Shaping our ends: the ethics of respect in a well-led NHS

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Introduction

JAMES Mackenzie was both an eminent cardiologist and a beloved general practitioner. To celebrate him, I too want to bring together two spheres of work — ethics and clinical medicine in general practice. I believe it is not possible to do our ordinary work well, nor achieve real and significant advances for the health of society, without a good sense of the partnership between morals and medicine. We need this partnership always, but particularly when negotiating difficult areas, such as helping people with decisions at the end of their lives. It is my thesis that an improvement in these decisions is a rate-limiting step in the improvement of our precious health service, and that such positive change can only be achieved by being clearer about individual or collective purposes and values. General practice is in a unique position to contribute to a better understanding of these purposes, but a new examination is needed of our frame of reference and of the things we hold dear. The particular contribution that general practice might make is what I choose to call the ethics of respect.

Current circumstances reveal some especially poignant dilemmas. Western societies in general appear increasingly to think that people should be in control of their own deaths, and that lawyers and doctors have yet to catch up with this change in public opinion.[1] Yet, in some places, health service cuts threaten to make it accepted practice to stop offering proper care to vulnerable groups like the elderly.[2] In our country, perhaps partly in response to such issues, general practice (as a major part of primary care) has been offered an unprecedented role in the leadership of the National Health Service (NHS), but this has come at a time of extraordinary lack of interest in this type of work from medical graduates. Meanwhile, general practitioners have at last learnt to care for themselves as essential components of the therapeutic process, but discussion of 'stress' in general practice seems to have lowered morale even further; for many, it has made formerly enjoyable work problematic. What can medical ethics offer in these dilemmas?

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The dilemmas of medical ethics

Ethics has at last been accepted as a legitimate area of study for medicine and is now an essential part of all medical training, but this may in some hands be at the expense of a simplification that has made its thinking too routine, or too 'thin', for the complexities of everyday practice. Medicine looks for answers, whereas ethics keeps on asking questions. Ways of thinking that fit secondary care may not always sit comfortably in the community. Different frameworks are hard to reconcile, and market economics is a harsh taskmaster.

Henry James, the novelist, once expressed delight in having found 'a key that, working in the same general way, fits the complicated chambers of both the dramatic and the narrative lock'.[3] I believe that the sort of work we are going to do now can help in a similar way by finding a key to unlock some difficult ethical issues in clinical practice. This makes proper sense of the expression 'medical ethics', which otherwise might be taken to indicate that the ethical thinking used in medicine is somehow different from ethics used elsewhere. It is not that moral judgements in medicine, about doing things better or worse, are disengaged from these sorts of judgement about good and bad or right and wrong elsewhere,[4] but that the bringing together of the complexities and uncertainties of ethics with those of medicine means that this Jamesian key, to fit the chambers of these two locked-away domains, will have to be carefully designed, with sensitive but truthful simplification, and will have to have a dual purpose. Different keys have been offered and used, but the one that I want to try in the lock today is respect.

A general outline

Kierkegaard is quoted as declaring philosophy to be like sewing: you must knot the end of the thread.[5] The knot at the beginning of this discussion must be the general shape of the ethical framework that clinicians are using at the moment (Figure 1). When patients meet professionals they are part of a system, and become part of a relationship. Both parties may take various *roles*, with related *responsibilities*. For example, they may be friends, or they may be involved in a research project: a doctor may be acting not for the patient but for an employer, or for a life insurance company. The patient may not yet be sure whether she is a patient, and so on. Two very different ways of viewing moral concerns have been outlined by philosophers. One makes reference to the *duties* one person owes another and the rights the other can therefore claim of the one. This way of thinking was put in its clearest form by Immanuel Kant.[6] The other approach starts by considering the *consequences* of whatever actions are contemplated. This is especially associated with thinkers like Bentham and Mill. We probably tend to use a mixture of these approaches,[7] and modern medical ethics has found it particularly useful to work from four well-known *principles*, seeking a balance or negotiation between them.[8] These principles are respect for autonomy, beneficence, non-maleficence (or the minimizing of harm) and justice or fairness, together with an understanding of the limits or scope of each of these (to whom or to what they may apply). How these principles operate and influence each other remains the dominant discourse of medical ethics at present.

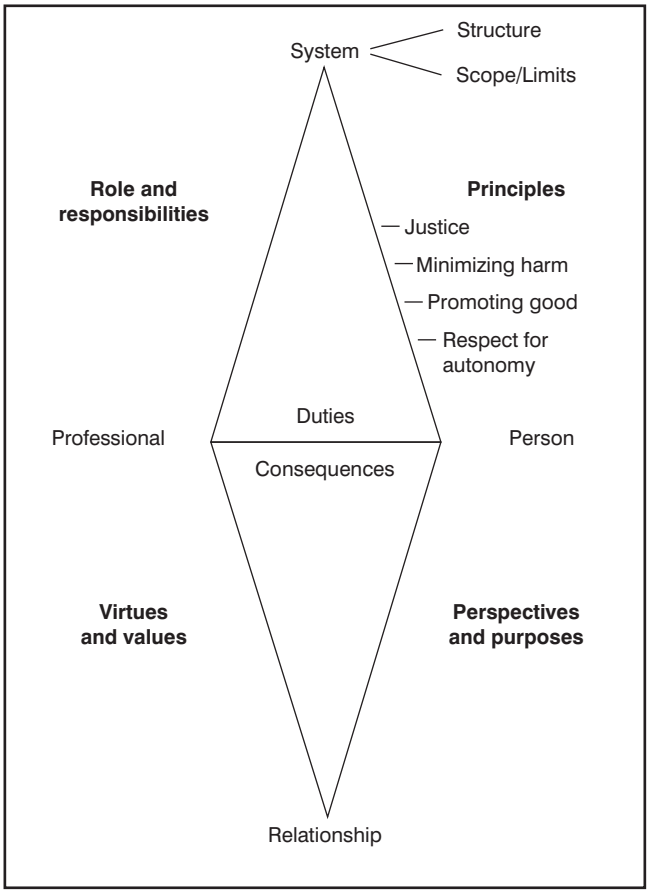

Figure 1. Interplay of the four main approaches of modern medical ethics.

Productive as this work has been, it can seem rather distant from the experience of general practitioners and their patients. To take a philosopher's phrase, we might say that these principles are entirely necessary, but not completely sufficient, for our work in general practice. Of other approaches that have been tried, two have found a particular home in British general practice. One approach returns to some of the thinking of the ancient Greek philosophers, particularly Aristotle, in asking not what a person should do, but what sort of person he or she should be: this is the approach of the *virtues*, and their related modern expression in *values*.[9] Toon[10] and Pratt[11] have both written helpfully and persuasively for us. A second approach, taken by Alastair Campbell and myself,[12] is to examine the *perspectives* and *purposes* of the different players or groups involved, in order to find the best way forward. Interestingly, this is similar to the approach described by Gilligan in her study of women making abortion decisions,[13] and it links with the work of philosophers who show people making sense of their lives by 'narrating themselves' through their own life stories.[14] As general practitioners, we are particularly interested in people's stories as well as their medical histories.[15] It is our particular purposes and insights that I want to focus upon. Are there special stories of care that we can tell that will cast new illumination? In order to do this, I should like to look at two accounts (already published and discussed) of patients and doctors struggling with end-of-life decisions.

The knitter and the sportsman

My first account concerns Miss G, a totally isolated spinster, who was on my list when I was a single-hander.[16] In return for my routine care of her rheumatic heart disease, she declared she wanted to knit me sweaters. There was a painful and extraordinary symbolism about her breast cancer when it was diagnosed, as it rapidly became 'en cuirasse'. At this stage, when cancer spread to the opposite breast, she called me to her home and told me it was now my job to end her life. My shocked denial made her very angry, but she was pacified when, after further thought, I went back to discuss her concerns again. I went through with her in detail how she might use her strong pain-killers to take her own life: I promised to keep her supplied with a full set, and I agreed not to initiate resuscitation measures if I found her in a coma. She seemed to be able to cope with this extraordinary responsibility, and my regular visits after that focused elsewhere. After another six months she died peacefully of pneumonia in her own flat; when the district nurse and I cleared it out, we found the pot of strong pain killers, untouched. At this distance, 20 years on, I feel sure that she had called me because she felt as if trapped in a room totally alone, and when I showed her that the door was open, and that she could leave at any time she wished, she felt able to stay.

My second story began with a phone call from a fellow practitioner, who said that a family of his was at loggerheads with a surgeon at the teaching hospital I was then connected with, and who wanted me to negotiate something before the crisis got totally out of hand.[17] The patient was a retired cricketer, widowed for some time, who had suffered initially from severe unilateral claudication and now had rest pain and incipient gangrene. The surgeon had strongly advised amputation, but the patient was adamantly opposed. He explained that he was a sportsman, and had always valued and lived by his legs — if he was to lose one, he would rather die. The surgeon's response was to suggest that he was confused by infection and incompetent as a result of depression, and that a court order would be applied for to enforce amputation. Luckily, we obtained the services of a humane geriatrician who suggested that this was not a case of a dying leg but of a dying man. Proper terminal care principles were applied, and the old sportsman died in peace.

Shaping their ends

This lovely but uncompromising pair enables us to confront some troubling ambiguities, among them the 'double entendre' of my title. The cricketer had a clear idea of the aims and purposes of his life, and these were connected with his human mobility and fitness in the most general sense. He admitted to being depressed, and asked how he could not be when he was in pain and facing death; but he was sure that this did not prevent him from making decisions about his future.[18] In a similar way, the patient with breast cancer had been the sole arbiter of her moves ever since the war: she had to be in control until the last moment. Both had made a choice that was not just a question of dignity, though this idea was wrapped up in their self-assessment. The struggle of these two brave people to mark out what was important on the little stretch of beach left to them by the incoming tide, and their determination to do so, is not only moving but motivating. They wished the ends of their stories to reflect the ends to which their lives had been lived.

The ends and values of general practice

These accounts will help us to get closer to the ways in which general practitioners and their patients negotiate and look for the way forward. They can make fascinating contrasts with what happens in secondary care, where procedures and purposes may be very different.[19,20] Here, as elsewhere, the medium may define

the message. General practice staff, in particular, are guided by a more demotic, everyday moral discourse. Although the choice must be personal, I believe we particularly respect *ambiguity and space in the encounter, ordinary life and avoidance of suffering, illness and potential, the particular and the complex,* and *ourselves.* I should like to look at these briefly in turn, before considering how these may help us more generally.

Ambiguity and space in the encounter

The first part of my title holds two meanings, but at a much deeper level than I realized when I tracked it to its source, in Shakespeare's *Hamlet*. It comes at the beginning of the last scene, when the hero finally prepares himself for what he must do:[21]

> Our indiscretion sometime serves us well
> When our deep plots do pall; and that should learn us
> There's a divinity that shapes our ends,
> Rough-hew them how we will.

Hamlet has already shared with us his concept of divinity, seeing our 'spiritual intentions' without necessitating any theistic approach. But the 'ends' that he sees being shaped are the purposes he was earlier committed to pursuing, and preparedness for the shape of his own death — a death that includes a larger shape, the death of Denmark as a separate kingdom, and that connects (as elsewhere in the play) the health of the state with the state of health of the leadership. We now all understand that the play too is coming to an end, both in its conclusion and in its dramatic denouement, which will in turn be brought about by the shaped and sharpened 'ends' of the rapiers used in the final fatal 'rough hewing' sword play.

Rich ambiguity is part of poetry, and it comes as no surprise that Shakespeare was its master. But ambiguity is equally part of our own lives and of clinical practice. We need ambiguities, both in our dreams and in our waking conversations, to deal with sensitive or difficult areas like being confronted by the possibility of our own death. In consultation we should be alert to this, and as doctors we should be able to use it — not to slide back into obfuscating professional paternalism, but to provide what everybody at intense and personal moments needs: a little latitude, a little space, someone who will listen without condemning, even if they don't completely understand or agree. To provide this, we need the connections, the overtones, the different levels.

Ordinary life and suffering

The original general practice commentator on Miss G's case, Luke Zander, had concentrated her signals through the sweaters.[16] Giving and receiving presents, enjoying clothes and their messages, looking after people, making and preserving relationships — these are all parts of the reciprocal and supportive nature of everyday life that don't get into medical textbooks much, nor (with certain notable exceptions) into medical ethics. Yet we cannot make proper moral judgements about who people are or what they stand for without considering these sorts of issues, because they are the ways in which we ordinarily express the choices we want to make. When it comes to major moral choices, these are unreal unless they are linked in to this side of our nature. In his extensive study of modern identity, the philosopher Charles Taylor finds the affirmation of ordinary life to be central to the modern expression of how we live and who we are. In general practice, we dismiss this at our peril. When we complain in our work about dealing with 'trivial' problems, we should remember where the word comes from.[23] 'Trivia' is the Latin word for crossroads, the three-way junction where people meet and gossip, certainly, but also where they make decisions about important changes in direction. It was where Hamlet's Ophelia, had she been an ordinary suicide, would have been buried. It was where Oedipus met and slew his father. We should always be able to see through to the important, but to confuse the trivial with the unimportant would be to miss what Hitchcock called a McGuffin — a small incident that leads to the main trail. Condensing encounters into ten-minute playlets may often produce revealing evidence. It is one of the insights of psychoanalysis that this 'acting out' may uncover a different form of reality. The play may be 'the thing' more real than the life, another message from Hamlet. Like that play, our encounter can be read as a detective story or a medieval mystery play, in which meaning is examined in as much depth as our being can muster.

Taylor connects modern views of identity and meaning, linking them closely with our concern to reduce or avoid suffering in every way possible. We want to save lives, certainly, but preventing suffering throughout the biosphere matters very much more now than it used to, perhaps because here at last is a potential resolution of one of religion's most difficult paradoxes. It now seems perverse to chose the way of suffering, either through repressing real emotion or through prolonging physical pain. High moral discourse has often seen in euthanasia the terrible, slippery slope leading to the holocaust: but ordinary moral debate also correctly sees the other slippery slope, to heartlessness and brutalization through our failure to give a proper moral response to suffering whenever we find it.

One peculiarly modern view of suffering acknowledges the pain of having to cope with something without having anyone to speak to about it — the suffering of the unheard story, or the story for which no words can yet be found. I follow the feminist Catherine MacKinnon[24] and the pragmatist Richard Rorty[25] in seeing that helping people to break their silence, or to find their voice, hitherto unheard or unacknowledged, is one of our major moral imperatives. If we are honest we acknowledge that being a person is not an all-or-nothing affair: there are degrees of being, and how people see themselves is all important in that assessment. I see Miss G as understanding that deep form of feminism.

Illness and potential

Where we find limits to our ability to reduce suffering is the beginning of another trail of modern understanding. Sometimes an illness may be more than a dysfunction: it may contain a message. Orthodox medicine may be failing to keep up with alternative approaches when it does not recognize symptoms as potential language. Just as we find it hard to communicate with each other and need ambiguity and space, the same systemic thinking may lead us sometimes to see a person's illness as the physical part of that person trying to communicate with the self. Depression enabled the cricketer to see things more clearly, if more painfully; it contained the therapist's link from possible breakdown to potential breakthrough. Respecting this, rather than blotting it out, is a common modern theme.

Although it has obvious limits, the power of looking at things in this way is enormous. It enables people to make sense of previously senseless symptoms. It returns to people the possibility of power over their own minds and bodies, and where their illness makes no sense we should use our abilities to bring the chaos back under their own control. As general practitioners, we do have the opportunity to help people to focus on their potential — their own untapped resources — as well as their pathology. One way in which we respect autonomy is by pointing out its possibility wherever we can, and by emphasizing the links between autonomy respected and health restored. In our profes-

sional concerns to detect disease, we should not forget that the person who is dying will want to make best use of the time that is left, and that the contacts and insights that are possible allow for real personal growth as the body declines, and for the restoration or re-creation of relationships. By analogy, our job at this stage may be much more like that of a modern midwife than that of a modern medic.

The particular and the complex

For the sufferer, one of the problems about disease, about being a medical 'case', is the way it threatens to eliminate one's own individuality. For the doctor, the need to generalize professionally also contains the 'same case, different face' trap. But our moral perspective supplies the understanding of the unique value of each individual. Whether it is the child's special toy, our best friend or our life partner, there are some 'others' in our lives that we acknowledge to be irreplaceable in the moral sense. While academic ethics has been powerful in examining the universals, it has been less good at examining particularities that prevent the moral cloning of situations or relationships. Philosophers like Martha Nussbaum[26,27] give us a style of thinking that must constantly move from the particular to the universal and back again, testing our ideas, attitudes and plans against both the overarching rules or principles and the context of the events in which we are involved.

This may appear to present us with an overwhelming complexity, but this is the way we normally live. We may have to simplify things to make conceptual progress, but we must always be aware of the moral risk. Respect for complexity must have at least two consequences. The first is that it must remind us about tolerance, giving people the benefit of the doubt when we haven't had time to call all the evidence (and we most undoubtedly haven't most of the time). The second is that people can often begin to find their own ways in this space. The historian Zeldin puts it so well:

> Nothing influences our ability to cope with the difficulties of existence so much as the context in which we view them; the more contexts we can choose between, the less do the difficulties appear to be inevitable and insurmountable. The fact that the world has become fuller than ever of complexity of every kind may suggest at first that it is harder to find a way out of our dilemmas, but in reality the more complexities, the more crevices there are through which we can crawl.[28]

Some doctors have the reputations of being crack diagnosticians. In general practice, a 'crack' physician should be someone who is able to help people to see the cracks, to find the way through in their own way. Ethics reminds us too that, even in the consultation, defining questions may be more helpful than offering answers.

Self-respect

This approach finally puts the lie to the idea of the physician as some form of cipher, some objective agent who can somehow stay out of the frame. We acknowledge that there may be different moral distances for different tasks, but in neither the cricketer's nor Miss G's experience were the views and personalities of their doctors unimportant. The odd thing about the fiction of professional objectivity is that it has also persuaded doctors to pay no attention at all to themselves. But the previous themes will not allow that: we are ordinary people, with ambiguities, with personal and professional personae, with our own potential for suffering and growth, and our own particulars and complexities. For these ideas to be presented in the foreground of medical practice is usually inappropriate, but to ignore them is a recipe for personal and moral disaster.[29] Time for reflection and imagination is not a luxury but a requirement for mental health, and not just in training but throughout our professional lives. If we allow open access or cost-savings to erode reflection in practice, or summative assessment to banish it from training, we destroy one of our most precious moral insights, and one for which general practice can be justifiably proud.

Real respect

This active involvement of a real person in a genuine, if transient, relationship seems to fit much more squarely with what we believe to be good general practice than do more desiccated models. In the principle of 'respect for autonomy' it is very easy to concentrate on the noun and not on the active verb. But medicine is a form of practice, with all the constraints (but also all the depth) that active work implies. In management of a health system or an illness, we need to respect the autonomies of all those who may be involved. We understand that the autonomy of the patient is particularly at risk, but end-of-life decisions remind us how much we should listen to the two people so seldom consulted: the person of the patient (and the professional in that patient) and the person of the professional (and the patient in that professional).

One of the models closest to the one I am offering today is that suggested by Alastair Campbell: that a professional–client relationship is a form of 'moderated love'.[30] But the further dimension of respect is important, because it enables us to value and give effect to the value of concepts (like law or complexity) as well as of persons and relationships. The word 'respect' (like 'regard') has a looking part, and implies a particular sort of gaze that is both perceptive and persistent. It involves attention but also a particular cast of mind, valuing positively (such as honouring) and negatively (not interfering). The gaze is steady and bifocal, not blindly accepting but evaluating at an appropriate distance, and so making a full and rounded assessment.

Zeldin sees that there is a 'world shortage' of respect, but that we are beginning, through our interactions, to increase the supply and to see how this scarce resource can be further increased. Part of that involves giving reality to the values that we can comprehend and communicate in general practice. I have suggested that these include understanding the purposes and processes of ordinary life and ordinary people. I have pointed out some contrasts between secondary and primary care, but also between 'high' and 'everyday' moral discourses. Without these connections, without the dialogue between these different voices and the espousal of the ones less often heard in management and policy making, I believe the health service will plunge even further off track.

Shaping our ends

For us, within the system, there are particular responsibilities. Respect is a doing thing, a verb. It has three 'cases' in grammar. There's the 'they', the public health, objective planners' view, where respect is a resource, scarce but renewable, and a framework to be sure that we've brought all the people and policies correctly into the frame. There's the 'you' across the desk, the patient with potential as well as pathology (how like an angel, even if in disguise). And there's the first person, very singular, very powerful. When it comes to increasing the world supply of respect, there are no prizes for knowing where we must begin.

So I ask, with Fulford, what are the outcome criteria by which

we can judge the sort of work we have been describing?[31] One, I believe, is that we begin to ask more of the right sorts of question. These may relate to the voice least heard, whether of a person or a group, or whether an inner voice inside ourselves. The questions will be about our aims and purposes, and about the different levels at which these may operate. They will acknowledge that at particular times, like the approach to the end of life, certain unspoken things will need to be said, and rhythms hitherto poorly heard will need to be accented. We may need to understand that we should be helping dying people to be as like themselves as they have ever been or can ever hope to be.

The second set of practical outcomes will not be far behind. They will mean that we in general practice will want to know, when we see a really ill person at home or in hospital, what that person would like with regard to interventions, resuscitation and further care, for example. Our practice routines will ensure that the care of those at risk, such as AIDS patients or the elderly, includes an assessment of values, aims and purposes, and that admission letters, clerking outlines and ward routines are altered. Personal views in the *British Medical Journal* are often by doctors who are suffering from particular conditions, and for whom the real needs of such people have just 'clicked'. Wonderful as this is, it remains sad (given our unique access, good understanding and daily use of imagination) that we cannot get there before that point, while we are well. Spurred on by my sportsman and Miss G, we can surely begin to understand the ends of the people in our care, and to shape the best ends of our own work. A framework of respect, I argue, will be a powerful tool in this endeavour.

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