

The medical humanities: literature and medicine

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ABSTRACT – The medical humanities attempt to emphasise the subjective experience of patients within the objective and scientific world of medicine. This article argues that the goal of medical humanities can be furthered by literature. Autobiographical accounts are used to illustrate the various ways in which literature can influence and enrich medical practice.

KEY WORDS: literature, medical humanities, narrative medicine

Christina Patterson writing in the *Independent on Saturday* (15 August 2009) asserted:

The big problem with the NHS is the people in it. Maybe they start out wanting to help their fellow human beings, to lift them, as our dear leader says, from pain to comfort, from despair to hope. Maybe they fill out a form in triplicate (two of which get lost) saying they want to help people, and get sent off to training schools: the consultants to one where they learn to flick through a file with a sense of harried self-importance and turn to you briefly and sneer; the receptionists to one where they regard the arrival of a patient as a nasty intrusion in a nice day's chatting, and one to be punished with a lengthy wait; and the nurses...It would be frivolous to mention Abu Ghraib. But tempting.¹

What is at the heart of these sentiments? There is an understandable desire to be treated with respect and compassion, to be understood, and for the objectivity of modern, technologically advanced medicine to be balanced by a more humane approach that takes account of the subjective experience of the patient. In other words that the objective, the cold and efficient not become overvalued or emblematic of medicine to the disadvantage of all that is uniquely human: kindness, sympathetic understanding and compassion that uphold dignity. This is where the medical humanities come in.

The aims of the medical humanities as set out by the Association for Medical Humanities include the desire to:

- contribute to the development of students' and practitioners' abilities to listen, interpret, and communicate, and to encourage their sensitive appreciation of the ethical dimensions of practice
- stimulate and encourage a fitting and enduring sense of wonder at embodied human nature
- develop students' and practitioners' skills in thinking critically and reflectively about their experience and knowledge.²

But, the aims of the medical humanities are more than just these programmatic elements. It includes what Evans refers to as 'understanding what is individual about me, and how my individuality is necessary to treating me'.³ In exploring this question Evans and Greaves discuss two possible options in this programme, either the 'additive' or the 'integrative'.⁴ The former simply referring to the arts or literature merely adding to an existing body of biomedical knowledge whereas the 'integrative' has a more ambitious intention, which is to refocus medicine such that it comes to incorporate within its ambit what it means to be fully human. It is truly an indictment of medicine that it is currently widely regarded as excluding what it means to be fully human.

This paper will explore how literature, in the form of autobiographical accounts, can contribute to medicine. Fiction, drama, letters, poetry and journals can also serve as literary forms of value to doctors but a discussion of these is outside the scope of this paper. There is already wide recognition of the utility of the humanities in undergraduate medical education.^{3,5} However, this consensus is yet to extend to postgraduate medical education.⁶ Charon *et al* have discussed the possible benefits of literature for medicine: literary accounts of illness can teach physicians lessons about the lives of sick people; fiction can inform physicians of the power and implications of what they do; and understanding narrative structure can help physicians grasp patient's stories more fully among other things.⁷ In addition to these utilitarian reasons for studying literature there is the additional objective of educating rather than merely training doctors.^{3,8} In this paper the role of literature in illuminating the lives of sick people will be discussed and the power of medicine to influence patient's lives explored.

Lives of sick people and the power of medicine

Jean-Dominique Bauby's account of 'locked-in' syndrome has done more for our appreciation of the inner experiences of people suffering this condition than any number of clinical texts.⁹ The following passage is instructive:

I have known gentler awakenings. When I came to that late-January morning the hospital ophthalmologist was leaning over me and sewing my right eyelid shut with a needle and thread, just as if he were darning a sock. Irrational terror swept over me. What if this man got carried away and sewed up my left eye as well, my only link to the outside world, the only window to my cell, the one tiny opening of my cocoon? Luckily, as it turned out, I wasn't plunged into darkness. He carefully packed away his sewing kit in padded tin boxes. Then, in the tones of a prosecutor demanding a maximum sentence for a repeat offender, he

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barked out: 'Six months!' I fired off a series of questioning signals with my working eye, but this man – who spent his days peering into people's pupils – was apparently unable to interpret a simple look. He was the very model of the couldn't-care-less doctor, arrogant, brusque, sarcastic, the kind who summons his patients for 8.00 a.m., arrives at 9.00, and departs at 9.05 after giving each of them forty-five seconds of his precious time.

Literature, in this case an autobiographical account, lets the reader into the patient's experience and at the same time reminds them that just as physicians appraise the patient's condition in their role as clinicians, humanity is also being reciprocally judged by the patient. In other words, there is reciprocity of evaluation going on.

The perception that doctors are less than caring, that they inhabit an imperious height that ignores the patient's need for comforting is commonplace. Ulla-Carin Lindquist's account of dying from motor neuron disease, *Rowing without oars*, describes it as follows:

A maxim coined by Hippocrates, the father of medicine, instructs: 'seldom cure, often ease, always comfort'. The medical profession today often cures, often eases, but what about comfort? How can it find time for the comfort aspect of care? I meet many comforters, among those whom doctors call 'auxiliaries'.¹⁰

This is not to say that all doctors are like this or even that most doctors are like this. But, the desire for objective medical knowledge, for clinical detachment and for rational decision making may all militate against taking genuine account of the subjective as it relates to the patient and vitiate expressing compassion for the patient's position. Physicians are trained to stand back, to observe dispassionately, and to apply rational principles to solving clinical problems. But, it may be that this stance compromises our capacity to directly respond to the human dimension of the clinical encounter. It may also be true that there is only so much emotional distress that any clinician can bear without the risk of 'compassion fatigue'.

Autobiographical accounts of illness do not necessarily all seek any excuse to complain about the nature of modern doctoring. In John Diamond's *C because cowards get cancer too*, there is a manifest understanding of the position of doctors:

Statistics tell us that anyone whose job is treating those diagnosed as having cancer will, in around 60% of cases, eventually have to dole out the worst possible news, and you'd suppose that after some years of doing it most doctors will find a way somewhere between the mawkish and the unnecessarily brusque which would serve them comfortably in the majority of cases. I suppose it's testimony to Peter Rhys Evans that he gave us the news white-faced, nervous, with eyes downcast, much as he must have given the news the first time he ever had to, as if it were something both unsayable and already said.¹¹

The delicate balance between detachment from the patient's dilemma and engagement with the patient's tribulation is a lifelong quest and often clinicians fail to achieve the right tone, to express with appropriate words what they know ought to be said. As William Golding put it in *Lord of the flies*:

He found himself understanding the wearisomeness of this life, where every path was an improvisation and a considerable part of one's waking life was spent watching one's feet.¹²

These accounts by patients bring to life how illness adversely affects life, in many cases, in subtle yet pervasive ways, and allow clinicians insight into what is now termed the 'lived experience' of illness. For example, Diamond and Lindquist who as journalists were very dependent on their voices such that their self-identity was more profoundly bound up with their ability to speak than it is for most other people. In referring to his loss of speech, Diamond wrote 'to say that I lived by my voice would be overstating the case, but not by much' and 'The fact is that I am talking: talking is what I do'.¹¹ He concluded 'this is what diseases do to us. It wrecks our faces and our voices and any talents we may have lying around, and makes us separately depressed so that we're unable to deal with the wreckage'. In a similar vein Lindquist wrote '[amyotrophic lateral sclerosis] has deprived me of the spoken word. My speech. The tool of my trade. Today nobody has understood what I said. Fury'.¹⁰

It is easy to forget that the patient is seldom the only person affected by their illness. The impact on family relationships both for good or ill cannot be understated. Mark Seaton writing about the death of his partner, Ruth Picardie, from breast cancer said:

If I close my eyes, and travel in time, I can still feel the delicious weight of Ruth's left breast in my right hand. Eros and, as it turned out, Thanatos gorgeously cupped in my palm. That was before we knew about her cancer. Once we knew, I found it unbearable to touch her there. She never seemed to blame my squeamishness, but in retrospect the lump not only grew within her, but between us, spreading, as inexorably as the cancer itself did.¹²

Knowledge of this possible outcome means that the doctor can explore the varying and multiple kinds of loss associated with illness thereby providing understanding and compassion. Lindquist, in her characteristic direct manner, put it thus: 'How does a woman who still wants to be attractive to her husband learn to accept that in all probability she no longer is'.¹⁰

The manner in which relatives and friends respond to knowledge of a diagnosis of a fatal disease is another aspect of the impact of the illness on others. Parents of fatally ill middle-aged children may wish to continue to want to protect them, utilising a minimisation strategy:

My mother aged 81, says I'm so young that the scientists will come up with some effective medication. She probably knows it's too late. But I agree, to comfort her.¹⁰

Or spouses may too quickly become emotional:

He comes towards me and his face is wet with tears. He comes like a dog with its tail between its legs, and whimpers. Does he want me to scratch him, to stroke him? I drag myself out of the car and say, without meeting the look on that wet face, that this isn't the time for tears. 'How will I cope if you start crying over me now? Perhaps you will be disappointed if I live for years'.¹⁰

Patients present to doctors with clinical symptoms but these symptoms in the home setting have a personal, indeed an intimate, dimension which operates at a register quite distinct from the clinical wherein the intention is to collect and collate in order to reach a diagnosis. What, for example, counts as muscle weakness in a neurology clinic in the patient's life is described as follows:

*The clothes-pegs are grey, wind-ravaged. Hauling the sheet over the line is heavy work. It changes gear from first to third by delaying a while in neutral. It is less painful that way. But I can't press open this clothes-peg. Or any other. I have no strength.*¹⁰

She goes on:

I fall prey to feeling sorry for myself when I am unable to wrap the Christmas presents. I can't even contemplate tying a bow – way back in the autumn I couldn't even tie my own shoelaces – or writing gift-tags.

Why is this important? Symptoms are, in the end, no more than symbols that signal potential pathologies, outcomes and treatments. But, these same symbols are impregnated with meaning and emotional investment in the patient's life. These meanings are certainly no less important, from the patient's perspective, than the uses to which medicine puts the symptoms. It is unarguable that the doctor's role is both to be technically competent as well as humane in his approach. Being humane involves connecting and engaging with the patient's concerns and worries, the patient's understandings as well as misunderstandings, and drawing from the same pool of cultural motifs as the patient so as to grasp the patient's apprehensions. Literature provides a ready source, an insight in to what Scott calls 'the common and shared patterns of response to critical situations, or into unique and individual responses to crises', and may also enrich the language and thought of the medical practitioner.¹⁴

Medical, technical language can and does set physicians apart from patients. At the time when the patient is most in need of support and understanding, clinical language can create a wider gulf, thereby isolating the patient from the proper concern. Diamond described it thus:

*When things go wrong we find ourselves hostage to men and women who use language we don't understand, talk of scientific principles we don't have the learning to grasp, who seem to be more confident than their results would allow, who offer us treatments which seem to work on some random basis which is never explained to us.*¹⁵

Conclusion

Lindquist wrote: 'to work as a doctor is a privilege, with all the contact it gives, all the insights into life, dying and death'.¹⁰ It is true that doctoring is a rare privilege to encounter life in all its variety of suffering, adversity, stoicism and heroism. A clinician's capacity to respond and to be enriched by this privileged position can be furthered by the way that literature sheds light on the human condition.

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