CHAPTER 1

INTRODUCTION

This work examines disease (ME *disese*, Ofr *desaise*, disease; *des-* priv., + *aise*, ease; L. *dis-* priv., and *esse*, to be). [1] The central thesis of this analysis is that our understanding of disease is contingent on commitments[2] to three types of presuppositions: metaphysical (which establishes the nature of reality), epistemological (which establishes how we know what we know), and axiological (which establishes what and how we value). The interplay among these three types of commitments makes disease both theory-laden and evaluative. This means that it is also best understood as context-dependent. Put another way, the term "disease" refers to descriptions of pathological processes abstracted from individual physiological processes that afflict individuals in the human species, bring patients to the attention of health care professionals, and serve as treatment warrants. Given this multi-dimensional character of disease, we can expect different understandings and responses to particular diseases.

1. WHY STUDY DISEASE?

It may come as a surprise to some that someone would question the meaning of disease. Large clinical textbooks are written on disease, such as heart disease, acquired immunodeficiency syndrome, and cancer. Vast amounts of time and money have gone into exploring diseases, and hospitals and clinics are full of their consequences. Debating the topic at all may appear to be either worthless or destructive to medicine. Yet, to adopt this attitude is to miss some critical lessons.

Decisions about the meaning of disease have direct and important consequences for daily life and the allocation of significant portions of social resources. As Arthur L. Caplan (1993) notes, the emergent concern with disease in the twentieth century is a function of many forces. To begin with, disease has served as a major classification in medicine since its beginning and it is important to be clear about what medicine is talking about when it uses the term "disease." The efficacy of twentieth century medicine, public health, and its attendant technology in preventing and reversing many forms of infection, dysfunction, and nutritional deficiency constitute reasons for attention to disease. Reproductive technologies, genetic engineering, cosmetic surgery, and physician-assisted suicide, for instance, challenge our view about what constitutes disease and the proper domains of medical attention and why. Concerns regarding the role medicine as a powerful social institution plays in assessing the worth and value of human beings through its clinical classifications are

M. A. G. Cutter, *Reframing Disease Contextually*

additional reasons for interest in disease. One is reminded of the abuse in medicine against women (Smith-Rosenberg and Rosenberg, 1981), blacks (Cartwright, 1981 [1851]), Jews (Proctor, 1988), and Russian dissidents (Pope, 1996). Finally, and as a result of numerous forces such as legal restrictions (e.g., Colorado Revised Statute 10-3-1104.7,[3] Equal Employment Opportunity Commission, 1995[4]), institutions such as the government, insurance industry, and business increasingly play roles in determining what clinical conditions are worthy of recognition as disease by deciding which are covered and which are not. Depending on how disease is understood, the investment of resources (e.g., funds, personnel, power, legal protection) will be seen to be indicated or unnecessary.[5] Given that developed countries are spending more and more in the treatment and prevention of disease [6], the allocation of health care presents the opportunity to consider just distribution of resources.

In addition to practical reasons to attend to the nature and scope of disease, there are conceptual ones. A literature review illustrates varying definitions of disease. A major focus of discussion involves the extent to which disease is, simply put, a biological concept. On the one hand, there are those who hold that disease is reducible to biological dysfunction or disadvantage. Christopher Boorse appeals to biological advantage or statistical normality when he defines disease as "a type of internal state which is either an impairment of normal functional abilities below typical efficiency, or a limitation on functional abilities caused by environmental agents" (1977, p. 555). Similarly for J.A. Barondess, "[d]isease may be viewed as a biological event....It is a disruption in the structure and/or function of a body part or system" (1979, p. 376). E.J.M. Campbell et al. (1979) provide this definition: "disease refers to the sum of abnormal phenomena displayed by a group of living organisms...by which they differ from the norm for their species in such a way to place them at a biological disadvantage" (1979, p. 761). Feinstein states that disease is deleterious changes, autochthonous or allochthonous--that is arising from the body tissues themselves or from foreign sources; or alternatively, from breakdown of the homeostatic mechanisms" (1967, p. 120). Contemporary genetics tempts many to see disease as simply a function of abnormal molecular processes (Lewontin, 1991). In short, a prominent view in late twentieth century thinking is that disease is a biological concept and subject to (strictly speaking) scientific explanation.

In contrast, there are those who hold that the concept of disease is not reducible[7] to biological dysfunction. On this view, disease is more appropriately understood as a state constituting some harm or threat to a person's well-being, where harm or threat are terms that require non-scientific interpretation. Consider Lester S. King: "Biological science does not try to distinguish between health and disease. Biology is concerned with the interaction between living organisms and their environment. What we call health or disease is quite irrelevant" (1981 [1954], p. 107). Engelhardt indicates the importance of the nonbiological perspective when he says: "The concept of disease is used in accounting for physiological and psychological (or behavioral) disorders, offering generalizations concerning patterns of phenomena which we find disturbing and unpleasant" (1981 [1975], p. 32). Margolis says, "disease is whatever is judged to disorder or to cause disorder, in the relevant way, the

minimal integrity of the body and mind relative to prudential functions" (1976, p. 253). Edmund D. Pellegrino and David C. Thomasma hold that in the realm of the lived body, "dis-ease is an interpretation of disruption, an interruption in the ability to cope" (1981, p. 76). Caroline Whitbeck (1981, p. 615) argues that disease (1) is a psychophysiological process, (2) compromises the ability to do what people commonly want and expect to be able to do, (3) is not necessary for doing that which people commonly want and expect to be able to do, *and* (4) is either statistically abnormal in those at risk or people have some other basis for a reasonable hope of finding means to prevent or effectively to treat the process. Charles M. Culver and Bernard Gert state that disease (or as they call the phenomenon, malady) "is a condition of the person that involves suffering or the increased risk of suffering an evil" (1982, p. 71). Lawrie Reznek summarizes the tradition of the foregoing when he says: "Disease is to be understood in terms of the evaluative notion of being harmed. ...[This] leads us to Normativism--the thesis that the concept of disease is value-laden" (1987, p. 170). In short, a prominent view is that disease is not reducible to biological correlates, but rather involves normative judgments concerning ability, function, normality, or harm.

Indeed, matters are not so easily settled. Pointing out that disease is not always something that is *dis*valued or harmful, D. Jennings reminds us that: "One can be seriously diseased without being ill; for example with silent hypertension or an occult malignant disorder" (1986, p. 870). Alternatively, Goosens (1980, p. 102) recognizes that disease can sometimes have benefits and so be valued. Examples such as cowpox providing immunity from the more serious smallpox, sickle cell mutation providing protection against malaria, and an absence of CCR5 genetic trait as a protection against AIDS (National Institutes of Health et al., 1999b, pp. 6-7) illustrate this point. Along these lines, Talbott Parsons (1958) argues that therapy carries benefits such as excuse from responsibility and blameworthiness, where such excuse can bring significant benefits. How values frame disease is a matter of serious discussion and complex matters.

Additional attempts to qualify the character of disease are evident. It has become popular, for instance, to demarcate between disease and illness (Parsons, 1958) in terms of objective and subjective criteria. For Alvin Feinstein, disease is a description of a set of events in morphologic, laboratory terms, while illness is a description in terms of signs and symptoms (1967, pp. 24-25). As Barondess puts it: "Illness is not a biologic, but a human event" (1979, p. 385). One advantage of distinguishing illness from disease is the ability to account for the different meanings of sickness within and between particular cultures. As he says, "Illness is by definition subjective and thus specific to time, place, and culture. Variations in illness are to be expected" (Caplan, 1993, p. 240). From this standpoint, illness accounts for the diversity of disease expression and disease accounts for the similarity of certain clinical problems within and across cultures.

In contrast, F. Kraupl-Taylor argues that the distinction between disease and illness is not so simple. He transcends the split between disease and illness when he contends that "so-called causal treatment of patients, as distinguished from mere symptomatic treatment, means that psychological events and clinical symptoms are

affected concomitantly..." (1979, p. 77). Similarly, Per Sündstrom develops the position that so-called icons of disease "are discovered in the *integral* clinical situation, where the 'things' that provide content and form for the icons include not only outer reality but also the inner subjective reality..." (1987, p. 185). This inner subjective reality includes "certain basic value-preferences, such as: life is preferable to death, [and] the integrity of the organism is preferable to pain, hope to despair" (1987, p. 185). The point is that the attempt to distinguish disease and illness may be unsuccessful. Much depends on the context (e.g., clinical care, research, public health) in which disease is understood.

We can conclude, then, that there is disagreement concerning the definition and boundaries of disease. In their study of classificatory habits, Campbell et al. (1979) find that 95% of laypersons and 99% of physicians classified infections (e.g., malaria, syphilis, and measles) as diseases. Conditions caused by physical agents (e.g., drowning, fractured skull, and heat strokes) are classified as diseases by only 9% of laypersons and 44% of physicians. 16% of laypersons and 54% of physicians classify conditions caused by chemical agents (e.g., barbiturate overdose, hangover, carbon monoxide poisoning) as diseases. To add to the analysis, the extent to which so-called asymptomatic, sub-clinical, or pre-clinical genetic conditions are disease engenders further discussion.[8]

In summary, there are debates regarding the character and boundaries of disease. The debates concern whether disease identifies a biological concept, normative state of affairs, or cultural construct. Such debates are not simply academic ones, but ones that affect how humans construct the clinical setting and the clinical classifications that are adopted to account for human disease and health and their treatment warrants. A major goal of this study is to reconcile the debates, and in so doing to provide an alternative way to understand disease.

2. FOUR PHILOSOPHICAL DEBATES

Four distinct but related philosophical debates regarding established definitions of disease may be distinguished and will frame the discussions in this work. The first three tie to the three types of presuppositions of disease, namely, metaphysical, epistemological, and axiological. The fourth is a consequence of the first three and demarcates the context of reality, knowledge, and values in disease.

A first debate concerns the metaphysics[9] of disease, the nature of its being. For this debate, the history of medicine sets the stage for contemporary discussions in the philosophy of medicine. On the one hand, ontological conceptions of disease take disease as an entity in itself. Thomas Sydenham (1624-1689) (1981 [1676]), for instance, argues that nature delivers the structure of disease, which is characterized by recurring, natural, and enduring patterns of signs and symptoms. On the other hand, physiological conceptions of disease rely on some understanding of normal functioning of the body and interpret disease as a deviation from that norm. F.J.V. Broussais (1772-1838) (1981 [1828]), for instance, argues that disease does not constitute a thing. Accounts of disease in terms of recurring, natural, and enduring patterns (such as offered by Sydenham) are derived from metaphysical speculations. Medicine must

rid itself of such speculations and conceive disease as a relation between and among actual occurrences of the different organs. This debate contrasts *metaphysical realist* and *metaphysical anti-realist* themes.

A second debate is one about the epistemology[10] of disease, about how we know disease. On the one hand, there are those who argue that reason provides access to knowledge of disease. John Brown (1735-1788) (1803), for instance, holds that it is possible by reasoning alone to ascertain the nature of particular disease mechanisms. On the other hand, there are those who argue that sense experience provides access to knowledge of disease. Pierre-Charles-Alexandre Louis (1787-1872) (1835) and Jules Gavaret (1840), for instance, emphasize that speculative theories and logical deduction cannot provide knowledge of the diseases brought about by environmental factors. Rather, clinicians must rely on positive facts, a legacy of Auguste Comte (1798-1857) (1988 [1830-42]). In short, *rationalist* themes contrast with *empiricist* ones[11] and we are faced with coming to terms with questions regarding how we know disease.

A third debate asks whether values must play a role in disease concepts. This debate focuses on the axiology[12] of disease. On the one hand, some argue that disease concepts are value-neutral and can be specified in terms of typical species functions. For example, being healthy for Christopher Boorse (1975) means being a proper specimen of the species to which one belongs, and being diseased is a state of failing to be a proper specimen. On the other hand, there are those who argue that disease is a normative or evaluative concept best understood in terms of harm or threat to well-being. Disease is a disvalued state of affairs. In this camp are included Pellegrino and Thomasma (1981, 1988), Engelhardt (1981 [1975], 1996), and Ruth Benedict (1934a, 1934b). In short, there are major disputes between *neutralists* and *normativists* about the extent to which values play a role in disease concepts.

Related to this third debate is one concerning the nature of the values that frame disease. On the one hand, some argue that the values central to disease concepts are universal or objective. Edmund D. Pellegrino and David C. Thomasma (1981) and Charles M. Culver and Bernard Gert (1982) contend that objective values, independent of individual opinion, are what secure the possibility of trans-cultural interpretations of disease in medicine. In contrast, others (e.g., Benedict, 1934; Szasz, 1961) argue that the values that frame disease are dependent on or relative to individual or cultural interpretations. Cross-cultural accounts of disease are possible not because of objective or essential values, but because certain physical and psychological patterns of function, action, or behavior are recognized by particular groups as undermining the achievement of human endeavors in a commonly shared environment. *Value objectivist* accounts of disease contrast with *value subjectivist* ones.

A fourth debate explores the extent to which a contextual account of disease is relative.[13] On the one hand, there are those who argue that disease is dependent on socio-historical factors. Ludwik Fleck (1979 [1935]), for instance, forwards the view that disease is a function of specific thought-styles and thought collectives. On the other hand, there are those who worry that any socio-historically conditioned view of disease will inevitably lead to a relativist view. Lawrie Reznek (1987) provides an overview of this concern. In short, there is a dispute between *contextualists* and *relativists* of disease. These and related discussions concerning the metaphysical,

epistemological, and axiological character of disease provide this inquiry its general framework for reflection.

3. OCCASION FOR INQUIRY

In this philosophical analysis of disease, one stands at the intersection of medicine and philosophy. On the one hand, an analysis of disease, in conjunction with first-person experiences as patients and advocates of patients, has much to gain from philosophical reflection.[14] Medicine considers questions that tie centrally to what it means to be human--as a knower, performer, and valuer. It inquires into the nature of human somatic and psychological health and disease in order to respond to that which patients bring into the clinic. Along with attorneys and theologians, health care professionals traditionally have not been seen merely as technicians, but as professionals with special obligations or duties to individuals as well as society. The learned professions (e.g., medicine, theology, law), after all, are those that can provide an account of themselves (including their methodologies), assume responsibility for their actions (Callahan, 1988), and place themselves within the general concerns of human culture. It is here that philosophy is able to assist. Philosophy offers medicine ways to think through intellectual and practical issues by providing methodologies for analysis, argument, and critique, ones that draw from logic as well as the history of ideas, thus preventing against conceptual blindness.

On the other hand, philosophy has much to gain from work in medicine, for any worthwhile conceptual analysis of life and death entails considerations of claims made by a discipline that studies life (e.g., biology) and death (e.g., thanatology). [15] Such claims play a critical role in philosophy in providing content to discussions. Reflections in ethics and religious studies on freedom and responsibility take on added dimension when considering new knowledge in genetics. Discussions in philosophy of mind and of psychology are greatly enhanced from work being done in neurobiology, neurophysiology, psychiatry, and behavioral genetics. Social and political philosophy takes on practical import and new perspective when considering the allocation of health care resources or policies protecting patient rights. Reflections in professional ethics find guidance from medicine that, since at least the Ancient times, has entertained questions concerning the proper boundaries of human conduct. In short, medicine has much to offer philosophy.

3.1. Philosophy

In endeavoring to study disease, one is introduced to one of philosophy's central tasks, namely, that of aiding a culture or community in clarifying its views of reality and of itself. *Philosophy* (Gr. *philos*, love + *sophos*, wisdom, or love of wisdom) is an attempt to resolve intellectual questions and quandaries about reality, knowledge, the moral life, and the social order.[16] In the context of medicine, for example, one might ask: "How can I understand what is true or correct in medicine and justify it to others?" "How can I understand what is right, good, or virtuous conduct on the part of health

care professionals and among biomedical scientists and justify that to others?" Philosophy is neither properly construed as an attempt to decide what people usually hold about true knowledge or about right, good, or virtuous conduct, nor is it an attempt to determine what viewpoint would be most credible to most people. It is not a survey. Rather, it is at its core an endeavor to evaluate reasons and to determine what reasons can or should be credited by impartial, unprejudiced, and non-culturally biased reasoners, whose interests are in the consistency and force of rational argument. Though no such culturally unprejudiced, transcendent, or deified viewpoint can be fully achieved[17], the goal of its achievement can serve as a guiding, regulative, or heuristic ideal, suggesting a direction to proceed in attempting to clarify one's ideas, concepts, or values on a subject. This approach, even when it cannot produce final answers, can at least enable us to progress by providing some tentative answers, and by offering some reasons to explain why some resolutions to metaphysical, epistemological, axiological, and cultural quandaries are better than others in terms of the extent to which claims are defensible.

3.2. Philosophy of Medicine

This analysis of disease contributes to a growing literature in philosophy of medicine. By philosophy of medicine, I mean a field of scholarship devoted to the study of the metaphysical, epistemological (e.g., logical, methodological), axiological, and cultural issues generated by or related to medicine (Schaffner and Engelhardt, 1998, p. 264). Involved in this scholarship is particular attention to salient concepts in medicine, such as disease and health, which shape medical theory and practice (Caplan, 1992, p. 73). Here I concur with Pellegrino (1976, pp. 13ff) that although philosophy of medicine may share common grounds with other philosophical disciplines (e.g., philosophy of science, philosophy of technology), the grouping of issues in philosophy of medicine proves useful for the development of an enterprise especially devoted to studying sets of issues and problems particular to life and death. Such sets include, for example, clinical nosology and nosography, decision-making in diagnosis and treatment, and ethical issues in biomedicine (e.g., abortion, euthanasia, cloning). Yet, philosophy of medicine offers practical guidance because it has distinct theoretical perspectives. It raises questions concerning the presumptions and conclusions of knowledge claims regarding life and death. For example, it asks how medicine understands its major concepts (e.g., disease) and what are the implications of such understandings. This is to agree with Pellegrino and Thomasma (1981, p. 22), who state that many of the metaphysical, epistemological, and axiological issues raised by medicine (e.g., disease, illness, health) are susceptible to comprehension only by philosophical analysis, if at all.

The understanding of philosophy of medicine offered here contrasts with one offered years ago by Jerome Shaffer, who asserts that philosophy of medicine can be resolved into philosophy of science and moral philosophy, so that there is "nothing left for the Philosophy of Medicine to do" (Shaffer, 1975, p. 218). It also contrasts with the view advanced by Caplan (1992), which holds that medicine is essentially the science of biology, and philosophy of medicine is (and should best be pursued as)

philosophy of science. What is left out can be assigned to the realm of moral philosophy. Nor is it to assert that philosophy of medicine involves everything, and that it can handle any and all philosophical quagmires (see Pellegrino and Thomasma, 1981, p. 21). Rather, my view is that philosophy of medicine offers a unique framework for discussions of issues and problems particular to medicine and to our experiences as patients and care-providers that integrate important and special issues concerning who and what we are, how we know, and what and how we value as human beings. These conceptual issues are intimately connected to questions concerning how we can and ought to transform or change ourselves. In other words, philosophy of medicine must address the connection between knowing and acting, theory and practice, diagnosis and treatment, science and technology, objectivity and subjectivity, and science and humanities (also see Khushf, 1997). In this way, I part company with Pellegrino, who holds that philosophy of medicine has primarily to do with the philosophical investigation of the clinical encounter with a human being experiencing health or illness, in a setting which involves intervention (1976, pp. 13-18). Instead, I am in agreement with Julius Moravcsik (1976, p. 337), who claims that philosophy of medicine requires broad reflection and integration of several philosophical disciplines (e.g., philosophy of science, philosophy of technology, philosophy of engineering, biomedical ethics, humanities, and religious studies) in light of current developments in health care education, practice, research, and administration. Philosophy of medicine is at its core interdisciplinary.

What it means to be interdisciplinary, to traverse disciplines, given the institutional constitution and methodological and epistemological cores of academic disciplines, is a key aspect of philosophy of medicine. In order to be interdisciplinary, One suggestion (Ceccarelli, 1995) is that some (but not all) methodological differences among disciplinary approaches may be subordinated when there is a common project and expectation for progress[18]. Evolutionary biologists and molecular geneticists, for example, find shared interests in understanding how Darwin's principles of natural selection operate at the molecular level within large populations (Fuller, 1995). Geneticists and ethicists find shared interest in thinking through the extent to which humans are determined (Lewontin, 1991). Philosophers and medical professionals create common ground in discussions of human psychosomatic existence, often resulting in novel ways to understand human existence, ways that are enriched by thinking in the humanities *and* the sciences (Khushf, 1997). In this way, interdisciplinary studies are marked by an attempt to bridge seemingly disparate ways of knowing (Gardner, 1993) and doing.

How and what one decides can be subordinated in interdisciplinary work is a matter of importance. It seems to me that there must at least be a shared sense of vision, values, and expected outcomes in the process of working together. Participants must agree upon the general purposes and value of the discussion and seek to achieve certain outcomes. As an example, health care providers, philosophers, and theologians may agree to think through the grounds for limiting access to critical care medicine that are shared by Roman Catholic clinicians and provide a consensus statement (Engelhardt and Cherry, 2002, pp. 35ff). In this way, philosophy of medicine provides

an exemplar of interdisciplinary studies, the result of which are reflections that cannot possibly occur in any other discipline.

This is not to suggest that philosophy of medicine is new.[19] Those from the humanities and sciences have an extended record of interaction. Physician-philosophers from Hippocrates (5th c. B.C.) and Galen (129-215) through Pellegrino (1976) and Engelhardt (1996) have concerned themselves with human health and disease. Hippocrates is noted for rejecting supernatural "explanations" and emphasizing the role of observation in medical discovery, thus associating him with the Aristotelian school of thought. Aristotle, the son of a physician, believes that medicine could aid in philosophic and moral tasks to a large degree (Owens, 1977). Galen (129-215) holds that it is possible to elaborate and to support theories concerning the fundamentals of the human body. Physician-philosophers Avicenna (980-1037) and Maimonides (1135-1204) preserve Aristotelian naturalism alongside the Scriptural idea of the contingency of the world by arguing that any finite being is contingent in itself but necessary in relation to its causes. Physician-philosopher Sextus Empiricus (third c. A.D.) advocates pyrrhonian skepticism, a kind of mental hygiene or therapy that cures one of dogmatism or rashness in all ideas of thought. John Locke's (1632-1704) (1975 [1690]) philosophic work is shaped to a great extent by his medical orientation through his relationship with English physician Thomas Sydenham (Romanell, 1974, pp. 69-91; Sanchez-Gonzalez, 1990). As Isaac Newton (1642-1727) (1999 [1687]) characterizes his work on dynamics as a contribution to natural philosophy, others of Newton's day, for instance, René Descartes (1596-1650) (1972 [1650]), think that a philosophic approach to such basic sciences as physiology, as well as to clinical or applied medicine, would be highly productive. In a sweeping claim, physician Rudolf Virchow (1821-1902) holds that medicine and philosophy share the goal of providing "general laws of the human race" (1981 [1895], p. 190). Physician-psychiatrist Sigmund Freud (1856-1939) (1966) develops the language of psychoanalysis to explain mental illness in a way that fits his observations in the clinic. Physician-philosophers H. Tristram Engelhardt (1985), Henrik Wulff (1981b), Kenneth Schaffner (1993), Lawrie Reznek (1987), and Robert Aronowitz (1998) engage in extensive analysis of concepts of health and disease. Then there are the calls for a reevaluation of taken-for-granted assumptions in medicine. Physicians Thomas Szasz (1961), Ivan Illich (1976), and M. Scott Peck (1978) reevaluate mental illness in light of socio-cultural forces. Physician Christiane Northrup (1994, 2001) and psychologist Joan Borysenko (1996) call for a revision of traditional medicine's approach to disease in light of woman's experiences. Physician Deepak Chopra (1998) envisions a reintegration of spirituality in health care. Thus, although activity in the philosophy of medicine accelerates,[20] it is really a reemerging field.

3.3. Medicine

Some unique features of the philosophy of medicine involve unique features of medicine (L. *medicina*, medicine, the healing art). Broadly speaking, medicine involves not only what physicians do, but also the intellectual and clinical endeavors of doctors of optometry, of chiropracty, of podiatry, as well as of nurses, physician

assistants, health care administrators, pastoral counselors, and allied health professionals.[21] This broad-ranging account contrasts with a more restricted account, such as offered by Donald Seldin (1977, p. 40). According to Seldin, medicine is a discipline that subserves a narrow but vital arena. It cannot bridge happiness, prescribe the good life, or legislate morality. Rather, it can bring to bear an increasingly powerful conceptual and technical framework for the mitigation of the type of human suffering rooted in biomedical derangements.

Despite attempts to constrain its focus, medicine is unavoidably a broad enterprise. Medicine can (and often does) refer to the basic sciences (e.g., theories about the way the eye functions) and applied endeavors tied to diagnosis (of, e.g., retinitis pigmentosa), prognosis, and treatment (e.g., low vision therapy). As a result, one may engender puzzles about theories of function and models of disease processes (e.g., as found in physiology, pathology, and genetics) (Schaffner, 1980, 1981, 1993), about the ways in which health care practitioners engage in their diagnostic, prognostic, and therapeutic activities (e.g., the ways internists make clinical judgments) (Feinstein, 1967; Wulff, 1981a, 1981b; Albert et al., 1988), about how patients assimilate clinical information (e.g., Sorenson, 1974; Blaxter, 1983; Berwick and Weinstein, 1985), and how social factors influence the understanding and treatment of disease (Macgregor, 1960; Shuval, 1981; Sassower, 1993). In this way, medicine is, as Engel (1977) puts it, a biopsychosocial discipline[22].

But medicine is more than a study of the human as object, for humans cannot fully be explained in terms of third person language.[23] Purpose, value, consciousness, reflection, fear, and self-determination complicate the laws of medicine. As this study illustrates, medicine must consider the special complexities of human as individual subject of his or her self-perceived history. In doing so, it must correlate the explanatory modes of the physical sciences with the interpretive modes of the humanities (Pellegrino, 1976, p. 15; also see Wulff et al., 1986, Ch. 9; Habermas, 1972; Gadamer, 1992). It must take into consideration te special complexities of the human person as subject interacting with the human person as object of and in science science.

On this view, medicine is rooted in the history and traditions of human thought, reflection, and experience.[24] Ancient Greek medicine (approx. 500 B.C.-500 A.D.) offers a naturalist, as opposed to a supernaturalist (Admundsen, 1990; Lund, 1936; Laín-Entralgo, 1970; Achterberg, 1991), approach to disease. It is as if all one has to do is to look to nature to deliver the structure of disease and instructions for therapeutics would be forthcoming. One could know fully, a notion that receives support in the Medieval Ages (500-1500 A.D.) by Judeo-Christian scholars. For them, the congeniality between the knower and the known is fortified by a Judeo-Christian God. Maimonides (1135-1204), Sextus Empiricus (b. early third century A.D.), St. Augustine (354-430) and St. Thomas Aquinas (1225-1274) understand reality and the known as created by the same God. Supernatural accounts of disease as punishment for sins, possession by the devil, and the result of witchcraft reflect a view of the universe as created by God, governed by natural law, but faulted by evil influence (Wulff et al., 1986, pp. 81-83).

In an attempt to rid science of faulty speculations and to develop scientific certainty, classical modern medicine separates epistemology from metaphysics, explanation from interpretation, reason from emotion, reason from faith, human reason from Divine reason, body from mind, facts from values, and disease from the sick patient. Fueling these divisions is a skepticism regarding non-rational forms of knowledge and their capacity to grant answers. Although this skepticism appears as far back as Sextus Empiricus, it gains wide acceptance with sixteenth- and seventeenth-century scholars, such as Francis Bacon (1561-1626) (1989 [1620]), Galileo Galilei (1564-1642) (1953 [1632]), and René Descartes (1596-1650) (1972 [1650]). Both accept a mechanistic view of the body as a machine (La Mettrie, 1961 [1748]; Robinson, 1976) and an "experimental" method that investigates the empirical workings of the body as part of the natural order.

Contemporary, or so-called "postmodern,"[25] ways of understanding our world arise from prior assumptions and question the legitimacy of a single narrative or answer to our more fundamental questions forwarded by modern scholars. Accounts (e.g., Fleck, 1979 [1935]; Kuhn, 1970 [1962]; Szasz, 1961) regarding the historical, socially constructed, and culturally-determined character of science and medicine gain prominence. Attention to the rights of minority groups (e.g., Jones, 1981), the mentally ill (e.g., Pence, 2000), prisoners (e.g., President's Commission, 1981, pp. 1145-1146), and women (e.g., Wolf, 1996) reinforce critiques of contemporary medicine. Studies on race and ethnicity (e.g., Roberts, 1996), class (e.g., Rothenberg, 2001), and gender (e.g., Tuana, 1988; Cutter, 1997; Tong, with Anderson and Santos, 2000) in medicine and science emerge. Human reason and its categories come under post-modern critiques, and science and medicine are seen as one way of knowing among others (Sassower, 1993, 1995).

Postmodern critiques have spawned a revival of traditions that encourage first-person reflections (e.g., existentialism[26], hermeneutics[27], phenomenology[28]) and previously disenfranchised minority voices.[29] The hope that a single tradition or philosophy can guide us in matters of epistemological and axiological dilemma increasingly fades (MacIntyre, 1981). As Lyotard (1984 [1979]) warns, the grand narrative has been lost and with it the hope that single answers to our questions will be forthcoming. An implication of the loss of a singular way to interpret reality is an opportunity for previously silenced voices to speak out and share their stories.

Nevertheless, all is not fractured. The technological revolution, undergirded by developments in information technology, link previously isolated voices, communities, and cultures. In that connections can be made that engender discussions, there appears to be some level of shared knowledge and values. We know immediately, for instance, where and when disease outbreaks (e.g., AIDS, severe acute respiratory syndrome [SARS], West Nile Virus) occur. There are crusades for world-wide causes that can be treated effectively (e.g., AIDS). Scholars call for a trans-national or global perspective (e.g., World Health Association, 2003; Po-wah, 2002; Tong, with Anderson and Santos, 2001; Fox 2001) on matters concerning life and death. An emphasis on alternative approaches in medicine (Jonas, 1993; Clouser and Hufford, 1993; "Complementary...," 1997) and the interaction among medicine, spirituality, and the world health situation (Cameron et al., 2000; Engelhardt and

Cherry, 2002; Shea, 2001) gains new momentum. In a sense, a "technoscience globalism" marks the beginning of the Third Millennium and finds expression in medicine. In short, discussions in the philosophy and history of medicine provide an expansive background for study and reflection of disease.

4. LIMITATIONS

This study of disease has its limits. It is not to be taken as an exhaustive treatment of disease. Rather, it selectively treats major debates regarding the status of disease in modern and contemporary medicine.[30] It is not meant to be an historical analysis, although it relies on influential discussions regarding disease in the history of modern Western medicine to highlight salient points regarding the nature of disease.[31] In addition, this study is not in any single way a treatise on disease classification[32], clinical diagnosis [33], clinical decision-making [34], or health [35], although these topics are discussed insofar as they provide insight into particular features of disease. To continue, this study focuses primarily on what is so-called "somatic disease" and does not claim to delve in any detail into the character of mental disease or disorder, which commands a unique history, methodology, and set of problems, some of which are shared. Nevertheless, the lessons learned here about disease have clear applications in a study of psychiatric disease, and references are made as such. Finally, the perspective taken in this essay is more often than not from the standpoint of the clinician, even though I am not one. This is the case because much of the discussions that I rehearse regarding the character of disease is provided by clinicians who have the talent to communicate in the humanities (e.g., King, 1982; Pellegrino, 1976, 1979, 1983; Reznek, 1987; Engelhardt, 1996; and Aronowitz, 1998). For sure, more work is needed from the perspective of patients (see, e.g., Tong, with Anderson and Santos, 2000), particularly given the position advanced in this book. Despite its limits, then, this work sets out to provide a geography of debates regarding the character of disease in order to gain conceptual clarity and practical guidance.

5. PROGRAM FOR INVESTIGATION

To recap, this book is centrally focused on how disease is understood and undertaken in modern and contemporary medicine in the West. It sets forth a contextual account of disease. Disease is theory-laden and evaluative in a way that is context-dependent. An implication of this view is that our understanding and treatment of particular diseases may differ.

This work is divided into eleven chapters. This first chapter serves as an introduction to the analysis. The next chapter, Chapter 2, provides a case study of the development of acquired immunodeficiency syndrome (AIDS), setting the stage for a more detailed analysis of disease. AIDS is selected because our understanding of AIDS has changed in the span of two decades (1980-2000), from viewing it as a syndrome to viewing it as a disease in its own right. Here AIDS is not meant to represent all disease types. Such a position would be misleading given the position

advanced in this book, that it will not be possible to map out *the* character of disease. Rather, AIDS is used as an example of how disease is understood and undertaken in contemporary medicine, one that might serve as a model for other inquiries. Along with Chapters 1 and 11, then, Chapter 2 serves as a summary of the project. The remaining chapters set forth the particular features of disease and provide the argument at greater length.

Chapter 3 focuses on the metaphysical question "What is disease?". The analysis draws heavily from the history of medicine in order to make conceptual points about the nature of disease. It considers the debate between ontological and physiological accounts of disease. It illustrates how competing accounts of the nature of disease offer limited yet complementary ways to understand disease. It argues in favor of a *limited realist* view of disease; disease is real yet bound up with the frameworks through which we interpret it.

Chapter 4 addresses the epistemological question "How do we know disease?". It draws again from the history of medicine in order to make conceptual points about knowing disease. It recasts the discussion of what is known in medicine in terms of how we know. It considers the debate between rationalist and empiricist accounts of disease. It argues in favor of a *representative realist* view of disease.

Chapter 5 illustrates a rather underappreciated topic in philosophy of medicine, namely, the relation between knowing and treating in medicine. It sets out to fill this gap. It refers back to Chapters 3 and 4 and extends the analysis of disease to include treating patient complaints. It argues that a pure or unapplied theory of disease is indefensible. Knowing and treating are necessarily linked in accounts of disease. Given this, a *practical epistemological* approach to disease makes most sense.

Chapter 6 considers the axiological character of disease and whether values are involved in disease and, if so, what are their nature. It considers first the debate between neutralists and normativists followed by one between objectivists and subjectivists of values. It argues that one's answer to the first debate about value involvement depends on one's answer to the second debate about the nature of values. It argues in favor of a *limited stipulative* account of the values that frame disease.

Chapter 7 extends the analysis in Chapter 6 by providing a geography of the values that inform disease. It argues that four major kinds of values frame disease concepts. Functional values tell us what ideals of function or activity are proper to an organism. Aesthetic values indicate what ideals of form and grace are worthy of achievement. Instrumental values illustrate how we single out phenomena to be manipulated for purposes of achieving a goal, such as the maximization of benefits and minimization of harm. Ethical values tell us how we assign judgments regarding moral praiseworthiness and blameworthiness.

Chapter 8 offers a synthesis of the foregoing discussions, leading us to conclude that disease is *contextual*. Our understanding of disease depends on the context in which it is expressed. This context is constructed of diverse ontological, epistemological, and axiological commitments. In the end, a "*localized*" account of disease is offered. Disease is located in particular contexts fashioned by historical, socio-political, and cultural influences. With these reflections in hand, the analysis

come to a close with Chapters 9, 10, and 11, and considerations of future directions for work on disease. The beginning of the twenty-first century has witnessed an explosion in genetic medicine and concerns about women's health. Taking this as a lead, accounts of genetic disease (Chapter 9) and those of gendered disease (Chapter 10) receive attention. Chapter 11 offers a final summary of the project, with additional thoughts about directions for further work.

6. CLOSING

The analysis of disease offered here provides, on the one hand, an overview of major debates in the philosophy of medicine concerning disease and, on the other hand, a defense of the view that disease is both theoretical and evaluative in a way that is context-dependent. The former is offered to those who wish to become acquainted with a rich discussion of the character of disease in modern Western medicine. An analysis of the former has, in my case, led to the latter conclusions of this project.

CHAPTER ENDNOTES

1. For an introduction to discussions regarding concepts of disease, one might start with the best guide to the literature, Caplan et al. (eds.) (1981), which unfortunately is no longer in print. For helpful overviews of key debates, see Caplan (1993, 1997), "Health and Disease" (Reich, 1995, pp. 1084-1113), Reznek (1987), Wulff et al. (1986, esp. Ch. 6), Aronowitz (1998), Nordenfelt and Lindahl (eds.) (1984, esp. Appendix, pp. 151-173), Engelhardt, with Erde (1980), Engelhardt (1996, Ch. 5), and Sigerist (1943).

2. By commitments, I mean that which is explicitly or implicitly presupposed in one's analysis. One of the jobs of philosophers is to uncover and make explicit such commitments.

3. Colorado Revised Statute 10-3-1104.7 limits the use of genetic testing information by insurers. The statute defines genetic testing as a direct laboratory test of human DNA, RNA, or chromosomes used to identify the presence or alterations in genetic material associated with illness or disease. The statute applies to entities that provide health, group disability, and long-term care insurance and are within the Colorado Insurance Commission's jurisdiction. The covered entities are prohibited from seeking, using, or keeping genetic information for any underwriting or nontherapeutic purposes. Violation of the act is an unfair insurance practice subject to Insurance Commission sanctions. The statute provides a private right of action for individuals injured by wrongful use of genetic information, with both legal and equitable remedies available. Additionally, the prevailing party may recover attorney fees. See Cutter (1998) and Fox (1995). For an overview of other state statutes, see Hudson et al. (1995)

Statutes prohibiting the use of genetic information by insurers became moot with the passage of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) (Public Law 104-191). Public Law 104-191 makes it illegal to count genetic disposition to disease as a pre-existing condition in group insurance policies. HIPAA limits the ability of group health insurers to deny coverage based on "preexisting" conditions. Under the law, these insurance plans may deny insurance based on a preexisting condition only when medical advice, diagnosis, care, or treatment, was recommended or received within the six-month period before enrollment. Most unexpressed genetic conditions would not meet this insurance exclusion requirement.

Moreover, HIPAA explicitly protects people seeking presymptomatic genetic testing. It does so by forbidding group plans from denying insurance based on genetic information when the person has not been diagnosed with the genetic condition. This creates an important distinction. Someday it may be possible to undergo genetic testing for depression. Doctors may recommend preventive treatments to people with depression but HIPAA would stop an insurance company from using the recommendation as evidence of a preexisting condition. Thus, HIPAA greatly reduces the risk of genetic discrimination by health insurance companies.

4. In March, 1995, the Equal Employment Opportunity Commission (EEOC) (1995) released new Americans with Disabilities Act defining disability. Disability now applies to individuals who are subject to discrimination in the workplace on the basis of genetic information predisposing them to illness, disease, or other disorders.

5. This is not to suggest that the choices are always rational. As this study shows, the forces contributing to how disease is understood and undertaken are varied and complex.

6. In the United States, nearly one out of every seven dollars is spent on some form of health care. In 1998, this amounted to approximately 13.6 percent of the gross domestic product (GDP), or $4,178 per capita. By way of comparison, health care in Canada, Germany, Belgium, and Austria in 1998 respectively represented 9.5, 10.6, 8.8, and 8.2 percent of each country's GDP, or approximately $2,312, $2,424, $2,081, and $1,968 per capita (Organization for Economic Cooperation, 2000). In the United States, this figure continues to increase, despite the attempt by managed care to contain costs.

7. Reductionism occurs when all laws of the "whole" (or more complex situations) can be deduced from a combination of the laws of the simpler or simplest situation(s) *and* either some composition laws or laws of coexistence (Audi, 1995, p. 492).

8. New knowledge in genetics now enables us to distinguish between pre-existing clinical conditions and existing ones, and to predict the occurrence and severity of genetic disease. Anticipation, for example, allows clinicians to forecast the onset and severity of clinical conditions, giving rise to the terms "sub-clinical events" and "asymptomatic illness." These and other considerations are taken up in Biological Sciences Curriculum Study (1996, 1997).

9. Metaphysics (Gr. *meta ta physika*, after those things relating to external nature, after physics) is the philosophical investigation of the nature, constitution, and structure of reality. In this analysis, the emphasis is on the nature of disease, and the question "What is disease?"

10. Epistemology (Gr. *episteme*, knowledge, + *logos*, discourse) is the study of knowledge and justification. In this analysis, the emphasis is on how we know disease and the relation between the knower and known.

11. Although the distinction between rationalism and empiricism is historically suspect, it provides a useful way to talk about major camps of thought in philosophy and medicine.

12. Axiology (Gr. *axios*, worthy, + *logos*, discourse) is the study of values, or a branch of philosophy dealing with the nature and types of values.

13. The debate is not whether disease is contextual but rather how. This is because the resolution of the previous debates preempts a non-contextual view of disease.

14. Recommended discussions include Pellegrino and Thomasma (1981), Englehardt (1996), McElhinney (1981), and Bickel (1986).

15. See Wartofsky (1975, 1976, 1977, and 1992).

16. Much, of course, has changed. In the Ancient times, philosophy was concerned with wisdom, understood as the highest form of truth. This continued through the Medieval period and complemented the search for God's truth. The Modern period holds that reason will deliver answers to our questions, and postmodernity calls into the question the possibility of truth. Nevertheless, there remains a search for wisdom , albeit a changed notion.

17. For more on human limitations, see Chapters 3, 4, 6, and 8.

18. What constitutes "progress" is anything but simple. See Lakatos (1970), Laudan (1977), and Gutting (1980).

19. There is a rich and complex history of philosophical reflection concerning medicine reaching back to the beginnings of Greek philosophy. These can retrospectively be recognized as part of philosophy of medicine. Nevertheless, it was not until the nineteenth century that the expression "philosophy of medicine" gained currency (Schaffner and Engelhardt, 1998, p. 265). Also see Jonsen (1998) and Stevens (2000).

20. The field of philosophy of medicine experiences new growth at the end of the twentieth century. Consider journals such as *The Journal of Medicine and Philosophy* (inaugurated in 1976), *Theoretical Medicine* (formally called *Metamed*, inaugurated in 1979), *Medicine, Health Care, and Philosophy*, and *Kennedy Institute of Ethics* (inaugurated in 1991). There are book series, such as *Philosophy and Medicine* (inaugurated in 1975) and *Clinical Medical Ethics* (inaugurated in 1991), and databases, such as "Bioethicsline," begun in the 1980s. There are courses with the title of "Philosophy of Medicine" that are offered to students at the undergraduate and graduate level. All of this has transpired since the 1970s.

21. For more on this broad-ranging character of medicine, see Engelhardt (1996, Ch. 5). Also see Engel (1977, pp.129-136), Pellegrino and Thomasma (1981, pp. 58ff), and Veatch (1997, p. 5).

22. The biopsychosocial model of disease emphasizes that how a disease affects any one individual requires consideration of psychological, social, and cultural factors and stresses individual variability of a disease (Engel, 1977, p. 132).

23. First person refers to the person speaking (e.g., I read). Second person refers to the person spoken to (e.g., You read). Third person refers to a person or thing other than the speaker or the one spoken to (e.g., He/she reads).

24. This account is admittedly general and highlights dominant themes for purposes of illustrating major conceptual shifts in medicine that influence what and how we know in the clinical setting.

25. Postmodernism is a complex set of reactions to modern philosophy and its presuppositions about the nature of reality and how it is known. See Foucault (1972 [1969]), Lyotard (1984 (1979), and Ermarth (1992).

26. Existentialism is a philosophical and literary movement that comes into prominence in Europe, particularly in France, immediately after World War II, and focuses on the uniqueness of each human individual as distinguished from abstract human qualities. See Camus, *The Plague* (1991) and Sartre, *Nausea* (1969).

27. Hermeneutics is a type of philosophy that addresses questions of interpretation. See Dilthey (2002 [1910]) and Heidegger (1996 [1927]).

28. Phenomenology is a philosophical tradition developed by Edmund Husserl (1859-1938) (and his followers, emphasizing the description of human experience as directed unto objects, in the sense in which thoughts or wishes have objects, even if unreal ones ("intentional objects").

29. One might note the explosion of courses in ethnic diversity and gender studies in higher education at the turn of the Third Millennium.

30. This is not to suggest that philosophers of science offer little by way of reflection on disease. One could consider in greater detail the account by Hempel (1965, p. 398) of why Jones contracted streptococcal infection. Then there is Achinstein's (1983, pp. 74-102) analysis of Dr. Smith's account of why Bill was overcome by a stomachache. Or consider the syphilis-paresis example offered by Scriven (1959).

31. I am indebted to Harlow Sheidley, Department of History, University of Colorado at Colorado Springs, and Roberto Trevino, Department of History, University of Texas at Arlington, for our discussions of philosophy of history and more specifically the methodology of using historical materials in scholarly analysis (also see Carr, 1969; Toews, 1987; Novick, 1988; Harlan, 1989; Elton, 1991).

32. For discussions on clinical classification, see Wulff et al. , 1986, Ch. VI.

33. For discussions on of clinical diagnosis, see Murphy (1976) and Wulff (1981b).

34. For discussions on clinical decisionmaking, see Feinstein (1967), Schaffner (1980), and Wulff (1981a, 1981b).

35. For sustained analyses of health, see Whitbeck (1981), Nordenfelt (1987, 2001), Mordacci (1995), Lennox (1995), and Lafaille and Fulder (1993).