

Preventing Overdiagnosis?

We need fewer systems and more philosophy

Part 2: Geology

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Contemporary medical practice now harvests two new and increasing tranches of diagnosis: first, subjective experiences of discordance, disturbance or distress; then symptomless but risk-linked biometric anomalies. These have led to a massive medicalisation of areas of life often better otherwise understood.

How and why has this happened?

This, the second of two articles, explores these questions through the worlds of two patients and their doctors.

A system is nothing more than the subordination of all aspects of the universe to any one such aspect

– Jorge Luis Borges. *Labyrinths* (1962)

The patterning of distress or risk into biomechanical models and language is one way to describe medical 'diagnosis'. The previous article¹ showed how such technical marshalling is sometimes entirely welcome, leading to decisive cures for many structural physical complaints: these are the kind of diagnoses that bring clarity, confidence and agreement – they constitute a kind of natural or home territory for medical practice. In these situations we pay little heed to questions of personal experience, meaning and agency: when, for example, Penicillin or Coronary Artery Surgery can rapidly cure a life-threatening illness, we are likely to dismiss wider and more personal considerations as being peripheral and unimportant.

So, any kind of philosophical consideration matters relatively little when diagnosis operates confidently in this home territory: questions of personal history, significance or meaning are not important to either the patient or doctor at the time, say, of a massive gastrointestinal haemorrhage. Though if the patient recovers then such personal and existential factors become increasingly decisive: first in healing and then for eventual prognosis. We can see how, while on home territory, our substantial diagnoses² may be questioned for their accuracy, but hardly for their legitimacy.

Elsewhere such confidence and congruence is much less assured. Here, to illustrate, are some scenarios from a working day of Dr G, a long-established family doctor:

1: Waleja and Dr G. Tuesday morning

Waleja is a young mother of two children aged two and five years. For eighteen months she has had dozens of consultations with a succession of GPs, hospital emergency departments and specialists in neurology, gastroenterology and cardiology. Most of these have run batteries of tests, decreed a variety of in-house biomechanical diagnoses and then derivative remedies. Each of these interventions may look competent but her protean symptoms continue.

After several fainting falls she received yet another referral, now to Dr F, a Falls Clinic specialist who arranged his familiar tranche of tests that crystallises his idiomatic diagnosis: 'postural orthostatic tachycardia syndrome'. This tells us little more than she often develops a rapid pulse and then faints when standing. An obscure drug is prescribed. Neither this, nor the arcane sounding diagnosis, changes the pattern of her faints.

Serial diagnoses and their predicated treatments have been applied to Waleja for many months – none has been of enduring benefit: these are all examples of nominal diagnosis, considered in the previous article.

Medically they cluster symptoms into 'syndromes' but often achieve little more.

What none of these practitioners, diagnoses or treatments attempts to engage is the personal geology of Waleja's experience and meaning: what may lie beneath? Who is she? What is her life? How might her symptoms reflect these?

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Waleja is caught in a maelstrom of, first, domestic uncertainty and, then, a web of acrimony. Her relationship with Akbar has departed far from its beginning as a fascinated trans-cultural exoticism: it is now impacted in a poisonous pall of litigious strife. Akbar – now fuelled increasingly by tribally righteous anger and his family's Middle East oil-revenued wealth – is fighting for sole custody of their children and then (Waleja supposes) their extradition to his family, culture, nation and religion of origin. Akbar's clever and expensive lawyers are ingeniously constructing a campaign of 'evidence' of Waleja's maternal unfitness. Waleja – impoverished and on Legal Aid – feels increasingly overwhelmed and powerless. Her many symptoms express intensity of feelings that are beyond her vocabulary or, she fears, others' understanding.

What eventually helps Waleja most is the opportunity to develop *her* personal language and understanding, not the prescribed carousel of nominal diagnoses.² As her symptoms become personally deciphered and contained, they lose their terror, though not all their trouble. Her personal

distress becomes clear; her protean illnesses recede. What enabled this? It was the bespoke skills and space made for Waleja, to accompany her and then to help her make the kind of personal understanding and engagements that were less passive and lonely.

Dr G, Waleja's most recent GP, has seen losses in these kinds of professional skills and possibilities. Two or three decades ago Waleja's distress would have been humanly perceived and deciphered much earlier by most good GPs or General Physicians of his acquaintance: she would have received less rapidly and readily packaged diagnoses and treatments, but the human understanding and response would have been much more likely.

Dr G is thinking of Dr F and the many contemporary doctors who in a similar way seem, increasingly, to process their patients into formatted biomechanical templates while remaining – apparently – uninterestedly oblivious to the larger matrix of patients' lives and personal meanings. How and why is this happening? If we follow Dr G for a while we can draft some answers.

2: Dr G and his colleagues. Tuesday afternoon

There are no conditions to which a man cannot become used, especially if he sees that all around him are living in the same way.

– Leo Tolstoy, *Anna Karenina* (1879)

Having recently offered Waleja some guiding and comforting support, Dr G thinks that more cardiovascular investigations and treatments are inapposite, burdensome and more likely to create than solve problems for her.

After much administrative difficulty he manages to contact Dr F on the telephone. Dr F sounds busy, distracted and then disconcerted by unfamiliar yet direct colleagueial contact. Dr G begins a brief précis of his understanding of Waleja's problems and his suggestions.

Dr F listens with a brief, polite hiatus for about ten seconds before peremptorily interrupting: 'Look, I'm in the middle of a busy clinic. If you've got a lot to say, just email me. I'll look at it sometime later.'

'Well I think that's not the best approach: we need to have a personal discussion. I know Waleja and her situation well and I don't think this diagnosis – "postural orthostatic tachycardia syndrome" – is the best way to understand her symptoms. I think we should parry further tests and treatments pending our discussion.'

'Look', says Dr F again, now more tersely, 'I don't see what there is to discuss. I'm doing what I'm paid to do by my Trust: to provide your Trust with an expert opinion and plan. There are numerous research papers in the specialist journals substantiating the diagnosis. I have a pile of references, if you care to inform yourself. In my view nothing here needs

much discussion. If you disagree with my diagnosis you're perfectly entitled to disregard it – you're accountable to your own employers ...'

Dr G sees any conversational path now impassable with thorned thickets. As he beats a courteous and rapid retreat he feels a deep tug of sadness: he recalls very different conversations many years ago with senior hospital doctors who were then interested in other perspectives – about patients' lives and stories – and about the many other constructions and responses that might be possible. Two words come to him now about those exchanges: *fraternalism* and *philosophy*: he had not used those words then, but as he sees them now imperilled he thinks it important to name them, before they disappear.

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Sebastian (see the previous article¹) faces Dr G with bustling impatience and a large envelope of contended papers. He leans forward to claim proactive space. His voice, too, soon attempts to dominate the space:

'You've got to help me, doctor ... I'm in trouble and it could go to Court...'

Not just one Court, Sebastian explains. His juggling of credit card debts has finally been exposed as fraudulent and uncontainable. More serious (to Dr G) is his failure to pay paternal maintenance to a woman he can hardly remember for a child, that, until recently, he did not know he had.

'You see, doctor, I need a medical report telling them I've got ADHD and that I take tablets for it. I can't get it from Dr P because he's left the country, so you'll have to do it...'

No; Sebastian didn't want 'any of that Counselling and stuff', he just wanted the report.

Dr G is thinking how thirty years ago no doctor was using the idea or language of ADHD. What happened with – and to – people like Sebastian?

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It is the end of a morning of medical-all-sorts and Phrep, the pharmaceutical representative, bids for Dr G's rapidly sinking energies. He is youthfully smart and suited, smiling with amiable diplomacy. His presentation is glossy-brochured and PowerPoint-perfect. Today's sales mission is to get Dr G to prescribe two products: an oral Vitamin D preparation and a new prophylactic asthma inhaler.

Phrep then artfully employs his prepared bait and leverage: mouse-clicking between graphics and statistics to explicate the importance of the problems and the potency of his products.

'I want to show you also how these conditions can present in so many, and often atypical, ways and, therefore, how doctors are massively

underdiagnosing – and therefore *undertreating* – these serious conditions.
The risks to patients become evident...'

Phrep's delivery is polished and sounds sincere. Dr G admires its apparent cogency but is doubtful about its integrity. Phrep sounds like a sophistic politician working a tired electorate and Dr G is aware his script accords entirely with the commercial interest of his employer, Big Pharma Inc, and thus Phrep's pay.

Dr G thinks, too, doesn't every specialist and researcher, lobbyist or fundraiser, maintain that *their* area of interest receives too little recognition, interest and money?

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3. Dr G in respite. Tuesday evening

Dr G prepares to leave his long working day: a vortex of so many kinds of demands and dilemmas. He is dizzied into a now familiar state of vigilant exhaustion: a kind of sediment from his many navigated compromises. He sits quietly now to mull, and settle in himself, this tense and kaleidoscopic professional world.

He is thinking about the word 'diagnosis' and its implication of compact authority and precise pragmatism. And yet how – in its many derivative

roles and guises – it often takes on very different qualities. How and why does this happen?

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Dr G can see that ‘diagnosis’ often starts as an essential device to dissect out common knowledge in any particular situation: it finds and defines what is generically ‘true’ with any kind of problem. But to define a generic truth we must make important exclusions: in practice diagnosis cuts out *individual* considerations and variations, treating them as a kind of extraneous and contaminating ‘noise’. So in order to assure a lean and clear system, diagnoses must first eliminate human vagary and meaning. Yet such efficiency-seeking systems then create secondary problems – for it is *only* through these latter, speculative, considerations that we can best understand *this* person and *this* situation.

In this way systems and philosophy are countervailing: systems attempt to extinguish doubt and ambiguity; philosophy attempts to ignite them.

Over many years Dr G has found that while his diagnoses work well with evident and acute biomechanical breakdown, this is very different if he attempts to cluster and systematise human complexity. Usually he soon realises that the ineffectiveness of such diagnosis here – with human complexity – needs much imagination, adjustment and flexibility.

But discretion in these matters is not easy: *because* diagnoses work so well with their initial task (more definite and structural physical illnesses) they have become aggrandised, promoted and executised to deal in a similar way with any and every kind of discord or discomfort that presents to a healthcarer. Diagnostic thinking then becomes the bedrock of all interactions and exchanges throughout healthcare: it becomes the singular convention of the consultation and its Mother Tongue: if we are not very careful its mandated tongue. Healthcarers now speak it because all others do, and it is assumed as the one language they can be confident and fluent with. Dr G thinks that Dr F felt empowered by, but was also in thrall to, this convention. He senses that their tense discord was due to the convention being broken – a taboo.

So diagnostic and technical language can convey – or at least illusion – many things: authority, a sense of professional belonging and identity, an aura of clear, definite – even powerful – knowledge. But the latter may be specious, and then the diagnosis becomes an Emperor-without-clothes. Yet our need for a magical sense of containment or mastery often resists unsettling this delusion. We continue to propagate it into unviable territory.

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Dr G thinks now of Sebastian and his insistent hunger for a diagnosis. Probably Sebastian thought that ‘having a diagnosis’ could lead effortlessly to his ‘not having’ a complex human problem of identity and

integrity. Sebastian's psychiatrist, Dr P, colluded with this self-alienation, forming a cordial, but shallow, bond. The psychologist, Si, risked a tack of greater integrity but was quickly cut off.

Dr G has seen these kind of diagnoses mushroom in the last two decades. Why are they increasing in this way? He can see how an increasing number of people – like Sebastian – want their problems to be split off, taken away from them and 'fixed' by an expert. Most of us want to be swiftly unburdened of difficulty, discomfort or responsibility. This may have always been so, but accelerates with modernity as our ever-increasing advances in technology have rendered us a push-buttoned world where physical wishes and expectations throughout our lives become not only possible, but our prerogative.

And, of course, the specialists become similarly invested: they necessarily create their careers, professions, salaries, faculties and academic exchanges by elaborating their particular systems of diagnosis and, then, requisite treatments. Belief and sincerity usually follows such social economics: in medieval times Papal emissaries selling after-life heavenly plots – 'indulgences' – wrote with impressive fluency and theological rhetoric of their mission and commitment.

And what of broader commercial interests? NHS Trusts now commodify diagnoses and treatments, and then tariff and trade in them. So then both individual and institutional professional survival depends – increasingly – on diagnosis being invented, manufactured, distributed and sold. And

beyond our health services are the gigantic pharmaceutical industries. To assure their stake in the growth-economy they need more patients to have more treatable diagnoses. For Big Pharma Inc and then Phrep it is essential to recruit practitioners like Dr G to do this.

This is a sticky web, hard to escape from.

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It is hard to resist being lured by the apparent objective clarity and certainty offered by some diagnosis: we hope that such short-circuiting will unburden us of our many difficulties of human complexity and ambiguity. We can see how that lure is redoubled by vast, multi-tentacled economic forces. So it is then even harder to stop the original pragmatic and solid sense of our older, traditional diagnosis becoming destructively mutated by overgrowth. Our resulting overdiagnosis then behaves like a neoplasm – it derives from healthy tissue but is not the same and will propagate in such a way as to destroy the health of the host tissue, and beyond.

So what can Dr G do? He can, at least, understand and identify these lures and traps and then buttress himself against them. To do this he will need to stand against the tide. He will need to secure his autonomous head-space and heart-space to not merely tolerate – but then embrace and find meaning in – each person's complex humanity. That is one essence of holism.

This mixture of philosophy and fraternalism lies behind whatever healing or palliating influence Dr G can muster. Many decades ago the work of Michael Balint³ introduced him to the importance and possibilities of such work. That wisdom has now all but vanished in the ineluctable rise of our healthcare's managed industrialisation and commerced commodification.

Overdiagnosis is just one – though serious – symptom.

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Such are Dr G's thoughts at the end of a typically demanding day. As he closes his surgery door behind him to leave he is simultaneously both sagging with exhaustion while still buzzing with ideas. He glances at his watch: yet again it is much later than he had supposed.

What else can he do?

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God is on the side not of the big battalions, but of the best shots

– Voltaire, *The Piccini Notebooks* (c 1750)

Notes and references

1. The previous article is *Part I. Preventing Overdiagnosis? Yes, but what kind?*
2. The terms *Substantial Diagnosis* and *Nominal Diagnosis* were defined in *Part 1 of Preventing Overdiagnosis. Yes, but what kind?* The notions were originally published much earlier in Zigmond, D (1976), 'The Medical Model: its Limitations and Alternatives', *Hospital Update*, August, 424-427.
3. Balint, Michael (1957). *The Doctor, His Patient and the Illness*. Churchill Livingston