Ethical dilemmas in general practice: matters of life and death

Lecture at the WONCA meeting in Ljubljana (June 19, 2003)

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The nature of ethics

The phrase an "ethical dilemma" expresses the same thing twice over in different words. Genuine dilemmas almost always involve ethics; in the absence of dilemmas, there is no place for ethics. I understand ethics to be about distinctions of right and wrong that come into play only when those distinctions are unclear, when different perspectives and judgments are possible and valid. If an action is unequivocally wrong, as in the murder of a child, ethics do not arise, but if, for example, a child is killed as "collateral damage" in an arguably just war, we are immediately and clearly in the territory of ethics.

Medical science has achieved enormous success through the application of general rules to individuals. Given the uniqueness of every human individual, there will always be a mismatch between the general and the particular which leads to the possibility of different courses of action, different views of what is right and wrong and hence a situation within which ethics are fundamental. This is how Zbigniev Herbert, Poland's great post-war poet, put it:

> I invented a bed with the
> measurements of a perfect man
> I compared the travelers I caught
> with this bed
> it was hard to avoid – I admit –
> stretching limbs cutting legs
> the patients died but the more
> there were who perished
> the more I was certain my research
> was right
> the goal was noble progress requires
> victims [1]

Nothing is more particular than the situation of the patient who is dying and so I want to use the rest of my time to try to explore issues of right and wrong in relation to our care of the dying – not the big issues of euthanasia and physician-assisted suicide but the small everyday issues of how we, as doctors, approach the reality and the detail of our patients' dying.

The nub of my argument rests in the famous claim by Bill Shankly, the legendary manager of Liverpool Football Club:

> Football is not a matter of life
> and death.
> It is more important than that.

I want to convince you that how we live is more important then when we die.

The denial of death

Why is it that so few of our patients die what would be recognised or described as a good death? What indeed is a good death? What manner of dying do we want for ourselves and those we love? Talking to friends and colleagues, I discover that many are able to describe their involvement in a particularly special death, where the dying person seemed able to control and orchestrate the process and to die with a dignity and calm which left everyone around them, the doctor included, feeling privileged to have been part of the story and in some strange way enriched by it. But what is striking is how rare these deaths are. So many more are bungled and undignified, marked by overwhelming fear or suffering or both, and leaving those remaining, again including the doctor, with feelings of anger, guilt and sorrow. What goes wrong?

In *A Fortunate Man*, John Berger emphasised the centrality of the role of the general practitioner in relation to death:

> The doctor is the familiar of death.
> When we call for a doctor, we are asking him to cure us and to relieve our suffering, but, if he cannot cure us, we are also asking him to witness our dying. The value of the witness is that he has seen so many others die ... He is the living intermediary between us and the multitudinous dead. He belongs to us and he has belonged to them. And the hard but real comfort, which they offer through him, is still that of fraternity [2].

However, during the last one hundred years, the spectacular success of scientific medicine has allowed doctors to turn away from this traditional role as the "familiar of death". The technological challenge of prolonging life has

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gradually taken priority over the quality of the life lived. By dangerous and insidious processes, we have lost sight of the extent to which how we live matters more than when we die. Perversely, nowhere is this clearer than in the care of the dying.

The hubris of scientific medicine fuels ever-increasing public expectations of perfect health and consistent longevity and these processes are eagerly exploited by both journalists and politicians, and, most of all, by the pharmaceutical industry. The aim of health care and the endpoint against which it is evaluated has become, to a very great extent, the simple prolongation of life. We talk all the time about preventable deaths – as if death could ever be prevented rather than merely postponed. We indulge in activities and restraints that we suppose will make us live longer, and the timeliness of many deaths seems never to be discussed.

Some years ago, an elderly patient on my list was admitted to hospital after she collapsed. She was in her late eighties, a widow and very frail. She was admitted to a coronary care unit and received the highest possible standard of care including fibrinolytic treatment delivered according to the latest evidence-based guidelines. She made a good recovery and was discharged home, apparently well, a week later. I went to see her and found her to be very grateful the kindness she had been shown but profoundly shocked by a course of treatment that she perceived to be completely inappropriate. She explained to me that not only her husband but almost all her generation of friends and acquaintances were already dead, that her physical frailty prevented her doing almost all the things that she had previously enjoyed and that she had no desire to live much longer. No one had asked her about any of this or attempted to discover whether the effective and therefore recommended treatment for her condition was appropriate in her particular case. She died three weeks later while asleep in bed.

Western societies collude in what the English poet, Philip Larkin, described as:

> The costly aversion of the eyes from death [3].

The cost is not just monetary; it is also one, which takes a deep toll of our experience of both living and dying.

The continual emphasis on lifestyle risk factors for disease creates a climate of victim blaming which adds a sense of guilt to the distress and terror suffered by those arbitrarily afflicted by serious disease. We all try to make sense of our lives by constructing a coherent narrative, which includes notions of cause and effect. We want to believe that if we behave well, eat the right foods in moderation, exercise regularly and so on, we will be rewarded with a long and healthy life. Arthur Kleinman reminds us that:

> Cancer is an unsettling reminder of the obdurate grain of unpredictability and uncertainty and injustice – value questions, all – in the human condition [4].

Doctors also pay a price for the "costly aversion". Feeling themselves blamed for every death, they are driven by a sense of guilt and unease to struggle more and more for the prolongation of life, often at the expense of its quality, with the result that:

> – It is now almost impossible to die with dignity in the USA unless one is poverty-stricken [5].

Scott Murray and his colleagues have used qualitative research techniques to compare the experience of dying in richer and poorer countries and have found that while patients in Kenya describe their desire to die in order to be free of pain, patients in Scotland describe wanting to die because of the side effects of medical treatment. This seems a terrible indictment of modern medical care.

I have argued that the hubris of biomedical science is largely responsible for the dangerous and damaging denial of death within contemporary society.

But, in January, visiting Daniel Libeskind's new building for the Jewish Museum in Berlin and standing in the cold empty awful darkness of the Holocaust Tower, I began to wonder whether the genocidal ugliness of so much death in the most recently completed century was at least partly responsible for our aversion; whether the causes were as much cultural as scientific.

The gift of death

Contemporary society seems to have lost all sense of the value of death; of the indissolu-

ble linking of death to life; of death as integral to life. The seventeenth century physician, Sir Thomas Browne was very clear that:

> ... We are happier in death than we should have been without it [6].

Paradoxically, it is death that gives us time and its passing, without which we would be lost in a welter of eternity with no reason ever to act or, indeed, to live. Without death, there is no time, no growth, no change.

In his poem, *Mr. Cogito and Longevity*, Zbigniev Herbert writes of his fear of immortality. Mr. Cogito is Herbert's alter ego:

> To the end
> Mr. Cogito would like to sing
> the beauty of the passage of time
> this is why he doesn't gulp down
> Geleé Royale
> or drink elixirs
> doesn't make a pact with Mephisto
> with the care of a good gardener
> he cultivates the wrinkles on his face
> humbly accepts calcium
> deposited in his veins
> he is delighted by lapses of memory
> he was tormented by memory
> immortality
> since childhood
> put him in a state
> of trembling fear
> why should the gods be envied?
> – For celestial draughts
> – for a botched administration
> – for unsatiated lust
> – for a tremendous yawn [7]

It is no coincidence that contemporary denial of death has been accompanied by a valuing of the length of a life over its intensity. If we avert our eyes from death, we also erode the delight of living. The less we sense death, the less we live.

> The shortness of life should not paralyze us, but stop us from diluted, unconcentrated living. The task of death is to force man into essentials [8].

Most people most of the time want to live forever, but most people some of the time and some people most of the time do not. As Samuel Beckett puts it:

> Better on your arse than on your feet,
> Flat on your back than either,
> dead than the lot [9].

Christopher Ricks describes Beckett as:

> … The great writer of an age, which has created new possibilities and impossibilities even in the matter of death. Of an age which has dilated longevity, until it is as much a nightmare as a blessing [5].

And in *Malone Dies*, Beckett seems to echo Sir Thomas Browne in finding relief in the inevitability of death:

> To know you can do better next time, unrecognizably better, and that there is no next time, and that it is a blessing there is not, there is a thought to be going on with [10].

The challenge for us

There seems a need to remind ourselves as doctors that dying is a part of living and not a part of death, that dignity in dying gives dignity to the life as a whole.

> All I ask is that the last of mine, as long as it lasts, should have living for its theme, that is all, I know what I mean. If it begins to run short of life I shall feel it [10].

There is value, even joy, as well as suffering and fear, in a final illness. With the decline of religion we have lost many of the historical rituals of dying and there is a need to rediscover the chance to share and relive memories, to say farewell, to give and seek forgiveness and to say the things, which should be said:

> "When two people quarrel
> they are always both in fault,
> and one's own guilt
> suddenly becomes terribly serious
> when the other is no longer alive."
> [11].

While there is time, there are always things, which should be said:

> We must talk to each other as much as we can.
> When one of us dies, there will be some things the other
> will never be able to talk of
> with anyone else [12].

Dying gives us an opportunity to make life whole. A sudden death is oddly unfinished and it is perhaps this sense of incompleteness, which adds to the distress of those who are left.

Almost two years ago, a friend rang me worried about his friend who had bowel cancer and whose fear seemed out of control. I asked about my friend's friend's general practitioner. My friend rang back a couple of days later and told me the name of the GP and I was delighted to discover that it was a young doctor who had trained in our practice. But – said my friend – they do not look each other in the eyes.

The same happens in Anna Karenina, when Levin finds it almost impossible to recognise, let alone acknowledge, his dying brother:

> The glittering eyes looked sternly and reproachfully at the brother as he drew near. And immediately this glance established a living relationship between living men [13].

Too often we, as doctors, treat dying as part of death not as part of life and too often we look away.

The earliest painted portraits that have survived were painted almost 2000 years ago. They were found at the end of the nineteenth century in the Egyptian province of Fayum and they were painted to be attached to the mummy of the person portrayed when he or she died.

> – The Fayum painter was summoned not to make a portrait … but to register his client, a man or a woman looking at him. It was the painter rather than the model who submitted to being looked at [14].

John Berger writes about the way sitter and painter "collaborated in a preparation for death" – is this also what is required of doctor and patient? If so, how does one find the moment to start?

> It was the painter rather than the "model" who submitted to being looked at. Each portrait he made began with this act of submission [14].

So perhaps there is a critical moment when the doctor too must submit to being looked at.

There is no flinching in the Fayum portraits. But it is very easy to flinch. Can it be made any easier not to?

The Goya portrait of the Marquesa de Solana was painted around 1795 very shortly before she died. It is extraordinarily like the Fayum portraits with the same steady directness in the gaze, which is almost naked in its vulnerability but at the same time, inexplicably, conveys enormous strength.

The woman in this picture was my patient for more than 25 years until her death in October 2001. She taught me a huge amount about both living and dying. She had an extremely tough life and this picture was taken on the day of her second marriage. Long ago, I learnt that all the huge courage she had was built on her honesty, that she was extremely perceptive and that she could only trust those who she believed. During her final illness – with three primary cancers – mouth, esophagus and lung – she needed me to look into her eyes and not to flinch but for a few weeks, perhaps because her pain was out of control and I was afraid of failing her, I had been avoiding her gaze – but then I managed to look again and it seemed better for both of us.

The poet, TS Eliot wrote that in poetry "honesty never exists without great technical accomplishment" – I suspect that the same is true in medicine.

> Horror can go with a kind of pity. True pity is different. ... Horror is horror, even when it's small and under control and is going with pity [15].

About three weeks before she died, my patient told me that she was happy to be dying and that she wished it could be quicker and she seemed to be trying to say good-bye to me as if she wouldn't be there to see me the following week. I told her that I thought she was wrong about that because she still seemed very strong to me – but how difficult such predictions are. And so I suddenly decided that I should ask her if I could talk and write about her after she had died. She was sitting with her oldest daughter who used to be a patient of mine and her niece who is still a patient of mine. And so I asked her, saying that I would like to because I had learned so much from her – and the two girls promptly burst into tears – but I could see that my patient was very pleased that I had asked such a thing and said that it would be fine. And I went away thinking that sometimes when someone is dying the mind is ready before the body – like it was with her – and much more often – the body is ready before the mind. And when the mind is first, it becomes impatient and sometimes even thinks of suicide, and when the body is first, there can be an overwhelming amount of fear and anger.

Perhaps, the task of medical care is to try and bring the two times into as close a harmony as possible.

In his essay about "Drawing on Paper", John Berger writes that all drawings are either direct studies of life, or they put down an idea or they evoke a memory and that each drawing is in a different tense. But looking again at the Fayum portraits and the ones by Goya I think I see that they touch all three elements and so contain all three dimensions of time – a past and a possible future and a present. Is that their power and their relevance to the doctor's conversation with the dying patient?

A dying friend talked to me a little about how the future somehow disappeared leaving him with only a past and a present. And then he said that, without a future, the past was more and more depressing, and the present seemed terrifyingly brief. This seemed to emphasise how important it is that those caring for the dying recite the achievements of the past within that very brief present – and say the things that are more usually said – too late – at funerals.

The absolute unpredictability of the pace of dying is profoundly problematic both for the dying person and for those who try to keep them company.

> It's like he's having his portrait done, his last portrait, no flattering, no prettying, and no one knows how long it will take. Two weeks, three. Nothing to do but sit still and be who you are [16].

Not knowing whether the process is going to last for months, weeks or hours – not knowing when to say and do things – and then sometimes it's suddenly too late.

> The principal characteristic of our existence is *suspense*. Nobody – nobody at all – can say how it's going to turn out [17].

The German philosopher Hans-Georg Gadamer died in March 2002 at the age of 102. Perhaps not surprisingly he had thought deeply about death and dying. He wrote:

> The doctor is burdened with terrible problems, especially in treating the dying. To what extent may the doctor seek to ease the patient's suffering when what is thereby taken away is not only the patient's pain but also their "person", their freedom and responsibility for their own life, and ultimately even awareness of their own death [18].

Biomedical technology enables doctors to relieve many of the symptoms of dying but Gadamer argues that, in so doing, they deprive their patients of the experience of their own dying. It is possible that, at the beginning of the twenty-first century, our care of the dying is at the point where obstetrics was when women were at last offered effective pain relief but before they reclaimed the right to choose whether or not they wanted it or whether they wanted to try other ways of coping and living with the pain. We use painkillers and relieve a lot of suffering but we anaesthetise people so that they do not feel death and so have no way of making sense of it and in so doing perhaps we devalue the life to which it is so inextricably bound. A "medical" death becomes almost as truncated as a violent one. In *War and Peace*, Tolstoy describes death and dying in a time before modern pharmacology and he also explores systematically the inverse relationship be-

tween free will and inevitability. It may be that by using painkillers and sedation we suffocate any possibility of freedom in death and so emphasise only its inevitability.

In Dirk Bouts' great painting of the Deposition, which is in the Louvre, Christ's mouth is so tense and so obviously parched. And his mother's face manages to combine the agony of loss with a palpable sense of relief that the suffering is over – the pain makes the death welcome.

It seems that all the things that we fight against – illness, pain and ageing – are, in some strange way, the things that make it possible to die. It's almost the same process as when the gradual onset of the indignities and physical discomforts of late pregnancy make the difficulties, demands and sleeplessness of looking after a tiny baby seem like a good idea. It is one of the things that need to be said when someone is given a fatal diagnosis – that you will not die until your body is ready to die – until it reaches the point when it actually wants to die.

The last thing I wish to do is to romanticise or sentimentalise pain but it is also important to recognise that not all pain is bad. Carl Edvard Rudebeck writes about how exactly the same physical sensation of a hand touching you on the shoulder is interpreted completely differently if it is the touch of a loved one at home and when it is the touch of a stranger in a dark street. The same physical input results in completely different physical outputs – one of contentment, the other of panic. And he links this to the fact that the lateral geniculate nucleus, which, as I'm sure you all know, is the part of the brain which processes vision, draws only 20 percent of its impulses from the eye – the rest from other parts of the brain which bring the context of memory and history, and allow association and selection to inform the interpretation of what is seen. Surely, pain must be just the same.

Illness and disease make dying possible – we need to pay attention to the usefulness, the intense human value of a final illness.

Ethics demand the recognition of every individual as fully human. I have tried to argue that, in modern medicine's care of the dying, we do not always achieve this and to the extent that we do not, our care is not fully ethical. Much of what I offer is my own perplexity, but I hope that the dilemmas I pose will provoke answers, which will help us all.

References

1 Zbigniew Herbert. Damastes (Also Known As Procrustes) Speaks. Report from the Besieged City and Other Poems, 1983.
2 John Berger. A Fortunate Man, 1967.
3 Philip Larkin. Wants. In Collected Poems, 1988.
4 Arthur Kleinman. The illness narratives, 1988.
5 Christopher Ricks. Beckett's Dying Words. The Clarendon Lectures, 1990.
6 Sir Thomas Browne. Religio Medici (1,44). 1643.
7 Zbigniev Herbert. Mr. Cogito and Longevity. Report from the Besieged City and Other Poems, 1983.
8 Sven Lindqvist. "Exterminate all the Brutes". 1992.
9 Samuel Beckett. Collected Poems 1930–78.
10 Samuel Beckett. Malone Dies. 1951.
11 Leo Tolstoy. War and Peace, Volume 6, 1865–9.
12 Attributed to both Matisse and Picasso by Francoise Gilot.
13 Leo Tolstoy. Anna Karenina.
14 John Berger. The Shape of the Pocket, 2001.
15 John Berger. To the Wedding, 1995.
16 Graham Swift. Last Orders, 1996.
17 Saul Bellow. Cousins.
18 Hans-Georg Gadamer. The Enigma of Health, 1996.