

Medical humanities and medical informatics: an unlikely alliance? Is there a role for patients' voices in the modern case record?

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The modern case record and the role of the patients voice

Immanuel Kant once said "Physicians think that they do a lot for a patient when they give his disease a name".

The individual, experiential side of medicine is nowhere more explicit than in the detailed case history upon examination. It is nowhere more ironically suppressed than in the patient record during treatment. Clinical notes must of course include the values of measurable variables—temperature, blood pressure, fluids in and out—but there seems no reason other than pressure of time (and, perhaps, a reluctance to contaminate the factually indisputable with the experientially unverifiable) to exclude from the notes first-hand expressions of the 'inner' natural history of disease which we may call illness. Of course, phrases such as "The patient complained of ..." may routinely appear, but it would take diligence and perhaps nerve on the clinician's part to transcribe faithfully the patient's attempt to convey the quality of her post-operative pain; "It feels like chewing rubber bands" was Karen Fiser's memorable and, one suspects, despairing description given in the hope that her pain management might be better-targeted, which is to say perhaps better-conceived.¹

The medical humanities calendar in the UK has two national events, the annual academic conference of the Association for Medical Humanities, and the annual conference organised by University College London. The question of writing down what patients say and feel was raised at both of these events this year. In July, Professor Brian Hurwitz gave a keynote to the AMH conference in which he reviewed how medical case notes had evolved from the 18th century and earlier up to the present day, detailing in particular the extent to which the personal has diminished as we approach the present. Hurwitz referred to a contemporary account of Severe Acute Respiratory Syndrome co-written by a sufferer who

was also a doctor, from which the personal elements had been thoroughly scoured, as if by an effort of self-censorship on the part of a clinician writing for his peers. Two months later a participant in the UCL conference made the arresting suggestion that a clinical record ought to have two parallel parts, of which one would be written in the first person by the patient or in the third person by a specific representative of that patient.

Such a suggestion can no doubt be objected to on various practical grounds but its challenge ought to be taken seriously (and the difficulties perhaps overcome or at least confronted) if within the medical humanities we are as serious about the therapeutic importance of the experiential dimensions of health and illness as most clinicians are about the diagnostic importance of those dimensions. We fall ill in particular ways; we will get better in particular ways, too, and this dimension of treatment needs as much attention and deserves as much honour as do the corresponding aspects of diagnosis. The patient's own metaphors of discomfort, distress, disability, regeneration, renewal and re-growth, may guide the design of what we might call 'differential therapy' as acutely as they inform a differential diagnosis—though even this latter is under threat, as we shall shortly suggest.

The obvious way to achieve this seems indeed to be to record the patient's own account, in his/her own voice, *verbatim*, for on-going reference by what may increasingly be a team of clinical carers. Sceptics will lay a number of objections ranging from the inability or reluctance of patients to contribute to a written record, to the unaffordable time and expense required in transcribing. The point has been made by one of our students that study of the medico-literary classics beloved of the medical humanities may itself blunt clinicians' appetites for the authentically-voiced

stories of their own less self-consciously literary patients.

These objections need a considered response. But they concern means, not ends. By contrast, the very goal of promoting the patient's voice alongside that of the clinician is thrown into sharper relief by ongoing debates in the professional and public spheres. In the professional sphere, there is the introduction of the computerised record; in the public, the legal changes that have allowed patients to access their own case notes.

As we learned from Hurwitz, even the doctor's *own* personal voice has steadily been disappearing from case reports as they have become more standardised, even in hand-written form. This decline has been rapidly accelerated by the introduction—particularly in general practice—of the computerised case record. Currently just over 10% of UK general practices are 'paperless'.² This means that when a patient visits the GP he or she does not consult the last handwritten note made about the person or flick through the case record to see what has been written by a hospital consultant, but rather clicks onto a computer screen containing brief summaries of previous visits and standardised diagnoses. Those diagnoses are suggested not by the clinician but by the computer in the form of Read Codes. Now this innovation may have many advantages, not least that the problem of unintelligible—and potentially dangerous—handwriting is overcome. But there is no room in such a system for opinion, suggestion or for concerns which the GP might wish to record to guide a different GP who may have to see this patient next time round. Some systems may be more forgiving in this way than others—allowing more space for conjecture—but the very fact of having to commit your clinical musings to the formality of a computer record is in itself inhibiting. In this way, much that may be useful in the sometimes long drawn out process of diagnosis may be lost. What certainly is lost is any sense of a clinical narrative that is readable as such on the page, either by clinicians or patients. Most clinicians, as human beings, do not instinctively record their thoughts along the tramlines suggested by the electronic record and work is therefore going on to look at how the electronic record can become more than a 'depersonalised [account recording] "information" centred upon the interaction between the individual and the "system" rather than upon the interaction of human beings with one another.'³

The clinical case record in both written and computer form has become

increasingly available to those about whom it is written. Legislation in 1990 allowed patients to access anything in their clinical case notes written since 1991.⁴ The medical profession has been criticised for all too often allowing value judgements to replace clinical judgement; unhelpful acronyms such as 'FLK' (funny looking kid), and 'NFN' (normal for Norfolk) have now disappeared from clinical notes. This openness has allowed scope for the patient's own views to be respected. In the past 'do not resuscitate' orders might be recorded in the case record unquestioned by the patient concerned. Such decisions were made as a result of judgements about the quality of a person's life, judgements, which should where possible be made only in consultation with the patient concerned. In this more open context, the patient's view can be respected because they have the opportunity to examine and challenge the views of those who are treating them.

It is clear, therefore, that the legislation allowing individuals to access their case records has potentially positive benefits in making sure that the patient's personality is represented in decisions about their care. But the conventional written or computerised case record still does not routinely allow for personal entries by its subject. One exception to this is the hand-held obstetric record, given to pregnant women at their first antenatal visit, explicitly including space for the woman or her partner to write in if she or he should wish. We have not found any research to suggest whether or not this opportunity is taken up and if so, with what frequency. However, personal experience would suggest that patients might be reluctant to do so, inhibited by the sense that they were making a mark on a document that was really the territory of clinical staff.

It may be that, although it would be valuable to have personal accounts from patients running alongside the clinical record, there is a kind of deep seated

taboo about contributing to a document that holds so much magical information about ourselves expressed in a scientific language most of us do not understand. The gulf between the selves we see recorded in our case records and the selves we know in everyday life is so great that to try to bridge it could seem impossible. The popularity of recent books written about the experience of illness, particularly cancer,⁵ is proof that this gulf exists and can lead to misunderstanding and pain; and it reveals the need felt by patients who can write (and some who cannot!) to tell their stories in ways that fully reflect their personalities as well as record their experiences.

We have not been able to conclude that there is currently scope for the personal stories of patients to become part of the clinical record. Indeed, there is evidence that even the personality of the clinician is in danger of becoming lost in the increasing formality of the clinical record in its electronic form. It is recognised, however, that this formality militates against the natural patterns of the way in which clinicians work, and against the idea that doctors understand patients from their stories and write them down and interpret them in this way in the clinical record.⁶ The challenge to medical informatics is to allow clinicians to continue this person-respecting way of working while enabling the benefits to patient care that undoubtedly would result from a fully integrated patient record system. There might well be a rather unlikely alliance to be forged here between information technology and the humanities.

As a field of enquiry the medical humanities is perhaps not yet ready to claim distinctive methods and results, although some of its emerging questions—such as concern the picture of human nature ostensibly painted by technological medicine, for instance⁷—could be said to be characteristic of the field. In the case of the centrality of the patient's voice, we are perhaps revisiting clinical, legal and ethical debates that

have run into the buffers of entrenchment, and have *in those arenas* gone stale. Like bioethics debates themselves when, a few decades back, they presented a widely-tolerated arena for expressing social dissent in a society that was otherwise uncomfortable with dissent⁸ perhaps medical humanities enquiries can offer an acceptably and enhearteningly fresh look at questions whose appeal had elsewhere faded through their resistance to consensus solutions. In this case, it may be that the medical humanities' insistence on the intrinsic, as well as the instrumental, importance of the patient's voice is the key to unlocking a stubborn dispute.

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