ETHICAL DILEMMAS IN GENERAL PRACTICE: MATTERS OF LIFE AND DEATH

ETIČNE DILEME V SPLOŠNI PRAKSI: VPRAŠANJA ŽIVLJENJA IN SMRTI

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Abstract

Ethics helps us to discuss and make sense of issues of right and wrong. Nowhere are such issues more pressing than in the care of those who are dying. Contemporary medicine appears, to a very large extent, to have lost touch with the view that how we live is more important than when we die. As doctors, we sometimes contribute to the fictitious illusion that the span of life can be indefinitely extended and in so doing we neglect those who are confronted by death and exacerbate their loneliness. There is a need to rediscover dying as a part of living. Ethics demands the recognition of every individual as fully human, only if this is achieved is a good death possible.

Key words: general practice, ethical dilemmas, death

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Izvleček

Etika nam pomaga razpravljati in doumeti, kaj je prav in kaj ne. Nikjer niso s tem povezana vprašanja tako neodložljiva kot na področju nege tistih, ki umirajo. Zdi se, da je sodobna medicina v veliki meri izgubila stik s stališčem, da je bolj pomembno, kako živimo, kot kdaj umremo. Kot zdravniki včasih prispevamo k navidezni iluziji, da je mogoče življenjsko dobo podaljšati v neskončnost, pri tem pa zanemarjamo tiste, ki se soočajo s smrtjo in tako še poglobimo njihovo osamljenost. Potrebno je ponovno odkriti umiranje kot del življenja. Etika zahteva, da priznamo vsakega posameznika kot človeško bitje in le če to dosežemo, je dostojanstvena smrt mogoča.

Ključne besede: splošna praksa, etika, dileme, smrt

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 (1) 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.

Nothing is more particular than the situation of the patient who is dying and so I want to use the rest of this paper 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.

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

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

How we live is more important than 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 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 more clear 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 (3). We indulge in activities and restraints that we suppose will make us live longer (4), and the timeliness of many deaths seems never to be discussed.

Standards of health care are dictated more and more by evidence-based protocols which, by their nature regard patients as standardised units of disease. Such protocols have no way of accommodating the unique story of the individual; their values, aspirations and priorities. As a direct result, a rational evidence-based intervention of proven efficacy can turn out to be inappropriate, wasteful and futile.

Some years ago, an elderly patient on my list was admitted to hospital when the warden in her sheltered accommodation called an ambulance after she had collapsed. She was in her late eighties, a widow and very frail. A furore over ageism in medicine was at its height and, perhaps as a result, 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 to her home, apparently well, a week later. I went to see her and found her to be very grateful for the care that she had been given 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 (5). She died three weeks later while asleep in bed. The considerable costs of her earlier treatment had been futile, distressing and wasteful.

Western societies collude in what Philip Larkin described as "the costly aversion of the eyes from death" (6). 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.

Such-and-such happened because I did this or because something else was done to me, but the link between cause and effect is often much more tenuous than we like to imagine. The current wave of exaggerated claims for the power of preventive medicine is part of the same phenomenon (7). 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 (8).

Doctors also pay a price. 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" (9). Murray and 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 (10). This seems a terrible indictment of modern medical care.

The gift of death

Contemporary society seems to have lost all sense of the value of death; of the indissoluble 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 (11).

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:

> 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 (12)

It is no coincidence that contemporary denial of death has been accompanied by a valuing of the length of a life over its intensity (13). 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 (14).

The processes by which we have lost sight of the importance and value of death have, in a similar way, transformed suicide from a human right into a preventable disease. Suicide is now held to be the fault of doctors in general and mental health doctors in particular. Undoubtedly, some suicide can be prevented by psychiatric care and, perhaps more, by the more equitable distribution of hope and opportunity within society, but nonetheless suicide remains a human right. More than three centuries ago, Sir Thomas Browne understood that:

> ... we are in the power of no calamity while death is in our own (15).

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 (16). As Samuel Beckett puts it:

> Better on your arse than on your feet,
> Flat on your back than either, dead than the lot (17).

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 (18).

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

> To know you can do better next time, unrecognisably 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 (19).

Ways of dying

The novelist Mary Wesley wrote:

> My family has a propensity - it must be our genes - for dropping dead. Here one
> minute, gone the next. Neat. I pray that I have inherited this gene. I have no
> wish to linger, to become a bed-bound bore. A short sharp shock for my loved
> ones is what I want: nicer for them, lovely for me (20).

This is a frequently expressed view but, on closer examination, it is perhaps just another manifestation of the contemporary denial of death. The belief that a sudden death is better for the person who dies is one that attaches no value to the opportunities provided by a final illness. These include the chance to leave one's affairs in order, to contribute to the planning of one's funeral, to share and relive memories, to say farewell, to give and seek forgiveness (21) and to say the 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 (22).

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.
In his poem *The Dead*, Miroslav Holub also writes about different ways of dying:

> After the third operation, his heart
> pierced like an old carnival target,
> he woke in his bed and said,
> 'Now I'll be fine,
> like a sunflower, and by the way
> have you ever seen horses make love?'
>
> He died that night.
>
> And another plodded on for eight
> milk and water years
> like a long-haired waterplant
> in a sour creek,
> as if he stuck his pale face out
> on a skewer from behind the graveyard wall.
> Finally his face disappeared.
>
> In both cases the angel of death
> stamped his hob-nailed boot
> on their medulla oblongata.
>
> I know they died the same death
> but I don't think they died
> in the same way (23).

At first sight, Holub seems to be arguing in favour of a sudden death, but the first protagonist is already sick and this seems more an argument about the need to live to the limit and to wear out our health rather than to nurse our lives out to the longest possible length (24). It is another plea for prioritising the manner of our living over its duration.
Dying is an integral part of living and part of the story of a life. It is the last chance to find meaning and to make coherent sense of what has gone before. Finding meaning in the story of a life is an act of creation.

> The story of our life is never an autobiography, always a novel ... . Our memories are just another artifice ... (25).

This process of struggling to understand ourselves continues throughout life or until memory and imagination cease to function. The understanding is expressed in words, in dialogue with others or, no less importantly with ourselves (26). Without words, we have no means of containing our fear.

> Children are dumb to say how hot the day is,
> How hot the scent is of the summer rose,
> How dreadful the black wastes of evening sky,
> How dreadful the tall soldiers drumming by.
>
> But we have speech, to chill the angry day,
> And speech, to dull the rose's cruel scent.
> We spell away the overhanging night,
> We spell away the soldiers and the fright.
>
> There's a cool web of language winds us in,
> Retreat from too much joy or too much fear:
> We grow sea-green at last and coldly die
> In brininess and volubility.
>
> But if we let our tongues lose self-possession,
> Throwing off language and its watery clasp
> Before our death, instead of when death comes,
> Facing the wide glare of the children's day,
> Facing the rose, the dark sky and the drums,
> We shall go mad no doubt and die that way (27).

Without words, experience may be more than we can stand. We may be overwhelmed by fear, horror, loneliness or suffering. But if words are to help us in our dying, we need to be encouraged and enabled to use them until the last possible moment. Paradoxically, contemporary society and modern medicine tend to isolate the dying, confining them to something approaching a wordless limbo. Doctors concentrate on eliciting symptoms, both physical and psychological, leaving the greater part of experience unacknowledged and unspoken.
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.

> 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 (28).

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 pain-killers 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 which is so inextricably bound to it. 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 between free will and inevitability. It may be that by using pain-killers and sedation we suffocate any possibility of freedom in death and so emphasise only its inevitability.
Ethics demands 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 is all.

'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.'

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