

Body Talk in the Medical Humanities

Body Talk in the Medical Humanities:

Whose Language?

Edited by

Jennifer Patterson
and Francia Kinchington

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We hope this book contributes to valuing the need for Medical Humanities in its many different forms, from diagnostic tools through social commentary to appreciation of close readings, ethical understandings and nutrition for the self. We hope it will help generate new ways of rethinking medicine and healthcare challenges, helping to enrich the lives of patients and all who work with health and illness and who are, patients themselves.

FOREWORD

ALAN BLEAKLEY

EMERITUS PROFESSOR OF MEDICAL EDUCATION AND MEDICAL
HUMANITIES, PLYMOUTH UNIVERSITY SCHOOL OF MEDICINE

I am pleased and honoured that the editors of this fine volume, Jennifer Patterson and Francina Kinchington, have asked me to write a foreword. I was a past President of the Association for Medical Humanities (AMH) and have been intimately involved with its annual conferences since 2003. The book also encourages a processional archive, established with the collection that I edited from the 2015 AMH conference at Dartington Hall: *Risk and Regulation at the Interface of Medicine and the Arts: Dangerous Currents* (Cambridge Scholars Publishing 2017).

‘Body Talk’ is a rich topic. As I write this, I have just been working with 4th year University of Exeter Medical School students. Our topic within the innovative medical humanities core curriculum, was “What is ‘Normal’?” We spent some time looking at radical performance art that involves body modification, such as ORLAN’s powerful questioning of female body stereotypes through elective surgical interventions, in which the operating theatre literally becomes a site for embodied performance. Our conversation came around to the topic of identity construction of medical students as trainee doctors engaged with ‘professionalism’. They acknowledged that it is important to recognise that ‘impression management’ during their clinical placements works at the level of the body, through complex inscriptions and regulatory processes.

What they did not fully realise, but were prepared to entertain, was the notion that this embodied socialisation process is grounded in a contradiction akin to trying to drive a car with both the accelerator and brake depressed at the same time. Medical Education promises an education of sensibility for ‘close noticing’ that in turn informs and shapes diagnostic acumen. The senses must be finely tuned to be able to recognise what the bodies (and embodied words) of patients display as ‘symptoms’ (a sensitising representing the car accelerator). However, simultaneously, in Medical education, a process of education of insensibility occurs, a dulling or an-aesthetising (resulting in applying the brake). In a real sense

this is, to borrow Paul Goodman's descriptor, a 'compulsory mis-education'. For 'professionalism' requires students to deny, repress, displace or in some other way overcome the 'natural' response of disgust and repulsion in the face of 'the abject' body; stinking piss and shit, noxious pus, bad breath, nasty bodily odours, fetid wounds, and so forth. Is it any wonder that by Year 4, as studies consistently show, students' empathy declines and cynicism (such as objectifying patients), sets in?

In many medical schools globally, anatomy is still learned through the ritual of cadaver dissection, a time-honoured initiation. But this involves exposing students to otherwise noxious formaldehyde fumes given off from the formalin-preserved cadavers. The first level of education for insensibility occurs as students learn how to physically and emotionally repress or displace the natural disgust that this occasion presents. It includes the physical barriers of masks, scarves, perfumes and nasal creams (repression), and the psychological ones of black humour and heroic 'toughening up' (displacement and denial). Of course, an answer to this (as employed in my own medical school) is to learn anatomy without dissection, with an emphasis on surface and living anatomy. However, this also encourages greater use of anatomical models. Students in all medical schools use varieties of plastic models in clinical skills settings for learning anatomy, but such models cannot help but objectify bodies and normalise them, with an in-built gender bias ('SimMan' but no 'SimWoman'). Further, in work-based clinical learning, dull educational models (opportunistic learning and ritual humiliation) so often trump sharper and smarter approaches, such as team briefing and debriefing, patient-led ward rounds, and so forth. Here, students will also encounter unproductive metaphors that serve to stigmatise patients (for example 'the war on cancer').

How then, will Medical Education approach this contradictory condition? One approach, among the body of evidence to support its efficacy, is through the introduction of the medical humanities into the core curriculum. First, the Arts and Humanities both generate ambiguity and educate us reading ambivalence and contradictions, rather than looking for problem solving approaches to rid us of such contradictions. Contradictions are resources not barriers, and the central psychological mindset that a young doctor must acquire is tolerance of ambiguity. Further, 'the abject' body is not a biological hurdle that medical students must wrestle into submission through 'professionalism'. Rather, this 'abject' is a rich source for understanding the depth and breadth of the human condition.

In short, we cannot afford to not have a considered and carefully designed medical humanities core curriculum. Such a curriculum is certainly not for light relief, but for learning about the meanings of the body as well as the more popular and necessary functions of promoting social justice and democracy in medicine. Where the body is so often treated as purely functional in Medical Education, let us reclaim its wider political, aesthetic and ethical concerns. This exciting collection plunges us straight into such deep and nourishing waters.

INTRODUCTION

BODY TALK IN MEDICAL HUMANITIES: WHOSE LANGUAGE?

JENNIFER PATTERSON

Contexts

All human beings have a body and all of our bodies are different, individual and unique. Yet, there is also no such thing as 'a' singular, homogenous body. We do not share 'a' body, and biological sex is not a basis for unilateral experiences, since this requires communication, corroboration and collaboration. How we understand and relate to our bodies varies in time and from where and how we live, through what we believe, to our different world-views or realities. Each body therefore becomes as it is talked about and is a concept constructed through language and culture, as much as it is a thing. Yet when bodies are ill, they are treated within a system that views them as though they were all essentially the same.

The physicality of a body also operates a cellular relationship to its environment. It is a product of internal influences such as aging, genetics and stressors but also the basic availability of food, water and air, including the influence of toxins, vitamins, medicines, and illnesses. While external factors such as weather and local geophysics, as well as fertilisers affect the soil where food is grown and the bioavailability of nutrients, internal factors in the body such as chronic thyroid conditions, digestive and stomach conditions can cause a lack of enzymes that inhibit uptake.

When our bodies become ill, we take on the role of patients; a role that is also treated as a homogenous one and often at odds with the individuality of other experiences and beliefs previously held about our bodies. In Western worldviews, for example, the Cartesian body/mind split has contributed much to thinking with the brain as a separated means of listening to, or feeling the body. To complicate the picture, treatment of illness also varies in time, relates to culture, and to what we believe.

Such a number of variables ensures that none of these things are fixed. Within a Medical Humanities context therefore, the medicalisation of the body through language embeds a separation, so that the homogeneity of 'the body' is simply a scientifically enacted fiction.

Moreover, the people who treat bodies that are ill, doctors, nurses and healthcare workers also have bodies. As they learn their professions, treating and caring for bodies that are ill, they enter a different world with a unique culture, characterised by hierarchical power structures, and find themselves being part of amazing institutions that paradoxically results in profound distress. Face to face every day with the mortality of bodies of others, they are challenged to perform roles whilst facing their own mortality. They too get ill.

Indeed, the way in which bodies that are healthy and ill are presented and represented in the biomedical world of Western Medicine (medicine), is particular to its own internal scientific and technical processes. Devolved from mainly Western discourses and philosophies, this operates a different reality or system of thinking and a way of knowing that views bodies in particular and singular ways. Biomedicine and its education systems have also varied through time, becoming firmly located in a scientific paradigm that views truth about body as objective, fixed, collective or quantitative, and linear (a function of time and technology) rather than subjective (individual), cultural, fluid and variable.

Thus, the people who treat and care for bodies that are ill work at the intersection of different worlds and ways of thinking. Their expertise is focussed on one perspective learned during immersive training. This is a biomedical one at variance with cultural frameworks of individual experience outside of the institution that is the healthcare workplace.

'Medical Humanities' is a fairly young subject and is both wide-ranging and complex by nature. It covers not only the wider aspects of Medicine and Healthcare at the interface with disciplines within the Humanities that range through History and Geography to Philosophy, the Arts, languages and literatures but also areas where these necessarily intersect with the Social Sciences through the social aspects of culture. These subjects offer alternative perspectives for exploring the place where Medicine and Healthcare meet. Therefore importantly, critical strategies and methodologies from within the humanities and social sciences necessarily frame both the individuals who are the products of their society and culture and intersects with the organisation, production and reproduction of health and healthcare that including technology, has been independently

generated from, yet maintains dependence on that society.¹ Thus Medicine, also known as ‘bio-medicine’, has an institutionalised framework that embodies many contested and complex arenas, and further incorporates not only its Western origins but importantly, also its legal and commercial aspects.

Indeed, while seeming to be evident, ‘Medical Humanities’ is a complex and politically contested term that is in a period of debate and change. As a label, the word ‘medical’ versus ‘health’ humanities, can present the internalised argument that ‘medical’ involves hierarchical concepts and roles, signifying doctors, and the exclusion of nursing and allied health professions.² As the field expands and shifts, becoming more inter- and trans-disciplinary, it might also be arguable that ‘Health Humanities’ is becoming a more appropriate term for the discipline, since this also encompasses wider readings including for example, general or individual health practices and public discourse.³ Yet, these could be argued not be about ‘health’ as a norm or as a subject that exists naturally, but about responses to illness, treatments, institutions and politics and as such about monolithic mainstream, Western or biomedical culture in the broader sense. Furthermore, the politics around the medicalisation of norms as measurably non-existent presents issues around what exactly health might mean or be. On the other hand, as a subject, things medical can be read as inclusive of all medicines and practices rather than referring to elitist hierarchies or roles, it may be seen as a clear sign of the subject focus.

Further to this exists a devaluing of traditional Western health practices, which are subsumed under the label ‘history of medicine’ in Western contexts. These are undervalued, culturally and pharmaceutically through the progressive Western biomedical lens that places them in ‘the historical past’. This discourse of medicine is essentially Western. It is neither universal, nor global and is embedded with a range attitudes to bodies, a strategic progressive vision, an economics of treatments, drugs

¹ Carlos Moreno-Leguizamon, Jennifer Patterson and Alexander Gómez Rivadeneira, “Incorporation of Social Sciences and Humanities in the Training of Health Professionals and Practitioners in other Ways of Knowing,” *Research and Humanities in Medical Education* 2 (2015): 18-23.

² Paul Crawford, Brian Brown, Victoria Tischler and Charley Baker, “Health Humanities: the Future of Medical Humanities?” *Community Mental Health Review* 15, no. 3 (2010): 4.

³ Therese Jones, Michael Blackie, Rebecca Garden, and Delese Wear, “The Almost Right Word: The Move From Medical to Health Humanities,” *Academic Medicine*: 92, no. 7 (2016): 932-935.

and care, that can be arguably claimed to drive colonising market practices over traditional medicines. So, there is an arguable, and politicised disingenuousness embedded linguistically and philosophically within this discourse. Global perspectives that currently challenge the humanities will no doubt engage to question the model.

Equally important are the various arguments advanced about the usefulness of Medical Humanities in education and practice. Very briefly, these originated with historical understandings of the practice of Medicine as an Art and a Science and the relationship between medicine and ethics in Western Philosophy and Medicine. The emergence of Medical Humanities out of Medical Ethics draws on the close relationship between ethics and aesthetics originating in Western Classical Philosophy. Yet while ethics is one area that may suggest a natural meeting place for the two, medical ethics and philosophical or even societal ethics are very different things. These crossing places are fraught with challenges and issues requiring discernment. The refining of taste in music and culture that is the stuff of aesthetics is allied to particular educational hierarchies that support the less tangible aspects of ethics.

The complexity of these aspects is compounded by further arguments around the division between practical and critical Medical Humanities (the one being applied to practice and the other being pure research, for example) and the different perspectives from which and through which, they present. Yet, there is so much inter-disciplinary and trans-disciplinary crossover it is arguably unhelpful to differentiate in an exclusive way between what constitutes 'critical' or 'practical'. Not least, all professionalism in practice necessarily involves a level of critique in the academic sense. Most academic study will have some concern with applied practice or application for practice, whether fictional or in the past.

The current Medical and Health Humanities teaching and research landscape in the UK involves different curricular aspects. A few universities offer specialist undergraduate, postgraduate masters or PhDs in Medical Humanities, usually taught from within Arts or Humanities faculties. A wider variety of medical and healthcare humanities research and teaching provision in medical university faculties and schools ranges from short courses and Student Selected Components (SSC) modules to intercalated degrees (1 year intensive) BAs, BScs and Masters between medical training. These are taught from within medical schools or in collaboration with humanities faculties and research centres. They involve a wide range of subjects including the creative arts, literature, and history through philosophy and law as well as sociological contextual understandings, linked with medicine and healthcare and broadly involving

a Medical Humanities approach. There is also some work in dentistry. Perhaps due to notions of elitism and Arts based curricula as described above, the importance of medical and health humanities is currently less recognised in healthcare and nursing, with Nottingham currently leading the way forward in the UK.

Finally, and possibly most importantly, it is for the practical support that Medical Humanities in its various forms offers to students and practitioners of medicine and healthcare that is most valued. These range from refining and promoting better listening skills, creative thinking about the challenges of their vocations to safe places for discussing critical incidents and transferring ways of rethinking reflective practice through to thinking like a doctor, nurse, healthcare worker or a dentist.⁴ They range from supporting diagnosis and strategies such as investigating, problem solving in difficult environments, multi-tasking, examining fine details, to understanding how to deal with the dark and messy side of being human, and how to remain human, without losing emotional understanding. Some applications are more obvious, others might relate to honing ethical skills, to supporting values-based education or better self-understanding and resilience or simply to understanding why things are as they are. They support the people who chose to be in our health service and do this work.

Therefore, the space where the fields of Medicine and Humanities (Medical Humanities) meet, offers a wealth of real-world ideas, concerns, debates and discussions about our relationship to bodies (physical and organizational or with and without organs). In dealing with the everyday reality of illness, Medical Humanities considers illness from the different perspectives of a range of stakeholders, originating in and intersecting with western biomedical, historical, literary, linguistic and other disciplines. They ask and refer to this reality through examining issues and questions that cut across cultural monoliths that have contributed to a unified and high-stakes biomedical perspective that has been previously presented as the only legitimised life-defining model of truth. Yet this monolith of medicine and healthcare comprises people whose aim is to help people. Medical Humanities tools help negotiate and understand where these worlds meet.

The way that the title of this book is written reflects, as it did for the conference of the same name that ‘Talk’ is a material manifestation of politics and dominance or ‘power over’. ‘Talk’ itself, taken to mean all

⁴ Neville Chiavaroli, “Knowing How we Know: an Epistemological Rationale for the Medical Humanities,” *Medical Education* 51 (2017): 13-21.

forms of languages, visual and verbal, often reflect powers of enunciation. As thinking with the head, capitalisation also reflects the dominant politics of knowledge about bodies. The capital lettering of 'Body Talk' is taken as a singular entity, or as two products that are juxtaposed with a lower-case question about ownership and identity (whose language) asked by referencing languages to interrogate notions of 'body talk' and of 'body' and 'talk' in the context of 'body talk'. Thus, this talk about 'our' bodies, is not to assume any shared sense but a language convention used here to facilitate writing and communication. Body experiences are individual and not collective although what is individual often resonates collectively as shared in particular times, places and spaces.

By exploring topics of bodies, talk and body talk and ownership of language and body within the field of Medical Humanities, this book necessarily touches on many of these aspects. It raises pragmatic questions and discusses issues that are practical, social and professional to find and explore why things are as they are and how these intersecting worlds within worlds, function. It presents thoughts and ideas about bodies from many intersecting and trans-disciplinary perspectives. It is mainly but not entirely written from Western perspectives by people of different nationalities, who submitted their work. It is therefore representative of these authors and while it covers a range of body politics, it does not attempt to interrogate more than those political agendas it contains. The Western mainstream healthcare system in UK is distinct from Western traditional and other cultural healthcare systems and as such 'incorporates' a 'body' of knowledge. Based on biomedical and scientific world views, it has developed to treat and cure individual bodies that are unwell. As a system, this is an amazing and effective organizing machine with its own language and culture, traditions and history, research methods and also practices, within which bodies, symptoms, illnesses and treatments are grouped in particular ways.

The 21 chapters presented here, highlight individual experiences and issues, open conversations and consider solutions to a wide range of these challenges. They are grouped in five broad sections and it must be said that several of the chapters could easily belong in more than one section.

The first section, "**Whose Bodies, Which Bodies**" presents individual and group talk about bodies and experiences that glance reflexively towards notions of ownership and identity. They also consider in detail particular approaches and aspects of social issues that are faced by people individually and collectively, such as ableism and sexuality, concepts of beauty, elder care, and HIV and labelling. Devolving from Western

philosophy and elitist educational selection practices, these ignore a range of differences and exhibit hierarchical and employment practices that are well documented. For example, in leadership work by the Race Equality Foundation, however, embedded philosophies and theories that are fundamentally Western and what this means for individuals and the practitioners that care for them, is less so.⁵ If medicine determines that as animals, we are human, it is itself embedded with invisible ‘civilising’ social and political ideologies, influences and traditions. Today we know more about how thoughts, feelings and beliefs are culturally influenced and different from one another but these have been historically grouped and embedded as singular, faceless and white in Western biomedicine and labeled in language and anatomy as an idealised form of ‘body’. The section presents discussion of bodies that provokes thinking against the mainstream grain. Abha Khetarpal, and Satendra Singh celebrate bodies that ‘don’t measure up’ referring to the ideologies of scientific rationalism as they interrogate social constructs of idealised bodies and self-image to frame living in disabled bodies. Returning to the theme of different bodies and different experiences, Jacqui Stevenson interrogates women’s experiences of HIV through their images of self-representation. Critical questions of further societal, medical and institutional practices are the focus of Toni Mortimer’s examination of how elder bodies are ‘cared for’, or ‘not’ especially in the images and realities of elderly ‘care homes’ in Western Society. This section ends with Stephen Bell’s celebration of the changes that a diagnosis of syndactyly has brought to his life.

Louise Younie’s chapter opens the second section, **“Whose Bodies? Patients, Doctors and Society”**, foregrounding the emotional divisions her students and others go through on the way to becoming medical professionals. She reflects on the loss and vulnerability faced through a well-documented emotional hardening towards horror, and the individual and shared vulnerability that demands the necessary development resilience from practitioners as human beings and/with bodies, with patients whose bodies are ill.

In consideration of patients’ bodies and the nexus of individual/patient roles, Lee Miller and Joanne ‘Bob’ Whalley perform a textual conversation through personal self-examination in a performative reflective practice of being a patient and what this means. Inclusion, exclusion and recognition of principles of autonomy, equity, power and ethics sit within institutions

⁵ Roger Kline, *The Snowy White Peaks of the NHS*, Project Report (London: Middlesex University, 2014).

of care as elements of the ongoing democratising projects of current social thought and that therefore also necessarily apply to critical understandings of institutions and institutional behavior.

Examining the use of body and illness as political metaphors for the organic nature and systematic organisation of society, Im Kyung Hwang's chapter discusses theories of kingship and the body politic in Eastern and Western culture prior to the concepts of ownership linked with liberal individualism, mechanistic body views and biomedical science's modern focus on the inside of the body. He argues for an applied Medical Humanities approach demonstrating the reciprocal interdependency of the inside and outside of the body or the individual and collective that necessitates the intervention of cultural physicians as doctor-philosophers working to heal the social body. This interconnected metaphor is exemplified in literature towards a new configuration of the mutual dependence of self and the other, as an ethics of immunity. Truths about the world and their relationships to power and leadership roles that began with Im Kyung Hwang's work on body systems continue from another perspective in Vassilka Nikolova's chapter. This investigates how forms of medical knowledge and performance of medical culture relates to particular forms of dominance and hierarchies of power in Western patriarchal culture. Words that can transform reality have performed a politics of knowledge as power, informing doctor roles that are depicted as heroic, visionary leaders.

Medicine is a particular and institutional lens presenting particular beliefs that also vary over time and in different spaces. Being allied to scientific ways of thinking about the world, biomedical beliefs about reality are, that it is measurable. Therefore, the fact that biomedical truth varies over time is a function of technological innovation and therefore of advancing knowledge. So, the model is fixed and progressive. Yet health and illness are social constructs that affect humanity individually. One way of exploring the instability of such notions of truth and reality as unstable, rather than fixed is expanded using the science of thermodynamics in John Smith's chapter on complexity that establishes the interlinking and intersubjective dynamic and ecological complexity of health and illness. Interrogating sociological concepts of need, he presents a framework of thermodynamic systems theory to look in at, to structure and explore the complicated and in-between ecologies of human, biological, cultural and sociological factors driving these concepts.

The third section in the book, **"Whose Language, Whose Voices"** considers some of the communications that take place inside medical

worlds and institutions. It is located around languages and offers insider insights relating to voices and talk. Bridget MacDonald speaks of historical and current expectation of communications within UK medical practice and of the emotional consequences of self-restraint, or emotional labour leading to burnout. For Saam Idelji-Tehrani and Muna Al-Jawad, the issue of communications lead to a creative arts approach in the form of graphic comics to explore in depth leadership issues that could not be clearly enunciated at meetings. This takes place within the NHS, an institutional body without organs in the form of healthcare management. The medium is used to negotiate dilemmas and effect communication differently. Haris Haseeb's chapter demonstrates how reading three pieces of literature (a medium of communication) can creatively trigger reflections and readings that offer support through new understandings in difficult times during his journey as a medical student. Meanwhile Rhada Bhat highlights how GPs can lack specific health expertise in communications and would benefit from better skills in mental health training. Understanding mental health communications that are commonly seen in practice every day, might help improve diagnosis and would certainly better support patients.

“What Language? Cultural Diagnostics”, the penultimate and fourth section, begins with images from the exhibition, *Translations*, that was held at the 2016 AMH conference. An explanatory chapter discusses how the work of two different artists and how art as a form of representation, parallels language as representation. In the work of Catherine Greenwood, it is used to therapeutic effect uniting inner and outer being. In contrast, Deborah Padfield's work uses art as a medium or skill, as the means to interrogate, investigate and dissect a particular figure of language or metaphor. Specifically, she forensically investigates and reproduces patients' metaphors of pain as visual images that reframe readings and understandings and that have been used as evaluation tools with patients in a chronic pain clinic. This is followed by Nicola Demonte's reading of Frida Kahlo's visual representations that document her life experiences of illness and chronic pain in vivid and extraordinary work. Thus, just as Kahlo's art is a means of representation, it also offers a means of diagnosing her illness and pain.

Taking up the concept of maternal voice as a form of cultural body talk, Bohena Zoritch's chapter diagnoses and theorises its absence from stories about mothers, from narratives under patriarchy and within myth, and from Freud through to the French feminist and mother, Julia Kristeva. She combines these readings with the latest neuroscience that evidences

chemical conversations in both male and female parent/child communications to consider embodied parenting.

The final section in this book **“What Language? Bodies Talking”** presents a wide range of the ways in which bodies themselves talk, and in which they can be differently listened to and indeed how talking and listening differently can change or alter illness or diagnosis or offer comfort.

Paul Dakin considers the benefits of signing for Deaf people as a literal form of ‘talk’ this is highly visual and has had repercussions for identity construction and insider/outsider dialogue that goes far beyond its practical applications. In its exploration of voice, this chapter essentially details aspects of communication in a particular environment through an exploration of its origins, history and culture of signing to consider the gains made through the interrelated aspects of gesture and neural programming.

For Eliza Groff medical readings of osteobiographies, the communications left in skeletal remains offers specialist tools, for reframing and contextualising the contexts of ancient death. This body communication involves forensic paleopathology, the study of the pathology of the bones of ancient bodies, in this case of children and particularly the normal and abnormal diagnosis of growth disorders with attendant social implications. The diagnosis is detailed, as microscopic in its detail as Padfield’s art in the previous section, demonstrating how earlier assumptions need to be reviewed and both biologically and socially contextualised.

Cinzia Scorzon’s chapter presents another form of clinical diagnosis for thinking about health and illness to biomedicine. This is a Chinese Medicine methodology for reading the body differently that brings together the inside and the outside in a network of multiple dynamic energetic activities, capable of psycho-emotional communication manifest and diagnosable in a patient’s physical body. It extends the theme of inner and outer differences in a practical and sensory manner, presenting underpinning philosophy and considering different ways of examining and understanding what a body tells or says, for the purpose of diagnosis and treatment.

The full potential of what ‘talking-with’ body can mean for health is exemplified in Hilly Raphael, Sarah Frossell and Jenni Mair’s example of a chronic fatigue life recovery practice involving body not simply talking back but also body listening to talk. This is a symbiotic feedback relationship where a conversation is made of ‘talking’ and ‘listening’. It is

one in which talking as a form of expression can be challenged, and in which re-thinking and re-enacting talking and listening forms part of an active physical therapeutic process.

Ultimately, Patricia Floriet's discussion and workshop of her practice of Listening to the Dying cuts across all talk, as she listens with expert focus to dying bodies that express what they need, here and now. Through this technique she senses the needs of people's bodies that can no longer speak using their voice. A founder member and pioneer in the early eighties of the then budding hospice movement *soins palliatifs* in France, she is still actively involved in listening to the bodies of people in her community. At eighty-eight she is still teaching and saying what needs to be said.

Importantly, when taken together as a collection, these chapters offer even more. They present examples in different fields, from different perspectives and in groups that point to the value and innovation that characterises Medical Humanities as a field. Broad themes emerge that cut across the topic of Body Talk. Such issues are inevitably social as much as they are cultural.

How doctors and health professionals interrogate and cope with concerns about wellbeing amid problems and challenges such as medicine's heroic culture, distress and burnout, frames the highly individual texts written by Louise Younie, Haris Haseeb and Bridget MacDonald, as well as others. These work alongside those that relate to being a patient such as that by Lee Miller and Joanne 'Bob' Whalley. Broader understandings of medical culture, support reflective working within that culture, enabling those who work within it to survive and flourish.

Experiences that lie outside of cultural norms and therefore the questioning of such norms, informs the work of Abha Khetarpal, and Satendra Singh as well as Stephen Bell, Im Kyung Hwang, Cinzia Scorzon, Bohena Zoritch and Nicola Demonte, if not all of these authors. For Toni Mortimer the issue is elder care, as it is for Patricia Floriet's elders who are dying. It is precisely these very different, disruptive, continuous and transgressive forms of knowledge and gaps in knowledge that brings new thinking to Body Studies.

Beyond all of this 'talk' that foregrounds particular issues, sits the reality that whether we are doctors, nurses, healthcare professionals, activists, academics or writers, we are all also patients. When a person becomes unwell, they move from the pragmatic reality of everyday life into a healthcare system with completely alien and different rules,

hierarchies and languages for treatment. Belonging to this different way of thinking that is also dominant, the system is inevitably alienating for people that encounter it. Much work has been done to bridge this gap but this is an everyday reality for those whose bodies are unwell. Working within the system is equally challenging, requiring institutionalization, cultural and language changes that are problematic for communication. Critically, when a person becomes a patient, they enter this space.

Illness and healthcare are complex, socially contested spaces, geographies and cultures. Traditionally, they and the bodies in which they are located and performed are universalised and separated from environmental and cultural contexts. In the West, identity rests on individuality and feelings of belonging to an environment and culture(s). So, when it comes to care of individuals whose bodies and minds are unwell or diagnosed as unwell, there are clashes of culture that challenge communication, experience and ownership.

Imagine illness as Susan Sontag⁶ did, a metaphorical country, with working citizens and visitors, somewhere through which everyone travels at some time. It has become one that has gained world-wide reach, colonising health and illness with particular organisational and linguistic systems. It is fundamentally dependent on a particular view of body and a capitalist approach to healthcare. Most of the people who work there do so because of their values. There is a collaborative international community and many believe in service to community, yet access varies from country to country. Access to healthcare is a fundamental human right. In this space of illness and disease, we are all refugees and immigrants. Yet there are problems too, for this space is also a different country. It does not reflect the intersubjective values of our internal and external realities, our environmental symbiosis.

Finally, Bodies ‘talk’ non-verbally in different ways, communicating individual sensations and emotions that relate to ease or ‘dis-ease’. Our facility to listen, understand and in turn interpret and communicate in our own languages varies enormously, combining personal, familial and cultural understandings. Our interpretation of sensory or emotional communications is influenced by our lives, our experience and by what we think. What is available to us is swayed and mediated culturally and in time and place through our networks, access to information and healthcare provision, and by public health messages and health discourse. When

⁶ Susan Sontag, *Illness as a Metaphor* (New York: Farrar, Strauss and Giroux, 1978).

becoming ill we try and work out what is happening, we seek help from those skilled in listening to bodies and symptoms, in diagnosing and in caring. That listening and interpreting is also influenced and mediated culturally and in time and place by availability of information, by healthcare education and discourse and by experience. Both spoken and non-spoken languages about bodies are also contextualised by contemporaneous social politics of diversities, cultures, genders and norms, expressed and interpreted through layers of meanings.

Starting to think and question whose language or which language is being spoken (and by extension whose or which body) reveals inter-subjective dialogic frameworks with layers of questions and possibilities: what body; what is a body; what language; what is language? Such questions subtly undermine and interrogate the relationship between identity and language, presenting layers of cultural diagnoses, an archeology of body readings and interpretations located in time and place. Communications exploring these dimensions in art, in literature, and in social documents offer and bear witness to other ways of thinking and perceiving, understanding, educating and translating across time. Listening and understanding how bodies talk and how individuals talk about their body opens up space for a rich critical and creative intersubjective experience that within a healthcare context, also supports ethical consideration of individual patients, their treatment and diagnosis.

Taken as a whole, the book aims to highlight some of the inherent complexity and conflicts across these enormous intersecting areas that are represented by body (individual and medicalised) using expert lenses developed in academic studies of the Humanities. Such studies about language, culture, cultural products and creativity currently and in the past, are the specific business of the Humanities and of Sociology with reference to social groups and the products of society. Working within these fields permits some unpicking and examination of what is happening and how to work with practical illness conversations, with diagnosis and with holistic readings of bodies that ‘talk’ their ‘dis-ease’.

This book emerged from collaborative conversations held at the Body Talk: whose language? Association for Medical Humanities international conference that took place in 2016 in partnership with the University of Greenwich in London. It includes some of the original material from the conference, some that has developed further since then and some additional contributions from interested individuals unable to attend. The range of topics is by no means exhaustive but highlights topics of

particular concerns to the authors who have contributed. The selection is representative of these people rather than the field. Each chapter is preceded by a short non-referenced synopsis/overview in lieu of a formal abstract to offer structural homogeneity.

In the tradition of the AMH conferences the editors have chosen to place emphasis on the eclecticism and stylistic variations of the contributions received. Any differences of referencing conventions reflect the diverse fields from which the contributors have come.

We hope you find chapters and ideas that are stimulating, interesting and useful.

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SECTION ONE:

WHOSE BODIES, WHICH BODIES?

CHAPTER ONE

BODIES THAT DON'T 'MEASURE UP': CELEBRATING DISABLED BODIES

ABHA KHETARPAL AND SATENDRA SINGH

Abstract

A bias for beauty, perfection and normalcy operates in almost all social situations. Our cultural fixation with the body is evident by the fact that each of us is subject to pressure to deny bodily weakness and to feel apologetic and responsible if we are unable to meet appearance and functional standards in relation to our bodies. Such pressure comes from myriad external variables including families, friends, co-workers but especially mass media. We have a visual culture and in the age of 'digitally improvised selfies', this remains hooked up to body image. Cosmetic surgeries and the use of Botox to disguise the aging process have become normalised.

The chasm between 'real' and 'ideal' widens all the more when stereotypes reinforce beliefs about body perfection and completely distort understandings of what is 'normal'. Societal stereotypes such as 'be like a man' or 'act like a lady' establish and confirm notions that unless you appear and act in a certain way you might be rejected or overlooked. When bodies do not 'fit in' according to normative standards, this typecasting becomes underpinned by negative and dismissive value judgments. Within such a culture, having a disability is viewed negatively. Images of deformity and disability are always dissected, exhibited and objectified.

Body Image and Bodies that Don't 'Measure Up'

This chapter proposes that cultural messages have an impact on body image. Our bodies become our main instruments for expressing ourselves, suggesting that external appearance reflects an individual's inner view of

themselves. In reality this view from inside us tends to be shaped by the outside world. It is influenced by how our culture(s) define attractiveness and ability so that social value is placed on our bodies, our looks, our differences, and abilities. Thus body and self-images are created in the interplay between people's internal views of themselves and the views of others that they internalize.¹

Body image is a subjective and multidimensional construct.² It encompasses an individual's self-perceptions and attitudes about his or her physical appearance. It also includes descriptive and evaluative beliefs about appearance that are influenced by more than perception.³ Cognitive, affective, attitudinal, and many other variables play a significant role in the judgements we make about our bodies. Body image is a powerful construct which has the devastating effect of establishing an ideal standard of societal 'fitness'.

Bodies are scrutinized at two levels: one characterised by societal icons and ideals of beauty and perfection and the other where bodies are viewed as 'abnormal'. Having a body that does not 'measure up' results in feelings of vulnerability, embarrassment, and can leave us open to verbal and even physical assault.

Body image is a part of human personality that has its own transformational path and is liable to change with the onset of physical impairment or disability. We perceive our body and its competence at three levels. The first is a general physical perception that includes the mental image people have of their external physical appearance such as skin wrinkles, hair loss, large stomach, physical fitness and even clothing. The second is an internal perception of the body and its function; that is perception of internal organs that are not visible such as feelings toward the symptoms of cardiovascular diseases, stomach and blood pressure. The third level of perception refers to physical competences that includes

¹ Lawrence S. Sugiyama, "Physical Attractiveness: An Adaptationist Perspective." *The Handbook of Evolutionary Psychology* (2005).

² Thomas F. Cash, Jennifer A. Morrow, Joshua I. Hrabosky, and April A. Perry, "How has Body Image Changed? A Cross-Sectional Investigation of College Women and Men from 1983 to 2001," *Journal of Consulting and Clinical Psychology* 72, no. 6 (2004): 1081.

³ Peter D. Slade, "What is Body Image?" *Behaviour Research and Therapy* 32, no. 5 (1994): 497-502.

mental evaluations of the physical abilities people consider for themselves to achieve physical goals, a level associated with self-efficacy.⁴

Distorted and damaged body image of people with 'problem bodies' adversely impacts this third perception.

Body image is also part of our sexuality—how we feel about our bodies. Whether we know it or not, the way we see our bodies has a big influence on us every day, including the decisions we make. People with disabilities are considered non-sexual and the main culprit behind this stereotyping is that their bodies are considered deformed, damaged and unattractive, such that they need to be either 'rectified' or ignored. Sex and expression of sexuality is perceived as a privilege only for people with specific kinds of bodies and certain kinds of lives. In contrast, those who have 'bodies that don't measure up' are precluded from seeing themselves as sexual beings. It is usual for people with disabilities to feel excluded from interactions concerning sexuality and relationships.

While forming intimate physical relationships, a person with disabilities confronts two kinds of attitudes: one is a societal attitude of individuals towards choosing a 'disabled' person as a partner; and the other attitude relates to one's own inner demeanour and a subconscious fear of being rejected during physical intimacy. Since 'disabled bodies' fall outside the realm of mainstream society, they become a reason for intrusive stares. Under such conditions, the disabled lose their self-confidence and a sense of dependence on others, grows in them. A decrease in self-confidence and an increase in negativity, a sense of inadequacy and affliction impact on their inherent abilities in an individual. They consider their bodies and lived experiences as contrasting to that of others, and they begin to lose confidence in their own knowledge and capabilities.

This is further accentuated by a phenomenon which is known as 'ableism', a system that is oppressive and loaded with discriminatory attitudes, beliefs or practices. In this system, persons with disabilities are taken as incompetent and unproductive and ascribed an inferior value suggesting developmental, emotional, physical and intellectual limitations. It constructs a predominant mindset that undermines and limits the potential of persons with disabilities. Ableism extends beyond literal discriminatory acts. It can also come under the garb of benevolence. The

⁴ A. Bahram, Mohsen Shafizadeh, and A. Sanatkaran, "A Comparative and Correctional Study of the Body Image in the Active and Inactive Adults and with Body Composition and Somatotype," *Research on Sports Science* (2002): 13-28.