International Journal of Osteopathic Medicine 28 (2018) 1–3

Contents lists available at ScienceDirect

International Journal of Osteopathic Medicine

journal homepage: www.elsevier.com/locate/ijosm

Evidence, alternative facts and narrative: A personal reflection on person-centred care and the role of stories in healthcare

In 1846, Ignaz Semmelweis, a Hungarian physician working in the General Hospital in Vienna noted that in that year 451 women in the doctors' Maternity Ward Number 1 died of puerperal (childbirth) fever. This contrasted with the midwives' Ward Number 2 next door, in which only 90 women died. The assumed explanation, based on miasma theory, was that Ward Number 1 had bad air which Ward Number 2 did not. The fact was that the doctors' post-mortem room, which midwives did not use, was conveniently close by and doctors moved regularly between it and their maternity ward without cleaning themselves up. Semmelweis began to suspect that this might have more to do with the tragic mortality figures than bad airs.

His hunch was given credence by the death of a colleague from a scalpel cut obtained while performing an autopsy in the mortuary. The symptoms were similar to those of puerperal fever. Against much resistance from the doctors, Semmelweis had Ward Number 1 thoroughly cleaned, then initiated a hand-washing regime for all staff using chlorinated lime. Within 2 years mortality from infection was almost zero, but resentment from the doctors was sky-high; they objected to being made to do something they did not consider necessary and which had never been part of usual practice.

Semmelweis published his findings backed by extensive statistics, but his ideas were heavily criticised by the medical establishment as absurd. Sacked from his post, he returned to Budapest. With his departure from Vienna, the old practices were restored and death rates quickly rose to pre 1847 levels.

Semmelweis had received only criticism and ridicule for his insights; he suffered depression and died in a mental asylum. It was only a few years later that Louis Pasteur, supported by Robert Koch, was able to isolate microbes and demonstrate the mechanisms of infection. The prevailing miasmic paradigm was abandoned and medicine entered the modern era [1].

I recount this story not merely to demonstrate the role of evidence in challenging harmful prevailing practices and the reluctance of established practitioners to abandon cherished mores, nor just to emphasise the importance of critical observation, curiosity and a reflexive willingness to consider different explanations for things we assume and take for granted, important as all of these are. My reason for drawing attention to this sad historical event is to make the point that progress and development is not simply a matter of making new discoveries. It is a complex, multi-faceted process that involves good science, yes, but in the context of prevailing socio-cultural ideas and, most importantly, of an individual's world-view. If everyone you know whose opinions you value, and if what you hear and read assumes that illness is caused by bad air (or not wearing a vest, being a bad person, obesity, spinal lesions, malalignment, or whatever), then no amount of 'evidence', will convince most people otherwise. New ideas must be "of their time" to be widely accepted, i.e., they must fit comfortably with what is known and the stories we tell ourselves about the world and how we experience it.

I also think that the story has relevance for better understanding patients and their sometimes irrational responses both to their condition and advice on how to modify their life-style to improve their outcomes. It has a particular cogency for osteopathy because of the claim to be person-centred, but if we are truly person-centred we must recognise that patients' narratives are central.

Challenging and changing existing assumptions and mores requires what Thomas Kuhn termed a 'paradigm shift' in the way the World is seen [2]. A paradigm shift is not just a new idea, but a completely different way of viewing the world that requires many other ideas to be re-evaluated or, perhaps, abandoned. Human nature is such that we resist this; we stand by what we have always know, even in the face of overwhelming evidence, as Semmelweis found.

Today, hygiene is not merely a desirable addition to, but a fundamental foundation of medicine. Humoral and miasmic theories have given way to contagion and gene-based theories. It is now a given that hygienic practices are instilled into healthcare, the food industry, indeed, everyone from an early age. It took the discovery of the world of microbes (and many found it difficult to accept that microscopic things could cause illness and death in organisms as large as human beings) and a new sense of what 'the world' is like for infection to be (reluctantly) accepted as a major cause of illness. Contagion theory became the new norm, the prevailing world view [1].

The point I am making is that facts alone—particularly those that involve numbers and statistics—do not persuade, change minds or behaviours. And this is not because we reason against or do not believe the figures. It is because we are not computers, we are not hard-wired to evaluate a mass of numbers and formulae in order to come to a rational decision, even when they are served up in front of us [3]. Some people might say, "but we should". That is not the point; we are not machines we are organisms, which, perhaps, is something we need to take more account of in our dealings with patients and dare I say, with colleagues? How does this apply to osteopathy? After all, we are already person and not condition-centred, are we not?

A recent *Lancet* 3-part Series reviewed current knowledge, evidence and practice across all clinical disciplines that deal with low back pain (LBP) [4–6]. Somewhat like Semmelweis's observations, the authors

https://doi.org/10.1016/j.ijosm.2018.04.005

highlight a number of searching and seriously challenging issues for practitioners working in this area. It has been known for some time that the correlation between musculoskeletal pain generally and pathological changes is poor and that treating it as a physical problem has inadequate outcomes, particularly in the long-term. *The Lancet* authors ask what LBP is [6]. LBP is not a specific disease or condition in the classic nosological sense, demonstrated by aetiological agent, typical signs and symptoms and pathological lesion [7]. *The Lancet* papers simply call it a symptom that has numerous, frequently unknown, non-specific causes and they focus on the management of the problem. But it leaves open the question of what the ontological status of LBP is–i.e. what is its essence, its nature and how should it be considered: is it physical, responding to physical interventions such as osteopathy; is it psychological or social, responding to cognitive intervention, or something else? The evidence, according to *The Lancet* review is ambiguous exhibiting physical, mental and social phenomena. This has been interpreted in recent years as requiring a bio-psycho-social (BPS) approach to diagnosis and treatment [8,9].

For the purposes of this paper I take it that we are dealing with a whole person phenomenon and that person-centred care is therefore foundational and central rather than a humanistic veneer appended to usual care if musculoskeletal problems and LBP in particular are to be managed effectively. It follows that there are at least two Kuhnian implications: first, the patient's narrative, which itself entails physical, cognitive, social and cultural factors will be the *starting point* for practice in osteopathy, as well as in other healthcare disciplines, rather than being a later, more superficial consideration, i.e., establishing a proper narrative precedes and is more important for management and care, than is providing a definitive diagnosis; and second, that the osteopathic profession may need radically to reassess some of its theory and long-cherished assumptions.

It is worth stating here that from the earliest days of osteopathy two views vied with each other for dominance: a focus on body mechanics and structural arrangement; and second, the individuality of the patient as a unique person with idiosyncratic responses to their condition, environment and treatment [10]. Osteopathy, for most of its existence has been dominated by the former, particularly in technique [11], with the latter being given mainly lip service. I am suggesting that this emphasis needs to be reversed. So let me expound on how this could develop.

The Israeli academics Daniel Kahneman and Amos Tversky in their famous studies about how human beings make decisions, argue that it is stories and not numbers that persuade [12,13]. Stories bring meaning and context to facts and events. It is through stories that we get our understanding of what the world is like and on which we make decisions that fit with that big picture; through stories we make sense of the array of experiences we encounter in life. It is why stories feature in childhood. Through stories children are introduced to ideas and situations they may not yet have met, or have met but cannot fit with their limited experience of the world. The truth, as with myths, is not in the facts of the matter, but in the meaning and understanding they convey. Stories are perhaps the most fundamental aspect of human life; they form the foundation and backdrop to our lives making them, arguably, the most important thing that distinguishes us from other animals.

It is significant, I think, that medicine, by introducing measurements, standards and health parameters, moved society away from a time when we understood and explained illness through stories and particularly folk-lore, old-wives-tales and so on, to an age when judgements and decisions are based on numbers and graphs. We are not judged to be ill or well today according to the stories we tell about how we feel. The narrative of 'me' in the context of what I am accustomed to feeling or doing, or of how my peers behave and the cultural norms I have grown up with, has been replaced by algorithms of measurements and numbers that are 'right' or 'wrong', 'good' or 'bad', such as blood pressure, Hb and WBC counts and so on. It is not that this is wrong—we know they provide better predictions and outcomes—it is more that they feel alien to us. We cannot relate to or identify with them as part of what it means to be 'me'. The danger is that the new narrative of illness, symptoms, treatment, doctor/osteopath/hospital consultations, etc., become the new narrative that defines a person and provides the meaning context for that person's life as a back/arthritis/heart/cancer/etc., patient'. It is another reason it can be so difficult to change pernicious attitudes and behaviours in chronic patients and challenge resistance to change.

Let me be clear: I am not suggesting we return to some mythical golden age when the village wise woman would read the signs and know whether someone was ill and what potion to give; neither am I arguing that modern technology is bad for human health. What I am trying to flag up is that we need to re-establish narrative at the centre of healthcare, because it is only through narrative, through the generation of a meaningful and coherent story that makes a positive sense of illness and health, that we become whole in ourselves, despite pain, illness and disease. It is through narrative that, as healthcare providers, we focus on the whole organic person rather than on the mechanisms operating within the body. Narrative establishes the 'big picture' that enables us to make sense of new experiences and then to use them to expand and enrich it.

This has come home to me in somewhat dramatic fashion with my recent diagnosis of metastatic prostate cancer. Even when it had been diagnosed, along with the knowledge that it is incurable and something that will eventually kill me, I felt as healthy as I had before. I had been walking up mountains in Norway only a couple of weeks earlier and felt great–for a 65 year old!! The blood tests and MRI scans bore no relation to or connection with how I felt. The evidence, the reports from the hospital must be wrong. I understood what those Viennese doctors experienced; the facts of this 'new world' just did not relate to my longer, trusted experience of life (or of medical practice for the Viennese doctors). I had to trust evidence that continues to feel other than me. I now better understand why people ignore symptoms until it is too late. Even now–and as I write I am half-way through my chemotherapy treatment–I feel well. I sense that my body is behaving and responding differently from how it used to–most of which is due to aggressive treatment rather than the condition–but I do not feel 'ill' to the degree suggested by my diagnosis. I have felt more ill with the common cold than I do now.

So what is the story that I should tell myself, or better still, what is the story that I should be getting from the many medical personnel involved in my care? And that is not intended to be a criticism of the care I have received, which has been excellent, it is a broader point about the general failure to recognise the significance that narrative and of being person-centred has for healthcare.

Understanding what person-centred means is much more complex and multi-factorial than I once assumed. It is not merely a question of considering a person's individual needs and concerns and putting them first. It is recognising that human beings face up to the challenge of illness, pain and disability differently from how we might understand and seek to correct a fault in a car, say.

It also raises the question of how we understand it for our patients. The pain or disease that comes "out of nowhere'" as it did for me (and as it does for much LBP) to threaten our sense of identity and challenge us to re-evaluate who and what we are, and what our body is, is as challenging as Semmelweis's evidence was to usual medical practice in 19th Century Vienna.[1]

The cognitive dissonance and confirmation bias that Kahneman and colleagues have drawn attention to in decision-making is the inadequate, human response to this contradiction. They have their equivalents in how we develop our sense of self and the ways that illness, among other things, disrupts and challenges it. Being person-centred entails recognising and integrating these into care for patients.

[1] For further analysis on this see Tyreman 2014 [14].

That is not to say that we must go all-out to get patients to understand the science of what has happened to their body; in fact it is explicitly *not* just that. It is somehow to help them to establish new norms and to accept a different and hopefully, enhanced sense of self–a new narrative that incorporates the new health 'evidence' in a way that is meaningful and which can provide a foundation for going forward. Semmelweis assumed his colleagues would adopt a new narrative of maternity care that incorporated cleanliness and hygiene. But for them it was a narrative that did not fit with their older, familiar, more dominant one. It was a narrative that not only did they not understand, they felt threatened by. The authors of *The Lancet* Series on LBP are asking practitioners to support patients in generating a different kind of narrative that focuses on living well and not on correcting body faults.

Before my diagnosis was made I experienced myself as 'me' in a way that I had taken for granted throughout my life. Of course I knew that I was getting older and that eventually I would die, but that was an abstract concept, in the distance, to be faced eventually; it was unlikely that anything significant would change in a long time. I have lived healthily and demographics suggested that I should have at least another two decades to go; "sixty is the new forty" and so on. That was the story I had told myself. Suddenly new, threatening facts are making me re-evaluate who I am, what I am, how I relate to the world and to other people, what it means for my future, even my understanding of future. This new 'evidence' is not part of the old story of 'me', it does not fit, it isn't comfortable and it holds the ultimate threat. A new person will emerge from this as a new person emerges from any challenge we face and work through. The usually ignored question for the practitioner is how we support a patient in this aspect of their healing. This, I suggest, is what it really means to be holistic and person-centred.

To be person-centred in healthcare is to recognise that although we know that such things as eating healthily, exercising, getting sufficient sleep and so on, are good for us, we can find them almost impossible to achieve when the world around us, the world that provides the meaning-structure for our lives, demonstrates and offers something else that is easier, comforting and unchallenging. Pain, illness, disease and impending death are some of the greatest challenges we each face. Unlike the Viennese doctors we cannot ignore, avoid or defer those challenges; they force themselves on us. The practitioner's task is not merely to explain and treat, but to provide support and insight into the meaning of illness experiences in order to enable a patient to develop a better, life-enhancing narrative and become a more whole person.

References

[1] ten-Have HAMJ. ten Have HAMJ, Kimsma GK, Spicker SF, editors. Knowledge and practice in european medicine: the case of infectious diseases in the growth of medical knowledge. Dordrecht: Kluwer Academic Publishers; 1997. p. 15–38.

[2] Kuhn TS. The structure of scientific revolutions. Chicago: University of Chicago Press; 1996.

[3] Adams T. On the other hand … in *Opinion*. Guardian 25th February 2018https://www.theguardian.com/commentisfree/2018/feb/25/on-the-other-hand-behavioural-psychology-sunday-essay.

[4] Buchbinder R, et al. Low back pain: a call for action. Lancet 21st March 2018https://doi.org/10.1016/S0140-6736(18)30488-4.

[5] Foster NE, et al. Prevention and treatment of low back pain: evidence, challenges, and promising directions. Lancet 21st March 2018https://doi.org/10.1016/S0140-6736(18)30489-6.

[6] Hartvigsen J, et al. What low back pain is and why we need to pay attention. Lancet 21st March 2018https://doi.org/10.1016/S0140-6736(18)30480-X.

[7] Greaves D. Disease concepts models and classification in western medicine - illustrated by reference to pulmonary tuberculosis and coronary heart disease. Soc Soc Hist Med Bull 1979;31–35(24).

[8] Engel GL. The need for a new medical model: a challenge for biomedicine. Science 1977;196:129–36.

[9] Engel GL. The clinical application of the biopsychosocial model. Am J Psychiatr 1980;137(5):535–44.

[10] O'Brien JC. John Martin Little John: a visionary paradox. In: Mayer J, Standen C, editors. Textbook of osteopathic medicine. Elsevier/Urban & Fisher; 2018. p. 41–7.

[11] Fossum C. The history of osteopathic techniques. In: Mayer J, Standen C, editors. Textbook of osteopathic medicine. Elsevier/Urban & Fisher; 2018. p. 315–25.

[12] Kahneman D, Tversky A. Choices, values, and frames. Cambridge University Press; 2000-09-25.

[13] Kahneman D. Thinking, fast and slow. Penguin; 2012.

[14] Tyreman S. Trust and Truth: uncertainty in health care practice. J Eval Clin Pract 2015;21(3):470–8.

Stephen Tyreman
University College of Osteopathy, London, UK
Kristiania University College, Oslo, Norway
E-mail address: s.tyreman@uco.ac.uk