

## PART IV

### IV.4 MEDICAL HUMANITIES



## Medical Humanities: Concepts, Practices and Perspectives

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This chapter aims at giving a preliminary overview of the rise, history, and organisation of the ‘Medical Humanities’ (Cole et al. 2015), as one of the main and historically first so-called new humanities (the others being the Digital Humanities, the Environmental Humanities, and the Public Humanities).

Originally created as a pastoral care, palliative medicine and ethical support unit within university hospitals, the field of the Medical Humanities has grown to encompass a broader range of objectives and fields of application. These range nowadays from disability studies and death studies to more clinical aspects such as pandemics, social health, and the public health consequences of the environmental crisis. Another important genealogical source is the bioethics discourses and institutions that were set up in clinical and academic structures as of the 1990s.

For this chapter, we have interviewed several key players in the Medical Humanities in Europe, at institutions which are connected to the Network of European Humanities in the 21st Century. These include James Wilson and Sonu Shamdasani of the Health Humanities at University College London, Johannes van Delden and Sarah Boers of the Medical Humanities at Utrecht University, and Marco Veglia of the Medical Humanities of the University of Bologna.

First, we will give an overview of the problems of definition and terminology within the field of Medical Humanities. From this analysis we will derive a threefold typology – Bioethics, Health Humanities, and Biomedical Humanities, as three sub-approaches within Medical Humanities. Our interviews from Bologna and London serve as case studies of the Health Humanities, whereas our interviews with Johannes van Delden and Sarah Boers serve as case studies for the Biomedical Humanities.

The medical, institutional and social challenges related to the COVID-19 pandemic accentuate the relevance of all the questions regarding the intersection between medicine – in the broadest sense of the term – and the humanities as both an academic discipline and a larger field of cultural intervention. COVID-19 shows how cultural factors are important in the collective and individual responses to the pandemic (Huynh 2020; Fiske et al. 2020): during the lockdowns people across Europe occupied themselves with reading literary texts, including science fiction, listening to music, organising their own drama and concert events – becoming media artists in their own ways. Culture kept people’s minds and souls occupied and hopeful during the darkest period of the pandemic.

The crucial role played by culture as a therapeutic device and the extent to which the arts influence healing practices and the pain of diseases have resulted in a renewal of attention and respect for the human body as a bio-cultural entity, and not only a biological one.

This qualitative shift is essential to the new definition of the Medical Humanities recently developed by Julia Kristeva and co-authors (Kristeva et al. 2018). The most important impulse, and one that has become all the more relevant in the global health crisis, is that to bridge and reconnect the dichotomy between biology and culture, the natural and the social, both the humanities and biomedicine have to shift their self-understandings. By defining themselves as bio-cultural practices, they can be more closely related to each other. In other words, the Medical Humanities thus defined assume a non-dualistic relationship between nature and culture, non-humans and humans – and thus are open to dialogues with critical revisions of both humanism and anthropocentrism.

In 2014, the ‘Lancet Commission on Culture and Health’ came to a similarly fundamental conclusion. Considering the reasons why health systems in different countries do not work or work poorly, the experts group concluded that prioritisation logics, collective behaviour, regulations and socially stipulated practices as well as spheres of responsibility are strongly influenced by different cultures (Lancet Commissions 2014: 1608). Due to the finding that ‘the systematic neglect of culture in health care is the single biggest barrier to the advancement of the highest standards of health worldwide’ (Lancet Commissions 2014: 1610), and that the concepts of health and well-being need to be redefined, Medical Humanities would therefore be ideally positioned for this conceptual renewal. If the Medical Humanities have the task to forge a cultural competence within medicine and health care systems, if they are able ‘to reshape medicine and health care’ (Lancet Commissions 2014: 1609), the time has come for a clear definition of what the Medical Humanities are, how they have developed in different countries and academic contexts, and how they are realising their recognised potential.

## Defining Medical Humanities

‘Medical Humanities’ is used as a term of organisation in contemporary university organisation. The term Medical Humanities emerged after the Second World War and was consolidated in the 1960s, but became current in the 1990s. Several related terms exist, such as: Biomedical Humanities (Atkinson et al. 2018), Bioethics, Biomedical Ethics (Liu et al. 2018), Biohumanities, Neural Humanities Evolutionary Humanities, and Health Humanities. As if the discipline were in search of a clear objective or felt the need to ‘rethink’ itself, many efforts have been dedicated in the last decade to the analysis and definition of the term Medical Humanities (Hurwitz and Dakin 2009; Evans and Greaves 2010; Chiapperino and Boniolo 2014).

Felice Aull from the NYU School of Medicine writes:

We define the term ‘medical humanities’ broadly to include an interdisciplinary field of humanities (literature, philosophy, ethics, history and religion), social science (anthropology, cultural studies, psychology, sociology), and the arts (literature, theater, film, and visual arts) and their application to medical education and practice. The humanities and arts provide insight into the human condition, suffering, personhood, our responsibility to each other, and offer a historical perspective on medical practice. Attention to literature and the arts helps to develop and nurture skills of observation, analysis, empathy, and self-reflection – skills that are essential for humane medical care. The social sciences help us to understand how bioscience and medicine take place within cultural and social contexts and how culture interacts with the individual experience of illness and the way medicine is practiced. (Aull n.d.)

The Medical Humanities presupposes a form of interdisciplinary work, between the fields of medicine and the humanities. The question of interdisciplinarity has been discussed in other contributions to this volume. Sometimes, the dedication to interdisciplinarity remains more rhetoric than practice. In reality, some departments of the Medical Humanities are strongly embedded within the humanities departments of their respective university, without much interdisciplinary research. In other instances, the Medical or Health Humanities emerge as an additional course within medicine departments, emphasising an applied approach towards the function of bioethics and the Medical Humanities. The full extent of interdisciplinarity within the Medical Humanities remains an open question. It also remains to be seen what the purpose of interdisciplinarity in the Medical Humanities is.<sup>1</sup>

Without reproducing these processes of substantive and institutional re- and self-discovery, which have unfolded very extensively in the discipline's journals and in anthologies, let us just recall as representative the initiative of a group of women scientists who in 2016 published 'Companion to the Critical Medical Humanities' (Whitehead and Woods 2016). Aware of the discussions that have taken place and are taking place about a definition of Medical Humanities, the authors characterise Medical Humanities as follows:

The medical humanities, we claim, names a series of intersections, exchanges and entanglements between the biomedical sciences, the arts and humanities, and the social sciences . . . The medical humanities is an area of inquiry that is highly interdisciplinary, rapidly expanding and increasingly globalized. (Whitehead and Woods 2016: 1)

The 'critical Medical Humanities' start from the consciousness of having to reorient and redefine themselves by embracing new perspectives (of a historical, cultural and political nature) and different methodologies. The declared, programmatic goal is to pose more critical and potentially uncomfortable questions, extending the range of action of the field. In this redefinition of the Medical Humanities an important step is taken: an expansion of the mission of this field also takes place. Critical Medical Humanities add to the classic three 'Es' – ethics, education, experience (of illness) – the concept of *entanglement*, of involvement. Entanglement is understood as an attitude to be cultivated in the critical Medical Humanities. This is a transversal approach that brings into the medical field knowledge and insights from the humanities, mostly narrative and media techniques, cultural analyses, historical background and philosophical enquiry.

In the light of these developments, both within the Medical Humanities itself and 'from the outside', a new awareness of the potentials and tasks of the Medical Humanities has emerged. The consequences of the process sketched here are partly visible on the institutional level – in the academic visibility and multiplication of the Medical Humanities.

## Medical Humanities Typology

We tentatively attempt to distinguish three categories within the Medical Humanities: Bioethics, Health Humanities and Biomedical Humanities. These terms are sometimes used interchangeably.

**Bioethics** studies ethical questions which are the result of progress in medicine and biology, and can include real-life practical or policy considerations, which can be related to various disciplines, such as life sciences, biotechnology, law, philosophy, etc.

**Health Humanities** attempt to understand and/or develop a hermeneutics of ‘health’ (and ‘disease’) from cultural, historical, philosophical and sociological perspectives. One of the central methodologies which have been developed in the Health Humanities is the idea of narrative medicine. One fundamental question in the Health Humanities is about the nature of health as opposed to disease.

**Biomedical Humanities** move beyond mere bioethics and Health Humanities but look at the implications of bio-medical-technological advancement for society, culture, the earth, politics, and philosophy.

## Medical Humanities as Health Humanities: What is Health?

At the University of Bologna, there is a small Centre for Medical Humanities, which brings about twenty-five researchers from various departments. The director of this institute is Marco Veglia, who we have interviewed for this chapter. Veglia informs us that the Medical Humanities at Bologna operate in the tradition of Italian physician Augusto Murri (1841–1932). According to Veglia, the Medical Humanities revolve around its central question: What is health? Medical science, according to Veglia, is a ‘science’, but ‘medicine’ as a clinical experience – as a clinical relation between the physicians, the patient and his family members, the nurses and health workers – is an art that involves scientific knowledge, but does not coincide with it. Therefore, we have to consider the complexity and latitude of the concept of ‘health’ as the centre of the Medical Humanities. This concept is firstly related to the idea of disease or sickness. According to Murri, for a medical doctor, the primary challenge they encounter is how to break through the wall of experience of him as a physician and the patient. What kind of bond is there between the story of the patient, his or her narrative speech and the disease in question? The art of medicine therefore has to be strongly embedded into a humanistic training, which is versed in the complexities of human persons and their experiences of what it means to be ‘sick’ or ‘healthy’, beyond the logical reasoning of the physician about the disease of the patient. In the Medical Humanities, we cannot make a clear distinction between clinical medical training and a certain critical approach to reality. With the help of a humanistic training, the Medical Humanities consider the human being in its historical, physical, social, personal dimensions and emphasise the imperfection of the human being. It is important not to privilege scientific knowledge over humanistic knowledge, because if we do that we would miss out on the complexity of human life in its historical, cultural, and moral dimensions.

## Medicine as a Topic of Humanistic Enquiry

From Sonu Shamdasani and James Wilson we have learned that the Health Humanities at the Health Humanities Centre at UCL is still very much a matter of ‘humanities’. In the Health Humanities we see that the (old) methods of the humanities are used to study a new object: health (for example in its historical dimension). Both Shamdasani and Wilson emphasised that what they do is fundamentally human-centred. The health and the bio-medical sciences are seen as dimensions of human existence, and in that shape should be studied with the methodological tools the humanities have to offer. Shamdasani’s research is focused on historical research into medical issues. James Wilson emphasises that the Health Humanities are subject-oriented, instead of discipline-oriented. The subjective experience of illness, as opposed to the ‘objective’ analysis of the physician, exemplifies

the phenomenological approach towards health in the Health Humanities. The aim of this research is also fundamentally slow (in a positive sense): not emphasising rapid changing hypes or future trajectories (such as those that COVID-19 might be pointing us towards) but rather focused on the historical genealogy and relationships between health and humanity. Health Humanities does not necessarily have to lead to 'doctors becoming better doctors', though this can certainly be an outcome of the study. It is important, however, to stress the subjective dimensions of health and wellness that cannot be approached by the perspectives offered by the methodologies of biomedicine. UCL offers two distinct master's programmes: one is called 'Health Humanities', and the other is 'Philosophy, Politics, and Economics of Health'. It also offers a PhD programme in Health Humanities, but this programme is significantly smaller.

## **Biomedical Humanities: Beyond Bioethics and Health Humanities**

The Biomedical Humanities move beyond bioethics and Health Humanities to develop an interdisciplinary field that studies the impact of new biotechnologies (genomics, synthetic biology, stem cell research, neural sciences, virtual realities in psychotherapy) on medical theory and practice. They examine the effects of these developments on the image of man and on the self-image of medicine; and they ask about their implications for physicians and caregivers, patients and society as a whole.

The Biomedical Humanities are involved with the transformation of the human and non-human on the cellular, molecular, viral and genetic level. They go beyond mere humanistic questions regarding the human individual and health. According to Alvan Ikoku, they are critically examining what it means to be 'alive', to be 'human', to be essential for the patients, doctors, nurse, social worker. Biomedical Humanities exist at the intersection of medicine (broadly defined), humanistic enquiry and humanistic expression. This could mean using the tools for analysing a poem or reading a novel in order to enable a 'translation' between humanities and medical sciences. What does a novelist see when s/he looks at disease? The Biomedical Humanities therefore emerge as a confluence of scientific – strongly evidence-based, and literary – phenomenological, subjective – thinking.

At Utrecht University, the Medical Humanities is predominantly represented in the form of an education programme. On the website, it states (our translation):

In education we try to understand modern medicine by looking together with students at the historical and philosophical roots and the contemporary ethical and judicial dilemmas. Students become better medical doctors when they, next to biomedical knowledge, also have an understanding of contextual meanings of health, illness, and healing. Furthermore, we try to create awareness of the duties and responsibilities of doctors vis-à-vis their patients. Because we stimulate students to train their observation skills, critical analysis and self-reflection, we hope to contribute to the academic and social formation of the future medical doctor.

At the Julius Centrum of Utrecht University, three main researchers each represent one of the three approaches within the Medical Humanities. Johannes van Delden, a pioneer in the field of Medical Humanities, focuses on medical ethics and patient participation. Frank Huisman specialises in the field of medical history. Annelien Bredenoord is the

lead researcher on biomedical innovation and new technologies. These three approaches – ethical, historical, and innovation focused – are a continuous pattern in the field of the Medical Humanities.

Johannes van Delden has been a seminal figure in the development of Medical Humanities in the Netherlands. His research operated on the intersection of bioethics and medicine from the beginning. Currently, Utrecht University is offering an education programme in Medical Humanities. He argues that though the study of medicine is still determined mostly by a positivistic scientific attitude, developments in the humanistic study of medicine and narrative medicine have impacted the field.

Recently, Johannes van Delden has been prolific in studying end-of-life ethics as well as the complicated ethical discussions on triage (Haas et al. 2020), which took centre stage at the onset of the COVID-19 pandemic in March and April 2020. In the Netherlands, the question of whether doctors might need to choose to deny ICU admission to the elderly led to heated debates in parliament, with lawmakers proposing legislation against age-based triage by medical professionals. According to Van Delden, our finitude, which is so gruesomely expressed in disease and dying, is in fact the necessary condition for our values in life. As a result of that, medical technologies might liberate us, but they discipline us at the same time.

Several ethical considerations are at play here. First, there is the question of physical integrity, and the limits within which individuals should be considered autonomous with regard to their bodies. This relates to the question of, second, personal autonomy. However, health programmes also have an impact beyond the individual, and can therefore also be considered, third, a public responsibility. Finally, there are the commercial interests of the pharmaceutical industry and the care ‘industry’ to take into account as well.

## **Art as Research Practice: The Intersection of Art and Organoids**

We have interviewed Sarah Boers of Utrecht University, who has been working on organoid biotechnology (Boers et al. 2019). The leading researcher at Utrecht University in this technology is Hans Clevers. An organoid is an artificially grown mass of cells or tissue that resembles an organ. The technology is a result of the advancements in stem cell research. It allows researchers to test medicine and therapy on organoids from the cells of patients, before applying these to the patients themselves. Especially in the case of highly idiosyncratic diseases, this form of technology is sometimes the only way to develop treatment for individuals. Organoid technology raises all sorts of ethical considerations regarding the philosophical nature of these organoids. Are they human or are they objects? Or are they something in between? These ethical considerations, and the difficulty for the general public to imagine an affective relation to organoids, has led Boers to work together with artist Rosa Sijben to create an immersive art installation. In this installation, the audience is invited to experience what it is like to be together with organoids and how they should relate to them. Since many biomedical developments are indeed challenging our imagination, the collaboration between academia and art practices seems like an important trajectory for the Medical Humanities.

## **Biomedical Humanities and Technological Mediation**

The Biomedical Humanities are gaining an increased relevance with the rise of biomedical technology. The traditions of ethical and humanistic considerations of health and the



medical are coming under increased pressure with regards to the expanding advance of the technology of human bodies. These posthuman convergences of the ethical, the technological, the medical and the humanistic are the concern of the new humanities in general. First there is the ongoing progression of eHealth applications and the monitoring apps. Our smartphones are becoming an extension of our body and our private doctors. eHealth start-ups raise significant attention from corporate investors.

The starting point is the idea that digital methods can be a foundation for improved health care, but there are important bioethical considerations about the legal and ethical boundaries or limitations of medical technology. On the one hand, there is the necessity of finding a balance between individual medical needs and collective values and interests. Especially the societal considerations regarding DNA modification are important to note here and constitute a metaphysical and ethical discussion about the distinction between the 'natural' versus the 'technological'.

The COVID-19 predicament has further increased this convergence of the medical and the technological. Citizens around the world were urged by their governments to install a COVID-19 contact tracing app on their devices, which has resulted in public discussions of privacy. In tandem with this are the COVID-19 symptom tracing apps, on which you report daily how you feel and whether you have any COVID-19 related symptoms. This data can then be used for epidemiological purposes, though the ownership of this data remains opaque.

Some of the most successful vaccines available for COVID-19 now are based on mRNA technology – a highly innovative technology, which, though already in the making, might have taken years to launch were it not for this particular crisis. Though mRNA vaccines are relatively innocent, these technological developments go hand in hand with technological advancements such as CRISPR-Cas9 technology, which allows scientists to rewrite human DNA.

The COVID-19 pandemic has also accelerated telemedicine (Bashshur 1995), the practice of medicine from a distance. With doctors now taking consultations via Zoom on the one hand, but also 5G technologies enabling robotic surgeries from long distances, everything is set for a continued revolution towards telemedicine. Another development is the rise of care robots, which could automate the care sector, but this comes with its own humanistic and ethical considerations, both towards patients, as well as its impact on the labour market.

Another frontier of the Medical Humanities is the consideration of 'health' beyond human health. The hypothetical zoonotic cause of the rise of SARS-CoV-2 has put this consideration to the forefront. How does the value of humans, animals and the broader environment balance out in our health considerations? What is human health worth to us in terms of biodiversity sacrifices? It is clear that there are no easy answers here. One approach is the so-called OneHealth paradigm, which is discussed by H el ene Verheije and Stegeman in Chapter 20 of this volume.

## Conclusions

The Medical Humanities have taken centre stage in the discussion around the 'new humanities', not least because of the devastating impact of the COVID-19 pandemic on our societies. In this chapter, we have tried to give a brief overview of how the field understands itself and the challenges posed to it. First, Medical Humanities find their foundation in the application of a humanistic tradition to the field of medicine. Questions

regarding the meaning of health, disease and human flourishing take centre stage. From this emerges an interest in 'narrative medicine', which enquires into the self-understanding of the patient of their condition, beyond the physician's logical or technical analysis of the disease. The communication between the physician and the patient is crucial here. But the medical or health humanities also aim to enquire into the domain of 'health' as a historical or societal phenomenon. Here, primacy does not lie with the clinical experience of physicians and patients, but with the construction of health and medicine as a social institution. For the Health Humanities, medicine is a topic of scholarly enquiry to be approached with the methodological tools of a humanities scholar.

Second, there is a long tradition of 'bioethics' both in philosophy and in clinical practice. From medical practice there arose early on a need to reflect on ethical challenges related to the practice: When is a medical intervention required? Unwanted? On what grounds? Bioethics applies the arsenal of philosophical reflection to clinical practice, to arrive at norms and values for the physician or medical practitioner.

Third, we have observed an interdisciplinary turn in the Medical Humanities. Whereas 'Health Humanities' is strongly embedded, to a greater or lesser extent, in humanities scholarship with a focus on health, 'bioethics' is often exclusively embedded in departments of medicine. As we have observed in this volume in sections devoted to other new humanities (Vienni Baptista et al., Rotolo and Gamberi), the challenge is to arrive at a genuine interdisciplinarity which equally values the epistemological fields of enquiry of both the humanities and the sciences, or even transdisciplinarity where the boundaries are transcended altogether.

Fourth, there are increased calls for a form of 'critical Medical Humanities', which takes these challenges even a step further (McFarlane 2022). Because of technological advancements, the relationship between the human body and technology has become increasingly fluid. The idea of the 'human person' as the central locus of meaning in the Medical Humanities, explicitly aimed at 'making doctors better doctors', is put into question as being too instrumental. Even a Medical Humanities based on narrative medicine and the humanistic tradition re-emphasises a duality between the mechanical body of medicine and the 'spiritual' dimension of the soul or consciousness of experience of the individual human being. But continuous biotechnological advancements, such as pacemakers, mRNA vaccines, health apps, Zoom interviews, and the enhanced possibilities for end-of-life care and extension urge us to start reflecting about the possibility of medical *posthumanities*. The research into organoid therapies has shown us an example of how the ownership and functionality of bodies is fundamentally embedded in a neo-liberal framework of economic value. The critical Medical Humanities could therefore function as a space where the question of how 'human subjects' are constituted within the medical-biological-social framework in the function of capitalist interests can be critically addressed.

Fifth, the ethical dimension is prominent and quite complex, building on the historical tradition of pastoral care, and moving beyond it to a range of different positions that revisit humanism and also anthropocentrism. The notion of 'care' has emerged in recent research as an overarching principle that reaches across the human/non-human divide and brings the Medical Humanities in closer contact also with the environmental field. Increasing convergences shape the ethical spirit of the new humanities.

## Note

1. The Consortium of Humanities Centers and Institutes (CHCI) hosts several institutes devoted to the Medical Humanities on its website, such as the Centre for the Humanities and Health at King's College London, the Institute for the Medical Humanities at the University of Texas Medical Branch, and the Mayo Clinic Center for Humanities in Medicine. In the US, there is also the American Society for Bioethics and Humanities, which is an interdisciplinary platform for the entire field. Several journals are exclusively devoted to the Medical Humanities, such as *Medical Humanities* and *Journal of Medical Humanities*. In the field of bioethics there are hundreds of journals, the most influential of which include *Journal of Medical Ethics*, *Nursing Ethics*, *American Journal of Bioethics*, and *Bioethics*.

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