Value of science for patients

Health(y) Science; increasing value, reducing waste
Federadag
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• Corruption/distortion of biomedical science for financial/career benefit;
• The enduring metaphor of the body as a machine
• The ascendancy of preventive science over therapeutic science;
• The absence of the suffering person
clinical medicine ≠ biomedical science
- acknowledge and respect the essential differences between scientific and medical knowledge - notably, the physician’s complex but indispensable fusion of the theoretical and the practical, the general and the particular, the universal and the existential -

Stephen Toulmin
Knowledge and art in the practice of medicine: clinical judgment and historical reconstruction, 1993.
- make it clear just how far the fusion of medicine with biological science can afford to go, if it is not to destroy the essential character of medical practice and understanding.

Stephen Toulmin

We all recognize certain injuries that almost invariably cause suffering: the death or suffering of loved ones, powerlessness, helplessness, hopelessness, torture, the loss of a life’s work, deep betrayal, physical agony, isolation, homelessness, memory failure, and unremitting fear. Each touches features common to us all, yet each contains features that must be defined in terms of a specific person at a specific time.

Eric Cassell

*The Nature of Suffering and the goals of medicine, 1991*
I invented a bed with the measurements of a perfect man
I compared the travellers 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

Zbigniew Herbert

*Damastes (Also Known As Procrustes)* Speaks, 1974
I have a well-grounded hope that others will continue my labour and bring the task so wonderfully begun to its end

Zbigniew Herbert

_Damastes (Also Known As Procrustes) Speaks_, 1974
… a formulaic, box-ticking, symptom-focused, response in which the totality of the patient's being is unacknowledged, where the unity of the individual is fragmented into discrete non-interacting systems, and where an ‘answer’ emerges from a sterile algorithm.

Jeremy Holmes
The Therapeutic Imagination, 2014
Depersonalisation of public health utilitarianism (in the name of justice)

Depersonalisation of biomedical science
- most of the research devoted to patient care has been more mathematical than clinical.

We have lost our belief that conversation and a careful examination can alter the course of an illness.

Practice

Theory

Practice
The 74 year old who is put on a high dose statin because the clinician applies a fragment of a guideline uncritically and who, as a result, develops muscle pains that interfere with her hobbies and ability to exercise, is a good example of the evidence based tail wagging the clinical dog.

In such scenarios, the focus of clinical care shifts insidiously from the patient (this 74 year old woman) to the population subgroup (women aged 70 to 75) and from ends (what is the goal of investigation or treatment in this patient?) to means (how can we ensure that everyone in a defined denominator population is taking statins?).

Both guidelines and shared decision making fail when they seek to inject certainty rather than do justice to the uncertainty of illness. ...The real challenge is to deal with illness and how it fragments, disarticulates, and renders uncertain the conduct and dignity of human lives.

Hargraves I, Kunneman M, Brito JP, Montori VM. Caring with evidence based medicine. BMJ 2016;353:i3530
The body as object: gaze of biomedical science; what this patient has in common with other patients (normative monological)

The body as subject: what is unique for this person; life context, story and meaning systems (dialogical)
Good general diagnosticians are rare, not because most doctors lack medical knowledge, but because most are incapable of taking in all the possibly relevant facts – emotional, historical, environmental as well as physical.

John Berger, Jean Mohr
A Fortunate Man, 1967
Even the least event had lines, all tangled, going back into the past, and beyond that into the unknown past, and other lines leading out, also tangled, into the future. Every moment was dense with causes, possibilities, consequences; too many, even in the simplest case, to grasp.

David Malouf
*The Great World*, 1990
... no complaint affecting a living being can ever be entirely familiar, for each living being has his own individual peculiarities and whatever his disease it must necessarily be peculiar to himself, a new and complex malady unknown to medicine ...

Leo Tolstoy

War and Peace, 1849-50.
The impersonal constructs of biomedical and social science are far removed from the inner life of fear, love and hope, an inner life which is, moreover, constantly in flux and, often, ambiguous.

Hunt SM. The researcher's tale: a story of virtue lost and regained. In Joyce CRB, McGee HM, O'Boyle CA (eds.) Individual quality of life: approaches to conceptualisation and assessment, 1999
“What I really want as a patient is NOT more time from the doctor, nor any solution. What I want is for the doctor to remain present in the face of my fear and attempts to process the reality of my situation.”
The new holism: P4 systems medicine and the medicalization of health and life itself

Henrik Vogt\textsuperscript{1} \& Bjørn Hofmann\textsuperscript{2,3} \& Linn Getz\textsuperscript{1}
P4SM represents a technoscientific holism resulting from an altered, more all-encompassing technological gaze on human life and related changes in biomedicine’s methods and philosophy.

[The tools of P4SM] also enable continued hope that, however complex, human wholes may yet be defined and controlled by science.

Preliminary results from the ISB ‘Hundred Person Wellness Project’ show how expansive P4SM may become in labelling well people: ‘So far, after having analyzed just a few types of data, we’ve found that 100% of the 100 Pioneers have multiple actionable possibilities’

We are now in a phase beyond medicalization when even health—the “opposite” of medicine’s focus, disease—has become medicalized. Biomedicine, assuming it knows what health is, imposes that understanding on everyone. Medicine used to claim authority over the cracks and interruptions in life; now it claims authority over all of life.

We need to be careful lest diagnostic or therapeutic exuberance in the individual case blind us to our patients’ needs for space and stature.

- immersion in experience and practice produces better questions for ... theory than those that emerge from simply considering extensions of pre-existent theorising.

Pattison S.  *Practical Theology*, 2013.
- there is no view from nowhere and so all writing and thinking that is practice and experience relevant and truthful must be self-aware and conscious of issues such as embodied existence, gender, socio-political context and interest, and behind that of justice and inequality.

Pattison S.  *Practical Theology*, 2013.