Diagnosis, Linguistics and Healthcare:

Why common medical language is often mythological

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How we use words has enormous influence on how we see and approach others. The ever-increasing use of medically-derived vocabulary is often much less helpful than hoped or assumed. Why does this happen? And what is the price?

> *When you know a thing, to hold that you know it; and when you do not know a thing, to allow that you do not know it; that is knowledge.*
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> – Chuang Tzu. *The Music of Heaven & Earth*. 4th-3rd C BC

The morning news of 18th August (BBC Radio 4, *Today*) had an intriguing and bewildering (to some) brief feature: a NICE working party could not agree on their practice guidelines for ME (myalgic encephalomyelitis) or CFS (chronic fatigue syndrome). Not only that, for there was such discordance that, exceptionally, three members of the committee abruptly resigned.

An expert was designated and interviewed: he said with paternal calmness that there should not be such contention about diagnosis, and that good treatments, ie CBT, were often helpful.

No, they are not! retorted a selected patient. CBT does *not* 'work', and in any case many were angered by the very prescription of CBT: this propagated the untruth that these conditions are caused by factitious mental mechanisms. Her resentment is widespread, she said. Not only about that but also the longstanding ineptitude of practitioners to either understand or relieve our complaints. More funds, research and training are needed, she concluded fractiously.

Such severely fracturing discordance is probably unprecedented within NICE's history: there may often be manageable technical disagreements about, say, chronic glaucoma, recurrent cystitis or acute sciatica, but useful consensus will usually and readily emerge. So why such an impassioned kerfuffle?

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One clarifying perspective on this may come from examining how we frame and name both our experience and our activity. These are areas of enquiry that academics colonise and then dauntingly designate: epistemology, cognitive science, linguistics … and many more, even more arcane sounding. But we can avoid getting lost in any academic maze or quicksand and, instead, simply study the words we use – their common assumptions, meaning and intent – because our use of language tells us much about how we operate, often with lost awareness, of these: our own assumptions, meaning and intent.

So what follows here is a kind of careful dissection of just four words and terms that were used in the BBC impassed exchange:

1. **Diagnosis**. Many people think of a diagnosis as a kind of definite 'thing' or fact. This is often spurious: our better understanding often comes, rather, from our considering diagnosis as a tool or system for grouping similar subjective experiences or objective observations. So, for example, feelings of misery or listlessness are subjective experiences. A bloodshot or jaundiced eye is objectively observed. Often the two converge: the 'no-go' feeling that is then found to be due to measurable anaemia; the broken hip that leads to the private world of intense pain.

   So diagnoses are thus a kind of administrative activity: like a filing system where we apply a language or code that becomes an agreed convention for our clusters. By grouping together subjective experiences and/or objective observations we hope to be helpful through classifying perceived patterns, and garnering commonalities. Why do we do this? Well, diagnoses have three main functions:

i. *Description* and then named classification. We usually feel better if we can name things or experiences. Something becomes more 'real' if it has a name, and that helps us feel less isolated: others can recognise what we have; we are not dealing with the unknown, alone.

ii. *Prescription*. A well-functioning diagnosis indicates what we should do either to help ourselves, or to enlist known technical interventions from expert professionals: 'treatment' or 'therapy'. A poorly functioning diagnosis cannot do this, in which case neither we nor the professionals know what to do, though – in our unexpressed hope, fear, shame or frustration – we often try to convince ourselves or others otherwise.

    We can call the former a *substantial diagnosis* in that it has potency and leads to 'tight' options. The latter we can call a *nominal diagnosis*. It has a clear name, but cannot lead us to probable effective action: our options are 'loose'. 'Myalgic encephalomyelitis' (ME) is certainly an impressive-sounding name, yet such arcanely named clustering is actually unimpressive in helping us find relief. By contrast, appendicitis – a substantial diagnosis – leads us swiftly to almost certain cure.

    So although many people think that a diagnosis will lead to helpful knowledge or action, this is often not so. A name may be all we get.

iii. *Prediction*. Diagnoses are made to tell us what will happen with, or without, the action defined by prescription (as above). Whether this is clear and accurate, or not, largely depends on whether the diagnosis is substantial or nominal.

For example, the prediction of 'appendicitis' is very accurate and important: with prescriptive action (appendicectomy) the cure rate is very high; without such action severe illness (peritonitis, septicaemia), often fatal, is most probable. There is no debate about the nature or plausibility of this diagnosis (where objective observation is indispensable) or for the course of action (invariably surgery) that follows. NICE is hardly ever involved with such substantial diagnoses.

Contrast this with a nominal diagnosis, say 'ME', 'CFS', or 'depression'. These diagnoses mostly cannot reliably lead to accurate prediction or effective prescription. Yet we often have difficulty in accepting this lack of knowledge, understanding or power: we then construct and cling to wishful thinking – *imagining* mythical compensations for such lacks. This is true not just for the sufferer, but often also for their attendant practitioners, too. The practitioners will obscure ignorance and impotence to protect either their subjective professional self-esteem or their publicly perceived professional image, status and financial worth.

Yet although nominal diagnoses may, in real terms, be fickle, even counterfeit, currency they can nevertheless often comfort us – albeit transiently – by illusioning understanding and control. The first time I heard the term 'myalgic encephalomyelitis' I felt an aura of real medical power. Then came the bewildered frustration. It took time and mental effort to unpeel this mask-of-words.

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In fact and in practice it is more useful and accurate to think of these two types of diagnosis as occupying opposite ends of a spectrum rather than as two always separate and distinct kinds of category. So, for example, 'fractured hip' is clear and substantial; 'menopausal dysthymia' is nominal and immersed in dense fog; 'irritable bowel syndrome' is midway, impeded but not immobilised by mist.

Is there any way we can understand where a diagnosis is operating on this spectrum, and why? Well, generally the more a diagnosis is rooted in objective observation, the more likely it is to be substantial; the more it must draw from subjective experience, the more nominal it probably is. Each derives from different domains – observable and measurable changes in the body, or relatively unmeasurable disturbances of subjective experience, respectively. Translated again, we have structural (substantial) pathology, and functional (nominal) distress.

All of this in no way discounts the importance and sometimes grave disturbance and suffering packaged into our growing inventory of nominal diagnoses. The question is not whether there is here a serious problem, but what is the nature of this seriousness. To be told that someone self-destructs due to 'alcoholism, opiate addiction and severe depression' gives us only a medically-worded description of the humanly and personally tragic: this is not the kind of genuinely useful knowledge that comes from substantial diagnoses. And even where a substantial diagnosis is dire – say, a disseminated cancer where 'nothing more can be done' – its predictions are mostly accurate. Where they are not we may either revise our diagnosis or bow with humility to the inexplicably benign.

The fact that nominal diagnoses' offerings are often, as we have seen, little more than administrative and illusory does not impair our appetite for them. As we have seen, they can offer us comforts of inclusion, commonality and – maybe most importantly – the apparent aegis of medical science and authority. In this way the nominal diagnosis functions much like a ritualistic religious incantation uttered by a revered and trusted priest – in reality it may not change events, yet it may change how we endure and tolerate those events. So the nominal diagnosis may – at least – contribute to any placebo transaction or effect.

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In the last few decades the power of much medical science – and the substantial diagnoses it uses – has transformed lives and society. Orthopaedic hip, coronary artery and cataract eye surgeries are now commonly encountered and clear evidence of this definitive power. And even in the decades prior to these triumphs our public health sciences had largely eliminated the most lethal infectious diseases: globally, this happened wherever we could apply such science.

It is not surprising then that the spectacular successes of medical and public health sciences become both adulated then emulated. Not only do we freely spin and transpose medical language and metaphors in our social and political lives – cancers, infestations, radical surgery and excisions, decontaminations are all there in our explanatory or declamatory speech, especially when political – we often medicalise our personal, even intimate, lives: we try to offload our humanly personal problems to medical definition and responsibility.

In prosperous societies – where medical and public health sciences have been most conspicuously successful – this is most rampant. The thinking goes like this: if some specialist physical disease and public health doctors can offer us such potent success, why not all? We can learn best from these very clever people. All of us must merely adopt the same kind of precise scientific language and make similar kinds of interventions; if we medicalise human problems, we can solve them…

The result is that, over the decades, any painful burden of human consciousness, any inassimilable anguish, discord, appetite or urge is likely to come under medical aegis. In this expanded medical arena new nominal diagnoses can be fashioned to vaunt feeble imitations of established time-honoured medical protocols.

This is most clearly evident and problematic across the vast terrain of mental health. And these are very knotty problems because anything 'mental' is largely unmeasurable subjective experience – rather than the largely observable, reliably measurable structures and functions of the body: the firm bedrock of any substantial diagnosis. But anything mental/emotional/psychological struggles to find such firm anchorage as we can in the body because *direct* observation or measurement of others' experience is not possible: we must, instead, construct our models (diagnoses) from inferences, assumed correlations and subjective descriptions or disclosures. This is an essential compromise whenever we medicalise (whether or not we medicate) any human discord and distress. True, that compromise works best with the rare acute and severe human disruptions ('major mental illnesses') which most resemble structural physical disease in course and response to treatment, at least in the short-term. But such assumptions unravel in sense and efficacy with the much commoner and frequently diagnosed anguishes.

This burgeoning medicalisation of personal and social problems is particularly evident in prosperous societies, especially those where Big Pharma plays a large part in the growth economy. The USA, a 'world leader' in pharmaceutical research, is also a prophetic model for the rest of the world as to how to increase our prescription-consumption of psycho-pharmaceuticals by increasing the number of legitimatising new psychiatric (nominal) diagnoses: the endless expansion of psychiatric nosology and hence the profit-mushrooming of Big Pharma Psychopharmaceuticals Inc – the two are mutually dependent.

This is well evidenced by the story of the *DSM*. The DSM is the Diagnostic and Statistical Manual published since 1952 by the American Psychiatric Association. Within those nearly seventy years successive committees of their practitioner-scholars have increased the number of defined psychiatric syndromes (often AKA 'illnesses') by several hundred per cent. Starting from the more massively disturbed and hazardously impaired original nucleus of 'major' mental illness (eg incapacitating depression or psychosis) the DSM attempted to cluster and code almost any type of mental distress or behavioural discord that a healthcarer, insurance or State officer, might encounter. So the 'diagnoses' (and prescriptions) have pullulated as the DSM and Big Pharma have expanded: the DSM is now adopted widely internationally and its diagnoses applied to almost any kind of disturbance or non-wellbeing of thinking, feeling, personality, social and intimate relationship, learning capacity, gender and body identification … there are few areas of human difficulty that have escaped colonisation by the psychonosologists.

And what have the results been, of this vastly expanded scholarly quasi-medical categorisation? And how does this compare with increased diagnosis in, say, cardiology or oncology? The judicious answer is ‘disappointing’ or, at least, ‘mixed’.

What does this mean?

Well, let us start with the positives: providing diagnoses – by observing, clustering and coding – can at least draw our attention to things we might otherwise ignore. So, if we have names for our human tangles, those names can then be initial ‘footholds’ for ascending lines of thought or bridges for discussion. Yet these words we invent remain, mostly, nominal diagnoses: their use is mainly in descriptive categorisation, they fare poorly with effective prescription and prediction.

This distinction tells us much about the evolution of psychiatry: over those last several decades years psychiatry has grown in scholarship far more than it has grown in effectiveness. Its academic and research output is now (compared with previously) enormous yet the rate of society’s reported suffering and disturbance continues to accelerate far beyond our capacities to deal with them using the prescribed tools. This is certainly not the case with our paralleled examples from oncology and cardiology: there any advance in therapeutic potency is directly derived from research and scholarship – a new diagnosis is likely to be substantial, ie practically effective. Yet in psychiatry – despite our best intent, wishes and illusions – our diagnoses remain largely nominal. We, here, all-too-often, cannot influence events as we wish.

Despite such frustration we should acknowledge that there have been associated advances: current psychoactive drugs are mostly ‘cleaner’ then their forebears, incarcerated institutional horrors are probably much rarer, IT can ensure better ‘compliance’ from patients and practitioners alike. But – and it is a big but – our rates of distressed BAMI (behaviour, appetite, mood and impulse) continue to rise. Despite all our impressive scholarly and administrative efforts, our diagnoses with BAMI remain largely nominal.

The recognition of this in no way implies incompetence or indolence on the part of practitioners, researchers or administrators. Nor can this conundrum be blamed simply on ‘inadequate funding’ (though inadequate funding will certainly amplify any other problems). This discrepancy – between diagnostic profligacy and therapeutic poverty – is not the ‘fault’ of any individuals or their groupings. Rather it is a manifestation of a very human collective folly or conceit: that of wishfully reifying the language we create – in believing that if we invent and use a word there must be a real ‘thing’. For example, our utterance of ‘God’ or ‘God’s word’ has often led to our most absurd and horrific history. Nominal diagnosis, in a gentler way, can sometimes sleepwalk us into the collectively-delusional.

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Let us return to three other terms used (too) confidently in the fractious radio discussion. These terms have now become commonplace among both healthcarers and healthcarees, yet the brevity of the terms and the ease of their use readily conceals the complexity and elusiveness of the underlying problems these terms encounter.

2. **Treatment.** What is this? Well, in the medical context the word is best used when agents external (to the self) are used to positively manipulate or influence a change in the body, often by directly entering within the boundary of the body. The external agents are chemicals (drugs), instruments, sutures, stents, catheters, energy and radiation forms – these are all externally resourced. All surgery, pharmacotherapy and physical manipulations are treatments.

   Generally, substantial diagnoses lead to specific treatments. Even when this is not successful, the substantial diagnosis can – at least – predict likely events, eg stable lifelong limb spasticity with cerebral palsy, insidious involutional death with motor neurone disease.

   Applying treatments to the looser clusters of nominal diagnoses is, generally, much less satisfactory. Treatments for tension headaches, poor vitality, menstrual pains or fibromyalgia are likely to be multifarious, less predictable and unreliable. Mental health, particularly, so often, must do what it can with its systems of extremely loose clusters (the DSM is the most magisterial of these systems), yet the authoritative tone of its nominal diagnoses nevertheless often manages to induce a belief that effective treatments will follow. All too often they do not: the spiralling use and then overuse of anxiolytics and antidepressants, for example, is a source of endless confusion and contention in a way that cataract or coronary artery surgery never is. And the USA – arguably the cradle of modern psychopharmacology and nominal diagnostic systems – is hardly coping well with the problems it defines and treats so extravagantly (and profiteeringly).

It seems clear to many that much psychiatry has thus grown by using inapt language and tools to deal with humanly nuanced problems that are often elusive to such quasi-medical terms and encounters. This is because, generally, we cannot directly change or manipulate another person's distress or disturbance in the way that we can raise a blood sugar, stent a blocked artery or suture a gaping wound. So, mostly, 'psychological treatment' is a misnomer for what we might best achieve in mental health.

What, then, is a more apt alternative? Well, to help the personal experiences of others we mostly have to help each of us re-view and re-process what we assume and perceive of the world, both globally and intimately – the self and the other. Such re-view generally needs the cooperative trust – a *relationship* – with an other in order to guide, encourage and model that process. But, in clear distinction to genuine treatments, it is the sufferer's capacity and willingness to do this – their personal *internal* resources – that are most essential. The professional relationship can help the sufferer develop and choreograph such internal resources, but cannot provide them. We cannot directly supplant others' experiences, nor live their lives. And while we can certainly, often, help those suffering from BAMI ailments, that help rarely has the prescriptive predictability of directly manipulative 'treatments'. What, then, do we call such helpful induction or evocation of another person's internal resources? A better term is 'therapy'.

This distinction – between treatment and therapy – is crucial to understanding. When it is not understood, there is much angry and sorrowed bewilderment: ricocheting complaints and accusations soon follow. Such is the disillusion of myths: 'Why didn't this treatment *work*?'.

3. **Cognitive behaviour therapy.** Like Myalgic encephalomyelitis (ME), this formidable sounding mouthful also needs an acronym for ease of articulation: CBT. Both ME and CBT are very technical sounding compounds: they easily lure us into thinking that the specialists who diagnose and prescribe such things must really know what they're talking about. But do they? Let us consider ME first: ME is a very good example of a loose and large cluster given a formidably phrased nominal diagnosis: it serves a purpose for administration and taxonomy, and tells us well what it is *not*, eg the ailing person does not have the substantial diagnosis of, say, anaemia, multiple sclerosis, hypothyroidism etc. But it hardly helps us be clear how to help this person, or what will happen to them with or without anything we can think of doing. We simply do not have the knowledge: the nominal diagnosis is here – actually – an administrative admission of ignorance, though it may be used to conceal this. All the fractious altercation comes from our reluctance to face this.

   CBT faces a similar, often embarrassed, predicament. CBT is talked of as a prescription, as if it can be 'given', like a drug. Indeed many doctors talk of 'prescribing CBT' for particular complaints as if the 'course of CBT' can relieve the sufferer's (often unexpressed) psychic-distress, like an antibiotic for infection. The practitioner, and maybe the hapless patient, are encouraged to see the CBT as a treatment.

   So what, then, is CBT? Well, in ordinary language it is a system which, if a person is willing and chooses, may help them think more clearly about how they think, feel and act and – hopefully – better steer and navigate their inner conflict or turbulence. But this is an *invitation* for use, and like an invitation to dinner the 'guest' may decline to attend; may attend politely, eat their dinner but not really engage with the host (or vice versa); may ingeniously conceal what they have only apparently eaten; they may leave unaccountably early … and sometimes all – thank goodness – will dine and talk well, with deepening rapport. These all find their analogies in therapy, much less in treatment. And CBT is a therapy, not a treatment: 'it' cannot cure us, but we may – sometimes – use it to help heal ourselves and help others heal themselves.

4. **Experts**. 'We've had quite enough of experts!' proclaimed a campaigning Michael Gove, a Cabinet Minister, while attempting to excite a top-down insurrection. This populist rhetoric possibly contributed to the campaign's success. Why? If experts really know a lot about what the rest of us do not, how can we have too much of them?

   Well, we have two varieties of 'experts', and we have to know which sort we are dealing with. Confusing them is where the mythology, and then sense of betrayal, start. Here they are:

   i. *Fixer-experts.* These are, for example, the mechanics who know how to fix your car's fuel-injection system. Like a substantial-diagnostician their technical terminology leads them to accurate explanation and then to prediction of what will happen with and without their remedy. Most important, they can fix the problem.

ii. *Scholar-experts*. These are people who know a lot about research or speculation; they are replete with ideas and scholarship. The problem is that all this does not reliably enable effective prediction or prescription. So, like nominal diagnosticians, they can describe clusters and patterns, but cannot fix problems for us. Scholar-experts are exampled by academic philosophers, economists, theologians, forensic psychiatrists, political analysts, drug addiction specialists. The inverse relationship of their high-scholarship to low-pragmatic effect does not reflect the competence of such expertise, rather the indeterminacy and indissolubility of the problems they study, at least with established methods of observation and engagement. Some of what we wish away, will not (yet or ever?) concur: we have neither the right kind of knowledge nor the leverage.

This seems particularly hard for us to accept in this era where so much of our world and our fate has seemed to increasingly submit to our methods of mapping and control. Where these powers elude us we *want* to believe that all experts – all who can speak with arcane scholarship – are also fixers. It is like the many who wish that the person attired in the bishop's gown and mitre and standing at the altar is really closer to God, and can bring us within His aura.

That is an important reason why we can become so angry with doctors who cannot fulfil the desired powers we project into them. Yes, medical science has made very clever advances into the realms of objectively observed pathology, but it is much less clever where we have merely distressed experience – without that anchorage of objectively observed

> pathology – as the irreducible problem. Medical science here often gets no further than the nominal.
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> And no-one is to blame for why we cannot effectively or reliably relieve or understand those anguishes-in-the-mist.

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No-one is to blame, but some scholar-experts can seem remarkably uninsighted about the nature and limitations of their scholarly conventions and language. And maybe this adds to our misunderstandings and misattributions.

Here is an example. Two days after the NICE debacle, the same radio programme broadcast a brief uncontended interview with an eminent academic developmental psychologist who was talking about autism: 'It's very under-diagnosed, but actually very common … Something that interests me greatly is why autism has so many different forms? That's a very important question that is crying out for more research to answer.'

But is it? Is it not more true that the term 'autism' is, or has become, a very large and elastic net in which we can stuff a very large number of both the similar and the dissimilar. Like 'depression', the medical and vernacular uses expand, become blended, and often indistinguishable from one another. These terms – these diagnoses – become less and less accurately substantial and more and more loosely nominal.

I remember some twenty years ago seeing a seven-year-old son of lovingly devoted parents with two other thriving children. The boy had no verbal language, made no eye contact and sought no affection – yet he was clearly attentive, observant, intelligent and dextrous in his manipulation of objects. Yes, this boy seemed to have some neurocerebral developmental skew. 'Autism' seemed a useful label to share with others, to help this family. Contrastingly and currently I am told that the formidable communicator Greta Thunberg "has a diagnosis of autism". If this is true, I think it tells us much more about our specious use of medical language – our nominal diagnoses – than it does about this highly competent and engaging young woman.

Remarkably, the eminent psychology professor seems not to see all this: I imagine that he and his colleagues are so immured and immersed in their academic language and concepts that they cannot see beyond, to greater human context and questions.

If we now return to the reported events beginning this article we may now better understand the kerfuffle: it was this kind of oblivion that lay behind the fractious misunderstanding between the radio discussants about ME and CBT.

In our shared confusions and ignorance, our words can sometimes blind us more than they can help us see.

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That knowledge which stops at what it does not know is the highest knowledge

– Confucius, *Analects*. 6thC BC

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