Science, society, suffering and the self:

A commentary on general practice for the twenty first century

Kieran Sweeney

Introduction

General practice is at a crossroads. Although the role of the general practitioner over the years has evolved and expanded, for the first time very serious questions are now being asked about our continued existence. In a recent report in the UK, the British Medical Association announced that *'in primary care, the first point of call for most patients could be a nurse practitioner, who would provide the patient with information and guide the patient to the relevant service.*'[1] Although doctors remain, for the most part, popular and respected members of society – repeated polls show this – nearly two-thirds of doctors who qualified in the last 10 years say they regret coming into clinical practice.[2] And while we are bombarded with media reports of health scares – toxoplasmosis, bovine spongiform encephalopathy, hepatitis C – we are continuously brought face to face with our patients, who suffer from chronic dispiriting diseases, mostly incurable, and disproportionately represented among the poorest and weakest in our societies. What, we are moved to ask, is the purpose of medicine?

In this commentary, I take four compass points of general practice – science, society, suffering and the self – and indulge in the luxury of reflecting on them to re-orientate us to the privilege of general practice.

Kieran Sweeney *holds Arts and Medical Degrees from the University of Glasgow, a Research Masters from the University of Exeter, and Doctorate from the Peninsula Medical School (PMS), in the southwest of England. He is a general practitioner, Director of Primary Care Research Governance for the Southwest Peninsula, and a Clinical Fellow at the PMS.*

General practice and the science of medicine

It seems at first sight a truism to say that science is the whole basis of our understanding in medicine. It is the basis upon which all our evidence is formulated, and it is the cornerstone of our explanatory model. It is clear that the advances in science have been of great benefit to patients. People in stable western societies are living longer and much of this increased longevity can be attributed to advances in medicine.[3] But one needs to make a case for being much more critical about the role of science and the type of science we draw upon for our clinical practice. We can consider a brief critique on two levels:

1. The nature of the evidence base we use.
2. The changing model of disease we implicitly deploy in practice.

1. The nature of the evidence base

'Evidence based medicine', reported Professor Barbara Starfield recently, *'is surely a desirable approach to ensuring the quality of practice: however existing evidence is not for the most part appropriate for primary care'.*[4] Starfield identifies three major flaws in the design of the trials, which contribute to the evidence base of primary care. They are, in general, seriously underpowered to detect any but the commonest of adverse events. This means that, when we extrapolate from small or even modest trial populations to large national, or even continental populations, we do not know quite what degree of harm we might inflict on those populations. Second, they fail to take into account the nature of the primary health care people receive while they are in trials: Starfield herself has shown how the absence or presence of a relationship with a source of primary care help can itself be expected to influence the outcome of medical interventions.[4] But the greatest flaw in the evidence based approach is the absence of evidence from comorbidity. A defining feature of the RCT is that it excludes people with coexisting medical conditions as this ob-

scures the attribution of the outcome. Yet we know that one quarter of people over the age of 65 will have three or more co-morbid conditions. What we know less about is how the parallel medications prescribed for such co-morbid conditions might interact over several decades of treatment.

2. The changing model of disease

In clinical medicine, practitioners hold a rational positivist view of science, to a large extent inherited from two philosophers, Vesalius and Descartes, who gave us the mechanical metaphors of medicine, seeing the body as a machine.[5] Their ideas helped shape the model of disease to which medicine has, for a long time, adhered. This is encapsulated in Virchow's triad of disease, which involved the causal organism, the pathological lesion, and the clinical condition.

The point at stake now is that we are moving into an understanding of disease process which is quite different from this. Many patients will attend our surgery feeling well, only to be informed that they are at risk of a potentially fatal disease, as a consequence of a constellation of risk factors which we tell them they have. These are people with hypertension, impaired glucose tolerance or raised cholesterol.

This poses two problems. First it challenges the way we make risk calculations. Second it challenges how we convey those risks to patients.

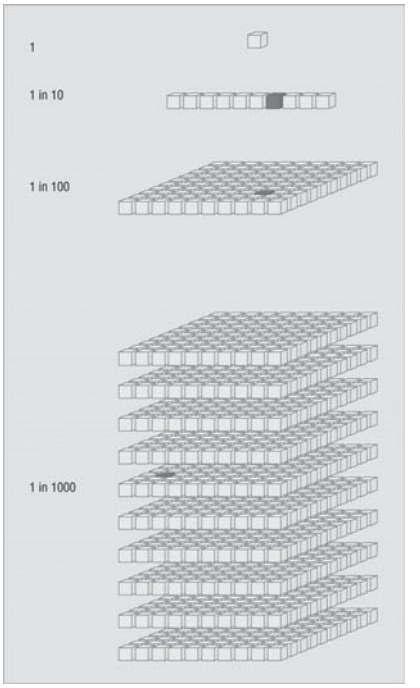
Consider how we clinicians are being asked to calculate estimates of cardiovascular disease. While nearly all the risk scores for cardiovascular disease are based on the Framingham risk equation, Fahey and Schroder have pointed out that this equation does not provide an accurate assessment of an individual's cardiovascular risk.[6] Their review suggests that the Framingham figures overestimate both fatal and non-fatal coronary heart disease by about 60%. There is, also, a documented variation in the way these figures are applied with overestimation occurring in areas where the mortality rate from heart disease is lowest, for example in England, where the average overestimation is 70%. The overestimation is lowest where the mortality from heart disease is highest, for example in Scotland, where the overestimate is about 30%.

Consider also how we convey risk to patients. One recent review of the vocabulary of risk brought together the various metaphors for conveying risk, one of which, a visual scale, is shown in Figure 1.[7]

In bringing together the various risk dialects, this review simply illustrated the poverty of our metaphors for conveying risk: and of course, we can't be sure at any time that patients share the same 'sense' of risk as the advising doctor. This is no longer an arcane debate; being healthy is soon going to become a minority sport. If you take just one European guideline for cardiovascular disease, and extract just two risk factors (BP and cholesterol), three-quarters of the entire European adult population will be identified as being at risk (it's 90% of the over 50s), all requiring external monitoring, and many requiring medication to modify those risk factors.

We calculate those risk factors with an ill-founded authority. Most of our computers have software programmes that define risk over 10 years to within a single digit and then, if there is a family history, we multiply it a bit. This is a form of bullying. Any proposition without at least a hint of doubt about its validity is a form of bullying.[8] When we convey risk in this way, it is like putting a drop of ink into the clear water of the patient's identity; it can never be completely clear again.[9] We are moving into a dangerous form of New Public Health where health is not a normal state of affairs, but the precarious outcome of a continuous struggle, requiring external vigilance, external monitoring and a preparedness to submit to regular screening tests.[10] We are, in short, in danger of creating suffering, rather than alleviating it.

Figure 1. Visual presentation of risk [7]



General practice and society

General practitioners are popular people. We come top of almost all the market research polls that ask respondents to rate their most trusted members of society and we have been doing so for decades. One can argue that it is quite a good time to be a generalist. We can do more things for more people, more quickly and more effectively. We are devising ever new creative solutions to the challenges of delivering health care services. But there is a malaise in the community of general practitioners. More of us regret coming into clinical practice now than ever before.[2] One survey suggested that half of all doctors would not recommend general practice to a junior doctor or medical undergraduate.[11] I speculate upon two factors that might contribute to this.

First there is an anomie in general practice, an uncertainty as to precisely what it is that we contribute to society that no other health care professionals can. This entails a sense that our unique portfolio of skills, a versatile and cost effective commodity, is being undervalued by our governments and our societies. Three years ago the British Medical Association produced their now notorious report suggesting that the

majority of a general practitioner's work could be done by a nurse practitioner.[1] The common policy response to this has been to encourage the development of a community of nurse practitioners on the assumptions that they can either enhance services delivered by doctors, or substitute for them, that they are cheaper to educate, and that they will work where general practitioners will not. While the available evidence only partly supports these assumptions,[12] the consequence for the professional has been uncertainty about our role, coupled with a feeling that our versatility is under-recognised.

Second, we are experiencing 'health scare fatigue', the process whereby we increasingly feel alienated by reports in the media (and journals) about impending epidemics of all sorts of (to us, at least) rare disorders, while we experience the daily grinding chronicity of the common diseases that we see. We are told to expect epidemics of dementia, aortic aneurysm, aortic stenosis and hepatitis C. We are chastised for under-diagnosing meningitis, heart failure, depression and impotence.When we do diagnose impotence we are chastised for not warning people that they might go blind on sildenafil.

Compare these scares with 10 of the most common diseases we see as general practitioners (Figure 2). These are diseases at the centre of the new quality framework of the general practitioner contract of the UK National Health Service.

This list is striking for several reasons. First, with the exception of some cancers, none of the diseases can be cured. Second, one is struck by how often people define themselves by these diseases – I am diabetic, I am epileptic or asthmatic. So greatly do these diseases invade the personhood of the sufferer, that the person becomes defined by the pathology. Third, one is struck by how disproportionately these diseases are over-represented among the poor. The socio-economically disadvantaged have the least democratic control over their predicament, yet the profession, recently, seems reluctant to speak out when we see social injustice contributing to disease. We fail to recognise that advocacy is a form of structural therapeutics.

Figure 2. Ten diseases of the Quality and Outcomes Framework.

• Asthma	• Hypertension
• Diabetes	• Stroke, TIA
• Epilepsy	• Hypothyroidism
• Cancer	• Coronary Heart Disease
• Chronic Obstructive Pulmonary Disease	• Mental Health

So, the tension here contributing to the malaise of general practice has something to do with the contradiction between the health scares we read about in the media and the grinding chronicity of the diseases we see in daily practice; a chronicity which taunts us to speak out more eloquently on behalf of the poor.

General practice and suffering

So what, one is moved to ask as the new millennium gathers momentum, is the point of medicine? Is it, as Berwick recently suggested,[13] to improve productivity in health services? Or is it to improve health? But health is impossibly difficult to define. We laugh at the old WHO definition of the *'state of complete mental physical and spiritual\well being'* and have to turn to the dictionary definition: *'Soundness of body. That condition in which functions are duly discharged, spiritual, well-being, safety and deliverance.'*[14] Tulloch[15] recently attempted another definition, arguing that health was the capacity to adapt to a hostile environment, so ill health could be defined as a failure to adapt to environmental forces and function normally in society. While we might debate the strengths and weaknesses of these definitions, a working definition has overtaken us. The purpose of medicine has become synonymous with the prolongation of life by pharmaceutical means.

I argue that the purpose of medicine is now, and always has been, the relief of suffering. Suffering is an egregiously under-researched term, little acknowledged in mainstream medical literature. One has to turn to the anthropology literature to explore the concept in any depth. Suffering, Cassell tells us, is the state of distress associated with the destruction of the intactness of one's personhood.[16]

We see the destruction of individuals' personhood every day in our practices. Personhood means a person's personality and character; some can remain kind and generous when faced with an overwhelming illness, others truculent at the most minor aberration from full health. Personhood entails a person's family and cultural background, from where the beliefs and attitudes that form the experience of illness, are constructed. The intensity of these connections is conveyed by the metaphors people use to describe suffering in relation to loved ones – 'when I lost my wife, doctor, it was like losing an arm.' But the most important characteristic of personhood, which is destroyed in suffering, is hope. *'Hope exists'* the philosopher McIntyre reminds us, *'precisely in the face of evil which tempts us to despair.'*[17] Suffering shatters hope.

Suffering is the defining feature of the lives of those with chronic diseases. Managing chronic diseases is the defining feature of general practice. The notion of suffering is thus central to general practice. But it has been demeaned intellectually and professionally, so that we now feel strangely uneasy when the topic is raised.

General practice and the self

The importance of suffering, then, is to reinforce the notion of context at the theoretical level. Here, I want to stress the utter uniqueness of the context of suffering and its expression

through personhood. It is that which introduces the need to reflect on the role of the self; not just the patient's self, which is the conventional level of analysis, but of both parties in the consultation dyad, the patient's and the doctor's self.

When introduced into a consultation, the notion of context and its expression through the self elevates the interaction to a new level. We move from the biomedical level of interaction, where the parameters are 'p' values, confidence intervals and risk calculations, to a biographical level, where the parameters are metaphysical: hope, despair, guilt, uncertainty and fear. The clearest examples of this transition occur when care moves from interventionist to palliative, when someone starts to die, or accepts that death is near. But it is met also when the doctor is forced to accept the exhausted impotence, the therapeutic redundancy of interventionist medicine. Here, both the doctor and the patient are confronted by the question, 'When is enough, enough?' This will be the defining question for the next generation of practitioners. Here, the concordance will not be about therapeutic plans but about therapeutic redundancy. The imperative will be to reach agreement about whether the patient has suffered enough.

It is this dilemma that will make demands on the doctor's personhood, the doctor's self, which conventional biomedical training simply does not address. Doctors are people too; we are not immunised by our medical education from the fears, prejudices, successes and failures of normal lay life. We may, over a period of three to four decades of our lives, witness the demise, the slow deterioration, of individuals whom we get to know well, who trust us to help. Doctors suffer in a different way, fearing our mistakes, secretly living with our unrecognised failures, constantly consulting with individuals with incurable illnesses who get old, more sick, deteriorate and eventually and inevitably die, despite our evidence-based efforts. This underlines the importance of the self and reminds us that there are two selves in any consultation.

Science, society, suffering, and the self: reviewing the compass points and changing tack

One can speculate, then, on what needs to change in general practice to address the challenges laid out in this essay. There is an urgent need to redefine the evidence base from which general practitioners draw to inform their decisions. This will entail a greater emphasis on 'n of 1' trials and a move towards different data bases from which to draw conclusions; real time series data bases, in which patterning and dimensionality can be interpreted with the new mathematics of chaos.[18] There will a greater importance attached to Bayesian reasoning and its role in diagnosis.

The profession should be encouraged to look to its roots as a public service and to re-invigorate its role as an advocate for the disadvantaged. This will require a re-birth of the structural therapeutics of advocacy. We live in a society in which many individuals are saved from what would have been fatal clinical events a mere 10 to 15 years ago. People live on to endure chronic disease, which impacts on their lives to a greater or lesser extent. The experience of suffering is, despite our medical advances, as pervasive now as it ever was. The notion demands greater attention.

What skills might be needed to rise to this challenge? We need look no further than the aspiration of Robbie Turner, one of the main characters in Ian McEwan's *Atonement*, an English graduate who decides to embark on a career in medicine.[19] This is what he aspires to and it eloquently encapsulates the challenge facing the doctors of today and tomorrow.

'A modified sensibility the better to make deep readings of human suffering, of the self-destructive folly, the sheer bad luck that drive men towards ill health.

Birth death and frailty in between...Broad tolerance the long view, an inconspicuously warm heart and cool judgment...Alive to the monstrous patterns of fate, to the vain and comic denial of the inevitable... reflecting on the puniness and nobility of mankind.'[23]

References

1. BMA Health Policy and Economic Research Unit: The future healthcare workforce, Discussion paper 9, February 2002. http://www.bma.org.uk/ap.nsf/Content/The+Future+Healthcare+Workforce
2. Le Fanu J. The fall of medicine. Prospect. 1999; 43(July): 28–32.
3. Bunker JP. Medicine matters after all. J R Coll Physicians Lond. 1995; 29(2): 105–112.
4. Starfield B. New paradigms for quality in primary care. Br J Gen Pract. 2001; 51: 303–309.
5. Sweeney KG. A conceptual and empirical investigation into the development and adequacy of explanatory models in modern medicine. Doctoral Thesis. Exeter: University of Exeter; 2004.
6. Fahey T, Schroder K. Recent advances in primary care: cardiology Br J Gen Pract. 2004; 54: 696–703.
7. Calman K, Royston G. Risk language and dialects. BMJ 1997; 315: 939–942.
8. Delblance A. Night vision (Review of Trilling L. The moral obligation to be intelligent: selected essays). New York Review of Books 2001; 48:1.
9. Pereira Gray D. Evidence based medicine and patient centred medicine: the need to harmonise. J Health Serv Res Policy 2005; 10: 66–68.
10. Fitzpatrick M. Commentary on Tulloch A. What do we mean by health? Br J Gen Pract. 2005 Apr; 55(513): 322.
11. Hutt P. Confronting an ill society. Oxford: Radcliffe Press; 2005.
12. Sibbald B, Shen J, McBride A. Changing the skill-mix of the health care workforce. J Health Serv Res Policy 2004 Jan; (9) Suppl 1: 28–38.
13. Berwick D. Measuring NHS productivity. BMJ 2005; 330: 975–6.
14. Cassell's Concise English Dictionary. London: Cassell; 1994.
15. Tulloch A. What do we mean by health? Br J Gen Pract. 2005 Apr; 55(513): 320–3.
16. Cassell E. The nature of suffering and the goals of medicine. Oxford: Oxford University Press; 1991.
17. MacIntyre A. Seven traits for designing our descendants. The Hasting Centre Report. 1979; 9: 5–7.
18. Sweeney K, Griffiths F. Complexity and healthcare: An introduction. Oxford: Radliffe Press; 2002.
19. McEwan I. Atonement. London: Vintage; 2002.