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Medical humanities and the 'fifth wave' in public health: parallel tracks?

Overview

Since 2008, the Centre for Medical Humanities at Durham University has been engaged in a Wellcome Trust funded programme of work entitled 'Medicine and Human Flourishing'. One important aim of this programme is to demonstrate that medical humanities has potential as a research field not just to impact on the education of health professionals, but critically to engage with major challenges in medical science and public health. The overarching critique represented by the medical humanities is that the powerful gravitational pull and success of medicine over the past century has led health to be viewed almost entirely from the perspective of medical science. Therefore health research, policy and practice tends to be informed by the methods, protocols and training approaches of biomedicine ignoring wider sources of understanding of what makes human lives go well. Those sources include the humanities, which are concerned with the nature of embodied existence, the importance of inter-subjectivity, the value of aesthetic experience, and the mysteries of spiritual feeling in human lives. These themes resonate strongly with the notion of the 'fifth wave'¹ in public health, and this lecture explored this relationship and connected ideas of balance, change and emergence.

Introduction

A GP who started out reading English Literature before studying Medicine, Professor Macnaughton went on to study philosophy with Robert Downey one of the originators of the field of medical humanities. More recently, as the result of a Wellcome Trust grant, Prof Macnaughton and colleagues have established the Centre for Medical Humanities in Durham with the aim of pursuing work under the theme 'Medicine and Human Flourishing'. Over time, Professor Macnaughton has come to see 'Medical Humanities' as a field that brings different subjects together, as an 'inter-discipline' rather than a separate discipline.

It was as part of this project that Professor Macnaughton encountered an article by Professor Phil Hanlon (University of Glasgow) and others entitled "Making the case for a fifth wave in public health" <http://www.ncbi.nlm.nih.gov/pubmed/21256366> . This was a seminal moment. The article presented both a critique of current thinking and proposed a way forward. This led to a meeting with Phil Hanlon and Andrew Lyon (International Futures Forum) to discuss how medical humanities might interact with their ideas. An invitation to this lecture was one outcome.

¹ The fifth wave perspective suggests that since the 18th century enlightenment there have been three main waves of ideas (reason, materialism and modernism). There have been four main waves of public health intervention associated with these (municipalism, the refinement of the scientific approach, the welfare state and risk theory of disease). The fifth wave suggests that the effect of these is diminishing and that a new fifth wave is needed.

Professor Macnaughton emphasised three things at the outset: that she is from outside public health and, while this can help ideas to be strengthened, she would welcome corrections to any naive assumptions; that her approach was to try and make a difference not just to be critical; that she is addressing these issues not just as a medical humanities specialist but also as a practicing clinician. The aim of this lecture is to give both a sense of the current trajectory of medical humanities and also how this might relate to the fifth wave of public health. She proposed to do this by firstly describing some common origins; then moving to parallel tracks and finally attempting to identify any advantages and disadvantages of walking along together.

Medical humanities

The field of medical humanities can be characterised by looking at two very different descriptions of breast cancer; one from a medical journal and the other from a poem.

From the *New England Journal of Medicine* 'Side Effects of Adjuvant Treatment of Breast Cancer':

Many women with breast cancer who are receiving adjuvant chemotherapy have fatigue, and about two thirds of them rate the level of fatigue as moderate or severe. The fatigue appears to resolve after treatment. In a survey of nearly 2000 women with breast cancer who were evaluated three years after adjuvant treatment, the level of fatigue was similar to that of age-matched women.

Poem by Julia Darling: 'Chemotherapy' from *Sudden Collapses in Public Places*:

I did not imagine being bald
at forty four. I didn't have a plan.
Perhaps a scar or two from growing old,
Hot flushes. I'd sit fluttering a fan.

But I am bald, and hardly ever walk
by day, I'm the invalid of these rooms,
stirring soups, awake in the half dark,
not answering the phone when it rings.

I never thought that life could get this small,
that I would care so much about a cup,
the taste of tea, the texture of a shawl,
and whether or not I should get up.

I'm not unhappy. I have learned to drift
and sip. The smallest things are gifts.

The medical perspective focuses on evidence, side effects and numbers. This is all important and useful, but it does not represent illness for patients in the way it does for doctors. For patients, illness is defined by what they experience.

Medical humanities has largely been known for re-introducing these patient representations to medical education. However, this type of approach leaves medicine largely untouched. It is an embellishment rather than an attempt to critically engage with how medicine goes about its practice, thinks about its evidence base or examines its place within wider ways of thinking about how life goes well or badly.

In Durham they have begun to articulate a different characteristic of medical humanities that of 'critical friend' or perhaps 'disruptive teenager'. This is a return to the roots of the field which started in the 1970s with the insight that the disciplines of bioscience or even bioethics were insufficient to explain or explore the concerns of medicine contextualised within the lived experience of humanity.

Bioscience

Professor Macnaughton emphasised that it is important to acknowledge how successful biomedicine has been. But it is also important to realise what assumptions about the body are being made in scientific medicine. The key metaphor is that of the body as a machine. The philosopher Mary Midgeley critiques the persistence of this metaphor which implies that the world is under human control, can be fully understood, taken to pieces and reassembled more satisfactorily.

In this framework new treatments depend on randomised controlled trials (RCTs) in which individual differences are flattened in group identity and sameness. Clinicians are trained to assume that patients pose particular questions and respond in particular ways. Public health is not immune from this way of thinking with the idea of 'nudging' to bring about behaviour change based on a vision of the human that is Pavlovian. This approach has been successful in delivering a certain kind of technical medical care, but it may be that holding to the conception of the human on which this progress has so far been based might hamper new directions and further understanding in medicine.

The field of medical humanities is currently being influenced by William James, an American philosopher and clinician who lived 100 years ago, and current scholars such as Antonio Damasio. Criticising the tendency to divide the body and psyche into separate parts, they suggest we should "broaden our notion of health instead of narrowing it".

Common ground

There appears to be common ground between this emergent thinking in medical humanities and the ideas of the *fifth wave of public health* which suggest that the narrow focus of scientific rationalism is holding back more creative thinking about the modern epidemics of obesity, respiratory disease and mental health problems. It is a time for new metaphors as the 'let's fix it' approach is no longer working.

The emergent qualities of the fifth wave are described by Phil Hanlon and colleagues as:

1. Complex adaptive systems with multiple points of equilibrium.
2. Rebalancing our mindset – ‘anti’ to ‘pro’, from dominion and independence to interdependence and co-operation.
3. Rebalance models – mechanistic to organic.
4. Rebalance our orientation – objective to subjective.
5. Develop a future consciousness to inform the present.
6. Iterate and scale up through learning – try things out and share.

In the second part of her talk Professor Macnaughton set out to illustrate how people working in the field of medical humanities are working with some of these principles in exactly the way envisaged here. Not by rejecting the achievements of the past but building on and refining them.

Words/labels/models

Medical humanities is interested in the implications and power of words. Once people are labelled with a diagnosis, a cascade of medical, social and economic consequences follows. What humanities can do is help take us back to the original words, to find out what the technical words might have obscured, like layers of varnish on an old painting.

One example of this in practice is the ‘Hearing Voices’ project. This is a multi-disciplinary project using medical humanities methodology to study the phenomenon of people hearing voices in their own head. This is an example of the role the humanities can play in rebalancing the mechanistic models and in shifting the orientation from objective to subjective.

Words are clearly of crucial importance in this project and part of the role of the humanities scholars is to pay attention to what power the words of science have in characterising the human beings experiencing this phenomenon or in implying mechanisms of action. Take the word ‘signal’ for example. Mechanical signals are usually characterised as strong or weak, but voices may be loud or soft, may also be gentle or aggressive, reassuring or menacing, recognised or strange to the hearer. These kinds of discussion in the research meetings, which are called ‘Voice Club’, have led to modifications of the research projects of the scientists. ‘Voice hearers’ undergoing functional brain imaging are no longer asked just about the absence or presence of a voice, but about the timbre of the voice and their emotional response to that voice.

New metaphors and images can emerge when we start specifically to focus on the experience. A voice hearer put it like this: “an important question in psychiatry shouldn’t be ‘what’s wrong with you’ but rather ‘what’s happened to you’.”

True, good, beautiful and emergent

A further example is the work Jane has had the privilege of doing over the past year with the writer Kathleen Jamie and the artist Brigid Collins to compile a book of words and images that illustrates the power of creativity to transform an unsightly operation scar into a series of beautiful things. At its heart lies a consideration of a particular way of looking. It contrasts the artist’s ‘looking’ with the ‘medical gaze’. In these works (as Kathleen writes) the scar “is not the end of the story, but instead leads out of loss, and back into the natural world, and

the beautiful". There is no denial here that the intervention was successful, the truth of science was clear. But the good in the sense of hope and recovery were compromised by the ugliness of what was left written on the body. Recovery and hope were rekindled when the mark on the body was set free to develop into something new and beautiful. These images and this sense of recovery could be said to be 'emergent properties' of the scar combined with the complex process of noticing, sitting, drawing, painting, comparing and letting go.

Smoking and public health

This final example engages with the institutional context of public health. Professor Macnaughton realised that she was alienated by the way public health clinicians were talking about the subject of smoking. She began to wonder what was missing and whether this might be related to the continuing prevalence of smoking at a level of around 20% in the UK.

From the perspective of medical humanities, some of the efforts to explore and address this ongoing prevalence are doomed to failure because of the methods and framework used. It would be difficult because of the steer of these methods to find responses other than guilt about failing to give up and a justification that smoking helps people to cope and get through the day. Turning away from a biomedical framework to the resources and viewpoint of medical humanities a different story emerges. In the arts and literature we find examples where smoking is described as a sensual pleasure and also signifies a relationship between the bounded internal space of the body and the free, unlimited space of the external world.

Simon Gray describes his memories of starting smoking (page 58 of *The Smoking Diaries*):

"...our smoking was exhilaratingly furtive, the deep, dark, swirling pleasures of the smoke being sucked into fresh, pink, welcoming lungs, it took me just three or four cigarettes to acquire the habit and you know there are still moments now when I catch more than a memory of the first suckings-in, the slow leakings-out when the smoke seems to fill the nostril with far more than the experience of itself, and I regret the hundreds or thousands of cigarettes that I never experienced, inhaled and exhaled without noticing..."

In a lot of tobacco control research the role of smoking as a 'coping mechanism' has become a kind of shorthand for the complex interdependence between human beings and cigarettes. Drawing on the insights from the humanities may lead to a more nuanced understanding where smoking conveys some symbolic control over the connection between the body and the world. This kind of analysis is not amenable to scientific explanation but invites us to try on a different world view.

This framework can be applied to smoking in pregnant women which is a particularly pressing problem. Qualitative research by Hilary Graham and her team at the University of York describes women as dealing with a major change in their sense of being on becoming pregnant, and also coping with guilt, confusion and stress because of the pressures on them to quit smoking. The result is a kind of ontological strife. A recent study found that midwives found it difficult to deliver smoking advice to pregnant women not because of lack of knowledge or resources but because of their role to support women in whom they sensed this confusion of feelings. Perhaps in spite of the 'truth' of science, the 'good' thing here, as sensed by the midwives through their relationships with these women, is to reduce the number of cigarettes smoked to just those that will keep them on an even keel, rather than giving up altogether?

Potential and challenges

The emergent qualities of the fifth wave as described previously can be drawn together with some of these examples and insights from medical humanities.

| Fifth wave qualities | Medical humanities |
|---|---|
| Complex adaptive systems with multiple points of equilibrium | People and communities are organic, adaptive and creative, and can come up with their own ways of transforming illness and moving on |
| Rebalancing our mindset – ‘anti’ to ‘pro’, from dominion and independence to interdependence and co-operation | Learning from communities of experience, such as ‘voice hearers’, and from other disciplines whose perspectives have not been dominated by bioscience |
| Rebalance models – mechanistic to organic | Using the different perspectives to build an awareness of how models can be modified to enable them to be more effective |
| Rebalance our orientation – objective to subjective | Central aim to rebalance from objective to lived experience and inner transformation focusing on what can be learned from experience |
| Develop a future consciousness to inform the present | Recognise the power implied by becoming |
| Iterate and scale up through learning – try things out and share | Process of learning is integral to medical humanities however there is a challenge of scaling up from the interpersonal to the collective |

At the heart of this is the insight that human beings function best and learn best in the interpersonal or intersubjective space where all our cognitive understanding, skills, physical instincts, emotions, and insights as well as our more mysterious existential feelings of being are primed and in use. This openness makes us vulnerable to sink under the pressures of large bureaucracies, where atmospheres may be imbued with fear, suspicion and failure. We have the power to affect interpersonal and institutional atmospheres with new cultures and this mysterious quality of people individually and collectively can be a potentially powerful agent of change within a culture or community open to learning and aware of its potential to develop for the better. We may not be able to change things overnight but to quote the anthropologist Margaret Mead: *“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.”*

The views expressed in this paper are those of the speaker and do not necessarily reflect the views of the Glasgow Centre for Population Health.

Summary prepared by the Glasgow Centre for Population Health.