THE NECESSITY FOR A THEOLOGY OF DISEASE: REFLECTIONS ON TOTALITIES AND FRAGMENTS

by Philip Hefner

Abstract. Our ideas of disease try to explain it, and they aim at facilitating cures. In the process, they become entwined in sociocultural networks that have totalizing effects. Disease, however, counters this totalizing effect by revealing to us that our lives are fragments. Unless we engage this fragment character of disease and of our lives, we cannot properly understand disease or deal with it. HIV/AIDS clarifies these issues in an extraordinarily powerful fashion. Medical, legal, commercial, political, and institutional approaches to disease overlook the fragment character of disease in favor of totalizing worldviews. A theology of disease is necessary in order to maintain the focus on fragments. Unless we recognize this fragment character, we do not really understand our lives, and we do not really understand either disease or healing.

Keywords: disease; fragment; HIV/AIDS; medicalizing; Ann Pederson; Robert Potter; totalizing.

THE NECESSITY FOR A THEOLOGY OF DISEASE: THE THESIS IN A NUTSHELL

Our ideas of disease try to explain it, and they aim at facilitating cures. In the process they become entwined in sociocultural networks that have totalizing effects. By totalizing I mean that they create and implement entire personal and social worlds. No one has described this totalizing effort more vividly than Donna Haraway in her commentary on technomedicine (Haraway 1991, chaps. 1–3, 10; 1997).

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The history of medical philosophy and practice is a history of paradigms self-destructing and expanding. Disease, however, is the enemy of totalizing explanations and practices, the nemesis of world construction and paradigms. Disease reveals to us, in very harsh ways, that in our actual daily existence we live in fragments, not totalizing wholes. Our lives themselves are fragments in a world that is fragmentary. That the fragments are pieces of a whole is the discourse of faith, not a conclusion derived from what is empirically given.

Disease points to this fragment character of life and the world. Disease reveals that our physical and mental vigor are fragments, that the time allotted to us in our life span is a fragment, that our dreams and hopes are fragments, that our communities are fragments, that the work we do and its accomplishments are fragments.

Our theology of disease must give prominent place to this fragment character of life and reality as we live it. Why is such a theology of disease a necessity? Because the medical, legal, commercial, political, and institutional approaches to disease are predominantly totalizing.

Unless we recognize this fragment character, we do not really understand our lives, and we do not really understand either disease or healing.

Preparing the Way for a Theology of Disease

The title of this symposium is "*Toward* a Theology of Disease." I emphasize the initial word because I consider a theology of disease to be a project, a conceptual framework under construction, not a ready-made, finished achievement. It is itself a fragment. This is why I begin the task with reflections on "preparing the way," that is, surveying the considerations that must precede the construction of a theology of disease.

The Role of Ideas. First of all, we must recognize that our discussion of disease will proceed on the basis of our ideas concerning disease. Disease is as much an idea as an empirical actuality, and how we approach that actuality is inseparable from our prior ideas of disease. Furthermore, these ideas are decisive, not banal. They make a profound difference in how we perceive disease. What is disease? is a question that is never fully answered.

Let me give an example that pertains to both secular and Christian understandings of disease. If disease is viewed as that which is "unnatural," interpretation requires an idea of what is "natural." Aristotle and the Stoics believed that human well-being is fostered by following the laws of nature. The Christian application of natural-law theory associated the laws of nature with the creation by God and God's purposes. Disease and even the diseased person were then not infrequently considered to be opposed to God's purposes. This reasoning has been applied to homosexuality, masturbation, and HIV/AIDS.

Natural-law theology, however, leads to several possible applications when we are dealing with specific diseases. Heart ailments, congenital crippling, genetic defects, cancer—all of these could be considered to be unnatural by certain criteria. However, not all curative or healing procedures are considered to be natural. Embryo manipulation aims at curing the unnatural Parkinson's disease, but, because it destroys the embryo, which can be understood to be, by nature, a human being, embryo research is denoted by natural-law theory as unnatural. So, not only is there more than one possible application of this theology of disease, but the various possibilities are in conflict with one other.

What are the lessons here? That we must be critical of the idea that disease is unnatural and critically aware also of the consequences of attaching the idea of "unnatural" to disease. This is, of course, only one example of the difference our ideas make. Other ideas of disease are comparable, such as the ideas of disease as dysfunction, or disorder, or happenstance, or evil, or demonic possession. Before we construct a theology of disease, we must be aware of the ideas we employ to think about disease, and we must follow a consistent methodology for criticizing and selecting the ideas on which we build.

Historical and Cultural Conditioning. Second, we must recognize that our ideas of disease are historically and culturally specific, with the result that a plurality of ideas resides in the very heart of our thinking. For instance, we can point to examples of how the understanding of pain and fever has changed historically in medical practice. In the eighteenth century, pain was classified by Linnaeus as one of ten major classes of disease and by Sauvages as one of eleven classes. Today, pain is considered a symptom, not a disease, and tends to be downplayed unless it is shown to have a pathoanatomical or pathophysiological cause (Engelhardt 1996, 196). The same could be said of fevers. The classifications of homosexuality and masturbation have evolved in the twentieth century. In 1952, homosexuality was described in DSM-I as "an instance of sociopathic personality disturbance," whereas in the current DSM-IV, it is a "mental disorder only if the individual has a persistent concern to change sexual orientation" (Engelhardt 1996, 193). A similar change could be noted in premenstrual stress syndrome.

Cultural location also is a significant conditioning factor. Feminists have described the difference that women's culture makes for approaching disease. We know very well how significant native cultures are for dealing with disease. Traditional Chinese culture and folk cultures of all sorts condition people's ideas of disease and healing.

The lessons here are that we must be critically aware of how our historical and cultural location conditions the ideas of disease that we attempt to incorporate into a theological interpretation. We know well how this affects our theological interpretation of homosexuality. We want to avoid

the kind of interpretation that we find in Thomas Aquinas' *Summa Theologica* 2-2 (153–54), where he judged, as Engelhardt writes, that, "all things being equal, masturbation is a greater sin than a naturally performed rape" (1996, 198). We can ascribe this to his metaphysical position, but it is also rooted in his historical and cultural location. As recently as the 1860s, physicians in Europe practiced clitoridectomy to cure women of the disease of masturbation (1996, 192). To refresh our minds on how recently this happened, remember that Abraham Lincoln was President of the United States 1861–1865.

Why cite such indelicate and disturbing examples? Because we do not experience disease as an empty abstraction. It is a concrete experience, and ugliness is one of its characteristics. Our theology must recognize this fact. At the very least, these examples, as repugnant as they seem, demonstrate how fragmentary the insights and great truths of even our greatest thinkers and practitioners are. Our critical awareness on this point may prevent us from giving too weighty theological credence to relative judgments, but, more likely, it will also move us to incorporate some kind of diversity and multicultural pluralism and critique in our theology of disease.

Changing Paradigms of Medicine. Our perspectives on HIV/AIDS will necessarily give considerable weight to the medical understanding of the disease, and our understanding of disease in general will to a greater or lesser extent do the same, depending on the disease and the situation. Consequently, third, our attempts to fashion a theology of disease must give attention to the paradigms that govern the practice of medicine itself. Terms like *medicine* and *the practice of medicine* do not refer to a static, abstract thing or set of practices but rather to a constellation of knowledge and practices that are in the process of redefining themselves. A theology of disease that relates itself to medicine must take this dynamic and unfinished character of medical practice into account. Furthermore, to the extent that a medical paradigm influences our perspectives on HIV/AIDS, changes within that paradigm are important for us.

Robert Potter (1991) documents how in the last twenty years the paradigm within which medicine is practiced has moved from the orthodoxy of a biomedical model to the recognition of a biopsychosocial model. He joins with Harold Koenig and others in moving further, into a model that incorporates spirituality, in their *Handbook of Religion and Health* (Koenig, McCullough, and Larson 2001). In that same volume Jeff Levin speaks of the "body-mind revolution in biomedical science several decades ago, which radically transformed the clinical practice of medicine and medical education." Now, Levin asserts, "the arrival of a newer and broader body-mind-spirit perspective promises to transform medicine and medical research just as radically" (p. viii). Potter likens this to a paradigm shift from modernity to postmodernity.

Theologian Ann Pederson, following ethicist Karen Lebacqz and speaking from her own experience of teaching in a medical school and a nurses' training program, speaks of this paradigm shift in large terms that pertain not only to the practice of medicine by physicians but also to caregivers, including nurses, and to the formation of healthcare policy as it affects patients, families, and communities (Pederson forthcoming). Pederson analyzes the paradigm shift in medicine under four rubrics: (1) health is a broader concept than the traditional medical model allows for; (2) human health is linked to ecological/cosmological health; (3) in matters of health, women (and I would add children) are comparable to the canary in the mineshaft in that they provide early signals for judging the health of the larger community and of the planet; (4) there must be a coherence in how we approach disease and health among all sorts and conditions of people and in our approach to the different stages of the life cycle.

1. Health is a broader concept than traditional medical models allow for. Disease and health are relational as surely as they are physiological. In 1999, I visited a farm outside Harare, Zimbabwe. HIV/AIDS had so decimated this family that a grandmother was in charge of the farm, joined by two of her daughters and a small grandson in the actual farming. All of the men in this extended family had died of the disease. Terry Williams writes that "an individual doesn't get cancer, a family does" (1991, 214). We can just as well say that an individual doesn't get HIV/AIDS, a family and a community do. In Zimbabwe and certain other places, we can say that a nation gets HIV/AIDS. Kofi Annan and other African leaders have been trying to tell us in the West that an entire world gets HIV/AIDS.

2. Human health is linked to ecological and cosmological health. A strictly biomedical paradigm emphasizes that pharmaceuticals are essential for treating HIV/AIDS. We also know, however, that the pharmaceuticals require a certain kind of strong infrastructure of support persons who monitor the distribution and the taking of the medicines, teach afflicted persons how to take the medicines, and follow up on their progress. It is one thing to press Western pharmaceutical companies and governments to supply medicines for African nations; it is another thing to recognize that the necessary infrastructural supports may not be in place in Africa. The challenge of this disease is not that individuals are sick and need medicines supplied by generous persons in the West but that communities are sick and require the assistance of communities.

3. Women and children are the signaling "canaries." Miners in earlier times took canaries into the mines with them, in cages. If the canaries died in the mine shaft, the miners knew that toxic gases were present and it was time to get out. In Cape Town on December 1, 1999, the Parliament of the World's Religions gathered in its opening ceremony with all those who were marking International AIDS Day and the presentation of the AIDS Memorial Quilt. Many of the speakers that day were loud in their criticism of the South African government for not endorsing the treatments

for pregnant women who suffered from HIV/AIDS that would enable them to deliver babies free from the disease. The speakers charged that the government leaders were motivated to withhold medicines for the mothers because they knew that, if the babies were saved, the country would be faced in a few years with a colossal number of orphan children. The women themselves were clearly in great need, but they and the babies they carried within them were also signals of a disease that went far beyond their own bodies and even the bodies of their babies. They signaled a disease of the society, of the political structures of South Africa, and of the world that could not or would not care for this megadisease.

The lessons here are that, if we fashion a theology of disease, it must be large enough, capacious enough, to touch not only the changing paradigm of medicine but also the realities that are opened up by the changes in the paradigm. The provisional statement of the Evangelical Lutheran Church in America on "Health, Healing, and Health Care" points in the right direction when it asserts that an adequate approach to illness and health must give attention to the efforts of activism that advocate for the policies and sociocultural changes that are required to support genuine health (ELCA 2001, 13–14). HIV/AIDS reveals to us that these required efforts include attention to the corporate business structure, including the pharmaceutical and insurance companies, to the governments and their policies, to the infrastructures of society, and to many other facets of human life in community today around the world.

Medicalizing Language and Reality—Attempts at Totalizings. Tristram Engelhardt makes the point, both in depth and in breadth, that "medicine medicalizes reality. It creates a world. It translates sets of problems into its own terms. Medicine molds the ways in which the world of experience takes shape; it conditions reality for us" (1996, 189). It would be foolish to attempt to ignore this world of medicine when we fashion our theology of disease and when we approach HIV/AIDS in particular. Medicine may even be the single most salient element in our understanding of disease and our theology of disease. It certainly seems to me to be the dominant force in our society for understanding disease, and generally public policy seems to be dominated by the older, biomedical, paradigms of medicine. Therefore it is essential that we understand the medicalizing that medicine works on our reality—both in order to build upon it in our theology and also in order to free ourselves from its potential bondage.

Engelhardt suggests that medicine shapes reality through what he calls the "four languages of medicine." He enumerates them: disease language as evaluative, as descriptive, as explanatory, and as shaping social reality (1996, 196). These categories are useful for our theological thinking and also for interpreting HIV/AIDS.

First, medical language is a language of *values*. When we speak of disease, we assert that something is wrong; disease is a disvalue. Disease refers

to some sort of failure. It may be a failure to achieve a condition free from pain or anxiety; this failure may be called suffering. Or, it may be failure to reach a level of beauty and grace, such as a deformity; or, failure to function normally; or, failure to reach an expected life span. These failures may be seen as pathologies or as problems to be solved. "The central point is that we encounter diseases, illnesses, disabilities, sufferings through a web of important values" (Engelhardt 1996, 206). When we say that a person is diseased, we are making a negative value judgment of some sort. It may be nonmoral; we disvalue broken legs, but generally we do not make a moral judgment against the victim. But it may also be a moral value. Health is often considered a moral value when it comes to smoking behaviors, to alcoholism, and, even more, to HIV/AIDS. We may not make a moral judgment about liver disease or emphysema, but people often intertwine those diseases with moral judgments about drinking and smoking. Quadriplegic activists and deaf mutes have in recent years made it very clear that they often feel disvalued as persons because of their afflictions. Handicapped persons and deaf people mostly want to be enabled to live with their diseases, not segregated as people whose value depends on their being repaired. This may also apply to persons with HIV/AIDS.

Disease language is *descriptive*, with no intended value judgments. But values do enter into our efforts to standardize descriptions and treatments. And descriptions raise expectations that are value-laden.

Disease language is *explanatory*. Medicine has made spectacular advances because of its increased power to explain the causes of diseases. The focus then becomes the nexus of causes and manipulating the causes so as to cure the diseases. The causal network becomes the essence of a disease. Disease tends to be not what the patient feels, nor the patient's disrupted network of relations in family or community, not even the patient's pain. The disease lies in the causes of the pathology, and that is what healing focuses on. Focusing on causes enters the realm of values, because there is pressure to do more research in order to understand the causes more fully. This has been very important in the HIV/AIDS context. Furthermore, there is the expectation that if we know the causes we can cure, and everyone ought to be cured. Responding to these pressures, we promise ourselves that HIV/AIDS will be cured one day, and that cancer, diabetes, cystic fibrosis, Parkinson's disease, and many other diseases will be cured. The pressure to do more research and find a cure and effect the cure becomes moral pressure. When I take my car in for service, I expect the service people to discover the causes of its malfunctioning and to repair them. That creates a value-laden situation which is nonmoral in character. When the same procedures involve human bodies, they are transformed into issues of moral value.

Disease language *shapes our reality*. When we are told, "You have cancer" or "You have AIDS" or "You are fifty percent disabled" or "You will

not recover from this ailment," our reality is changed. We are moved into a specific social category, a pigeonhole, with certain prescribed benefits and certain prescribed limitations.

Our theology of disease needs to take the medical languages of disease seriously, both positively and critically. If the medical language speaks of terminality, suffering, and disability, we need to develop theologies that can respond positively and constructively to those realities. Our theology of disease should motivate and inspire active work in the world in behalf of health. We will also want to respond critically to what the medical language leaves out or distorts. Medicine cannot, for example, teach a person how to die, even though death awaits us all and bonds patient, physician, and caregiver as nothing else does. Our theology of disease needs to include death in its purview.

Medicine may be more oriented toward expensive procedures for the well-to-do few than toward public health services for many who are poor. Or it may focus on diseases that seem more glamorous or that can attract more research dollars. Our theology will include critique of inequalities and underscore the drive for justice.

Theologizing Disease

I have focused on the medicalizing of disease. Disease is also, of course, legalized, as when stem-cell research on Parkinson's disease is legally regulated. Disease is commercialized, by hospitals that must abide by the bottom line and by pharmaceutical and insurance companies that must bring a return to their stockholders. Disease is politicized when it requires the interventions of elected officials. Disease is bureaucratized or institutionalized when caregivers must structure their caring through organizations, private and public. On one hand, theology of disease must take all of these "izings" into account, because they constitute much of the real world of disease. People do not suffer diseases abstracted from medicine, law, commerce, politics, and bureaucracies.

On the other hand, theologizing disease should carry its own distinctive marks as well. What are those marks?

Theology will recognize the significance of *fragment* and work from that basis. What do I mean, fragment? Disease reminds us that we live in fragments and that we are ourselves fragments. Disease reminds us that we are a fragment of what we seem created and destined to be. If I am disabled, I know that my body is created for more, for ability rather than disability, but I live in that disabled fragment. If disease lays me up for a period of time, I recognize that I am losing the days of my life, and I must settle for the fragments of time that I have. If disease takes friends and loved ones from me, or leaves me in a solitary, shut-in situation, I recognize that my community has been fragmented and that I must live in the

fragment of community that is available to me. If disease weakens me to the point where I am more dependent on others to care for me, I recognize that my autonomy is fragmented and that I must live in dependency and give thanks for those who care. If disease thwarts my plans and my hopes for my life, I recognize that plans and hopes are but fragments, and I must work out my destiny in fragments. If disease is bringing my life to an end, I recognize that lifespan is a fragment; even a span of fourscore years and ten is a fragment.

In these fragment situations, theology will focus on the question, fragment of what? My depleted energies, my depleted autonomy, my solitude and even loneliness, my depleted dreams, my depleted life span—what are they fragments of?

The fragmentation of our lives through disease reveals to us that our lives are fragments of a larger and deeper healing. We are fragmented because we live our lives caught between wholeness and integration on one hand and disintegration on the other. Disease clarifies this for us, revealing to us that we live at a fundamental level within this dialectic of integration and disintegration. There are dimensions of integration and disintegration—organic, psychological, personal, communal, and spiritual—and each dimension opens a richer and deeper vista of the healing of which we enjoy only a fragment.

Finally, there is the historical dimension of disease and healing. This is the dimension that takes us out of ourselves and points beyond history. Christians refer to the kingdom of God, and they mean that the history we live in our lives and the history of our people and of our universe are fragments of a larger history. Jewish Kaballah traditions, and apocalyptic and eschatological visions, and the traditions of lament also point to this larger history.

Medicine, law, commerce, and bureaucracy do not speak of what lies beyond the fragment. The benefits they give us derive from their preoccupation with the one-dimensional here and now. This preoccupation also accounts for their demonic aspects. But they point to a richer set of dimensions, and that is what religion and theology speak of. On one hand, this focus on richer dimensions of the fragments of life relativizes the other worlds of medicine, commerce, law, and bureaucracy, relativizes them by saying that they are not enough. This is also a critique of those worlds, and the critique is not all from the outside; the work of Koenig, Potter, and others too numerous to mention is critique and reform from within. Many people within the world of medicine are redrawing the paradigms under which medical practice proceeds and giving attention to alternative medical philosophies and practices. Of course, the world of commerce, law, politics, and bureaucracy must also entertain alternative paradigms, and we know that some people within these worlds are working for the reform of theory and practice.

This focus on the richer dimensions beyond the fragment brings wholeness and healing, because such dimensions testify to the fact that the fragment has meaning and purpose, even when we do not see it. Meaning is wholeness, because it holds that disintegration does not finally define us—or the rest of the creation.

It may be that theology can make its most forceful witness to meaning and to the belief that the fragments of life share in meaning by speaking of death and dying. A theology of disease will teach us about death and how to die, because otherwise we will not know how to live in a diseased world. In reflecting on death, we can advance our belief that disease does not, finally, define us. American society badly needs instruction on how to die. Czech novelist Milan Kundera reminds us that all societies need this instruction. Death is perhaps the single most certain reality that all humans face, and it is also perhaps the single reality which we try hardest to ignore or deny. I recommend Kundera's novel *Immortality* (1991) for a stunning portrayal of our unwillingness to face death. We expend enormous amounts of money and energy in strategies of ignoring and denying death. And a great deal of that energy and money is channeled through the practice of medicine in its fight against disease.

All of these considerations raise the question of God—because, if fragments do cohere with something, if they are fragments of something, if they do mean, then God is real, because God *is* that meaning and that coherence. Saint Paul pointed in this direction when he preached to the Athenians that we "live and move and have our being" in God. He said it even more vividly in Romans, when he wrote, "Whether we live or whether we die, we are the Lord's." The process philosopher Charles Hartshorne made the point in this way: "We belong to God and God never dies. That is all we need to know." Nowhere is this belief more relevant than in the consideration of HIV/AIDS.

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