life.

Competing interests: None declared.

Provenance and peer review: Commissioned; not externally peer reviewed.

Cite this as: *BMJ* 2013;346:f2589

legal system in the decades since the development of cardiopulmonary resuscitation.<sup>3-4</sup> Most adults die of chronic life limiting illnesses such as cancer, end stage heart and lung disease, and complications of dementia. In these illnesses the choice between comfort and prolongation of life is usually a false one. Patients with dementia do not die faster without feeding tubes.<sup>5</sup> Patients with advanced cancer do not die faster if they choose hospice or palliative care, and may in fact live longer, even though they are less likely to receive artificial life support.<sup>6-8</sup>

### Focus on best care

The real question is not whether patients should be told that they are “terminally ill” but how can we provide excellent care to patients with incurable, progressive illnesses? Patients do not need to know that they are terminally ill (whatever that means) but what we can and cannot do for them, and what the trajectory of their illness is likely to be.<sup>9</sup> We cannot cure widely metastatic lung cancer, so no one can “choose” to die from it.

Treatments may improve the quality and quantity of life, but these will eventually stop working. Although we cannot say how long any individual patient with cancer may live, we do know that as the illness progresses these

## The choice between comfort and prolongation of life is usually a false one

patients become weaker and have more symptoms, eventually needing help with all the activities of daily living. Pronounced functional decline is a prognostic marker and defines a portion of the illness trajectory where chemotherapy and artificial life support are increasingly unlikely to provide benefit.<sup>10</sup>

In this situation, framing end of life care around the notion of patient choice often creates a tortured situation. We insist that patients be told that they are dying and choose to forgo treatment even when their doctors think that treatments will do more harm than good. Patients think that they are being asked to accept that they are dying and to choose death instead of treatment. Not surprisingly, they often resist both the label and the choice.

Refusal to accept the label “terminally ill” does not improve prognosis, however, and the result is confusion about direction of care, moral distress in clinicians, and anxiety and trauma to patients and their families.<sup>11-13</sup> Patients with advanced cancer and poor functional status do not need to know that they are terminally ill so

that they can “refuse” chemotherapy or cardiopulmonary resuscitation. In most cases they should not be given these treatments exactly because they are terminally ill.

Although patients have a right to the best prognostic information available, they also have a right to ignore that information.<sup>14</sup> To make decisions about care, patients with life limiting illnesses do not necessarily need to know how long they have to live or be informed when they pass some ill defined threshold of “terminal illness,” or choose to accept death. Instead, they need to understand the limitations of disease modifying therapy for their condition; what medical care can do for this disease; what side effects treatments might have; and what may happen as the illness progresses—or to delegate that task to a trusted surrogate.

This is not an argument for deceiving patients, or for reverting to a paternalistic mode of care. On the contrary, it is an argument for honesty about the efficacy of various types of medical care throughout the spectrum of life limiting illness.

Competing interests: None declared.

Provenance and peer review: Commissioned; not externally peer reviewed.

Cite this as: *BMJ* 2013;346:f2560