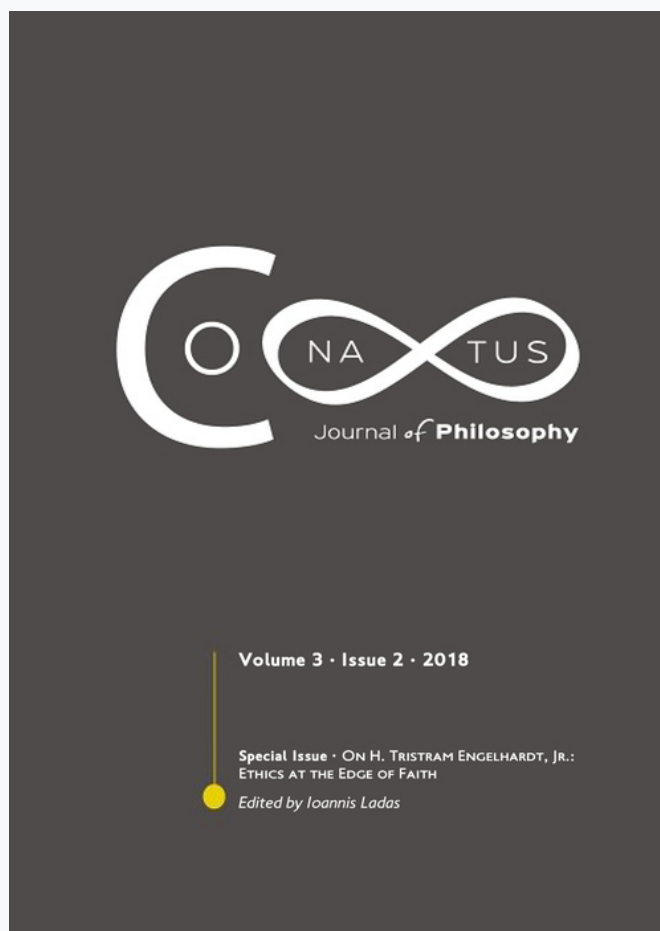


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### Epistemologies of Biomedical Ethics: A Tribute to Dr. Engelhardt

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# Epistemologies of Biomedical Ethics: A Tribute to Dr. Engelhardt

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## Abstract

*In this essay, and in his honor, I focus on two of physician-philosopher H. Tristram Engelhardt, Jr.'s many contributions, namely, his view that biomedical ethics (1) cannot offer a singular content-driven theoretical approach and (2) requires an appreciation of epistemologies of knowing in medicine. While these two positions remain controversial, because we all want definitive answers to our questions concerning what we ought to do in medicine and elsewhere, Dr. Engelhardt's view makes possible discussion and debate in medicine to include diverse, defensible ways of knowing. In the end, Dr. Engelhardt's approach in biomedical ethics is one of shared decisionmaking and negotiation. This is an important model if we take respect for patients seriously in the clinical setting.*

**Key-words:** *epistemology of medicine; biomedical ethics; H. Tristram Engelhardt, Jr.; concepts of disease*

## I. Introduction

In honor of physician-philosopher H. Tristram Engelhardt, Jr.'s passing in April 2018, I share a few words about his contributions. There is much to say: He has been one of the founders of the resurgent of philosophy of medicine in the United States. He is the inspiration behind the *Journal of Medicine and Philosophy* as well as the *Philosophy and Medicine* series. He has framed discussions in contemporary biomedical ethics since the 1970s, thought through difficult conceptual issues in Christian biomedical ethics, and formulated discussions in philosophy of medicine regarding how clinical concepts are understood and function as treatment warrants. His influence is significant and has guided my own scholarship and writings in philosophy of medicine these past thirty years. In this essay, and in honor of Dr. Engelhardt, I focus on one of his many contributions, namely, his view that biomedical ethics (1) cannot offer a singular content-driven theoretical approach and (2) requires an appreciation of epistemologies of knowing in medicine. While these views remain

controversial, because we all want definitive answers to our questions concerning what we ought to do, Dr. Engelhardt's views make possible discussion and debate in medicine to include a variety of ways of knowing. In the end, Dr. Engelhardt's approach in biomedical ethics is one of shared decisionmaking and negotiation. This is an important approach if we are to respect for patients seriously in the clinical setting.

In what follows, I review Dr. Engelhardt's approach in biomedical ethics, focusing on his permission principle. I show how his approach requires an appreciation of epistemologies of knowing in medicine. Throughout the discussion, I apply his thinking to the case of breast cancer to show the relevancy of Dr. Engelhardt's position in today's discussion about knowing and treating breast cancer. I end with reflecting upon Dr. Engelhardt's account of the dual dependence between biomedical ethics and epistemology of medicine.

## II. Dr. Engelhardt's Approach in Biomedical Ethics

Biomedical ethics (Gr. *bios*, life + Gr. *ēthikē*, ethical, or study of standards of conduct) is the study of the ethical or moral implications of biomedical discoveries and practices. It gained notoriety at the end of the twentieth century for its incisive analyses and critiques of practices in medicine.<sup>1</sup> The term "Bioethics" was coined by Dr. Van Rensselaer Potter, a research oncologist at the University of Wisconsin in the early 1970s.<sup>2</sup> Potter published an article entitled "Bioethics, The Science of Survival" (1970) and, in 1971, followed it with his book *Bioethics: Bridge to the Future*. In it, Potter defined "Bioethics" generally as "a new discipline that combines biological knowledge with a knowledge of human value systems."<sup>3</sup> Biomedical ethics has since become influential in western medicine, especially as many have become concerned about the role, power, and limits of medicine in their lives and as biomedical ethicists enter into mainstream medical school teaching and research to offer analyses and critiques of medical practices.<sup>4</sup>

According to Dr. Engelhardt, the success of biomedical ethics at the end of the twentieth century comes from a variety of sources. First, "there was a cultural hunger to locate medicine within larger cultural concerns."<sup>5</sup> In the late twentieth century, health care in every developed country was claiming a larger portion of the gross

<sup>1</sup> Albert Jonsen, *The Birth of Bioethics* (New York: Oxford University Press, 1998).

<sup>2</sup> *Ibid.*, 27.

<sup>3</sup> Van Rensselaer Potter, *Bioethics: Bridge to the Future* (New Jersey: Prentice-Hall 1971), 2.

<sup>4</sup> H. Tristram Engelhardt Jr., "Bioethics After Four Decades: Looking to the Future", Portugal Talk, March 16, 2012, accessed December 7, 2018, [www.apbioetica.org/fotos.gcal/1331984832discurso.pdf](http://www.apbioetica.org/fotos.gcal/1331984832discurso.pdf).

<sup>5</sup> Tristram Engelhardt Jr., "The Philosophy of Medicine and Bioethics: An Introduction to the Framing of a Field", in *The Philosophy of Medicine: Framing the Field*, ed. H.T. Engelhardt Jr., 1-15 (Netherlands: Kluwer Academic Publishers, 2000).

domestic product. Nations and states began to grapple with challenges regarding the allocation of funds and resources in medical care and research. Second, “new technologies ...pressed for clarity about issues.”<sup>6</sup> Moral problems raised by new technologies, such as organ transplantation and gene therapy, spawned significant discussions in Bioethics. Third, “old” moral problems, such as abortion, “became more acute because the technologies that occasioned them had become safer.”<sup>7</sup> As a consequence, there arose the need to rethink some formally settled moral matters in medicine. Fourth, “there appeared to be purely philosophical issues, such as the nature of a clinical problem and illness, that were addressed neither by philosophy of medicine nor even the philosophy of biology.”<sup>8</sup> For Dr. Engelhardt, such philosophical issues undergird the biomedical ethical ones and thereby need attention in discussions today.

According to Dr. Engelhardt, “two major moral principles”<sup>9</sup> guide actions in clinical medicine. These include “The Principle of Permission” and “The Principle of Beneficence.” First, the principle of permission states that:

Authority for actions involving others in a secular pluralist society is derived from their permissions. As a consequence,

- i. Without such permission or consent there is no authority.
- ii. Actions against such authority are blameworthy in the sense of placing a violator outside the moral community in general, and making licit (but not obligatory) retaliatory, defensive, or punitive force.<sup>10</sup>

The principle of permission expresses the circumstance that authority for resolving moral differences in a secular, pluralist society can be derived only from the agreement of the participants. Health care professionals cannot force patients to come into the clinic for care. They cannot force patients to receive medical care or continue with the medical care that they are receiving. Alternatively, patients cannot force health care professionals to practice in ways that go against their professional standards. Second, the principle of beneficence states that:

The goal of moral action is the achievement of goods and the avoidance of harms. In a secular pluralist society, however, no particular account or ordering of goods and harms can be established as canonical. As a result,

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<sup>6</sup> Ibid., 2.

<sup>7</sup> Ibid., 2.

<sup>8</sup> Ibid., 2.

<sup>9</sup> H. Tristram Engelhardt Jr., *Foundations of Bioethics* (New York: Oxford University Press, 1996<sup>2</sup>), 121; also see Tristram Engelhardt Jr., “The Search for a Global Morality: Bioethics, The Culture Wars, and Moral Diversity”, in *Global Bioethics*, ed. H. Tristram Engelhardt Jr., 18-49 (Massachusetts: M & M Scrivener Press, 2006), 25.

<sup>10</sup> Engelhardt, *Foundations of Bioethics*, 122.

within the bounds of respecting autonomy, no particular content-full moral vision can be established over competing senses (at least within a peaceable secular pluralist society). Still, a commitment to beneficence characterizes the undertaking of morality, because without a commitment to beneficence the moral life has no content. As a consequence,

i. On the one hand, there is no general content-full principle of beneficence to which one can appeal.

ii. On the other hand, actions without regard to concerns of beneficence are blameworthy in the sense of placing violators outside the context of any particular content-full community. Such actions place individuals beyond claims to beneficence. In particular, malevolence is a rejection of the bonds of beneficence. Insofar as one rejects only particular rules of beneficence, grounded in a particular view of the good life, one loses only one's own claims to beneficence within that moral community; in either case, petitions for mercy (charity) can still have standing.<sup>11</sup>

The principle of beneficence expresses the circumstance that the promotion of patient welfare and the avoidance of harm to a patient are central to the goals of medicine. It serves as a basis for health care professionals' determinations regarding what interventions are in the patient's best interest. In these determinations, there is a moral mandate to minimize patient harm through non-malevolent acts and maximize patient benefits through beneficent acts. This is, in part, because such moral mandates are part and parcel of the practice of the helping profession. But what these benefits and harms specifically look like needs to be worked out within the context of particular communities of persons who grant permission.<sup>12</sup> As Dr. Engelhardt says, "within the bounds of respecting autonomy, no particular content-full moral vision can be established over competing senses (at least within a peaceable secular pluralist society)."<sup>13</sup>

The principle of permission grounds mutual respect for a person's self-determination and is binding of all moral agents. Particular moral communities appeal to specific understandings of beneficence and are constrained from forcing their understanding of the good on unconsenting others. This is in keeping with how medicine works today since health care professionals cannot force treatment on unconsenting patients, without some exceptions. Alternatively, again with some exceptions, a health care professional cannot be forced to provide treatment to a patient.

In the end, then, biomedical ethics offers guidance regarding how to respect

<sup>11</sup> Engelhardt, *Foundations of Bioethics*, 123.

<sup>12</sup> See, e.g., H. Tristram Engelhardt Jr., *The Foundations of Christian Bioethics* (Massachusetts: Scrivener Publishing, 2000).

<sup>13</sup> Engelhardt, *Foundations of Bioethics*, 123.

members of the health care professional-patient relationship. All members in the relationship have a binding obligation to secure consent for actions, unless, of course, the situation requires emergency intervention. Such is the basis of law, policy, and practice in medicine today. Beyond this, all members of the health care professional-patient relationship can share their views of what is beneficial and good. Consent-based permission permits actions that may lead to such goods. Lack of permission prevents such actions from taking place, unless, of course, there is a reason to do so. In this way, according to Dr. Engelhardt, biomedical ethics cannot provide a singular view of what is beneficial for the patient outside the context of permission granted in the health care professional-patient relationship.<sup>14</sup>

### III. Epistemologies of Knowing in Medicine

As previously stated, part of the reason that a biomedical ethics delivers a diversity of defensible views on what is right or wrong, or good or bad, is because permission guides such views. Another reason is that biomedical ethics, as Dr. Engelhardt envisions it, draws upon a range of epistemologies of knowing in medicine. I'll focus in this section on the epistemology of knowing clinical problems, which serve as underpinnings in biomedical ethical discussions since biomedical ethical discussions concern how we know and respond to clinical problems. Examples are drawn from breast cancer medicine to illustrate Dr. Engelhardt's influence in my own work.<sup>15</sup>

The ways in which health care professionals speak of and react to clinical problems, such as disease, illness, deformity, and dysfunction, are shaped and directed by a number of interests. According to Dr. Engelhardt, these interests include descriptive, explanatory, evaluative, and social ones. These interests reflect "four conceptual dimensions" or "modes of medicalization."<sup>16</sup> They constitute the "language of medicine"<sup>17</sup> in that they provide the "grammar" and "rules," so to speak, for constructing meaning about and practical guidelines for addressing the problems that are attended to in the clinic. They reflect epistemologies of knowing in medicine, and such epistemologies undergird discussions in biomedical ethics.<sup>18</sup>

<sup>14</sup> Engelhardt, *Foundations of Bioethics*, 123.

<sup>15</sup> Mary Ann Cutter, *Thinking through Breast Cancer: A Philosophical Exploration of Diagnosis, Treatment, and Survival* (New York: Oxford University Press, 2018); also see Mary Ann Cutter, *The Ethics of Gender-Specific Disease* (New York: Routledge, 2012).

<sup>16</sup> Engelhardt, *Foundations of Bioethics*, 195.

<sup>17</sup> *Ibid.*, 195.

<sup>18</sup> Also see H. Tristram Engelhardt Jr., "Is There a Philosophy of Medicine?", *PSA 1976 2* (1977): 94-108; H. Tristram Engelhardt Jr., "The Concepts of Health and Disease", in *Concepts of Health and Disease: Interdisciplinary Perspectives*, ed. A. L. Caplan et al., 31-46. (Massachusetts: Addison-Wesley Publishing Company, 1981 [1975]); H. Tristram Engelhardt Jr., "Clinical Problems and the Concept of Disease", in *Health, Disease, and Causal Explanations in Medicine*, ed. L. Nordenfelt and B.I.B. Lindahl, 27-41 (Netherlands: D. Reidel Publishing Company,

### 1. *Descriptive Dimension*

A clinical problem is “seen through a set of descriptive assumptions.”<sup>19</sup> In medicine, description takes place by providing “facts”. The term “fact” is derived from the Latin “factum”<sup>20</sup> and refers to “a thing done” or a “reality of existence”, that is, to something that has really occurred or is actually the case. Such a view assumes that there is a reality “out there” to be discovered, a position called a *realist* view in philosophy. In medicine, a typical test for a fact is verifiability, which seeks to confirm whether the facts correspond to experience. Such a view assumes that matter is the basis of reality, a position called a *materialist* view in philosophy. The position in which matter is reduced to its component parts is known in philosophy as *reductionism*. Here the properties of the material whole are the addition or summation of the properties of the individual parts.

Consider how our understanding of breast cancer reflects both a realist and materialist view of a clinical problem. The National Cancer Institute states that “[i]n all types of cancer, some of the body’s cells begin to divide without stopping and spread into surrounding tissues.”<sup>21</sup> Such cells can lead to what is called a “tumor”. In the case of breast cancer, a breast tumor is submitted to pathological testing to determine its size, shape, and, if available, biomarkers and/or genetic characteristics. The description of breast cancer assumes that breast cancer is a reality out there to be discovered and composed of empirical or physical matter. Such matter can be reduced from the whole to its parts and can be studied, tested, and verified.

But a realist and materialist view of a clinical problem is insufficient. Dr. Engelhardt<sup>22</sup> reminds us that the so-called “facts” in medicine are not neutral. They are seen through theoretical frameworks.<sup>23</sup> “Descriptions require standardization of terms”<sup>24</sup>, and, as such, are framed by prior discussions, presumptions, claims, and language within particular frameworks. For instance, surgeons describe clinical problems in terms of surgical features, geneticists describe them in terms of genetic factors, and pathologists describe them in terms of pathological criteria. Such descriptions can and do change. One thinks of the change that the American Joint Committee on Cancer (AJCC) Breast Cancer Task Force made from the fifth to the sixth edition in

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1984); H. Tristram, Engelhardt Jr., “From Philosophy and Medicine to Philosophy of Medicine”, *Journal of Medicine and Philosophy* 11 (1986): 3-8.

<sup>19</sup> Engelhardt, *Foundations of Bioethics*, 207.

<sup>20</sup> *The Complete Oxford English Dictionary* (England: Clarendon Press, 1994), 560.

<sup>21</sup> “What is Cancer?”, National Institutes of Health, National Cancer Institute, last modified December 7, 2018, <http://www.cancer.gov/about-cancer/understanding/what-is-cancer>, 1.

<sup>22</sup> Engelhardt, *Foundations of Bioethics*, 208.

<sup>23</sup> Also see Ludwik Fleck, *Genesis and Development of a Scientific Fact*, ed. T. J. Trenn and R. K. Merton, trans. F. Bradley and T. J. Trenn (Chicago: University of Chicago Press, 1979 [1935]).

<sup>24</sup> Engelhardt, *Foundations of Bioethics*, 208.

2003 in recommending that the N (node) category of the TMN (tumor, metastases, node) cancer staging system be changed from one to three categories based on the number of axillary (i.e., under the arm) lymph nodes that are present.<sup>25</sup> This change came about in part because of a theoretical shift in understanding the role of lymph nodes in determining the extensiveness of breast cancer and the need for more specific diagnoses of breast cancer so that treatments for breast cancer can better be tailored.

Given that the so-called “facts” of medicine are not neutral, and depend on a host of perspectives, it may be misleading to say that a clinical problem is “out there” to be discovered. Rather, a clinical problem reflects the “lenses” the clinical knower brings to the so-called reality. A clinical problem is the experience of a disability, dysfunction, and/or suffering reported by a patient that hinders the achievement of certain goals. On this *idealist* view of reality, a clinical problem may not be fully reducible to matter that can be studied using laboratory tests. It is not a thing but an idea of a *holistic* event in the life of a patient. In the case of breast cancer, breast cancer reflects not simply a collection of mutated cells that have spread in the breast and perhaps elsewhere in the body. It constitutes an evolving event in the life of an embodied being who seeks to minimize dysfunction, pain, and suffering.

## 2. Explanatory Dimension

Further, the “facts” of a clinical problem are structured around explanatory claims and assumptions. In this way, a clinical problem is an explanatory concept, and as such “brings coherence ...to the multiplicity of events we encounter in medicine.”<sup>26</sup> It brings coherence to the signs and symptoms that bring patients into the clinic, and the pathoanatomical and pathophysiological data that are generated by laboratory findings by gathering and interpreting empirical data within the framework of observations and interpretations that have been handed down in history. This approach is known in philosophy as *empiricism*. Here clinical facts are verified by repeatable experiments and data and they maintain an accepted status until they are falsified. In this approach, a clinical problem relates “two worlds of observations”<sup>27</sup>, namely, the world of the clinic and the world of the laboratory.<sup>28</sup> “The findings of the clinician are related to the observations of the pathoanatomists and pathophysiologicalists and take

<sup>25</sup> American Joint Committee on Cancer, *AJCC Cancer Staging Handbook* (Netherlands: Springer, 2010), 423.

<sup>26</sup> Engelhardt, *Foundations of Bioethics*, 209.

<sup>27</sup> *Ibid.*, 209.

<sup>28</sup> Also see H. Tristram Engelhardt, Jr., “The Subordination of the Clinic”, in *Value Conflicts in Health Care Delivery*, ed. B. Gruzolski and C. Nelson, 41-57 (Massachusetts: Ballinger, 1982); Michel Foucault, *The Birth of the Clinic: An Archeology of Medical Perception*, trans. A. M. Sheridan Smith (New York: Pantheon Books, 1973 [1963]).



on a new significance through these anatomical and pathological observations.”<sup>29</sup> With shifts in explanations of a clinical problem come “an expansion...of the explanatory powers of medicine”<sup>30</sup> and the ability to diagnose and treat clinical problems with greater reliability and specificity.

In contemporary medicine, a clinical problem is often explained in terms of a causal relation between that which brings a clinical problem about and a clinical problem itself, the result of which is used to predict the onset, severity, and future path of a clinical problem. But one might note, following Engelhardt, that the notion of cause in medicine is far from simple and involves appeal to what can be called *empirical* (or evidence-based) and *rational* (or logical) criteria. “The term *cause* can be used to identify conditions that are sufficient to produce effects, necessary to produce effects, or that contribute to the likelihood of an effect’s occurring.”<sup>31</sup> Health care professionals continue to search for sufficient and necessary conditions for clinical conditions, such as breast cancer, in order to provide more specific accounts of the relation between what brings a clinical problem about and the resulting clinical problem. Although medicine may aspire to discover sufficient and necessary causes of a clinical problem, “[i]n medicine, where the data are often statistical [or contributory], causal factors are frequently identified in the last sense.”<sup>32</sup> While clinicians hope to find sufficient and necessary conditions for breast cancer, for instance, they often cannot and are instead left with working with contributory factors (e.g., effects of hormones on breast cells, diet) to guide treatment and survival care.

Given that medicine typically offers contributory causal accounts of a clinical problem, a tension arises. A statistical causal account of a clinical problem provides less certainty than, say, a necessary causal account. This recognition of the “limitations of human reason” causes “tension,” as Dr. Engelhardt puts it, “between the universal aspirations of knowers and the particular context in which real individuals actually know and frame explanations.”<sup>33</sup> In breast cancer medicine, for instance, while we may rally on behalf of “the cure,” we know that a “cure” is an ideal goal and not usually the actual result. Such is the condition of knowing enough about what we do not know about and working with an empirical methodology that cannot guarantee 100% certainty.

### 3. Evaluative Dimension

Further, “facts” and “explanations” of a clinical problem are structured around evaluative claims and assumptions. A clinical problem is an evaluative concept: “To

<sup>29</sup> Engelhardt, *Foundations of Bioethics*, 209-210.

<sup>30</sup> *Ibid.*, 210.

<sup>31</sup> *Ibid.*, 223.

<sup>32</sup> *Ibid.*, 223.

<sup>33</sup> *Ibid.*, 218.

see a phenomenon as a clinical problem, illness, or disability is to see something wrong with it.”<sup>34</sup> A clinical problem is experienced as a failure “to achieve an expected state, a state held to be proper to the person afflicted.”<sup>35</sup> This may be a failure to achieve an expected freedom from pain or suffering, an expected level of function or ability, a realization of human form or grace, and/or an expected span of life. This may also be a failure to achieve a state sought by a patient, determined to be beneficial to a patient, and/or in keeping with the standards of moral integrity and the virtues of the health care profession. In other words, the “facts” of a clinical problem are inextricably tied to the “value” of a clinical problem and its treatment, where value is understood as an important and enduring sign of significance or worth.

For Dr. Engelhardt, a clinical problem is an evaluative concept because a clinical problem is not simply reducible to physical dysfunction. Consider the case of osteoporosis.

“The species-typical character of calcium metabolism for post-menopausal women is one of negative calcium balance. More calcium is absorbed than deposited, leading to the development of osteoporosis and painful debilities such as collapsing vertebrae and greater exposure to risks of fractures. Such phenomena are as species typical as menopause itself. Yet, one would usually want to say that osteoporosis in postmenopausal women is a disease.”<sup>36</sup>

Osteoporosis is a clinical problem not because it is abnormal function but because the present or future pain and disability experienced by individual patients leads them to seek the treatments offered by health care professionals. In seeking clinical help, patients determine that their condition is, all things considered, disvalued and harmful to their life experiences and, as a consequence, changes are in order.

In the case of breast cancer, the American Joint Committee on Cancer announced changes in the seventh edition of its cancer staging manual<sup>37</sup>, resulting in the publication of the eighth edition in 2018. Once again, revisions have been made to the primary tumor, lymph node, and metastasis (TNM) classification of breast cancer commonly used around the world. More specifically, a major effort is made to incorporate biological factors, such as tumor grade, proliferation rate, estrogen and progesterone receptor expression, human epidermal growth factor 2 (HER2) expression, and gene expression prognosis panels into the staging system. Such efforts are

<sup>34</sup> Ibid., 197.

<sup>35</sup> Ibid., 197.

<sup>36</sup> Ibid., 203.

<sup>37</sup> Armando E. Giuliano et al., “Breast Cancer - Major Changes in the American Joint Committee on Cancer Eighth Edition Cancer Staging Manual”, *CA: A Cancer Journal for Clinicians* 67 no. 4 (2017): 291-303.

for purposes of developing better ways to predict the outcome of breast cancer occurrences and its treatments given advancements in testing and treatment for breast cancer. A hope is to develop better personalized cancer treatments for breast cancer patients as it incorporates emerging biomolecular knowledge of breast cancer into the traditional staging system for breast cancer.

#### 4. Social Dimensions

Further, “facts,” “explanations,” and “evaluations,” of a clinical problem are socially nested. A designation of a clinical problem takes place within the social practices of developing professional clinical standards, devising educational requirements and licensure agreements, formulating funding options, and instituting health laws and policies. To claim that a patient has a clinical problem “is to cast that individual in social roles where certain societal responses are expected.”<sup>38</sup> Some of the social responses include assigning individuals a sick role, expecting that such persons seek help from socially recognized therapists, excusing sick persons from responsibilities for certain tasks while recovering from a clinical problem, and expecting that treatment for a clinical problem is covered by medical insurance plans.

In the case of breast cancer, staging and grading breast cell mutations is in part a social endeavor. “The decisions in such circumstances [in staging and grading cancer] are made not simply in terms of the character of reality as it is taken really to be, but also in terms of which modes of classification will be most useful in organizing treatment and care.”<sup>39</sup> Choices to divide cancer stages and grades, and sub-divide cancer stages and grades, into a certain number turn on cost-benefit calculations and understandings of prudent actions that have direct implications for the ways patients are treated within social contexts.

In some sense, then, medical reality is a social phenomenon. The choice among different understandings of reality within medicine is a matter of communal interest. As a consequence, “[c]ommunities must begin with a recognition of the constructed character of medical reality. This recognition underscores our choices and indicates our responsibilities as individuals who not only know reality but also know it in order to manipulate it.”<sup>40</sup> In this way, the social dimension of a clinical problem is constituted by the descriptive, explanatory, and evaluative dimensions of a clinical problem. It is framed by the clinical evidence of the time, how the evidence is explained, and what values are central to clinical medicine as well as the patients who seek medical services. With this comes the responsibility on the part of clinical professionals to provide the best care that is possible within the boundaries of available resources. Patients have responsibilities as well. They are charged with being decisionmakers and co-navigators of their path to their goals in medicine.

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<sup>38</sup> Engelhardt, *Foundations of Bioethics*, 217.

<sup>39</sup> *Ibid.*, 219.

<sup>40</sup> *Ibid.*, 226.

### 5. Facts, Theories, Values, and Social Contexts

According to Dr. Engelhardt, the descriptive, explanatory, evaluative, and social dimensions of a clinical problem are not separate and distinct. As he says, “[t]he interplay of descriptive, evaluative, explanatory, and social labeling languages in health care...shapes our appreciation of a medical problem.”<sup>41</sup> Further, they define and situate each other.<sup>42</sup> Facts are theory-laden, the fact/theory dyads are evaluative, and the fact/theory/value triads are socially framed. Consider, again, the case of breast cancer. In classifying breast cancer, a decision has to be made regarding how many cells with deviant changes of a certain kind in the biopsied breast tissue must be present before the cells are labeled as “cancer”. An explanation is given about the relation between the mutating cells and the result called “cancer of the breast”. To be too liberal in classifying cells as “cancer” will lead to unnecessary treatment, which harms women, costs money, and wastes resources. To be too conservative in the classification will lead women to receive treatment too late, which leads to increased pain and suffering, as well as unnecessary deaths among women. On this view, the lines among “normal,” “hyperplasia,” “dysplasia,” and “cancer”<sup>43</sup> are in part discovered and in part created. They involve appeal to the facts, theories, and values that frame an understanding and subsequent action set within social frames of reference.

According to Dr. Engelhardt, one will not be able simply to discover, by appeal to factual issues alone, what diagnoses and treatments are indicated and what diagnoses and treatments are appropriate. “Integral to such judgments will be appeals to particular hierarchies of values and to peaceable processes for resolving disputes in these matters.”<sup>44</sup> In the case of breast cancer, one will not be able simply to discover by appeal to factual issues alone which diagnoses are indicated and what ones are minimal or excessive. Determining the difference, for instance, between 190 cells and 210 cells and the extent to which a patient has cancer micrometastasis (as determined by a 200 cells threshold) involves more than a factual judgment. Similarly, determining the difference, for instance, between stage IB and IIA breast cancer in the case of a patient with an invasive 1.8 centimeter ductal tumor in an area of the right breast, a second area of ductal carcinoma in situ (DCIS) in another area of the right breast, and one positive axillary node involves more than a factual judgment. Such determinations involve appeals to what benefits ought to be sought, what risks ought to be avoided, what medical resources ought to be expended, and what goals ought to be achieved in the clinical situation. Such leads us back to biomedical eth-

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<sup>41</sup> Ibid., 196.

<sup>42</sup> Mary Ann Cutter, *The Ethics of Gender-Specific Disease* (New York: Routledge, 2012).

<sup>43</sup> “What is Cancer?”, National Institutes of Health, National Cancer Institute, last modified December 7, 2018, <http://www.cancer.gov/about-cancer/understanding/what-is-cancer>, 4.

<sup>44</sup> Engelhardt, *Foundations of Bioethics*, 221.

ical considerations.

#### IV. Intersection of Epistemology of Medicine and Biomedical Ethics

The dual dependence between biomedical ethics and epistemology of medicine come about for a number of reason. These reasons harken back to those justifying the emergence of Bioethics in the late twentieth century. First, biomedical ethics finds itself part of discussions in epistemology of medicine and the much larger concerns about what constitutes the proper focus of boundary of medicine. These concerns are not only ethical ones, but knowledge-based ones concerning the nature of medical reality, how we understand it, and how we will manipulate it. Second, biomedical ethics relies on epistemology of medicine in order to find clarity on new bioethical issues that challenge our sense of clinical reality and require new ways of thinking. Understanding how worldviews and associated knowledge frameworks change and evolve lend insight into what claims and assumptions fuel the bioethical debates and which ones are open to revision and rethinking. Third, biomedical ethics turns to epistemology of medicine in order to address “old” moral problems that reemerge in contemporary culture in new ways. “Old” settled moral problems are no longer so settled given shifts in what constitutes clinical reality and how we know it. Exploring these dimensions of the debate provides new insights into old problems. Fourth, biomedical ethics needs epistemology of medicine in order to reorient itself to a central focus of medicine, i.e., treating the clinical conditions that patients bring into the clinic or hospital. This is not simply an epistemological claim, but one lodged in understanding how health care professionals understand their rroles and responsibilities.

Consider an example of the dual dependence between epistemology of medicine and biomedical ethics. There is a debate in breast cancer medicine today about the extent to which ductal carcinoma in situ or DCIS should be treated. DCIS is a state in which cells that have mutated have not spread outside the walls of the breast ducts. At present, DCIS is not considered cancer, although there are plenty of examples to show how it is referred to in the literature as a form of “breast cancer.”<sup>45</sup> Because breast cancer clinicians do not have reliable ways to predict which cases of DCIS will develop into later stage cancers and which will not<sup>46</sup>, some clinicians recommend treating DCIS in ways similar to how Stage I ductal breast cancer is treated. Others prefer a “wait and see” approach, but this does not reflect the general practice in breast cancer today. As seen here, how we understand a clinical problem (or

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<sup>45</sup> “Ductal Carcinoma In Situ (DCIS),” American Cancer Society, last modified December 7, 2018. <http://www.cancer.org/cancer/breast-cancer/understanding-a-breast-cancer-diagnosis/types-of-breast-cancer/dcis.html>, 1.

<sup>46</sup> “What is Cancer?,” National Institutes of Health, National Cancer Institute, last modified December 7, 2018, <http://www.cancer.gov/about-cancer/understanding/what-is-cancer>, 4.

better, how we do not understand it) sets up treatment warrants. Because some of these treatment warrants have well established side-effects for patients, such as harm from radiation and chemotherapy, treating a precancer stage raises a host of ethical questions, including how informed consent is secured, how benefits and harms are weighed, and how access to breast cancer medicine is structured in a context of not fully understanding a clinical condition. The interplay between knowing and doing, knowing and valuing, and epistemology and ethics becomes evident and brought to our attention by Dr. Engelhardt's contributions.

Further, how questions and issues are worked out rely not only on clinical epistemological standards but the binding obligation of the permission principle that Dr. Engelhardt develops. With regard to the scenario above, whether a patient seeks treatment for DCIS will turn on what information clinicians provide and how the patient weighs the benefits and burdens of the proposed interventions. Responses will vary and patients will choose a range of options, along with their clinicians. Such is in keeping with making choices in a world of uncertain clinical information and a world in which the permission principle guides ethical decisionmaking.

In his expansive work, Dr. Engelhardt shows us an important connection between the project of making ethical decisions in medicine and knowing in medicine. His insight is that there is no one single approach in biomedical ethics to determine the welfare of a patient. Rather, there many. There are many approaches because the permission principle in concert with epistemologies of knowing guide how we think about what is beneficial to a patient. The many approaches are lodged in biomedical ethics in a commitment to respect persons and in clinical epistemology in a commitment to modes of conceptual dimensions. In this framing, Dr. Engelhardt creates expansive room for discussion, debate, and options in biomedical ethics. While we all may want more definitive answers, these are not forthcoming. Answers will be framed by participants in the debate. And this is no small ethical endeavor. As Dr. Engelhardt says, "[t]his recognition underscores our choices and indicates our responsibilities as individuals who not only know reality but also know it in order to manipulate it."<sup>47</sup> Note that "[t]he issue of who decides is thus moved from the area of individual free and informed consent to a communal area of negotiation regarding construals of reality"<sup>48</sup> and what it means to live the ethical life.<sup>49</sup> Such is the message Dr. Engelhardt delivers. Such is the legacy Dr. Engelhardt leaves us with as we navigate the terrain of understanding clinical reality and making ethical decisions about how we ought to act in medicine.

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<sup>47</sup> Engelhardt, *Foundations of Bioethics*, 226.

<sup>48</sup> *Ibid.*, 226.

<sup>49</sup> Also see: H. Tristram Engelhardt Jr., "Confronting Moral Pluralism in Posttraditional Western Societies: Bioethics Critically Assesses", *Journal of Medicine and Philosophy* 36 (2011): 243-260.

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