A case conference revisited: Commentary 2

An obstructed death and medical ethics

Roger Higgs  
Department of General Practice and Primary Care,  
King's College School of Medicine and Dentistry, London

Author's abstract
The dilemma of whether or not a doctor should tell a patient dying of cancer the truth remains a difficult one, as the disagreement between the two previous writers shows.

One favours giving priority to patient autonomy, the other feels the doctor's duty of beneficence should be the overriding principle governing such decisions. To this contributor it seems both approaches have something to offer. By being sensitive to what and how much the patient wishes to know and by learning from the insights provided by the study of medical ethics, doctors can learn how to make better moral decisions in this and in other areas. Both lying and truth-telling carry risks of harm to the patient. Learning to work with and balance these risks is part of clinical practice. So is minimising risks by clear thinking.

A case disturbed a doctor ten years ago. It was written up, and commented upon shortly afterwards (1). Eight years later, in spite of the writing that has emerged in the meantime, the case is still important and commands the attention of two thoughtful non-medical writers. And they disagree.

At the time this case demanded to be published because failure to tell the truth seemed to have done harm in a direct sense to a patient and a family. When I was a medical student I was surprised how the harms of speaking openly (for instance, the possible destruction of hope) had been constantly emphasised in discussion of this issue at medical school. (Scott Dunbar must have felt similarly, since he spends some time in his article looking at the idea that learning the unpalatable truth might lead to suicide.) But in the clinical context the opposing argument about the possible harms of deception were in my experience seldom clearly analysed. In the original case a woman seemed to have been deprived of several months of useful and productive life by being told a lie and was in some sense left in limbo. This required description and comment.

Should doctors tell the truth to patients who are dying of cancer? Peter Byrne, perhaps with a trace of a sigh, defines this as 'familiar territory'. This is a significant turn of phrase. Some ground is familiar because we feel at ease there - there was a time when as a child I misunderstood what a 'relief map' was - but some ground is familiar because it is well known for all that has happened and continues to happen there, that it is somehow problematic or disputed. In geographical terms these are often border lands, where several cultures, races or languages mix. Boundaries change, power and control change, names change. The study of medical ethics works in such a territory of the intellect, where cultures and languages meet: and it thrives not in spite of, but because of, the conflict and challenge. Some areas, like the one considered here, are well known not because we feel comfortable there but because the issues remain unresolved.

Both writers have reminded us of some of the conflicts they see: between theory and practice, between medicine and philosophy, between hope and fear, between truthfulness and kindness. It is also important to look at what they agree about. Both are unhappy about what happened to Mrs Jasper, though Peter Byrne's phrase 'appropriate noises of disgust and indignation' suggests that he may be also concerned that the issue could be taken too seriously or is being handled in an unreal or in an insincere way. (Is it that a patient in Britain is supposed to be just that, and to stay quiet?) Both writers are also interested in looking at relationships rather than rules, in examining trust and in defending truthfulness. But they still disagree.

Relationships are the focus of both papers, in particular the relationship between a doctor and a patient. Trust is seen to be essential. In comparison with Mrs Jasper's experience Scott Dunbar faces a challenging question when he asks why there is usually direct communication in a case of AIDS. There an (often young) individual is faced with a currently incurable condition which he or she may have already unwittingly passed on to others in the closest of all relationships, a sexual one. Such a situation would, we could imagine, put a strong pressure on doctors to fudge or prevaricate. That they don't do so in most instances when the patient has AIDS is very surprising. Perhaps it is just because nothing medically useful of an ultimately curative nature can be done that attending to the relationship and the communications
which occur within it becomes so important. Doctors must come out into the open, and maintain trust as part of the available therapy. This not so with other lethal diseases where styles of behaviour have been built up over many years. Under cover of medical advice, things can be done by doctors which sometimes leave a hope of a cure, the incurable nature of a condition in a specific case may be gratefully hidden. Also AIDS sufferers are articulate and young and may be thought to have more obvious things to put in order than older patients. Thus age emerges as a significant, but surely inappropriate factor when truthfulness is in question in the doctor-patient relationship.

What is this doctor-patient relationship like? Much ink has been spilt here, and Peter Byrne introduces the idea that it ‘ideally partakes of some of the character of friendship’. Some, I agree, but not all: and it is precisely at the point where doctors are not acting as friends, or vice versa, that the discussion should start. Paradoxically, a doctor may have to be more intimate with our bodies than our friends, but may be a great deal less intimate than a friend with our life story, our intentions or our values. Equally professionalism often correctly implies a measure of objectivity, consistency and fairness which challenges very uncomfortably ‘the irreducibly different’ in our relationship with our friends. Referral to another doctor may be one of those accepted behaviours which remind us that a doctor’s fidelity to his calling requires a type of infidelity to the patient. Many things can go wrong at this point, and it has been called with some justification ‘the moment of maximum deceit’.

Peter Byrne develops a concept of faithfulness in communication which is helpfully defined. However, we wait anxiously for an example – but, oh dear, what do we get? An eight-year-old who wants to know about Father Christmas. I believe that many of our difficulties in discussing telling the truth are based on the confusions of childhood experience. (If anyone can find any other good reason why ‘kid’ means ‘to deceive’ in colloquial internationala I should like to hear about it.) But the Father Christmas example reveals all the more what model comes to mind – a child-parent relationship, paternalism surfacing just when we thought that Friendship II was showing at the cinema and we could be discussing adult interchanges. Before we examine Peter Byrne’s more helpful definition of faithfulness in communication, we should ponder on the childhood analogy. If we accept both that being truthful is important but not necessarily the most important principle when principles conflict (and that absolutism is absolutely out), what is to guide us? Surely not age – truthful intercourse between consenting adults only please – so much as the importance of what we have to communicate. If my colleague’s tie doesn’t match or someone aplogises for doing something a bit silly, we are not compelled to go round putting the record straight. But if as I sit with my child at Christmas I realise that the man in the red suit and white whiskers is a known paedophilic psychopath, or if I am an Armenian and the man coming down the chimney is an Azerbaijani with a rifle, I shall tell my child the truth and quick, however old she is. I recorded a discussion between medical students where one remembered the experience of being lied to about her mother’s death when she was six, and was insightful enough to see how it had affected her attitudes to truth-telling ever since (1).

At the other end of the spectrum of importance where something very serious indeed is at stake, veracity might not be the most important issue. There is the knock on the door in Baku: ‘Are there Armenians in there?’ A patient is brought back from the brink of death after a road accident and wants to know what’s happened to the spouse who died. In the latter case the principle of veracity may be set aside because the patient’s welfare overwhelmingly demands that it is: but this is justified properly and is set right as soon as possible afterwards so that trust may be restored and grief handled properly. (Though restoration of trust after racial conflict may take generations.) However, in life in general and in science in particular we expect the truth to be told and expect there to be justifiable reasons if it is not.

Is terminal cancer such a reason? Peter Byrne’s helpful definition moves us on: ‘To be faithful in communication is to be alert to the other’s perceived need and desire to know and to respond to these honestly and with a true awareness of his interests’. We are here faced squarely with what we perceive to be the other’s need and interests. These two things may be very different – a person may feel the need to hide away with his problem, but it may not be in his best interests - but let us assume they coincide. The crucial issue is how do we perceive them, how do we become aware? In the process the answer emerges to the question of the patient who does not wish to be treated autonomously. Nothing in any modern textbooks of philosophical medical ethics that I know or respect would advise the doctor, ‘bearing down on the vulnerable patient’, to see respect for autonomy in terms of unwarranted disclosure to an unwilling patient. The important question is what or how much does this patient want to know. This is defined by the patient, not by the husband or the general practitioner. Sensitive, professional and morally correct doctoring and caring takes account of this vulnerability, as both writers understand. Ultimately the only way the doctor can find out if or what the patient wants to know is to ask the patient. How this is done will depend on the circumstances. A general practitioner may promise to be open whenever he does a test or refers a patient and may then check out what is needed when the patient returns. In hospital this method of proceeding may not be available but approaching the issue with care and sensitivity normally shows what the patient needs and desires.

Most of us, probably, need to live by rules of thumb for most of the time, and then to stop and think and modify if they don’t work out. The rule of thumb for
talking to dying patients should surely be to be open and honest. If the patient doesn’t respond as seems appropriate, more time should be taken so we can get closer to how the patient is thinking. This may be just a question of hearing about his experiences, hopes, fears and values, or it may require more time, a different context or a different person. This is what I think is meant when sensitive and caring physicians in terminal care suggest that doctors ‘wait for the patients to tell them’. If one then understands that there is a refusal to accept information the patient is clearly acting autonomously and the doctor is respecting it. The offer must be made realistically and be truthful in its style of delivery. The intention of the professional must be to communicate, not to hide information (2). Realistic time must be devoted to the discussion and a follow-up or an offer of further discussion given whether the patient has turned down the offer or not. However, if the patient has been offered the chance to be informed and has clearly turned this down by verbal or non-verbal communication, the patient is being treated as autonomous.

But if thoughtful people still disagree there must be other issues as yet unrevealed in this discussion. It is difficult to talk about hope, as false hopes do not seem ultimately to be very helpful things. Helping people to concentrate on the positives may prevent contact with health professionals being a ‘memento mori’. But there still is an argument which says that humankind, if not the authors of their own existence, can at least be encouraged to create their own future. If they are fearful what they fear may be more likely to happen, which is another twist to trust. As an example outside medicine, when the Chancellor of the Exchequer gives an unduly rosy account of the economy this is considered to be justified to prevent economic panic and a further slide in the markets. But this argument for self-deception or otherwise in medicine hinges on what doctors are really saying when they make predictive statements. A doctor’s prognosis is a well-informed guess, not a curse. If there was more openness practised, a patient might be able to use defiance as a positive survival mechanism: ‘I’ll show them’. There are many living who were told it would turn out differently by doctors.

But if as health professionals we use the insights of medical ethics to challenge our behaviour, and decide to modify that behaviour, we should expect, first, to practise to get it right, and second, to be aware that we may not always succeed. Just because there is intrinsic harm in telling lies to patients does not mean that there are not harms or side-effects of being open and truthful. Learning to work with and balance these risks is part of clinical practice. So is minimising risks by clear thinking.

Roger Higgs is Case Conference Editor, a General Practitioner and Professor of General Practice Studies, King’s College School of Medicine and Dentistry, London.

References