Words and Numbers: Servants or Masters?

Caveats for holistic healthcare Part I

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Holism's fuller engagement with realities is an aspiration and ideal. It can never be complete, and in practice, there are many obstructions. These range from our use of language to our highly managed and industrialised culture. How does this happen? What are the consequences? This is the first of two articles.

Prologue: caveats for holistic healthcare

Holism (and its lack) may be easier to recognise than define. It is more readily communicated and perceived by stories, rather than data or abstract formulations. This presents problems: holistic mindsets are now becoming harder to access and maintain, for our culture is now one that increasingly conceives and conveys in *packages*: food, fuel, news, entertainment, even thought are all likely to be coded, metered, monitored, measured or packed. This causes fewer problems when our encounters are with inanimate or less complex life-forms: the production and distribution of eggs or detergents cause fewer ethical and social conundrae than the industrialisation of complex welfare activities (though even our simpler activities eventually confront us with wider ecological – ultimately Gaian – consequences).

We thus have an insoluble handicap. It is always easier to think in parts than wholes: language, analytical thinking, our micro and macro economies ... all tend to fragment our perceptions and activities: 'this is this, and that is that'. In contrast, holism's tenet of infinite and often hidden interconnectedness tends to erase boundaries and conflate territories: 'this is that as well as this'. Such thinking largely eludes schemes, packaging, academia, economic analyses. Our use of language, too, struggles to convey any sense of holism without serious loss or distortion.

The following two articles present a collage of notions illustrating, very partially, the extent of our difficulties and task. The notions themselves are presented without usual conventions of academic thoroughness or cohesion. The first article presents the skeleton of the view: the second provides further illustrations and variations. Overall, they represent some unsystematised, though summative, personal reflections from one practitioner's decades of working in human healthcare – a chimeric and often paradoxical world. Philosophical contention is ever-present. We are accelerating our mandates for factory-like language and procedures to service increasingly complex healthcare: human nature and predicaments remain considerably more ambiguous.

1. I've got a measurement – it must be a fact The rise of data and the curse of scientism

'Nothing vast enters the lives of mortals without a curse'
- Sophocles (c 496-405 BC)

There was life and technical success before computers, yet these are rapidly becoming harder to understand. Some examples: the manufacture of antibiotics, the D-Day Landings, Man on the Moon, Concorde – all of these were achieved with minuscule or no computer-power – things we could not manage now in our 'progress'. We have become empowered but deskilled: in healthcare, as we shall see, these subtle discrepancies lead to grievous losses.

Before the widespread use of computers, the harvesting and collation of measurements – data – was manual, labour-intensive and therefore slow. It thus required much deliberation and discrimination and – relative to today – its volume was tiny and consequently much more manageable.

The electronic unshackling of these activities has freed them from the constraints of our individual capacities for engagement, assimilation or understanding: data has multiplied exponentially and is now pumped and piped at us like gas or water – public commodities.

Measurement, the blood-brother of data, has thus been conferred preeminent status in many humanly-complex activities. Numbers are the most easily digested 'food' for computers, and computers are now essential to the functioning of any public service. Existence of people and their activities must be continually monitored and broadcast in a form that can ensure their organisational recognition, management and survival. The virtual world now defines and commands the real: measure or perish. Once started, this is difficult to slow or stop.

So, our institutions are now electronically held together by computers, computers need data, data need statistics, statistics need measurements; ergo: measurement becomes the basic language and activity.

What does this mandatory measurement mean for healthcare? The consequences vary greatly with the type of activity. Sometimes the effect is facilitating and benign. For example, with activities that can be easily and directly measured, standardised and proceduralised: here the measurement culture can be applied with relative ease and evident benefit. Laboratory services, vaccinations and cataract extractions all serve as common examples. All have in common a clear, circumscribed physical basis, little variation in technique or human response and a high completion/success rate. In short, they can be easily humanly 'mechanised'.

But much of healthcare does not offer this kind of simplicity for measurement, and then the effects often depart widely from the benign and facilitative. Measurements are at their most competent with physical objects or phenomena: a blood-count is far less problematic or contentious than a mood-rating scale. This is because attempts to assess, measure and code other people's experiences must be derived from something else: self-reports, or other people's perception being the commonest. All are subject to massive contention, contamination and compromise. What does this mean? Here are some personalised examples:

• Ms B is in dispute with the Department for Work and Pensions (DWP)¹ over her Disability Living Allowance. Ms B claims severe symptoms and invalidity from Depression, but her invalidity seems invalid to the DWP assessor: he asks the GP, Dr F, for his opinion. Dr F,² in a complex but rapid judgement, agrees with the assessor. This 'objective' assessment is stymied by Ms B's continually high self-reported, but quantified, depression scores. 'Something's wrong' they all say in different ways. 'Only the wearer knows where the shoe pinches' says an old adage, but when is this untrue? Who decides? How?

Kenny is sixty-two years old, a single, lonely man, appeasing and selfdeprecating in his manner. Harsh and neglectful parenting left him with impoverished self-esteem. A working lifetime as a road worker has riddled his lower body with degenerative arthritis. He left school at fourteen: his intelligence exceeds his words. After several years of courteous wariness he is, with Dr F's gentle encouragement, beginning to talk of his burden of fear, loneliness, shame and longing. The ancient story behind it is poignant and powerful. Kenny has great faith in Dr F, but continues anguished in his small and crumbling world. Dr F asks for help from NHS Psychological Services, to help Kenny occupy his limited life more positively. Kenny returns to Dr F a fortnight later, fearful, tearful and trembling. He nervously indicates the immediate cause of his distress: a tightly-stuffed, freshly opened envelope. It is from the Psychology Services. Dr F surveys several detailed questionnaires³ aiming to define diagnosis, severity, disability and numerous personal and demographic details. In addition are various bureaucratically prolix letters and documents explaining 'The Service', a Complaints Procedure and instructions for the Service User. No one has spoken to him.

In his frightened and faltering language Kenny conveys to Dr F his sense of bewildered humiliation and abject inadequacy: 'I don't understand all this, doctor ... I just can't do it ... I just want to talk to someone – like I do with you, doctor.

The doctor remembers many years ago reading of Heisenberg, an early 20th century physicist. Heisenberg found that it was impossible to plot simultaneously the velocity and locus of an electron without changing these in an indeterminate way: the observation changed the reality. Dr F as a young man could not identify how this was relevant to his meagre knowledge of physics. Many years later he is seeing clearly how personal observation – when formulaic and non-bespoke – can adversely affect people he knows well.

• Philip is eighty-six and Dr F is visiting him at home, the week after his discharge from hospital. He had taken a first-ever overdose of his medication to end his life. An earlier than expected visit from his Carer had found him collapsed and vomiting.

Philip now looks tired and Dr F again senses immense melancholia beneath the mask of rigid discipline, of understatement. The doctor knows some of Philip's recent trials and sorrows: his wife's gruelling and fatal malignant illness, followed rapidly by the sudden death of his beloved son, their only child. And then the increasing impoverishment of his own Parkinson's Disease, a gathering bass-note.

Dr F had premonitioned Philip's trapped but mute anguish and its possible tragic fruition, and had asked for help from his mental health services. Their (non) engagement proceeded by asking Philip to fill in detailed mood and anxiety questionnaires. These indicated mild, stable disturbance — measurements meriting merely a brief psychological care package from a Low Intensity (skills?) Worker, and a routine, templated report of all this, electronically conveyed to Dr F.

Dr F's perception is discrepant. He shares his unease with Philip, whose intelligence and insight survive his ravages of grief: 'I don't like to tell anyone my troubles, doctor ... I wasn't brought up like that. I have my pride, you know ... It's different with you: I've known you years, and I don't have to say much, for you to understand. But answer all those questions for a stranger? No.'

Dr F thinks of Philip's formative years: a harsher, crueller, braver world of much greater trials, losses and endurance; a black-and-white world where contained and stoic fortitude was a social essential. Dr F understands this with few words, and Philip understands that he understands. But a questionnaire?

Yet Dr F now inhabits a professional world in thrall to designated experts who are keen to quickly code and quantify the distress of Philip and Kenny, as well as Dr F's ministrations, and then to instruct them all. Dr F's understanding can seem piecemeal, slow and never finished: features of the intersubjective, one-person-and-situation-at-a-time. By contrast the questionnaire has slick allure: its 'objectivity' may be specious, but it is quantifiable and can be given to all — a demotic science. Dr F is thinking of the distinction between the scientific and the scientistic: which is which? He is thinking, too, beyond his

own professional end: who then will be speaking to the Philips of the world, and what kind of conversations will they be?

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2. I've got a word – it must be real The trap of reification

'In the Beginning was the Word'

- *Genesis*, Revised Version, Oxford University (date uncertain)

Language does far more than merely 'communicate': words first contain, then command and control our experience, and then our influence of others. The implications of this for healthcare are subtle, powerful and rarely discussed. A brief linguistic analysis will help us understand these.

All words are there to package and convey a description of, or notion about, human experience. All ultimately come from our perceptions, then our constructions. The basic components of language are: adjectives, describing qualities of experience (what something is like); verbs, describing activity producing change (what something does); and nouns, which attempt to capture a more static state, a 'something', from which these other two emanate (what something 'is'). For example, I describe a small vertical platform supported by four vertical supporting posts: someone comes and sits on it – it is a 'chair'. Generally, we think such 'real' things endure and we attribute them by nouns: adjectives and verbs are more the flux of experience.

In our usual waking life this may present few problems, with nouns seamlessly providing apposite bridges and anchors for the rest of our sense-experience, and those of others. But potential dislocation is everpresent.

An example: I am at a friend's table, eating an unfamiliar dish. I do not recognise the texture or flavour of the meat, although I enjoy both. I enquire what 'it' is.

- #1. I am told: 'It is lamb'. I am mellow with appreciation for my sensations, my friend and the cosmos.
- #2. I am told: 'It is Alginon, my ginger cat. She was very old and was dying anyway'. What is in my mouth now triggers an explosion of nausea, and retching. I jump up with disgust and mistrust. My friend and the cosmos turned malign.

The 'actual' experience is transformed by the idea of the 'real' source-object (lamb v cat). This noun now determines my subsequent experience and action: the adjectives (pleasure or revulsion) and the verbs (sitting and eating v jumping up and retching). All this happens despite my never seeing the putative lamb or cat: they are abstractions rendered powerfully 'real' by the noun. Such is the power and gravitational force of nouns.

Nouns work with greatest clarity and efficiency when applied to physical objects: the words 'table' or 'television' rarely cause problems except to a foreigner, a lawyer or certain kinds of academic. We generally accept these object-nouns as 'real'. Elsewhere the use of nouns is more problematic and more interesting: God, democracy or love may sound like (sacred) 'things', yet are essentially variegated ideas. Innumerable stories from world or domestic histories show how little clarity and consensus the nouns manage here, yet how real they are to their believers.

There are striking analogies in healthcare. One working definition of medical diagnosis is the organisation, then transformation of adjectives (a) and verbs (v) into professionally conferred nouns (n) which then determine explanation, therapeutic action and prediction for others. With afflictions that are predominantly physical – 'structural pathology' or disease – we can call this type of noun a 'Substantial Diagnosis'. Here is a simple example.

• Tommy is six. Last night he became listless (a), pushed away (v) his favourite supper, complained of soreness (a) in his throat and abdomen and then started to shiver and vomit (v). Dr Y is now with Tommy and his mother. His job is to

find and then confer the right organising noun, or diagnosis. When he sees
Tommy's much enlarged, reddened tonsils, flecked with creamy pus, he has the
precise constellated noun: 'Acute Pustular Tonsillitis', though he thinks
'Tonsillitis' sufficient for his verbal communications. The formulation and
conveyance of this word are beneficial for all: Dr Y knows what to do and what
to expect, Tommy will almost certainly get better, Mother is comforted by this
and the containing, reassuring clarity of this noun – the Substantial
Diagnosis. For all, this process is helpful and uncontentious: the doctor's
knowing and naming the 'thing' of Tonsillitis is a cooperative and shared
blessing. Importantly, Dr Y's diagnosis also relieves the sufferers from having
to search for their own explanation, meaning of, or influence on, events.

In other areas of healthcare this hegemonic use of nouns runs into many more difficulties. This is particularly so where the doctor is dealing with bodily dysfunction (functional dis-ease) in the absence of the evident structural changes of bodily disease. Equal difficulties are encountered with disorders of behaviour, appetite, mood or impulse (BAMI): the core of psychiatry and clinical psychology. The results here are more mixed: our medical-noun type diagnosis may sometimes bring evident clarity and relief to these physically non-fixated forms of distress, but often it will not. Then the professionally conferred noun – the diagnosis – is conveyed, but the benefits do not follow. In these situations the diagnosis may be 'correct', but clarification, relief or prediction remain poor. The doctor has – by convention – done his job, but none of the participants are gratified. We can call this a 'Nominal Diagnosis'. Here are two examples:

• K, a tense, conscientious, sensitive woman of twenty-six years has seen several doctors over several years with benign abdominal and bowel symptoms. All have agreed she has Irritable Bowel Syndrome (IBS) and prescribed the usual medications, always with little or transient effect. Dr T realises that a wider vocabulary is needed to differently understand and influence her complaints. In his endeavour to do this, he learns a lot about her unhappy childhood home and how this has led to her guarded perfectionism and her painful ambivalence about close relationships. The long-term effects of this widened dialogue and vocabulary were slowly gratifying for both K and her doctor.

Here the conventional noun-diagnosis of IBS was relatively ineffective and – probably – obscuring or obstructing more helpful personal understanding: it thus proved to be a Nominal Diagnosis only. The idiomorphic understanding she developed with Dr T proved much more helpful.

• Maggie, fifty-five years, has collected a variety of diagnoses from her many years of faltering contact with psychiatrists and psychologists: Generalised Anxiety Disorder, Agoraphobia, Panics, Emotionally Unstable Personality Disorder with Cyclothymia, Recurrent Depressive Disorder, Bipolar Affective Disorder. All are documented in the usual formalised language of designatory healthcare which then rhetorically confine and define Maggie by Nominal Diagnoses. These conferred nouns may superficially appear to offer real therapeutic understanding, leverage and prediction, but actually do not. None have offered Dr V greater personal understanding of Maggie.

Dr V decides to create a larger and different kind of space for Maggie to talk. This dramatically changes not only Dr V's view and understanding of Maggie, but also Maggie's behaviour: her symptoms become much quietened.

How does this happen? Dr V wants to know Maggie's story, not for a Management Plan, but so that he can better understand. Her story has obscurely disturbed her for decades and it will disturb Dr V now.

Twenty-five years ago she was married – happily she thought – with three children. She experienced her husband as kind, attractive and funny, but a bit feckless: he drank a lot. She suddenly has unmistakable evidence of his alcoholically hazed, repeated sexual contact with their ten-year-old daughter, Amanda. In a volcanic eruption of mixed and primitive feelings, her marriage and family are destroyed. Years later the ruined landscape of her life is still littered with explosives. She tells Dr V of a current torment: Amanda – now a tough, cynical, sexually alluring, drug-abusing, spiky thirty-four year old single mother – has restored affectionate contact with her father and his second wife, and takes her children to see them. Maggie's feelings towards her daughter are raw, kaleidoscopic and irresolvable: 'My mind goes crazy with it,

doctor ... She was only ten: I should have known, should have protected her: but she knew, and she knew that I didn't know ... She was a child, but was — I didn't know then — a serious sexual rival. Now she is stronger and healthier than me, and has more of a family — mine is destroyed. I love her as a mother, but hate her for what she did, what she does, what they have all done: but can I blame her? ... Has she triumphed over me? I feel crazy and terrible for having just said all that, doctor, yet it's such a relief that I can say these things and that you can understand ...'

Dr V has a bespoke and ongoing dialogue with Maggie about her tragic story and her responses to it. Her distress often exceeds her capacity for words, yet words and ideas are what they exchange and they are many: guilt, shame, loss, rage, hate, love, contrition, resentment, despair, despondency, alienation, disconnection, blame, humiliation, revenge, sorrow, defeat ... All touch on part of Maggie's poisoned cauldron, but only part, and only transiently. Maggie now talks less of her symptoms and Dr V does not much offer his vocabulary of diagnoses or treatments. As their language has changed, so has the nature of their exchange, and then the pattern of Maggie's distress. Maggie, so long burdened and defined by her multi-diagnoses, is now freer to suffer with her unique and humanly-understood tragedy. Dr V, too, though distressed by her story, is also touched and, paradoxically, nourished by such candid and courageous contact – the staple of compassion.

Others have asked: what is 'really' wrong with Maggie? Is there a word: is it 'Depression'? What is the 'correct treatment'?

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'Language is, by its very nature a communal thing: that is, it expresses never the exact thing, but a compromise – that which is common to you, me and everybody.'

– Thomas Ernest Hulme (1923), Romanticism and Classical Speculations

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This article continues in If you want good personal healthcare see a Vet

Notes

- 1. DWP a UK nationwide governmental department that administers and manages state pensions, sickness and welfare benefits etc. Assessing disputed levels of distress and disability is a task it currently often subcontracts to other agencies.
- 2. The doctors, patients and situations throughout this article are real but anonymised. The examples of doctors' encounters will be relevant now to many other types of healthcare professionals, especially those working for the NHS or large corporations.
- 3. Detailed questionnaires are now being vaunted and proceduralised throughout most NHS Psychology and Counselling Services. This is explained by authorities as making the services more scientifically efficient. This is contentious, at least. In this author's view it leads to specious science, dehumanisation, and a healthcare cult of Scientism. The obstructive and destructive effect of these is extensive and subtle. See my articles 'How to Help Harry' (Zigmond, 2012) and 'Sense and Sensibility' (Zigmond, 2011a).

References

Zigmond, D (2012) How to Help Harry – Friend or Foe? The scientific and the scientistic in the fog of the frontline Zigmond, D (2011a) Sense and Sensibility: The danger of Specialisms to holistic, psychological care

The above are available online at www.marco-learningsystems.com/pages/david-zigmond/david-zigmond.htm

Published in Journal of Holistic Healthcare, vol 10, issue 3, winter 2013/14

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