

Concepts of Health and Disease: Comments on Chapter 5 of Engelhardt's *The Foundations of Bioethics, 2nd Edition*

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Tris Engelhardt's *The Foundations of Bioethics* stands out in its field for the amount of sustained attention it pays to the *epistemological* foundations of ethics. Among those working in the field of bioethics, no one has devoted more attention to those foundations, and in particular to the matrix of concepts associated with medical classification, diagnosis, explanation and treatment. This is the principal focus of chapter five of *Foundations*, and will be the principal of focus of these comments.

1. Examples in Epistemology

As Professor Engelhardt tells us in the first endnote to his discussion of 'The Language of Medicalization', he is speaking Kantian, though with an Hegelian accent. He assures us that:

...Kant's arguments are essentially correct (at least when given an Hegelian accent): we know reality only through our concepts. We never know reality uninterpreted by our understandings.¹

And thus, the first sentence of the chapter announces that "Medicine medicalizes reality" a remark followed by claims that it "creates a world" and "conditions reality for us."² Certain of his examples suggest a relatively innocuous gloss on these assertions - it is true that once a felt pain or discomfort become diagnostic of a disease such as hepatitis or diabetes, that discomfort acquires new significance, and becomes a signal to sufferers to change their behavior, and a signal to others to alter their expectations of sufferers. It may also incline us as patients to allow certain people - health care professionals - to do things to us that would otherwise be considered criminal.

But the examples that make up the bulk of the first few pages of the discussion, and which continue to be central throughout, carry a less innocuous message. The message is this: What medical practitioners have been, and are, willing to consider sickness or disease, is strongly influenced by historically and culturally relative values. And at the very least, studying medical texts and case descriptions from the past teaches us that the way in which diseases are diagnosed, classified, explained and treated continuously changes over time, and changes more in respect to changes in our values than to changes in our empirical understanding.

What lessons does Professor Engelhardt expect us to draw from these historical and cross-cultural considerations? Some lessons, clearly, are of a practical variety. "Medicine's theories lead to actual interventions" he reminds us: "How one fashions such [medical] classifications will have implications for morbidity, mortality, and financial

costs."³ And given that that is the case, philosophical reflection on the nature of these practices is important. There is, then, great practical significance to the fact that health care professionals, no less than their patients, are capable of letting their "values and expectations" influence their theories and classifications. And there is no question that they are *capable* of doing so, so that this chapter serves as a valuable reminder of the nefarious ways in which the label of 'sick' and 'diseased' can be applied, sometimes with the official sanction of medical and/or political authority, both as a means of stigmatizing, ostracizing, or even coercing, individuals - or alternately, as a means of excusing individuals from personal responsibility for the consequences of their behavior.

Such examples *cannot*, however, carry the *epistemological* burden Engelhardt imposes on them when he uses them to support claims that "[w]e see the world through our social, scientific and value expectations" or "[a]ll knowledge is historically and culturally conditioned..."⁴ Such claims, backed up with references to Thomas Kuhn and Ludwig Fleck, need the additional support of philosophical presuppositions about the nature of reality, of perception, and of the relationship between perception and concept formation. There are a variety of empiricist, realist, and naturalist epistemological positions staked out on these questions, and *The Foundations of Bioethics* provides the reader with little in the way of argument that its idealist and constructivist position is to be preferred.

Certainly, examples of historical figures "importing their values or theoretical expectations"⁵ into their investigations are of no epistemological significance. In the first place, the examples will have no value unless we can know them as they are. But if we can know them as they are, why assume less about practitioners of biology and medicine? In the second place, such historical and cross-cultural examples at best support claims about how people sometimes actually behave; they do *not* support epistemological claims that such behavior is inevitable given the nature of cognition. And finally, such examples nearly always backfire on anyone trying to support 'constructivist' epistemological conclusions with them. As an example, consider Gregor Mendel's inquiries in plant hybridization. He clearly designed his experiments on pea plants with theoretical expectations (i.e. with a hypothesis!), and they obliged. Unfortunately, when he went on, with the same expectations (in fact probably held, on the basis of his earlier experiments, with *greater* conviction) to experiment with the genus *Hieracium*, reality refused to cooperate. In the words of Robert Olby:

Mendel failed to find any agreement with *Pisum* [the genus of his peas] although he hybridized them [*Hieracium*] for five years (1866-1871). Indeed, he experienced great difficulties in producing any hybrids at all, and the majority he raised bred true much to his surprise.⁶

His theoretical expectations simply could not create a world in which he could confirm his *Pisum* results in *Hieracium*.

Apart from these concerns, to adopt such an epistemological stance threatens the very value of being reminded of the dangers of mis-diagnosis and mis-classification: if medical practitioners are *incapable* of objectivity in their research, diagnostic, or explanatory

activities, and patients at any rate would not know it if they were, there is not much point in worrying about it.

The epistemological framework of Engelhardt's constructivist conclusions consists in a false contrast between a realism couched in Platonic terms and his preferred Kantianism, flavored with overtones of Fleck and Kuhn. The realist is characterized as one who assumes some sort of direct, god-like grasp of the essences of things-in-themselves, a grasp that somehow bypasses sense perception and concept formation. Given the implausibility of *that* epistemological stance, and given the alternatives we are offered, the reader will likely find Engelhardt's use of examples seductive.

But there are more reasonable realist alternatives to the idealism and constructivism that Engelhardt prefers. Human beings, like other chordates, acquire information about the physical world by means of perceptual systems evolved for just that purpose. At some point our central nervous system added to its information detection and processing abilities the ability to form concepts for objects sufficiently similar to each other and sufficiently different from others, and to link those concepts propositionally. This ability can be exercised well or badly.⁷ Scientific inquiry, done well, is the result of many hundreds of years of learning how it can be done badly, and how to avoid doing so. It has been amazingly successful. The more that medical knowledge emulates and builds on that success, the less likely is it to tolerate inappropriate intrusions into the processes of disease classification, diagnosis, and treatment of which Engelhardt vividly reminds us.⁸

2. Health, Disease and Value

Nevertheless, I am sensitive to the examples, and to the fact that medicine raises especially thorny problems of this kind. For not only do many 'extra-scientific' values play a role in the practice of diagnostic inquiry, classification, and treatment - the very act of deciding that a physical condition *deserves* the label 'disease' is an act of evaluation. Add to that the ways in which concerns about health and disease arouse powerful feelings of hope, fear, loss of power, and anger, and you have a nexus of human interactions where objectivity can be the first casualty. This is a central theme of chapter five of *The Foundations of Bioethics*, and it is on this theme I will now focus. The focus will, in fact, be restricted to the concepts of 'health' and 'disease', while recognizing that these terms are, in their actual use, part of a web of overlapping notions like sickness, illness, syndrome, lesion, or trauma.

It will be useful to begin my analysis of Professor Engelhardt's account of these concepts by borrowing a distinction from the biological sciences - the distinction between *Taxonomic Categories* and *Taxa*. Roughly, *taxonomic categories* are concepts that have as their units the various *levels of classification* to which groups of organisms may belong; *taxa* are concepts that have as their units those groups of organisms themselves. Taxa may be organized into a *hierarchy of generality*, e.g. the types of Hepatitis can be grouped together into the taxon 'Hepatitis', which in turn can be grouped into the category of 'Liver Infections'. Categories are, however, on another *level of abstraction*. Philosophically, categorical problems center on the question 'What are the features in virtue of which we say that a group of organisms is a species (as opposed to a deme or a genus)?'. Taxonomic

problems center on such questions as, 'What are the features in virtue of which we say that an organism belongs to the species *Panthera leo*?'.

The 'disease concept' problem is a *categorical* problem: it centers on the question 'In virtue of what are various organic conditions⁹ properly thought of as diseases?', rather than on questions such as whether the presence of a certain virus and/or associated pathology and symptoms is properly classified as a new form of Hepatitis, or a mere variant of a known form.

But it is a special sort of categorical problem, because there has been a persistent debate over whether these categories are 'descriptive' and 'empirical' in nature, or rather 'normative' and 'evaluative'.

Chapter five of *The Foundations of Bioethics* argues effectively against a variety of attempts to do away with the normative component of these concepts. A convincing case is made that identifying a biological condition as a *disease* carries with it a negative evaluation of that condition - by comparison to some standard condition identified as healthy. Convincing reasons are also given for rejecting three distinct approaches to understanding that normative component: [i] rooting standards of health in divine purpose¹⁰ [ii] treating such standards as merely statistical, and [iii] taking Darwinian fitness, the disposition of certain members of a population to leave more offspring than others, as the measure of health.

But while arguing against this third position, Professor Engelhardt erroneously concludes that to adopt a neo-Darwinian perspective is simultaneously to reject the idea that the evaluative component in medical concepts such as health and disease can be grounded in the biological sciences. I will return to this issue momentarily. Here I simply want to point out that a quick peek at Daniel Dennett's *Darwin's Dangerous Idea*, or the Wainwright et al. gem, *Mechanical Design in Organisms*, or the last chapter of George C. Williams' *Adaptation and Natural Selection* suggests otherwise.¹¹ All discuss organic design and make judgments of advantageous and disadvantageous design. By 'well-designed' these thoroughly neo-Darwinian authors do not mean, at least not immediately and directly, reproductively successful - they mean *successful functioning relative to specific environments*. Reproductive success, *ceteris paribus*, is - at any rate, in animals that do not consciously control their reproductive behavior - a *predictable* result of proper functioning in a specified environment. But for a variety of reasons - among them disease - the prediction can fail. One can investigate, independently of reproductive success, the range of biological adaptedness found within a population.¹²

What of Engelhardt's own, positive account of the Disease Category, then? First, he wants to have his readers distinguish four different dimensions to the concept, corresponding to what he believes are four 'interests' at play in 'medical reality': the Evaluative, Descriptive, Explanatory, and Social Labeling dimensions. And, while he takes these dimensions up individually in his discussion, he consistently adheres to his initial claim that within medicine there is a "complex interplay"¹³ among all these interests in medical practice. I will return to this point later.

As a sociological claim about medical practice, this multi-dimensional analysis is instructive. Exactly a year ago, I was two weeks post-diagnosis as a patient suffering from *Hepatitis A*. As a *classification*, this label summarizes a great deal of symptomatic, anatomical and pathophysiological information. In addition, it provides an understanding of how certain parts of that information package are *explanatory* of others. Furthermore, as a *diagnostic* category it sends the clear evaluative message that what is happening to me involves not *mere* change, such as the increase in my heart rate when my running pace accelerates, but *life-threatening* change, possibly entailing suffering, pain, disability, disfigurement, and compromise or loss of function. And finally, I can well attest to the changes in people's expectations of me following diagnosis, while more than once I learned painfully to change my own expectations of myself. I will focus principally on Engelhardt's account of the evaluative and explanatory dimensions of the Disease category.

I mentioned earlier that Professor Engelhardt appears to reject the idea that "there are value ingredients in natural processes that can be disclosed as guidelines for appreciating what should count as biological norms..."¹⁴. Yet, as I suggested above, his arguments are not powerful enough to reject that idea outright. It is true, as he claims, that judgments about individual well-adaptedness must be relativized to specific environments and goals¹⁵; but that is not sufficient to rule out biological guidelines for formulating such norms. Nor does it force us to the conclusion he reaches on the next page: that "one will not be able to turn to biological conditions or the outcomes of evolution in order to discover what ought or ought not to be seen as a medical problem."¹⁶

And when we finally reach his own *positive* account of the evaluative component in medical concept formation, something *very like* biological norms play a prominent role. Indeed, one of the attractive features of his account is the recognition that since 'disease' is a *negative* evaluative concept, the decision to consider a biological condition a 'disease' depends on there being some *standard* condition which the disease organism is failing to achieve - such judgments, that is, require a *standard of evaluation*. To quote *Foundations*, the application of such concepts "reflect ideals of freedom from pain, of human ability and of bodily form and movement" or "ideals of anatomical, physiological, and psychological achievement and realization."¹⁷ Problems stand out as medical, we are told, because they are disvalued, seen as pathological. "Health care," we are assured, "is directed to the realization of a wide range of *nonmoral values* regarding bodily and mental function, form, and freedom from distress."¹⁸

This latter claim is, admittedly, ambiguous. It might mean that the norms in virtue of which a bodily condition is evaluated as healthy or diseased are not moral norms, but involve ideals grounded in anatomy, physiology, bodily and mental function. If so, they would seem to be *biological*.

On the other hand, the word 'ideal', as used here, may well be intended to suggest the *importation* of certain standards into medicine, historically and/or culturally relative standards of a quasi-aesthetic kind, as a number of Engelhardt's remarks suggest. After all, an anatomical ideal need not be one based on the science of anatomy.

But if we are attempting to account for the evaluative character of the concept of disease, biological standards for such judgments are surely available, and preferable. Clinical research, for example, has determined a standard of proper, life-supporting, liver function against which the Hepatitis sufferer's liver is measured, and found wanting. In such cases clinical research has developed a variety of ways of *measuring the range of function that is thus healthy*. Such norms are decidedly *not* statistical - in a culture populated by people who are more or less alcoholic, the *statistical* norm for liver function would be far from the parameters defining healthy liver function.¹⁹ Nor, clearly, are these norms related to reproductive success. But nor are they merely aesthetic preferences. They appear to be biomedically grounded standards of proper liver function.²⁰

I am not sure why Engelhardt does not take this tack, but I have my suspicions. In Engelhardt's view, these ideals cannot *rest on* a biological basis; they must rather be *imposed on*, or if you prefer, *structure* or *condition*, what the biomedical researcher, the clinician, and the rest of us, experience. As he puts it:

One draws a line between innocent physiological findings and pathological findings because of particular human values in a particular circumstance, not because of the discovery of an essential difference that exists outside of particular expectations.²¹

Well - if those 'particular human values' and 'particular expectations' include the value of life, I suppose I can agree! In fact, this quote embodies the false epistemological dichotomy I mentioned previously. One need not be a Platonic essentialist to argue that determinations of pathology can be objective. Put simply: Apart from one's values and expectations, it is a matter of fact that if one's liver, heart or pancreas fails to function, and nothing is done about it, one dies; while if they are functioning within a certain measurable range, one will *not*, at least not on account of *them*. Of course, along any continuum, the line between minimally satisfactory function and sufficient loss of function to become harmful will be difficult to establish - but not for the reasons the above quote suggests.

The last comment quoted from *Foundations* comes at the conclusion of an argument that medical conditions fall on a continuum between those which are "likely to be disvalued in whatever culture one lives, and in terms of whatever goals are possessed by individuals or societies" and others which may be seen as diseases only under very narrow and special circumstances, or in certain cultures.²² When, however, one looks at the examples used to denote extremes of the continuum - myocardial infarction is at one end, the inability to roll one's tongue is at the other - another continuum, no less evaluative, is also clearly present. At one extreme there is a life-threatening organ failure, at the other a trivial, genetically based trait of no significance to health. Again, it is sociologically true, and important to stress, that things can be labeled diseases for reasons that having nothing to do with this latter continuum, and everything to do with cultural traditions. That is a good reason to seek a more objective ground for the label.

3. Disease as an Explanatory Concept

In the next section of his discussion, to which I am about to turn, Engelhardt emphatically insists that "[d]escribing reality is always infected with both evaluative and explanatory expectations."²³ I find the use of the metaphor of "infection" puzzling here - does it make sense to say an activity is *always* infected? Does that imply there is no such thing as an epistemic state of health? If so, how is it that "medicine provides excellent examples of *missteps* in the psychology of discovery?"²⁴ What should count as a misstep, if we can not determine where our steps should go?

Approximately one year ago, I attempted to impose the explanatory expectation that I was suffering from a bad flu on an evolving cluster of symptoms, symptoms I experienced both subjectively as the sufferer and objectively as an observer. And at first, like Mendel, I got away with it, for at first the symptoms were quite generic - nausea and intermittent periods of chills and fever. I noted, as a mere curiosity, the facts that my usual enjoyment of a glass of wine with dinner had turned to loathing at the mere thought, and that there was a common feature - fat - in the foods that made me nauseous. But as time went on, I found I simply could not fit into my theoretical expectations such things as the overnight conversion, despite drinking huge quantities of water, of my urine to a dark orange hue; nor the yellowing of my skin and its incessant itching; nor the absence of symptoms I usually experience with flu. Upon seeing me, it took my very sharp personal physician 30 seconds to determine I had Hepatitis. Given that, he and I (after he explained the differences to me!) wished for it to be Hepatitis A. Thankfully, my bloodwork strongly suggested it was - but my *wishing* for that result had little to do with *getting* it, and I dare say the lab techs doing the blood work-up could not have cared less.

Neither my theoretical expectations, nor my firmly established network of evaluative concepts, could make it the case that I had a flu - as much as I would have preferred it to the truth.

Now it is entirely *possible*, I would maintain, to describe my biological condition at that time in a value neutral way. I could, that is, describe the entire process, as far as it is now understood, without ever describing the situation in the language of viral *invasion* or *threat to my life*. But to categorize the process as a *disease* is precisely to stress and underline that the condition so described is not merely disvalued by me, though it certainly is, but is a threat to my life - whereby I do not necessarily mean that it is likely to kill me, but *do* mean that it threatens to compromise a number of my important biological functions, and thereby my actions. It is simply a category mistake to think that because such a judgment is an evaluation it is therefore non-objective.

In discussing the *explanatory* dimensions of medical language, Engelhardt highlights the historical changes that our clinical understanding of various diseases have gone through. We are reminded that the 17th and 18th century understanding of tuberculosis, typhus or syphilis was entirely different from ours. And, it is predicted, "we are likely to experience similar changes in classification when we develop *better* etiological accounts for that cluster of diseases called cancer."²⁵

These two claims are interesting on two counts. First, the fact that the example must change shows an implicit recognition on Engelhardt's part that our current understanding of TB is not only *different* from that in the 18th century - it is *better*. And this is underscored by the reason we are given for the prediction that our current conceptualization of 'cancer' will change. The classificatory change will follow not merely *different* etiological accounts, we are told, but *better* ones. This is surely right; but is it consistent with the historical and cultural relativism that is a constant theme of this chapter?

A similar story is recounted about the move of Jaundice from the category of a disease into the category of a symptom of (among other things) Hepatitis. This, we are told, "required a major recasting of medical reality."²⁶ Again, there is an innocuous way to take this claim. The discovery of acute infectious Hepatitis *did* require recasting of the classification of a certain range of diseases - indeed, since such distinctions as that between Hepatitis B and C are recent, we can say the recasting is still taking place.²⁷ What had once been thought of as evidence of a disease characterized by an overabundance of yellow bile, and thus causing all those symptoms I found so unpleasant, is now understood as another symptom, one underlying cause of which is a viral infection of the liver. This reorganization of our prior explanatory and classificatory expectations is a consequence of deeper, and better, biomedical understanding.

This brings me to my last concern about the strongly 'constructivist' account of medical concept formation that permeates this chapter. Chapter 5 of *Foundations* concludes with a section entitled 'The democratization of medical reality'. Throughout this chapter there is an overriding concern with the ways in which the language of medicine can both be infused with values and attitudes from the wider culture in which it operates, and, can shape the attitudes of people by means of its decisions about what should be considered a 'disease'. These are legitimate concerns. And advocating a more active, skeptical, and inquiring attitude, on the part of both users and practitioners of health care, toward medical practices such as diagnosis and treatment triage strikes me as good advice. But, despite the assurance that "[t]his [call for democratization of medical reality] is not a plea that staging systems for cancer be decided by referendum," talk of a "democratization of medical reality"²⁸ strongly suggests that the clinical and biological basis of medicine, no less than decisions about which cancer treatment fits best with one's personal values, is a matter for social negotiation. Democracies can be as coercive as any social order there is, and thus I have trouble integrating this suggesting with the feature of *The Foundations of Bioethics* I most admire - its strong and principled insistence on medical decision-making by cooperation and agreement, rather than by coercion and force.

Endnotes

1. Tristram Engelhardt, Jr., *The Foundations of Bioethics*, 2nd edition (New York: Oxford University Press, 1996), pp.227-28. Cited here after as *Foundations*.
2. Engelhardt, *Foundations*, p.189.
3. Engelhardt, *Foundations*, pp.194-5.
4. Engelhardt, *Foundations*, p.190.
5. Engelhardt, *Foundations*, p.208.
6. Quoted from my colleague Robert Olby's *Origins of Mendelism* 2nd Edition, (Chicago: University of Chicago Press, 1985), p.103. For a thorough critique of Kuhn's use of examples for similar purposes, cf. Stephen Toulmin, *Human Understanding*, Princeton: Princeton University Press, 1972, pp.96-130; and Philip Kitcher, *The Advancement of Science: Science without Legend, Objectivity without Illusions*, Oxford: Oxford University Press, 1993, ch.5.
7. For a defense of a realism of this sort, see David Kelley, *The Evidence of the Senses: A Realist Theory of Perception* (Baton Rouge: Louisiana State University Press, 1985).
8. Let me make it very clear that precisely because people may be inclined to classify diseases according to criteria that have little or nothing to do with biology and pathology, it is especially important that the case be made that these are the sources of appropriate criteria. For example, issues of the cost of a diagnosis or a treatment should have nothing to do with selecting criteria for the proper classification or diagnosis of disease.
9. I'm using 'condition' not to achieve vagueness but because certain diseases are more naturally considered states, others processes; and because disease classification is sometimes based more on probabilistic associations among symptoms, at other times more on an underlying causal basis, depending on the state of our knowledge. An organic 'condition' can either be a state or a process, and can either be a symptom of a presumptive cause or a cause of one or more symptoms.
10. As an aside, however, I take issue with his treatment of Aristotle as an ingredient in the Christian Creationist view of the natural world as a designed artifact. Aristotle's biological teleology is *antagonistic* to that dependent upon an intelligent creator, such as he found in Plato's *Timaeus* - it rests on the idea that well-adapted organisms reproduce by means of a generative capacity which directs biological development toward other, similarly well-adapted, organisms. Aristotelian biology certainly lacks any sense of the importance of constantly and gradually changing environments and thus of the phylogenetic history of the animals he studied, including their evolutionary origins. But it is the antithesis of a creationist teleology. For a full defense of these claims see James G. Lennox, 'Teleology', in Evelyn Fox Keller and Elisabeth A. Lloyd, eds., *Keywords in Evolutionary Biology*, (Cambridge MA: Harvard University Press, 1992), pp.324-333.

11. Daniel Dennett, *Darwin's Dangerous Idea: Evolution and the Meanings of Life*, (New York: Simon and Schuster, 1995); S.A. Wainwright, W.D. Biggs, J.D. Currey, J.M. Gosline, *Mechanical Design in Organisms*, (Princeton: Princeton University Press, 1976); George C. Williams, *Adaptation and Natural Selection: A Critique of Some Current Evolutionary Thought*, (Princeton: Princeton University Press, 1966).

12. A vivid way of recognizing this point is to reflect on studies, such as Rosemary and Peter Grant's study of the Galapagos Finches, in which environmental conditions put such stress on a population that reproduction ceases. This in no way impeded the Grants from distinguishing those better adapted to the stressful conditions from those worse adapted, and doing so in precisely those terms. (cf. *Evolutionary Dynamics of a Natural Population: The Large Cactus Finch of the Galápagos*, (Chicago: University of Chicago Press, 1989); or the popular account of their work in Jonathan Weiner, *The Beak of the Finch: A Story of Evolution in Our Time*, (New York: Vintage Books, 1995).

13. Engelhardt, *Foundations*, p.195.

14. Engelhardt, *Foundations*, p.198.

15. Engelhardt, *Foundations*, p.201.

16. Engelhardt, *Foundations*, p.202.

17. Engelhardt, *Foundations*, p.206.

18. Engelhardt, *Foundations*, p.207.

19. Note here that I am talking about *alcoholism*, not moderate consumption of alcohol.

20. For a defense of this concept of health, see James G. Lennox, 'Health as an Objective Value', *Journal of Medicine and Philosophy*, 20:5 (October 1995), pp.499-511, and the helpful commentary of Robert M. Sade 'A Theory of Health and Disease: The Objectivist-Subjectivist Dichotomy', pp.513-525.

21. Engelhardt, *Foundations*, p.205.

22. Engelhardt, *Foundations*, p.204.

23. Engelhardt, *Foundations*, p.208.

24. Ibid.

25. Engelhardt, *Foundations*, pp.210-211.

26. Engelhardt, *Foundations*, p.226.

27. A text I happened to have on my shelf from the early 1970s simply distinguishes acute from chronic Hepatitis.

28. Engelhardt, *Foundations*, pp.227-228.