

Too much diagnosis ... and not enough art – the gift of narrative to medicine

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Summary

This article is a response to the BHMA workshop held as part of the International Preventing Overdiagnosis Conference in Oxford in September 2014. It concerns alternatives to diagnosis as a way of making sense of illness. Overreliance on diagnosis easily leads to a neglect of the person who is ill, particularly the rich understandings that can come from their story. I use insights from narrative medicine to explore the limitations of diagnosis and the strengths of imaginative and creative approaches in bringing hidden issues to light.

During 30 years as a GP in Somerset I watched and shared with people struggling with misfortune, laughing at absurdity, weeping with joy or misery, showing their resilience or giving up at the first hurdle: above all, living out who they are. Over this time my wife and I brought up our two children, numerous pets and chickens. In my medical role I became exasperated by the dominance of diagnosis, technical treatment and commodification at the expense of the human side of illness. Now retired from clinical practice, I work towards restoring this balance. I am chair of the BHMA and also chair of a local experimental community development network in the town where I worked.

The search for meaning

Those who have a 'why' to live, can bear with almost any 'how'.

Viktor Frankl

The above quotation comes from Frankl's celebrated book, *Man's Search for Meaning* (Frankl 1946). Frankl was an Austrian neurologist, psychiatrist and Nazi concentration camp survivor. This present essay is fundamentally about finding the 'why'. It is about making sense of what life throws at us, and particularly providing a critique of the role of a medical diagnosis for this. When a doctor makes a diagnosis, they are making a particular kind of sense of the patient's illness. Diagnosis is very useful to doctors, and may be useful to the patient, knowing what to expect and how to feel better. During his incarceration in Auschwitz and elsewhere, Frankl often found himself acting as camp medical officer for his fellow inmates. The guards found that

Frankl could keep his fellow prisoners able and willing to work. This was not through correct diagnosis of their fever, or diarrhoea, or infected skin, or loss of weight. They were all starving and cold, and their hapless medical officer, Frankl, had no tests to use and no medicines to give. But he came to understand that the men could stay alive only so long as they could find some meaning in the life they were living. Each man's meaning was always unique to him. But one common feature was 'a question of getting them to realise that life was expecting something from them; something in the future was expected of them' (Frankl 1946). This gave them hope, a reason to survive. Those who lost their meaning quickly died. But 'lack of meaning in your life' is not a diagnosis as we know it.

So what *is* a 'diagnosis' as we know it? The contemporary diagnosis relates to having a 'disease' or being at risk of so having (BHMA 2014). In stark contrast to Frankl's person-centred approach in the truly terrible context of the prison camp, modern diagnosis

too often says very little or nothing about the sick person or their context. Disease and diagnosis as explanation of human suffering involve a certain selective inattention to the person except as a potential recipient of technological treatments. This narrow approach has come to dominate modern healthcare. Since the early 1980s the BHMA and many others have been voicing concerns over this. The BHMA talks in terms of adopting a more holistic approach to balance the reductionism of the medical model. Among the other synergistic ways of characterising the widespread and growing unease over healthcare is a relatively new grass roots movement. This has been gaining support, particularly in primary care and parts of medical academia by focusing on the dangers of medicalising human life by expanding the domain of diagnosis. The movement has become known as 'Preventing Overdiagnosis' (see www.preventingoverdiagnosis.net).

Preventing overdiagnosis

One particularly obvious sign of overdiagnosis and medicalisation is the huge growth in the number of possible diagnoses. The current International Classification of Disease (ICD-10) includes almost five times as many disease codes as ICD-9 (1979). At the same time there has been growing emphasis on risk factors for disease and 'early diagnosis'. This has the effect of giving a medical label to large numbers of well people whose body chemistry or blood pressure or weight predicts disease in years to come. There are others who are found to have a possible abnormality on X-ray or the increasingly sensitive scans – often an incidental finding when the imaging is done for another reason, or perhaps on a private screening exercise. The vast numbers of new diagnoses, the growing number of risk factors and questionable screening programmes greatly expand the number of people offered medical investigation and treatment. Much of contemporary primary care is now consumed by the obligatory medicalisation. This includes helping people to cope with ambiguous or borderline results and supervising the long-term drug treatment which so often ensues. Some of this amounts to damage limitation. For the many healthcare professionals with misgivings about being part of an exercise in medicalisation, this is demoralising and frustrating. Though this is at the opposite extreme to the demonic forces faced by Frankl and his fellow inmates, it is nonetheless oppression.

BHMA workshop at international preventing overdiagnosis conference

In September 2013 the first international preventing overdiagnosis (POD) conference was held in the USA, sponsored by the Dartmouth Institute in New Hampshire and the British Medical Journal. Building on its success, a further three-day conference was held in Oxford UK in September 2014 where the BHMA was chosen to present

a workshop with the title: 'If we want to diagnose less, what are the alternatives?' This workshop was a response to the essentially negative frame of the POD movement. It set out to help physicians make sense of the haziness, or even vacuum, that is revealed when diagnosis fails us. In our workshop abstract we wrote that this sense-making 'must embrace both the ecology and the uniqueness of illness in a way that provides useful meaning in the everyday practice of professional healthcare, and in the perceptions of the public'. Both our workshop and the conference were fully booked several months ahead of the first day. Five hundred delegates came from all over the world to create a truly exciting and inspiring three days.

For the workshop, we 'grounded' the content by asking the delegates to bring anonymised case histories of patients for whom making a medical diagnosis proved to be unhelpful or impossible. We divided the 40 delegates into seven small groups and most of the two hours was spent in small group discussions. With the exception of one case history submitted ahead of the event, we heard only snippets that happened to condense out of these conversations in the group feedback: pieces that seemed important enough to share. Everyone in that room was trying to make sense of a story in their own way. No one heard all of it; we were in different patterns of darkness. Nevertheless, the public offerings were recorded on audio, some on video, and what follows is what I have made of them: an international group of medics grappling with the challenge of transcending the core medical construct: diagnosis.

Many approached this challenge by trying to ensure they took a wider view by including social and emotional context. Some used helpful mnemonics, such as FIFE: feelings, ideas (of patient), function, effects (of illness on usual life and expectations). There was also the importance of attending to the patient's agenda. For instance, the US-based Institute of Health Improvement (IHI) suggests asking the patient: 'What matters to you? What are your goals of care?' One group, in particular, was keen on the physician being able to 'wear different hats', by changing roles, for instance, to priest, social worker, friend, or parent. Another group spoke of CBM: complexity-based medicine, using complexity theory to understand the patient, the family, the community and society as embedded complex systems. The acronym, CBM, also stands for corporation-based medicine! However, the most commonly mentioned non-diagnostic approach was *narrative*.

Narrative medicine – partner with, or alternative to medical diagnosis?

Perhaps narrative was an inevitable theme given the focus on stories about their patients and their attempts to help them. We could record only what delegates chose to say in the reporting back. So I present here my own formulation of this aspect of the discussion, making sense of what I

heard in the workshop, and using my own knowledge, experience and, of course, imagination. I cannot envisage any consideration of narrative in medicine without a central role for the imagination. As I did this, I realised the similarity of this process of sense-making in the workshop to the sense-making of a clinical consultation with an individual patient: I heard and saw only what the other chose to reveal.

Whether we choose to develop it or not, narrative is deeply embedded in the clinical encounter. Yet, according to Donald Schon, the herald of reflective professional learning, many practitioners are 'locked into a view of themselves as technical experts' (Schon 1991). The language and structure provided by diagnosis is beguiling. It is easy, often unconsciously, to use selective inattention to hear and see only what corresponds to the ready-made categories within the towering edifice of biomedical knowledge. In the view of the late psychologist Carl Rogers, the problem is, of course, that under the gaze of science the patient is objectified. The scientifically unknowable inner self is unrecognised and unappreciated. The same applies to the experiential knowledge of the practitioner (Rogers 1961). Paying surface attention to the story is not sufficient to overcome this. One constructive response has been to promote a different style of relationship between physician and patient, described variously as 'patient-centred care', 'sustained partnerships', and 'relationship-centred care'. With regard to this, ethicist and family physician Howard Brody writes: 'Despite differences in details, these models share important features that bring the patient's story front and centre' (Brody 2003).

Many writers on clinical narrative attribute a vital part of our identity to our life story, applying to both physician and patient. A particularly evocative metaphor from physicist and philosopher Danah Zohar compares us with a tapestry, woven from innumerable threads of story (Zohar 1990). Many threads are required to create a picture and the richer our experiences, the richer and more complex is the tapestry. To physicians this is a different kind of anatomy of the person. Crucially you can see and appreciate the overall pattern of the tapestry only by standing back and seeing it all at once. This is vital to understanding suffering. US physician and professor of public health Eric Cassell argues that suffering is closely related to fear, and 'fear itself always involves the future' (Cassell 1991). Holding an image of the person as an *unfinished* weaving inspires a different curiosity, a different beauty, and a different understanding of suffering to that which emerges from images of the body as diseased biological structure. But humans are both biological structures and unique and gifted beings with their own past, present and future, connected within themselves and with all of nature by threads of memory. This other sort of anatomy must find its place in equal partnership with the extraordinary revelations and potential of the natural sciences.

A new story for medicine

According to Scottish moral and political philosopher Alasdair MacIntyre, '...man is in his actions and practice, as well as in his fictions, essentially a story-telling animal. He is not, but becomes through his history, a teller of stories that aspire to truth. But the key question for men is not about their own authorship... [but rather] the prior question "Of what story or stories do I find myself a part?"' (MacIntyre 1985). Our culture offers us innumerable, sometimes ancient stories, to help us make sense of our circumstances. This present essay contends that the dominant stories in contemporary healthcare are not serving us well. We are serving them. Canadian sociologist Arthur Frank argues in his book, *The Renewal of Generosity: Illness, Medicine and How to live*, that our culturally ready-made stories are letting us down ... 'A new story – a new possibility of being a physician – has to be created' (Frank 2005). This new story must be able to integrate the material body and the part of us that is deeply connected to all of nature. This quest is not new. Here, Roman poet and philosopher Lucretius (99BC to c.55 BC) writes on mind and spirit:

'For the two are interlocked by common roots and cannot be torn apart without manifest disaster. As easily could the scent be torn out of lumps of incense without destroying their nature, as mind and spirit could be abstracted from the whole body without total dissolution. So from their earliest origin the two are charged with a communal life by the intertangled atoms that compose them.... It is by interacting notions of the two combined that the flame of sentience is kindled in our flesh.' (Lucretius 1986)

Here is the much more modern Renaissance physician and scientist Paracelsus tackling the same problem from the specifically medical perspective in the 16th century AD:

'If the physician ... sees and recognizes all illnesses in the macrocosm outside man, and if he has a clear idea of man and his whole nature, then and only then, is he a physician.... The physician should speak of that which is invisible. What is visible should belong to his knowledge and he should recognise illnesses just as everybody else who is not a physician can recognise them by their symptoms. But this is far from making him a physician; he becomes a physician only when he knows that which is unnamed, invisible, and immaterial, yet has its effect.' (Paracelsus 1951)

You could argue that, through modern science and technology, what was invisible and unnamed in the 16th century, is now visible and named. To some extent this is true, but I think this is not what Paracelsus meant. At the time of his writing there was already a reaction against the

burgeoning materialism of the Enlightenment. His voice and others warned against ignoring the kind of knowing that is part of the relationship between things. I suggest the 'new' story that Arthur Frank and many others seek for the rebalancing of our approach to illness can be achieved by using the language of the creative arts to express the ineffable, the invisible and the unnamed through diverse modes of representation. This will need to be done, not so much through gestures such as paintings hung in hospital corridors, art therapy as a minor component of mental health services or poems in GP waiting rooms, welcome though these are. It must be done by reinterpreting and developing the everyday practice of healthcare, that is, what experienced practitioners already do intuitively, but using the fundamental conceptual and imaginative approaches of the creative arts to validate them and bring them to wider notice.

Attention, representation, affiliation

In 2004 I attended a remarkable lecture in London by Dr Rita Charon who is both physician and literary scholar, and a leader in the US narrative medicine movement. I captured this quote (with resonance from the biblical book of Genesis): 'When we see things in the world, we rescue them from formlessness by giving them form'. Then she drew on French philosopher Paul Ricoeur's interpretation of the Aristotelian concept of *mimesis*. This involves a threefold process expressed by Ricoeur as *attention*: taking notice, looking, listening; *representation*: in visible and/or audible form; *affiliation*: sharing the representation with others. This is a creative and imaginative process still pursued by most artists and with obvious resemblance to the medical consultation – history and examination (= attention), establishing an interpretation such as a diagnosis (= representation), sharing with patient and perhaps others (= affiliation). Less obvious is its resemblance to science.¹ All three of these areas, touch on the key issue of *truth*. Aristotle said an artist's 'copy' of nature could be true. Plato disagreed. This conflict resonates to this day. I'm with Aristotle. Picasso put it well: 'We all know art is not the truth, art is a lie that makes us realise the truth'. Yet thanks to the European Enlightenment, the scientist's representation is considered truer than the artist's – taking Plato's position in which philosophy (ancient forerunner of science) was

truer than art. Medicine has fallen in with the science camp. It is now time to fall out to some extent and become a bridge between the two.

Returning to Viktor Frankl's story, how do his ideas play out in terms of these new understandings? Frankl had plenty of time to pay close *attention* to his fellows and to his own experiences. He recognised, like Cassell (see above) that attention includes awareness of *intention*, that life has a past-present-future configuration, just like the beginning-middle-end of a story or play. He knew that the core of their suffering was not so much the malnutrition and diseases they had, but their fear for the future. This was his *representation* of their predicament. This and his psychiatric knowledge enabled him to communicate (*affiliate*) this to both himself and his men, by helping them to find a reason for hope. The nature of that hope was always particular to each man, but our need for hope is universal. Later he affiliated with the world through his remarkable book which has sold more than seven million copies. He wrote that above all else, it was his need to share his insights with the world that kept him alive. This was his hope. We are all part of his world. He stayed alive for us. Now we are all woven into his, and many other unfinished tapestries.

'We live inside the dreams of others. We might be imprisoned by them'. Ben Okri 1998

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¹ The Nobel Laureate scientist Sir Peter Medawar made the case for scientific enquiry beginning with 'a story about a Possible World – a story we invent and criticise and modify as we go along, so that it ends by being, as nearly as we can make it, a story about real life'. Medawar PB, *Induction and Intuition in Scientific Thought*, London, Methuen, 1969, pp59.