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### **SUFFERING TRANSFIGURED:**

# PHENOMENOLOGICAL PERSONALISM IN THE DOCTOR-PATIENT RELATIONSHIP

A Thesis Submitted to the Yale University School of Medicine in Partial Fulfillment of the Requirements for the Degree of Doctor of Medicine

by
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2011

#### **ABSTRACT**

From antiquity, one of the primary goals of medicine has been the alleviation of patients' suffering. Despite remarkable advances in modern science and technology, patients continue to experience suffering, which is frequently unnoticed and unaddressed by physicians.

Phenomenology incorporates an understanding of illness-as-lived, which provides the physician with a view more expansive than the purely biomedical model of disease. There exists a decisive gap between the way a physician thinks about disease and the way illness is experienced by the patient. As a result, there is a separation between the "lifeworlds" of the physician and patient. A fuller description of suffering in illness offers the physician an expanded paradigm of illness to enable her to narrow the gap between her own lifeworld and that of the patient. This thesis employs a clinically based phenomenological approach, observing the phenomena of disease and illness as they are encountered in the clinical setting, the nucleus of which is the doctor-patient relationship.

Suffering is certainly something that should be eliminated by all reasonable means and costs. It is also clear, however, that sometimes suffering is unavoidable in the patient's experience of illness. We hold these two truths in tension. On the one hand, it is a duty for physicians to try to alleviate unnecessary suffering. But what about inescapable suffering, particularly in cases of chronic and terminal illness?

Viktor Frankl notes that meaning can be a powerful avenue to the elevation of the human person in moments of unavoidable suffering. This thesis proposes that *suffering* can be transfigured by way of meaning and that physicians can play a powerful role toward this end. The will to meaning is a means to gains such as love, self-transcendence, achievement of a good, and the dignity of the person amid the losses experienced in suffering. This work offers a novel contribution to the medical literature by demonstrating that unavoidable suffering potentially can be transformed into a positive experience and that the doctor-patient encounter can be instrumental in this pursuit.

Rather than waiting for systemic changes in health care or medical education, this thesis argues that physicians can be instrumental in the alleviation and transformation of suffering simply by adopting phenomenological personalism in the practice of medicine. Premised on a heightened attentiveness to the patient's lifeworld, phenomenological personalism serves as a catalyst for the patient's discovery of meaning in unavoidable suffering. This approach does not exclude the biomedical model, but rather expands the lifeworld of the physician so that she is able to acknowledge and address the uniqueness of the patient's experience of suffering in illness. Thus, in moments of unavoidable suffering, a personal tragedy is transfigured into a human triumph.

#### **ACKNOWLEDGEMENTS**

"Arise, my beloved, my beautiful one, and come!
For see, the winter is past, the rains are over and gone."

-Song of Songs 2:10-11

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#### INTRODUCTION

From antiquity, one of the primary goals of medicine has been the alleviation of patients' suffering (Cassell, 2004, p. 29; Hanson & Callahan, 1999, p. 4). Despite remarkable advances in modern science and technology, patients continue to experience suffering which is frequently unnoticed and unaddressed by physicians.† Little attention has been given to the problem of suffering in medical education, research, and practice. As a result, much suffering continues to be unrecognized and unrelieved.

Physician Eric Cassell defines suffering generally as "the state of severe distress associated with events that threaten the intactness of the person" (Cassell, 2004, p. 32). He argues that there is "an evolving and necessary change in the goals of medicine from their narrow focus on the body to a wider concern with the sources and relief of illness in persons" (Hanson & Callahan, 1999, pp. 110-117). He further asserts: "The timeless goal of the relief of suffering remains the challenge to change and the enduring test of medicine's success" (Cassell, 2004, p. ix). Many experts agree with Cassell that medicine must concern itself more centrally with the suffering patient (Daneault, et al., 2004; Jansen & Sulmasy, 2002).

This thesis offers a novel contribution to the medical literature by applying insights from Cassell and others to the realm of *unavoidable suffering*. Although many have addressed the topic of suffering, this work goes one step further by both addressing *unavoidable suffering* in the patient's experience of illness and applying these insights within the framework of clinical relevance. I will demonstrate that, by way of

<sup>†</sup> In this work, I frequently opt to use the words "physician" and "doctor." My hope, however, is that these insights will be applicable to any health care professional engaged in the care of the patient.

phenomenological personalism, it is possible for the doctor to accompany the patient in her unavoidable suffering and, by doing so, to transform these distressing moments into a positive experience.

The words of Dr. Francis Peabody in 1927 hold true today: "Medicine is not a trade to be learned but a profession to be entered" (Peabody, 1927, 1984). In the first and second chapters of this thesis, I will establish the context in which the present dilemma of unalleviated suffering resides. Medicine is a *practice*<sup>‡</sup>, which is defined by philosopher MacIntyre as a complex organized social activity with an evolving tradition (MacIntyre, 2007). Clinical medicine is not a theory, pure or applied. Rather, it is a practice: a practice that is best understood as an interpretive meeting between the physician, on the one hand, and the patient on the other. At its core, the practice of medicine is a relationship between persons, with the central focus being the doctor-patient relationship. This thesis employs a clinically based phenomenological approach, observing the phenomena of disease and illness as they are encountered in the clinical setting, the nucleus of which is the doctor-patient relationship (Taboada, Cuddeback, & Donohue-White, 2002, p. 187). The goal of the relief of the suffering patient will be primarily situated within this context (Hanson & Callahan, 1999, p. 4).

Throughout the thesis, certain questions will recur that will be addressed throughout. First, within the practice of medicine, what is the predominant contributing factor to the phenomenon of unalleviated suffering in the patient? More profoundly, what is the nature of suffering in illness? Can anything be gained in suffering? What are the distinguishing characteristics of those individuals who flourish and find fulfillment

<sup>‡</sup> Please refer to the Glossary section for definitions of various terms presented throughout the thesis.

amidst unavoidable suffering? Finally, what are simple ways that physicians can better recognize and alleviate their patients' suffering?

The first question is primarily addressed in the second chapter of the thesis, which describes the present crisis ("*krinein*," in its Greek root, meaning "separation") in the doctor-patient relationship. There exists a decisive gap between the way a physician thinks about disease and the way it is experienced by the patient. As a result, there is a separation between the "lifeworlds" (e.g. horizons) of the physician and patient. Trained in the biomedical model, a physician's view of disease precludes a comprehensive understanding of illness (Baron, 1985, p. 606).

The biomedical and disease-focused emphasis of the physician, although frequently successful in identifying disease, lacks the full perspective necessary when caring for persons as they suffer with illness. Therefore, a paradox exists in modern medicine: "Even in the best settings and with the best physicians it is not uncommon for suffering to occur not only during the course of a disease but as a result of its treatment" (Cassell, 2004, p. 29). This paradox stems from the present worldview of the physician; when it is rooted solely in the biomedical model, the concept of suffering is often overlooked.

Consequently, the disease-based model frequently classifies the patient as having been successfully treated, yet the patient's suffering remains and sometimes increases. Such an absence of the acknowledgement of suffering can have devastating effects on the patient and can even augment his suffering. Thus, despite remarkable advances in science and technology over the past century, the suffering in a patient is frequently unnoticed and unalleviated. This empirical reality shows that the "biomedical dogmatism" in

medicine is insufficient in caring for the patient as it falls short of reaching a primary goal of the practice of medicine, namely, the alleviation of suffering.

In chapters three and four, the main body of the thesis, I offer a description of the nature of suffering in illness. This description draws mainly from phenomenological writings and is complemented by writings from the personalist tradition insofar as they are grounded in experience. I posit that a fuller description of suffering in illness offers the physician an expanded paradigm of illness to enable her to narrow the gap between her own lifeworld and that of the patient. This paradigm incorporates an understanding of illness-as-lived, which provides the physician with a view more expansive than the purely biomedical model of disease (Toombs, 1987, pp. 220-221). In chapter three I discuss the nature of suffering in illness and delineate some of its most salient features. I employ Boethius' timeless definition of the human person to describe the uniqueness of suffering, both to human beings as a species as well as to the individual person. Furthermore, John Paul II's definition of suffering creates harmony with Eric Cassell's, as the latter is a more suitable description for the topic of this thesis. John Paul II's observation, that a person suffers whenever experiencing any kind a privation of a good, provides a framework for examining the multifaceted losses that follow from suffering in illness. These privations include the loss, or perceived loss, of bodily integrity, control, order, the familiar world, dynamic equilibrium, and meaning.

Suffering is certainly something that ought to be alleviated by all reasonable means.† However, it is also quite clear that sometimes there is unavoidable suffering in

<sup>&</sup>lt;sup>†</sup> The preferred standard for a physician is that she ought to do "as much as is reasonable" in the alleviation of suffering. Doing "as much as possible" can be achieved only rarely and it would necessarily be unreasonable because, for example, it would take so much time that it would interfere with a physician's

the patient's experience of illness. "Man is a being which sooner or later must die and before doing so, must suffer—despite the advances in science so much worshipped by progressivism and scientism" (Frankl, 1988, p. 72). We hold these two truths in tension. On the one hand, it is a duty for physicians to try to alleviate unnecessary suffering. But what about inescapable suffering? Viktor Frankl argues that a painful fate ought to be avoided, but if that fate cannot be changed, it has the potential to "be transmuted into something meaningful, into an achievement" (Frankl, 1988, p. 72). A profound phenomenological analysis of such transmutation is present in the writings of Max Scheler (Scheler, 1960).

This acknowledgement of unavoidable suffering leads to the fourth chapter. At the heart of this section is an attempt to show that something can be gained in the losses of unavoidable suffering. More specifically, I posit that suffering can be transfigured by way of meaning. To say that suffering can be transfigured implies a state of transformation, whereby there is a change in outward appearance, form, or nature. Such transfiguration always encompasses a gain, even amidst the significant losses of unavoidable suffering.

Although there exists a plethora of literature demonstrating that suffering is inadequately addressed in modern health care, there is a paucity of resources on the specific ways unavoidable suffering can be transfigured into a gain. Through the attribution of meaning, integrating the illness within one's life narrative, and reorienting one's life towards fulfillment rather than worldly success, suffering has the potential to be transfigured into gifts such as love, self-transcendence, and authentic communion.

Drawing upon the work of Viktor Frankl, John Paul II, Max Scheler, Gabriel Marcel, Robert Speamann, and Eleanore Stump, chapter four provides a foundation to analyze the ways in which suffering, especially unavoidable suffering, can be transfigured.

The fourth chapter most distinguishes this thesis from other contemporary efforts toward more patient-centered medicine. Pursuits such as narrative medicine, patient-centered care, and the biopsychosocial model have prompted many physicians to better recognize and respond to the patient as a *person* rather than merely a pathology. This thesis is unique, however, by directly addressing the *unavoidable suffering* frequently encountered in medicine's daily activity, but rarely discussed or considered how to alleviate. I offer both a philosophical basis and feasible applications on how these occasions of unavoidable suffering can be transformed.

The fifth chapter applies these phenomenological insights to the doctor-patient relationship, the nucleus of the practice of medicine. It illuminates ways in which the physician can expand her horizon to encompass her patient's suffering, through adopting a phenomenological personalism in the practice of medicine. This section highlights the importance of attentiveness to the subjectivity of the patient and the "voice of the lifeworld" in the clinical narrative. Furthermore, it emphasizes the importance of the physician's docility to mystery and vivid presence in the clinical encounter. I argue that incorporating phenomenological personalism in the practice of medicine is a gateway to helping the suffering patient discover meaning in her suffering, which opens the patient to interior fulfillment and a host of other goods.

I argue that, rather than waiting for systemic changes in health care or medical education, physicians can play a powerful role in the alleviation and transformation of

suffering simply by adopting a phenomenological personalism in the practice of medicine. Phenomenological personalism is premised on a heightened attentiveness to the patient's lived experience of suffering in illness. It does not exclude the biomedical model, but rather expands the physician's view to encompass the lifeworld of the suffering patient. It can be seamlessly incorporated into most ordinary clinical encounters, requiring minimal demands on time and potentially offering prosperous outcomes in patient compliance and overall satisfaction. Through a developed phenomenology of suffering and its application in the clinical encounter, physicians have the opportunity to be a powerful conduit of relief for their suffering patients.

This thesis is not an empirical work, nor is it a type of exercise to test a particular hypothesis. Rather, it seeks to offer a theoretical and analytical foundation to facilitate future empirical pursuits. By drawing upon a body of writings from clinicians, patients, and academics, I hope to provide a more comprehensive description of the nature of suffering in illness, which will offer a basis for the testing of future hypotheses germane to this topic.

#### CHAPTER I

#### THE PRACTICE AND GOALS OF MEDICINE

In 1927, Dr. Francis Peabody made a timeless observation: "Medicine is not a trade to be learned but a profession to be entered" (Peabody, 1927). In this chapter, I will describe the professional context in which the patient's unrecognized and unalleviated suffering occurs.

Understanding medicine as a socially organized activity with a tradition entails viewing medicine as a *practice*. Central to the practice of medicine is the doctor-patient relationship, and one of the primary goals of this relationship is the relief of the suffering patient.

#### **Medicine as a Practice**

When I describe medicine as a *practice*<sup>†</sup>, I am referring to the writings of Alasdair MacIntyre who provided a philosophical basis applicable to modern medicine. He defines practice as

any coherent and complex form of socially established cooperative activity through which goods internal to that form of activity are realized in the course of trying to achieve those standards of excellence which are appropriate to, and partially definitive of, that form of activity, with the result that human powers to achieve excellence, and human conceptions of the ends and good involved, are systemically extended. (MacIntyre, 1981, p. 175)

<sup>&</sup>lt;sup>†</sup> Although I will provide definitions to the various terms presented in the text, there is also a glossary at the end of the thesis that defines the terms presented in this work.

internal goods are those goods only obtainable through a particular practice and realized through the exercise of the virtues. External goods are those goods that can be obtained in other ways that are not necessarily intrinsic to the practice and only contingently attached to the practice (MacIntyre, 1984, p. 190). A virtue is "an acquired human quality the possession of which tends to enable us to achieve those goods which are internal to practices and the lack of which effectively prevents us from achieving such a good" (MacIntyre, 1981, p. 191). Virtues concern internal goods, those shared goals that define the community of practitioners. See the Glossary for an explanation of how Aristotle's theory of virtue presents a similar perspective to MacIntyre's definitions.

Thus, a practice is defined as involving a purpose and a community that shares common ways of performing activities according to standards comprehended by those in the community. According to MacIntyre, throwing a ball with skill is not a practice but the game of football is. Clinical medicine is a practice but a clinic or hospital, as an institution, is not. Furthermore, under MacIntyre's definition, clinical medicine is not a theory, pure or applied; at its core, the practice of medicine is a relationship between persons that aspires to internal standards of excellence.

Dr. Joseph Merrill explains that "internal goods" are one characteristic that distinguishes a practice. "[I]nternal goods are shared values and goals which cohere the community of practitioners and which cannot be well understood outside the practice" (Merrill, 1990). For example, anyone can evaluate a person's ability to pole vault over a high bar. But being a good pole vaulter includes much more than leaping over high marks and is more complex than what can be evaluated by anyone unfamiliar with pole vaulting. Practices of all kinds, medicine included, "share the interdependent relationship between the practice and the goods internal to that practice" (Merrill, 1990).

Internal goods are distinct from external goods. External goods are those goods that can be obtained in other ways that are not necessarily intrinsic to the practice; external goods are only contingently attached to the practice. In the practice of medicine, external goods might include prestige, financial reimbursement, or power; they have nothing to do with the intrinsic quality of the practice. For example, a national newspaper

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In this thesis, the *practice* of medicine is comprised of members who have gone through the education and training called for to care for patients in their respective professional roles. Other thinkers would say that *patients* should also be considered members of the practice of medicine. For simplicity, I stipulate that patients are not members of the practice of medicine; members of the practice of medicine are those who have completed their medical education, including those in subsequent residency and/or fellowship training.

could praise "Dr. Fink" as "the best surgeon" because he has the lowest mortality rates in the operating room. This accolade refers to an external good in the sense that people outside of the practice of medicine can appreciate it. However, a physician within the practice quickly knows that Dr. Fink's lower mortality rates do not necessarily correlate with him being the best surgeon, as he could very well preselect patients with the most straightforward presentations and the fewest comorbities. Thus, although external goods in medicine may be desirable, they have no bearing on the values that determine the qualities of a good physician.

Internal goods are those "standards of excellence" held in esteem within the practice. They are learned as a prerequisite for participating in the practice and become increasingly appreciated and comprehended in this learning (Merrill, 1990). Consider the case of a patient, "Ms. Jones," who presents to the Emergency Department declaring, "I have the worst headache of my life!" A physician could choose to prescribe a dose of an analgesic, such as morphine, and send Ms. Jones away without any further diagnostic tests. Although Ms. Jones may be quite pleased that her headache is relieved, the physician's colleagues would immediately classify her care as "bad medicine." Those within the practice of medicine know that "the worst headache of my life" is potentially a red flag for a ruptured cerebral aneurysm, which can be lethal if not treated immediately. In addition to a brain hemorrhage, physicians would likely be concerned about a possible tumor or stroke, depending on the patient's particular presentation. For the Emergency Room physician to send Ms. Jones away solely on narcotics, without first obtaining a CT scan of her head, or even a thorough history and physical, would most definitely be dubbed as "bad medicine."

In this example, we see how the clinical skills and decisions to properly care for the patient are best evaluated by those within the practice of medicine. Those within the practice know that what Ms. Jones requires is a high quality clinical evaluation. Such an evaluation is an internal good of the practice and can be recognized and fully appreciated only by members of the practice. Those outside of the practice of medicine, including the patient herself, cannot fully appreciate the complexity of the clinical "standards of excellence" held in esteem by physicians within the practice.

The internal good, related to medicine's goal to relieve suffering, is the skillful selection and accomplishment of the various interactions and appropriate interventions that are most likely to accomplish the relief of suffering. Such selections, interactions, and interventions are the standards of clinical excellence that are evaluated and esteemed by physicians within the practice. In this thesis, I posit that the physician's incorporation of phenomenology in the doctor-patient relationship will assist the physician in achieving this particular internal good.

One of the first systematic and coherent attempts to identify and bridge the gap in the doctor-patient relationship was the 1981 publication *A Philosophical Basis of Medical Practice* by physicians Edmund Pellegrino and David Thomasma (Pellegrino & Thomasma, 1981, p. 80). The authors offered a simple definition of medicine, with *relationship* as the central emphasis. This relationship is exercised in the "medical event," namely the meeting between the doctor and the patient. Echoing Peabody, Pellegrino and Thomasma concur that medicine is first and foremost a practice, not a theory. As a practice, it is not to be considered merely applied medical theory or applied

† Pellegrino and Thomasma define *medicine* as "a relation of mutual consent to effect individualized wellbeing by working in, with, and through the body" (Pellegrino & Thomasma, 1981).

biological science; rather, the essence of medicine *is* clinical practice itself, with its nucleus residing in the relationship of the caregiver and patient. This conception of medicine as primarily a practice, rather than a theory, is bolstered by the fact that in the most important medical textbooks, there are no references to a general *theory* of disease or health.

Calling medicine a practice does not deny the importance of modern medical science, nor does it mean that medicine is solely an art. This description of medicine rather seeks to explain how art and science are *united* in the encounter and activity we call medical practice. Medical science undoubtedly has a significant role. Peabody expounds upon the importance of this unity of art and science in the practice of medicine:

The practice of medicine in its broadest sense includes the whole relationship of the physician with his patient. It is an art, based to an increasing extent on the medical sciences, but comprising much that still remains outside the realm of science. The art of medicine and the science of medicine are not antagonistic but supplementary to each other. There is no more contradiction between the science of medicine and the art of medicine than between the science of aeronautics and the art of flying. (Peabody, 1927)

In this way, "medicine is unique in being so thoroughly steeped in the practical on one hand and so dependent upon the humane and the scientific on the other" (Pellegrino, 1979, p. 31).

By describing medicine as a practice, I am attempting to pierce to its essential elements, namely, the doctor-patient relationship and the internal goods within the practice. I will use a phenomenological, person-centered approach to explore the doctor-patient relationship, as opposed to other interpretations of the clinical meeting, such as consumerist or legal-based interpretations. Phenomenology<sup>†</sup>, informed by and consonant

<sup>†</sup> Phenomenology is to be distinguished from, and related to, the other main fields of philosophy: ontology (the study of being or what is), epistemology (the study of knowledge), logic (the study of valid reasoning),

with the personalist<sup>‡</sup> tradition, will offer insight into the present state of the practice of medicine.

The term "phenomenology" is a compound of the Greek words *phainomenon* and *logos*. It signifies the activity of giving an account, a *logos*, of various phenomena; phenomena refers to the empirical events themselves that are manifest, revealed, or shown in experience. The historical movement of phenomenology is the philosophical tradition launched in the first half of the 20th century by Edmund Husserl and later by figures such as Martin Heidegger, Edith Stein, Maurice Merleau-Ponty, and Jean-Paul Sartre. Phenomenology studies conscious experience as experienced from the subjective or first person point of view (Stanford University. & Center for the Study of Language and Information (U.S.), 1997).

#### The Goals of Medicine

It is frequently assumed that the goals of medicine are well understood and selfevident, needing only sensible implementation. Without thoughtful reflection, however, various aspirations to excellence in health care throughout the world may fail altogether

or ethics (the study of right and wrong action). (Stanford University. & Center for the Study of Language and Information (U.S.), 1997)

Personalism" is a philosophical school of thought searching to describe the uniqueness of a human person. One of the main points of interest of personalism is human subjectivity or self-consciousness, experienced in a person's own acts and inner happenings. Personalism posits ultimate reality and value in personhood. It emphasizes the significance, uniqueness and inviolability of the person, as well as the person's essentially relational or social dimension. The title "personalism" can therefore legitimately be applied to any school of thought that focuses on the reality of persons and their unique status among beings in general. The term "personalist" normally acknowledges the indirect contributions of a wide range of thinkers throughout the history of philosophy who believed that the human person should be the ontological and epistemological starting point of philosophical reflection. These thinkers are concerned to investigate the experience, the status, and the dignity of the human being as person, and regard this as the starting-point for all subsequent philosophical analysis. Personalists include figures such as Dietrich von Hildebrand, Karol Wojtyła, Gabriel Marcel, and Edith Stein. I use the terms "personalism" and "personalist" tradition interchangeably and broadly throughout this thesis. (Stanford University. & Center for the Study of Language and Information (U.S.), 1997)

or not reach their fullest potential (Hanson & Callahan, 1999, p. 4). One reason we should care about the goals of medicine is that "modern scientific medicine seems to have elevated some goals of medicine—its intent to save and extend life, for instance—over other important goals, such as the relief of the suffering and the pursuit of a peaceful death" (Hanson & Callahan, 1999, p. xi). By recognizing the ensemble of medical goals and their proper relation and order to one another, physicians can become aware of the goods internal to the practice of medicine.

In 1993, the Hastings Center initiated a project, "The Goals of Medicine." This international multidisciplinary effort sought to offer a fresh articulation of the goals of medicine in light of contemporary possibilities and challenges. Ultimately, the working group identified four goals: (1) the prevention of disease and injury and the promotion and maintenance of health; (2) the relief of pain and suffering caused by maladies; (3) the care and cure of those with a malady, and the care of those who cannot be cured; and (4) the avoidance of premature death and the pursuit of a peaceful death (Hanson & Callahan, 1999, p. xi). In this thesis, I will focus on one dimension of the second articulated goal, namely, the "relief of...suffering caused by maladies." A dimension of the third goal—" the care of those who cannot be cured"—as it relates to the relief of suffering, will also be addressed.

Physician Eric Cassell argues that, when we examine the problem of suffering in medicine, we must conclude that there is "an evolving and necessary change in the goals of medicine from their narrow focus on the body to a wider concern with the sources and relief of illness in persons" (Cassell, 1999). In agreement with other experts, he asserts

that the timeless goal of the relief of suffering "remains the challenge to change and the enduring test of medicine's success" (Cassell, 2004, p. ix).

From antiquity, a primary goal of medicine has been the alleviation of the patient's suffering. The relief of suffering—one of the most important duties of the physician—also has significant contemporary relevance as chronic illness becomes increasingly prevalent in the West.

Suffering has myriad manifestations. Some suffering that accompanies disease is a response to the experience or knowledge of the disease itself. Fear, despair, profound fatigue, anxiety about the future, and a sense of futility and helplessness are examples of this kind of suffering. Other forms of suffering, often experienced in times of chronic or terminal illness, raise existential questions about the meaning of life and the meaning of the suffering itself. These questions seem to be outside the domain of the biomedical boundaries of medicine. Adopting a phenomenological view in the clinical relationship, however, allows the caregiver to "call upon his or her experience and perception of the world, simply being one human being with another human being..." (Hanson & Callahan, 1999, p. 25). Certainly even the most empathetic care has its limitations, as all human beings are finite. However, such an approach to the practice of medicine can vastly overcome the limitations of the biomedical approach and offer relief to the suffering patient as well as care for those who cannot be cured.

It is also important to note that the virtues have been integral to the tradition of philosophy and medicine. In classical times, the development of the virtues was emphasized by way of the practice of particular behaviors until these acts became habits. Virtues could be acquired (at least in part) as the result of a person's choices, by

deliberately forming habits and choosing to act in certain ways. Thus, there is a strong relationship between virtues and habits.

Similar to Aristotle's vision of instilling the virtues in the preparation of a person to become a "good citizen," virtues have an integral role in becoming and being a "good doctor." Virtues allow a physician to pursue internal goods in the practice of medicine. A physician pursues these internal goods by developing particular habits, which some writers call "habits of the mind" or "habits of the heart."

Each practice, medicine included, inculcates certain "habits of mind." These habits of mind derive from the familiar world and narrative tradition internal to the practice in question. They represent a distinct approach to the world and comprise the culture of a practice. It is relevant that these habits of mind provide a *horizon of meaning* by means of which reality is interpreted (Kestenbaum, 1982, pp. 6-7). Kestenbaum notes that a professional's "sense" of a situation is grounded in his habits of mind, some of which are the planned results of socialization, some of which are accidental outcomes, and some of which are tacit to the culture of the practice itself. Such habits have an enormous impact on the professional's understanding of the world.

Within medicine, the physician's habits of mind largely determine what he notices about the patient and what meaning he assigns to what he sees. Although there are notable contemporary efforts toward more patient-centered care, the prevailing habits of mind in several areas of modern medicine understand an illness mainly in terms of

<sup>&</sup>lt;sup>†</sup> Kestenbaum notes that habits of mind constitute experience—construct it—in ways that are not quite captured by concepts like paradigms, models, and worldviews. Paradigms, although a powerful way of talking about how we orient ourselves to the world, are a result of habits of mind. To the extent that a professional culture is a network of paradigms and models, it is a structure of naturalized, spontaneous, and taken-for-granted habits of mind (Kestenbaum, 1982).

"objective," quantifiable data. Indeed, it is often assumed by physicians that such clinical data *exclusively* represent the "reality" of the patient's illness (Toombs, 1992, p. 12). I will later discuss how these habits of mind make the physician susceptible to categorizing the patient's illness solely according to scientific constructs, which omit the concept of the patient's experience of suffering in illness.

#### Relevance of Phenomenology

Pellegrino and Thomasma go on to explain that whatever philosophical approach is used for the practice of medicine, it must resonate with the practice of medicine from the very beginning. In other words, a philosophy of medicine must reveal the meaning of practice—in phenomenological terms, its *ontology*. It must be a search for meaning in the practice of medicine and its many components; it also must have specific applications as a result of this search (Pellegrino & Thomasma, 1981, p. 50).

Pellegrino and Thomasma introduce the phenomenological tradition as a fitting philosophy for medicine. They note that Edmund Husserl's introduction of the "lifeworld" (*lebenswelt*)—a world of practical experience—is used as a condition of theory and ideas. Each person's experience is uniquely shaped by a variety of factors—cultural, ethnic, familial, spiritual, financial, educational, etc. The lived experience of the person forms his lifeworld; things that are not somehow connected to a person's lifeworld of practical experience cannot be fully understood or appreciated by the individual. Thus, in phenomenology, the lifeworld is the limiting factor on the realm of theory. Hence, "theory is derived only from the lifeworld as its condition of possibility, its necessary basis, and must be capable of being applied back to the everyday realm of *praxis* to gain

its acceptance" (Pellegrino & Thomasma, 1981, p. 51). Husserl's phenomenology requires that the concrete lifeworld be brought into consideration for the final clarification, both of science and all other human activities and their results. This notion of a lifeworld, a world of practical experience, is vitally important to medicine, as medicine is a practical discipline. *Praxis*, as distinguished from theory, is the application or use of professional skills and knowledge.

MacIntyre's concept of *practice* relates strongly to these phenomenological terms. In the practice of medicine, a physician is embedded in a community that shares common ways of performing activities, which are according to standards of excellence comprehended by those in the community. The culture, standards, knowledge, and interactions within the practice of medicine actively shape a physician's *lifeworld*. A physician's *lifeworld* can be limited or expanded depending on these defined standards of excellence (e.g. internal goods) as well as the milieu that shapes the actualization of these goods.

Two different but similar approaches are often employed in attempting to come to grips with problems of practical life. One approach starts with empirical data and seeks to classify such data according to categories that are not grounded in the essence or reality of things but, rather, in a certain way of thinking. The other approach consists in predefining a framework, an abstract theory. It then attempts to deduce from that abstract theory what should be done in a concrete case, or the manner in which empirical data should be adjusted. Such "adjustments" often prove difficult or even impossible when incorporating the complexities of reality, since this way of thinking sets the scientist's

primary aim at preserving the purity of his theoretical approach (Taboada, et al., 2002, p. ix).

Phenomenology<sup>†</sup> offers a third approach. Phenomenology believes that "in the empirical material itself there are elements of rationality, and recurring forms in the presentation of empirical data" (Taboada, et al., 2002, p. ix). These rational elements and recurring forms allow us to discern the fundamental essences of particular phenomena as well as the essential laws that govern them.<sup>‡</sup>

All phenomena can be explored when we realize that consciousness is a consciousness "of" something, that it is not locked within an egocentrically enclosed box or bubble. Cartesian, Hobbesian, and Lockean traditions, the dominant traditions in post-Enlightenment Western culture, present an "egocentric predicament," suggesting that all we can be sure of at the start is our own conscious existence and the states of that consciousness. This consciousness, then, is like an enclosed box, not directed toward things "outside." Phenomenology liberates modern man from the cramped confinement of the Cartesian mind by recognizing the reality and truth of phenomena, of *things as they appear*. It stands at the interface of subjectivity and objectivity. Phenomenology contends that appearances are real; they belong to being. Things that the Cartesian tradition classified as existing merely in the mind are now found to be ontological, part of the being of things (Sokolowski, 2000, pp. 8-15). To Descartes, the "I," the *ego cogito*, is

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<sup>&</sup>lt;sup>†</sup> In the beginning of the 20th century, a group of prominent thinkers crossed paths at the University of Freiburg in Germany. These scholars included Edmund Husserl, Edith Stein, and Martin Heidegger. Their insights incepted a new method of inquiry called phenomenology. As previously noted, the term "phenomenology" is a compound of the Greek words *phainomenon* and *logos*. It signifies the activity of giving an account, a *logos*, of various phenomena; "phenomena" refers to the empirical events themselves that are manifest, revealed, or shown in experience

<sup>&</sup>lt;sup>‡</sup> In related Kantian metaphysics, phenomena are objects and events as they appear in our experience, as opposed to objects and events as they are in themselves (*noumena*).

an immaterial thing. As such, it is irrevocably sealed off both from its own material body and from the bodies of other egos. Phenomenology rejects this mind-body dualism, most importantly because such dualism "flies directly in the face of the irrepressible evidence of our own concrete experience as willful, desiring, sentient beings" (Aho & Aho, 2008, p. 29).

Although there are a variety of schools or approaches to phenomenology, there are commonalities that allow one to speak of an overall "phenomenological approach." The most critical common denominator derives from Husserl's injunction: "to the things themselves." The phenomenologist is committed to setting aside his or her presuppositions and prejudices about the nature of objects or "reality" and begins instead with immediate experience. Thus, phenomena are encountered simply and precisely as they are encountered (Toombs, 2001, p. 1).

One of the principal aims of the phenomenological approach is to allow whatever is given to be received as pure phenomena (the things-as-meant) and to compose descriptions of the invariant features of such phenomena. In this sense, phenomenology is essentially a "reflective enterprise" (Toombs, 2001, p. 1). Through the phenomenological lens, both the common sense world itself *and* one's experiencing of that world become the focus of reflection. The pursuit is to expose and test one's taken-for-granted assumptions about everyday life, in an effort to account for one's consciousness of the world.

Phenomenology, therefore, is a radical inquiry, or *epoche*, in which the questioner sets aside all preconceptions. It attempts to understand the world as it is given in consciousness rather than as it is explained scientifically. Phenomenologists believe that

it is in consciousness that the "objective" world is perceived as objective, and therefore it is man's consciousness that necessarily constitutes the world. Thus, *persons and their experience are at the center of phenomenological inquiry*. The scientific world remains, but it loses its dominance over the total world of experience, and it is understood as only one aspect of consciousness.

#### Phenomenology in Medicine

Medicine, informed by phenomenology, maintains its biomedical dimension.<sup>‡</sup> However, this dimension is interpreted in light of the lived reality of the patient as a person. Rather than accepting scientific descriptions as definitive, phenomenology takes seriously the world as it is *experienced*. In this way, phenomenology seeks to unite the experience of the human person with science, as it examines "the ground on which natural science walks" (Baron, 1985, p. 608).

A phenomenological approach to medicine provides a rich and powerful means to render explicit the different, and often divergent, perspectives of the physician and the patient. When we focus on the physician's lifeworld, defined by a scientific conceptualization of disease, and then contrast it with the patient's lifeworld, defined by an experience of illness, the differing meanings and horizons of meaning experienced by the physician and patient become apparent. The explication of these phenomena—the physician's and the patient's differing horizons of meaning—can then help us understand the present gulf between the physician and patient.

<sup>‡</sup> It is important to note that phenomenological approaches within medicine are not altogether new. For more on this history see: (Kestenbaum, 1982, pp. 1-34)

This phenomenological perspective reveals a "decisive gap" in the physician-patient relationship: There exists a fundamental disjunction of meaning between the lived experience of the patient and the scientific explanation of the physician (Toombs, 2001, p. xv). This systemic distortion can have dramatic effects on the physician-patient relationship. Most notably, it can lead to a failure on the physician's part to recognize and relieve a patient's suffering in illness.

In the upcoming chapters I will describe how a patient's apprehension of suffering in illness is distinct and often at odds with a physician's apprehension of illness as a disease state. Thus, when a physician and patient communicate about "illness," they are often discussing two qualitatively different realities and, consequentially, often have different therapeutic goals. An explicit recognition of these fundamental differences—between the illness-as-suffered and what I have called the disease state—is important for developing shared meaning between a physician and patient. Attentiveness to the patient's experience of suffering in illness, rather than an exclusive focus on the biomedical issues of the disease state, allows the physician, both in the clinical encounter and in the determining of therapeutic goals, to acknowledge and address the uniqueness of the patient's suffering.

Maurice Merleau-Ponty observed that "phenomenology can be practiced and identified as a manner or style of thinking, that it existed as a movement before arriving at complete awareness of itself as a philosophy" (Merleau-Ponty, 1962, p. viii). In this spirit, my approach will be to draw upon phenomenology as a "style of thinking," more than as a formal methodology. I will not be strictly wedded to phenomenology in its ontological and epistemological features as a philosophical discipline. Rather, I will share

the rich insights of various voices within the phenomenological tradition, within its "habit of mind." By utilizing such an approach, I hope to develop the phenomenological "habit of mind" toward the present state of the doctor-patient relationship (Kestenbaum, 1982, p. 16).

Moreover, I will draw from a number of thinkers outside the phenomenological tradition whose approach is similarly grounded in experience. Much of the work of scholars such as Frankl, Cassell, Pellegrino, and John Paul II also turns to natural experience as the starting point of every kind of thinking that goes beyond natural experience (Stein, 2002, p. 333). Even though not all knowledge resides exclusively in experience and even though there is experience which can be known by pure reason, it nonetheless remains the aim of this work to arrive at an understanding of the world through experience, both in the doctor-patient relationship and in the patient's experience of suffering with illness. Accordingly, I will draw from various thinkers insofar as their thought is grounded in experience. My hope is that the insights of these writers will resonate with phenomenological insights.

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At various points in the text, distinguishing factors between phenomenologists will be identified as such differences are relevant to the issue under discussion. This inquiry does not aim at confronting the phenomenological tradition with other traditions, such as Thomism and existentialism. To do this would require a special treatise of vast scope and would deflect from the centrality of the work. This piece is merely concerned with employing the richness of such writings as they are relevant to the practice of medicine and the suffering patient. I will draw from these writings insofar as they are oriented to this end. <sup>‡</sup> Thinkers grounded in the basis of experience include Thomas Aquinas, Viktor Frankl, John Paul II, Max Scheler, Gabriel Marcel, Edmund Pellegrino, S. Kay Toombs, Richard Zaner, and Eric Cassell.

#### Summary

In summary, medicine is considered to be a particular form of practice with a certain inter-subjective framework, rather than an assembly of scientific theories and technologies applied in the clinic (Pellegrino & Thomasma, 1981; Svenaeus, 2001, p. 177). More precisely, medicine is viewed as an interpretive, helping meeting between two persons<sup>†</sup> with one of its goals being the relief of suffering in the help-seeking patient (Svenaeus, 2001, p. 177).

Phenomenologists and other thinkers grounded in the basis of experience offer fruitful insights into the present state of the doctor-patient relationship. These writings reveal a decisive gap between the physician's apprehension of the patient's illness and the patient's experience of suffering in illness. My inquiry will first observe the physician's apprehension of the patient's illness in the context of modern medicine. I will then offer a description of various dimensions of the patient's experience, focusing on the nature of suffering in illness. I will argue that the goals of medicine, particularly the alleviation of suffering, can be more adequately met when the physician brings a phenomenological gaze to bear upon the patient's experience of illness-as-lived. This is especially relevant in cases of incurable illness, and it is increasingly important as chronic illness in the West increases.

Without supplanting the advances of medical science and technology, I posit that an adequate phenomenology of suffering in illness will help physicians to better recognize and alleviate suffering in their patients. A fuller perspective on illness-as-lived will also help lay a new foundation for the care of patients who seek medical help but

 $<sup>^{\</sup>dagger}$  In this work I will refer to the two persons as the "patient" and the "physician" (or "doctor"). However, I hope that these insights bear relevance to any health care professional.

manifest none of the clinical symptoms of disease in the biomedical framework (Hanson & Callahan, 1999, p. 24). Thus, when all or parts of a patient's presentation do not fit neatly into a biomedical structure, physicians will still be equipped to care for patients by relieving their suffering. This thesis seeks to formulate essential insight into the state of the doctor-patient relationship and the nature of suffering in illness that may then lead to concrete action in meeting the goals of the practice of medicine.

#### **CHAPTER II**

#### CRISIS IN THE DOCTOR-PATIENT RELATIONSHIP

Hans Jonas observed, "Any problem is essentially the collision between a comprehensive view (be it hypothesis or belief) and a particular fact which will not fit" (Zaner, 2004, p. 130). Jonas' lesson becomes clear when we examine the dynamics of the doctor-patient encounter in modern medicine; there are frequently "particular facts" presented by the patient that do not fit within the "comprehensive view" of the physician. Vomiting due to nervousness before an exam is just as real as vomiting due to pyloric obstruction. Headaches from emotional stress may be just as painful as those from a brain tumor. Furthermore, medical cases often considered "successfully treated" by the physician frequently result in the patient's suffering being unrelieved, or perhaps even augmented as a result of the treatment. Many times, particularities of the patient's experience do not fit within the comprehensive view of the physician.

What Jonas would consider a problem, I call a crisis. The word crisis is derived from the Greek root "krinein," which means, "to separate." Indeed, a separation presently exists between the doctor and the patient; there is a decisive gap between the patient's experience of illness and the doctor's apprehension of the patient's illness. Although this separation seems to be widely recognized in contemporary medicine, the gap is often regarded as a matter of different levels of knowledge, with the physician's conceptualization being seen as the more accurate representation of the "reality" of illness. The following analysis of the constitution of meaning in the relationship between physician and patient reveals that the difference in understanding is not only more

significant than is generally recognized, but it is also *not* simply a matter of quantitatively different levels of knowledge. Rather, the difference in understanding is a *qualitative* distinction.

Phenomenologist Edmund Husserl notes that the manner in which an object is experienced strictly correlates with the way in which a particular individual attends to it (Husserl, 1969). In Husserl's language, this activity of consciousness renders the object "thematic." Each individual is situated in a lifeworld that is unique, that has particular themes. The further apart the respective lifeworlds of two individuals, the higher the probability that they will not understand each other.

In medicine, this activity of consciousness determines the meaning of illness and, therefore, the understanding between the doctor and the patient. Each is motivated to attend to different aspects of the experience, and each thereby renders it thematic in a qualitatively distinct manner. It is normative for the physician to be trained to perceive the patient's illness as a collection of physical signs and symptoms that define a particular disease-state. By contrast, the patient attends to the illness as a lived reality and, when the patient suffers in illness she experiences a threat to the integrity of her self within her respective lifeworld. The physician and the patient therefore have distinctive and qualitatively different foci. The more exclusively the physician relies on a biomedical, disease-based framework, the greater her difficulty in understanding the patient's apprehension of illness.

S. Kay Toombs<sup>†</sup> elucidates these fundamental differences in light of her firsthand immersion in clinical medicine as a multiple sclerosis patient. She reflects: "In discussing my illness with physicians, it has often seemed to me that we have been somehow talking at cross purpose, discussing different things, never quite reaching one another" (Toombs, 1987, pp. 219-220). Toombs notes that this inability to communicate does not necessarily result from inattentiveness or insensitivity on the part of the physician, but rather from a fundamental disagreement about the nature of illness itself. The thematic divergence is qualitative in origin.

Richard Baron, a physician and phenomenologist, describes this gulf during his routine interactions with patients on rounds. While auscultating a patient's chest, the patient began to ask him a question. "Quiet," Baron said, "I can't hear you while I'm listening" (Baron, 1985, p. 606). This brief exchange holds broad implications; it is "as if physicians and patients have come to inhabit different universes," Baron comments (Baron, 1985, p. 606).

Leo Tolstoy similarly captures this difference in thematic orientation between the physician and the patient in *The Death of Ivan Ilyich*. Ivan, the novel's protagonist and patient, reflects on his clinical encounter:

For Ivan Ilych only one question mattered: was his condition dangerous or not? But the doctor ignored this inappropriate question. From the doctor's point of view it was an idle question and not to be discussed; there existed only the weighing of probabilities—a floating kidney, chronic catarrh, or appendicitis. It was not a question of Ivan Ilyich's life, but an argument between a floating kidney and the appendix... On the way [home] he [Ivan] kept going over what the doctor had said, trying to translate all these complicated, vague scientific terms into simple language and read in them the answer to the question: bad—is it very bad for me, or still all right? (Tolstoy, Pevear, & Volokhonsky, 2009)

<sup>&</sup>lt;sup>†</sup> Toombs' background as a philosophy professor underscores her observations on the physician and the patient's inability to communicate. She argues that phenomenology can provide important insights in the fundamental differences in perspective between the physician and the patient.

These reflections of Toombs, Baron, and Tolstoy all suggest that illness represents two distinct realities for the doctor and the patient, where the meaning for one is significantly and qualitatively different from the meaning for the other (Toombs, 1987, pp. 219-220). Consequently, there exists a decisive gap between the patient's experience of illness and the physician's perspective on the patient's illness. Toombs writes, "The nature of this gap must be recognized by the practicing physician if he is to constitute a shared world of meaning with his patient and thereby assist him in dealing with the existential predicament of his illness" (Toombs, 1987, p. 220). But Baron asks: "How can we [physicians] train ourselves to listen and hear at the same time? Is there any intellectual system that allows us to take human experience as seriously as we take anatomic pathology?" (Baron, 1985, p. 606)

Further on, I will describe how phenomenological personalism in the practice of medicine helps physicians to incorporate more fully the experience of their patients.

First, however, I will examine more closely the meaning of the patient's illness through the lens of the physician.

#### The Physician's Apprehension of the Patient's Illness

#### Historical Roots

Several historical realities have been influential in shaping the world of modern medicine and, at the same time, the physician's apprehension of the patient's illness.<sup>†</sup>

<sup>†</sup> Note: This historical overview coincides with how knowledge became decontextualized in post-Enlightenment philosophy. This decontextualization reflected "a historical shift from practical philosophy, whose issues arose out of clinical medicine,...to a theoretical conception of philosophy... Thus, from 1630 Here I am centrally concerned with the impact of the evolution of medical knowledge on the meeting between the physician and the patient. The principle focus of modern medical practice is on the concept of disease. Dr. Robert J. Levine offers the following definition:

In the modern concept of disease, it is a distinct entity, the presence of which is verifiable objectively; it has a cause, and if we can identify the cause the physician can either cure or prevent it, or the means of its cure or prevention inevitably will be developed by the biomedical researcher. This view of disease presupposes that it is something distinct from the person who contracts it and that if rid of it, the person will be normal (healthy). (Levine, 2008, p. 211)

The doctrine that each disease is a distinct entity, the presence of which is objectively verifiable, underpins the birth of modern medicine.

Most prominent historians agree that the genesis of modern medicine took place in Paris during the turbulent years following the revolution of 1789 (Foucault, 1994). Under the intellectual leadership of Xavier Bichat, a group of Parisian physicians established the doctrine that each disease is a distinct entity (Levine, 2008; Shryock, 1948, p. 129). The philosophical perspective of these physicians was that of the French *ideologues* who adopted the philosophical empiricism of Locke. Under the influence of the Parisian group,

[T]wo major traditions of medical science—each of which had yielded a classification of disease—were fused: (1) careful and systematic observation of the living sick person (clinical observation), and (2) systemic dissection of the dead person (necropsy), which yielded a body of knowledge known as morbid anatomy (forerunner of pathology, the study of diseases). (Levine, 2008)

Modern medicine arose through the unification of these two fields of study: clinical observation and pathological anatomy. Although neither the clinical nor the anatomical

on, the focus of philosophical inquiries has ignored the particular, concrete, timely, and local details of everyday human affairs: instead it has shifted to a higher, stratospheric place on which nature and ethics conform to abstract, timeless, general, and universal theories" (Toulmin, 1992, pp. 34-35).

investigations were invented in Paris around 1800, they were united there in a way that resulted in a new approach to the human body and disease.

Furthermore, the emergence of education in the hospital setting provided fertile soil for this new approach to prosper. Once necropsy was linked to clinical observation, most diseases were named after the abnormality found at dissection. For example, hepatitis (*hepar*=liver; *itis*=inflammation) was named for a disease that produced inflammation of the liver. Levine notes that the ultimate test of a diagnosis was if it could predict what would be found in dissection. Likewise, the ultimate test of a physician was if he or she could predict what would be found in the morgue (Feinstein, 1967, p. 385).

The early 19th century marked the commencement of the era of disease-based medicine, which began with the "discovery" of diseases by this French school of physicians. The success of modern medicine rests on this clinical-pathological connection, which is a combination of disease theory and science (Cassell, 2004, p. 19). The genius of the disease-based theory is that it provided both a common basis of understanding for physicians and a reason for bringing science to bear on the problems confronted in clinical medicine. The clinician's aim was to "discover in the sick patient that unique phenomenon with its unique cause that is the disease (and thus the source of the sickness), and to base diagnostic and therapeutic actions accordingly" (Cassell, 2004, pp. 6-7). Patients began to be classified according to an investigation based, not on what they told the doctors about their symptoms, but primarily on signs detected through the inspection of their bodies. The merging of clinical observation and necropsy led to the body of a patient being looked upon as a functional space where diseases reside.

The idea of disease as a cause that produces clinical symptoms was elaborated by Rudolph Virchow in 1860 when he argued that the origin of all illness is a pathological process that ultimately resides in the cells of the organism, not in its tissues or organs. Virchow asserted that illness derives its being from disease, and disease is said to explain or cause specific clinical phenomena. General intellectual currents of the mid-19th century further supported and promoted this reductionist view. Ideas and practices migrated from France to Germany where, under the influence of the German school of physiological medicine, anatomic pathology and pathologic physiology came to be seen as the focus and end point of clinical medicine. Virchow described the prevalent ideals of the practice of medicine in mid-19th century Germany:

The ideal which we shall strive to realize, as far as it is in our power, is, that practical medicine shall become applied theoretical medicine, and that theoretical medicine shall become pathological physiology. Pathological anatomy and clinical medicine, the justness and independence of which we fully recognize, are essential to us as sources of new questions, the answering of which will fall to pathological physiology. (Faber & Cole, 1923, pp. 67-68)

Clinical medicine became a source of questions to be addressed by the higher, overarching discipline of pathologic physiology. The theoretical orientation of pathologic physiology became increasingly the determining principle of clinical medicine.

Throughout the 19th and 20th centuries, other natural sciences were brought to bear on the identification of the causes of diseases, and of the mechanisms through which they produce malfunction. Levine notes:

With time, names began to be assigned to diseases according to their causative agents, for example, streptococcal sore throat (named for the bacteria that cause it); or by the physiological (e.g. high blood pressure) or biochemical (e.g. phenylketonuria) aberrations through which they might be identified... Although the scientific disciplines used to identify and explain disease have evolved, the necessity of objective verification remained constant. Lack of objective

verification may cast doubt on the legitimacy of a discipline, on a proposed disease entity, or on the credibility of a patient. (Levine, 2008)

The rise in technology resulted in further reliance on objective verification. By the early 20th century, medicine began to be characterized by a hunt for precision with the introduction of techniques such as X-rays and blood tests. Progress in fields such as physiology, microbiology, and chemistry offered physicians ever greater opportunities to base diagnoses on an objective understanding of bodily mechanisms.

Jodi Halpern, MD, PhD notes the effect of this emphasis on scientific objectivity in the clinical relationship:

Even before this understanding yielded the improved health outcomes of midcentury, physicians enamored of the laboratory scientist's power donned white coats and wrote of the importance of emotional detachment, severing the link between reliability and emotional depth. (Halpern, 2001, p. 22)

Seeking ever greater objectivity in data collection, physicians began to develop tools and techniques such as the stethoscope and arms-length visualization, which distanced them further from their patients (Halpern, 2001, p. 22).

Sir William Osler, the "father" of modern American medicine, brought the new ideal of scientific medicine into the domain of the doctor-patient relationship.<sup>†</sup> Osler originated bedside patient rounds at John Hopkins University Hospital, in which "physicians, dressed like scientists in white laboratory coats, stood before a patient's bed, asking questions like detectives" (Halpern, 2001, p. 22). Although Osler himself exhibited profound empathy, this ritual led to even greater distancing from the patient in later decades. One physician comments when reflecting on 21st century medicine: "The

<sup>&</sup>lt;sup>†</sup> It is important to note that Osler *himself* exemplified empathic understanding toward his patients. For example, he cured a girl with hysterical paralysis not by employing a technical intervention, but by recognizing her fear and linking it to her paralytic state. Osler did contend, however, that overcoming subjective bias is necessary to acquire true knowledge of a disease.

fact that a ward round now can be done round the charts rather than round the beds is an indication of how far we have gone" (McWhinney, 1993, p. 8).

The disease-based model escalated after World War II when the use of antibiotics became firmly established in the practice of medicine. This was quickly followed by other drugs for endocrinological, immunological, and mental diseases. Biochemistry was now being employed not only as a diagnostic tool, but to treat diseases once considered incurable. Physicians and patients alike were impressed by these developments.

Likewise, the face of medical education began to change in the early twentieth century following the publication of the Flexner Report; disciplines such as microbiology, biochemistry, and genetics moved swiftly into medical education. A new theme was sounded: "every doctor should now become a scientist" (Svenaeus, 2001, p. 37).

These trends reinforced a tendency that had been present since the birth of modern medicine: medical specialization. Since the late 1880s, the general practitioner—the family doctor—"has been on the retreat," if one compares the proportion of generalists to specialists. In the 1950s, the specialization of medicine became even more firmly established. As a result, the patient began to be shuttled between different medical specialties that observe and treat different parts of the patient's body (Svenaeus, 2001, p. 38).

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The Flexner Repost is a study published in 1910 under the Carnegie Foundation that influenced the American medical education to conform to a single model that emulated that which prevailed in the European university-based model. It called for American medical schools to enact higher admission and graduation standards as well as to adhere to the protocols of mainstream science in their research and teaching. It also called for the incorporation of the "laboratory sciences" (e.g. the "preclinical sciences") into the first two years of the medical school curriculum. After the Flexner Report's publication, nearly half of American medical schools merged or closed from not meeting its standards. Although the Report is over 100 years old, many of its recommendations are still relevant and active today.

What are the implications of this history? One observation from Hans-Georg Gadamar is that the appearance of medical specialization promoted "the disintegration of the person," as the medical specializations objectify the individual patient according to a multiplicity of data (Svenaeus, 2001, p. 38). Gadamar was not the first to critique modern medicine's lack of attentiveness to the patient as an integrated person. The first efforts to introduce a more person-centered approach into undergraduate medical curricula date back to Adolph Meyer's program at Johns Hopkins in the early 20th century (Engel, 1977, p. 135). There was concern even at this early point that the popularity of the disease-based model would lead physicians to regard disease as more "real" than the lived experience of the patient. Dr. Francis Peabody voiced further concerns in his 1927 address to Harvard Medical Students:

In all your patients whose symptoms are of functional origin, the whole problem of diagnosis and treatment depends on your insight into the patient's character and personal life, and in every case of organic disease there are complex interactions between the pathologic processes and the intellectual processes which you must appreciate and consider if you will be a wise clinician. There are moments, of course, in cases of serious illness when you will think solely of disease and its treatment; but when the corner is turned and the immediate crisis has passed, you must give your attention to the patient... Disease in man is never exactly the same as disease in an experimental animal, for in man the disease at once affects and is affected by what we call the emotional life. Thus, the physician who attempts to take care of the patient while he neglects this factor is as unscientific as the investigator who neglects to control all the conditions that may affect his experiment. (Peabody, 1927, 1984)

Peabody advised students to consider the patient in a more comprehensive manner, and to not rely solely on the disease-based model. In order to be truly scientific, a physician must consider all the variables that impact the patient. Since the patient is a human person, such variables necessarily include the intellectual and emotional life.

Looking back at medicine's history, we can follow the developing intimacy between medicine and science that resulted in medicine's adopting a scientific worldview. Modern disease theory inaugurated this application of science to the practice of medicine, and made it viable. As a result, "medical science and disease theory have become amalgamated in the minds of physicians (and patients)" (Eric J. Cassell, 2004, p. 99). The dominance of the biomedical model in modern medical practice is a product of this amalgamation.

## Biomedical Dogmatism

The prevailing model of illness in modern western medicine is the biomedical model, where illness is identified as a pathological or pathoanatomical fact (Baron, 1981; Engel, 1977; Kleinman, 1988; Schwartz & Wiggins, 1985; Toombs, 1992).† George Engel, in his seminal article, "The Need for a New Medical Model: A Challenge for Biomedicine," charged that medicine is under the sway of "biomedical dogmatism" (Engel, 1977). This dogmatism assumes that disease can be fully accounted for by deviations from the norm of measurable biological (somatic) variables. Engelhardt expanded this observation by noting that, within the biomedical model, the level of "disease state" is conceptualized according to the neologies of the basic sciences, namely pathoanatomical, pathophysiological, and microbiological neologies (Engelhardt, 1982b, p. 47). The physician thus schematizes the patient's illness *as* a pathophysiological process.

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<sup>&</sup>lt;sup>†</sup> Engel offer a broad definition for this model as "nothing more than a belief system utilized to explain natural phenomena, to make sense out of what is puzzling or disturbing" (Engel, 1977).

The biomedical approach can be more fully understood in light of Husserl's distinction between the world of everyday experience ("lifeworld") and the world of science. Husserl calls these varying worlds the "natural attitude" and the "naturalistic attitude." In the "natural attitude" we find ourselves always within the world of immediate experience. The natural attitude of everyday experience is presupposed and pre-given in all that we do, as we take the existence of the world (and the objects within it) for granted without explicitly investigating the world *as* world (Toombs, 1992, p. 13). In contrast, the "naturalistic attitude" considers the world itself as a scientific *theme*. The aim of the naturalistic, or scientific, attitude is to grasp the nature of "reality" and describe it "objectively," characterizing the "thing-in-itself" apart from one's experience of it (Toombs, 1992, p. 14). Objective truth, according to the naturalistic attitude, can be captured in quantifiable data.

Husserl's distinction between the natural and the naturalistic attitude sheds lights on the different worlds of the physician and the patient. The physician, insofar as she is engrossed in the biomedical model, remains in the naturalistic attitude, conceptualizing the patient's illness in terms of objective, scientific constructs. In effect, the naturalistic attitude of the physician reifies the illness and conceives of it as an objective entity—a disease state (Toombs, 1992, p. 14).

Engel reflects on how steeped Western society is in the biomedical, naturalistic attitude. Beyond providing a basis for the scientific study of disease, Engel claims that biomedicine has become Western culture's specific perspective on disease, "our folk model":

Indeed the biomedical model is now the folk model of disease in the Western world. In our culture, the attitudes and belief systems of physicians are molded by

this model long before they embark on their professional education, which in turn reinforced it without necessarily clarifying how its use for social adaptation contrasts with its use for scientific research. The biomedical model has thus become a cultural imperative, its limitations easily overlooked. In brief, it has acquired the status of *dogma*. In science, a model is revised or abandoned when it fails to account adequately for all the data. A dogma, on the other hand, requires that discrepant data be forced to fit the model or be excluded. Biomedical dogma requires that all disease, including mental disease, be conceptualized in terms of derangement of underlying physical mechanisms. (Engel, 1977, p. 130)

In the present practice of medicine, the physician is an "assigner of understandings" in that she takes the patient's subjective report of illness and reinterprets it in terms of her own understanding of disease processes, highly influenced by the biomedical model (Toombs, 1987, p. 227). The physician's assignment of meaning is, therefore, quite different from the patient's assignment of meaning. Thomas Aquinas' axiom is relevant: "the received is in the receiver according to the mode of the receiver" (Aquinas & Dominicans. English Province., 1947, pp. q. 84, a. 81). The "mode" of the physician is phenomenologically distinct from the "mode" of the patient. Inevitably, they will have different understandings of one another.

There are certainly advantages to the biomedical model, which can bring order to the complexity of patient presentations. With its firm basis in the biological sciences and its vast technological resources, the biomedical model has been successful beyond all expectations, elucidating mechanisms of disease and creating effective treatments (Engel, 1977, p. 129). Monumental 20th century breakthroughs, such as the eradication of certain infectious diseases, are a testament to the scientific, naturalistic approach. Such remarkable feats, however, have come at a cost.

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<sup>&</sup>lt;sup>†</sup> Aquinas was speaking metaphysically in that primary matter receives individual forms, whereas the intellect receives absolute forms. I am applying his observation in the context of the distinct lifeworld of the physician and the patient, in this case, as the physician has been influenced and formed in the biomedical perspective.

## The Way Doctors Think

The biomedical model, grounded in disease-based theory, has molded physicians' understanding of disease. Throughout the history of medicine there has been much confusion and dispute about the nature of disease. The early Hippocratic school saw disease as a generalized phenomenon, an imbalance between the forces of nature external and internal to the ill person. Today, the prevailing viewpoint is an ontological conception of disease, where diseases are understood as *entities* that invade and are localized in the body (cited in Cassell, 2004, p. 4; Taylor, 1979, p. 2). Since the rise in the disease theory, versions of the ontological conception of disease have held sway in the practice of medicine. For example, *Harrison's Principles of Internal Medicine*, a contemporary medical textbook commonly used by clinicians and medical students, explains the clinical method as "an orderly intellectual activity, which proceeds almost invariably from symptom to sign, to syndrome, to disease" (Rawlinson, 1982, p. 78). In this description, the *telos* of the clinical encounter is the identification and then, if possible, the eradication of the disease.

But erroneous assumptions often follow when physicians think about patients in terms of "diseases." First, it is frequently assumed that diseases have been present in the same form throughout history. This assumption ignores the fact that the constitution of the disease state has been dynamic throughout the generations of medicine. † The second fallacious notion is that diseases are real, freestanding entities (Goldberger, 1965, p. 17).

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<sup>&</sup>lt;sup>†</sup> Foucault details the shift in understandings of disease that takes place between the 18th and 19th century (Foucault, 1973). In addition, the following works offer a detailed description of the changes in the constitution of "disease" throughout history: (Cohen, 1981; Engelhardt, 1982a)

In his 1965 book, *How Physicians Think*, Emanuel Goldberger elucidates these general apprehensions of disease by physicians:

When a physician thinks of a patient in terms of "disease," he often assumes that "in" every patient there must be a localized fault or "disease" which is the "cause" of the illness; and that for every "disease" there is an appropriate mechanistic type of treatment—for example, remove a patient's appendix by surgery, manipulate a painful joint, neutralize painful stomach acids by alkali medications, temporarily disconnect painful nerve synapses by administration of drugs, and so on. (Goldberger, 1965, pp. 107-108)

Although doctors generally conceive of a disease as a specific entity, the reality of the clinical encounter suggests otherwise. Goldberger offers a vivid phenomenological description of the way in which certain words and terms used for diseases actually refer to *patients* with certain symptomatic experiences and clinical signs.

Physician Eric Cassell similarly asserts that diseases are real only in the same sense that ideas are real, concepts are real, and categories are real (Cassell, 2004, p. 98). Diseases do not have an *independent* existence in the same way that a liver and a heart do. Pneumonia, for example, does not have a freestanding concrete existence. Rather, it is an abstraction, a concept that serves a purpose; the purpose being the need for *classification* during a clinical presentation.

English physician Clifford Allbutt pointed out the difference between a disease and the patient in his dialogue with a medical student. The understudy inquired whether a certain disease was an entity. Allbutt replied, "Never call anything an entity which you can't put on a plate on a table" (Goldberger, 1965, p. 15). Although the physician's response was hyperbolic, the point was made: "There are no diseases but only patients" (Goldberger, 1965, p. 16). Allbutt was reminding the student that a physician could not treat a disease; he must treat a patient, a real person, not a statistical average but a person

who is unique, different from all other persons in the world (Goldberger, 1965, pp. 107-108).

## **Implications for the Practice of Medicine**

Medicine's total embrace of science has had profound effects on the doctorpatient relationship. The naturalistic attitude of science is based on a belief that science
and its methods are *value free*. In other words, anything that happens in the scientific,
naturalistic attitude is neither good nor bad; it simply *is*. Medicine, on the other hand, has
an engrained tradition of hierarchical values, both explicit and tacit. Examples of such
values are that the patient comes first and that doctors must above all do no harm.

Besides aspiring to being value free, a scientific description does not ascribe *qualities* to
things. In contrast, medicine could not exist without references to qualities; adjectives
like warm, tall, swollen, or painful are both norms and living realities for the ill patient,
and hence must be part of the clinical conversation. Science, on the other hand, deals only
with measurable quantities—temperatures, diameters, and rates—in its purpose of
objective data.

The final problem with the naturalistic attitude is that it does not deal with individuals—the uniqueness of the human person. It deals only with generalities, which are the point of its methods. But medicine has everything to do with individuals, as the clinical encounter is predicated on a particular person's experience in illness (Cassell, 2004, p. 17). This points to a glaring shortcoming in the naturalistic attitude when it is applied to medicine: it neglects the particulars of the ill patient. The way of science is admirably suited to understanding the lungs—well or diseased. It is suited to pursuing

knowledge about universals and generalities. But it is unsuited, by itself, to understanding or caring for a sick individual.

Levine similarly notes the uniqueness of each clinical encounter in the practice of medicine. He states: "The physician does not speak in a language appropriate to the average layperson, but rather to the unique individual who is the patient. Even more important, the physician listens and responds to that unique person" (Levine, 1983). The physician evaluates each patient according to her uniqueness as manifested in the clinical relationship. The naturalistic attitude neglects such particularities in the clinical conversation, which are tailored to the unique individuality of each patient.

Disease, as it is conceived within the naturalistic attitude, represents a scientific abstraction that is divorced from the lived experience of the patient (Toombs, 1992, pp. 14-15). Solely employing the biomedical model directs the physician to make a diagnosis of a disease state or syndrome rather than to comprehend the patient's experiences that brought on his awareness of the illness and incited the clinical encounter. These two ends are quite distinct and can have consequences for the care for the patient.

Phenomenologist Robert Sokolowski asks a series of questions when contemplating the extremes of scientific discourse:

But can we project this possibility, in which we exclude the entire personal dimension and try to treat the other human being as an entity subject only to the laws of nature? Can we explain the person away into being only a prepersonal, natural system? Can a community of scientists speak of him—and of themselves—only in terms of thermal gradients, voltage drops, and hyperactive amygdalas? To claim that they could do so would be to expand a partial view of things, a maneuver within the conversational attitude, into being a view of the whole. (Sokolowski, 2008, p. 218)

Sokolowski notes that if a person "reduces" his discourse in this way, he will not make use of any of the categories that deal with truth. "He will not be able to speak about

pictures, about propositions, or about correctness or falsity. Such phenomena will no longer show up on his radar screen" (Sokolowski, 2008, p. 218). He continues:

Once we have entered into the activity of speaking with others, we necessarily engage in dimensions of syntax, grammatical signaling, propositional reflection, confirmation, and refutation, correctness, picturing, and other issues in truthfulness, including responsibility. There cannot be science without the presence of such aspects of experience. If a scientist is working on the human nervous system, he will have to ask the subject what he sees at this moment, what he feels, whether the colors look different, or whether the face in this picture is male or female; he will have to make sure the subject understands his questions; and he will have to determine whether his subject has paid attention and whether he has told him the truth. (Sokolowski, 2008, p. 218)

Sokolowski asserts that a physician cannot function in the scientific attitude without also engaging in the "conversational attitude" that is "the original, default way in which we are related to things and to one another as agents of truth" (Sokolowski, 2008, p. 218). The proposal that a physician could restrict himself to the discourse of science amounts to the impossible claim that a person could deal with others without the language appropriate to conversation. (Sokolowski, 2008, p. 218)

#### Reductionism and Exclusionism

The biomedical model allows for only two alternatives when the lived-reality of the patient's experience of illness cannot be reconciled with the disease-based framework of the physician. The first alternative is *reductionist*, which says that all behavioral phenomena of disease must be conceptualized in terms of physiochemical principles. The second is *exclusionist*, which says that whatever is not capable of being explained must be excluded from the category of disease. In an exclusionist view, any of the patient's experiences or symptoms of illness that do not neatly fit within the conventional medical

<sup>&</sup>lt;sup>†</sup> The "conversational attitude" is the ordinary natural attitude of everyday interactions.

model are considered not to fall within the purview of the doctor-patient relationship and are therefore excluded from the therapeutic goals.

Central to the reductionist view is the belief that complex phenomena are ultimately derived from a single primary principle (Engel, 1977, p. 130). While reductionism can be a powerful tool for understanding complex phenomenon, it can also create profound misunderstandings when unwisely applied. "Reductionism is particularly harmful when it neglects the impact of non-biological circumstances upon biological processes... Some medical outcomes are inadequate not because appropriate technological interventions are lacking but because our conceptual thinking is inadequate" (Holman, 1976).

Arbitrary exclusion can certainly be acceptable in scientific research, especially when concepts and methods appropriate to the study of excluded areas are not yet available. It becomes counterproductive, however, when such exclusionism becomes commonplace, and when the areas originally set aside are excluded *permanently*. Such habituated exclusion is common in the biomedical model. Many patient complaints that do not correlate with pathophysiological findings, neatly fitting into the biomedical model, are simply ignored by many biomedical practitioners (Toombs, 1992, p. 39).

Indeed, entire dimensions of the patient's experience of illness remain inaccessible or incomprehensible to the caregiver committed solely to biomedical dogmatism. Baron observes, "We seem to have a great deal of difficulty taking seriously any human suffering that cannot be directly related to an anatomic or pathophysiological derangement. It is as if this suffering had a value inferior to that associated with 'real

disease'" (Baron, 1985, p. 607). The tacit attitudes toward diagnoses such as irritable bowel syndrome or fibromyalgia support Baron's point.

# Physician as Applied Scientist

The reductionist and exclusionist tendencies are even more evident when we consider the physician who is aspiring to be a scientist. An enduring reminder of this marriage between medicine and science is the white laboratory coat—a shining symbol of the modern physician as applied scientist. Although science and medicine are inextricably bound, Cassell declares "the paradoxes and strains produced by believing they are the *same* led to a conception that could not last—that of the ideal physician as a scientist" (Cassell, 2004, p. 17).

The physician, as an applied scientist, is susceptible to viewing the patient as an object for or an exemplification of the results of scientific research. "The patient is no longer envisaged as a whole person, but only as a body; and the body itself is envisaged as a collection of parts or subsystems, each of which may fruitfully be studied in isolation from the rest" (MacIntyre, 1985, p. 89). The physician essentially reenacts with the parts of a patient's body what the scientist first achieved on the laboratory bench.

Thus, in modern medicine, the patient is vulnerable to being reduced to an object and disappearing as a person. Before the birth of modern medicine, the meeting between the doctor and the patient—a meeting between persons—was the essence of the practice of medicine.<sup>†</sup> This foundation has gradually been replaced by a new image: the scientist

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<sup>†</sup> It is important to point out at this juncture that although the *nature* of the medical meeting has changed in recent centuries, medical practice in its essence still remains a meeting between persons.

examining an object. This is most problematic because this "object"—the patient—never ceases to be simultaneously a person.

As previously noted, the origin of this new image stemmed from the demand for objective validation, which originated in Paris around 1800. It invaded the practice of medicine in the United States, however, with the realization of the Flexner Report in the 1920s to 1930s. It then came to fuller fruition in the post World-War II successes of discovering cures as well as in the development of sophisticated technology, such as MRIs and gamma knives, for diagnosis and treatment.

When the role of the physician is acting as an applied scientist, it follows that the specific complaints of the patient and the genuine care of the patient have the possibility of being excluded from the practice of medicine. MacIntyre contends that this kind of scientific approach on the part of the physician renders several aspects of the human person invisible. "For to view the human being as an assemblage of bodily parts and processes is to deprive the patient qua patient of every moral as well as every social dimension" (MacIntyre, 1985, p. 90). This further results in blindness to a variety of types of cause and effect in medically important conditions.

Causes and effects are less easy to ignore however in contemporary medicine, the focus of medical care has moved from infectious diseases to the major chronic conditions prevalent in modern practice. In the long-term care necessitated by chronic conditions, factors beyond the biomedical classifications become imperative for satisfactory therapeutic outcomes. "Stress and anxiety, conditions experienced in the family and the workplace, the quality of care, the patient's hopes, fears, and expectations—factors which stubbornly resist operational definition because of their intentional character—become

crucial both to explanation and to therapy"<sup>†</sup> (MacIntyre, 1985, p. 90). These factors are intimately linked with the patient's experience of illness, yet they have been sorely neglected in the biomedical framework with its reductionist and objectivist tendencies.

#### Inadequacy in the Alleviation of Suffering

As I have said, the stunning progress modern medicine has made in diagnosing and treating disease cannot be overstated. The complete (or nearly complete) disappearance of infections such as smallpox, cholera, and the polio, are only a few of the many triumphs of modern medicine. Few changes in human life have been so great as those wrought by the progress of modern medicine and the biomedical sciences ("The goals of medicine. Setting new priorities," 1996). But it must also be said that while treating a disease may *cure*, it does not necessarily *heal*; and that although disease may be resolved, suffering may still linger, threatening the integrity and the wholeness of the person. This raises the question whether the intensity of medicine's focus looking through the microscope has paradoxically created a medically myopic culture, where the experience of the patient's suffering in illness is now a distant blur in the physician's vision.

G.B. Maddison's *On Suffering* is a radical enquiry into the meaning of suffering in human life. Maddison asserts that science, overall, has a tragic view of human life and a reductionist perspective. He argues that the biomedical approach to illness has eclipsed

MacIntyre contends that medicine's inability to capture the full story of the patient does not derive from an inadequacy peculiar to the theory or the practice of medicine; "[I]t derives from the way in which our culture, in thinking about human beings, oscillates between two unsatisfactory metaphysical alternatives: an inadequate materialism and an equally inadequate dualism. Sometimes we behave like the heirs of Descartes, at others like those of LaMettrie." Because of this oscillation, physicians tend to revert to a simple but false view of both the nature of science and the nature of the patient. A consequence of this view is the reductionist and exclusionist habits frequently observed in medical practice. (MacIntyre, 1985)

the essentially restorative function of the art of medicine, by failing to account for suffering (Madison, 2009).

The omission of suffering from the clinical picture appears to transcend socioeconomic divisions. Indeed, many who have adequate access to the best modern health care complain that physicians are uninterested in their suffering, are preoccupied with procedures, and are unaware of the impact of their illness on their daily life.

Oftentimes the more renowned the medical center is for its biomedical research, the more common are such complaints (Duff & Hollingshead, 1968, p. 134; Engel, 1977). Engel notes a growing awareness of this contradiction between the excellence of a physician's biomedical background and his inability to provide good patient care (Engel, 1977, p. 134).

Arthur Frank's reflections on his sufferings, first as the victim of a heart attack and later as a patient diagnosed with testicular cancer, strongly dramatizes the neglect of the suffering patient by a medical establishment's intent on a cure. Frank's book, *At the Will of the Body*, is a sober witness to modern medicine's lack of integration of patient's suffering into the clinical picture (Frank, 1991). Dazzled by recent technological developments, the doctors who treated Frank often seemed to have lost perspective on his personhood. Frank describes the medical professionals as concentrated solely on the mechanics of the pathologies, while Frank desired that the doctors address his fear and the sense of threat he was experiencing.

Frank vividly notes that the doctors often disregarded everything unique and personal about him, and "dealt with him merely as a given locus of organs found generically in all males of his species" (Frank, 1991). The physicians he encountered on

two climatic occasions, first with his heart attack and then with his cancer, appreciated neither the lived-reality of his suffering, nor the importance of Frank's own role in any full healing. Frank's experience and myriad other testimonies attest to the fact that the vast majority of patients seek out a physician not for continuing useless efforts to *cure*, but for *care*.

## **Summary**

In summary, there is a crisis in the doctor-patient relationship, a radical separation between the physician's apprehension of the patient's illness and the patient's lived experience of suffering with illness. Such a separation is not based on levels of knowledge, but rather on qualitatively distinct points of view. In light of modern developments in pathological anatomy and other biological sciences, the doctor-patient relationship has shifted in its approach to one that tends "to efface the patient and transform the encounter from one in which two subjects meet to one in which a knowing subject confronts a mute, passive object" (Davis, 2000).

The birth of modern medicine was a watershed event resulting in "biomedical dogmatism." Although biomedicine has led to monumental breakthroughs in modern medicine, it has failed to acknowledge the patient's experience of illness-as-lived. It also can lead to erroneous and potentially harmful ideas, which end in reductionism and exclusionism. As a result, the patient's suffering in illness, particularly in chronic and terminal illnesses, can be unrecognized and unaddressed. In the next chapter I will explore this critical, yet frequently overlooked reality: the patient's experience of suffering in illness.

## **CHAPTER III**

#### THE NATURE OF SUFFERING IN ILLNESS

The effort to elucidate the nature of suffering is ancient. Suffering is a mystery, which has persisted throughout the millennia. Great thinkers throughout history have explored the question of suffering,<sup>†</sup> and modern medicine finds itself confronted every day with its gravity:

We don't understand the mystery of life very well... Aristotle differentiated himself from Plato by finding a place for grief, even cultivating it. Secular society approached suffering as something to be eliminated. Medical efforts are dedicated to the relief of suffering (or at least pain)... Yet despite our best efforts, millions of people suffer from myriads of causes. Modern medicine extends life and reduces physical pain, but suffering is not reducible to physical and material terms. We scapegoat objects of blame—smoke, fat, microorganisms, stress. (Kavanagh, 2007, p. 20)

A more comprehensive understanding of suffering offers the physician a broader view of the patient's experience of illness than does the purely biomedical model of disease.

Indeed, the nature of suffering is much wider and more multi-dimensional than the field of biomedicine acknowledges:

<sup>†</sup> Max Scheler offers a global perspective on suffering in modern society. He argues that modern civilizations have *alienated* people from the protection of community, tradition, and nature. As a result, "each civilized person alone bears responsibility for himself and his behavior. Worry and anxiety are the inevitable counterparts of this isolation and insecurity." Within Western civilization, suffering has advanced even faster than happiness. Scheler affirms Rousseau and Kant on their point that civilization creates even more, even deeper, suffering by its successful struggle against the cause of suffering. He writes: "The new sources of pleasure and enjoyment in the West are considerable, but they pertain only to the more superficial feelings. The deeper emotions touching the substance of humanity, such as peace of conscience or joys of love, are only slightly changeable over time. In these deeper emotions the organization of our senses is already so set that the intensity of pain is greater than that of pleasure...We more easily accustom ourselves to (pleasure stimuli) of advancing standard of living, to inventions, new machines, and tools than to miserable situations" (Scheler & Bershady, 1992, p. 96). Aquinas' statement that interior sorrow is more intense than interior joy affirms Scheler's observations, as Scheler claims that interior joy has been dulled in modern civilization.

Medicine, as the science and also the art of healing, discovers in the vast field of human sufferings *the best known area*, the one identified with greater precision and relatively more counterbalanced by the methods of "reaction" (that is, the methods of therapy). Nonetheless, this is only one area. The field of human suffering is much wider, more varied, and multi-dimensional. Man suffers in different ways, ways not always considered by medicine, not even in its most advanced specializations. Suffering is something which is *still wider* than sickness, more complex and at the same time still more deeply rooted in humanity itself. (John Paul II, 1984, p. no. 6)

Moreover, this "wider" suffering that exists outside the control of the physician cannot be reduced to merely "psychological effects" that accompany a disease state. Such a flawed interpretation prompts physicians to bequeath these "issues" to the psychiatrist or psychologist. Yet these characteristics "are integral elements of the human experience of illness and they must be attended to as a part of that experience" (Toombs, 1992, p. 143).

There are many definitions of suffering. The intent of this chapter is to awaken readers to the many meanings associated with suffering, as they are relevant to the patient's experience of illness. I will use physician Eric Cassell's definition of suffering as my primary working definition, and then draw from various other descriptions in order to achieve a broader understanding.

The Latin root of the words *suffering* and *patient* are strikingly similar, both meaning "to bear." More precisely, the Latin root of patient, "patiens," means "one who endures or suffers." This etymology points to the overlapping nature of the patient and suffering. Suffering is intrinsic to the experience of being a patient; a patient, in his or her experience of illness, is one who endures some degree of suffering. Patients may experience contingent forms of suffering, such as acute serious illness, or routinized forms, such as chronic illness. There is also suffering resulting from extreme conditions, such as intense trauma, as well as suffering from cultural interpretations of particular

symptoms (Kavanagh, 2007, p. 52). Regardless of the variety of forms and their intensity, to be a patient means to be subject to some degree of suffering.

In his seminal work, *The Nature of Suffering and the Goals of Medicine*, Cassell describes suffering as "the experience of a threat, or a *perceived* threat, to the integrity of the person." Suffering occurs when the person perceives or experiences an impending destruction. It continues until the experience of disintegration has passed or until the integrity of the person is restored (Cassell, 2004, p. 32). Based on years of bedside care for patients, contemporary physicians reinforce this connection between the experience, or perception, of the patient and the onset of suffering (Cassell, 2004; John Paul II, 1984).

John Paul II's definition of suffering does not contradict Cassell's definition, but his emphasis is different. John Paul II describes suffering as "the experience of a privation of a good." He notes that a person suffers "whenever he experiences any kind of evil... Suffering is the undergoing of evil before which man shudders" (John Paul II, 1984, para. 7, 18). This evil, according to John Paul II, is a certain lack, limitation, or distortion of a good. In this sense, one always suffers *relative to a good*, insofar as the person does not share in that good or is cut off from that good. One suffers particularly when, in the normal order of things, he or she "ought" to have a share in this good and does not have it. Cassell might respond to John Paul II's definition by saying that the particular good involved is the integrity of the person and the privation is the threat or perceived threat to that integrity.

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<sup>&</sup>lt;sup>†</sup> Throughout this section, I draw from *Salvifici Doloris*, a document written by Pope John Paul II (Karol Wojtyła). The work of phenomenologist Max Scheler and the scholastic tradition, primarily Thomas Aquinas, were strong influences on John Paul II's writing. The description of suffering in *Salvifici Doloris* has Thomistic roots (Aquinas & Dominicans. English Province., 1947, Part II-I, Q 35, Art 1).

In the vocabulary of the Old Testament, suffering and evil are identified with each other and overlap to the extent that there is not even a specific word for "suffering;" the Old Testament identified as "evil" everything that was suffering. Later, the Greek language offered a verb,  $\pi\dot{\alpha}\sigma X\omega^{\ddagger}$ , which meant, "I am affected by... I experience a feeling, I suffer" (Bauer, Danker, Arndt, & Gingrich, 2000; Brown, Robinson, Driver, Briggs, & Gesenius, 1907). Because of this mediating verb, suffering was no longer directly identified with objective evil, but rather expressed a situation in which a person "experiences evil and in doing so becomes the subject of suffering" (John Paul II, 1984, para. 7).

#### As Distinct from Pain

It is important to distinguish between pain and suffering. Although the two are related and can occur simultaneously, they are distinct and their differences may be clarified. Thomas Aquinas observes that outward pain is caused by an exterior apprehension; outward pain arises from the apprehension of sense, chiefly the sense of touch. Sorrow, on the other hand, is the interior apprehension of pain, where this inward pain arises from the interior apprehension of the imagination or of reason. The cause of exterior pain is a conjoined evil repugnant to the body; the cause of interior pain is a conjoined evil repugnant to the appetite (Aquinas & Dominicans. English Province., 1947, Part I-II, Q 35 Art 7).

<sup>†</sup> Although it is said that there are two forms of evil, moral evil and natural evil, this thesis will not address the former. Examples of natural evil include natural disasters, such as hurricanes and earthquakes, as well as illnesses, such as ovarian cancer and heart disease.

<sup>&</sup>lt;sup>‡</sup> The present infinitive of this verb is  $\pi\alpha\theta\in \hat{\nu}$ , which means "to experience."

Aquinas further notes that inward pain [e.g. sorrow] is, "simply in and of itself, more keen than outward pain." Outward pain can sometimes be accompanied by inward pain, and then the pain is increased overall. He continues:

Because inward pain is not only greater than outward pain, it is also more universal: since whatever is repugnant to the body can be repugnant to the interior appetite; and whatever is apprehended by sense may be apprehended by imagination and reason, but not conversely. Hence...it is said expressively: *Sadness of the heart is every wound*, because even the pains of outward wounds are comprised in interior sorrows of the heart. (Aquinas & Dominicans. English Province., 1947, Part I-II, Q 35, Art 7)

This "inward pain" of sorrow, as noted by Aquinas, is distinct from outward pain. Such interior pain is closely linked to the experience of suffering in illness. Furthermore, this interior suffering can be keener, more universal, and greater than outward pain.

Aquinas' assertion reinforces the phenomenological perspective that pain and suffering are distinct. Suffering, as an interior reality that is connected with one's rational and imaginative capacity, involves context, meaning, and interpretation. A person can, and often does, suffer without experiencing outward pain; suffering is an *interior* reality.

To be precise, pain and suffering are not two of a kind, and therefore are not items on the same scale (Solomon & Oxford University Press., 2003, p. 169). *The Goals of Medicine* project from the Hastings Center clarifies this distinction:

[M]ost people seek the ministrations of medicine for the relief of pain and suffering. Their bodies are hurt in some way and they want help, or they are psychologically burdened and seek relief; and often both pain and suffering are experienced together. Pain and suffering, however, while often joined in a patient, are not necessarily the same. Pain refers to extreme physical distress and comes in many varieties: throbbing, piercing, burning. Suffering, by contrast, refers to a state of psychological burden or oppression, typically marked by fear, dread, or anxiety. Severe and unrelenting pain can be a source of suffering, but pain does not always lead to suffering (particularly if a patient knows it is temporary or part of an eventual cure). Nor does suffering always entail pain: much of the suffering of mental illness, or simply ordinary fears of life, does not necessarily include physical pain. ("The goals of medicine. Setting new priorities," 1996, p. 23)

Although pain is a common cause of suffering, suffering and pain are distinct forms of distress. Patients may report suffering when a pain is overwhelming, such as the pain caused by a dissecting aortic aneurysm. However, patients may also tolerate extreme pain if they know what it is, know that it can be controlled, or know that it will soon end. The pain of childbirth, for example, can be extremely severe and yet be experienced as uplifting by some women. In childbirth, studies show that the degree to which the woman feels she is in control of her pain seems to be more important than the elimination of the pain itself (Cassell, 1999, p. 106). A sense of control in this case does not eliminate *pain*, but it may alleviate *suffering*. A woman's knowledge of the cause of the pain and its foreseeable end also contribute to a woman's high tolerance of pain in childbirth.

The suffering of a patient is frequently relieved simply by having the awareness that his or her pain can be controlled. Terminal cancer patients often experience intense suffering when they believe their pain cannot be controlled. However, upon realizing that their pain truly can be managed properly, these same patients will often tolerate the same pain without any medication, preferring the pain to the side effects of their analgesics (Cassell, 2004, p. 34). In the Thomistic sense, when the patient brings reason to bear on the experience of pain, the pain remains chiefly an exterior pain and does not penetrate to an interior sorrow, which afflicts the reason or imagination. Cassell notes that pain that can be controlled often is not experienced as a threat or perceived threat to the integrity of the person.

Pain leads to suffering when one of the following conditions occurs: 1) the source of the pain is unknown, 2) negative meaning is ascribed to the pain (e.g. "cancer"), 3) the

pain is uncontrolled, or 4) there is no foreseeable end to the pain. All of these conditions are connected to the threat or perceived threat of the integrity of the person. Even if the pain level is low, under one of these four conditions, it can become a source of intense suffering. For example, chronic pain can be a cause of great suffering precisely because the pain seems "never-ending." Even a mild lower backache can prompt significant distress when there is no foreseeable end. By contrast, although a kidney stone can be intensely painful, patients often do not report suffering as a result of the experience, as there is a foreseeable end to the pain (Cassell, 1999, p. 105).

Pain of unknown origin is also a cause of suffering. Cassell recalls a visit with a young woman who complained of severe lower back pain. For months she went from physician to physician with no reports or hints of an etiology. After obtaining a new set of X-rays, however, Cassell discovered a healing fracture in the woman's upper spine. He explained the source of the pain to the patient and that it was not serious, although there was nothing medically that could be done. "I don't mind," the woman replied. "I'm so glad to know that there really is something wrong, that I wasn't just going crazy" (Cassell, 2004, pp. 3-4). This case sheds light on the fact that unexplained pain can be a great cause of suffering. Although there was nothing medically that could be done to attenuate the woman's symptoms, her mere knowledge of the spinal fracture relieved her suffering; this allowed her to tolerate the same levels of pain that she previously considered intolerable in her serial visits to the doctor.

Suffering may involve physical pain, but it is not necessarily limited to physical pain. This further indicates that suffering and pain are distinct. There may be pain without suffering and there may be suffering without pain (Cassell, 1999, p. 106). Consider the

difference between the pain experienced by a patient with terminal cancer and the pain a runner experiences after a race. Not only will certain pain *not* be apprehended as illness, but the meaning the patient assigns to the pain will determine whether or not such pain will also encompass suffering (Engelhardt, 1989). In the case of the patient with terminal cancer, the patient may ascribe proximity of death to the pain and such an attributive meaning may then lead to intense suffering. It is the particular *significance* accorded to such pain that prompts and intensifies suffering.

One researcher compared manifestations of pain in wounded soldiers from the Anzio beachhead at the end of World War II with those in civilians after serious surgery (Beecher, 1956). In response to questions about whether they wanted something to relieve their pain, only one-third of the soldiers answered affirmatively, compared to 80 percent of the civilians. This discrepancy can be explained in terms of the meaning attributed to the wound and the pain. The soldiers' wounded condition meant that the threat of annihilation was reduced, as the war was ending and they were still alive. By contrast, the civilians associated pain with a surgery that meant that death might be imminent. Therefore, "the discrepancy in the data between the two groups is explained by conceiving of a separation of the sense of annihilation from pain per se and a differential effect of the situations on the sense of annihilation" (Bakan, 1968, p. 87). This study reinforces the importance of *meaning* in exacerbating or relieving suffering, an issue I will explore later in greater detail.

#### **As Uniquely Human**

While pain is widespread in the animal world, suffering is a uniquely human experience. Only the suffering human being knows that he is suffering and wonders why. Only the suffering person asks these deeper questions in his distress and cries out for answers. We might say that suffering is an experience that reveals to humankind the very mystery of his being. Suffering seems to be "particularly *essential to the nature of man*. It is as deep as man himself, precisely because it manifests in its own way that depth which is proper to man, and in its own way surpasses it" (John Paul II, 1984, para. 2).

Furthermore, suffering is inseparable from human life, "inseparable from man's earthly existence" (John Paul II, 1984, para. 3). It occurs at various moments in life, and assumes a variety of guises. An experience of illness and suffering, at whatever age and in whatever form, thrusts a person into contact with a reality that all persons eventually traverse.

At this point it is important to ask what it means to be a *person*. This will help us delineate the nature of suffering itself, as suffering is a uniquely human phenomenon. Attempts to develop an ontology of personhood go back at least to the 5th century, with Boethius (475-524). Similar efforts continue in contemporary philosophy, especially in phenomenological and existential circles. Despite the fruitful observations of our contemporaries, Boethius' concise definition remains timeless; he defines a person as "an individual substance of rational nature." In Boethius' framework, a person is a "unit member" of a species and, therefore, an individual entity that is distinct from all other "unit members" of that species (Pellegrino, 1985, p. 99). To be an individual "unit member," however, does not necessarily make one a person. Boethius further specifies

that it is the possession of *rationality* that makes man a person, an individual distinct from other individuals.

Boethius' definition proposes two aspects of personhood—a rational nature and its expression in a personal identity that results from the use of that rationality. The experience of illness, however, vitiates this second aspect of Boethius' definition. When patients refer to an "ontological assault" on their integrity, or a threat to the same, they are describing an infringement on the actual expression of their personhood. Pellegrino elucidates:

Illness is, however, a serious assault on the actual expression of personhood, on the freedom to make choices, to fashion a personal identity, and to reshape that identity in response to our changing life experiences. When he senses himself as ill, the patient perceives a transformation in his personal existential status. He has become *Homo patiens*, a man bearing a burden of pain, anxiety, or disability. He is marked off from the universe of those who are healthy. He recognizes that he is still a person, but a person in an impaired state. A patient is a member of a subset of humanity characterized by the loss of crucial human freedoms—those we normally associate with being fully persons. (Pellegrino, 1985, pp. 100-101)

The uniqueness of the human experience of suffering in illness is rooted in this "ontological crisis." It is a perceived or real assault on the unity or wholeness of the one who is ill. A person in illness remains a person: In Boethius' terms he remains "an individual substance of rational nature." But Pellegrino points out that the actual *expression*<sup>†</sup> of that personhood is hindered in illness. Suffering in illness, therefore,

It is important to note, however, that even if this rationality cannot always be expressed, it is the *capability of rationality* that makes each man and woman a person. Such capability is an intrinsic part of his or her nature even when one is in infancy, in sleep, or in a coma. It is also present in cases of irrevocable cognitive disability, such as patients with Alzheimer's disease. Therefore, nascent periods of development, illness, and other physical and mental impairments cannot alter the ontological nature of personhood because it resides in a capability rather than actual expression.

Maritain provides insight into these observations: "Disease imposes limitations on the free construction of the individual's personal being." Illness, like so many other evils our being is exposed to, limits the freedom that Jacques Maritain called "freedom of spontaneity": the spontaneity of every being to act, without external restrictions, according to the being's nature. This freedom of spontaneity, which is carried

prompts a particular kind of self-awareness. The person, accustomed to seeing himself as an active agent in his own life, perceives a serious assault on the expression of his personhood, on his freedom to fashion a particular identity, for example, or to pursue a specific desire or goal. As a result of this "ontological assault," illness ushers in an altered state of everyday existence for the ill person. (Pellegrino, 1982, p. 157)

Suffering in illness deeply alters one's subjective existence. Challenging our capacity "to be," it affects not just one aspect of our existence, but many, including our sense of self. In suffering, events seem to "crash" into our lives, forcing us to struggle to adapt. This struggle is not merely an exterior struggle, in a physical sense, but a struggle of the entire person, a struggle that engages one's reason and imagination.

It is the awareness of this "assault," of its infringement on the expression of one's personhood, that particularly defines the uniquely human experience of suffering:

Within each form of suffering endured by man, and at the same time at the basis of the whole world of suffering, there inevitably arises the question: *Why?* It is a question about the cause, the reason, and equally, about the purpose of suffering, and, in brief, a question about its meaning. Not only does it accompany human suffering, but it seems even to determine its human content, what makes suffering precisely human suffering. (John Paul II, 1984, para. 9)

Persons seek to understand suffering, and their efforts usually take the form of a question. The dominant ethos is that one is offended and even shocked when becoming ill. Why me? Why now? What did I do to deserve this? These are common questions for those who experience a threat to their integrity. Suffering in illness is "a wounding [of a person's] very humanity," and intensely evokes a quest for meaning (Pellegrino, 1982, p. 157).

out in varying degrees in the different types of beings in nature, reaches its perfection in the human being, "who being able to go beyond the moment of feelings and to know being and intelligible natures, knows what he is doing, and the purposes of his acts as such; deciding himself, by his own intellectual activity, the purposes of his actions" (Lavados, 2002, pp. 204-205; Maritain, Gallagher, & Gallagher, 1967).

### As a Subjective Reality

To this point, we have looked at suffering as a uniquely human experience as well as an unavoidable one. We have also considered Boethius' two facets of personhood. The latter characteristic of Boethius' definition, namely the individuality of each person as a unit member of a species, points to the unique *subjectivity* of every human experience, suffering included. Besides being an objectively and definitively human experience, suffering is unique to the individual. In its subjective dimension, suffering is a personal fact contained within a person's concrete and unrepeatable interior (John Paul II, 1984, para. 5).

Building on these observations and synthesizing the reflections of several other physicians, Rodgers and Cowles further illuminate the nature of suffering. They describe suffering as "an individualized, subjective and complex experience characterized primarily by a person's assigning to a situation or a perceived threat an intensely negative meaning. This meaning involves the loss, or perceived loss of one's integrity, autonomy, and actual humanity" (Rodgers & Cowles, 1997). As does Cassell, Rodgers and Cowles include *perception* in their definition of suffering, which points to the subjective dimension of suffering.

Suffering in illness is perceived as a threat to the integrity of the person in as much as the experience of illness "deviates from the normal threshold of pain and suffering that accompanies our healthy lives," and limits, or threatens to limit, the activities of our routine healthy lives (Taboada, et al., 2002, p. 192). It follows that although suffering often occurs in the presence of acute pain, shortness of breath, or other bodily symptoms, it extends beyond the physical. Most generally, Cassell says that

suffering is "the state of severe distress associated with events that threaten the intactness of the person" (Cassell, 2004, p. 32). This idea of a threat, or perceived threat, to the integral unity of the person affects the *meaning* a person assigns to their symptoms (Cassell, 2004; E.D. Pellegrino & Thomasma, 1981; Rodgers & Cowles, 1997).

The subjective dimension of suffering is further highlighted in the observations of Pellegrino and Thomasma (Pellegrino & Thomasma, 1981). Pellegrino and Thomasma note that because suffering is connected with the patient's *response* to illness, it involves the patient's *will to meaning*. More specifically, the attributive meaning the patient ascribes to his or her experience is an integral aspect of suffering.

Just as no two people have the same genotype or phenotype, no two people have the same life-context. Likewise, suffering is unique to each person. Francis Peabody's historic words are a living reminder of the individuality of each patient: "What is spoken of as a 'clinical picture' is not just a photograph of a man sick in bed; it is an impressionistic painting of the patient surrounded by his home, his work, his relations, his friends, his joys, sorrows, hopes and fears" (Peabody, 1927). Attuning to this "impressionistic painting" of the patient's suffering in illness, calls for an attunement to the unique subjectivity of the patient as a person.

A person is unique in both his essence and his existence. Just as no person's unique existence can be replaced, so does each person have an individually distinct experience of suffering. Uniqueness<sup>‡</sup> defines not merely in the patient's singular situation of illness, but also the quality of his life as a whole, in all of its particularities. Indeed, the

<sup>&</sup>lt;sup>†</sup> The importance of the will to meaning will be elucidated in the next chapter with a particular focus on the work of Viktor Frankl.

<sup>&</sup>lt;sup>‡</sup> I am deliberately adopting the word "unique," rather than relative, in describing the subjectivity of suffering in illness.

experience of suffering in illness often brings this life-context in a concentrated form to the forefront of the patient's consciousness.

The unique subjectivity of each patient can be noted even in a person's initial decision to go to the doctor. The clinical encounter is grounded in the medical meeting, that is, when a person—the patient—first seeks medical attention. This initial "search for help" by the patient reveals distinct aspects of patient's attitude to illness, especially the subjective element of illness-as-lived (Taboada, et al., 2002, p. 190). When acutely afflicted with severe or unusual symptoms, people almost invariably seek medical attention and, accordingly, can be said to be ill. However, many people who are ill do not visit doctors. Visiting the doctor is not an automatic response to a symptom; in fact, only a minority of people who consider themselves sick seek medical attention.

In a 1981 survey performed over a two- to four-week period, about 75 percent of people in the general population experienced symptoms they recognized as being due to illness; however, only 24 percent of these people consulted doctors. The ones who consulted doctors were not necessarily sicker than those who did not. In fact, the two groups were indistinguishable when the number and type of symptoms were compared (Barsky, 1981). Regardless of whether or not a person seeks medical attention at a particular moment, it is clear from this data that the *subjective* experience of symptoms influences the foundational medical meeting between the doctor and patient.

Physician and ethicist Mark Siegler reinforces this observation by classifying the "prepatient phase of clinical medicine" as the "first clinical moment" (Siegler, 1985, p. 23). He similarly observes, "Even if a problem is seen as a health problem, one may choose not to make it a problem of clinical medicine by not presenting it to physicians.

Individuals can define a problem as a nonmedical one even when severe disease exists" (Siegler, 1985, pp. 25-26). Siegler draws from Tolstoy's novel *The Death of Ivan Ilyich* for an insightful picture of the prepatient phase. The individual's perception that he is ill and his decision to seek medical help are influenced by a variety of factors. Tolstoy reveals several subjective characteristics in this "first clinical moment," such as the social, cultural, and psychological factors that strongly influence an individual's judgment.<sup>†</sup>

The patient is both the one who experiences the symptoms of illness, and the one who assigns them understandings and meaning. "Different individuals can define similar conditions in different ways, just as one individual can, at different times, define the same condition in different ways" (Siegler, 1985, p. 26). Cassell notes that the meaning of illness to a particular patient will depend upon "the collectivity of his meanings." This collectivity is necessarily a function of the autobiographical situation. For example, pain in the chest may be interpreted as a heart attack by one patient and as merely indigestion by another (Cassell, 2004, p. 153).

These personal meanings are dependent upon the patient's unique life experiences. The present suffering is constituted in light of past experiences and future anticipations, which relate to the individual's unique life plan (Toombs, 1992, p. 17). Therefore, each patient reacts both to the news of the diagnosis, as well as to the symptoms experienced, according to the peculiar relevance to these issues to their concrete situation in the world. Reflections from a middle-class American further illustrate the way one's life context generates particular meanings:

<sup>†</sup> For an elaboration on this point, see: Levine, R.J.: AIDS and the physician-patient relationship. In <u>AIDS</u> and <u>Ethics</u>. Ed. by F.G. Reamer, Columbia University Press, 1991, Chapter 8, pp. 188-214. (Levine, 1991)

Later that same evening, the way my upset stomach, lower back pain, and headache give themselves to me is shaped by cultural assumptions I have already absorbed as a white, middle-class, American male. Among these is the conviction that discomfort signifies that something is "wrong" with my body and that if it is severe enough then I should seek out a doctor trained to "fix" it. Had I been raised in other socio-historical settings, in other hermeneutic situations, these same sensations would not appear this way. Rather (if I were a devoted Hindu from a twice-born caste), they might disclose themselves as automatic consequences of "bad karma," that is, as inevitable results of my own earlier unclean acts and attitudes. Or, if I were a Haitian peasant, I might see them as hexes laid upon me by a local witch; if I were a born-again Christian, as divine punishment for my sins; or, as a secular cynic, as dumb fate. Whatever the case, the interventions called for would differ. (Aho & Aho, 2008, pp. 11-12)

It is also true that the patient's differences in his unique apprehension of illness may actually relieve or exacerbate suffering. For this reason, it is critical for physicians to seek to understand the meanings the patient ascribes to their subjective experience of illness.

The subjective experience of the patient is increasingly recognized as important in light of recent changes in disease patterns. Acute diseases, such as pneumococcal pneumonia, usually depend very little on what things mean to the patient. "Symptoms are so dire as to drive anyone for help, and, within limits, penicillin works, personal beliefs and values notwithstanding" (Cassell, 1985, pp. 160-161). With the increasing prevalence of chronic diseases, however, the predicament changes. Both the presence and the symptomatic expression of conditions like diabetes and hypertension are determined, in part, by who the patient is, by the meaning he attributes to his condition, and by his behavior. Dietary habits, lifestyle, and patient compliance are strong influences on and predictors of the course of the patient's experience of illness (Cassell, 1985, pp. 160-161).

#### As the Privation of a Good

In addition to being deprived of the good of health, the patient often experiences a host of other privations, which can incite and intensify his suffering in illness. Following S. Kay Toombs, we can categorize these privations as the loss of the goods of bodily integrity, control, order, the familiar world, and a person's dynamic equilibrium. A further examination of these privations will help clarify the nature of suffering in illness.

Phenomenological accounts of illness commonly emphasize the disruption of self—a break or split in one's sense of personhood that is normally experienced as a complete whole (Brody, 1987, p. 47). Such "loss of wholeness" is what we mean by the privation of bodily integrity, often experienced as an "ontological assault," as previously noted. In order to grasp the implications of the loss of wholeness, it is important to understand that the human body is the territory where—and even the medium by which—a person expresses himself.

The problem of the relation between "body" and "soul" has been the theme of countless speculations and theories. Plato conceived of man as a spiritual substance endowed with a material body for his terrestrial existence; Aristotle proposed a "substantial unity" of soul and body—form and matter—within an individual human being. In this thesis, however, we are only concerned with the impact that illness has on a person's ability to express his personhood *through the body* (Wojtyła, Tymieniecka, & Potocki, 1979, pp. 204-205). As noted earlier, Pellegrino reinforces this concern with his

<sup>&</sup>lt;sup>†</sup> S. Kay Toombs states that the patient's experience of illness displays certain "eidetic characteristics", which are those that are "essential to the thing-itself and that remain unchanged regardless of any varying empirical features." Toombs lists these characteristics as "a loss of wholeness and bodily integrity, a loss of control, a loss of freedom to act in a variety of ways, and a loss of the hitherto familiar world" (Toombs, 1992, pp. 220-221).

emphasis on illness infringing the expression of one's personhood (Pellegrino, 1985, pp. 100-101).

The body is intimately connected to a person's self-possession and self-determination. The territory and the means of expression of a person's individuality—his personhood—*is* his human body (Wojtyła, et al., 1979, pp. 204-205). Consequently, the integration of the person is both connected to, and expressed by the body.

Coining the word "embodiment," the founders of phenomenology  $^{\dagger}$  made a further distinction between two terms,  $K\ddot{o}rper$  vs. Leib:

Körper is a reference to the corporeal body, what we are as physiological, neurological, and skeletal beings. It is what modernity's preeminent philosopher, René Descartes (1596-1650), refers to as that aspect of ourselves "extended in space," visible to the eye, and hence subject to scientific investigation. In contrast, *Leib* concerns how we experience this physical matter in our everyday lives. If *Körper* is the abstract body-in-general, one object among others that is simply "there," *Leib* is *my* body in particular, my life here and now, what I am as a volitional, sensing person. It is what I see, think, and remember about my own skin and bones, and how I feel about them. (Aho & Aho, 2008, pp. 1-2)

The distinctions between *Körper* and *Leib* parallel the differences between disease and illness (Aho & Aho, 2008, pp. 35-37; Kleinman, 1988, pp. 3-6; Toombs, 1992). It is the widely accepted view of "body-ness," or *Körper*, that predominates in the present biomedical perspective of the physician. By contrast, *Leib*, the lived-body, is a word closely related to *Leben*, life, which resonates with the lived experience of embodiment. Husserl and his disciples argue that however helpful the objective measures of *Körper* may be, they are incapable of capturing everyday experiences. Caloric intake, blood pressure, lipid profiles, and prostate specific antigens—these are scientific measurements in the domain of *Körper*. Although such data are useful, they do not capture the actual

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<sup>†</sup> Specifically Husserl, Stein, and Heidegger in this case.

lived experiences of the embodied person, for example, her appetite, stress, chest pain, fear, anxiety, and apprehension of symptoms (Aho & Aho, 2008, pp. 1-2).

Leib, the lived-body, is the proper place of suffering, in the etymological sense of suffering as pathos (Granados, 2006, p. 553). Suffering is spoken of as bodily, not because it is equated with pain, but because human suffering is rooted in Leib. Having a tumor proliferate in one's body (Körper) is not suffering, but its presence will likely prompt suffering. This suffering resides in the Leib; it follows from an awareness of the proliferating tumor, and from a perception of the losses of particular goods. The person recognizes the failure of the body (Körper) to support his life (Leben) desires and goals.

# Loss of Bodily Integrity and Control

An ill patient often feels betrayed by her body. The patient's lifeworld is challenged, particularly in interpersonal and communal relationships. There is a loss of the unity ordinarily experienced between the self and the body, specifically the ability to face the world and others and to interact with them as "one being," with integral wholeness. The body is in pain, suffers a disability, or experiences a malfunction that no longer makes it the cooperating instrument of the self. The patient can no longer use the body for trans-bodily purposes—a means to reach self-defined ends. Instead, the illness takes center stage and becomes the main object of concern; rather than serving the person, the body demands to be served. This loss of ontological unity may be subtler and deeper for an emotionally or mentally ill person. The psyche or spirit of the person becomes an impediment and results in an even more complex fracturing of the unity of the person (Pellegrino, 1985, p. 101). But whether in physical or psychological illness,

what is essential to our current concern is the fact that illness attacks the fundamental unity of the person, and this attack is experienced as a privation of bodily integrity and wholeness (Pellegrino, 1982, pp. 158-159).

In the loss of bodily integrity, a patient experiences both a heightened awareness of embodiment—which was previously taken-for-granted—as well as a heightened alienation from her body (Campbell, 1995, p. 175). Illness itself is strangeness; it marks an end to the "taken-for-grantedness" † of everyday life. Paradoxically, we most attend to ourselves as embodied when something goes wrong with our bodies. When I am healthy, my body does not assert its presence in my consciousness in unexpected ways. With the onset of various symptoms of illness, however, my body begins to present itself as "other": that *ache* in my legs; that *burning* in my throat. In spite of a sharper focus on my body, I feel increasingly *alienated* from my body in the experience of illness. I have lost the familiar, taken-for-grantedness of everyday life.

Since the body is essential to one's personal identity, the difference that this new sense of "otherness" makes can be dramatic. Increasingly, this new and differently experienced body begins to engulf aspects of our consciousness. Richard Zaner elaborates:

[I]llness and impairment have a unique way of cutting into that fabric and the person's life may sometimes be radically altered—temporarily, as with a case of the flu, or for longer times, as with diabetes. Whichever it may be, the person's embodying organism, especially that part or member that has been affected,

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Alfred Schutz states that the veritable mark of everyday life is what he terms as "taken-for-grantedness." By way of cultural and socially inculcated typifications, we learn in the usual course of habitual affairs to take things for granted, that is, to assume things will be as they have been in the past, for all practical purposes. Only when something does not conform to our typified expectations do we adapt and change according to it. Our attention is then directed to settle what becomes unsettled in order to proceed with the normal routines of daily life. Should we be obliged to change a habit, such as using eyeglasses, or alter our lives more substantially, such as in becoming blind, "we even then more or less grow used to it, and our respective stocks of taken-for-granted habits of knowledge remain governed by the pragmatic motive of daily life."

becomes "front-and-center," often dominating the person's awareness (...the "lack of energy," the "pounding heart," the "acute belly-ache")...or at least hovering constantly, if silently, in the background of experience (the lump in the administrator's armpit that "just sat there, silent and painless, except for occasional funny feelings down my arm and in my hand"). In short, the afflicted person is no longer able to take for granted some of what he or she had hitherto been taking for granted, to whatever extent it may be for however long it may go on. The woman with flu can no longer be up and about in the same ways; the man with end-stage kidney disease must now maintain a rigorous dietary regimen and undergo regular dialysis. Now daily things must be done differently, or they may even have to be done for the person by someone or something else. (Zaner, 1988, p. 67)

Toombs designates this "disembodied" body described by Zaner as the "oppositional body": the body that frustrates one's life possibilities and everyday routines and is increasingly experienced as "other" because it is increasingly beyond one's control.<sup>†</sup>

Neurologist Oliver Sacks' personal reflections buttress Toombs' observations. Sacks recalls his fall and subsequent broken leg from a mountain climb. This incident resulted in considerable nerve damage, necessitating a prolonged rehabilitation to regain sensation and movement. In neurological terms, Sacks' experienced a peripheral lesion. He notes, however, that it was "not just a lesion in my muscle, but a lesion in me" (Sacks, 1984, p. 67). Sacks vividly recounts the experience of his oppositional body: He was not able to move his leg even with intense effort; he could not tell without looking at his leg whether it was positioned on or off the bed. He describes, "In that instant...I knew not my leg. It was utterly strange, not-mine, unfamiliar. I gazed upon it with absolute non-recognition" (Sacks, 1984, p. 72). Sack's reflections show that his experience of injury

<sup>†</sup> S. Kay Toombs' experience as a patient with multiple sclerosis brings firsthand insights into this phenomenon (Toombs, Barnard, & Carson, 1995).

went much deeper than merely a paralyzed leg with loss of sensation; his injury was a disruption of his very being, an ontological assault.

With the assistance of medical expertise, a patient may eventually regain control over his body. However, in instances of chronic illness, where ongoing technological assistance may be required, any control gained may be at the expense of increased "otherness," since the supporting technological intervention is an artifice alien to the body (Campbell, 1995, p. 175). These disruptions frequently have a lasting effect on the concept of self, even if the performance of activities is restored (Garro, 1992, p. 103).

Toombs asserts that this loss of control seems to be more acutely felt by modern man because of the illusions he often harbors about the power of technology and modern science. Since science and technology have been successful in eradicating many diseases, the patient commonly expects medical intervention to provide a complete restoration of bodily integrity and control, and he approaches the physician with unrealistic expectations. As a result, the technology that promises control paradoxically often intensifies the *loss* of control the patient experiences (Toombs, 1992, p. 94).

### Loss of Order and the Familiar

Illness also interrupts daily life. Falling ill disrupts the patient's usual experience, disordering her relationships to the world, the self, and others (Zaner, 1993, pp. 249-250). This disorder may be of different kinds and varying magnitudes. Disruptions caused by simple illnesses may be easily correctible, and the crisis may be short-lived. At the other end of the spectrum, there are monumental crises that result in a prolonged or final disruption of daily life, as in cases of chronic or terminal illness.

The disorder caused by illness can affect the most basic constituents of one's reality. "One's existence is, as it were, shaken to its ontological foundations" (Wiggins & Schwartz, 2005, p. 80). Even the experience of time and space may be altered. When the speed and mobility of a person's body are radically changed in illness, other people and things outside of the patient become more distant as it takes more time and effort to reach them.

A patient's experience of modern medicine's technology and its biomedical "gaze" further exacerbate this "loss of the familiar":

When undergoing investigation patients find themselves at the mercy of faceless machines—machines with barely understood functions but whose dictates must be obeyed. In this encounter with machines, one perceives oneself to be an object of investigation, rather than a suffering subject. This transformation to objecthood is correctly felt not only in the "gaze" of machines, but also in the "gaze" of health care professionals. (Toombs, 1992, p. 94)

Even when a patient is "cured," the experience of illness often leaves its imprint. Body and self are never again quite so comfortably united; the taken-for-grantedness of everyday life has been replaced by a consciousness of one's vulnerability and even mortality—for "the proof of man's mortality is felt in the experience of illness in a way it can never be felt vicariously even in the illness and death of one we love" (Pellegrino, 1982, pp. 157-158). Arthur Frank vividly describes his experience:

Having a heart attack is falling over the edge of a chasm and then being pulled back. Why I was pulled back made no more sense than why I fell in the first place. Afterward I felt always at risk of one false step, or heartbeat, plunging me over the side again. I will never lose that imminence of nothingness, the certainty of mortality. Once the body has known death, it never lives the same again.

People who think of themselves as healthy walk that edge too, but they see only the solid ground away from the chasm. (Frank, 1991, p. 16)

Illness forces a person to recognize the fragility of his bodily integrity. "A dialysis machine may be a miraculous imitation of the kidney, but no one on dialysis would mistake it for the real thing" (Baron, 1992). This is obviously most relevant in chronic and life-threatening illnesses than in mild, passing ones. The person who has been seriously ill recognizes that at any time his body or mind may betray him, may come into opposition with his self, as an "oppositional body."

The suffering experienced due to privations such as the loss of bodily integrity, control, order, and the familiar world remain in the person's memory. As a result, suffering may persist even when the disease has been successfully treated in biomedical terms

### Loss of Dynamic Equilibrium

Illness is also a loss of our dynamic equilibrium. It threatens our self-image, which is a product of our past exercise of rational choice. Pellegrino asserts that such a self-image is carefully constructed over time from our choices and compromises, based on our aspirations and shortcomings. Normally these choices are in dynamic equilibrium with our existential state. Illness challenges this equilibrium and "forces the reshaping of a new equilibrium through a new set of decisions often having un-welcomed alternatives. To become a diabetic, a cardiac, or a patient with cancer awaiting death demands the most fundamental reconstruction of personal identity" (Pellegrino, 1985, p. 101).

Pellegrino notes that this reconstruction is "managed" by the "I," which is "the historical continuing entity that persists beneath all changes, past and future" (Pellegrino,

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<sup>&</sup>lt;sup>†</sup> The loss of dynamic equilibrium can be seen as an umbrella for the other losses previously mentioned, as it encompasses a loss of integrity, control, order, and the familiar world.

1985, p. 101). The urgency and intensity of the assault on a person's dynamic equilibrium demand a reshaping of his personal identity. The patient craves "to be free again to make his own choices, define his own ends and choose the kind of life he wishes to live" (Pellegrino, 1985, p. 101). Zaner concurs with Pellegrino that serious illness challenges a person's sense of self. Zaner writes, "What and who we are, what we hope to be and become, even whether we continue to be at all, is in one way or another at stake in these circumstances" (Wiggins & Schwartz, 2005).

The onset of serious illness raises basic questions about how the patient desires to live life. The patient as well as the people closest to the patient—family, friends, and loved ones—are compelled to respond to these existential questions in some way.

Oftentimes the circumstances result in confusion and uncertainty for both patients and their loved ones. There can arise a felt need to gain a new comprehension of the patient's identity, and to re-assess the "equilibrium." Although medical facts and procedures are relevant to the conversation, this question of the patient's identity and dynamic equilibrium demands more than merely biomedical information. The "need to understand is a need to understand what this means for one's life, for one's future, and for one's relationships to others" (Wiggins & Schwartz, 2005, p. 81).

Goals, plans, and expectations about life itself are radically revised in the face of illness, particularly in chronic and terminal illness. One patient writes of her chronic fatigue syndrome: "The destination and map I had used to navigate before were no longer useful." Frank notes that the patient describes how, in the midst of an illness that never really ends, she needs "to think differently and construct new perceptions of [her] relationship to the world" (Frank, 1991).

Illness calls forth a different, unaccustomed way of seeing oneself, one's past, present, and future; it propels a reconstruction of one's identity, in an effort to find a new equilibrium. Perhaps this is why Dostoyevsky exclaimed, "Suffering! Why it's the sole cause of consciousness!" (Dostoyevsky, Magarshack, & ebrary Inc., 2005, p. 140; Parish, 2008, p. 126)

Patently, suffering provokes us to struggle, to try to rearrange existence, to rearrange ourselves. As we struggle with it we may in certain ways become remade, before our own eyes. Human beings are not passive in relation to the process of suffering. In fact, suffering may provoke efforts to transform, to remake the self, to renew life. Dostoyevsky's declaration that suffering constitutes the "sole cause of consciousness" is literary exaggeration; but suffering does incite and shape consciousness of the world and self. As people respond consciously and self-consciously to suffering the suffering provokes developments in the self, and pushes the self to search for possibilities. (Parish, 2008, p. 127)

Patient narratives offer insight into this reconstruction of identity. Through patients' stories we see, that even in the midst of drastic adaptations and reconstructions, a particular struggle to preserve his fundamental identity—the "I," mentioned by Pellegrino, that "persists beneath all changes." Patient narratives reveal diligent and successful efforts to maintain a sense of self and purpose in the face of a profound life disruption. Physician Howard Brody describes this as the "dual nature of sickness," insofar as a patient becomes different while remaining the same person. Such striving toward a new dynamic equilibrium is an integral part of the narratives told by sufferers of chronic and terminal illness (Brody, 1987, p. x). One commentator describes:

The suffering in one's life must be written into the plotline of one's personal story so that the unforeseen episode not only fits with or bridges what has gone before but also blends into and harmonizes with the plotlines of projected future episodes. Imaginative projections of the future can be dismal and defeating,

unrealistic and unachievable, or they can be constructive, liberating images. (Harris, 2007, p. 71)

Harmony with a projected future is critical for a patient's dynamic equilibrium. By contrast, when a patient's apprehension of the future is *not* in harmony with her past, she can experience much suffering.

Cassell points out that suffering and a sense of the future go together. Bodies do not have ideas, hopes, fears, and aspirations necessary to create a future—only persons do (Cassell, 1999, p. 106). Serge Daneault, a palliative care physician in Quebec, interviewed patients diagnosed with terminal cancer. His research shows that patients with terminal cancer define their suffering in terms of three "core dimensions": 1) being subjected to violence, 2) being deprived and/or overwhelmed, and 3) living in apprehension (Daneault, et al., 2004). In the third category, the patient links her current suffering with potential future suffering. "Living in apprehension" means that the patient experiences trepidation, suspicion, and dread regarding the future, particularly future suffering. *Present* suffering is thus frequently triggered by an apprehension of *future* suffering.

Suffering in other words begins not merely with a present loss, but also with the perception of future losses (Cassell, 1999, p. 109). For example, at the time of a diagnosis of amyotrophic lateral sclerosis, a patient may not have lost a significant amount of motor functioning, yet the mere apprehension of a grave future loss prompts immense suffering.

The biomedical perspective of the physician can fail to recognize that a person's *fear* of illness, disease, or injury may itself be a source of significant suffering. "The threat that possible pain, disease, or injury represents to the self can be profound,

equaling their actual effects on the body; and physicians are appropriately called upon to help allay such anxieties" ("The goals of medicine. Setting new priorities," 1996, p. 24).

# Loss of Meaning

Suffering is one of the greatest challenges to the question of *meaning*. Friedrich Nietzsche proclaimed, "What really raises one's indignation against suffering is not suffering intrinsically, but the senselessness of suffering." He added, "He who has a *why* to live can bear with almost any *how*" (as cited in Harris, 2007, p. 60). His general fatalism notwithstanding, even Nietzsche recognized the central importance of *meaning*. In this vein, Viktor Frankl<sup>†</sup> stressed that meaning is essential for life and that humans are intentional beings, always consciously or subconsciously searching for or creating meaning; for this reason, senselessness, or meaninglessness, is almost impossible for persons to endure (Frankl, 1988; Heidegger, 1962). Suffering begs for an explanation, and a lack of understanding about one's suffering causes a person to suffer more (Wright, 2005). Indeed, a conviction of senselessness in suffering blocks the sufferer from integrating new meaning into his or her life story, an integration that is crucial to personal unity and coherence. The loss of meaning is one of the most devastating privations to the thriving of the human person.

Frankl asserted that the lack of meaning is *the* paramount existential stress;<sup>‡</sup> an existential crisis is always a crisis of meaning. Frankl believed that our modern era, in

<sup>&</sup>lt;sup>†</sup> As the survivor of four concentration camps, Frankl bore witness "to the unexpected extent to which man is, and always remains, capable of resisting and braving even the worst conditions. To detach oneself from even the worst conditions is a uniquely human capability" (Frankl, 1988).

Frankl comments that it has been unfashionable to refer to such "trans-subjectiveness," much due to the impact of existentialism and its emphasis on the subjectivism of being human. Frankl notes that this is actually a misinterpretation of existentialism. A truly phenomenological analysis reveals that to understand

which traditions and universal values are crumbling and vanishing, leaves many people caught in an "existential vacuum," which Frankl described as "a total lack, or loss, of an ultimate meaning to one's existence that would make life worthwhile." Such a vacuum leaves the person vulnerable to both conformism and totalitarianism, and also to utter despair in moments of unavoidable suffering. Husserl, in turn, connects this contemporary existential vacuum to the dominance of the scientific worldview:

The exclusiveness with which the total world view of modern man, in the second half of the nineteenth century, let itself be determined by the positive sciences and be blinded by the "prosperity" they produced, meant an indifferent turning away from the questions which are decisive for a genuine humanity. Merely factminded sciences make merely fact-minded people...In our vital need—so we are told—this science has nothing to say to us. It excluded in principle precisely the questions which man, given over in our unhappy times to the most portentous upheavals, finds the most burning: questions of the meaning or meaninglessness of the whole of this human existence. (Husserl, 1970, pp. 5-6)

Husserl did not mean to gainsay the monumental achievements of modern science. He rather meant to place those achievements in larger human context. A physician's biomedical explanation of a patient's illness simply does not address the patient's questions of meaning. Patients may benefit from biomedical breakthroughs, yet their questions about the *meaning* of their suffering—their "most burning" questions remain. And yet it seems to be taboo in modern society to speak of life as having any

the Heidegerrian phrase of "being-in-the-world" properly, "one must recognize that being human profoundly means being engaged and entangled in a situation, and confronted with a world whose objectivity and reality is in no way detracted from by the subjectivity of that 'being' who is 'in the world.'" To preserve the "otherness," the objectiveness, of the object means preserving that tension between object and subject; this is the same tension between reality and ideal, between being and meaning. Frankl seeks to preserve this tension as it prevents meaning from coinciding with being (Frankl, 1988).

Ironically, even the nihilists are not exempt from ultimately embracing an idea of meaning in life. A graduate psychology student from the University of California at Berkeley explains: "It is strange. The nihilists first laugh at your concept of meaning through suffering—and ultimately their tears dissolve them" (Frankl, 1988).

meaning; it seems especially taboo to speak of *suffering* as having meaning. We might say that *Logos* (the Greek word for "meaning") is repressed in contemporary culture.

# **Summary**

Phenomenological writings on embodiment demonstrate the inadequacy of the biomedical view, rooted in *Körper*, to capture the lived-reality (*Leib*) of suffering in illness. The Latin root of patient, *patiens*, means "one who endures or suffers." Although pain is a common cause of suffering, suffering and pain are distinct forms of distress. There may be pain without suffering and there may be suffering without pain. We can more fully understand a patient's suffering in illness *through* various descriptions and narratives offered by phenomenologists, physicians, and patients, writings rooted in the experience of the human person. Cassell describes suffering as a threat, or a *perceived* threat, to the integrity of the person, while Pope John Paul II notes that a person suffers "whenever he experiences any kind of privation of good." I narrow the latter definition to harmonize with Cassell's, as Cassell's is a more suitable tool for the specific purpose of this work. These descriptions, along with a variety of other writings, offer insight into the nature of suffering.

Suffering is a uniquely human experience as well as an unavoidable human experience. Besides being an objective human experience, suffering is unique to the individual. Each person is absolutely unparalleled and unrepeatable; there is an unrepeatable "thisness" about every person (Seifert, 2004, p. 104). Suffering is a personal fact contained within a person's concrete and unrepeatable interior.

Illness is the privation of the good of health; suffering in illness encompasses the privation of a host of goods, as experienced or perceived by the patient. Such goods include the loss of bodily integrity, control, order, and the familiar world. Pellegrino's observation of the patient's loss of dynamic equilibrium is another overarching privation that can be experienced in suffering.

Finally, Husserl notes that the naturalistic, scientific perspective fails to acknowledge those questions "most burning" within persons when confronted with suffering: questions of meaning. Frequently a patient experiences senselessness in his suffering, an experience that seems to be prevalent in the "existential vacuum" of modernity. This loss of meaning is one of the most devastating privations to the thriving of the human person. Viktor Frankl notes, however, that meaning can be a powerful avenue to the alleviation and elevation of the human person in moments of unavoidable suffering. In the next section, I will discuss Frankl's writings on the will to meaning. I will show how Frankl's ideas can be a tool to unleash the goods of love, fulfillment, communion, and transcendence in times of unavoidable suffering.

# **CHAPTER IV**

### SUFFERING TRANSFIGURED

Let me not pray to be sheltered from dangers but to be fearless in facing them.

Let me not beg for the stilling of my pain but for the heart to conquer it.

Let me not look for allies in life's battlefield but to my own strength.

Let me not crave in anxious fear to be saved but hope for the patience to win my freedom.

Grant me that I may not be a coward, feeling your mercy in my success alone; but let me find the grasp of your hand in my failure.

Rabindranath Tagore, Fruit-Gathering

Throughout history, humanity has sought to discover meaning in times of unavoidable suffering. Many profound responses have emerged from this search, some partial and others more thorough. An important distinction needs to be made between the ultimate reason for the very existence of suffering and the meaning that may be found in it *once it exists*. In this chapter I will speak to the meaning that can be found in suffering *once it exists* in the patient's experience of illness.

Suffering is certainly something that should be eliminated by all reasonable means and costs. It is also clear, however, that sometimes suffering is unavoidable. We hold these two truths in tension. Physicians are daily immersed in this reality: "Man is a being which sooner or later must die and before doing so, must suffer—despite the advances in science so much worshipped by progressivism and scientism" (Frankl, 1969, p. 72). The last section discussed how the event of illness in the lifeworld of the patient causes multiple privations that result in suffering. It is a duty for physicians to take reasonable measures to prevent unnecessary suffering. But what about inescapable

suffering, particularly in cases of chronic and terminal illness? Suffering in illness certainly must be avoided as long as possible, but when suffering cannot be avoided, not only must it be accepted but "it may be transmuted into something meaningful, into an achievement" (Frankl, 1969, p. 72).

Medicine regularly meets inevitable suffering. Every patient encountered by a physician is suffering to some degree, and medicine's present resources cannot alleviate some of this suffering. Physicians feel paralyzed in these situations, most especially when they are solely dependent upon biotechnological solutions. They may be tempted to declare those infamous hopeless words: "There is nothing we can do." Perhaps this is true from a biomedical perspective, as the therapeutic options have reached their limit. The phenomenological perspective, however, offers hope and resources for these patients. In this chapter I suggest that the losses experienced in suffering can sometimes be transfigured into a host of goods, contributing to the fulfillment and well being of the patient.

#### **Direction and Definition**

The heart of this chapter addresses the claim that something can be gained through suffering. Various accounts of suffering and its consequences will allow us to explore the depths of this claim. I will draw mainly from the insight of Jewish psychiatrist Viktor Frankl who stated that, hidden in the depths of the worst forms of inescapable suffering, there is a meaning to be discovered that is uniquely related to the

<sup>&</sup>lt;sup>†</sup> In addition to the works of Viktor Frankl and John Paul II, I will draw from the insights of Eleanore Stump's recent book, *Wandering in Darkness*. Stump states that a person suffers when something undermines either her flourishing or her having the desires of her heart, or both. From a Thomistic perspective, Stump shows that there are benefits and goods that defeat suffering (Stump, 2010).

person's fulfillment. This discovered meaning is then a means to gains such as love, self-transcendence, achievement of a good, and the dignity of the person amidst the losses experienced in suffering. I propose, therefore, that *suffering can be transfigured by way of meaning*.

To say that suffering can be *transfigured* implies that a transformation takes place, a change in outward appearance, form, or nature. To be transfigured also suggests being exalted or glorified. This latter definition recalls the scriptural account of the transfiguration of Jesus Christ on Mount Tabor. This illumination served as a remembered, elevating light amidst the intense sufferings later experienced by Jesus on Calvary. By analogy, from a Christian point of view, one is called to be a bearer of transfigured light in the midst of the darkness of suffering. Although suffering is sometimes unavoidable, it always harbors the potential to be transfigured into new light and life. My claim is that it is the *experience of suffering*, not the patient, which is transfigured. Thus, my historical reference to the event on Mount Tabor is presented metaphorically to offer vivid imagery of the transformation of the experience of suffering.

The Kabbalah school of thought, the mystical school of Rabbinic Judaism, also draws from the rich imagery of transfiguration, referring to Sandalphone, for example, as an archangel who is the transfiguration of Elijah. Buddhism, too, has references to transfiguration: It is written that the Buddha was transfigured at the moment of his enlightenment, and again at the moment of his death. Each of these accounts connects suffering to an elevated state of resplendence. The suffering is not eradicated but becomes an occasion when something new is manifested. What was once invisible—or,

perhaps nonexistent—becomes visible. Love, communion in relationships, self-transcendence, and the achievement of a good are some of the ways this newness may manifest.

Moreover, when suffering is transfigured, beauty is revealed to the beholder, a beauty that may not have been revealed or actualized otherwise. Beauty is that property of being which gives pleasure because of its integrity (wholeness), harmony, and brightness or splendor (Wuellner, 1956, p. 13). I propose that the presence of beauty may be a sign to the observer of transfigured suffering. The patient, on the one hand, may experience firsthand goods such as love, friendship, or the achievement of a good. The physician, on the other hand, as an observer of the transfigured suffering, may behold the three qualities of beauty in the patient's experience: that is, a newly formed integrity, harmony, and perhaps even a glimpse of the elevated dignity or splendor of the human person. The third condition of "splendor" is intangible and, in many ways, ineffable. It is a supreme "crowning" that points to the source and summit of life, which is love. Phenomenologist Gabriel Marcel's words, "The [supreme] life...is light, because it is love," connects the *means* of the transfiguration—its light—to the end of love (Marcel, 1954, p. 249).

Consider the 2007 documentary titled *Into Great Silence*. This film about the ascetic Grande Chartreuse monastery, consisting only of images and sounds of the rhythm of monastic life, offers one interview with an elderly, blind monk. To the astonishment of the viewer, the monk gives thanks for being made blind. He says that

The transfiguration of suffering is not limited to persons of a religious tradition; it transcends all boundaries and encompasses all persons. We will see later in this chapter how the *will to meaning* is the means to such transfiguration. This method is equally accessible to "religious" and to "non-religious" persons.

while the world has lost sight, the gift of his blindness has allowed him to see life more clearly; therefore his loss has been for the better (Gröning, et al., 2007). The blind monk's statement is not metaphorical or analogical; it is an authentic discovery of meaning. He experienced an overall gain in a situation that, from an outsider's view, would be considered an overall loss. Moreover, the viewer cannot help but be captivated by the monk's peaceful presence and insightful wisdom. In the midst of his suffering, the monk displays the three conditions of beauty—integrity of self, harmony of life, and an enlightenment of the mind and heart. This beauty is a sign pointing to the transfiguration of his experience of suffering. In the darkness of his blindness, his life "is light, because it is love" (Marcel, 1954, p. 249).

We recall the words of Rabindranath Tagore, Bengali poet and playwright as well as the winner of the 1913 Nobel Prize for Literature: "The water in a vessel is sparkling; the water in the sea is dark. The small truth has words that are clear; the great truth has great silence" (Tagore, 1916). The blind monk discovered "the great truth" in the "great silence." This truth was the unique meaning of his suffering, and this meaning was a means to the transfiguration of his suffering. Through a discovery of meaning—a *will* to meaning—the losses of his blindness became an avenue to greater gains.

I acknowledge that many people may be resistant to this point of view. This chapter may provoke incredulity or indignation in some readers, especially to those who consider human suffering to be precisely *meaningless*—those who subscribe to a Nietzschean view of the senselessness of suffering. I understand the affect underlying this disposition, even while I reject the claim that suffering is pointless (Stump, 2010).

<sup>†</sup> I recognize that the accounts in this section are limited in so far as they apply to the suffering of mentally fully functional human beings. This position will not apply to human beings who are not adult or not fully

functional mentally.

Philosopher Eleanore Stump observes that to conclude that there is no point in suffering is to conclude that every person whose life included serious suffering would be better off if they had died at birth, had never been born at all, or simply had died before the onset of suffering. It is to suggest that whatever is good in life is diminished by serious suffering (Stump, 2010). This view, Stump submits, is false. It is true that sometimes the suffering endured by a person breaks him or her past healing. There are events that can crush a person's mind or shatter a person's body and what was broken may be incapable of restoration. And yet, in spite of all this pain and brokenness, it is possible that life was nevertheless a *good* for the person (Stump, 2010). Philosopher Eleanore Stump stresses that a person must decide: life is meaningful—despite the circumstances of suffering—or life is not meaningful. If it is meaningful, it must have an unconditional meaning from which no suffering can detract. Although Stump's tone is more absolute and assertive than Frankl's, the principles that underscore their positions have areas of agreement—namely, that there is meaning to be discovered in moments of unavoidable suffering.

Stump writes, "There is more than one way of facing suffering; and consigning those who suffer to the scrapheap of human history is not the only way to respect their suffering" (Stump, 2010). In cases of inevitable suffering, particularly in chronic and terminal illnesses, I will try to show that the experience of suffering can be transfigured into a *gain*, a paradoxical position, since suffering, by John Paul II's definition, is an experience of *loss*. Even if the ability to transfigure suffering to have positive value is demonstrated, the paradox remains. It is a paradox that goes beyond philosophical analysis and leads us into the mystery of suffering, relationships, and the meaning of life.

The concept of paradox is a norm in the Judeo-Christian tradition and other major world religions. It is also a norm within the lived-reality of daily life experience. Honest reflection reveals that there is no sorrow that cannot open to some form of joy, and no joy without some limit in sorrow (Farley, 2002, p. 18). Furthermore, there is no presence without some form of absence, and there is a kind of absence that makes presence possible. Likewise, there is a kind of emptiness that makes fullness possible; there is a kind of death that makes new life possible.

# Can there be gains in the midst of the losses of suffering?

First, there is compelling evidence that suffering can promote human flourishing, and that in the experience of the loss of a good, another good<sup>‡</sup> may be gained. Empirical evidence, from psychology's recent exploration of the regeneration of the person in serious illness, supports this view. Researchers have become increasingly interested in how illness and traumatic events can sometimes be a springboard for greater personal growth. This phenomenon of positive change following serious illness and trauma has been variously labeled posttraumatic growth, adversarial growth, and quantum change (Shaw, et al., 2005).

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Von Hildebrand describes a *good* as follows: "By a good I understand any being having importance and capable of motivating an act of the will or an affective response according to one of these three categories of importance (the merely subjective satisfying, the objective good of the person, and value). From this broad sense of the good we have to distinguish the other sense according to which good has value, or in other words has an importance that rests in itself. For our purposes it is important to bring out this latter concept of good in relation to the concept of value. Value is that which makes these goods to be goods. A good by contrast is the whole real being in its value. An act of love of neighbor is a good on the basis of a special moral value that it embodies. A beautiful landscape is a good on the basis of the fact that it is beautiful. Beauty itself is a value. In a good, a value finds its realization." This realization of a value to the good embodying it can vary greatly (Von Hildebrand, 2009, p. 79).

The term "posttraumatic growth" (PTG) was coined in the 1990s by Tedeschi and Calhoun to describe reports of lasting positive change following an unusually stressful event. Since that time, PTG has been the

This theory, that serious illness may foster personal growth, is bolstered by the striking findings of researchers studying patients with cancer. A recent investigation reveals, "[M]ost people diagnosed with cancer report that they experience positive changes in their life as a result of their disease, and many say their experience with cancer was more positive than negative" (Ransom, Sheldon, & Jacobsen, 2008, p. 811).

Another group of researchers refer to this phenomenon as "adversarial growth." They summarize the expanding research and literature on adversarial growth as follows:

Positive changes following adversity have long been recognized in philosophy, literature, and religion... They have been reported empirically [by psychologists and other researchers] following chronic illness, heart attacks, breast cancer, bone marrow transplants, HIV and AIDS, rape and sexual assault, military combat, maritime disasters, plane crashes, tornadoes, shootings, bereavement, injury, recovery from substance addiction, and in the parents of children with disabilities... Studies of adversarial growth are an important area of research. (Ransom, et al., 2008, p. 17; Shaw, et al., 2005, p. 8)

These findings suggest practical applications to clinicians, exhorting that they should "be aware of the potential for positive change in their clients following trauma and adversity" (Linley & Joseph, 2004, p. 17). Indeed, the facilitation of adversarial growth "may be considered a legitimate therapeutic aim" (Linley & Joseph, 2004, p. 17).

Certainly the idea that persons can grow through struggle and strife is not novel. Numerous psychological, religious, and philosophical systems over the centuries have promoted this view. Only recently, however, have researchers developed a conceptual framework for studying this phenomenon (Park & Helgeson, 2006, p. 74). Types of positive change noted in these systemic studies are "identification of new possibilities,"

changed priorities, an increased sense of personal strength, and growth in the domain of spiritual and existential matters" (Rabe, Zollner, Maercker, & Karl, 2006).

"Quantum change" has been another area of recent research that has revealed the transformative experiences associated with great suffering. One way of describing quantum change experiences is that they represent a "turning point in the life journey where major change simply must occur because the person is unable or unwilling to continue in his or her present course." This is further described as a moment of desperation, a breaking point of sorts where "something has to give" and, in fact, it does. "The result is a new, dramatically reorganized identity... Strained and separate aspects of the identity are reordered" (W. R. Miller & C'De Baca, 2001, p. 157; cited in Stump, 2010).

Consider the following case of a traumatic event that occurred to "Charles" when vacationing in Florida. While jumping into the Sarasota Bay for a swim, Charles hit a sandbar and fractured his sixth and seventh vertebrae. Waking up in the intensive care unit with a severed spinal cord, this active and athletic young man was told that his paralysis would be permanent. Charles had severe despondence and suicidal ideation in the initial months after his trauma. Through the love and encouragement of friends and caregivers in rehabilitation, however, Charles gradually set goals and a time frame for achieving them. Two years after his injury he became involved in a national spinal cord injury association and eventually served as president of its local chapter. He began visiting newly injured patients in the local hospital. While serving as chairman of a board for housing development for the disabled, he trained for a national marathon for handicapped people. Seven years after his paralysis, Charles reflects:

Socially, I'm much happier today that I was before my accident... [B]efore I was so caught up in my career that I didn't take time to enjoy life... Now I am involved in very worthwhile projects that are fulfilling and also help others...[I]n so many ways I am much better today than I was before the accident. Losing my ability to ambulate was a devastating loss. Yet while people may find it hard to believe, in many ways my life is much richer now. I've gained a lot. (Kachoyeanos & Baisch, 1996, p. 173)

Charles' reflections reveal the fulfillment that can follow from finding meaning in unavoidable suffering. He acknowledges the "devastating loss" of paralysis, yet describes his life as "much richer now." Charles alludes to a change in values, a movement toward self-transcendence, where he now gives of himself by helping others rather than being "caught up" in his career.

Viktor Frankl employs a "dimensional anthropology" to illustrate the phenomenon of finding meaning in suffering. *Homo sapiens* usually move on the horizontal dimension in everyday life, where the positive pole is success and the negative pole is failure. *Homo patiens*, however, is the suffering man who is capable of rising in a vertical dimension. In doing so, the suffering person shifts into a dimension in which the positive pole is fulfillment and the negative pole is despair. Charles' testimony is a vivid example of someone reorienting his life from a horizontal axis of worldly failure and success to a vertical axis of interior fulfillment.<sup>†</sup>

Suffering is transfigured not in the horizontal dimension of worldly success and failure, but in the vertical dimension of interior fulfillment. A person is capable of finding meaning and reaching fulfillment even in situations classified as "failures" by the horizontal axis. Charles' case of losing his worldly successful career once he became a paraplegic would be classified as a failure in the horizontal dimension. Through their

<sup>&</sup>lt;sup>†</sup> For a visual graph of "dimensional anthropology" see Appendix 1 in: Frankl, V. E. (1969). *The will to meaning; foundations and applications of logotherapy*. New York, NY: World Pub. Co. p. 75.

discovery of meaning, however, he reached a high level of fulfillment on the vertical dimension; in Charles' words, his life is "much richer now." Transfigured suffering follows from a person's orientation to the vertical dimension, where one seeks interior fulfillment rather than worldly success.

Similarly, "Roberto," a 42-year-old coronary bypass patient describes an experience of gain in the losses of illness:

I wouldn't take anything for this total experience, wouldn't trade it with anyone. This will sound stupid, I'm sure, but it was one of the best things that happened to me my whole life, having the heart attack, having the angiogram and having the bypass...It brought back what I would consider for myself, not necessarily for others, a new set of values. Many things which I had been overlooking for years now have a great deal of meaning for me. Life itself has more meaning for me, each day, each breath. Things which I had taken for granted for so many years are important...You're always one breath or one heart beat away from extinction. (Zaner, 1988, pp. 88-89)

Roberto explicitly connects the concept of meaning to his experience of gain in the midst of suffering. "Life itself has more meaning for me," he reveals.

Furthermore, the three conditions of beauty characterize these accounts of transfigured suffering. Although Charles and Roberto were not cured from a biomedical perspective, both persons displayed a newfound wholeness and integrity, a new harmony in their lives, and an element of resplendence. Charles, a man paralyzed for life, gives compelling testimony that his "life is much richer now," and that he has "gained a lot."

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<sup>&</sup>lt;sup>‡</sup> Through "dimensional anthropology," just as one can reach *fulfillment despite failure*, one can also *despair despite success*. *Despair despite success* is noted in Rolf Von Eckartsberg's study at Harvard University investigating the life adjustment of Harvard's graduates. Among 100 subjects, who had graduated 20 years before, there was a significant percentage of people who complained of a crisis. They reported that they felt their lives were meaningless, despite noteworthy professional success. They were caught in an existential vacuum. This phenomenon of *despair despite success* is explicable via Viktor Frankl's dimensional anthropology (Frankl, 1969).

There are certainly rare cases where one can reach both success and fulfillment, even in moments of unavoidable suffering. One example of *fulfillment and success* is mentioned later in "Team Hoyt."

These reflections, coupled with his service to other paraplegics, reveal a striking, radiant dignity—the third condition of beauty—as a revelation of the intrinsic worth of the human person.

Someone may protest at this point that suffering is frequently associated with psychological disintegration; a person's suffering can, therefore, lead to negative and even grave consequences (Stump, 2010). The literature on posttraumatic growth, adversarial growth, and quantum change acknowledges this rebuttal. The research on quantum change, for example, says that while trauma can function as a catalyst for the reconceptualization of the self, such reorganization can manifest in negative as well as positive ways (W. R. Miller & C'De Baca, 2001, pp. 157-158). As a result, the sufferer can react to the suffering in negative ways rather than ways that foster posttraumatic growth. Suffering, therefore, can *contribute* to growth, but it cannot *guarantee* growth. Still, negative reactions to suffering are not sufficient evidence to negate the reality of positive reactions. Rather, these different reactions point to the critical role of *the will* in the sufferer's trajectory.

# The Imperative of the Will

Suffering in no way *automatically* leads to meaning and a transfigured state; rather, suffering presents both a challenge and an opportunity. In most cases, a person undergoing suffering remains free as to how he or she will respond to the trial. These free choices often determine whether or not the situation will be transfigured into a gain (Colosi, 2009b, p. 30). Viktor Frankl witnessed this imperative important role of the will firsthand as a prisoner of four concentration camps. He analyzed it in the following way:

Even though conditions such as lack of sleep, insufficient food and various mental stresses may suggest that the inmates were bound to act in certain ways, in the final analysis it becomes clear that the sort of person the prisoner became was the result of an inner decision, and not the result of camp influences alone... In the concentration camps, for example, in this living laboratory and on this testing ground, we watched and witnessed some of our comrades behave like swine while others behaved like saints. Man has both potentials within himself; which one is actualized depends on decisions but not on conditions. (Frankl, 1984, pp. 87, 157)

Frankl recalls those who gave away their last piece of bread amidst the starvation of the concentration camps. Even though these cases were few in number, "they offer sufficient proof that everything can be taken from a man but one thing: the last of the human freedoms—to choose one's attitude in any given set of circumstances, to choose one's own way" (Frankl, 1969).

Voluntary sacrifice explicitly shows that love can transform the experience of suffering by way of meaning. Phenomenologist Max Scheler elucidates: "Sacrificial love releases feelings of hidden bliss that compensate for the increasing pain and raise the concern of the spirit above pain... It is the 'pleasure of love' that 'finally compensates' for the interior pain of suffering" (Scheler & Bershady, 1992, p. 97).

The willful choice of the individual determines what he will do in a given set of circumstances. Frankl notes that between a stimulus and a response, there is a space. In that space is a person's power and opportunity to choose a response. In that *response* resides the person's growth and freedom. Considering the free will we are endowed with as rational individuals, there is compelling evidence that times of great suffering can lead to goods such as love, existential growth, dignity, and fraternal communion. When we are

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Note: Although Scheler draws from Nietzsche in this analysis, he specifically notes: "Nietzsche did not comprehend this meaning, as he was interested only in the multiplicity of life and the scope of its movement." Furthermore, although the feelings of pleasure and pain are "only the accidental terminal points reached by the pendulum of life in its full swing." But the very "meaning of the swing is sacrifice" (Scheler & Bershady, 1992).

no longer able to change a situation, we are challenged to change ourselves. Thus, even the most tragic and dismal circumstances in life can be transfigured by the attitude we adopt toward the suffering itself. This perspective is by no means pessimistic; on the contrary, it is realism permeated by hope<sup>‡</sup> (Frankl, 1969, pp. vii-x).

# **Discovering Meaning**

There is meaning to be discovered in every suffering. Frankl asserts that the most fundamental of all strivings is the search for the meaning of life, or at least for *a* meaning in life. These words are predicated on a belief that life holds meaning for each and every individual and, moreover, that life has meaning literally until the person's final breath.

This is a far cry from a reductionist view that man is nothing but a biochemical machine.

According to this view, suffering not only has objective meaning, it is also subjectively unique to a person's situation at any given moment: something to be found rather than given, discovered rather than invented (Frankl, 1969, p. 62). Suffering, therefore, can only be transformed by way of the subjectivity of the person. The person *participating in suffering* is capable of making a personal response to it—only then is a gain amidst the losses of suffering possible (John Paul II, 1984, para. 26).

Frankl emphasizes that just as to each question there is one answer—the right one—so "there is only one meaning to each situation, and that is its true meaning"

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The scholastic tradition reinforces this connection between the will to choose and love. Aquinas comments: "Therefore love is found in both appetites: as found in the sensitive appetite, it is properly called love, given that it implicates the passion, instead, as found in the intellective part, it is called 'dilection,' a term that implies choice, which pertains to the intellective appetite" (Lohr, 1980, III, Q 2, Art 1). In Aquinas's description of love, he applies love to both the sensitive and intellective appetites. Love, he says, is a transformation of the *affectus* into the thing loved. By "transformation," he means that the affective power of the subject receives and, in a sense, becomes the form of the thing loved. Man, being a rational creature with an intellect, is capable of having an intellective or rational love. Here Aquinas specifies that love is something more than desire or beneficence. This love can be intensified; thus *amatio* signifies intensity in addition to love (such as friendship adding the notion of communion).

(Frankl, 1969, p. 61). A person is free to search for this meaning. Such freedom is not to be confounded with arbitrariness; rather, it is to be understood in terms of responsibility. Frankl comments, "Man is responsible for giving the *right* answer to a question, for finding the *true* meaning of a situation" (Frankl, 1969, p. 62). Consider the question of seven plus seven. Although one could respond in various ways, 14 is the right answer. Other answers, such as 33, do not fit; they do not correspond to the structural demands and the objective requirements that give order to the context of the problem. Meaning possesses similar objectivity. This objectivity means that freedom demands a certain level of responsibility; in other words, each person "is responsible for what to do, whom to love, and how to suffer" (Frankl, 1969, p. 74).

These observations align with Frankl's assertion that "the most fundamental of all strivings is the search for the meaning of life, or at least for *a* meaning in life," as *the* meaning (objectively) for each indivdual's unique experience of suffering is, in reality, *a* meaning (subjectively particular), which is unique to and only discovered by the suffering person. In addition, it is important to clarify that there is a difference between the obligation to discern *the* meaning in a situation and the obligation to find *a* meaning in a person's lifeworld or even that component of that lifeworld called "suffering." I posit that the physician can be particularly instrumental in the patient's quest for the latter.

Furthermore, meaning is not an end in itself but a means to an end. According to Frankl, "that end is an experience of community, attachment, union with self, with others, with the Other, however perceived" (Mount, 2003). Such an end can be described further in terms of the unleashing of love, communion in relationships, and self-transcendence.

Upon discovering meaning, a person is likely to find that it has a "Gestalt quality—the

whole of an experience is, in some indefinable way, greater than the sum of its parts" ("Psychiatry: Meaning in Life," 1968). This "Gestalt" pierces to the heart of the paradox, that in the losses of suffering one can, in some indefinable way, experience an overall gain.

A woman named Sylvia who was dying of an incurable disease, asked the Rabbi Earl A. Grollman how she could meet the thought and reality of death, as she was in hopeless despair over her sufferings. The Rabbi recommended that she read Viktor Frankl's work. Frankl's insights sparked Sylvia's curiosity. She was especially impressed by his firsthand experiences in Nazi concentration camps, which proved that his work was not simply an abstract theory. The woman dying of cancer resolved that if she could not avoid the inescapable suffering, she would determine the manner and mode in which she would meet the illness.

Through Sylvia's will to meaning, she became a tower of strength to those around her whose hearts were also lacerated with interior suffering. She describes, "At first it was a 'bravado,' but as time passed it became invested with purpose." Sylvia later confided in the Rabbi, "Perhaps my single act of immortality might be in the way I face this adversity. Even though my pain at times is unbearable—I have achieved an inner peace and contentment that I had never known before." The woman died with dignity and was remembered in her Jewish community for her "indomitable courage" (Frankl, 1969, pp. 70-71). Her testimony reveals that "it a prerogative of being human and a constituent of human existence, to be capable of shaping and reshaping oneself" (Frankl, 1969, p. 73).

The transfiguration of Sylvia's suffering in the midst of her terminal illness, is a poignant illustration of Sokolowski's phenomenological insight:

Someone who remains in control, as much as a human being can remain in control, during a mortal illness, for example, is admirable not because he is witty or resourceful, but because in the presence of this painful and fearful thing he remains "himself," he remains a rational being; he remains capable of truthfulness...in regard to *this*. (Sokolowski, 1985, p. 172)

Sylvia was admired in her Jewish community for the manner in which she, as a rational being, chose to endure her suffering. Her will to meaning became her means of achieving an inner peace and contentment that she had never before experienced. In the face of mortal illness, Sylvia's reorientation to the vertical dimension of fulfillment was instrumental in the transfiguration of her unavoidable suffering.

Frankl links the will to meaning to two phenomena that he considers essentially human: love and conscience. A person is guided in his search for meaning by his conscience. Conscience, Frankl says, is "the intuitive capacity of man to find out the meaning of a situation" (Frankl, 1969, p. 63). Love, on the other hand, is the ability to grasp another human being in his very uniqueness. The phenomena of love and conscience are the most striking manifestations of another uniquely human capability: self-transcendence. A person's self-transcendence is either oriented toward another in love, toward meaning, or both.

Frankl offers a vivid illustration of self-transcendence, in this case toward another in love, in his recollection of an arduous journey as a prisoner of a World War II concentration camp:

We stumbled on in the darkness, over big stones and through large puddles, along the one road leading from the camp. The accompanying guards kept shouting at us and driving us with the butts of their rifles. Anyone with very sore feet supported himself on his neighbor's arm. Hardly a word was spoken; the icy wind did not encourage talk. Hiding his mouth behind his upturned collar, the man marching next to me whispered suddenly: "If our wives could see us now! I do hope they are better off in their camps and don't know what is happening to us.

That brought thoughts of my own wife to mind. And as we stumbled on for miles, slipping on icy spots, supporting each other time and again, dragging one another up and onward, nothing was said, but we both knew: each of us was thinking of his wife. Occasionally I looked at the sky, where the stars were fading and the pink light of the morning was beginning to spread behind a dark bank of clouds. But my mind clung to my wife's image, imagining it with an uncanny acuteness. I heard her answering me, saw her smile, her frank and encouraging look. Real or not, her look was then more luminous than the sun which was beginning to rise.

A thought transfixed me: for the first time in my life I saw the truth as it is set into song by so many poets, proclaimed as the final wisdom by so many thinkers. The truth that love is the ultimate and the highest goal to which man can aspire. Then I grasped the meaning of the greatest secret that human poetry and human thought and belief have to impart: *The salvation of man is through love and in love*. I understood how a man who has nothing left in this world still may know bliss, be it only for a brief moment, in the contemplation of his beloved. In a position of utter desolation, when man cannot express himself in positive action, when his only achievement may consist in enduring his sufferings in the right way—an honorable way—in such a position man can, through loving contemplation of the image he carries of his beloved, achieve fulfillment. For the first time in my life I was able to understand the meaning of the words, "The angels are lost in perpetual contemplation of an infinite glory." (Frankl, 1963)

Frankl's reflections, amid the horrific trials of the concentration camp, speak of love as the ultimate and highest goal. His story testifies to the fact that an unleashing of love may be one of the goods experienced in the transfiguration of suffering.<sup>†</sup>

opera *Figaro*, *because of* its beauty. The beauty motivates my delight... Yet love is distinct from all other value-responses as it refers to the whole person and not just to the values of the person. It means that we give our heart to this individual, unique person; that we are in solidarity with them. Love always refers to an individual and unique person as this individual being" (Von Hildebrand & Crosby, 2007, p. 58).

Von Hildebrand's *The Heart* connects value perception, beauty, and love. He writes: "A person can flourish only if he is imbued with the values he perceives, only if his heart is moved and kindled by these values and burns in responses of joy, enthusiasm, and love. Value perception 'opens the gates' to the real heights and depths of the other... In stressing here the role of the heart and affectivity, we in no way deny the basic role of knowledge to which value perception belongs as a cognitive act. But value perception already presupposes a great and deep heart." Von Hildebrand further ties in the concept of beauty: "It holds for all value-responses that the response refers to the good and not the value. I take delight in Mozart's

## Unleashing of Love

Pope John Paul II gave one of the most concise and direct responses to the "reason" for suffering when he stated "Suffering is...present in order to unleash love" (John Paul II, 1984). He says that love is "the richest source of the meaning of suffering" (John Paul II, 1984, para. 13). Recall that it was in the content of great suffering that Frankl experienced the revelation that, "love is the ultimate and the highest goal to which man can aspire" (Frankl, 1963).

The realm in which this unleashing of love takes place is in the *interior* life of persons, as witnessed above by Frankl. The will to meaning is an aspect of the interior life, which can open the heart and mind to a certain disposition toward suffering; such a *sensitivity* of the heart has a unique affective expression (Colosi, 2009a).

Recognizing the limitations of a theoretical approach, Frankl points to phenomenology as a way of understanding these mysterious issues. His approach is neither moralistic nor strictly intellectual; it is empirical in the broadest sense. He considers phenomenology the avenue to discovering meaning as it reveals itself in everyday life. Even a "simple person in the street" can find meaning in life "by creating a work or doing a deed or by experiencing goodness, truth and beauty, by experiencing nature and culture; or, last but not least, by encountering another unique human being in the very uniqueness of this human being—in other words, by loving…" (Frankl, 1988, p. 69).

Clara Claiborne Park could be categorized as "a simple person in the street" who encountered the gift of love through unavoidable hardship. A middle-class mother, Clara described herself before the birth of her fourth child, as "terribly proud to have produced

three lovely children" (Claiborne Park, 1995, pp. 15-29). Park said her desire was for her family to be "lovelier than anybody else's." She took great pride in her three bright and beautiful children, and had equally high hopes for her fourth child, Jessy, who was eventually diagnosed with autism.

In many respects, Park was shattered, as the image of her picture-perfect family was ravaged by the daily hardships of autism. After years of struggling with the effects of autism on Jessy and the family, Park concluded:

Our lives change and change us beyond anticipation. I do not forget the pain—it aches in a particular way when I look at Jessy's friends, some of them just her age, and allow myself for a moment to think of all she cannot be. But we cannot sift experience and take only the part that does not hurt us. Let me say simply and straight out that simple knowledge the whole world knows. I breathe like everyone else my century's thin, faithless air, and I do not want to be sentimental. But the blackest sentimentality of all is that trahison des clercs which will not recognize the good that has been given to understand because it is too simple. So, then: this experience we did not choose, which we would have given anything to avoid, has made us different, has made us better. Through it we have learned the lesson that no one studies willingly, the hard, slow lesson of Sophocles and Shakespeare—that one grows by suffering. And that too is Jessy's gift. I wrote now what fifteen years past I would still not have thought possible to write: that if today I were given the choice, to accept the experience, with everything that it entails, or to refuse the bitter largesse, I would have to stretch out my hands because out of it has come, for all of us, an unimagined life. And I will not change the last word of the story. It is still love. (Claiborne Park, 1995, p. 320)

Like Frankl's, Park's story is a witness to the triumph of love transcending suffering. Park's reflections dramatize the growth that can occur as one discovers meaning in unavoidable suffering. She declares that the experience of raising an autistic child, with all of its sacrifice and suffering, "has made us better"; she has learned "that one grows by suffering."

Although her suffering was not eliminated, Park's experience was dramatically transfigured by way of meaning, and she came to see the experience itself as a gift. Her

insights affirm that the fullness of love, particularly in unavoidable suffering, can be both a source of meaning and an end. She shows us, too, that our awakening to this gift of love depends on our openness and receptivity to the vertical dimension of fulfillment. In the words of John Paul II:

In order to discover the profound meaning of suffering...we must open ourselves wide to the human subject in his manifold potentiality. We must above all accept the light...insofar as it illuminates this order with Love, as the definitive source of everything that exists. Love is also the fullest source of the answer to the question of the meaning of suffering. (John Paul II, 1984, para. 13)

Great minds throughout history have affirmed this insight. Augustine wrote, "We are more sensible to love, when we lack that which we love" (Aquinas & Dominicans. English Province., 1947, Part I-II, Q 25, Art 2). Remembering Frankl's dimensional anthropology, we note that Park's former love was located on the horizontal continuum of success-failure, while her latter love, redirected in the vertical dimension, led her to authentic fulfillment. When her initial love of a "picture perfect" family was shattered, Park became more attuned, more "sensible," to gain a love of fulfillment, what we might call *true love*.

Thomas Aquinas affirms these observations in his comments on how interior sorrow, paradoxically, can be a cause for joy. "In one way, in so far as from sorrow at the absence of something...one seeks the more eagerly for something pleasant: thus a thirsty man seeks more eagerly the pleasure for a drink, as a remedy for the pain he suffers" (Aquinas & Dominicans. English Province., 1947, Part I-II, Q 35, Art 3). In addition to the absence of health, we have seen how suffering in illness leads to the privation of many other goods. In responding to these losses, the sufferer may seek all the *more* for the good. In cases of chronic and terminal illness, the good of health cannot be fully

restored. However, this thirst for the good, when reoriented to the vertical dimension, may be transfigured into a thirst for the higher good of interior fulfillment. This is the path by which "joy comes from the discovery of the meaning of suffering" (John Paul II, 1984, p. 1).<sup>†</sup>

#### **Authentic Communion**

The unleashing of love can also be witnessed in the communion and solidarity of people who suffer together. Although every person has a uniquely personal meaning to discover in his individual experience of suffering, there are also situations where such a discovery leads to an authentic *communion*<sup>†</sup> in love.

The world of suffering possesses it own solidarity. "People who suffer become similar to one another through the analogy of their situation, the trial of their destiny, or through their need for understanding and care, and perhaps, above all through the persistent question of the meaning of suffering" (John Paul II, 1984, para. 8). This sometimes results in an extraordinary witness of communion and solidarity, a vivid manifestation of love.

A dramatic expression of this is seen in a prayer that was found scribbled on a crumbled piece of paper next to the body of a dead child in the Regensburg concentration camp of World War II:

<sup>†</sup> There is an intimate connection between joy and love in the Scholastic tradition. Aquinas describes love as the very aptitude or proportion of the appetite to good, which is complacency in good. Desire is the movement towards the good, while joy is the interior pleasure of resting in the good. Thus, an unleashing of love can certainly manifest as the state of joy. Joy is often experienced in the overcoming of the sense of

the uselessness of suffering, which has already been noted as one of its most intense pangs.

<sup>†</sup> *Communion*, in this context, means fellowship and close fraternity from the interchange of sharing common experiences, thoughts, and emotions. Communion is not meant to imply participation (or membership) in a religious community or ritual.

O Lord, remember not only men and women of good will, but also those of ill will. But do not remember all the suffering they inflicted on us. Remember the fruits we have born thanks to this suffering: our comradeship, our humility, our courage, our generosity, the greatness of heart which has grown out of this; and when they come to judgment let all the fruits that we have born be their forgiveness. (Colosi, 2009b)

It appears that a group of prisoners was praying this prayer together in the camp: a prayer that evolved precisely out of the unleashing of love in communion in the midst of intense individual and collective suffering. A story like this offers empirical evidence that the link between suffering and love is not merely coincidental, but causal. The world of human suffering calls for, so to speak, another world: the world of human love (John Paul II, 1984, para. 29).

It would be impossible to elucidate fully the mystery of suffering, which remains "an especially impenetrable one" (John Paul II, 1984, para. 31). Nor can I present a step-by-step explanation of how prisoners achieved such breathtaking transfigurations in World War II concentration camps. Still, the prayer expressed in the horrors of the Holocaust suggests a link between suffering and love: "the love increased dramatically because a rare intensity of suffering drew from people an opportunity to respond in this way" (Colosi, 2009b). The intensity of their suffering was an occasion for them to choose a corresponding intensity of love, which manifested both in their heroic forgiveness of the Nazi guards as well as in their noted fruits of courage, generosity, and greatness of heart. The prisoners affirm that these fruits grew from the experience of suffering itself.

Here we see that compassion, suffering with another, does not end simply with a *feeling*, but leads rather to a gift of self. In this way, suffering makes love visible in the world; it becomes an occasion that unleashes love in the human person, which is that

unselfish gift of one's "I" on behalf of others. Through this gift of oneself, suffering becomes an opportunity for self-transcendence.

# Self-Transcendence

Paradoxically, suffering belongs to man's transcendence: it is one of those areas in which man is, in a certain sense, "destined" to go beyond himself, and is called to this in a mysterious way (John Paul II, 1984, para. 2). Leo Tolstoy's novel, *The Death of Ivan Ilyich*, illustrates how suffering can prompt an individual toward self-transcendence. Ivan, the novel's protagonist, is a man about 60 years of age who suddenly learns that he is to die within a couple of days. Through this knowledge he realizes that he has wasted his life, that his life has been virtually meaningless. But Ivan is able to grow beyond himself, toward self-transcendence, so that in his last moments before death, his life is flooded with infinite meaning (Tolstoy, 2009). Ivan seems to embody the words of Tagore: He dipped his empty life into the ocean, "plunged it into the deepest fullness," and encountered that "lost sweet touch in the allness of the universe" (Tagore & Berata, 2002).

Max Scheler describes how the very essence of the human being is this capacity for transcendence and self-transcendence:

Thus man's intention beyond himself and all life constitutes his *essence*. This precisely *is* the essential concept of "man": He is a *thing which transcends its own life and all life*. The essential core of his nature—from all special organization—is in fact this movement, this spiritual act of transcending himself! (Scheler, 1973, p. 283)

Frankl's reflections resonate with Scheler's. Frankl states, "Self-transcendence is the essence of existence." Being human, by definition, is directed to something other than

itself, and the realm of the "trans-subjective" is presupposed when speaking of self-transcendence (Allers, 1962; Frankl, 1969). This experience of the "other" may refer to another person, or to the "Other" of the Divine. Indeed, meaning itself has a transcendent character in that it is something "other." Meaning is more than a mere expression of the self, more than a mere projection of the self. Persons transcend themselves as they move toward meaning, which is always something *discovered and not invented*. †

Personalist phenomenologist Josef Seifert links the unleashing of love to the experience of self-transcendence. He states, "In love...we transcend ourselves in quite another sense: through the right use of freedom, namely, in freely recognizing and acknowledging the being and value of someone else in his or her intrinsic preciousness, dignity, and significance." Seifert observed that self-transcendence can be achieved in such different contexts as the experience of a work of art or music, the achievement of a good, or in the respect and love one feels for the unique dignity of another person (Seifert, 1997, p. 108). But in each of these cases, the person who experiences self-transcendence relates to realities *for their own sake*, because they have their own objective meaning, and this in turn often results in happiness in one's inner life.

The phenomenon known as "Team Hoyt" is a testament to Seifert's observations.

Born with cerebral palsy, Rick Hoyt was dismissed by numerous doctors as a hopeless case. Medical teams repeatedly advised his parents, Dick and Judy, to institutionalize

<sup>&</sup>lt;sup>†</sup> Note: This is opposed to Jean-Paul Sartre's assertion that ideals and values are designed and invented by man.

<sup>&</sup>lt;sup>‡</sup> Seifert comments that the central discovery of value-response in Dietrich von Hildebrand's ethics and philosophy of love elucidates this profound essential mark of the person.

Seifert elaborates: "In as much as human life is personal and mental life, it is in all its aspects governed by a principle of transcendence, in which the being and essence of things disclose themselves to the mind. We find a reaching of mental life beyond its immanent actuality, an openness of its subject to what is beyond his or her own life, a participation in the essence and existence of things themselves. In absolutely certain knowledge, this transcendence and the discovery of things themselves and of things in themselves, as they exist independently of human consciousness, become indubitable" (Seifert, 1997, p. 108).

their firstborn son, but Rick's parents refused. The sufferings endured by the Hoyt family were innumerable. In 1977, however, Rick was inspired by an article on racing he saw in a magazine. After their first race, with Rick being pushed in a wheelchair by his father, he said, "Dad, when I'm running, it feels like I'm not handicapped." After this initial five mile run, Dick began running every day with a bag of cement in the wheelchair because Rick was at school and studying, unable to train with him. As of February 2008, the Hoyts had competed in 958 endurance events, including 65 marathons and six Ironman triathlons. In the triathlons, Dick pushes Rick for the foot race; then, with Rick sitting in a boat for the swim portion, Dick pulls him with a rope attached to his body. For the cycle portion of the triathlon, Rick rides on the front of a specially designed tandem bike (Hoyt & Yaeger, 2010).

The father-son duo is affectionately known worldwide as "Team Hoyt." Their trademark motto, "Yes, you can," continues to inspire millions of people through their living testimony of transfigured suffering (Hoyt & Yaeger, 2010). But the most striking aspect of Team Hoyt is the self-transcendence of the father, whose selfless devotion to his son has awakened multitudes of people to the intrinsic dignity of the human person (Vanier, 1998, pp. 158-159).

John Hull, in his memoir about his slow descent into blindness, offers another poignant example of self-transcendence, triggered in his case, when he surrendered, not to another person, but to a piece of beautiful music. Hull spends many pages documenting his strong aversion to going blind and his great suffering when the blindness finally enveloped him. He then recounts a profound experience while listening to sacred music, when he began to discover meaning in his suffering. Hull describes:

[T]he thought keeps coming back to me... Could there be a strange way in which blindness is a dark, paradoxical gift? Does it offer a way of life, purification, and an economy? Is it really like a kind of painful purging through a death?... If blindness is a gift, it is not one that I would wish on anybody... [But] as the whole place and my mind were filled with that wonderful music, I found myself saying, "I accept the gift. I accept the gift." (Hull, 1992, pp. 205-206)

Like Clara Claiborne Park who, if given the choice, would still stretch out her hands and accept the suffering, Hull concluded that he accepted the gift of his blindness.

It is important to write here that experiences of transcendence or self-transcendence do not transcend experience itself but rather *are experiences*. In Gabriel Marcel's words:

Not only does the word "transcendent" *not* mean "transcending experience," but on the contrary there must exist a possibility of having an experience *of* the transcendent as such, and unless that possibility exists the word can have no meaning. (Marcel, 1978, p. 46, vol. 1)

Testimonies like those of Team Hoyt, John Hull, or Viktor Frankl for that matter, reveal that through an *experience* of the transcendent, new and perhaps higher goods can be discovered in a person's life. These personal experiences possess far greater significance than an abstract answer to the meaning of suffering. Not only are they specific and personal to the suffering person, they also possess *authority*, an authority that influences others, as we saw in Sylvia's reaction to Frankl's writings. At bottom, we see in each of these cases that, by way of meaning, the individual's suffering was transfigured into an unleashing of love. Such love manifested itself in a variety of ways, including authentic communion, dignity of the person, and self-transcendence. We also witnessed a particular kind of beauty in the new integrity, harmony, and resplendence revealed in the bearers of these testimonies.

Each person discovered—in various manners and degrees of intensity—a new fulfillment in their experience of suffering. This occurred by way of their will to meaning. To enter into the mystery and discover the "why" of suffering—to experience its meaning—is to enter into the greater mysteries of love, communion, and self-transcendence. Only by such strategies can the patient's experience of unavoidable suffering be transfigured into a gain.

#### **Summary**

In summary, medicine regularly meets inevitable suffering. Every patient encountered by a physician is suffering to some degree. Suffering is certainly something that should be eliminated by all reasonable means and costs. It is apparent, however, that sometimes suffering is unavoidable. Physicians are daily immersed in this reality.

Suffering in illness certainly must be avoided as long as possible, but when suffering cannot be avoided, not only must it be accepted but "it may be transmuted into something meaningful, into an achievement" (Frankl, 1969, p. 72). Frankl stated that, hidden in the depths of the worst forms of inescapable suffering, there is a meaning to be discovered that is uniquely related to the person's fulfillment. This discovered meaning is a means to gains such as love, self-transcendence, achievement of a good, and the dignity of the person amidst the losses experienced in suffering. I propose, therefore, that suffering can be transfigured by way of meaning.

There exists compelling evidence in support of this view that suffering can promote human flourishing—that in the experience of the loss of a good, another good may be gained. This phenomenon of positive change following serious illness and trauma

has been variously labeled posttraumatic growth, adversarial growth, and quantum change (Shaw, et al., 2005). Moreover, testimonies from Sylvia, Roberto, Team Hoyt, John Hull, and the film *Into Great Silence* reveal that through an experience of meaning in unavoidable suffering, new and perhaps higher goods can be discovered in a person's life.

Viktor Frankl employs a "dimensional anthropology" to illustrate the phenomenon of finding meaning in suffering. Suffering is transfigured not in the horizontal dimension of worldly success and failure, but in the vertical dimension of interior fulfillment. A person is capable of finding meaning and reaching fulfillment even in situations classified as "failures" by the horizontal axis. Frankl considers phenomenology the avenue to discovering meaning as it reveals itself in everyday life.

In most cases, a person undergoing suffering remains free as to how he or she will respond to the trial. These free choices often determine whether or not the situation will be transfigured into a gain (Colosi, 2009b, p. 30). Considering the free will we are endowed with as rational individuals, there is compelling evidence that times of great suffering can lead to goods such as love, existential growth, dignity, and fraternal communion. When we are no longer able to change a situation, we are challenged to change ourselves. Thus, even the most tragic and dismal circumstances in life can be transfigured by the attitude we adopt toward the suffering itself.

### CHAPTER V

#### PHENOMENOLOGICAL PERSONALISM IN MEDICINE

## The Uniqueness of the Relationship

Suffering is not alleviated in a vacuum. Relationships, particularly the doctorpatient relationship, can be a means to the alleviation of suffering and can help a person find meaning in unavoidable suffering. A story from the Babylonian Talmud illustrates the significance of interpersonal relationships in the relief of suffering:

Rav Hiyya bar Abba falls ill and Rav Yohanan comes to visit him. He asks him: "Are your sufferings fitting to you?" "Neither they nor the compensations they promise." "Give me your hand," the visitor of the ailing man then says. And the visitor lifts the ailing man from his couch. But then Rav Yohanan himself falls ill and is visited by Rav Hanina, and he lifts Rav Yohanan from his couch. Question: Could not Rav Yohanan lift himself by himself? Answer: The prisoner could not break free from his confinement by himself. (Lévinas, 1998)

This account suggests that the presence of another person is indispensible. Physicians, by the very nature of their profession, are often called to be this other person, present to those suffering with illness.

In his 1849 tract on the physician-patient relationship, Worthington Hooker, professor of the theory and practice of medicine at Yale University, said that physicians see patients in their unguarded moments, with suffering and trials of every kind:

He sees much that glitters before the world become the merest dross in the sick chamber; and he sees too the gold shining bright in the crucible of affliction. He sees human passion in every form and condition...thought and feeling are often revealed to him unconsciously, and the very foundations from which they rise are almost open and naked to his view, and I may add to his influence also. (as cited from Halpern, 2001, p. 20)

Hooker speaks to the uniqueness of the doctor-patient relationship, and implies that a physician's effectiveness and reliability may depend on her attunement to the particular sufferings of her patients.

More than a century after Hooker, the relationship between a doctor and her suffering patient continues to be a unique relationship. Physician Mark Siegler writes, "The essence of the doctor-patient relationship is the exchange of a deep bond of trust between patient and doctor" (Siegler, 1985, p. 48). Pellegrino further notes that although friends, family, and even psychologists provide healing relationships, they do so within a certain range of human need. Physicians, however, play a specific role in the care of those who are ill:

It is the fact of embodiment that creates the need for the physician. Only [the physician] can unravel the connections between the subjective experience of illness and its linkage to bodily function. Without denying the part others may play, the physician comes closest to what healing means—to restore wholeness or, if this is not possible, to assist in striking some new balance between what the body imposes and the self aspires to. (Pellegrino, 1983, pp. 162-163)

It is the special relationship between the physician and the patient that distinguishes the practice of medicine from mere biomedical science. This is another reason why Toombs emphasizes that attention should be "focused on the experience of one who is ill rather than simply the disease process itself" (Toombs, 1992, p. 117).

It is important at this point to clarify who the patient is. Toombs posits that the patient is "a suffering person who comes to the physician for assistance in regaining a former state of well being or, at least, a more optimal one" (Toombs, 1992, p. 111). Pellegrino comments that the patient comes to the physician with a specific purpose in mind: "to be healed, to be restored and made whole, i.e., to be relieved of some noxious element in his/her physical or emotional life which the patient defines as dis-ease—a

distortion of his/her accustomed perception of what is a satisfactory life" (Pellegrino, 1979, p. 171). Moreover, the patient seeks a physician in order to *communicate* his or her "dis-ease," with the hope of finding meaning in his or her particular experience of illness.

Homo patiens, according to Pellegrino, is therefore a person in "an altered state: wounded, vulnerable, needing help, and afflicted with a special anguish that must be adequately ameliorated in a bona fide healing relationship with other human beings." A patient never seeks only a scientific explanation of symptoms, but also some manner of understanding, and help in integrating a personal experience of bodily dis-ease. These realities constitute the healing relationship between the doctor and patient. Pellegrino asserts, "Genuine healing must be based on an authentic perception of the experience of illness in *this* person." The physician's consciousness, or lifeworld, to use Husserl's term, should expand to encompass the unique experience of the person in illness (Pellegrino, 1979, p. 171).

## The Decisive Gap

I have noted previously the gap that exists between the doctor and the patient. Conversation between the two often seems at cross-purpose, as if they were talking past each other. Although important information may be shared in the medical meeting, "the patient's talk seems structurally dislodged from its context, its communicative intent set aside or narrowed to its locational directives." Even physicians with the most laudable intentions converse far more with the body, computers, and charts than with the actual person of the patient. It is as if the patient's account of his experience of illness has

significance for the physician "solely as a sort of directional guide to the patient's malfunctioning or discomforting body parts" (Toombs, 1992).

Toombs elaborates on the ramifications of this displacement of the patient:

To talk to a physician, thus, is not only to provide locational indexes to hurts, aches, and the like, but also to disclose oneself, to whatever degree it may be. For a physician to displace such talk with clinical-diagnostic and scientific interpretations, then, is to do far more than merely describe the same experience differently. It is, in truth, to invite and even encourage the patient to adopt the physician's interpretation, that is, to view himself or herself in the way the physician does, and in this respect to ignore or mute those experiences and focus instead on that interpretation. (Toombs, 1992)

Such a displacement of the patient within the clinical relationship contributes to a displacement of the patient's lived experience of embodiment. The patient may begin to conceive of her body as an objective scientific entity for clinical diagnosis and treatment, replacing her firsthand experience of embodiment with the physician's diagnostic attitude. Furthermore, "because the physician takes the medical view of things as the correct one, clinical discourse necessarily tells the patient that her own view of 'what's wrong' is *not* correct" (Toombs, 1992).

Earlier, following Husserl, we noted the difference between the lifeworld of the patient and the physician's biomedical, naturalistic interpretation of the disease state. Elliot Mischler's analysis of medical interviews between physicians and patients shows that these two competing frameworks of meaning often characterize the discourse in the medical encounter. Mischler's research describes a "voice of medicine," which represents the technical-scientific assumptions of medicine, and a "voice of the lifeworld," which represents the ordinary attitude of everyday life. The medical history taken by the doctor reflects the "voice of medicine," while the patient's clinical narrative reflects the "voice of the lifeworld" (Mishler, 1984, p. 14; cited in Toombs, 1992, pp. 102-103).

Mischler's research shows that in standard medical interviews, the "voice of medicine" predominates as the physician controls the form and content of the interview. When the patient's "voice of the lifeworld" breaks in periodically, the physician quickly reintroduces the "voice of medicine," focusing on objective symptoms that coincide with the biomedical model of disease. Mishler's research also shows that the physician typically treats the "voice of the lifeworld" as not medically relevant, and so quickly suppresses this voice in the typical interview (Mishler, 1984). One study found that, on average, physicians interrupt patients 18 seconds after the patient begins to speak and patients were able to complete their statements only 23 percent of the medical visits (Silberman, 1991, p. 15).

### **Affective Atrophy**

Sole reliance on the biomedical model, dominated by the "voice of medicine," contributes to "affective atrophy" in the doctor-patient relationship. Dietrich von Hildebrand, whose doctoral dissertation was overseen by Husserl, claims that a "hypertrophy of the intellect" can sometimes lead to affective atrophy. Von Hildebrand describes hypertrophy of the intellect as "being imprisoned in a research spell," where experience is treated first and foremost as an object of knowledge (Von Hildebrand & Crosby, 2007, p. 55). If every experience becomes simply an object of knowledge, a physician becomes incapable of suspending, even temporarily, an attitude of intellectual analysis. Thus, the physician no longer possesses authentic affective responses such as joy or sorrow, love or enthusiasm.

The biomedical model certainly provides the physician with necessary critical thinking skills. However, affective atrophy may develop when the physician begins to thematize every aspect of the patient encounter according to the terms of a scientific view. Referring to a patient as "that interesting case of" a particular disease, rather than by name, may be an explicit sign of such intellectual hypertrophy. Von Hildebrand comments:

Those afflicted with this intellectual hypertrophy glide into an attitude in which every given object immediately becomes a topic of scientific...research. They fail to understand the many situations in which the object calls for an affective response or of an active intervention on their part. (Von Hildebrand & Crosby, 2007, pp. 55-56)

Von Hildebrand says that intellectual hypertrophy is not only fatal to the affective sphere, but that it also precludes a comprehensive knowledge of the patient. Such intellectual reductionism prevents physicians from taking a genuine interest in the living, ordinary reality of the patient as a suffering person. When the naturalistic, science-based view of the patient dominates, the other living themes of the patient's experience are no longer esteemed or even strongly considered (Von Hildebrand & Crosby, 2007, p. 56).

Von Hildebrand notes a second type of crippled affectivity, which he calls "hypertrophy of pragmatic efficiency": a basic, utilitarian approach, according to which a person treats every affective experience as superfluous and a waste of time. Von Hildebrand notes, "Physicians who succumb to this pitfall neglect compassion for the suffering person and declare, 'Compassion cannot help—either do something or, if nothing can be done, do not waste your time with sentiment'" (Von Hildebrand & Crosby, 2007, p. 56). Physicians with hypertrophy of pragmatic efficiency are attracted to

what is most pragmatically useful; compassion, caring, and interpersonal moments are regarded as utterly useless, and a waste of time.

It is also true that various external pressures on the practice of medicine can worsen this condition that Von Hildebrand calls hypertrophy of pragmatic efficiency.

Government bureaucracy, insurance reimbursements, mounds of paperwork, and the like can encourage a physician to take a predominantly utilitarian approach to the practice of medicine.

### Phenomenological Personalism in Medicine

This chapter argues that a personalistic perspective<sup>†</sup>, or phenomenological personalism, within the doctor-patient relationship can serve as a catalyst both for the alleviation of suffering as well as for the patient's discovery of meaning in unavoidable suffering. A personalistic perspective does not exclude the biomedical model but, rather, expands the lifeworld of the physician so that he is able to acknowledge and address the uniqueness of the patient's experience of suffering with illness. To say that the relationship is personalistic implies that the individual patient is not subordinated to societal goals, scientific goals, or goals which she has not chosen herself (Donohue-White & Cuddeback, 2002, pp. 165-166). The considerations offered in this section do not presume to exhaust the applications of phenomenological personalism to the practice of medicine. Nevertheless, I hope to offer fresh insight on a topic whose relevance has not been fully explored.

<sup>†</sup> A personalistic approach includes writings mainly from personalist phenomenology as well as philosophical anthropology. Scholars in these traditions include Martin Buber, Gabriel Marcel, Robert Spaemann, John Paul II, Edmund Husserl, Max Scheler, Dietrich Von Hildebrand, and Viktor Frankl.

The patient as a person is decisive for what constitutes the beginning and the end of the practice of medicine. Seifert declares, "Reductionist theories of health will never be properly understood if they are not seen in their specific personal dimensions" (Seifert, 2002, p. 110).† The first task for the physician wishing to bring a personalistic perspective to her practice is for her to respond to her patients prereflectively and spontaneously. The personalistic physician attends to the patient's lived experience of illness, introducing into the medical encounter an element of subjectivity excluded by the biomedical model.

Husserl's phenomenological distinction between the "naturalistic" and the "personalistic" orientation is a guide to understanding phenomenological personalism in medicine. The naturalistic orientation denotes the propensity of the natural sciences to explain the world and its events by examining the relations of physical causality that obtain among the items in that world. It is abstract and artificial insofar as it considers the scientific and physical strata of the human being "in isolation from the soul and the intellect" (Sawicki, 1997, pp. 79-80). Consequently, the naturalistic view also excludes such realities as intersubjectivity, the will, and the discovery of meaning in suffering.

By contrast, the personalistic view encompasses the "I" and its connections with other "I's." Phenomenologist Marianne Sawicki writes, "Paradoxically it is the

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Feifert elucidates four facts on how reductionist views are in need of personalistic meaning, when referring to health in the human person: 1) All the pre-biological aspects of health (e.g. those features of health which, *as such*, can also exist in non-living beings) receive a radically new character and meaning when they are part of the health of persons. 2) All the specifically *biological* aspects of health which depend on the primary datum of *life* (as it is found also in plants and animals) receive an entirely new personalistic meaning and new characteristics when they exist in human persons. 3) There are many uniquely personal dimensions of health, which do not exist in plants and animals at all. 4) Personal health, while it constitutes a basic human good, neither constitutes the absolute and highest value in human life nor can it be realized fully without reference to higher moral and social values (Seifert, 2002, p. 110).

Edith Stein saw that the science of science—phenomenology—ought to coordinate the two strands rather than oppose them.

personalistic orientation that is more 'natural,' because it takes the human subject to be originally a member of a social world" (Sawicki, 1997, pp. 79-80). Even the scientist, in adopting a naturalistic orientation in order to conduct natural-science investigations, does so as a person. A personalistic orientation, therefore, is a prerequisite even for a naturalistic orientation.

Throughout the remainder of this thesis, I will interweave concrete examples and proposals of how phenomenological personalism can be actualized in everyday patient encounters.

### Subjectivity

The physician with a personalistic practice sees the patient "from within" rather than "from without." He strives to see the patient in terms of his self-understanding, subjectivity<sup>†</sup>, and interiority. The patient is not classified merely according to biomedical pathology but is seen as a person who has a "world for himself"—his own center—and who exists as an entirely unique entity.

Phenomenology awakens the physician to this unique and unrepeatable lifeworld of the patient.<sup>‡</sup> In the words of Max Scheler, each patient's world contains an "ultimate peculiarity," an "original trait," belonging only to the "world" of this person and nobody

<sup>†</sup> In this section, "subjective" and "subjectivity" are used in a positive sense to express personal interiority. This is not a concession to "subjectivism," where reality is nothing more than private experience.

<sup>&</sup>lt;sup>‡</sup> Central to Max Scheler's phenomenology is the contrast between the "vital center" and the "personal center" in each human being. Scheler conceives the vital center to be in relation to biological life, whereas the personal center is seen as the real "seat" of individuality in a human being. When a patient is living out of his vital center, he will have a relatively weak individuality. By contrast, a stronger individuality develops when a patient lives and acts from the interior subjectivity of his lifeworld.

else.§ Each world necessarily has an *individual, personal* character and has a different content for each individual person.

A personalistic physician, therefore, will listen to the patient to the point of discerning the "personal center out of which he lives" (Crosby, 2004, pp. 158-159). The patient, after all, is not *something*, but *someone* (Spaemann, 2006, p. 72). If the patient is a *someone*, a person, than he has a unique "I," who is inseparable from all his life experiences, including his experience of suffering in illness. "[I]t is one and the same "I" that now acts through itself, now is acted upon" (Crosby, 2004, pp. 166-167). There is but one human subject in human beings, after all, one who both determines himself in freedom and also undergoes illness.

The physician who incorporates phenomenological personalism will view his patient as the "subject of the illness." This ensures that the patient does not become a mere "object of treatment," where the physician becomes so preoccupied with disease that he hears only his own "voice of medicine" and is aware only of his own center of acting (Crosby, 2004, pp. 158-159). The physician's attentiveness to the voice of the patient's lifeworld allows the patient to be a co-subject, rather than an object, of medical care.

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<sup>§</sup> One commentator states that these insights from Max Scheler are a "remarkable individualization and personalization of the Husserlian transcendental (phenomenological) consciousness," which made an "almost revolutionary impression" in his day (Dooyeweerd, 1997).

Spaemann notes: "It belongs to the personal pronoun 'I' that no one can use it in direct speech to refer to an imaginary individual. It always has a reference. For a person, to be real is always to be alive. The relation of the person to him- or herself is the original paradigm for the thought of contingence, which the Islamic philosopher Avicenna was the first to articulate the difference between 'quality' (*Sosein*) and 'existence' (*Dasein*). Persons are beings who experience the difference immediately... [C]ontingence is generally understood as an aspect of existence itself' (Spaemann, 2006, p. 72).

By relating to the patient as a co-subject, rather than as an object, the physician can help prevent what John Paul II calls a problematic *conformism*<sup>†</sup> of the patient to the biomedical perspective. This use of conformism denotes a tendency to comply with an accepted custom, but in a passive superficial way, without conviction or genuine engagement. Because of his heightened weakness in times of illness, the patient is vulnerable to this type of conformism, vulnerable to assimilating the medical team's biomedical outlook. Passivity can lead to resignation, which results in the patient becoming merely a passive subject of *what happens* instead of being the *actor* or *agent* responsible for building his or her own meaning and personal commitment (Wojtyła, et al., 1979). Even when the servile attitude of conformism does not become an outright denial or limitation of the patient's subjectivity, it always seriously compromises a patient's capacity for personal transcendence and self-determination.

Conformism can block the will to meaning, which is essential for the transfiguration of moments of unavoidable suffering. It can prevent a patient from seizing an opportunity to obtain goods such as self-transcendence, the unleashing of love, and authentic communion in suffering. When the physician validates and encourages the patient's subjectivity, however, the patient may be emboldened to make use of his freedom and will to meaning. When the physician is mindful of the subjectivity of his patient, when he tempers medical manipulation of the body with the consciousness of

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Conformism does not lie solely in submission to the physician's perspective. In fact, voluntary submission is often quite positive and beneficial. Conformism lies much deeper and consists in a definite renunciation of seeking the fulfillment of oneself in and through "acting together with others." Therefore, even if the patient externally appears to agree with the medical team, the patient can be in conformism if his very self is withdrawn from the team. In these cases, the patient no longer authentically participates in their medical care; he has a superficial compliance that lacks conviction and engagement. Hence, conformism brings about uniformity rather than unity. This can have especially negative effects in cases of chronic disease and terminal illness, where the authentic engagement of the patient is an integral part of the success of his care (Wojtyła, et al., 1979).

acting on an embodied person, then the patient is seen and cared for as one who can experience in a new way what it is to act through oneself in freedom, to possess a will to meaning, and to determine oneself (Crosby, 2004, p. 115).† By contrast, when a physician only focuses on the patient as an objective bodily being, when he gives into dualism and regards his patient's body as separate from his patient as a person, the patient is vulnerable to being acted upon.‡

Karol Wojtyła urges that a patient must stay intact as a "subject of illness." Such intactness means resisting the dangers of depersonalization that are inherent in being treated for illness. We might even say that, for Wojtyła, the exercise of one's self-possession is a necessary but not a sufficient condition for the flourishing of a suffering person (Crosby, 2004, pp. 156-157).

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Karol Wojtyła, writing from a personalistic perspective, stresses the self-possession of the person as the avenue to self-determination and authentic freedom. He says that persons first of all possess themselves—they belong to themselves—and only for this reason are they positioned to determine themselves. Persons are not simply "there," as if they were things; they exist rather in reflexivity, or belonging to themselves. "Indeed, this reflexivity is constitutive of persons; it is the very heart of personal being." For this reason, Wojtyła finds it too cosmological to think of persons as merely a substance, or even as a body-soul composite. Rather, he strives to gain the more personalistic perspective by turning within and discovering the self-possession that gives the body-soul substance of man its distinctly personal form. This allows us to see a fundamental distinction between person and nature. By person, Wojtyła means the active principle of acting through oneself; by nature, he means the passive principle of being acted upon or of undergoing. To Wojtyła, human beings live according to their personhood insofar as they act through themselves. But what exactly does this mean to "act through oneself"? According to this framework, the answer is in subjective terms: we act through ourselves when we live out, or actualize, our self-possession. "We begin to act through ourselves already in being present to ourselves, and we eminently act through ourselves in determining ourselves" (Crosby, 2004).

What mischief does dualism cause in the understanding of the doctor-patient relationship? The answer seems to be that a dualistically minded physicians is liable to treat the body of a patient like a broken machine; likewise, the dualistically minded patient will want to have his body treated like a broken machine. Both the physician and the patient will see the patient's body as an object; neither of them will see it as the patient's very self, or as an extension of his person. Rather than thinking of the subjectivity of the patient as being embodied, the dualistically-minded physician and patient will consider the subjectivity of the patient as being hidden by the patient's body. As a result, the physician will think that his treatment of the patient's bodily sickness is not exactly the treatment of a person, in all his subjectivity, who is ill. The physician might easily objectify the body of the patient, considering it a broken machine. Such an outlook presents a towering barrier to the patient integrating the experience of illness and, thus, discovering personal meaning in his suffering.

#### Compassionate Care

The personalistic perspective affects the quality of *care* given to the patient. When illness is defined solely in terms of a disease-based biomedical paradigm, the goal of the medical encounter is understood primarily in terms of diagnosis and cure. Certainly diagnosis and cure are important. However, this focus has little to offer when a person faces a chronic or terminal illness, where a "cure" is unattainable. I argue that the *cure* of the patient should not be the sole end of the clinical encounter; if the alleviation of suffering is also a primary goal of medicine, then the *care* of the patient becomes vital.

The majority of patients who seek help from a physician suffer from illnesses that *cannot* be cured (Kleinman, 1988, p. 47; Leder, 1984). Physician Ian McWhinney notes that illnesses that do not fit into the conventional taxonomy account for at least half of the morbidity in the general population. For example, only 21 percent of patients with abdominal pain receive a specific diagnosis after three months. This is one of a long list of patient experiences that are unexplained within the biomedical framework. In this day of cancer, chronic disease, and the problems of the aging, the caring, healing function of the physician is again central. Particularly in instances of incurable illness, a qualitative shift in emphasis on the *art of medicine* can have profound implications (McWhinney, 1984, pp. 1, 3-8).

In light of the current prevalence of morbidity and chronic illness, the *care* of the patient is increasingly significant:

In an aging society, where chronic disease is the most common cause of pain, suffering, and death—where, in other words, the illness will continue over time regardless of what is done medically—caring becomes all the more important, coming back into its own after an era in which it always seemed a second-best choice. In the cases of chronic illness patients must be helped to make sense of their condition, and helped to learn how to cope with it and live with it, perhaps

permanently. By their sixties, most people will have at least one chronic condition, and by their eighties, three or more... It has indeed been noted that medicine may have to help the chronically ill person forge a new identity. This is hardly a situation restricted to the elderly, even if they are likely to be the most numerous among the chronically ill. Those with AIDS, or disabled children, or injured young adults, will no less need care. Indeed, the very success of saving lives—whether low birth weight babies at the beginning of life, or nonagenarians at the end of life—has increased, not decreased the overall morbidity. People are now able to live with illnesses, sometimes well and sometimes not, that would have killed them a generation or two ago. (Hanson & Callahan, 1999, p. 27)

Patients with chronic and terminal illnesses greatly benefit from a more caring medicine. Kleinman emphasizes that, in cases of chronic and incurable illness, the quest for a cure is a "dangerous myth that serves patient and practitioner poorly" (Kleinman, 1988, p. 229). Such a "myth" distracts the patient and the physician from working within the lived-reality of illness. Toombs adds, "If cure of 'disease' is taken to be the overriding goal of the medical encounter, intractable illness poses a frustrating challenge to the physician's capabilities" (Toombs, 1992, p. 115). On the other hand, there is much a physician can do in these cases to alleviate "dis-ease" and suffering. "Indeed, the doctor is perhaps one of the most effective allies that the patient can have in the struggle to deal with the limitations imposed by illness" (Toombs, 1992, p. 115).

What precisely is care? We have noted that in a predominately biomedical context, the principle of care may be understood simply as responding to the bodily medical condition of the patient. To ignore the medical condition or to consider it negligently, certainly constitutes bad care. Yet more is a stake in care than medical diagnosis and a plethora of treatments, because there is more to the concrete reality of the person than her medical condition. To offer true care to the patient requires that she be understood as a person, within the unique lifeworld of her illness.

Cassell supports these observations by noting that the *care* of the patient in her lived-experience of suffering should be directed toward the patient's existential predicament; caring for the patient relieves (to the extent possible) the perceived lived body disruption which the illness engenders. This is not to be equated simply with giving reassurance, acceptance, and patience. Rather, the physician can be instrumental in restoring the patient's integrity as a person. It is precisely this integrity that is threatened in Cassell's definition of suffering (Cassell, 1976, p. 149; Toombs, 1992, pp. 115-116).

Arthur Frank's experience and many other testimonies attest to the fact that the vast majority of patients seek the physician not for continuing useless efforts to *cure* but for complete *care*. One physician described the case of Mr. Harvey<sup>†</sup> who, undergoing continuing cutting-edge treatments, kept asking to be returned to his ward, to the company of his three ward companions. Instead, "he died alone, denied what he most wanted, the unspoken comfort of people—any people—around him" (Ramsey, 1970). In retrospect, the physician saw that Mr. Harvey simply desired friendship and companionship, even of recent origin, in his last moments of life. To many, the sting of dying is solitude; the loneliness of abandonment is more choking than death itself, and more feared.

But when the cure of the patient is the overriding goal, the inability to cure is often equated with failure. Consequently, patients who cannot be cured frequently are avoided by health care professionals, as they become an uncomfortable reminder of failure. This trend becomes explicit in dying patients who write of their isolation from caregivers. One terminally ill cancer patient noted that in the hospital "no one seemed to

<sup>&</sup>lt;sup>†</sup> Note: In this instance, and several others throughout the thesis, I will provide an alias name for the person presented in the cases. I hope such naming will enliven a more personal dimension of the patient's experience while maintaining the patient's anonymity.

want to look at me." To look at her "might have meant to see, in a place where only successful cure was acceptable, that she was incapable of being cured" (Stoddard, 1978, p. 21; Toombs, 1992, p. 115). In Richard Zaner's words, those who cannot be cured not only "stand outside medicine as beyond its apparent powers, but also are living affronts to it." To be "incurable" is to be "beyond help, and this all too easily becomes the motive for being abandoned" (Zaner, 1985, p. 240).

Thus, in the predominant culture of *cure*, we recognize an ever urgent and timely need for the *care* of the patient. Intrinsic to care is attentiveness to the patient's lived experience of suffering in illness. Attentiveness necessitates being affectively present to the patient's lifeworld, which is the central focus of phenomenological personalism.

One prerequisite for care is compassion. "If care is the affective response to persons in need, compassion is this same response with the added notion of 'suffering with' the one in need" (Farley, 2002, pp. 39-40). The word compassion comes from the Latin stem *compati* meaning "to suffer with, to feel pity." From the Latin, the word *compassion* is the ability a person has to feel the emotional grief and suffering of another, with them, in the present moment.

Recent publications attest to the efficacy of emotional engagement on the part of medical practitioners in the alleviation of suffering (Angoff, 2002; Halpern, 2001).

Certainly, there are many known factors and influences that present barriers to such "suffering with," for example, non-compliant patients, and the apparent repulsiveness of some patients. All caregivers experience fatigue, impatience, and "humanly-limited generosity of spirit" at one time or another. Yet at the heart of the medical encounter

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<sup>†</sup> It is assumed that the reader is already aware of the reasonable and necessary cautions to caregivers on inordinate emotional involvement with those for whom they care.

there is not only the possibility but also the call for some form of compassion (Farley, 2002, pp. 39-40).

Appeals to compassion can sometimes remain empty, not because of indifference, but because the meaning of compassion, and the best way to express it, remains unclear. Compassion involves empathy—"being so stricken with the suffering of another that one suffers as the other does" (Kavanagh, 2007, p. 21). Compassion is a co-suffering, a knowing and entering into the suffering of the other. Yet compassion also may be expressed more profoundly by simple moments of silence in the presence of a patient who is suffering (Davis, 1981, pp. 1-8).

Isolation is one of the greatest hardships of suffering.<sup>†</sup> When compassion or understanding is lacking, the healer and the sufferer may be increasingly isolated from one another. This isolation can lead to a shutting down of certain important and basic exchanges, what Ingrid Harris called *intersubjectivity*, which is integral to human experience and enrichment (Harris, 2007, pp. 66-67). Intersubjectivity is the activity whereby the sufferer and the healer work together to bring the interior and exterior pain and privations to expression, as part of the healing process. The physician and the patient become "collaborators with each other in consummate reciprocity" (Harris, 2007, pp. 66-67). Intersubjectivity can be one of the most powerful means to the alleviation of suffering.

I should stress here that receiving true compassion is not an experience of humiliation for the patients because true compassion is always grounded in the dignity of the person who suffers. Philosopher and theologian José Granados explains,

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<sup>†</sup> According to phenomenologist Merleau-Ponty, our perspectives are able to coexist through a common world.

"[C]ompassion is the adequate answer to the call of suffering, an identification with the suffering person that awakens suffering in us." Compassion allows us to see the intrinsic dignity of the person who is suffering. "This is because our suffering with our neighbor, flesh of our flesh, means the reawakening in us, through our own compassionate suffering, the question of the origin, of the need to look for the good that precedes all evil" (Granados, 2006, p. 556).

Thus, in the face of suffering, which John Paul II defines as an experience of a privation of a good, we are instinctively reminded of, and in search of, the good. With compassion illuminating this search, we are reawakened to the dignity of the human person and goods such as love and transcendence. Compassion, therefore, becomes "a call to love in return and by doing so to give one's own suffering the form of love. The cycle of compassion is thus completed in the form of love, of a rebuilding of love in man's heart and body" (Granados, 2006, p. 556).

At this point, we must bring to mind the vast semantic range of the word "love." There are several Greek words for love, as the Greek language distinguishes their varied meanings. For example, *agápe* is traditionally described in ancient texts as unconditional self-sacrificing love, whereas *eros* is principally known as an intimate romantic love. Amid this multiplicity of meanings, *philia*, the love of friendship, is most closely related to the "love" referenced in this work. *Philia* is the bond of friendship that binds us together in community; it is a virtuous love that includes loyalty to and enjoyment of friends, family, and community (Benedict, 2006). In the context of the doctor-patient relationship, compassion for the suffering patient connects with *philia* in the physician's loyalty to the patient and the practice of the virtues in medicine.

Granados continues: "[T]his movement of our compassion is a new revelation for the suffering person. Someone takes care of him, in the midst of his pain, even more: someone wishes to suffer with him. This compassion reawakens in him the sense of his own dignity" (Granados, 2006, p. 556). By way of compassion, the sufferer's dignity is awakened. This, in turn, sheds light on the ubiquitous question of the *meaning* of one's suffering. Through compassion, by a caregiver's experiencing suffering with and for the suffering patient, the meaning of this patient's suffering is revealed (Granados, 2006, p. 555). Thus, the one who suffers in the compassionate presence of another often is better able to answer the question of meaning.

Compassion is a profound response to human suffering and can be a gateway to its transfiguration. "What is revealed about the body in suffering is its openness to the world in the form of vulnerability. This openness guides us to solidarity with our fellow men: the body becomes a place of communion" (Granados, 2006, p. 553). Indeed, compassion is an explicit manifestation of fraternal communion in suffering.

But all of this is possible only when the suffering patient is recognized as unique and irreplaceable. Responding to suffering is not a matter of categories. Rather, caring is recognizing and addressing the unique experience of illness-as-lived by the patient. As Arthur Frank says, "Caring has nothing to do with categories; it shows the person that her life is valued because it recognizes what makes her experience particular" (Frank, 1991, p. 48).

Underscoring the importance of particularity in the doctor-patient encounter,

Stephen Toulmin, philosopher and educator, writes that the physician's perspective needs to be:

[P]articular rather than general, individual rather than collective, even (so far as is predictable) empathetic rather than intuitive. He will focus attention entirely on the particular problems of individual patients, whatever these turn out to be, rather than view patients merely as "nice cases of x-itis." (S. Toulmin, 1976, pp. 46-47)

When the clinical encounter focuses on particular problems within a particular patient, the goal of the encounter, in addition to the cure of "disease," will naturally include the relief of suffering in the particular lifeworld of the patient's "dis-ease" (Toombs, 1992, p. 117). The physician committed to phenomenological personalism will offer *care* and *compassion* to a unique, suffering person.

# Voice of the Lifeworld

Just as Husserl distinguishes the "scientific attitude" from the "personal attitude," so he distinguishes between the medical history, based on the biomedical model, and what he calls the clinical narrative. The scientific or "naturalistic" attitude is a thematic attitude directed at the "objective" world. By contrast, the personal attitude focuses on *the meaning that an experience* of illness has for an individual. By explicitly attending to the patient's *story* of illness—what Husserl refers to as the clinical narrative, or the "voice of the lifeworld"—the physician is adopting the "personal attitude." Husserl further directs physicians:

[I]n the personal attitude, interest is directed toward the persons and their comportment toward the world, toward the ways in which the thematic persons have consciousness of whatever they are conscious of as existing for them, and also toward the particular objective sense the latter has in their consciousness of it. In this sense what is in question is not the world as it actually is but the particular world which is valid for the persons, the world appearing to them with the particular properties it has in appearing to them; the question is how they, as persons, comport themselves in action and passion—how they are motivated to their specifically personal acts of perception, of remembering, of thinking, of valuing, of making plans, of being frightened and automatically starting, of

defending themselves, of attacking, etc. Persons are motivated only by what they are conscious of and in virtue of the way in which this (object of consciousness) exists for them in their consciousness of it, in virtue of this sense—how it is valid or not valid for them, etc. (Husserl, 1970, p. 317, appendix III)

The physician adopting a personal attitude in the clinical encounter can bring valuable insight to the patient's lived experience of illness. Integrating the "voice of the lifeworld" allows the physician to understand the illness in terms of the patient's experience, particularly his experience of various privations.

The clinical narrative explicitly situates illness within the context of the patient's unique life and her attributive meanings: "[T]he clinical narrative—as opposed to the medical history—discloses what illness means to the patient" (Toombs, 1992, p. 104). Consequently, the clinical narrative can be one of the richest sources for learning what is personally significant about an illness and its attended suffering. The clinical narrative is distinct from the medical history, because the medical history, even when it includes family and social history, is interpreted according to the biomedical paradigm. One researcher underscores this distinction by sharing with us 16 diseases, both as they are medically diagnosed and treated and as they are suffered in the lives of individuals. Before conveying the patients' narratives of illness, the researcher gives us the textbook definitions of the disease-states. Then we hear what the patients have to say. Clearly, the textbook definitions capture very little of the patients' experiences of illness and accompanying suffering (Buchanan, 1989).

As noted earlier, suffering occurs at the reflective level; suffering is experienced by persons, not merely by bodies. Consequently, suffering is intimately related to the meanings assigned to suffering by the patient. The alleviation of suffering, therefore,

calls for an explicit attunement to such understandings, and the clinical narrative, with its phenomenological, personalistic bias, may reveal important information about these assigned meanings. "[S]uch meanings determine the manner in which a patient construes illness and, furthermore, to a large extent such meanings determine whether 'disease' involves suffering" (Toombs, 1992, p. 109).

A very simple and useful question a physician can pose to a patient is, "What is this experience like for you?" Toombs notes that in 17 years of living with multiple sclerosis she had never been asked what it is *like* to live with multiple sclerosis or to experience any of the associated disabilities. Furthermore, no neurologist had ever inquired if she was fearful or, for that matter, whether she was concerned about the future. Yet concern for the future is necessarily integral to chronic illness, as chronic illness has no foreseeable end. Indeed, such concern may be one of the greatest causes of suffering in chronic illness (Toombs, 1992, p. 106).

Toombs' observations are supported by one patient's reflections on his experience of suffering with paralysis. He writes:

Nobody has ever asked me what it is like to be a paraplegic—and now a quadriplegic—for this would violate all the rules of middle-class etiquette...

Polite manners may protect us from most such intrusions, but it is remarkable that physicians seldom ask either. They like "hard facts" obtainable through modern technology or old fashioned jabbing with a pin and asking whether you feel it. The tests supposedly provide good, "objective" measures of neurological damage, but...they reduce experience to neat distinctions of black and white and ignore the broad range of ideation and emotion that always accompanies disability. (Murphy, 1987, p. 87; Kay Toombs, 1992, p. 106)

This patient further comments that some medical people are so wedded to these objective measurements that they consider a paraplegic to be doing quite well if he has "no skin breakdowns…and has clear bowels and bladder" (Murphy, 1987, p. 185).

A physician can deepen her understanding of the patient's experience of illness simply by temporarily suspending a naturalistic, biomedical interpretation of illness. This in no way implies that the physician should forgo her understanding of illness as a disease state. Rather, it is to suggest that she perform "a temporary 'shift in consciousness' from a purely 'naturalistic' construction of the patient's disease, to a lifeworld interpretation of the patient's disorder." Such a "shift" makes possible a more comprehensive understanding of the patient's illness. Not only may the physician gain insight into the human experience of illness, he may also be enabled to address the patient's suffering more effectively (Toombs, 1992, p. 98).

## **Docility to Mystery**

Docility to mystery is another aspect of phenomenological personalism in medicine. The patient, as a person suffering with illness, always retains an element of mystery. Physicians may be well equipped to tackle "problems" biomedically, yet poorly prepared to recognize and honor the mystery of the patient. Phenomenologist Gabriel Marcel distinguishes between problem and mystery:

A problem is something which I meet, which I find complete before me, but which I can therefore lay siege to and reduce. But a mystery is something in which I myself am involved, and it can therefore only be thought of as a sphere where the distinction between what is in me and what is before me loses its meaning and its initial validity. A genuine problem is subject to an appropriate technique by the exercise of which it is defined; whereas a mystery, by definition, transcends every conceivable technique. (Marcel, 1978, p. 212, vol. 1)

Thinking about Marcel's distinction, we may say that the naturalistic, biomedical perspective understands patient presentations in terms of "problems," which the physician can lay siege to, reduce, and meet with professional "techniques." By contrast,

a mystery "transcends every conceivable technique." Mystery calls for presence, a personalistic presence, and demands a temporary suspension of the scientific, naturalistic view. The physician is, in truth, intimately involved with the mystery of the suffering patient, as it is the foundation upon which the clinical encounter stands.

Marcel explains that for a physician to apprehend the element of mystery in the lifeworld of the patient he must be open to the patient's transcendence in suffering. The doctor should not stand merely on the horizontal level of causality but, through a personalistic presence, mediate the lived-reality of the patient's experience. Marcel elaborates:

[I]f the doctor's account of my illness as a breakdown in an apparatus is inadequate, the priest who comes to visit me and tells me to regard the illness as a trial or tribulation inflicted on me by God is not a much better case; for he also places himself outside the troublesome and mysterious reality which is that of my illness itself. Just like the man for whom I am merely a machine, the priest shows himself incapable of transcending the plane of causality. But it is just that transcendence which is necessary here, and it is only on condition that we effect such a transcendence that we can acknowledge the mystery of our illness. But let me express myself more strictly: to recognize my illness as a mystery, is to apprehend it as being a presence, or as being a modification of a presence... Where it is I myself who am ill, my illness becomes a presence to me in the sense that I have to live with it, as with some room-mate whom I must learn to get along with as best I can; or again the illness becomes a presence in so far as those who care for me, and play the part of a Thou to me in my need, become intermediaries between me and it. Of course, in the case in which my illness has utterly prostrated me, in a state either of complete collapse or acute pain, my illness, paradoxically, ceases, as a separate presence, to exist for me; I no longer keep up with it that strange acquaintanceship which can be a struggle, or a dangerous flirtation, or the oddest blend of both. (Marcel, 1978, p. 210, vol. 1)

Marcel believes that a mystery is not necessary unknowable. The recognition of mystery "is an essentially positive act of the mind, the supremely positive act in virtue of which all positivity may perhaps be strictly defined" (Marcel, 1978, p. 212, vol. 1). The

physician who practices phenomenological personalism in the doctor-patient relationship will demonstrate an appropriate awareness of and respect for this mystery.

#### Vivid Presence

In speaking about mystery and about a physician's disposition toward his suffering patient, word *presence* has been utilized, a concept missing from the biomedical model. This concept of presence is difficult to define because it transcends scientific verification: yet, few would deny that life encompasses such experiences. Marcel notes the power of presence as he describes a very simple experience. He writes:

We can, for instance, have a very strong feeling that somebody who is sitting in the same room as ourselves, sitting quite near us, someone whom we can look at and listen to and whom we could touch if we wanted to make a final test of his reality, is nevertheless far further away from us than some loved one who is perhaps thousands of miles away or perhaps, even, no longer among the living. We could say that the man sitting beside us was in the same room as ourselves, but that he was not really *present* there, that his *presence* did not make itself felt. But what do I mean by presence, here? It is not that we could not communicate with this man; we are supposing him neither dead, blind, nor idiotic. Between ourselves and him a kind of physical, but merely physical, communication is possible... Yet something essential is lacking. One might say that what we have with this person, who is in the room, but somehow not really present to us, is communication without communion; unreal communication, in a word. He understands what I say to him, but he does not understand me: I may even have the strange disagreeable feeling that my own words, as he repeats them to me, as he reflects them back to me, have been unrecognizable. By a very singular phenomenon indeed, this stranger interposes himself between me and my own reality, he makes me in some sense also a stranger to myself. (Marcel, 1978, p. 205, vol. 1)

Marcel's phenomenological analysis dramatizes what can happen when solely the biomedical model motivates a physician. If the physician fails to understand the "I" of his patient's lifeworld, the clinical encounter will likely result in "communication without

communion." This decisive gap in communication can contribute to a patient's becoming a stranger even to himself.

The opposite phenomenon, however, can also take place. Marcel describes: "When somebody's presence does really make itself felt, it can refresh my inner being; it reveals me to myself, it makes me more fully myself than I should be if I were not exposed to its impact" (Marcel, 1978, p. 205, vol. 1). Phenomenological personalism in medicine enacts such efficacious presence. Physician Richard Zaner reflects on the simplicity and profundity of vivid presence in his interactions with a patient:

Perhaps all that can and even should be done is simply to be there: seeing each other, touching hands...talking together...joshing with the nurse, and we do all of this without ever taking much note of it so much as just sensing that things are better this way. If you are dying, Tom, the notion ran through me, maybe these simple gestures are all I can do, but they, like your gestures toward me, are precisely what they are, no more nor less, which may be their magic: affirmations of each other as worthwhile, worth the time...it gradually dawned on me how vividly present we had already become to one another, despite how short and temporary the relationship. (Zaner, 2004, pp. 36-37)

Affectivity is fundamental to presence. This is another reason why Von Hildebrand's "affective atrophy" can be detrimental to the doctor-patient relationship. Affectivity attunes the physician to non-verbal cues given by the suffering patient. Physician Jodi Halpern observes, "Intense states of suffering that involve fragmentation of the self are communicated non-verbally, primarily through inducing affective states in others." Physicians can help alleviate this suffering that cannot be articulated in words by enduring with patients in their distress. "By allowing patients to move them emotionally, it is as if physicians allow patients to *inscribe* in them, or use them to contain, what is otherwise intolerable to hold onto and 'work through'" (Halpern, 2001, p. 135).

The affectivity of vivid presence is essential if a physician is to acknowledge the pain and suffering that a patient sometimes cannot even articulate in words. Suffering, by definition, is difficult to bear, and thus, is often denied, resisted, or hidden.

Acknowledging the core of one's suffering is very hard, as one must battle the natural defenses we erect against dying, loss, abandonment, shame, and self-fragmentation.

Restoring equilibrium and well-being requires coming to an acceptable understanding of the event(s) in relation to the overall direction and purpose of one's life (Frank, 1991).

Rather than instilling overwhelming fear, or hope against hope, the physician can help the patient seize the present, realistic circumstances and transform losses into gains.

Attentiveness to both verbal and non-verbal communication is a critical aspect of vivid presence. There is a particular kind of listening that a physician must not neglect, namely being attentive to the patient's account of how she experiences her own body and her bodily illness. Cassell points out, for example, that the word choice a patient uses can show the physician how the patient conceives of herself in relation to symptoms, events, objects, or other people. Verb choice can provide clues as to whether the patient has been active or passive in the face of her illness: a patient may say she was "put in the hospital" or, in contrast, that she "went to the hospital." Cassell further observes that adjectives, adverbs, and even tonal emphasis can be signs of the patient's values and state of suffering (Cassell, 1985, p. 164).

Vivid presence can also manifest in simple, human gestures that bring hope and order to the patient's suffering. Howard Brody, in *Stories of Sickness*, describes these brief, yet beneficial exchanges:

Consider the very commonplace office visit for an upper respiratory infection. The reassuring story told by the physician to account for the illness experience

("It looks like you've picked up that virus that is running around town—you're the sixth person I've seen today with exactly the same symptoms"), coupled with the caring and solicitous attitude of physician and office nurse and the reassuring rituals that promise control of events ("Take two acetaminophen four times a day, gargle with warm salt water every hour, and stay in bed till the fever goes away") may well effect a speedier recovery than could be accounted for either by the usual spontaneous remission rate of the illness or by the purely pharmacological efficacy of the remedies administered. (Brody, 1987, p. 14)

Brody's anecdote reinforces the finding that physicians who transmit positive messages and assurances that treatment will work may have twice the cure rate compared to colleagues who are not as positive (Thomas, 1987). The power of positive, yet realistic, presence not only strengthens the possible cure but also the *care* of the patient.

In cases of incurable illness, on the other hand, the physician can play a critical role by helping the patient to "come to grips" with his predicament, particularly if his condition involves unavoidable suffering. The physician can be one of the first to facilitate the patient's quest to establish a new life equilibrium.

Another aspect of vivid presence is *constancy* in the physician's interactions with the patient. Cassell reflects:

Constancy is necessary. Constant attention and maintained presence are not difficult when things are going well. It requires self-discipline to maintain constancy when the case is going sour, when errors or failures have occurred, when the wrong diagnosis has been made, when the patient's personality or behavior is difficult or even repulsive, when impending death brings the danger of sorrow and loss because emotional closeness has been established. When constancy is absent or falters too frequently, patients lose that newfound part of themselves—the doctor—that promised stability in the uncertain world of sickness arising from their relationship. (Cassell, 1991, p. 78)

Constancy of presence to the lifeworld of the patient can be a strong means of offering a stable equilibrium amidst the uncertainties and privations of illness. Certainly such consistent presence can be challenging, especially given the demands of modern

medicine. Zaner recalls a series of interpersonal difficulties with Mrs. French, a patient in intensive care. As the physician, he opened himself to the challenge of maintaining a constant presence despite many communication gaps and annoyances. His consistent presence became a gateway toward both the alleviation of Mrs. French's suffering as well as toward his own fulfillment and education. Despite the formidable situation, Zaner and the patient developed a mutual gratitude and respect. He concluded:

One other thing, Mrs. French: I want you to know how much I appreciate your willingness to talk with me, and your honesty. I learn a great deal from talking with patients, and I feel I should thank you for that. We're all still learning about this kind of thing. Your thoughts and feelings will help me know how to help other people, too. (Zaner, 1993, p. 135)

Zaner's simple, humble affirmation became an opening to the alleviation of suffering for the patient and the personal growth of the physician. Constancy of presence and openness in dialogue were important elements in Mrs. French's care.

#### Discovery of Meaning

Given the inevitability of suffering in illness, patients naturally ask about the *inner meaning* of such suffering. Phenomenological personalism recognizes the importance of these inquiries. An awareness of and respect for such questions on the part of the physician can catalyze the patient's interior search for the discovery of meaning in suffering. Although the caregiver cannot show the patient *what* the meaning is, she may communicate to the patient that there *is* a meaning, and that the meaning perdures under any and all conditions.

As previously emphasized, one does not discover meaning in a vacuum.

Relationships are integral to a patient's discovery of meaning in suffering. While the

process of finding meaning is primarily an inward journey, it also depends on the sufferer being able to share the experience of his suffering and its effects. Such sharing may be experienced in language, in the eyes, through the hands, or simply by the posturing of one's body. A physician whose expanded lifeworld recognizes and affirms these expressions of suffering creates an opening in the doctor-patient conversation for the patient to begin to discover meaning in suffering.

This brings us to a central point of this chapter: the reification of meaning when it is truly communicated to and with someone who both understands and cares. A physician's expansion of her lifeworld, incorporating the patient's experience of suffering in illness, begets a momentous opportunity for meaning to become concrete, rather than merely an abstract concept, for the patient. The physician, therefore, becomes instrumental in the relief of suffering by way of facilitating the patient's will to meaning.

Not all patients will find meaning in suffering. However, sometimes the very *search* for meaning elicits the patient's growth. "The caregivers willingness to promote the patients' quest for transcendence promotes holistic healing, the integration of body, mind, and spirit" (Bryson, 2004). Even if a patient never discovers specific answers, the caregiver can still be present to the patient in these times of questioning and doubt.

A personalistic presence in the clinical encounter encourages the patient's will to meaning in his experience of suffering with illness. Humanistic psychologist David Bakan writes, "There are two major points in life which are beyond the scope of the individual will. One is conception; the other is death. Between these, but not including them, the will of the individual has its proper sphere" (Bakan, 1968, p. 128). Bakan's

words resonate with Frankl's belief that the will to meaning can be a means of fulfillment even in times of grave and unavoidable suffering.

Frankl's *logotherapy*<sup>†</sup> is rooted in phenomenological analysis. It leans on a phenomenology of pre-reflective self-understanding. Through logotherapy, the depths of the patient's heart are brought to the surface of consciousness. Frankl underestimates phenomenology as *translating* the wisdom of the heart into scientific terms; *logotherapy* means *retranslating* this wisdom of the heart into plain words, into the language of ordinary life so that one might understand and benefit from it (Frankl, 1997, p. 128). Finally, logotherapy takes these everyday experiences—about how the ordinary person discovers meaning and fulfillment—and makes them accessible to persons in severe suffering. Frankl coined logotherapy from *logos*—usually translated as word, speech or reason—which he defines as "meaning." "Logos' means the humanness of the human being—plus the meaning of being human!" (Frankl, 1969, p. 18)

The discovery of meaning in suffering is an undertaking that takes place within the unique interiority of the person. A person is capable of choosing his attitude toward his self. In this sense, a person is free to shape his own character: "[W]hat matters is not the features of our character or the drives and instincts, per se, but rather the stand we

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Rather than *judgments about facts as values*, logotherapy is based on *statements about values as facts*. Logotherapy is an existential approach, but Frankl notes that there are almost as many kinds of existentialism as there are existentialists, so we must specify Frankl's distinct qualities. Frankl states that without a sense of meaning even the pursuit of happiness leads to a dead end. A man who is driven to seek pleasure through sexual gratification will, Frankl believes, defeat himself. Likewise, in the man who lusts for power, for even its achievement will avail him nothing unless it involves some inner goal ("Psychiatry: Meaning in Life," 1968).

Recall that the term "phenomenology" is a compound of the Greek words *phainomenon* and *logos*. It signifies the activity of giving an account, giving a *logos*, of various phenomena; this is an account of the various ways in which things can appear. This etymology shows how Frankl's *logotherapy* stems from phenomenology.

take toward them. And the capacity to take such a stand is what makes us human beings" (Frankl, 1969, p. 17). Frankl continues:

Taking a stand toward somatic and psychic phenomena implies rising above their level and opening a new dimension, the dimension of the noetic phenomena, or the noological dimensions—in contradistinction to the biological and psychological ones. These are the dimensions in which the uniquely human phenomena are located.<sup>‡</sup> (Frankl, 1969, p. 18)

Frankl's insights stem from three essential tenets: the freedom of the will, the will to meaning, and the meaning of life. He contends that there *is* a meaning to life—"a meaning, that is, for which man has been in search all along—and also that man has the freedom to embark on the fulfillment of this meaning" (Frankl, 1969, p. 69). Such embarkation calls for an orientation to the vertical dimension. Especially in the unavoidable sufferings of incurable illness, the physician's recognition of this vertical dimension can assist in the transfiguration of the patient's suffering.

A personalistic presence in the clinical encounter may open the path not only to meaning but also to the unleashing of love. As phenomenologist Robert Spaemann writes, "Personal life is not, like other life, centered on itself. It is not defined by the imperative of self- and species-preservation. Its essential distinguishing mark is self-transcendence, the highest form of which is called love" (Spaemann, 2006, p. 115). The will to meaning allows suffering to be transformed into love—a love that creates good, drawing the good out of the suffering.

Grankl clarifies: "It could be defined as the snip

<sup>&</sup>lt;sup>‡</sup> Frankl clarifies: "It could be defined as the spiritual dimension as well. However, since in English 'spiritual' has a religious connotation, this term must be avoided as much as possible. For what we understand by the noological dimension is the anthropological rather than the theological dimension. This also holds for 'logos' in the context with 'logotherapy.' In addition to meaning 'meaning,' 'logos' here means 'spirit'—but again without any preliminary religious connotation" (Frankl, *Will to Meaning*, 18). It is also important to distinguish *phenomenon* (an observable thing) from *noumena* (a non-observable or immaterial thing, such as an attitude). In Kantian philosophy, the unknowable *noumenon* is often linked to the unknowable thing-in-itself. The term *noumenon* is generally used in contrast with, or in relation to phenomenon, which refers to anything that appears, or observable objects and events.

Max Scheler notes that there is a depth and intensity to suffering such that to strike at the "objects" of suffering rather than the actual experience produces the opposite effect—the suffering intensifies (Scheler & Bershady, 1992, p. 106). Such "objects" of suffering in medicine could be terminal cancer or chronic disease. If a physician aims solely to eradicate such "objects," rather than addressing the actual *experiences* of the suffering patient, the patient's suffering may intensify.

The physician who incorporates phenomenological personalism is open to this truth. He is equipped to recognize the real lived *experiences* of the suffering patient—to "strike at the…actual experiences" of suffering—in order to optimize care, rather than possibly to intensify suffering through futile biomedical treatments.

# Pursuit of Higher Goods

Phenomenological personalism acknowledges that health is not the allencompassing good of the human person; it is utopian and unrealistic to conceive of
health in this manner. We have seen how, in the personalistic view, the focus is not solely
on the cure of the patient, but also on the care of the patient. Phenomenological
personalism in medicine recognizes other goods of the patient, beyond the biological.
Such goods include interpersonal relationships and the fulfillment that can ensue from
them. Seifert asserts that human goods such as love, community, virtue, transcendence,
knowledge, friendship, and beauty clearly surpass the realm of biological health and are
goods of an entirely different nature (Seifert, 2002, p. 138).

Certainly, health has a close relationship to these higher goods. Seifert comments, "The health of a person ultimately presupposes a full givenness to goods which transcend health, i.e., only the person who seeks the True, the Beautiful, and the Good in all their forms and especially in their highest forms, can be fully happy and healthy" (Seifert, 2002, p. 138). Although an illness may be incurable from a biomedical perspective, the discovery of meaning in unavoidable suffering can orient a person toward these higher goods.

Throughout this thesis, we have seen that the patient is capable of many other goods besides health. In fact, some of these other goods the patient might consider greater than health. Through a sensitive, personalistic presence to the interests and concerns of the patient, a physician becomes attuned to these other goods. Since the patient knows himself in relation to these other goods in a subjective manner, and since the patient is the one who participates in these goods, it follows that certain priorities of the patient may sometimes trump medical recommendations. In phenomenological personalism, a physician is attuned to these values and considerations of the patient.

Suppose, for example, that a patient with a serious heart condition is called to the bedside of a dying parent. In order to reach the place where the parent lies dying, the patient must traverse high altitudes that will cause serious stress to his heart. It is the patient himself who knows whether this is a risk he should take. The doctor can present the great risk and assist the patient in the assessment of the risks and benefits. However, the doctor is not in a position to make the final decision. The serious medical concern of the doctor has force only *prima facie* for the patient. Hence, the doctor's recommendation can be overruled and set aside by still more serious non-medical concerns of the patient. If the patient decides to travel to the parent's deathbed, the task for the physician is then to find ways to minimize the risk to the patient (Crosby, 2004, p. 160). Moreover, by

being present for the patient and in communion with the patient, the physician assists in facilitating the achievement of what the patient declares as the higher good, namely, to be with his dying parent.

## **Summary**

In summary, this chapter argues that a personalistic perspective, or phenomenological personalism, within the doctor-patient relationship can serve as a catalyst both for the alleviation of suffering as well as for the patient's discovery of meaning in unavoidable suffering. A personalistic perspective does not exclude the biomedical model but, rather, expands the lifeworld of the physician so that she is able to acknowledge and address the uniqueness of the patient's experience of suffering with illness.

Phenomenological personalism recognizes that the doctor-patient relationship can be a powerful means to the alleviation of suffering and can help a patient find meaning. Although the caregiver cannot show the patient *what* the meaning is, she may communicate to the patient that there *is* a meaning, and that the meaning perdures under any and all conditions. Meaning is reified when it is truly communicated to and with someone who both understands and cares. A physician's expansion of her lifeworld, incorporating the patient's experience of suffering in illness, begets occasions for meaning to become concrete and actualized for the patient. The physician, therefore, becomes instrumental in the relief of suffering by way of facilitating the patient's will to meaning.

Phenomenological personalism calls for several characteristics including, but not limited to, compassionate care, attunement to the "voice of the lifeworld" in the patient's clinical narrative, docility to mystery, vivid presence, and acknowledgement of higher goods. Phenomenology awakens the physician to the unique and unrepeatable lifeworld of the patient. A personalistic physician, therefore, will listen to the patient to the point of discerning the "personal center out of which he lives" (Crosby, 2004, pp. 158-159).

In the predominant culture of *cure*, phenomenological personalism recognizes an ever urgent and timely need for the *care* of the patient. Intrinsic to care is attentiveness to the patient's lived experience of suffering in illness. Attentiveness necessitates being affectively present to the patient's lifeworld in a compassionate manner.

Furthermore, phenomenological personalism calls for an attunement to the "voice of the lifeworld" in the patient's clinical narrative. The clinical narrative can be one of the richest sources for learning what is personally significant about an illness and its attended suffering, as "the clinical narrative—…opposed to the medical history—discloses what illness means to the patient" (Toombs, 1992, p. 104).

Gabriel Marcel notes the importance of docility to mystery, which demands a personalistic presence and a temporary suspension of the scientific, naturalistic view. Connected to mystery, the affectivity of vivid presence is essential if a physician is to acknowledge the pain and suffering that a patient sometimes cannot even articulate in words. Attentiveness to both verbal and non-verbal communication is a critical aspect of vivid presence. This positive, yet realistic, presence not only strengthens the possible cure but also the *care* of the patient.

Phenomenological personalism also recognizes other goods in the patient's life, beyond the biological. Seifert asserts that human goods such as love, community, virtue, transcendence, knowledge, friendship, and beauty clearly surpass the realm of biological health and are goods of an entirely different nature (Seifert, 2002, p. 138). Although an illness may be incurable from a biomedical perspective, the discovery of meaning in unavoidable suffering can orient a person toward these higher goods. Physicians can employ insights from Frankl's *logotherapy* to help orient patients to a vertical dimension of fulfillment in moments of unavoidable suffering.

Phenomenological writings reveal that suffering is always personal, and unique to the individual. Suffering relates explicitly to a particular patient's life context and to the meaning of his experience of illness. Thus, "suffering may only be relieved if explicit attention is paid to the meaning that illness has for a particular patient within the context of as unique lifeworld" (Toombs, 1992, p. 118). An adequate understanding of the patient's lived experience is important both for the physician acknowledging the patient as a person and for the physician treating the patient.

The physician's role is not as a scientist, but as a craftsperson skilled in applying the fruits of science to the lived-reality of the patient's experience of illness. By having an adequate understanding of the patient's lived experience, the physician is better equipped to apply her scientific knowledge in devising effective therapies for the patient (Toombs, 1992, p. 119).

## **CONCLUSION**

Medicine has fallen short of one of its primary goals: the alleviation of suffering in the patient. The present biomedical and disease-focused emphasis in modern medicine, although frequently successful in identifying disease, lacks the full perspective necessary to address unavoidable suffering in illness. Such "biomedical dogmatism" is often insufficient in the care of the patient, especially in cases of chronic and terminal illness.

Baron observes that when physicians are searching for the disease within the body, "the identity relationship [between the body and self] is only considered by the traditional model as a result of synecdoche ('Have you seen the mitral stenosis in 6024?') or of metonymy ('or the IV drug user down the hall?'" (Baron, 1992). Neither of these rhetorical devices serves to expand the physician's vision of the body-self relationship; rather, they mitigate it to a one-dimensional, reductionist correspondence.

The traditional biomedical view, however, has several attractions for physicians; it is familiar, reassuringly broad and encompassing, and offers a valid framework in which complicated questions may be asked and answers expected. "Medicine is, after all, a discipline designed to provide solutions to vexing human problems." As we experience the urgency and pressure of corporate, government and patient demands "we reach for the assurance of a positivist world-view" so solid and clear in practical, objective truth. But doctors who limit themselves solely to the biomedical model may be forgoing relevance for clarity. "Medicine is valueless if it does not respond to the agenda created by the experience of illness" (Baron, 1992).

In this thesis I addressed these most pressing concerns regarding the present "crisis" in the doctor-patient relationship. I explored the way doctors are trained to think of the clinical encounter and how this method of thinking can often lead to a reductionist view of the patient. I then drew upon phenomenological writings to more fully elucidate the patient's experience of suffering in illness. Often the most profound experiences of suffering in illness is the loss of meaning. In fact, such loss of meaning can be one of the most devastating privations to the thriving of the human person.

Suffering is certainly something that should be eliminated by all reasonable means and costs. It is also clear, however, that sometimes suffering is unavoidable. Viktor Frankl notes that meaning can be a powerful avenue to the alleviation and elevation of the human person in moments of unavoidable suffering. I proposed that *suffering can be transfigured by way of meaning* and that physicians can play a powerful role toward this end.

Writings in narrative medicine, patient-centered care, and the biopsychosocial model have prompted many physicians to better recognize and respond to the patient as a *person* rather than merely a pathology. This thesis is novel, however, by directly addressing the *unavoidable suffering* frequently encountered in medicine's daily activity. In this work, I progressed the insights of Cassell and other thinkers by both addressing *unavoidable suffering* in the patient's experience of illness and applying these insights within the framework of clinical relevance. I demonstrated that, by way of phenomenological personalism, it is possible for the doctor to accompany the patient in her unavoidable suffering and, by doing so, to transform these distressing moments of loss into meaningful gains.

Phenomenological personalism in medicine must encompass a kind of goal-reorientation that is neither simple nor straightforward. In fact, for most physicians, it may seem counterintuitive, "because what is really being demanded of physicians when we cross these 'boundary' cases is an honest appreciation of our limitations."

Incorporating a personalistic perspective necessarily means that "we must somehow leave the clarity and certainty of our model and help our patients—and ourselves—deal with the very human reality of unfulfilled—even unfulfillable—desire" (Baron, 1992).

The clarity and power of the biomedical model is not something that will be readily expanded by physicians. Yet, a phenomenological perspective may be exactly what physicians and patients need. "A greater respect for this approach will rise if we can find a role for it in the exigencies of practice where the model of body-as-machine fails to give us an appreciation of medicine's practical limitations, particularly in the relief of suffering" (Baron, 1992). Baron continues to note the barriers to implementing phenomenology:

Phenomenology will remain for us, however, a 'hard shell.' His insurance company will not pay for it the way they would if I would study his coronary arteries. His employer and his government will not pension him for it, nor will they provide him with respite from everyday obligations. The Cartesian, objective dualistic world in which we live will see his problems as his own creation—they are, after all, in his mind—rather than as the inescapable dilemma of being an embodied creature with desires outstripping capability. Clinical physicians flirting with phenomenology risk a reenactment of *The Emperor's New Clothes*—what if the world sees how limited our capabilities really are? (Baron, 1992)

Thus, in many ways medicine will have to be persuaded of the practical value of phenomenology. The strongest, soundest, most urgent role for phenomenological personalism is that it informs clinical decision-making by providing an understanding of

the human goals and aspirations that is lacking in the biomedical model; it offers a rigorous way to incorporate this dimension into medical practice. Phenomenological personalism is distinct from other patient-centered approaches to the doctor-patient dyad in its effort to transfigure the unavoidable suffering encountered everyday in medicine.

At first glance, phenomenological personalism may appear to be an enormous, time-consuming responsibility. This assessment, I submit, is inaccurate. Incorporating a phenomenological approach will not require additional time or burden to the physician; in fact, it will likely create greater efficiency in the doctor-patient encounter, as the physician will approach the unique lived-reality of the patient's experience of illness more directly and personally. Thus, adopting a personalistic approach is not a time-consuming task. Rather, it is a mere reorientation, a moderate shift in perspective in the clinical encounter. It primarily entails approaching the patient with a different attitude—simply "being present" with a more expansive view of the patient's experience of illness as a lived-reality. This method is not to be "in addition to" the biomedical model, but rather infused within the already existing interactions and conversations between the doctor and the patient.

Furthermore, a personalistic perspective does not exclude the biomedical model but, rather, expands the lifeworld of the physician so that she is able to acknowledge and address the uniqueness of the patient's experience of suffering in illness. This serves as a catalyst both for the alleviation of suffering as well as for the patient's discovery of meaning in unavoidable suffering.

Although a physician's personalistic perspective on the patient calls for several characteristics, I chose to focus on a select group—namely, attentiveness to the patient's

subjectivity, attunement to the "voice of the lifeworld" in the patient's clinical narrative, openness to the mystery of the suffering, and vivid presence. These simple ways of approaching the patient can facilitate the patient's discovery of meaning in moments of unavoidable suffering, resulting in the patient's achieving goods such as authentic communion, self-transcendence, and the unleashing of love.

It would take an additional thesis to elucidate the many ways phenomenological personalism manifests in the doctor-patient relationship. I would, however, like to employ these final pages to elucidate a few further applications of the personalistic perspective in the clinical setting.

"The medical interview is a surprisingly complex dance, with the physician sometimes leading and sometimes allowing the patient to lead" (Fortin, 2010). A personalistic presence allows the *patient to lead* the first part of the medical interview. The commencement of the interview is patient-centered, where the physician authentically listens to the unique set of experiences that led the patient to seek medical assistance. This requires the physician to use non-verbal encouragement and to ask openended questions.

Kleinman suggests simple questions for the physician to ask the patient in order to understand the meaning the illness has for the patient: "What is the chief way this illness (or treatment) has affected your life? What do you fear most about this illness (or treatment)?" (Kleinman, 1988, p. 239) By entering into the lifeworld of the patient, the physician may find answers to these types of questions: What is the patient's understanding of her illness? What does the patient believe caused her illness? What are

her expectations of the doctor? What hopes, dreams, and everyday happenings have been influenced by her illness? What are her fears? (McWhinney, 1993, p. 11) Knowing a patient's fears, for example, can be crucial to understanding his personal lifeworld, as fears, in their specificity, always reveal the particularities of the patient.

This initial approach to the medical encounter allows the physician to integrate the patient's "voice of the lifeworld," through the patient's narrative. The "voice of the lifeworld" directly relates to the patient's lived experience of illness. Expanding her view beyond the biomedical "objective" data, a physician is better able to understand the illness as a lived-reality to the patient. Such patient-centered interviewing skills also allow the physician to elicit important psychosocial information, including beliefs about etiology and treatment, important cultural, spiritual, family, work and financial information, etc., all of which can affect the choice of treatment, patient education and treatment adherence (Fortin, 2010).

It is important to recognize that, as a physician, the patient's ideals may be mine too, but I must learn how to grasp them in a clinical setting; "I will need the courage to step beyond my pragmatism into his idealism" (Baron, 1992). This will require a unique *pathos*, a profundity of understanding the other, which is a skill that will never arise from the most refined knowledge of body-as-machine. Certainly the biomedical is a necessary component of medicine, but we have witnessed how it falls drastically short of meeting medicine's goal of the alleviation of suffering.

Listening carefully to a patient's narrative and responding empathically to emotion strengthens the doctor-patient relationship, increases trust, and even leads to better health outcomes (Kaplan, Greenfield et al. 1989). Halpern emphasizes that in

seeking true "objective reality," physicians must open themselves to an important source of understanding, which is empathy (Halpern, 2001, p. 145). By way of empathy, a physician is capable of attuning to the reality of the patient's suffering, thus making the privations in suffering as immanently real as the biomedical condition.<sup>†</sup>

Furthermore, simple courtesies extend a great deal in developing a relationship with the patient. Such gestures include welcoming the patient, using the patient's name, sitting at eye level in conversation, removing barriers to communication, and ensuring the patient's comfort. Wendy Haphram, a physician who became a patient after her diagnosis with cancer, reflects: "I realize the vital role my health care team played in saving my 'self.' Instead of pumping data into a computer charting notes, my doctors looked me in the eye...whenever they were listening or talking to me" (Harpham, 2009, p. 177). These everyday courtesies build the foundation for a person-centered approach to medicine.

An additional step to a phenomenological personalism in medicine is to have the goal of the medical encounter centered on the integrity of the patient as a person. Cassell emphasizes that a critical goal in the healing relationship is to maintain the integrity of the person, even in cases of incurable illness; maintaining integrity of the person directly addresses suffering. Particularly in chronic illness, suffering may arise because the integrity of the person is threatened by an interior unrest. Patients often harbor conflicting desires by trying to fulfill the expectations of the social world or are haunted by a negative perception of others' attitudes toward their illness.

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<sup>&</sup>lt;sup>†</sup> This brings up the very difficult question of the emotional engagement of the health care provider with their patients. It seems that there are two extremes: on the one hand, an exaggerated or unhealthy degree of personal involvement in the lives of patients, and on the other, a complete suppression of any and all affective relating to patients. Neither of these two extremes is appropriate.

Recall that Cassell defines suffering as "that state of distress induced when the intactness of the person is threatened or destroyed: such distress continues until the threat is gone or the integrity of the person is restored" (Cassell, 2004). Even when an illness is terminal, the integrity of self can be preserved (Cassell, 1977, p. 19). Frankl's will to meaning, in the face of unavoidable suffering, offers vivid testimony to the preservation of integrity in the gravest of trials. Physician Wendy Harphram reinforces: "The person who dies of incurable disease or some complication of treatment, but who obtained good medical care and connected lovingly with family and friends to the end, has triumphed" (Harpham, 2009, p. 141).

A paradigm of phenomenological personalism should also include the recognition of the *potential opportunity of illness*. "The concept of illness is socially and culturally defined as a negative experience—at the least, a nuisance; at the most, a disaster" (Miller, 1975, pp. 28-29). However, illness could also be used creatively, as we read in the testimonies of transfigured suffering; it can be an opportunity to experience remarkable growth in identity, strength, and personal meaning. A physician acting from this broader definition can assist the patient in redefining his illness to have some positive meaning in the broader context of his life (Miller, 1975, pp. 28-29). When health care providers' words and actions say, "You are you, no matter what is happening medically," they are helping patients integrate the challenges that accompany their illnesses, fostering them to discover a triumph that transcends the mere battle with their diseases (Miller, 1975, pp. 28-29).

Finally, in contrast to affective atrophy, physicians can play a critical role in the unleashing of love in suffering through an attunement to the patient's lifeworld. The

physician has the unique opportunity to model that "unselfish gift of one's 'I'" on behalf of other people, especially those who suffer. The unique context of the physician-patient relationship can catalyze this unselfish gift of one's "I" in an affectivity toward the suffering person. This is not only efficacious for the patient, but also ratifying for the physician.

The affective ground toward a suffering person is almost visceral in the way alertness is drawn to and by the ill person. Zaner calls this an "intangible tug," where one must now be *mindful* of the person suffering, here and now, within the actual context of his vulnerability. Zaner elucidates this by describing his clinical moments with Tom, a suffering patient:

These feelings propel me *beyond* myself, take me out of myself, beyond my own concerns of the moment, *toward* Tom. They are an elemental and literal *ec-stasis*; to be myself before Tom is to be beyond myself, always already with him. I find myself busied with *him*, not me. Being myself, as it were, is something I have to accomplish within these very circumstances: it is with Tom that I am brought to myself; "self," more a prize won through complex developmental experiences than some "inside" entity brooding in me. (Zaner, 2004, p. 34)

Zaner's personal reflections display how he propelled beyond himself in his care for the patient. In this way, he describes his experience as *ecstasy*. † He continues:

Thus is understandable that otherwise odd sense of gratitude one feels in being able to help someone like Tom, even if it is merely to have placed a full glass of water next to him as he asked... Tom's presence there, in that bed, that room, this hospital—this *ecstatic* moment, pulling me out of myself and into concern for him, his sphere of life—is deeply imbedded and inscribed in my life. He remains there, lodged. I had the sense then, and still have it now, that his being sick is what does this, and contributed to what I, this self, am. For that, for what in addition he taught me to see... I am grateful." (Zaner, 2004, p. 34)

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Marcel comments that, it "by a regrettable perversion of language," that the word *ecstasy* is being commonly used for "the sort of lyrical orgasm which is still the activity of the self" (Marcel, 1978, p. 215, vol. 1). Ecstasy, in its true definition, means to be drawn out of one's self: to go beyond one's self and enter into the experience of the other.

Zaner's account is a striking example of a physician who has tapped into the profundity of the doctor-patient encounter. Many will rebut that it is impossible for every patient encounter to encompass such strong affectivity and unleashing of love, particularly considering the external demands, heavy patient load, and time-constraints in modern medicine.

Concentrating on Zaner's reflection is not intended to impose further expectations or burdens on the physician; rather, it is to propose a new freedom that the physician can discover in the face of the suffering patient. "Suffering seems to belong to man's transcendence: it is one of those points in which man is in a certain sense 'destined' to go beyond himself' (John Paul II, 1984, para. 2). The physician has the opportunity to engage in this transcendent dimension of suffering. By integrating the lifeworld of the patient, indeed, the physician "goes beyond himself" and enters into the transfiguration of suffering in a mysterious way.

The opening of one's "I" to the "I" of the other person, as proposed by Zaner, is a sincere gift of the self that, in addition to aiding the patient, can be personally rejuvenating for the physician. Such "going beyond" begets reciprocity in the healing relationship where, in giving of one's self one receives. This is seen when volunteer help aids express in surprise, "I received so much more from those whom I served than I could ever have given to them!"

Phenomenologist Robert Spaemann describes this phenomenon in cases of persons with severe disabilities. He claims that, although they receive help at the level of sustaining life, in fact, "they give more than they get." He continues:

[F]or the hale and hearty portion of mankind giving this help is of fundamental importance. It brings to light the deepest meaning of a community of persons. Love, or recognition directed to a human being is not, as we have seen, directed merely to personal properties, though it is the personal properties that allow us to grasp that a person is there. Friendship and erotic love develop mainly in response to the beloved's individual personal properties. A disabled person may lack such properties, and it is by lacking them that they constitute the human community of recognizing *selves*, rather than simply valuing attractive *properties*. They evoke the best in human beings; they evoke the true ground of self-respect. So what [disabled persons] give to humanity in this way by the demands they make upon it is more than what they receive. (Spaemann, 2006, p. 244)

In giving to the sufferer, one receives abundantly more in terms of love<sup>†</sup> and, in Spaemann's words, this builds an authentic "community of recognizing *selves*, rather than simply valuing attractive *properties*" (Spaemann, 2006, p. 244). Therefore, although persons ought never to be conceived of as mere means to the achievement of any end, even if that end is love and happiness, it nevertheless seems that there is some sort of mysterious ordination within suffering to achieve the end of the flourishing of love.

Phenomenological personalism is a powerful means to actualize medicine's goal of the alleviation of suffering. In moments when the cause of suffering cannot be removed, when the situation cannot be changed, the superiority rests in the person's will to meaning. Throughout this work, we have seen how the will to meaning can dramatically elevate a patient's experience of suffering in illness. To enter into the mystery and discover the "why" of suffering—to experience its meaning—is to enter into the greater mysteries of love, communion, and self-transcendence. The patient experiences these higher goods firsthand. And in moments of unavoidable suffering, a personal tragedy is transfigured into a human triumph.

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Note: It is important to emphasize that the flourishing of love is a kind of side-effect. If one held that the *ultimate* meaning of suffering were its ability to cause love to flourish, than it may come to close to reducing persons in their suffering to a mere means to the achievement of other ends.

## **GLOSSARY**

**Communion:** Fellowship and close fraternity from the interchange of sharing common experiences, thoughts, and emotions. In this work, communion is not meant to imply participation (or membership) in a religious community or ritual.

**Conformism:** A tendency to comply with an accepted custom, but in a passive superficial way, without conviction or genuine engagement. Conformism consists in a definite renunciation of seeking the fulfillment of oneself in and through "acting together with others."

**Conversational attitude**: The ordinary natural attitude of everyday interactions that is the original, default way in which we are related to things and to one another as agents of truth.

**Eidetic characteristics:** Those traits and elements that are essential to the thing-itself and that remain unchanged regardless of any varying empirical features.

**Exclusionism:** In the practice of medicine, the belief that that whatever is not capable of being explained must be eliminated from the category of disease. In an exclusionist view, any of the patient's experiences or symptoms of illness that do not neatly fit within the conventional medical model are considered not to fall within the purview of the doctorpatient relationship and are therefore removed from the therapeutic goals.

**External goods**: Goods that can be obtained in ways that are not necessarily intrinsic to the practice and only contingently attached to the *practice*.

**Horizon of meaning:** Means by which reality is interpreted by a person.

**Internal goods:** Goods only obtainable through a particular practice and realized through the exercise of the virtues.

**Intersubjectivity:** The sharing of subjective states by two or more individuals, where a phenomenon is personally experienced (subjectively) but by more than one subject.

**Körper:** Refers to the corporeal body, what we are as physiological, neurological, and skeletal beings. Rene Descartes (1596-1650), refers to this as that aspect of ourselves "extended in space," visible to the eye, and hence subject to scientific investigation.

**Leib:** From the word *Leben*, life, which refers to the lived experience of embodiment. How a person experiences the physical matter (e.g. *Körper*) in his everyday life. If *Körper* is the abstract body-in-general, one object among others that is simply "there," *Leib* is *my* body in particular, my life here and now, what I am as a volitional, sensing person.

**Lifeworld** (*lebenswelt*): How the world is experienced or lived (German: erlebt). The lifeworld is a pre-epistemological stepping stone for phenomenological analysis in the Husserlian tradition. Each world necessarily has an *individual*, *personal* character and has a different content for each individual person. In brief, it is the world of practical, everyday experience. Of relevance in the doctor-patient relationship, the further apart the respective lifeworlds are of two individuals, the higher the probability that they will not understand each other.

**Logotherapy:** A directive existential psychotherapy that emphasizes the importance of meaning in the patient's life. Viktor Frankl coined logotherapy from *logos*—usually translated as word, speech or reason—which he defines as "meaning."

**Love:** The unselfish gift of one's "I" on behalf of others. There are several Greek words for love, as the Greek language distinguishes their varied meanings. For example, *agápe* is traditionally described in ancient texts as unconditional self-sacrificing love, whereas *eros* is principally known as an intimate romantic love. Amid this multiplicity of meanings, *philia*, the love of friendship, is most closely related to the "love" referenced in this work. *Philia* is the bond of friendship that binds us together in community; it is a virtuous love that includes loyalty to and enjoyment of friends, family, and community. In the context of the doctor-patient relationship, *philia* connects with the physician's loyalty to the patient and the practice of the virtues in medicine.

**Natural Attitude** (Husserl): What is within the world of immediate experience. The natural attitude of everyday experience is presupposed and pre-given in all that we do, as we take the existence of the world (and the objects within it) for granted without explicitly investigating the world *as* world.

**Naturalistic Attitude** (Husserl): Considers the world itself as a scientific *theme*. The aim of the "naturalistic," or scientific attitude is to grasp the nature of "reality" and describe it "objectively" characterizing the "thing-in-itself" apart from one's experience of it. Objective truth, according to the naturalistic attitude, can be captured in quantifiable data.

**Naturalistic Orientation:** Denotes the propensity of the natural sciences to explain the world and its events by examining the relations of physical causality that obtain among the items in that world. It is abstract and artificial insofar as it considers the scientific and physical strata of the human being "in isolation from the soul and the intellect" (Sawicki, 1997, pp. 79-80). Consequently, the naturalistic view also excludes such realities as intersubjectivity, the will, and the discovery of meaning in suffering.

Noetic phenomena (or the noological dimensions): In its narrow sense, noesis is identified as noetic with the nous being immediate or intuitive thinking; it is contrasted to dianoia ( $\delta$ iávoia) which is rational or discursive thinking. *Noesis* means understanding, as the ability to sense, or know something, immediately. These are the dimensions in which the uniquely human phenomena are located.

**Noumenon**: In Kantian philosophy the unknowable *noumenon* is often linked to the unknowable thing-in-itself. The term *noumenon* is generally used in contrast with, or in relation to phenomenon, which refers to anything that appears, or observable objects and events. *Phenomenon* (an observable thing) is distinct from *noumena* (a non-observable or immaterial thing, such as an attitude).

**Person:** According to Boethius, a person is "an individual substance of rational nature." In Boethius' framework, a person is a "unit member" of a species and, therefore, an individual entity that is distinct from all other "unit members" of that species.

**Personal attitude:** As defined by Husserl, the personal attitude focuses on *the meaning that an experience* has for an individual. "[I]n the personal attitude, interest is directed toward the persons and their comportment toward the world, toward the ways in which the thematic persons have consciousness of whatever they are conscious of as existing for them, and also toward the particular objective sense the latter has in their consciousness of it." (Husserl, 1970, p. 317, appendix III).

**Personalism:** A philosophical school of thought searching to describe the uniqueness of a human person. One of the main points of interest of personalism is human subjectivity or self-consciousness, experienced in a person's own acts and inner happenings. Personalism posits ultimate reality and value in personhood. It emphasizes the significance, uniqueness and inviolability of the person, as well as the individual's essentially relational or social dimension. Though personalism comprises many different forms and emphases, certain distinctive characteristics can be discerned that generally hold for personalism as such. These include an insistence on the radical difference between persons and non-persons and on the irreducibility of the person to impersonal spiritual or material factors; an affirmation of the dignity of persons; a concern for the person's subjectivity and self-determination; and particular emphasis on the social (relational) nature of the person.

**Personalist:** One who investigates the experience, the status, and the dignity of the human being as person, and regard this as the starting-point for all subsequent philosophical analysis. The *personalist tradition* acknowledges the indirect contributions of a wide range of thinkers throughout the history of philosophy who believed that the human person should be the ontological and epistemological starting point of philosophical reflection. Personalists include thinkers such as Dietrich von Hildebrand, Karol Wojtyła, Gabriel Marcel, and Edith Stein. I use the terms "personalism" and "personalist" interchangeably and broadly throughout this thesis. (Stanford University. & Center for the Study of Language and Information (U.S.), 1997)

**Personalistic:** Implies that the individual in the relationship not subordinated to societal goals, scientific goals, ideologies, or goals which she has not chosen herself. A personalistic approach includes writings mainly from personalist phenomenology as well as philosophical anthropology. Scholars in these traditions include Martin Buber, Gabriel Marcel, Robert Spaemann, John Paul II, Edmund Husserl, Max Scheler, Dietrich Von Hildebrand, and Viktor Frankl.

**Phenomenology:** A compound of the Greek words *phainomenon* and *logos*, which signifies the activity of giving an account, giving a *logos*, of various phenomena; this is an account of the various ways in which things can appear. Phenomenology is a philosophy or method of inquiry based on the premise that reality consists of objects and events as they are perceived or understood in human consciousness and not of anything independent of human consciousness. The historical movement of phenomenology is the philosophical tradition launched in the first half of the 20th century by Edmund Husserl and later by figures such as Martin Heidegger, Maurice Merleau-Ponty, and Jean-Paul Sartre. Phenomenology studies conscious experience as experienced from the subjective or first-person point of view. This field of philosophy is then to be distinguished from, and related to, the other main fields of philosophy: ontology (the study of being or what is), epistemology (the study of knowledge), logic (the study of valid reasoning), or ethics (the study of right and wrong action). (Stanford University. & Center for the Study of Language and Information (U.S.), 1997)

**Practice:** As defined by MacIntyre: "any coherent and complex form of socially established cooperative activity through which goods internal to that form of activity are realized in the course of trying to achieve those standards of excellence which are appropriate to, and partially definitive of, that form of activity, with the result that human powers to achieve excellence, and human conceptions of the ends and good involved, are systemically extended" (A. C. MacIntyre, 1981, p. 175).

**Reductionism:** A philosophical position that a complex system is nothing but the sum of its parts, and that an account of it can be reduced to accounts of individual constituents. In medicine and science, this describes the belief that all phenomena can be reduced to scientific explanations. It is a belief that the behavioral phenomena of disease must be conceptualized in terms of physiochemical principles.

**Subjectivity:** The interior reality of a person's experience. In this thesis, "subjective" and "subjectivity" are used in a positive sense to express personal interiority. It is important to note that this is not a concession to "subjectivism," where reality is nothing more than private experience.

**Suffering:** The state of distress induced when the intactness of the person is threatened or destroyed; such distress continues until the threat is gone or the integrity of the person is restored. Cassell describes suffering as "the experience of a threat, or a *perceived* threat, to the integrity of the person."

**Scientific attitude:** The "naturalistic" attitude, as stated by Husserl, which is a thematic attitude directed at the "objective" world.

**Thematic:** A phenomenological modification, a reorientation, whereby we make the world in which we live and usually take for granted into the object of our thoughts (e.g. we make it "thematic"). In Husserl's language, this activity of consciousness renders the object "thematic."

**Virtue:** According to MacIntyre, a virtue is "an acquired human quality the possession of which tends to enable us to achieve those goods which are internal to practices and the lack of which effectively prevents us from achieving such a good" (A. C. MacIntyre, 1981, p. 191). Aristotle's theory of virtue is similar to MacIntyre's and worth noting. For Aristotle, a virtue is "a state or disposition of character that is acquired by habit through the persistent practice of morally good actions" (Shelp, 1984, p. 13). The exercise of the virtues is a critical component in "the good life" for a person, his *telos*.

**Voice of Medicine:** Represents the technical-scientific assumptions of medicine. The medical history taken by the doctor reflects the "voice of medicine," while the patient's clinical narrative reflects the "voice of the lifeworld."

**Voice of the Lifeworld:** Represents the ordinary attitude of everyday life as well as the clinical narrative of the patient. By explicitly attending to the patient's *story* of illness—what Husserl refers to as the clinical narrative, or the "voice of the lifeworld"—the physician is adopting the "personal attitude."

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