

Chapter 13

Existential Medicine and the Intersubjective Body

John Russon and Kirsten Jacobson

Traditionally, medicine has been based on an organic interpretation of the human body. In this way, health and disease in the human being are understood in the same way that we understand the normal or abnormal functioning of other organisms—plants and animals—that make up our natural environment. While there is something unquestionably right about this model of medicine, in that it clearly does speak to the functioning of our organic bodies, it falls short of grasping the true character of the human body, namely, that it is an *existential* reality, and it also therefore stands as an insufficient model for human medicine. Most importantly, grasping the existential character of the human body is recognizing it as an intersubjective and hence expressive body. Correspondingly, an existential conception of medicine requires treating the body first and foremost as a reality situated within and participating in relationships of recognition and communication.

This notion of an existential conception of medicine is not new: It was given an extraordinarily rich and insightful treatment in 1966 by J. H. van den Berg in *The Psychology of the Sickbed*, and more recently Fredrik Svenaeus (2011) has done an excellent job of articulating the basic relevance of Heidegger's notion of being-in-the-world for the philosophy of medicine. We understand our approach to be of a piece with these earlier analyses, but we take a unique slant by emphasizing the distinctive character of the body within the existential perspective opened up by Heidegger, a theme powerfully articulated in Heidegger's *Zollikon Seminars* (2001), but especially developed in the French existentialists Sartre and Merleau-Ponty.¹

We will lay out our conception of existential medicine in three sections. First, we will outline the distinctive way that the body is understood within the context of existential phenomenology. Second, using the examples of inflammatory bowel disease and infection with HIV, we will explore how this

existential conception of the body leads us to recognize a different “essence” to these experiences of illness than does organic medicine. Third and finally, we will consider how our reconceptualization of illness leads as well to a reconceptualization of health; this last reflection will also motivate a critique of contemporary, institutionalized health care.

THE EXISTENTIAL CONCEPTION OF THE BODY

An existential conception of medicine depends on an existential conception of the body. To grasp the existential conception of the body, one must grasp the interrelation of three phenomenological aspects of our experience: First, the body is one’s “I can”; second, the “I” is always implicated in relationships of mutual recognition, always a participant member of a “we”; and, third, our reality as a participant in a “we” is always experienced in and through a *world*—in other words, we experience our relations with others not just as one discrete aspect of experience but in and as the very fabric of our being-in-the-world. Let us consider each of these three notions in turn.

What does it mean to refer to the body as the “I can”? The body can, of course, be understood as a thing in the world—it *is* a thing in the world. *My* body, however, is not just one among many things in the world, but is the very medium and means of my existence, of my existence *as* an experiencing subject, of my “I.” My body is distinguished from all other things in the world by the way that I *experience* it. And how, fundamentally, do I *experience* my body? I experience it *as my ability to act*. In a typical situation, I am absorbed with my surroundings, grabbing the cup, answering the telephone, running to the bus, and so on. In such situations, my attention is “occupied,” so to speak, by the cup, the telephone, or the bus, which I experience *as* graspable, *as* answerable, *as* accessible by running. In each case, my attention is occupied by the thing that is the explicit object of my intention and action, but, though my body as such is not the focal object of my attention, I experience that focal thing *in terms of* the capacities for interaction with things that my body affords. My fundamental experience of my body is not the detached recognition of it as a thing in the world, but is rather the non-thematized experience of it as the very condition of my *having* things—my *having* a world—at all.

Just as my primary experience of my body is *as* my ability to interact with the things of my world, so do things at root exist for me first as calls to action, as invitations, solicitations, or demands that elicit from me—from my body—a behavioral response. Prior to being the objects of intellectual reflection, things are, so to speak, “under my skin” as prods and provocations

summoning up my action, as, for example, the stairs that call forth my raised step or the handrail that draws my hand to it before I have even noticed them explicitly. My body and the things of my world thus form an interlocking system, my body's powers illuminating for me the meaning of things and things illuminating for me the resources that are my body. As Merleau-Ponty (1963) writes in "The Philosopher and His Shadow,"

The relation between my body's movements and the thing's "properties" which they reveal is that of the "I am able to" to the marvels it is within its power to give rise to. And yet my body must itself be meshed into the visible world; its power depends precisely on the fact that it has a place *from which* it sees. Thus it is a thing, but a thing I dwell in. . . . We can just as well say that the entire functioning of the body proper hangs upon the perceived thing the circuit of behavior closes upon. (166, 173)

My body and things form an interlocking system such that I experience myself as *in* a world that calls for my action. To conceive the body existentially is thus to recognize that, first and foremost, my body exists for me as *my capacity to have a world*, and the specific powers of my body determine the specific parameters in which the world can present itself to me as meaningful.

This interlocking system of body and world means that it is as true that things reveal to me the nature of my body as it is true that my body reveals to me the nature of things. This point is especially pertinent for grasping the second essential feature of the existential conception of the body, namely, its essentially intersubjective nature. The world that we live in is a human world: We experience ourselves as persons in the midst of other persons. Now, just as we noted about our own bodies, we can note about another person that she is a thing in the world. A person is a very special sort of thing, though, and understanding what kind of thing the other person is allows us to understand the distinctive way that person impinges upon and reveals the existential nature of the body.

A person is there, present before one as that animate body grasping a cup or answering a telephone, but to experience that presence *as* a person is precisely to experience that bodily presence as the *annunciation* of a human reality—a person—that can never itself be present before one: A person, *as a person*, is always *inherently* absent from one's experience inasmuch as that person, (like oneself), is a center of meaning and initiative: That person is a *subject*, and hence never adequately presented in any object.² And, furthermore, inasmuch as that person is an experiencing subject, one thus necessarily exists for that subject as an object in *her* world. This recognition of the other as a subject has the further implication that to experience that body over there as the presentation of a subject is to experience *oneself* as an object of

that person's experience: I experience the other *as* a person in and as experiencing myself as an object *for* her.

Now, we noted earlier, that the body is the "I can," it is our capacity for engaging with objects. But how is it, then, that my body is my capacity for experiencing that object that is another subject? On the one hand, as we have just seen, it is in and as experiencing my body as an object that I experience myself in the presence of another subject. Our experience of other persons, though, does not stop at the simple fact of an encounter between aliens; on the contrary, we experience other persons—just as we experience other things—as realities *with which we can interact*. The most relevant sense of our bodily "I can" in relation to the experience of other people is this, its capacity for interaction with them. The interaction with other persons, though, unlike the material interaction of physical bodies, takes a fundamentally different form from bodily contact as such and the bodily changes that thus result; interactions with other persons take the form of *communication*; that is, it takes the form of the *intersubjective* contact and the *intersubjective* changes that can result *through* bodily interaction. It is thus in its capacity for *expression* that the body exists for us as the "I can" by virtue of which we are able to interact with other persons.³

In expression, my body becomes a sign: I use my hand to wave "hello" to you, I shake my head to say "no," I hug you to express my compassion for you in your suffering, or, most fully, I expel breath from my mouth to make the sounds that you and I recognize as language. In each case, the present bodily action—waving, head-shaking, hugging, or making a sound—is not itself the proper content or object of your experience or of mine; instead, at least in the case of successful communication, each of us is occupied with *what is expressed in and through* that present action, that *gesture*. The waving, head-shaking, hugging, and sound-making and their bodily effects upon you can all be studied and understood physiologically, but your *understanding* of my expression of sympathy, enthusiasm, or disagreement is not the same as the simple feeling of objective pressure against your skin, the excitation of receptors within your retina, the transduction of sound waves in your inner ear, and so on; on the contrary, it is your *recognition* of what I *as a subject* am expressing to you *as a subject*. The realities of expression are enacted within the materiality of our bodily interaction, but they exist only insofar as they are matters of our intersubjective recognition. The bodily, existentially speaking, is our means of participating in the unique space of shared experience.

Though our sharing of experience with others can take the form of an explicitly thematized action, such as asking a stranger for permission to sit at the table she is using or trying to get the attention of one's friend who is otherwise occupied, our sharing of experience is not always or even, indeed, typically such a thematic matter. More commonly and more fundamentally,

our sharing of experience is the already, mutually accomplished medium for our engagement with the things of our world: Our sharing of experience with others is primarily the way in which we inhabit a world *together*, a cohabitation that is thus the implicit meaning of our explicit, thematic interactions with other things. Indeed, because our very sense of self is rooted in the dialog of “recognition” that we enact with others, it is this basic meaning that is the pivot for the meaning of our world and, hence, of the things that make up that world.⁴ When, with the support of their parents, infants learn to walk, for example, new spaces, new things, and new activities become available and thus alive to them, and these spaces, things, and activities, as well as being an enrichment to the material contents of their world are also new and richer means for their enjoyment of inhabiting the reality of their shared life with their parents. Similarly, when adolescents are given permission to walk somewhere on their own, new sites for exploration appear for them in the neighborhood they have “seen” so many times before and, again, just as this is a material expansion of the material possibilities of their world, so is their engagement with them an engagement with their parental “permission” (just as any previous “illegitimate” entry into these places would have been experienced by them as exciting precisely because it was transgressive of that permission). And, of course, the inhabitation of these new worlds by the child or the adolescent—the world made available through walking or the world made available through solitary travel—is not just an inhabitation shared with parents and familiar others, but is also a world shared with strangers. A female adolescent, for example, may be given permission to walk a certain distance away from her family home during the day, but not at night, owing to her guardian’s perceived sense that there may be people out at night that she should not encounter. And, indeed, as she herself experiences her adolescent body changing, she may, with fear or excitement, pointedly find her inhabitation of public spaces to be an engagement with strange others inasmuch as she experiences her body as an object of their sexualized gaze. Walking through the grocery store may no longer feel like the simple and innocent thing it formerly was—a solely instrumental activity, or a fun part of family life—but may become a threatening or exhilarating challenge as she experiences others who previously would not tend to notice her now inspecting and evaluating her. In all these cases, we can see both how our bodily engagement with the world is implicitly an engagement with other people and, reciprocally, how our engagement with other people is enacted as our bodily engagement with the world.

Existentially conceived, then, the body is not understood as an organism (though, to be sure, it *is* an organism). First, the body, existentially conceived, is my capacity to be *in the world*: It is my “I can,” by which I participate with things in constituting the tissue and fabric—the very “flesh”—of the world.

More specifically, the body, existentially conceived, is my lived capacity to participate in a world with other people. In this sense, my body, existentially conceived, is (a) *how I am* on display to others and (b) my capacity to express myself to others. It is this conception of the existential body that must underlie truly human medicine. Let us now consider this conception of the body as our capacity to participate in the intersubjective world can inform medical practice.

ILLNESS IN THE CONTEXT OF INTERSUBJECTIVE RECOGNITION

Because I live my body as my being an object for others, I experience my body as the site for their approbation and desire or, alternatively, their disapprobation and disgust. While a so-called medical model of medicine need only construe an illness as a disease—as a dysfunctional state of an organic system—an existential medicine must recognize the illness as a malady of the body-as-site-of-intersubjective-recognition as much as a malady of the body as an organism. Any medical problem raises these themes: One can experience the black eye one has from being punched in the face as a horrible embarrassment, in the case, for example, of an abused wife who finds it a challenge both to reveal to others that she was involved in such a bad situation and to reveal to herself that she has failed to live up to her husband's expectations, no matter how unjust his assessment and subsequent reaction may have been; one can also equally experience the black eye as a "medal" of which one is proud, in the case, for example, of a pre-teen boy who is eager to display to his peers that he has entered the world of fist-fighting.⁵ These *existential* realities of the black eye cannot be analyzed or understood in biological terms; they are, however, the *lived reality* of the black eye: they are *what it is* as a property of the body of this person. Furthermore, as the preceding example shows, there is no way to deduce from the organic situation—the bruised tissue around the eye—what that existential reality is: The existential reality of this and any such illness *cannot be grasped in separation from the lived experience of the person who suffers it*. At the same time, the need to go beyond the objective terms of the bodily condition to the subjective terms of the human situation does not make the meaning of the illness something mysterious, nor does it make it a matter of private stipulation; on the contrary, as our examples also make clear, it is quite possible to understand the significance of the illness through grasping the situation of that person.⁶ The limitations of the "objective" analysis are thus not a matter for "throwing up one's hands." They indicate, rather, that medicine cannot honestly claim to care for the health of people—that is, to be *healthcare*—if it restricts its diagnoses

and treatments to impersonal and generic interpretations: an authentic, human medicine—an existential medicine—must *in principle* include the personal interaction between healthcare providers and patient, oriented to the understanding of the *meaning*—the *necessarily personal* meaning—of the illness.⁷ Any medical situation is a phenomenon of the existential body and, thus, like our example of the black eye, engages the reality of that body as the way the person is on display before others. Some medical conditions, at least in our contemporary culture, thematize this dimension very dramatically, and we will briefly consider two such condition: IBD (inflammatory bowel disease) and HIV-AIDS (human immunodeficiency virus-acquired immune disorder).

“Inflammatory bowel disease” is a name that covers two distinct conditions, Crohn’s disease and ulcerative colitis, that are characterized by a chronic inflammation of the digestive tract; both are autoimmune disorders, and there is no known cure for either. Symptoms associated with these conditions include bloody diarrhea, painful bowel movements, fecal incontinence, and, consequently, weight loss and fatigue. These symptoms can be more or less severe, and they can manifest themselves at unpredictable times over the course of an entire life. These conditions are normally treated with a mixture of drug therapies or surgery; in some cases, surgery may include the creation of a stoma—an opening in the abdomen—to which is attached an ostomy bag for the collection of stool.

IBD is a medical condition that is powerfully correlated with issues of stigma.⁸ Because IBD involves feces, it engages with issues that are socially taboo; coupled with the fact that the disease can, unpredictably, involve incontinence and extensive use of the toilet, this condition can produce reactions of disgust, certainly in the one suffering from it but especially from others who are confronted with it. As a consequence, people suffering from IBD can feel stigmatized because of their condition. Furthermore, because these issues of taboo and disgust are closely integrated with our most intimate sense of what is proper and improper—what is “clean” and what is “dirty”—such reactions typically carry with them an implicit moral weight. As a result, the stigmatized person can feel that he or she is morally criticized and held responsible for having the “disgusting condition” and bringing it into the world.⁹

Reaction to the stigma associated with IBD can manifest itself in various different arenas. Because stigma is primarily a social matter—a matter of how one stands in the perception of others—the issues associated with it especially show up in sites where the engagement with others is thematized. Those who experience the symptoms of IBD may, for example, be unwilling to seek medical help in the first place out of a sense of the embarrassment or shame they anticipate feeling in talking with the clinician. Again, they may be reluctant to reveal their condition to their intimate companions—whether family

members or romantic partners—out of fear of the reaction they might receive. (In fact, online support groups have proved especially valuable for sufferers from IBD, presumably because the relative anonymity of online interaction offers individuals a buffer from the direct experience of the encounter with another person.) And, in general, social activity in general—whether at work, at school, or for recreation—may seem intimidating, and the individual with IBD may well fear or retreat from such situations.¹⁰

Let us reflect briefly on these issues of the stigma of IBD and the various forms reaction to it can take in terms of the toll they take on the life of the individual with IBD. The stigma associated with IBD can result in the person with IBD being subjected to unfair treatment from employers or fellow employees, from teacher or fellow students, from medical practitioners, or, indeed, from family members and friends. In this sense, IBD brings with it the possibility of substantial practical problems in the most substantial and the most intimate sectors of life in addition to the severe problems of self-esteem and, in general, in happiness and a sense of joyful existence. Fear of such consequences can fuel an attitude of withdrawal and secrecy, which, in the very act of trying to ward off these crippling life problems, may produce comparably troubling results of social alienation and personal unhappiness as well as practical problems caused by reluctance to seek medical help or to solicit the care of potentially supportive individuals.

What is particularly noteworthy here, and the reason we have chosen to emphasize this particular condition, is that in IBD a problem of the body precisely intervenes in our participation in intersubjective life—that is, *for* the one suffering from IBD *and for* most others with whom that person deals, the condition is precisely a malady *of the existential body*: It is one's "I can" with respect to other people that is damaged through the inflammation of the bowel. In other words, *as a lived experience*, IBD is an *existential* problem rather than simply a physiological phenomenon. Said otherwise, the problem a person with IBD faces is not primarily a problem with the bowels: It is primarily a problem with living a happy and healthy *life*, with how one has and navigates an interhuman world.

Something quite similar can be seen in the case of persons suffering from HIV-AIDS. HIV is a virus that attacks the immune system, destroying the CD4 ("T") cells that fight infection; AIDS—acquired immune deficiency syndrome—is the condition that results from prolonged damage to the immune system by HIV, a condition in which the infected individual is subject to any number of opportunistic infections with which the compromised immune system can no longer cope. Currently, there is no cure for HIV infection, though antiretroviral therapy (ART), introduced in the 1990s, can significantly mitigate the effects of infection if taken correctly, every day. Because HIV is typically contracted through sexual activity or through sharing a

needle used for injection with a person infected with HIV, this infection, like IBD, draws our attention to matters that are generally taboo or considered “dirty,” with the result that HIV-AIDS, like IBD, is a condition marked by stigma; indeed, it has not been uncommon to hear AIDS interpreted as divine punishment for immoral behavior.¹¹

The stigma associated with HIV-AIDS can result in the infected individual being subjected to many forms of disabling discrimination, including such substantial matters as loss of employment, refusal of housing or, indeed, refusal of medical treatment; at a more intimate, personal level, these individuals may suffer from being shunned by family, by friends, or by the wider community; and, of course, these forms of discriminatory treatment, as well as the condition itself, may have crippling effects on the infected individual’s sense of self-worth. And, as in the case of IBD, the way infected individuals react to the stigma can itself magnify their problems. Phil Hutchinson and Rageshri Dhairyawan (2017a) have systematically articulated five ways in which the shame experienced in response to the stigma of HIV-AIDS can produce severe problems for the infected individual. The experience of shame can prevent the infected individual from going for testing, when early diagnosis is one of the most important factors in controlling the infection; it can encourage the infected individual not to disclose the condition to medical practitioners, which can affect the timely diagnosis of problems; it can inhibit the infected individual from rigorously maintaining antiretroviral therapy (ART), which dramatically reduces the effectiveness of the therapy; it can lead the infected individual not to disclose his or her condition to partners in situations where that would otherwise be desirable; it can trap the individual in a “psychological hell.”¹²

As a *lived experience* of illness, then, rather than as an *organic condition* of disease, HIV-AIDS is prominently characterized by the problematic negotiation of intersubjective and psychological life experienced by the infected individual.¹³ As Hutchinson and Dhairyawan (2017b) write,

The bio-chemical and the psycho-social are fully intertwined in the pathology of HIV, and to make this claim is uncontroversial. We know that poverty, culturally-bestowed attitudes to sex and sexuality, laws on sex work, drug use, immigration, and poor mental health, to name but a few items from a long list, are significant drivers of infection rates, take-up of testing, and development of clinical AIDS. Believing we can achieve good clinical treatment and public health policy without taking full account of the psycho-social aspects of HIV pathology is folly. (6–7)

With the destruction of the T-cells, the *intersubjective life-world* of the infected individual is compromised—it is the *existential* body that is ill—and successful management of the illness requires careful attention to the nature and dynamics of these existential problems.

We have chosen to discuss the examples of IBD and HIV-AIDS because these are two conditions that dramatically thematize the intersubjective dimensions of illness. The point, however, is that *all* medical problems are such existential problems, because all medical problems are problems of *a person*. Through the organism, a *person* is injured, and it is a *person* who must be treated, and the treatment ought, therefore, to address the injury as belonging to a way of being-the-world.

EXISTENTIAL MEDICINE AND AUTHENTICITY

The existential conception of the body requires us to reconceive illness, and it similarly requires us to reconceive “recovery.” On the “medical” model, recovery is a matter of recuperating the normal state of organic functioning. An existential conception of health, however, is not articulated in terms of the organism, but in terms of the existential needs of the human being. Most strikingly, this entails that existential health and illness do not vary directly with organic health and disease.

Existential health is ultimately a matter of what Heidegger called “authenticity” (*Eigentlichkeit*): It is a matter of living in a way that is true to our existential reality. Fundamentally, our reality is the fact that we are *free*, and this fact of freedom entails that the terms of our life are not—*cannot be*—given to us in advance; instead, we are ourselves ultimately responsible for establishing the terms in which our lives are meaningful. In short, the fact of our freedom means that it is incumbent upon us to *recognize* our freedom—to recognize about ourselves that we must find for ourselves the answers to our questions about life rather than looking for someone or something else in the world to supply those answers for us. Our existential health, then, fundamentally depends upon whether we have made this recognition or whether we are living in denial of our freedom. The crucial thing to note here is that this recognition is possible in situations of organic disease just as much as it is possible in situations of organic health and, equally, living in denial of our freedom is just as easy in conditions of organic health as it is in conditions of organic disease.

This recognition of the dissymmetry between existential and organic forms of health and illness is, in fact, quite pertinent to our analyses of IBD and HIV-AIDS as existential problems. This is because individuals suffering from each of these conditions sometimes strikingly report that their organic maladies are actually a *blessing*. Frohlich (2014), for example, reports that many individuals with IBD who turned to their romantic partners for support actually felt that their IBD strengthened their relationship. Indeed, he writes that,

The stigma people experienced, however, was far overshadowed by the support they received from those around them. Those in committed romantic

relationships often believed that the disease strengthened that relationship, not harmed it. (132; cf. 130)

and

This dichotomy [of good and bad] was also expressed by many of the participants in this study: there is much bad that comes with this disease, but there is also much good, and the good outweighs any temporary stigma—perceived or realized. (134)

Whether or not the results of Frohlich's study are representative of the population of people with IBD as a whole, they indicate the important reality that *how* we live our situations is not inflexibly determined by the objective features of that situation, and situations of organic disease can in fact be provocative occasions for recognizing what it is that truly matters to us in life. This point is even more powerfully made by Renée Gilhousen (2017) in her study of individuals suffering from HIV-AIDS in rural Appalachia. Through her interviews with individuals with HIV-AIDS, Gilhousen discovered a characteristic narrative arc that developed in their self-interpretation as persons with HIV-AIDS. Specifically, after initial forms of self-interpretation that reflected low self-esteem and considerable pessimism about life, the individuals in her study typically eventually developed the view that it was the difficulties forced upon them by their illness that required them to own up to the realities of their own lives, and they subsequently credited their illness with being their occasion for positive self-transformation.¹⁴ With IBD and HIV-AIDS, then—both of which are lifelong conditions—a situation of existential health understood as authenticity is both compatible with and perhaps even encouraged by the situation of organic disease.

This conclusion points to a final observation about the problems of an organic model of human health and illness. We have so far been arguing that the organic model of medicine fails to recognize the distinctly *human* dimensions of illness and thus fails to address the real problems people face. Beyond this “sin of omission,” though, we can also recognize a “sin of commission” in contemporary organic medicine. Specifically, contemporary medicine, as an institution, actually often *works against* existential health in that, as a *rhetorical* system, it precisely encourages the denial of our existential reality.

Hutchinson and Dhairyawan (2017a), in their study of shame and stigma in HIV-AIDS, make the important point that the attitudes involved in shame and stigma are not deliberately formed propositional beliefs of the form “I think that . . .” On the contrary, the attitudes intrinsic to experiences of stigma and shame are more deeply held, “framing” perspectives that belong to one at an unreflective, affective level. Consequently, these attitudes are not changed by argument; if they are changed, they are changed by a fundamental reorientation in “how one sees things” (4, 7–8). Furthermore, these “framing” views

are culturally rooted, which is to say they are not so much a matter of how an individual has come to interpret things as they are the correct assimilation by that individual of the values expressed to him or her behaviorally, materially, and structurally by the persons and institutions that define his or her life-world.¹⁵ Whereas we can identify organic causes for organic diseases, when we seek the etiology of *existential* illnesses, we must look for the forces in the life-world that have shaped how those experiences have come to have the *meaning* they have. What the analysis of Hutchinson and Dhairyawan draws our attention to is that the values embedded within our formal and informal social institutions—including our institutions of healthcare—are significantly responsible for how we define our experiences and hence how we interpret our illnesses. The very fact of the stigmatization of IBD and HIV-AIDS—and hence the cause of much of the suffering of individuals in these situations—is the system of values embedded in our social practices and institutions; consequently it is by changing these values rather than by discovering new forms of biochemical therapy that much of the suffering associated with IBD and HIV-AIDS will be alleviated.

In light of this analysis, we can note the *existential* force of the massive system of institutionalized health care and all its attendant institutions, such as pharmaceutical companies, insurance companies, and medical schools. Inasmuch as these institutions are premised on the “medical” model of health and disease, which treats human illness as an organic matter, these institutions powerfully *work against* existential health insofar as they precisely encourage in us a false self-interpretation in which we deny *our own* responsibility for establishing the terms in which our lives are meaningful, and instead treat our bodies as mere things in the world rather than as the very medium of our existence, of our way of being-in-the-world. The institutional model of medicine is based on values of instrumentality, security, and impersonality, all of which are fundamentally impoverished models of human meaning.¹⁶ For instance, in her study of the narrative surrounding birth that pregnant women heard and adopted, Lesley Kay (2015) notes that it was virtually universal for the women of this generation to think of childbirth as a painful situation to be managed, and one that would be justified by the fact of a healthy baby. Such a narrative, first of all, is a bulwark in defense of the standard operating procedures of contemporary hospitals, which is to say, it is, effectively, the voice of the hospital speaking through the voice of the expectant mother, rather like a ventriloquist. Second, and perhaps more strikingly, though, such a narrative does not treat the experience of childbirth as something of intrinsic worth. Indeed, there is no sense in it at all that it is an experience that one might find “meaningful”; instead, it is construed as an instrumental state to be managed instrumentally. The power of implicit, cultural narrative to shape our experience shows up strongly here insofar as an experience so rich in

human significance has become interpretively shaped as a simple biological issue (even veering on a problem), and its existential significance erased. Just as these values have been put in the mouths of expectant mothers by the immersion of these women in a social and cultural world shaped and structured by the rhetoric of the institutions of contemporary healthcare, so have these values in general become our unquestioned presumption—our “frame,” in the language of Hutchinson and Dhairyawan (2017a, 2017b)—in interpreting our own conditions of health and illness more broadly.

We have tried here to outline the basic meaning of an existential conception of the body, illness, and medicine. On the one hand, this is a model for interpreting the situations of individuals living with specific illnesses. On the other hand, though, it is a model for the very system of healthcare: a model that stands in critical opposition to the prevailing rhetoric embodied in contemporary, institutional practices of healthcare and, indeed, a model that cannot be realized without fundamental changes in the current institutional system.

NOTES

1. Our approach throughout is rooted in Heidegger’s analysis of “being-in-the-world” in *Being and Time* (1962), relying especially on his discussions of “world,” “being with,” “discourse,” and “authenticity.” Our interpretation of the philosophical import of these notions especially draws on Merleau-Ponty’s analysis in “The Body as Object and Mechanistic Physiology” and “The Body as Expression and Speech,” Part I, chapters 1 and 6, respectively, of *Phenomenology of Perception* (2012).

2. This theme is studied in detail in chapter 1 of Russon (2017).

3. For the fuller articulation of this notion, see Russon (2016b). For the existential import of this notion, see Jacobson (2016).

4. For a fuller development of the themes in this paragraph, see Russon (2014) and Jacobson (2011).

5. On the existential dimensions of bruises and other forms of visible wounds or scars, see Buchbinder and Eisikovits (2003), Phillips (2003), and Anderson (1999, especially p. 239).

6. See Hutchinson and Dhairyawan (2017a): “Understanding an emotional expression will therefore be arrived at through reconstructing the (internal) relationship that holds between a person’s conceptualisation of a situation (including their conceptualisation of self) and the concept of the emotion” (4).

7. Such an approach is, therefore, necessarily qualitative and interpretive, and involves the role of the doctor as participant, rather than a quantitative and procedural method in which the doctor is merely an observer. Such an approach brings problems that cannot be avoided: because the interaction is personal rather than impersonal, there are unavoidable problems of bias and trespass. See Maxwell (2013) and van Manen (1997) for rich discussions of qualitative method.

8. For discussion of stigma in relation to IBD and related conditions, see Smith, Loewenstein, Rozin, Sherriff, and Ubel (2007), Frohlich (2014), Jones, Keefer, Bratten, Taft, Crowell, Levy, and Palsson (2009), Norton, Dibley, and Bassett (2013), and Dibley, Coggrave, McClurg, Woodward, and Norton (2017). Also, the authors wish to thank Lesley Dibley for extensive insights into stigma and disease that she shared with us during the August 2017 workshop “The Body as We Live It: Phenomenological Approaches to Embodiment and Illness” held by the Institute for Hermeneutic Phenomenology at the University of Colorado College of Nursing.

9. On this theme of disgust and moral disapprobation, see Hutchinson and Dhairyawan (2017a, especially p. 7). For further discussion of stigma, see also the classic work on shame by Goffman (1974) and also Falk (2001).

10. For an overview of all of these issues, see Frohlich (2014, especially 126–128).

11. On the theme of stigma and HIV-AIDS, Parker and Aggleton (2003), Hutchinson and Dhairyawan (2017a, 2017b), and Fowler (2014).

12. See especially Hutchinson and Dhairyawan (2017b) for an extended discussion of these five problems.

13. For the distinction between illness and disease, see Engelhardt (1982).

14. See also Carel (2007, 2008) and Jacobson (2016) on the topic of positive transformations that can come with a chronic and/or life-threatening illness.

15. See Hutchinson and Dhairyawan (2017a, 3–4) and Hutchinson and Dhairyawan (2017b, 3–4).

16. For a fuller development of this theme, see Russon (2016a). These characteristics of contemporary, institutional health care reflect the “enframing” that Heidegger (1993c) identifies with the technological worldview.