

Preventing Overdiagnosis?

Yes, but what kind?

Part 1: Geography

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'Preventing overdiagnosis' should be an undeniable call. Yet even to agree a definition may prove impossible. To understand why requires us to look far beyond the workaday tenets of our professional practice: the hinterland is vast. This is the first of two parts.

I must create a system or be enslaved by another man's.

– William Blake (1804-20), *Jerusalem*

Introduction

The mission to 'prevent overdiagnosis' seems undeniable in its common sense and importance. Who would want to obstruct or deny such wholesome counsel?

Yet in our efforts we will soon find that – as so often – any slogan is soon choked by the complexity of the problems. It is like 'abolishing poverty' or 'stopping addictive behaviours': the determining motivations are often encoded and elusive. In addition, there are vast economic and cultural forces. Fears of uncertainty and rising litigation, consequent defensive herd-behaviour, our ubiquitous industrialisation and overpackaging, formulaic investigation displacing personal understanding ... all are here in overdiagnosis. None are easily undone. In the face of all this any slogan to *Reduce Overdiagnosis!* will blow away as rootless tumbleweed.

This essay explores such complexity. Understanding it is akin to charting new territory that is obscure and often treacherous. As with the early terrestrial explorers we may benefit from two basic approaches:

Geography can help us configure both broad and detailed outlines – the visible 'land mass' – of our overdiagnosis.

Geology then defines the problem's less visible subterranean: what lies beneath – how our problems have arisen and what they are made of.

From these profiles we can construct 'maps', and maps can guide us in what to avoid and where to navigate. They can also direct us to where we might, later, best prospect: where we might succeed.

A: Geography: where is overdiagnosis?

Big mouthfuls often choke – Italian proverb

Maybe we should first ask: what is the evidence that overdiagnosis exists? We can never give a definite answer to this because all measurements or estimates involve contentious judgements and conflicted interests. For example, allopathic specialists or pharmaceutical manufacturers will have a very different view about robust and meaningful diagnosis – what is a 'real' illness – from those tending to healing or holistic practice, or social perspectives.

Who is to decide?

But certain facts are incontestable. Generally, not only are we living longer, but also our earlier lives are far less hazardous. Yet within these longer – and mostly healthier – lifespans we find doctors applying an ever-greater number and variety of diagnoses to these healthier patients – with or without their consent. So we are both healthier *and* harbour more illnesses. A paradox, surely?

How do we explain this? And what are these new and proliferating diagnoses?

We need here to consider different forms of diagnosis and their nature: *structural* and *functional*, *substantial* and *nominal*, and, finally, *biometric*.¹

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Much of our increasing and newer diagnoses consist of 'Functional Disorders'. These are labels for clusters that we apply when we cannot objectively find change in the body (particularly its *structure*), yet the subjective experience of the *function* of the body or mind remains dis-eased or distressed.

Within the rubric of mental health such ailments mostly become systematised as some disordered form of *BAMI* (behaviour, appetite, mood and impulse).

Categorisers of psychological and psychiatric syndromes have, increasingly, attempted to schematise and name almost any marketable form of human discordance or distress: disobedient children, sexual proclivities or disinclinations, gender identity confusion and social inhibitions are examples of recent recruits to our disease lexicon. This illustrates the way many specialties continue to grow: they colonise the troubles and vicissitudes of ordinary life. Potentially then, all our difficult humanity can be deemed 'pathology'.

In physical health we have a similar expansion to our range of functional disorders: varieties of migraines and headaches, irritable bowel syndromes, sleep disorders, fatigue and low energy states, muscular aches and pains, menstrual and menopausal discomfort ... the list is very long and continues to grow.

So what is happening? How do we account for this fecund spawning of diagnosis in a *healthier* population? It seems that if the wearer's body, mind or life does not fit or feel right it is now healthcare's task to find, or create, a diagnosis.

But perhaps the boldest initiative of diagnostic colonisation has come with the rise of 'biometric diagnoses'. These pathology attributions are made by health professionals to patients who have no symptoms or disabilities but are found, on routine testing, to have a (statistically) abnormal measurement that is deemed to (statistically) increase the risk of developing structural and symptomatic disease in the future. So a risk factor (a future possibility) becomes conflated with a physical disease (a current actuality). Common examples are Hypertension, Hyperlipidaemias, Subclinical Hypothyroidism, low Vitamin D and much of mature-onset Diabetes. Inevitably, the more we measure, the more statistical deviance we reveal and then the more diagnoses we are urged to make. Medical professionals find this responsibility now almost impossible to deal with, yet hard to resist or jettison. This is often due to pressure from management, peers and the spectre of litigation. Diagnosis increasingly must deal with the possible as well as the actual.

Our bounteous diagnostic catch now has parallels to our industrial trawler fishing of the seas: enormous and fine-meshed nets can corral and trap almost every macroscopic maritime creature for processing. But the larger the net and smaller the mesh the more indiscriminate the catch: we risk first the elimination of 'irrelevant' individuals (eg dolphins or sharks, rather than sardines), then whole species, and eventually the ecosystems on which we all depend.

In a similar way healthcare's ever vaster and finer diagnostic screening nets catch commensurately greater yields. But this is achieved only at the expense of the excess or the unwanted. When these are maritime creatures they are separated, die and are then dumped overboard.

But what happens to humans, with the over-catch of our diagnoses? At its least harmful overdiagnosis impoverishes our health-economy: it wastes time and resources on unnecessary investigations, procedures and drugs. More harmful is the unanticipated adverse reaction, catastrophe or even death from vaunted but redundant activity: adverse reactions to lipid-lowering drugs are common; deaths from prostate biopsies are much rarer, but evidently tragic.

Equally problematic is the nocebo effect of diagnosis. Diagnosis can easily connote, for the recipient, notions of dread, loss of agency, or ineradicable flaw.

Here are two examples of the power of such unaccounted vagaries:

Example: Sebastian

Sebastian, an uneasy and agitated man in his early thirties, has trouble maintaining commitment and interest. His relationships with potential mates soon disperse into promiscuity rather than anchoring in growing intimacy. Dr P, a psychiatrist, has told him he has Attention-Deficit Hyperactivity Disorder (ADHD) 'which is a brain abnormality' and for which medication has been prescribed. Neither the diagnosis, nor the explanation, nor the tablets have helped.

A subsequent psychologist, Si, attempts another tack. Sebastian's family is solidly and conspicuously Roman Catholic in belief. Sebastian, too, is publicly avowed and committed; his vigorously scattered sexuality – the concealed rebellion against his faith – remains an anxiously guarded secret.

Sebastian parries the psychologist's best efforts to consider how this hidden conflict might be driving his symptoms. 'No', he says, 'it's private and I don't want to talk about it. The psychiatrist said all my problems were due to ADHD...'

Short-term the diagnosis would suit Sebastian and his psychiatrist, and the psychiatrist's marketised Trust, very well. But what happens longer term?

Example: Heloise

Ever since Heloise had a 'borderline abnormal' Cervical Smear two years ago, she has had ill-defined gynaecological complaints, especially discomfort connected with intercourse. Neither her GP nor gynaecologists have been able to help or clarify this problem.

In a much extended and less structured consultation Heloise unwrapped much of her internal world. Prior to her smear she had given, and received, much joy and pleasure from her sexual self and anatomy. In her mind's eye these were sources of sensuality and life: libido. 'Since that [smear] test, doctor, I keep thinking I might have something bad – cancer or something – down there ... I can't give to him [her partner] like I used to

... Yes, doctor, I know what you think about that being irrational, but I can't stop thinking and feeling like that...'

Diagnoses can have very different meanings for patients and doctors. Their power, both as placebos and nocebos, is much more considerable than deliberate. Even with good personal knowledge of people such effects are difficult to predict.

B: Geology: what is overdiagnosis?

If it works it is true – Lord William Kelvin (1824-1907)

Geology tells us what lies beneath the visible shapes of our land masses: what they are made of, their history and why they are there.

But before we consider this, it is necessary to clarify the nature of diagnosis itself: its sources, purpose and limitations.

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Diagnoses are systems: they are our devices to cluster commonalities of ailments for our purposes of identification, prediction and control. So, when a diagnosis works well it tells the practitioner what is the topography of a problem (identification); what is likely to happen, with and without intervention (prediction); and most crucially (usually) diagnosis tell us where subsequently to look for levers of control (manipulation). All diagnoses draw from commonalities, so they are mostly

regardless of individual experience, variation or meaning. Their 'reality' is confined to, and defined by, consensus and objectification.

All this has very secure home-territory. In our modern era of medicine many diagnoses have been dramatically successful in curing, sometimes eliminating, structural disease. Hip fractures, ear infections, appendicitis and cataracts are all common conditions that are cured with great efficiency due to diagnostically-centred treatments. Previously they were fatal or ruinous.

These kinds of diagnoses – of structural change – can be termed 'Substantial Diagnoses'. This reflects their real powers of designation, prediction and manipulation: and because these powers are both evident and successful they are little contested. With few exceptions these are not the subjects of overdiagnosis allegations. In Lord Kelvin's understanding most of these diagnoses are 'true'.

Elsewhere – away from the solid ground of substantial diagnosis – the problem-territory is very different and so, then, is the preeminent role of diagnosis. With functional disorders we find that although diagnoses can assemble coherent topography (accurate sounding identification), they become much less effective in either prediction or manipulation. Instead, with these kinds of diagnoses, we find ourselves left without either much understanding or relief of our ailments. For example, a proffered diagnosis of 'Depression' or 'Chronic Fatigue Syndrome' may sound assured, but usually offers little of the kind of authoritative prediction and prescription that follows so many Substantial Diagnoses. For this reason they can be called 'Nominal Diagnoses': mostly these consist of functional problems – ailments now mostly and increasingly presented to GPs and mental health services. When we

add to these the new species of biometric disorders, we can account for most of the contended territory of overdiagnosis. Lord Kelvin would have struggled with claims to their 'truth'.

However, lack of clarity and effectiveness does not protect us from their increasing overuse. Why and how does this happen?

Part 2 considers these questions.

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Seek simplicity, then always mistrust it

– Alfred North Whitehead (1861-1947)

Note and reference

1. *Structural and functional pathologies and their equivalence in substantial and nominal diagnoses* were first described in a much earlier article: 'The Medical Model: its Limitations and Alternatives', Zigmond, D, *Hospital Update*, August 1976, 424-427. *Biometric diagnosis* is a much more recent, now timely, concept.