

## **At the Place Where the Willow Don't Bend: A Phenomenological Perspective on Illness and Healing at the End of Life**

**Timothy A. Burns, Ph.D.**

It is more than a platitude to admit that we are always dying. It is a recognition of the fundamental finitude that marks our existence as human persons. It says something essential about the human condition. We are all born. We all die. And the very living of life is, leaving aside for the moment religious considerations, oriented toward death. Phenomenologists make much of this observation, perhaps none more so than Martin Heidegger who argues that our being-toward-death permits the ontological grasping of Da-sein as a whole.<sup>1</sup> Indeed for him, the “existential and ontological concept of death” is “*the ownmost nonrelational, certain, and, as such, indefinite and not to be bypassed possibility of Da-sein.*”<sup>2</sup> However, if one spends much time around those who are very close to death it can begin to sound disingenuous to talk about death as one’s ownmost possibility. It is easy to think *these patients* are dying—not me. Still, the phenomenologist might claim that, vis-à-vis our being-toward-death, the difference between me and the terminally ill patient is a matter of degree and not kind. But, is this so? One may be excused for thinking not. There appears to be an important difference in the kinds of possible experiences open to us. I may experience healing if I become ill; on the other hand, the very condition of the patient with a terminal illness is defined by the *impossibility* of her experiencing healing.

I would like to consider the situation of the person who is terminally ill, the person whose death is, ontologically, her ownmost possibility and, factually, her immediate, inevitable future. The primary aim of this paper is to argue that the terminally ill patient can, in fact, experience

---

<sup>1</sup> See §§46-53 of Heidegger’s *Being and Time*. Martin Heidegger, *Being and Time*, trans. Joan Stambaugh (Albany, NY: SUNY Press, 1996), pp.219-246. Emphasis in the original. Hereafter, BT.

<sup>2</sup> BT, 239.

healing at the end of her life and in the face of impending death. I will not argue that the possibility of experiencing healing at the end of life means leaving room for divine intervention, though neither do I intend to preclude such a possibility. Rather, I will argue that healing is something that we experience quite apart from what happens to our biological make-up. While healing is often correlated with a change in the state of our bodies, it need not be.

This argument requires me to articulate the distinction between two pairs of related concepts, viz., to distinguish disease from illness and cure from healing. The terminological distinction can be made quickly enough, but I will then examine the structure of the experiences of illness and healing. This is the task of the first half of the paper. The task of the second half is to show that one can still experience healing, even as one recognizes and faces the inevitability of one's own death.

I should indicate from the beginning that Heidegger's analysis of being-toward-death proves to be a fruitful way to enter into a consideration of the question that intrigues me, but this essay is not an attempt to answer the question of the possibility of healing at the end of life from a Heideggerian perspective. My concern is neither a Heideggerian interpretation of the possibilities of the terminally ill patient nor is it an attempt at a criticism of his would-be position.

In *The Healer's Art*, Eric Cassell observes that "the idea that illness and disease are the same is...culturally derived."<sup>3</sup> He argues that the success of the germ theory of contagious diseases plus the establishment of the cellular basis of disease have led medicine into the "age of the cure," beginning with the development of sulfonamides in the 1930s.<sup>4</sup> The age of the cure is marked by an exponential increase in diagnostic and therapeutic technologies, rapidly developing

---

<sup>3</sup> Eric J. Cassell, *The Healer's Art: A New Approach to the Doctor-Patient Relationship* (Philadelphia & New York: J.B. Lippincott Company, 1976), 48. Hereafter HA.

<sup>4</sup> HA, 61-62.

and increasingly effective drugs, and the accelerated development of effective therapies and interventions.<sup>5</sup> It has also led to the popularization of the belief that illness and disease are the same thing. The effectiveness of modern medicine at curing diseases represents a cultural shift in the way that we look both at ourselves and at the practice of medicine. Illness and disease have become the same thing.<sup>6</sup> To treat the illness is to cure the disease.

However, one can distinguish between the two and it is important to do so. Disease names a pathology of a biological system or organ. Illness designates the aspect of the disease that the person suffers. Or, as Cassell puts it, “let us use the word ‘illness’ to stand for what the patient feels when he goes to the doctor and ‘disease’ for what he has on the way home from the doctor’s office.”<sup>7</sup> People get ill. Bodies get diseases. Edmund Pellegrino and David Thomasa articulate this distinction in terms of the “empirical and phenomenological aspects of illness.”<sup>8</sup> They define illness as “the subjective perception of a person that he has experienced a change from the customary state he regards as health.”<sup>9</sup> Health, in this sense, does not refer to a state free from all disease but rather to a state of “equilibrium established between inborn or acquired diseases or limitations and the use of our bodies for transbodily purposes.”<sup>10</sup> Thus, by illness I mean what the patient suffers and by disease I mean the biological disorder that affects the body.

Disease and illness stand on opposite sides of the distinction between the physiological and experiential aspects of our being unwell. There is also a distinction to be made between treating these two, that is, between curing and healing. Diseases are cured but patients are healed.

---

<sup>5</sup> HA, 62.

<sup>6</sup> Cassell also points out that the fact that we think and speak of diseases as *things* at all is the outcome of a long cultural struggle dating back to 400 B.C. This is the struggle between the physiologists and the ontologists. See HA, 63ff.

<sup>7</sup> HA, 48.

<sup>8</sup> Edmund D. Pellegrino and David C. Thomasa, *Helping and Healing: Religious Commitment in Healthcare* (Washington D.C.: Georgetown University Press, 1997), 131. Hereafter HH.

<sup>9</sup> HH, 131.

<sup>10</sup> Ibid.

Curing belongs to the disease half of our distinction and may be defined as “the radical interruption and reversal of the natural history of the disorder” that afflicts the patient’s organ.<sup>11</sup> The act of healing corresponds to the treatment of the ill patient. It means repairing the wounds that the illness has caused, a return to the state of balance in the person’s life, a restoration of the disrupted equilibrium in the patient’s life.<sup>12</sup>

The relationship between disease and cure is evident enough. Kill the bacteria to cure the infection. The relationship between illness and healing is less clear, especially in severe cases. If the illness involves a distinct kind of experience that isn’t necessarily ameliorated by the cure of the disease, how does one effect healing if not by curing? I now wish to examine more closely the experience of illness so that we can also arrive at a better understanding of healing, and this will allow me to transition to the final claim of my essay, that one can experience healing at the end of life even with the impossibility of a cure and in the face of inevitable death.

There is an inextricable connection between the concepts of health, illness, and healing; and there is a tradition of understanding health as an equilibrium, illness as a disturbance in it, and healing as the restoration of that equilibrium.<sup>13</sup> I have described illness as what the patient suffers. In this sense, and as is clear in the definition of illness Pellegrino offers, illness upsets an equilibrium; it is a disruption of a project, an interruption of a more or less coherent course of life, a disturbance of the normal, or a fracturing of a previously existing whole. I must then offer some preliminary definition of health in order to talk about the experiences of illness and healing. I don’t wish to offer a biological definition of health; what I am after, rather, is both a working definition and one that recognizably describes the lived-experience of being healthy.

---

<sup>11</sup> HH, 27.

<sup>12</sup> HH, 131-132.

<sup>13</sup> See for instance; HA, especially Chapter One; Hans Georg Gadamer, *The Enigma of Health* trans. Jason Gaiger and Nicholas Walker (Stanford, CA: Stanford University Press, 1996), 33-34; and HH, 133.

I suggest that the tradition of referring to healing as the restoration of equilibrium offers us a nascent definition of health. As Donald Landes describes in an exposition of Gadamer's *The Enigma of Health*, "the art of healing aims to *re-establish* something that already did exist."<sup>14</sup> Healing aims at restoring a natural equilibrium to the life of the patient. Landes also observes that, because of the temporal requirements of a phenomenological analysis, we must admit that it would be impossible to restore "the *exact* condition of the lost equilibrium."<sup>15</sup> He continues, "In medicine, the patient is herself or himself a trajectory of experience, not a mechanical part of a static system."<sup>16</sup> Therefore, we ought not conceive of healing as hitting the 'reset' button. It does not restore the patient to an identical state of biological functioning that pre-existed the abnormal condition. Rather, healing involves helping a patient in "*rendering coherent* ... a new equilibrium that will be a meaningful phase in an ongoing trajectory of life."<sup>17</sup> If the target of healing is a rendering coherent of a new equilibrium, then a decent definition of health might be "equilibrium." Landes offers a more precise, working definition of the state of equilibrium that typifies health.

[A] state of generally "good" (if not optimal) physical and mental functioning of a person, making possible their well-being within their environment, social context, and overall life trajectory – where "good" is (at least implicitly) defined by the person in question in light of their past experiences, present possibilities, and future anticipations, and where the "social context" is not unduly influencing that definition of "good."<sup>18</sup>

I will adopt this definition for the purposes of this essay.

This provides an opportune time to look at the experience of illness insofar as it exceeds classification by traditional symptomology. Illness disrupts the equilibratory trajectory of the

---

<sup>14</sup> Donald Landes, "*Phronēsis* and the Art of Healing: Gadamer, Merleau-Ponty, and the Phenomenology of Equilibrium in Health," *Human Studies* 38, no. 2 (June 2015): 273. Emphasis in the original.

<sup>15</sup> *Ibid.* Emphasis in the original.

<sup>16</sup> *Ibid.*

<sup>17</sup> Landes, 276. Emphasis in the original.

<sup>18</sup> Landes, 270.

patient's life in a number of ways. 1) the foregrounding of finitude, 2) exposure and vulnerability, 3) fractured reason, and 4) disconnection.

Consider first the way that illness brings finitude to the foreground. Even if we know we are finite creatures, when we are healthy our finitude recedes from our thoughts. Cassell argues that we need a sense of omnipotence and indestructibility to, in his words, “soar above our bodies” even for the simplest of tasks such as crossing a busy city street or riding a bicycle.<sup>19</sup> He describes the way illness brings finitude to the foreground as a loss of those feelings of omnipotence and indestructibility.<sup>20</sup> Our bodies do not usually occupy our attention when we are healthy; but when we are ill, they are suddenly obtrusive. Pellegrino writes, “Illness interposes the body—or the mind—between the self and reality or our perception of reality.”<sup>21</sup> Consider the simple example of biting your tongue. When the tongue is well, you don't notice it. Once you have bitten it, it protrudes in your experience; even the slightest swelling is noticeable, cumbersome, impedes your normal speech, and is almost impossible to ignore. The example is trivial but informative; the more severe the illness the more prominent our finitude becomes.

Second, the experience of being ill is one of exposure and vulnerability. Cassell believes this may be the most destructive aspect of illness.<sup>22</sup> The ill patient's body is exposed to the physician in ways that are usually reserved only for those with whom she is most intimate. The patient is vulnerable. She is exposed to treatments, medications, and the power of others. She is in an unequal situation, in most cases, vis-à-vis knowledge of what is causing her illness and how to treat it. She loses the ability to control her world, to run the day to day business of her life, and

---

<sup>19</sup> HA, 34.

<sup>20</sup> Cf. HA, 30 and 34.

<sup>21</sup> Edmund D. Pellegrino. “Being Ill and Being Healed: Some Reflections on the Grounding of Medical Morality.” In *The Humanity of the Ill: Phenomenological Perspectives*. Ed. Victor Kestenbaum. (Knoxville: University of Tennessee Press, 1982), 158.

<sup>22</sup> HA, 44.

may experience inactivity and confinement to the house or to bed. Cassell sums it up nicely. “The sick do not; they have done to them.”<sup>23</sup>

Third, illness can cause a fracturing of our powers of reason. The basic assumption that people think, more or less, in the same way and come to decisions by using the same rational faculties must disappear in light of clinical reality. Cassell writes, “While the sick may think rationally when they are able to consider the presidency or the Constitution, their thoughts about themselves or their illness appear to be primarily emotional.”<sup>24</sup> Fear, he argues, comes to play a more and more prominent role in the way that the patient interprets her symptoms or reports the history of her illness to the doctor.<sup>25</sup> He illustrates his point with an anecdote about a patient, whose wife was a nurse. During the early years of their marriage, in the Second World War, the husband had contracted tuberculosis and had to spend an extended period in a sanatorium. This was a dominant and defining experience of the early years of their marriage. When he began to experience chest pain, they were overcome with fear that he might have to return to a sanatorium. It never occurred to them that his symptoms were typical of angina pectoris, heart disease, even though upon discussing the diagnosis they all agreed it was obvious, and should have been all along given his wife’s experience in the medical field. “[T]he meaning of the pain was completely distorted by past experience and fear.”<sup>26</sup>

Finally, consider the way illness can occasion an experience of disconnectedness from the world. This can be on a sensory level by disrupting our normal sensory experience of the world. It can also be on the social level. Something as simple as being in the hospital is a form of disconnection from one’s normal world. Or the social disconnection can be more striking and

---

<sup>23</sup> HA, 44.

<sup>24</sup> HA, 35-36.

<sup>25</sup> HA, 36.

<sup>26</sup> HA, 37. He also cites evidence that ill patients typically respond to classic tests of reasoning on the conservation of volume in the same manner as children of the age of six. See HA, 38-39.

more complete. Tuberculosis patients, those who have contracted venereal disease, and people with leprosy are three of the examples Cassell uses to highlight the way that social attitudes and mores tend to distance the sick from their communities.<sup>27</sup> Illness also disconnects us from the world by sapping our interest in things.<sup>28</sup> This might be the most striking form of disconnection from the phenomenological point of view because taking up and maintaining a coherent project presupposes a connection to the world in the form of interest. To strike a blow that severs interest in the world is to attack the very form of our being-in-the-world.

The list is not exhaustive, but illustrative of four common and ways that an individual lives out her illnesses. They will vary between individuals and from illness to illness within a given person's experience. They are also likely to differ in intensity in direct proportion to the severity of the disease suffered. A cure of the patient's disease may heal some of these wounds. The isolation of the patient suffering from the flu is easily overcome when she has recovered and returns to normal day-to-day life. Other times though, cure does not bring healing. Witness the stigma and isolation from friends and community that may follow a person diagnosed with a sexually transmitted disease, even if the disease is cured. The pressing question for this essay, though, is this: can these aspects of illness be overcome, and thus healing take place, in the life of a patient who is terminally ill?

To speak of healing at the end of life is not to speak of the elimination of the aspects of the experience of illness described above. It is rather to speak of their transformation.<sup>29</sup> This transformation takes place through the community and often in what Pellegrino describes as "mundane ways."<sup>30</sup> Finitude cannot be overcome, but our encounter with it can be transformed

---

<sup>27</sup> HA, 27-29.

<sup>28</sup> HA, 27.

<sup>29</sup> Cf. HH, 46 ff.

<sup>30</sup> HH, 46.

through “creative action by the community” that engages and embraces the ill person. Life, like art, music, and poetry, is passed from generation to generation. Exposure and vulnerability can be transformed through addressing the needs of the patient and responding to the call of the ill person who finds herself exposed to increasingly invasive treatment and technology, in need of the physician and the community’s healing power. The fracturing of reason can be overcome only through the transformation of fear and resisting the temptation—on the part of both doctor and patient—to objectify the body as some “thing” that has betrayed the ill person. As Pellegrino writes, “The aim of all technological interventions, therefore, should not just be their improvement of organ system function. Rather it should include the restoration of personal wholeness through human healing.”<sup>31</sup> Finally, disconnection can be transformed through abolishing the stigma of death and actively integrating the ill person into all of her communities, be they religious, social, familial etc. Let the sick man call!

In the remaining space, I can only indicate the ‘what’ and not the ‘how’ of affirming the possibility of healing in the face of inevitable death. If the nature of sickness is a disruption of the patient’s projects, a rendering incoherent of the tasks to which she commits herself, then healing must be understood as the enabling of a return to the project. Being healed means the patient’s return to a coherent project that she recognizes as hers and toward which she orients her life as meaningful. David Power expresses this neatly when he says, “It is not by coming out of sickness that the crisis is resolved, but by some word that indicates its meaning and reshapes the sick man’s relation to the earth and to human community.”<sup>32</sup> Or, as Ortega y Gasset articulates this insight, “the reabsorption of circumstance is the concrete destiny of man.”<sup>33</sup> Dying can be a

---

<sup>31</sup> HH, 48.

<sup>32</sup> David Power, “Let the Sick Man Call,” *The Heythrop Journal* 19, no. 3 (1978), 263.

<sup>33</sup> Jose Ortega y Gasset, *Meditations on Quixote*, trans. Evelyn Rugg and Diego Marín (Urbana and Chicago: University of Chicago Press, 2000), 45.

project when there are no other projects left. And I can do it well or poorly. Just as I can fail to live well, I can fail to die well.

The ability to absorb circumstance, and to meaningfully reorient one's life despite it, marks human suffering as distinct from mere physical pain; it is the "rational response to both the meaninglessness and the meaning of pain."<sup>34</sup> Ortega y Gasset calls circumstance, "the mute things which are all around us... We walk blindly among them, our gaze fixed on remote enterprises, embarked upon the conquest of distant schematic cities."<sup>35</sup> But, when dying is our circumstance the mute can miraculously speak. We are no longer permitted to be blind to our circumstance when it signals the end of all other projects, our ultimate confrontation with finality. When our previously mute circumstance confronts us with a lurid voice, we must absorb the circumstance of death.<sup>36</sup>

---

<sup>34</sup> HH, 121.

<sup>35</sup> Ortega Y Gasset, *Meditations on Quixote*, 41.

<sup>36</sup> This essay is dedicated to the life of William S.K. "Scott" Cameron who absorbed the circumstance of death in 2016. He was at various points in my life a teacher, a confidant, and a colleague. He was the first to introduce me to the work of Gadamer, and was incredibly patient in helping me understand both Gadamer and Heidegger. His cancer was incurable, but he died a whole man—as healed as anyone can be. I miss you, Scott.