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Medical Humanities With and Beyond Bioethics – Disciplinary Diversification in Medicine Facing the Complexity of the Bio-Cultural Corporeality

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Medical Humanities is a research and teaching field that is just fifty years old. Unlike disciplines that enjoy a long tradition and a clear academic profile within a fixed faculty, the Medical Humanities are very diversified and emerged at different locations at different times. By means of a few examples, I would like to show how the paths of institutionalisation of this bundle of disciplines, which has medicine and the problems and questions it raises as its subject matter, are closely linked to the respective academic contexts and to the self-image of already established disciplines – first and foremost bioethics, medical ethics and the history of medicine. This comparative reconstruction work, which does not claim to be exhaustive, focuses on three aspects in particular: the establishment of Medical Humanities with and in distinction to bioethics; the critical-performative self-understanding of the humanities emphasised by Derrida and its potential when biomedicine and humanities cooperate and expose themselves to critique; and, finally, the merits of epistemic diversity to do justice to bio-cultural entities such as life, health and illness. Global experiences such as the COVID-19 pandemic demonstrate how health depends on bio-cultural factors.[1] This makes the cooperation of medicine and humanities all the more ethically required for the treatment of urgent questions and the joint search for answers.

Defining what the humanities in medicine are is not trivial. Various academic realities and historical developments have led to the emergence of adjacent but independent disciplines that define themselves as Medical Humanities or as a part of it (Evans and Greaves 2010). What characterises them is that they seek to explore cultural, social, representational and ethical problems and issues that arise in and through medicine. These lines of questioning therefore challenge medicine because their complexity and critical scope can only be adequately explored by raising questions that do not pertain to the tradition of medical scholarship. These involve taking into account the actors' and subjects' perspectives, their socio-epistemic conditions, the power relations that frame them, and the respective historically evolved cultural contexts. Typical fields of research in the Medical Humanities include, for example, manifestations and narratives of illness experiences in literature and art, the medicalisation of phases of life with high existential and cultural significance such as pregnancy, birth and death, or the boundaries between norm and optimum as in enhancement practices. The extent to which medical factors are interwoven with existential, socio-political, ethical and cultural factors in any context traditionally understood as purely medical is not only demonstrated by the extreme example of pandemic outbreaks of infection. Relatively common individual experiences of illness, dying and death, or situations of vulnerability in which dignity and self-determination are threatened by dependence on others, also show that medical knowledge cannot be

isolated from social and cultural factors. In other words, my case is that medicine is intrinsically integrated with humanistic knowledge and in this respect the Medical Humanities is a necessity (Chiapperino and Boniolo 2014).

It is a given by now that biomedicine, which provides crucial assistance to us in all phases of life, does not have an exclusive understanding of life practices and consequently cannot and should not bear the burden of its increasing responsibility for them alone.

My argument is that the Medical Humanities need to combine the competence and methodological diversity in medicine with genuinely interdisciplinary efforts across the humanities. That entails more intense collaboration between basic research, biotechnologies, clinical practice and the humanities, in order to provide the urgently needed potential for tackling and solving complex health problems (Evans and Macnaughton 2004).

Mapping the Field of Disciplines and the Common Grounds

Currently, there is an upsurge of Medical Humanities in some European countries. Institutes and centres have been renamed or newly founded. Sweden, Switzerland, Germany, Austria and Italy are following the model of their neighbours in the UK and in the USA, where in 1973 the Institute for Medical Humanities of the University of Texas (Galveston) marked the beginnings of what is now a resurgent disciplinary cluster.

What we are experiencing today in several EU countries already started taking place in Britain between the end of the 1990s and the beginning of the new millennium. If the interest in Medical Humanities has been – to use David Greaves and Martyn Evans's definition – 'the second generational response to the shortcomings of medical culture' in Britain around 2000, then we might now speak of a third generational response (Greaves and Evans 2000). As a rough chronology of these wave-like developments, one could note a first phase in the 1970s in the US, followed at the end of the 1990s by a second wave to be located mainly in Britain; the third phase is the one in which we are now, and which affects some European countries.[2]

One question discussed during the 'second wave' of the rise of the Medical Humanities was their relationship with other traditionally related disciplines such as medical history, medical ethics or medical sociology, but especially with bioethics. This last has become increasingly important in medical schools as it addresses both the classical questions of the limits of life or the morality of medical actions that affect vulnerable individuals as well as the problems posed by emerging biotechnologies (Kopelman 1998; Evans and Greaves 2010; Fangerau and Gadebusch Bondio 2015).

Different solutions have been found for shaping the relationship between bioethics and Medical Humanities in different contexts. Let me illustrate this with three examples.

In the US, the American Society for Bioethics and Humanities (ASBH) was founded in 1998. The act was symbolic and pragmatic at the same time. Since then, scientists who were and are active in bioethics and the Medical Humanities have been able to join forces under one interdisciplinary umbrella. In the year of the merger, the vast majority welcomed this possibility as time-saving and as promising synergies (Kopelman 1998). While the first years were characterised by the effort to define a common field with which the representatives of different disciplines could identify, today the focus of ASBH is on the development of intersectional methodologies within the field, which is constantly being redefined.

The second example concerns the then still European British peninsula. The history of the journal *Medical Humanities*, reconstructed by the editors on the tenth anniver-

sary of its founding, exemplifies the original interconnectedness of medical ethics and Medical Humanities as neighbouring disciplines in Britain (Greaves and Evans 2000). *Medical Humanities* was originally fashioned as a special issue of the prestigious *Journal of Medical Ethics* (*JME*), part of the BMJ Publishing group. From this initial format as a special issue of *JME*, the idea of an independent magazine emerged. The editors of *Medical Humanities* consider this beginning to have been crucial to both fields: it has enabled *Medical Humanities* to be placed in the established context of medical ethics, on the one hand, and has broadened the philosophical scope of the *Journal of Medical Ethics*, on the other (Greaves and Evans 2000).

The third example comes from Germany, where the history and ethics of medicine at medical faculties have so far enjoyed a co-existence characterised by cooperation and competition (Fangerau and Gadebusch Bondio 2015). While the beginnings of the humanities in medicine are represented exclusively by medical historians and doctors with a knowledge of classical philology, in the 1980s, with the professionalisation in these humanistic fields of medicine, the need for corresponding competences also increases both in the GDR and in the FRG (Gadebusch Bondio and Bettin 2010). In 1986, the Academy for Medical Ethics (AEM) was founded with the participation of medical historians. With the licensing regulations for doctors in 2002, 'History, Ethics and Theory of Medicine' became a compulsory subject in medical training. Most institutes subsequently renamed themselves. Since then, medical ethics and medical history have been considered and practised either as separate professional profiles or as complementary to each other (Fangerau and Gadebusch Bondio 2015). Depending on the specialist background of the researchers, the state medical faculties in Germany have varying research foci, specialist understandings and institutional profiles. A diverse landscape took shape in which only one institute (Bonn) and one department at the Charité (Berlin) have chosen the denomination 'Medical Humanities'. While in Germany the humanities have a foothold within medicine and are involved in the teaching curricula for students of medicine, biomolecular medicine and dentistry, in other European countries the development of the Medical Humanities also takes place in philosophy faculties (e.g., in Austria or Sweden), where there is a clear trend in this direction.

These examples show a high degree of diversity in the institutional structures that have provided the frameworks for the development of Medical Humanities. Interfaces, contact zones, or even points of friction between disciplines grouped under the 'umbrella' of Medical or Health Humanities vary across academic contexts and have manifested themselves differently in the waves of development outlined.

Current discussions by representatives of the Medical Humanities are therefore centred around concepts such as interdisciplinarity and multidisciplinarity and strive to provide a basis for redefining common goals, shared grounds and methods, in addition to questions of definition and identity (Evans and Macnaughton 2004). An increasingly strong trend, which will be analysed in the following section, is concerned with the potentials of a bi-directional exchange between the clinical disciplines and the Medical Humanities or the 'Critical Medical Humanities' (Chiapperino and Boniolo 2014; Atkinson et al. 2014; Viney et al. 2015; Kristeva et al. 2018).

Cross-disciplinarity, Interconnectedness and Critique

> . . . this force of resistance, this assumed freedom to say everything in the public space, has its unique or privileged place in what is called the Humanities. (Derrida 2002: 207)

The reason why the humanities are predestined to explore and question the interconnectedness of the cultural, social, representational and ethical dimensions of medicine, including its epistemology, lies in their special, indeed privileged position. This notion rests on a definition of criticism (from the Greek *krínein* to separate, to decide) and critical thinking as being constitutive for the humanities. From philological textual analysis (starting with biblical criticism) to (post-)constructivism and post-transhumanism, the power of the humanities lies in their discriminating, comparative, analytical and critical reflection on all aspects of human experience. This idea is foundational, among other things, for the linguistic branch of poststructuralist philosophies, which were very influential in the humanities in North America.

Michel Foucault provoked with the statement that criticism or a critical attitude is a virtue ('. . . there is something in critique that is akin to virtue'; Foucault 1997: 25), when at the same time he equated criticism with disobedience. Within Foucault's theory of power, critique is a form of counter-power, notably the political art of resistance, in the sense of the art of 'not being governed'. That is, for example, the gesture of sovereignly rejecting unjust laws, but also the more general art of resisting all processes that shape our subjectivities in accordance with a given 'dispositive', or a regime of power – including processes of knowledge creation (Foucault 1997). In Judith Butler's reading:

> So critique will be that perspective on established and ordering ways of knowing which is not immediately assimilated into that ordering function. Significantly, for Foucault, this exposure of the limit of the epistemological field is linked with the practice of virtue, as if virtue is counter to regulation and order, as if virtue itself is to be found in the risking of established order. (Butler 2001: 3; Foucault 1997: 25)

The virtue-ethical and epistemic function of critique is given further emphasis by Jacques Derrida in his 'The Unconditional University' (L'Université sans condition), a speech that he gave at Stanford, California, in 1998 (Derrida 2002). He insists here on the role of the 'new humanities' in the development of an academic freedom that allows for the professing of truth and that only democratic states can tolerate, endure or come to terms with. The 'deconstructive resistance' of which he speaks is an appeal to consider the original meaning of the word professor, linked to the act of professing a faith – in the case of science, the professing of truth. Humanities according to Derrida should dedicate themselves to the recovery of this meaning and become promoters of a critical movement capable of questioning their own academic limits. In fact, their aim should be to oppose and negotiate, to expose themselves and operate in the border and friction zone between university, society and politics, thereby taking part in the socio-cultural and scientific developments of our time as well as interrogating them. This would, therefore, according to Derrida, mean moving from a contemplative to a performative attitude – in the original sense that John Austin gave to the term and Derrida revived: 'In a certain way, it is the Humanities that made it [the distinction between performative speech acts and constative speech] come about and that explored its resources; it is to and through the Humanities that this happened, and its consequences are incalculable' (Derrida 2002: 209). Finally, Derrida combines the emphasis on the privileged position of the humanities with an appeal: the subversive power of the humanities becomes an obligation to assume responsibility and to expose oneself publicly. The humanities as a privileged place where the unconditionality principle is negotiated and rethought is a place of resistance, of diso-

bedience. Responsibility combined with cultural awareness is the cornerstone of Derrida's speech dedicated to the future of the university.

In *The Edinburgh Companion to the Critical Medical Humanities*, published in the UK in 2016, editors Anne Whitehead and Angela Woods characterise the Medical Humanities with the attribute 'critical'. The 'critical medical humanities' defined by Whitehead and Woods arise from the consciousness of having to reorient and redefine themselves by embracing 'new historical, cultural and political perspectives, as well as different questions and methodologies' (Whitehead and Woods 2016). With the intent to pose more critical questions and therefore potentially uncomfortable ones, the critical Medical Humanities extend the range of action of Medical Humanities as they had hitherto been conceived. Add to the classic three 'Es' – ethics, education, experience (of illness) – the concept of entanglement, of involvement, understood as an attitude to be cultivated in Medical Humanities that define themselves as critical (Whitehead/Woods 2016).

In this context, where the humanities and criticism are so programmatically linked, the previous contributions of scholars such as William Viney, Felicity Callard and Angela Woods receive great recognition (Viney et al. 2015). The latter had contributed to a series of programmatic articles that preceded the publication of the *Companion*. These laid the conceptual groundwork for new forms of interdisciplinary and cross-sector collaboration (Viney et al. 2015; Atkinson et al. 2014). At the core of this initiative is the desire to reposition the Medical Humanities 'as a powerful tool through which to address not only the meaning and historico-cultural *contexts* of health and illness, but their very production, concrescence and dispersal across the precarious, unequal and environmentally degraded societies in which we live' (Viney et al. 2015: 2). Viney and co-authors see the representatives of the Frankfurt School, Theodor Adorno and Max Horkheimer as well as Michel Foucault, Judith Butler, Hannah Arendt and Bruno Latour as pioneers of this understanding of a critically engaged stance that aspires to venture into the traditional domain of biomedicine in order to address the ontological questions that underpin this domain.[3] These questions arise from the complex interrelationality of human and non-human. Viruses or computer chips – as non-human entities – co-exist with and *in* humans, but this co-existence can sometimes upset the fragile balance of health, as can be seen in the case of infections and rejection reactions. In addition to the problems caused by the manifold biotechnological interdependencies in intercorporal, socio-political and environmental realities, a number of issues also arise from the cultural conditionality of epistemic regimes, discourses and subjective experiences related to health and medicine. The need for additional epistemologies that contextualise, relativise and complement concepts such as evidence and objectivity in medicine is increasingly felt (Atkinson et al. 2021). In this case, it is not only representatives of the Medical Humanities, but of medicine and society in general that are providing the impetus for the development of new epistemologies and forms of critique in the face of experiences such as inequality in health care systems and discrimination based on climatic, epidemic and pollution factors that endanger the health and lives of affected groups. The final section addresses this topic.

Epistemic Diversity to Address the Biocultural Complexity of Health

The following developments illustrate how the need for cultural competences that the humanities in medicine have been drawing attention to is now also becoming increasingly clear within medicine.

In 2014, the Executive Summary of the Commission on Culture and Health was published in *The Lancet*. Over thirty-two dense pages, it sets out and justifies the key role of culture in health. For the definition of 'culture', the Lancet Commissions refers to UNESCO, which in turn adopted the concept of anthropologist Edward Burnett Taylor (1870) and defined culture as ' the set of distinctive spiritual, material, intellectual and emotional features of society or a social group, and that it encompasses, in addition to art and literature, lifestyles, ways of living together, value systems, traditions and beliefs' (p. 2) (UNESCO Universal Declaration on Cultural Diversity 2 November 2001; http://portal.unesco.org/en/ev.php).

The Lancet Commissions emphasise several times that the Medical Humanities should help to understand *how* these attitudes, moral values and beliefs emerge and manifest themselves in different contexts related to human health and the practice of medicine, and in different historical periods (p. 1609). The agenda proposed pursues the ambitious goal of achieving the highest attainable standards of health care worldwide by addressing hitherto neglected cultural factors at the levels of education, research and care. In this plan, the Medical Humanities are given a crucial function. The abolition of the dichotomy between the objectivity of science and the subjective values of culture – which can also include the individual experiences and interpretations of illness – assumes a central role in this programme, with epistemic consequences: 'Although culture can be considered as a set of subjective values that oppose scientific objectivity, we challenge this view in this Commission by claiming that all people have systems of value that are unexamined' (p. 1607).

The epistemic significance of this observation cannot be overemphasised. The fact that scientists and experts are also shaped by the historical and cultural context in which they generate evidence was clearly demonstrated by Ludwik Fleck (1896–1961) in 1935 with a series of examples from the history of venereology. The cultural identity of the people involved in research and clinical care – according to Fleck – influences the topics and questions that drive scientific research, the nature of scientific projects and initiatives, the methods of research and its tools, right through to the analysis and interpretation of results. According to Fleck, researchers specialised in a field are part of a 'thinking collective' that develops its own attitudes (habitus) and styles of thinking depending on the context and works according to fixed rules that are usually passed down unconsciously. Fleck's astute observations make it possible to understand the different disciplinary cultures within medicine. These cultivate their own normative traditions and convey a discipline-specific professional ethos (just think of the differences in habitus between surgeons, palliative physicians, epidemiologists, etc.). Reflection, relativisation, questioning and self-criticism, as essential prerequisites for the development of a conscious judgement of an ethical and epistemological nature, however, tend to take place outside the clinical and biomedical disciplines. One more reason to use the interlocking of humanities and biomedicine as a technique of cross-fertilisation: on the one hand, to allow the critical potential of the humanities to take effect already in the development of questions and the discussion of problems, and on the other hand, to bring complex topics that cannot be solved biomedically only onto the agenda of the humanities.

Another development shows how the importance of the Medical Humanities is now also recognised by medical professionals themselves. In their response to funding cuts imposed by Prime Minister Theresa May in 2018, a group of academics from the Centre of Biomedicine, Self and Society at the University of Edinburgh highlighted the manifold contributions of the humanities and social sciences (anthropology, medical history and

philosophy) to medical research and medical education (Pickersgill et al. 2018). The cuts mainly affected education in the fields of the humanities and social sciences. However, according to the authors, it is areas such as public health and global health that benefit in particular from the qualitative and quantitative methods of the 'cut' disciplines: 'Practitioners now commonly finish their degrees conversant not only with ethical and legal issues but also with the ability to think more broadly about the moral, social, and political dimensions of health, disease, and health care' (Pickersgill et al. 2018: 1462). The vision of medicine as both scientific and humanistic becomes a prerequisite for understanding and solving human problems. At the point where it is emphasised that the humanities and biomedical disciplines should jointly raise questions and launch research projects in order to jointly seek answers, there is an indirect reference to the need for competences to be pooled across different disciplinary fields of expertise, methodologies and academic cultures.

The emancipatory gesture of a genuine interdisciplinarity in medicine was taken up by Julia Kristeva and three Norwegian scholars when they declared the need for a 'cultural-crossing of care' (Kristeva et al. 2018). The path they propose combines epistemic considerations with practical, therapeutic experiences and leads to the problematisation of the concept of evidence in relation to the concepts of health and illness, culture and nature. Starting from the assumption that the body is a bio-cultural entity, and that culture has an influence on healing and disease, the authors question the conventional separation of humanities and natural/biological sciences. Here, the Medical Humanities are given a cross-disciplinary space:

> Medical humanities should not be construed as a humanistic perspective on medicine. They should rather be seen as a cross-disciplinary and cross-cultural space for a bidirectional critical interrogation of both biomedicine (simplistic reductions of life to biology) and the humanities (simplistic reductions of suffering and health injustice to cultural relativism). The humanities and medicine are thus both declared biocultural practices. (p. 56)

These recent contributions, arguing for the necessity and anchoring of the humanities in a culturally aware medicine of the twenty-first century, take on a special significance just now. The complex interdependence of the environment, animals and humans has never been more evident than in the uncontrolled spread of the SARS-CoV-2 virus. An experience shared by most people is that health is a fragile commodity that medicine alone is not always able to protect. The importance of individual, family, social, cultural and political circumstances in the likelihood of becoming ill and recovering has also become more apparent in the handling of the pandemic (Fiske at al. 2020). Given this global experience, the need for a multidisciplinary effort that understands and promotes health in a new way and views it as a vulnerable relational good (One Health) becomes clear. The COVID-19 crisis has heightened this awareness and highlighted the urgency of an integrative, culturally sensitive approach (Huynh 2020). In this context, it is precisely the concept of 'translational medical humanities' that can be made useful. It contains the idea that knowledge should be made 'translatable' and the concept of evidence redefined (Engebretsen et al. 2020). What does this mean? That the Medical Humanities 'are not only an auxiliary to medical science and practice, but also an interdisciplinary space where both medicine and the humanities mutually challenge and inform each other' (Engebretsen et al. 2020). Examining the 'cultural assumptions' that shape biomedicine

and health policy is declared as the central task of the humanities. But has not attention to the very context in which research is conducted and evidence is 'made' been the catalyst for research in the history of science, history of medicine, and epistemology over the past five decades? The individual and group-specific as well as cultural shaping of researchers, recognised so early by Fleck, is accompanied by a questioning of concepts such as 'objectivity' and 'evidence'. This is one of the core tasks of the historically and theoretically reflective humanities. The urgent need to expand and rethink the concept of evidence has long been recognised even by the proponents of evidence-based medicine (Goldacre 2015; Greenhalgh et al. 2015) and has become one of the most urgent tasks that involves not only theoretical disputes but also the quality of epistemically sound and self-critical clinical research (Anjum et al. 2020). The contexts in which evidence is generated (laboratories, clinics) are different from those in which evidence is needed and required, i.e., the reality of the individual patient. This explains why so often the promises of research and the results generated can be disappointing or that the 'gold standards' set in guidelines are not applicable in every socio-economic and cultural context (Chowdhury et al. 2019). The epistemology of medicine, too, must be sensitive to culture and context if it is to develop its potential for medicine's target group, patients and people who are still healthy.

Conclusion

The developments outlined illustrate how the humanities have become, or are in the process of becoming, an integral part of a problem-aware, self-(critical), ethically reflective biomedicine.

With the impetus given by the critical Medical Humanities, the humanities and medicine have formed a productive new alliance. This alliance is based on the advocacy of the humanities as critique, following French philosophical debates about power, language, representation, performativity and translation. The epistemology of medicine, grounded in the history of science and medicine, has also provided indispensable impulses. It enables us to understand the importance of spatial, temporal, material and cultural frameworks for the generation and application of medical evidence. The critical Medical Humanities require rigorous interdisciplinarity. Whether located directly in biomedicine or in other academic arrangements, the Medical Humanities face important twenty-first-century tasks. They can meet them only if they work with their reference discipline to find solutions to problems. The pandemic with its long-lasting consequences has highlighted complex interdependencies such as health and environment, culture and behaviour, health policy and discrimination. In order to do justice to this complexity, disciplinary boundaries must be crossed, and the methodological competencies of the respective disciplines must be strengthened and utilised in order to jointly develop creative approaches to solutions.

Notes

1. With 'biocultural factors' affecting health, the interaction of biology and culture is emphasised. Biological factors include, for example, age, sex, genetic predispositions and epigenetic elements; culturally determined dimensions of health include environment, dietary habits (which may also be religiously influenced), education, profession, physical activity, etc.
2. The popular wave metaphor is used inconsistently to characterise different stages of development: Kristeva et al. (2018: 56) define as second wave the initiative of 'critical medical humani-

ties' that took place around 2015/16. If you look at the long history of Medical Humanities from its beginning, it cannot be reduced to two wave-like phases.

3. The clear reference to the Frankfurt School may have been the reason for the startling omission of Jacques Derrida in this context. His thoughts on the unconditional university, first published in English, are too pertinent to the topic of 'critical humanities' to have been overlooked in the philosophical location of the term 'critical medical humanities' (Waniek and Vogt 2008).

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