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Health Humanities



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Introduction

Health Humanities is a term that has been used for the past 10 years to describe a broad field within the humanities. Because researchers who identify with this field come from a variety of disciplines, the description of the content of this field and its demarcation from other disciplines is not clear-cut. What everyone does seem to agree on is that Health Humanities are a critical complement to Medical Humanities. Therefore, let us first briefly discuss what is meant by Medical Humanities, a field that emerged in the 1970s. Contemporary medicine, from the nineteenth century onward, has evolved from “bedside medicine” to “laboratory medicine,” with the person who is ill disappearing increasingly into the background (Jewson 1976). With expanding technology and automation in the second half of the twentieth century, there has been less and less focus on the patient’s story and voice. Even though it is often said that medicine is both science and art, the last decades of the twentieth century were mainly dominated by making medicine as scientific as possible, which culminated in the implementation of evidence-based medicine (EBM) since the 1990s. Medical humanities seek to

counterbalance these trends in medicine, by revaluing patients’ narratives and experiences, and by strengthening medicine as an art.

As an academic discipline, the medical humanities primarily gained a place within medical education. It is through humanities subjects such as philosophy, ethics, history, comparative literature, and religion, and through arts, that medical students are invited to look at and listen to patients with eyes other than the biological, physiological, and pathological ones. Particularly in the Anglo-Saxon countries, it is not unusual for medical schools to offer a MA in medical humanities. Even when there is no separate medical humanities program, most medical students still receive (minimal) training in (medical) ethics. Within the separate medical humanities programs, most attention is paid to literature and narratives. For it is claimed that it is important for doctors that, in addition to identifying all kinds of clinical symptoms, they must also be able to interpret their patients’ experiences and stories. Rita Charon (2006), the founder of narrative medicine, an important branch of the medical humanities, states that by reading literature, doctors learn to put themselves in their patient’s shoes.

Since the 2010s, various researchers (and professionals) have indicated that the aspiration of the medical humanities should be extended to non-medical professions within health care (Crawford et al. 2010; Jones et al. 2017; Wear and Jones 2016). Due to all kinds of political and technological developments, the medical encounter

between physician and patient is now only a single aspect within the increasingly complex jungle of health care, in which it is becoming increasingly difficult to determine whether the distribution of care is fair, or whether people are being excluded. To analyze this, medical humanities must become much more critical. Instead of focusing only on improving the clinical encounter, on increasing empathy, the humanities should also be used to look at the broader (social, political, cultural, technological, and economic) context of health and illness (Crawford et al. 2015; Viney et al. 2015). Health Humanities is the interdisciplinary field that examines health care in its broad context from this critical stance. It is an academic discipline that addresses everyone active within the health care system, including informal caretakers, activists, and patients' representatives. In this entry, I will elaborate on what role phenomenology can play within Health Humanities.

Back to the Things Themselves: The Meaning of Health and Illness

At the previous turn of the century, Edmund Husserl wrote in his *Logical Investigations* that phenomenology must return to things themselves. As we all know, this statement by no means implies the resuscitation of a Platonic search for essences behind phenomena. The things themselves are found only within the phenomena. The return that Husserl proposes is a movement in thinking. In a sense, we could refer to this movement in thinking as "critical reflection." For, after all, the return to the things themselves is about detaching oneself from all kinds of preconceptions. If we want to interpret the meaning of things as they appear to us, we should not simply be led by what positive sciences say about them, nor should we be led by our own – often naively realistic – natural attitude. After all, phenomenology is not interested in the, more or less fixed, meanings of things. Instead, it sets out to investigate how meaning (or sense) emerges in the interaction between self, other, and world. Without going further into the details of, and discussions

surrounding, Husserl's proposed line of thinking, we could say that Health Humanities can also be understood as a way of thinking about illness and health that suspends commonly held and science-dictated views.

In contemporary Western industrialized societies, conceptions of health and illness are largely dictated by the medical and behavioral sciences. However, health and illness are particularly complex phenomena. Moreover, both the everyday and scientific meanings given to them are constantly changing over time. This is made painfully clear by Roy Porter at the beginning of his masterly historical analysis of medicine *The Greatest Benefit to Mankind: A Medical History of Humanity* (1997): "These are strange times, when we are healthier than ever but more anxious about our health" (p. 3). What the history of medicine teaches us is that new solutions or new inventions in healthcare nearly always come together with new views on health and, subsequently, with newly identified health problems. More than 25 years after the publication of Porter's major work, we can acknowledge that this paradoxical situation has only been reinforced. While life expectancy is steadily increasing (because of all kinds of new technologies and treatments), the prevalence of chronic, disabling health problems – such as COPD, heart and vascular diseases, Diabetes Mellitus II, and arthritis – is enormously increasing in the aging population (which call for yet new treatments and technologies). While preventive medicine becomes increasingly successful, people are much earlier diagnosed as "being at risk" – a precursor of "being sick" – which leads to growing health consumption. While public health education is rocketing and more and more people constantly monitor their bodies – with or without monitoring devices – health-related worries grow, which may again lead to an increase in care consumption.

What all these paradoxes show is that the meaning of health fluctuates on the waves of technology developments and other transformations in science, culture, and society. To understand health as a phenomenon that is always related to a societal, cultural, scientific, and technological context, we need a humanities

perspective on health, and that is what Health Humanities can offer. A humanities perspective on health can complement health and medical sciences since it allows us to consider healthcare and medicine not only as a solution for humans but also as a typical *human practice*. Health care systems, as well as conceptions of health and illness, are embedded in all kinds of *human activities*: producing knowledge, inventing, discovering, communicating, caring for one another, living together, setting rules, making profit, venerating gods and idols, narrating stories, and making pictures. It is the various disciplines of the humanities that are specialized in analyzing these various human activities, practices, and products. Methodologies used in the various humanities disciplines – and also often in a cross-disciplinary way – include language analysis, text and data analysis, cultural analysis, hermeneutics, ethnography, narrative analysis, normative and ethical analysis, conceptual analysis, epistemological analysis, and historical analysis. What all these methodologies have in common, when they are geared toward the analysis of health care, is that they seek to explore the meaning of health and well-being in a particular context. Health Humanities can therefore be defined as an interdisciplinary approach to analyze and interpret the meaning of health, illness, and healthcare while focusing on human practices and its products. As I will explain further below, phenomenology offers exquisite methods (both theoretical and empirical) to analyze and describe specific dimensions of the meaning of health, well-being, and illness. Very generally, we could say that phenomenology fits so well within Health Humanities because it investigates the emergence of meaning (or sense), first and foremost seeking to distance itself as much as possible from existing scientific and everyday judgments and prejudices.

The phenomenological appeal to return to the things themselves, to not simply assume a given reality, aligns well with other critical (mostly social constructivist-oriented) approaches within the Health Humanities. From critical race, gender, fat, queer, and crip perspectives, it is emphasized that health problems are not simply reducible to problems of individuals, problems in individual

bodies, but are always embedded in power relations, in cultural, economic, and political contexts. And Science and Technology Studies (STS) show how the production of scientific knowledge about diseases, health, and effective interventions and technologies is never a purely scientific matter but is also always embedded in cultural, economic, and political contexts. However, phenomenology also makes a distinctive contribution to the health humanities by offering an alternative to body-mind dualism, which is still very persistent within contemporary health care, and by providing a space for investigating illness experiences from a first-person perspective.

Back to the Things Themselves: Body and Lifeworld

As a critical sequel to Husserl's call for breaking the natural attitude to understand the constitution of meaning, Maurice Merleau-Ponty describes in his *Phenomenology of Perception* (1945) that meaning-making is a motor rather than a mental affair. Consciousness, he writes, is not an "I think" but an "I can" (p. 171). The subject for whom the world discloses, for whom meaning appears, is not disembodied, but rather embodied. Merleau-Ponty designates this subject by the terms *corps sujet*, *corps propre*, and *corps vivant*. So, where the body in modern times was always referred to as an object (with Descartes an extended thing, *res extensa*), Merleau-Ponty argues that the body can also be subject. And the typical thing about this embodied subject is that, unlike the body as object, it is experienced (*vivant*) as its own (*propre*) and from within itself. So, what we see here is that in the explanation of how meaning comes about, of how the world is disclosed, a new perspective on the body emerges. Or rather it can be said that here it becomes clear that, phenomenologically speaking, the body can have two different meanings. This was also already indicated by Husserl in his *Ideas II* where he refers to the difference between the body as *Körper* (objective body) and *Leib* (lived body) (Husserl 1952 [1912]; Slatman 2019). We can experience our own body as an object, a thing, something that

can be examined, that can be placed in space, to which physical characteristics can be attributed. This is also usually the way the body is viewed in health care, the body as an object as a biological, physiological, genetic thing. But in addition, the body can also be experienced as *Leib*, and that happens, for example, when you feel pain, when you are touched or when you touch something yourself, when you feel yourself moving or feel your own body position, or when you feel heat or cold. These sensations are localized, and as such, they do not constitute the body as a thing or object, but rather the experience of “here,” “now,” and “mine.” This *Leib* experience constitutes the embodied and as such experienced zero point from which the world opens up. It is from that zero point that our perceiving, acting, thinking, and willing departs. This phenomenological analysis that shows that the body can appear in different ways and thus have different meanings is extremely relevant for the way we – professionals, patients (and their relatives), informal caregivers, and the wider audience – consider illness and health.

Where previously disease was understood in terms of disbalance of the four bodily humors (yellow and black bile, blood, and mucus) which was closely related to climate and nutrition, in modern medicine, since the eighteenth century, disease is understood as a defect in an anatomical structure or a physiological function. Pathology thus became equivalent to an identifiable problem in the anatomical body. This is the idea of the body as an object, the body as an extended thing. Therefore, the phenomenologist Drew Leder (1992) argues that the body so central to medicine is the “Cartesian corpse.” This objectification of the body has only continued to grow in the twentieth and twenty-first centuries. One cannot ignore that this instrumental and objectifying view of the body has advanced medicine – just think of disciplines such as surgery and transplant medicine – and therefore it should not only be seen as something negative. Objectification of the body becomes a problem, however, when it comes at the expense of attention to the patient. And that is very often the case these days. When examining and treating their patients, doctors

generally rely more on objectively measurable parameters than on what their patients have to tell them. Several studies in the phenomenology of health and medicine show that if more attention is paid to the lived body, health professionals would have a much better understanding of how a health problem can change someone’s life (Leder 2016). If it is assumed that the body is the zero point from which the world can be disclosed, then it must be realized that physical conditions such as multiple sclerosis (Toombs 1995), lymphangioliomyomatosis (a rare lung disease) (Carel 2008), diabetes (Morris 2008), or the traces of breast cancer treatment (Slatman 2016; Slatman et al. 2016) can have a great impact on people’s being in the world, on how they can give meaning to their lives and world.

The idea of the embodied subject also constitutes an alternative to body-mind dualism. The “I can” indicates that there is no such thing as a thinking, immaterial agency that precedes bodily actions and perceptions. This means that we cannot distinguish and separate the mind or psyche from its embodiment. This view has important implications for what we commonly call mental health care. In contemporary medicine, a health problem such as depression is commonly understood as either a brain disease or a disease of the psyche. From a phenomenological perspective, on the other hand, depression can also be understood as a phenomenon through which corporealization occurs, i.e., that one’s own body is increasingly experienced as a thing, preventing one from resonating with others (Fuchs 2005, 2013; Svenaeus 2013). Depression can therefore be characterized as a fundamental loss of having possibilities (Ratcliffe 2015), or as a reduction or even the elimination of one’s “I can” (Aho 2013; Slatman and van de Ven 2021). This more embodied view of depression, as well as of other mental health complaints, also provides openings for alternative interventions. For example, embodied therapies such as dance or jogging can help to make bodies stiffened by anxiety or depression feel and resonate again (Fuchs and Koch 2014). In general, it can be said that phenomenological studies of both somatic and mental problems can help to bring patients’ experiences more to the forefront and to

interpret these problems within a broader context. A phenomenological approach can indeed contribute to so-called patient-centered care.

Phenomenology in Empirical Research

Even though phenomenology, as initiated by Husserl and further developed by thinkers such as Merleau-Ponty, is first and foremost a philosophical and theoretical discipline that calls for a reversal of thought, a suspension of preconceptions, and claims about reality, it is enjoying increasing prominence outside the philosophical realm, particularly within the field of qualitative research. As opposed to quantitative research (which is based on numbers and statistics), laboratory, and experimental research, qualitative research is often described as research in the real world. Scientific experiments and quantitative measurements always presuppose an organized and controlled research environment. Qualitative research, on the other hand, which has its roots in anthropology and ethnography, seeks to intervene as little as possible in what it investigates. Instead of trying to measure people's experiences in questionnaires with quantitative outcomes, the qualitative researcher will collect "thicker" data, for example, by conducting in-depth interviews, by (participatory) observations, by having respondents take pictures or draw pictures, by having them write stories or diaries, etc. Depending on the research question, the qualitative researcher can choose from different approaches to collect and analyze these data. Phenomenology is seen as a specific approach, alongside grounded theory, narrative analysis, case study, ethnography, for example (Creswell and Poth 1997). Especially through the work of Max van Manen (1990), of Jonathan Smith et al. (2009), and of Karin Dahlberg and colleagues (2008), the phenomenological approach is widely used in qualitative studies on health and illness issues, particularly so in nursing studies.

Even though different authors place different emphases on what empirical phenomenological research should look like, what they all have in common is the central idea that the focus in this

type of study should be on lived experience. These are often studies in which the perspective of patients (or of people with a particular need for help) is further explored. By conducting in-depth interviews, but it can also be done by having them keep a diary or by (participatory) observations of certain practices, it is then examined how people make sense of certain health problems, or certain treatments. While focusing on people's experiences, empirical phenomenology is not about registering people's feelings, whether people feel good or not, whether they liked the treatment or not. Specifically, the empirical phenomenological approach aims at relating lived experiences to the constitution of meaning or the appearance of phenomena.

Because many researchers who employ the phenomenological method in qualitative research are not at all schooled in philosophy and thus not in phenomenology, the question is quite often raised as to whether qualitative research that is self-referentially phenomenological is really phenomenological. For example, Max van Manen (2017) wrote an article in which he argues that much phenomenological qualitative research is not worthy of the name "phenomenological" because it does not draw on primary phenomenological literature and researchers do not explicitly engage with the meaning of the phenomenological reduction. Dan Zahavi (2020) disputes this position and suggests that such a rigorous approach to phenomenology within nursing studies is not productive at all. The relevance of phenomenology to nursing studies is that it can contribute to understanding the impact of illness or treatment on the patient. Zahavi (2020) therefore claims that health professionals or health researchers who like to draw on phenomenology should conceive of it rather as an "open-minded attitude" and a theoretical framework instead of a rigorous method. In the end, when phenomenology is applied in a nonphilosophical way, as is the case in health studies, then the phenomenological reduction can be ignored (Zahavi 2021).

Whereas van Manen insists on a stricter conception of phenomenology within empirical research, Zahavi is more pragmatic. I think these two positions could be brought a little closer

together. It is true, as Zahavi writes, that for an empirical study, which ultimately aims to understand and improve healthcare practice, it is not necessary to pay attention to the phenomenological reduction. But it is also true, as van Manen points out, that not every study that revolves around patients' experiences should be called phenomenological. At the very least, one might expect an empirical phenomenological study to start from a theoretical framework based on some core phenomenological concepts. The collected data must then be analyzed through the lens of these concepts. For example, in my empirical research, I often use the phenomenological distinction between the objective body and the lived body as a theoretical frame. For me, this theoretical frame is only a starting point. As I see it, empirical phenomenological research can also be used to enrich existing theories and concepts. For instance, in our phenomenological study on the impact of breast surgery in breast cancer, my colleagues and I have shown that the major response to breast surgery consists of self-objectification of the body – which implies that one's own body appears as an object – yet, at the same time, we were able to identify different meanings of “body as object.” Whereas the “body as object” that appears when women inspect their amputated bodies in the mirror has the meaning of “distancing,” the “body as object” that appears when women are engaged in a farewell ritual prior to amputation has rather the meaning of “nearing” (Slatman et al. 2016). Our empirical analysis thus provides an enrichment of phenomenological theory regarding the distinction between body as object and body as subject: It shows that the idea of “body as object” can be refined. From a practical perspective, our distinction between “distancing” and “nearing” can provide patients, nurses, and caregivers with tools to switch between different situations.

Conclusion

Health Humanities is an interdisciplinary approach to critically explore how health care is organized while considering the cultural, societal,

technological, political, and economic context in which human beings need and provide care. Phenomenology is a good fit with Health Humanities for several reasons. First, the phenomenological call to return to the things themselves, to bracket preconceptions and prejudices, and to explore how meaning (or sense) emerges in the interaction between self, other, and world, ties directly into the critical commitment of Health Humanities. Indeed, unlike the biomedical and behavioral sciences, Health Humanities does not assume that illness and health are positively given. The difference between health and illness is always based on human-made norms, and these norms are embedded in scientific, cultural, political, and economic contexts. To make sense of the meaning of health and illness, we must bracket the positivist perspective of the sciences and make explicit their presuppositions. Second, phenomenology offers a conception of the body and of embodiment that can be used productively to analyze the impact of various conditions and different therapeutic interventions. When you are dealing with a health problem, it is not just about a problem somehow located in your body (as an object). It equally affects your embodied subjectivity, and as such it affects your being in the world, your (existential) possibilities, and your “I can.” This phenomenological understanding of embodied subjectivity also helps to narrow the gap between somatic and mental health care. Indeed, phenomenology teaches us that a mental health problem such as depression should not simply be regarded as a psychological disorder (or a brain disease), but primordial as a loss of possibilities, a loss of “I can,” and a diminishment of embodied resonance. Third, when the phenomenological approach is used in empirical studies, it helps to highlight the lived experiences of patients (but also of relatives or professionals, and caregivers). In today's scientifically and technologically driven health care environment, phenomenology can make the voices of the people involved (patients, patients' representatives, professionals, activists, and informal caregivers) more heard. Because phenomenology can be used well in qualitative empirical research (even by researchers who are not trained in phenomenology or philosophy), it is of great

value for critical research within health care that can be conducted by different types of researchers, including activist and participatory researchers. Because the goal of Health Humanities is to cover the entire field of health care, including all the different stakeholders involved, and not just the doctor-patient relationship (as in Medical Humanities), phenomenologically inspired research fits seamlessly here.

Cross-References

- ▶ [Applied Phenomenology](#)
- ▶ [Attunement](#)
- ▶ [Care; Life World; Being in the World](#)
- ▶ [Dance](#)
- ▶ [Disability](#)
- ▶ [Edmund Husserl](#)
- ▶ [Embodiment](#)
- ▶ [Epoche; Reduction](#)
- ▶ [Experience; Lived Experience](#)
- ▶ [Ideas II](#)
- ▶ [Illness and Health](#)
- ▶ [Intentionality; Motricity](#)
- ▶ [Logical Investigations](#)
- ▶ [Maurice Merleau-Ponty](#)
- ▶ [Medical Humanities](#)
- ▶ [Medicine](#)
- ▶ [Natural Attitude](#)
- ▶ [Nursing](#)
- ▶ [Pain](#)
- ▶ [Phenomenology of Perception](#)
- ▶ [White Gaze; Race](#)

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