

Medical Humanities handbook

Kelley Swain

This is a document in progress and further session outlines will be added when they are received

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Reading list

Sontag S (2002). Sontag, Susan. *Illness as metaphor and AIDS and its metaphors*, Chapter 4. London: Penguin.

2. The poems 'Ode to a Nightingale' and 'La Belle Dame Sans Merci' by John Keats.

3. It may be useful to review the following video clip on epigenetics: www.youtube.com/watch?v=kp1bZEUgqVI

4. Poem 'Failing and Flying' by Jack Gilbert.

5. Lennard J. Davis, 'Visualising the Disabled Body: The classical nude and the fragmented torso', from L.J. Davis (1997) 'Nude Venuses, Medusa's body, and phantom limbs: disability and visibility,' in D.T. Mitchell and S.L. Snyder (eds), *The Body and Physical Difference*, Ann Arbor: University of Michigan Press.

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Tuesday 25 September 2012

8. Humanities in Global Health Introduction: Considering Medical Humanities

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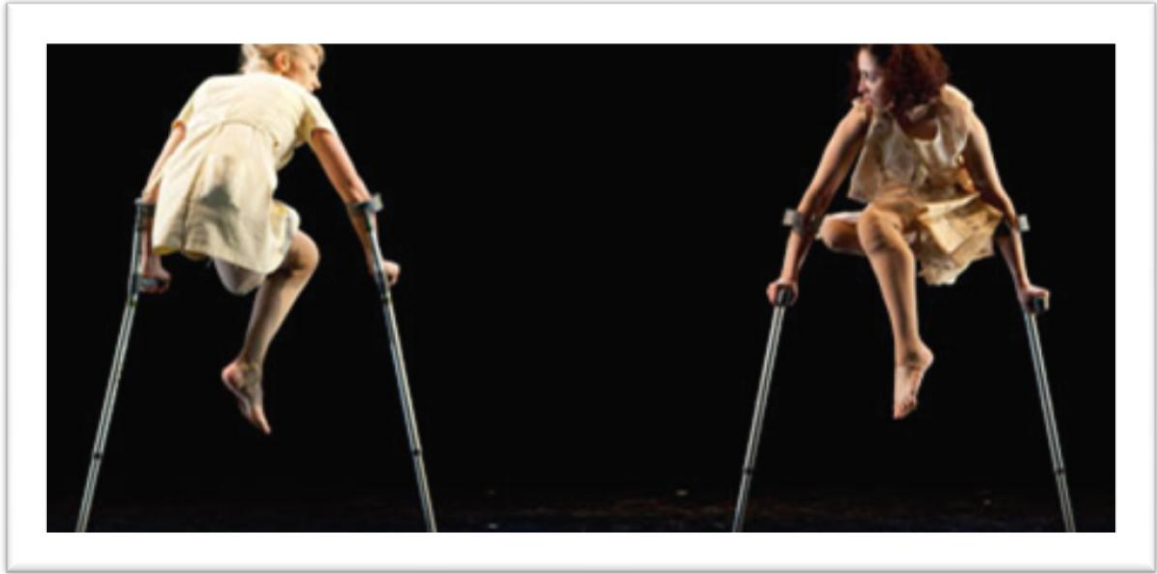
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Hippocrates:

- 'I swear ...to consider dear to me, as my parents, him who taught me this art; to live in common with him and, if necessary, to share my goods with him; to look upon his children as my own brothers, to teach them this art; and that by my teaching, I will impart a knowledge of this art to my own sons, and to my teacher's sons, and to disciples bound by an indenture and oath according to the medical laws, and no others.'

'Medicine' comes from Latin *ars medicina*: 'the art of healing'.

'Unlimited' Festival at the Southbank Centre, 2012 (Photos, SBC)



Above: 'Parallel Lines' performance.



Above: Sue Austin in her self-propelled underwater wheelchair.

From Berlin Conference on Medical Objects (Photo, K.S.)



AnanaGram (adj):
Original, Constantly Evolving

- ❖ Matt Rinaldi: performance
- ❖ Q&A with Matt

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ILLNESS AS METAPHOR:

What, according to Sontag, did TB come to represent in the 19th century?

Come up with a list from the reading:

'With the new mobility (social and geographical) made possible in the eighteenth century, worth and station are not given; they must be asserted. They were asserted through new notions about clothes ('fashion') and new attitudes toward illness. Both clothes (the outer garment of the body) and illness (a kind of interior décor of the body) became tropes for new attitudes toward the self.'

Metaphor examples:

- The interior drapery of tuberculosis.
- Tuberculosis is like a fine cloth draping my lungs.
- I am as ghostly as one with TB.
- I am draped with the spectre of tuberculosis.

'The Perfect Code'

There is a great deal of mess in hospital medicine, literal and figurative, and the code bunches it all into a dense mass that on some days seems to represent everything wrong with the world. (p. 139)

'He needs a halo.'

A halo is one of those excruciating-looking devices you may have seen somebody wearing: a ring of shiny metal that encircles the head (hence the name), supported by a cage that rests on a harness braced on the shoulders. Four large bolts run through the halo and into the patient's skull, gripping the head rigidly in place like a Christmas tree in its stand. A little crust of blood where the bolts penetrate the skin completes the picture. They look terrible, but patients tell me that after the first day or so they don't really hurt. Getting one put on, however: that hurts. (p. 144-5)

I...saw through the open door of Mr Mongay's room a strange tableau: two tall men in green scrubs wielding socket wrenches around the patient's head, a tangle of chrome, and the patient's hands quivering in the air, fingers spread as if calling on the seas to part. Sometime later I looked up again and the green scrubs were gone. Mr Mongay lay propped up in his bed, his head in a halo. From the side, his nose was a hawk's beak, the rest of his face sunk in drugged sleep, but his mouth still snarled as if it remembered recent pain. He looked like a strange, sad bird in a very small cage. (p. 146)

This, I thought as we left the room (the lines on the monitor dancing their steady dance, the ventilator measuring breath and time to its own slower rhythm), this is what a code should be. A clean thing. A beautiful thing. The patient hadn't died. (p. 149)

He had become something unreal to me – something beautiful, like a work of art, but unreal. Amid all the mess and squalor of the hospital, with its blind random unravelling of lives, in their patient dignity and kindness he and his family stood apart. In his case, for a little while at least, everything had gone exactly as it should have. The perfect code. (p.151)

Metaphor-Making

'Metaphor usually involves talking about one thing in terms of something else. Good metaphors often surprise us, making connections we don't expect. We recognise in them a rich and profound truth – one we can't always put our finger on; can't always put into straightforward explanation. A metaphor's deepest effects might occur because we can't explain it in a straightforward way.'

Writing on Death

Eight years ago, after our production of *The Grapes of Wrath* ended, my students and I tore down the set on which we had performed and rehearsed for several months of our lives. In the theatre world, we call this process 'strike', as you strike or remove the elements of the set to make room for the next production. After strike, I walked back to my car with my son. It was his second big production, but the first one in which he was old enough to help until the end of strike. As we left the barren stage for the car, he held on to the door handle and suddenly crumpled into a ball of tears on the asphalt of the parking lot. 'What's wrong?' I asked. He replied, 'To work so hard and to give up months of your life every day only to see it torn down into a pile of rubble is tearing my heart out.'

I was touched by how keenly he felt the loss of the production in his life. And I was glad to be able to give him the experience because, for me, it is the essence of life. We are born a blank slip of paper. There is nothing written yet. If we are lucky, we passionately and fervently pour all of our selves into living our lives and into crafting the production that we know will ultimately come to an end... even if it's *Cats*. And it does have to end. Every time I've closed a show, I experienced a little death. A life in the theatre teaches you as much about impermanence and non-attachment as life in a Buddhist monastery. People often mistake non-attachment with indifference – with some kind of holding back from the work at hand. But without our full engagement, our art, our life, and our relationships can never reach their full potential. Yet the ending is always the same whether we have lived purposefully or we have passed through this life half asleep. We have to walk that lonesome valley. But back to ALS.

ALS is a condition in which your body is rendered completely useless while your mind remains unimpaired. Someone with ALS is literally trapped in the prison of his or her own body. The other day, my sheet had wrapped around my arms while I slept. I woke up and I needed to call my caregiver for help. It was then that I realised I no longer have the arm strength to move a single twin sized sheet. I was unable to ring my call bell and did not have the lung strength to yell for help. I was trapped in my own bed. In this kind of situation, one's first instinct is to panic. Trust me. This



Leave them laughing

does not help at all. I lay in the bed, let my imagination run freely, and this poem by the Persian lyric poet Hafiz, called *Dropping Keys*, nudged its way into my conscious mind.

*The small man
Builds cages for everyone*

He

Knows.

While the sage,

Who has to duck his head

When the moon is low,

Keeps dropping keys all night long

For the

Beautiful

Rovdy

Prisoners.²

This poem made me realise that by calling my body a prison, I was that small man. I had to transform the metaphor of *body as prison* into something else. I imagined my body was a sandbag in a hot air balloon that must be hoisted over the edge of the basket in order to gain altitude. I needed to release my body – my sandbag – to allow my imagination to soar. Don't like how you feel? Describe the feeling in metaphor, then change the metaphor.

Shakespeare's Hamlet is a perfect example of a man who consciously decided to allow his perceptions to be coloured by his state of mind when he said to his old chums, Rosencrantz and Guildenstern... 'There is nothing either good or bad, but thinking makes it so.'

I think one key to happiness is to think about what Hamlet would do and do the exact opposite, like Superman's Bizarro World where everything is turned on its head. Unlike Hamlet, Bizarro Hamlet would have a much better shot at happiness and a much smaller body count at the end of the play. My favourite monologue of Hamlet's is 'What a piece of work is a man'

² HA'Z SHIRAZI. 1325-1389.

Writing on Death: The Natural Death Handbook, 5th Ed.

Changing the Metaphor

- ❖ Gather into groups
- ❖ Make a list of medically-related objects/things that you have encountered in your studies, ie: stethoscope, gurney, stitches, blood pressure – feel free to use your expertise and go beyond the obvious!
- ❖ Write in the form: 'A ____ of ____'
- ❖ 'A gurney of steel' 'Stitches of thread'
- ❖ Focus on at least five examples
- ❖ Then take the second word ('steel' or 'thread') and replace with an emotion.
- ❖ 'A gurney of sorrow' 'Stitches of laughter' – some will make more sense than others. Be creative and change words if you think they'll fit better. 'Stitches of laughter' is cliché; what about 'stitches of anger'?

NEXT TIME: TUESDAY 9 OCTOBER

- ❖ Meet outside John Snow Pub, Soho at 2:55 for 3pm sharp!
- ❖ Be prepared for a guided walk lasting about 2 hours: wear comfortable shoes, warm clothes, bring a brolly, etc.

Tuesday 9 and Wednesday 10 October

9. Humanities in Global Health: Cholera

Two parts: Guided walk by Dr Richard Barnett, and discussion the day after the walk.

By the end of this session you should be able to:

- Explain the two main methods John Snow used to understand the 1854 cholera epidemic in Soho:
 - The Broad Street water pump
 - Investigation of the Southwark and Lambeth Water Companies
- Understand the context of London's cholera outbreaks and explain at least three reasons for these outbreaks.
- Link the historic cholera epidemics in London to present-day epidemics, such as the 2010 cholera outbreak in Haiti. Are there similar reasons for such epidemics? Provide at least three examples.
- Provide at least three examples of how we approach the treatment of such epidemics differently due to our understanding of the spread of the disease.
- Consider Dr Barnett's guided walk. This is, effectively, a performance, albeit an educational one. How might this method of humanities help communicate medical history more effectively than pure book learning?
- The Humanities in Global Health session on cholera will focus on a guided walking tour by Wellcome Trust Engagement Fellow Dr Richard Barnett. 'Death by Water: John Snow and Cholera':
- *'Through the late 1840s John Snow, a Soho GP, watched helplessly as dozens of his patients succumbed to cholera. In 1854, working against the grain of contemporary medical thought, he used pioneering medical detective work to argue that the disease was transmitted by polluted water from a communal pump on Broad Street. Walk in the footsteps of Snow – and some less savoury characters – to uncover the story of dirt and disease, pleasure and revolution in the grubby heart of the West End.'*
- This walk is available for free as a Smartphone app at <http://www.sickcity.co.uk/walk/5>. The class will be treated to a guided tour by Dr Barnett on Tuesday 9 October, however, students can refresh their memories by going to the above link and taking themselves on the walk.
- The day after the walk, we will discuss the relevance of understanding the 1854 Soho cholera epidemics in light of Global Health studies today, drawing on the article 'Cholera in Haiti and the Modern 'John Snow''.

Essential reading

Cholera in Haiti and the Modern 'John Snow':

http://www.ph.ucla.edu/epi/snow/cholera_haiti.html

Recommended reading

Rosenberg CE. (1992) *Explaining epidemics and other studies in the history of medicine*. Cambridge: Cambridge University Press, chap 6, 'Cholera in nineteenth-century Europe: a tool for social and economic analysis'. pp 109 – 121.

R. R. Frerichs, P.S. Keim, R. Barrais, R. Piarroux. (2012) Nepalese origin of cholera epidemic in Haiti. 'Clinical Microbiology and Infection', Vol 19, Issue 6, pages E158 – E163.

Snow J. (1849) *On the mode of communication of cholera*. London. [First edition of John Snow's celebrated pamphlet; several versions available online such as <http://www.ph.ucla.edu/epi/snow.html>.]

Bynum WF. (1994) *Science and the practice of medicine in the nineteenth century*. Cambridge: Cambridge University Press, chap 3, 'Medicine in the community'.

Tuesday 16 October

10. Humanities in Global Health: Tuberculosis

By the end of this session you should be able to:

Describe two cases / case studies of tuberculosis in the arts based on the lecture:

- Opera:
 - La Boheme
 - La Traviata
 - Moulin Rouge! (Modern-day musical based on La Traviata)
- Poetry:
 - John Keats
 - Specifically considering poems 'Ode to a Nightingale' and 'La Belle Dame Sans Merci'
- Painting
 - Edvard Munch
 - Specifically considering 'The Sick Child' painting (different versions of painting)

Consider how, or whether, the examples you've chosen to describe are applicable to our understanding of TB today. How do the examples fit with Sontag's description of 'TB as metaphor' and the stereotypes she identifies in CH 4 of 'Illness as Metaphor'? Is this stuck in the past? Could it be useful for our understanding of TB today, or useful for the education of the public about TB today? If not, does it hold its own as a work of art?

Overview

The Humanities in Global Health session on Tuberculosis will consider a series of case studies of 'Tuberculosis in the Arts'. We will look at the operas *La Boheme* and *La Traviata*, and the modern musical film, *Moulin Rouge!* We will consider the life of poet John Keats, and consider his poems 'Ode to a Nightingale' and 'La Belle Dame Sans Merci'. We will consider the life of painter Edvard Munch, and look closely at his repeated painting of 'The Sick Child'.

We will listen to a podcast about TB in London today, and take some time to draw: either art based on the Expressionism of Munch in 'The Sick Child' (an image based on memory & emotion) or applying ideas from one of the case studies to our consideration of TB today.

Discussion questions include:

How can we revise our ideas of tuberculosis to fit today?

Can the case studies help us understand TB now?

Can the public awareness of TB be affected via the arts?

Do we need a modern version of 'La Boheme' (etc)?

Even the most recent work in the case studies above (*Moulin Rouge!*) is set in the past – does this treatment perpetuate the myth that TB is a disease of the past?

How do these pieces of art / Opera / literature work artistically/emotionally – consider 'art for art's sake' - ?

Video clips that we will look at in the lecture:

Death of Mimi in 'La Boheme':

<http://www.youtube.com/watch?v=VTyUThD28TA&feature=related>

Death of Violetta in 'La Traviata': <http://www.youtube.com/watch?v=8Hc0HOb4Z-w&feature=related>

Death of Satine in *Moulin Rouge!* (end of film; not available online)

Podcast about TB in London today: <http://www.ucl.ac.uk/news/news-articles/1003/10032303>

Tuesday 30 October

11. *Humanities in Global Health: Polio*

Wild viruses and wildfires have two things in common. If neglected, they can spread out of control. If handled properly, they can be stamped out for good. Today, the flame of polio is near extinction — but sparks in three countries threaten to ignite a global blaze. Now is the moment to act.

■ Ban Ki-moon, Secretary General of the UN, 17 May 2012

By the end of this session you should be able to:

- Describe some of the themes in Philip Roth's novel *Nemesis*.
- Have an understanding of the impact of polio prior to effective vaccination programmes, and the dramatic change that vaccination had on the disease.
- Provide examples of polio in the world today, and some challenges to the vaccination efforts.

Overview

The Humanities in Global Health session on Polio will centre on Philip Roth's novel *Nemesis*, which the students have been asked to read ahead of time. We will consider the major themes in the novel, particularly the panic and misunderstanding surrounding the polio epidemic at the centre of the story. We will then consider recent news stories (podcasts & articles listed below) and discuss in relation to the novel.

Podcasts & articles we will discuss:

'On literature, science, and polio' <http://www.newappsblog.com/2011/10/on-literature-science-and-polio-for-jon-cogburn.html>

NPR Podcast: 'Wiping out Polio: How the U.S. Snuffed Out a Killer' (7min 34sec)
<http://www.npr.org/blogs/health/2012/10/16/162670836/wiping-out-polio-how-the-u-s-snuffed-out-a-killer>

BBC News: 'Defeating polio' <http://www.bbc.co.uk/news/health-18181521> (We will look particularly at the scroll-through photos on 'the history of polio')

NPR Podcast: 'At Polio's Epicenter, Vaccinators Battle Chaos and Indifference' (7min 34 sec)
<http://www.npr.org/blogs/health/2012/10/17/162811569/at-polios-epicenter-vaccinators-battle-chaos-and-indifference>

BBC News: 'Polio outbreak: Where now for global vaccination drive?'
<http://www.bbc.co.uk/news/health-15095623>

'Double Act' by Adam Smyth, London Review of Books: <http://www.lrb.co.uk/v34/n19/adam-smyth/double-act>

12. *Disability, Ability, Representation: Bodies and Sculpture*

By the end of this session you should be able to:

- Consider and describe your opinion on the comparison between the Venus de Milo (an example of 'one of the most beautiful sculptures in the world') with both Alison Lapper and (essayist: reference below) L. J. Davis's question as to why the living female example is considered disabled whilst the Venus de Milo is not. Discuss some flaws in the argument of comparing the animate and inanimate. Does the comparison help us consider ideas of disability, and how?
- How might the myth of Icarus be an example of failing or not failing? Consider Gilbert's poem.
- How might the myth of Icarus be useful in considering transformation, and ideas of disability? Consider Ayrton's sculptures, and Ovid's *Metamorphoses: The Story of Daedalus and Icarus*.
- The Humanities in Global Health session on Sculpture will consider how the following relate to one another, and how, by juxtaposing these examples, we might consider the ideas of disability and sculpture differently:
- Sculptor Michael Ayrton (1921-1975): In particular, we will consider his works 'Icarus transformed' (1961,) 'Icarus rising' (1961,) and 'Icarus falls' (1959). Though not disabled himself, Ayrton was compelled to begin sculpting by seeing a blind girl feel her way from sculpture to sculpture in a gallery.
- Extract from Ovid's *Metamorphoses: The Story of Daedalus and Icarus*: 'In tedious exile now too long detain'd...Naming the country from the youth interr'd.' (We will use the translation from www.classics.mit.edu)
- Poem 'Failing and Flying' by Jack Gilbert (What can be seen as a failure isn't necessarily.)
- Quote from L.J. Davis (reference below): 'We tend to group impairments into the categories of 'disabling' (bad) or just limiting (good). For example, wearing a hearing aid is seen as much more disabling than wearing glasses, although both serve to amplify a deficient sense.'
- Taking Davis's quote 'there are no pregnant Venuses,' we will look at the anatomical waxwork model known as the 'Florentine Venus,' made as a medical teaching tool – which is depicted as being pregnant.
- Consider *intentionality*: the Venus de Milo was originally created as a whole figure, and was not intended to represent disability, whereas 'Alison Lapper Pregnant' is depicting Alison Lapper as she is naturally (without arms). The Florentine Venus was made as a medical teaching tool, but is now considered a piece of art.
- Creative Work: Finally, we will consider *A Humument* (Fifth Edition). Students will have an opportunity to 'treat' pages 178-179 of *Nemesis* and see what they can 'carve' from the text.

Essential reading

Lennard J. Davis, 'Visualising the Disabled Body: The classical nude and the fragmented torso', from L.J. Davis (1997) 'Nude Venuses, Medusa's body, and phantom limbs: disability and visuality,' in D.T. Mitchell and S.L. Snyder (eds), *The Body and Physical Difference*, Ann Arbor: University of Michigan Press.

Video clip of Alison Lapper: <http://disabilityaesthetics.blogspot.co.uk/2009/02/alison-lapper.html>

Extract from Ovid's *Metamorphoses*: The Story of Daedalus and Icarus: 'In tedious exile now too long detain'd...Naming the country from the youth interr'd.' (We will use the translation from www.classics.mit.edu)

Poem 'Failing and Flying' by Jack Gilbert

Recommended reading

Double Act, by Adam Smith, reviewing *A Humument*: <http://www.lrb.co.uk/v34/n19/adam-smyth/double-act>

Tuesday 27 November

Humanities in Global Health: Cardiovascular disease & Epigenetics

By the end of this session you should be able to:

Come up with three different ways of considering the heart, based on the material we've shared. (This can be medical, philosophical, poetic; through story-telling, humour, sculpture, waxwork, metaphor, etc.)

Provide a metaphor that you've come up with which helps to illustrate epigenetics and genetics. (Example: genetics are the hardware, epigenetics are the software.) Analyse how this might help clarify an abstract concept to a patient. Will your metaphor help make things clearer? Try not to come up with a metaphor that requires more explanation than the original science!

Provide a brief explanation of why we've spent so much time discussing metaphor and how it may be of use to you.

In the Humanities in Global Health session on Cardiovascular disease, we will begin with a 'story matching' game: the students will pass around cards that have stories on them about heart transplants and patient's experiences following the transplant. Each story will be split into two cards, which the students must match by talking with one another about what their story is

about. Some stories are apocryphal (urban legends,) some are direct anecdotes from patients, and some are from the news. We will discuss the likely bias of the stories, whether some of them may be true, and what that might mean about the human heart.

I will then move on to share three published poems with them, wherein I write about my father's death of a heart attack. We will talk about 'therapist's couch' poetry – things that may be useful for the writer but are best not to share, versus crafted work that springs from personal experience. We will look at the Human Genre Project (www.humangenreproject.com) - a poetry and creative writing website inspired by the Human Genome Project, and my poem, 'Jargon,' published on chromosome 11.

Next, I'll share the book of performance poet Richard Tyrone Jones: 'Richard Tyrone Jones's Big Heart' (www.richardtyronejones.com) and read some extracts of his performance, which he wrote after nearly dying, at the age of 30, of idiopathic dilated cardiomyopathy. (I highly recommend seeing his show!)

We'll then read 'A Seagull Murmur' by Robin Robertson.

Next, we'll watch the following video clip on epigenetics:
www.youtube.com/watch?v=kp1bZEUgqVI

And we'll discuss whether it is a useful educational film for a general audience. Students will be asked to make a note of all of the metaphors (verbal or visual) in the film, and we'll discuss. (Some of these include genetics as a paragraph with the punctuation moved around, genome as hardware and epigenome as software, epigenetic 'tags,' 'silencing' the bad genes, and genes as blueprint.)

Finally, students will be asked to write their own original metaphors of genetics and epigenetics, and we'll look at these and discuss which ones work best, and why.

Essential reading

Robin Robertson's poem, 'A Seagull Murmur'.

Recommended readings

Richard Tyrone Jones's Big Heart (and other complications,) Allographic, 2012. (See www.richardtyronejones.com)

Explore www.humangenreproject.com

Watch video on epigenetics: www.youtube.com/watch?v=kp1bZEUgqVI