

Invisible Suffering

The Experience of Breathlessness

HAVI CAREL

This chapter presents a philosophical framework for the understanding of the experience of breathlessness. I suggest that the experience of breathlessness is total and overwhelming to the sufferer, but also largely invisible to the outsider. How does this tension play itself out for the respiratory patient? How does this tension affect respiratory medicine and clinical work? How could the first-person experience of breathlessness be better understood? Can it be usefully harnessed in the clinic? And what can a distinctively philosophical analysis offer this process? These questions are explored in the chapter, in the hope of providing a sketch of such a philosophical framework aimed at understanding this debilitating and common symptom.

The structure of the chapter is as follows. It begins with an overview of breathing and the symptom of breathlessness, and how breathlessness is interpreted in the clinic and outside it. The second section provides a phenomenological account of breathlessness, moving away from understanding it as a medical symptom to understanding it as a broader existential, social, personal, cultural, and psychological phenomenon. The final section examines how such a philosophical framework may be operationalized in a respiratory clinic, providing some examples of its possible clinical uses.

What Is Breathlessness?

Breathing is a basic physiological process but also has deep cultural, spiritual, and personal meaning. It connects our inner and outer physical realms via the air

drawn into and expelled from the lungs. It is generally under autonomic control, but we also have some voluntary control over our breathing, and can override its “default settings” by holding our breath or otherwise consciously manipulating it. Breathing plays a central role in cultural and spiritual practices such as meditation and is also associated with our state of mind and in particular our well-being and emotional state. Breathing’s pathological derivative, breathlessness, is a major symptom in both respiratory and cardiac disease, as well as in anxiety disorders and some disorders that affect the chest muscles. Whilst the physiology of breathlessness is well understood, the subjective experiences of breathing and breathlessness are understudied and our vocabulary and concepts with which to understand them are limited.

Breathing contains interesting tensions and juxtapositions. For example, it takes place continuously but mostly unconsciously. It is essential to life but can be artificially sustained despite the absence of consciousness. Much of the time we are unaware of it, but when it goes wrong (e.g., in respiratory disease), it takes up our entire attention. In some disorders, for example panic disorders, breathing itself can become the focus of pathological ideation and fears. When we exert ourselves physically, breathing becomes labored, eventually leading to breathlessness. In such situations, our breath becomes the focus of attention, and the experience can be uncomfortable. In cases in which breathlessness is pathological, experiencing it can be much more extreme and become debilitating, life limiting, and the focus of much anxiety.

Breathing is also intimately connected to emotion: surprise or horror make us gasp, hearty laughter leaves us gasping for breath, crying involves involuntary short, sharp inhalations. Breathing is richly modulated by emotional experience, be it pleasurable or painful. The lungs are the only bodily site (other than the skin) where interior and exterior spaces are in constant exchange. We breathe in the air and what it contains, extract the oxygen we need, and expel carbon dioxide. The air around us, with its pollutants, odors, humidity, and heat, becomes internalized briefly, connecting us to the environment and exposing our lungs to pollutants, irritants, and potential sources of infection. The lungs are thus vulnerable and open to the external environment in a way that does not occur with other internal organs.

The very idea of breath is suffused with metaphor. The German poet Rainer Maria Rilke described breath as “an invisible poem.” Breath takes place in the chest, the center of our body; metaphorically, it is the core of life: our first and last breaths mark life’s beginning and end, and breathing continuously happens throughout life. However, biomedicine does not acknowledge how everyday experience and its meanings are implicated in breathing, and thus neglects to incorporate this rich vein into its understanding of breathlessness. Metaphor, emotion, and the spiritual and existential dimensions are not part of the language of the clinic, yet they are a central part of the experience of breathing and of breathlessness. This

tension between medical and cultural or intuitive understandings of breathing and breathlessness lies at the heart of this chapter.¹

Turning to breathlessness, we can see that it is a major symptom that appears in a number of very common diseases with high morbidity and mortality rates. According to improving and integrating respiratory services, 25 percent of attendees to emergency departments, 62 percent of elderly people, and almost all people with chronic obstructive pulmonary disease (COPD) (around 95 percent) report breathlessness.² Breathlessness is a key symptom in a number of common and serious diseases, such as heart failure and lung cancer, as well as in COPD, a condition with an increasing global prevalence owing to its association with smoking. Air pollution has been an important cause of respiratory disease and breathlessness historically, and women in developing countries often develop COPD as a result of time spent by cooking fires.³ The World Health Organization currently ranks COPD as the fourth most common cause of death in developed countries, and it is estimated that it will become the third largest global killer by 2020.⁴ COPD affects an estimated 3.7 million people in the UK, but only 900,000 of them are aware of having the condition.⁵

Gysels and Higginson have described both the symptom of breathlessness, and the patients suffering from it, as invisible. This invisibility stems from the fact that breathlessness is a condition that usually has an insidious onset and is often attributed by those who experience it to aging, lack of exercise, or smoking.⁶ The stigma associated with smoking is also a factor encouraging people to hide their condition or its severity. Clinicians, who are increasingly less likely to visit people in their own homes, are unaware of the complex needs, limitations, and adjustments required when living with breathlessness.⁷ And of course either moderate or severe breathlessness has a dramatic impact on mobility and can cause people to go out less, socialize less, and hence be seen less. All of these factors contribute to the invisibility of breathlessness and breathless people.

The traditional clinical approach to dealing with a symptom is to find out what is causing it, treat it, and wait for the patient to improve. This rarely happens in chronic breathlessness. As Johnson and colleagues argue, chronic breathlessness frequently results from incurable, often long-term, progressive conditions, and the symptom persists despite treatment of the underlying condition.⁸ They have termed such breathlessness “refractory” and suggest that the attitude of clinicians and patients toward it is one of helplessness, with clinicians holding the view that “nothing more can be done,” and patients feeling more helpless and hopeless. This leads to hopelessness and lack of attention to the symptom from both parties. Patients may no longer report increasing distress to their doctors; clinicians may fail to ask about the problems caused by the breathlessness, as they feel unable to help. The problem of invisibility is compounded by a sense of helplessness.⁹

When we reflect on our breathing or try to describe the experience of breathing, we filter this reflection and experience through a rich set of influences that

has a long cultural history. These influences can determine, in part, our reactions to a diagnosis of a respiratory illness, and how we might understand it. When this lay understanding approaches the clinic, it comes up against a biomedical view of breathing. The lay perspective is met by a particular series of prescribed questions (e.g., breathlessness questionnaires) against which patients must assess their breathlessness and through which their understanding begins to change. That change may be temporary, until they leave the clinic or hospital and return home. But the influence of the biomedical view may be more sustained. For example, as a result of listening to a clinical discourse, a patient might adopt a deficit approach to her breathlessness, having been shown through lung function tests what percentage of predicted lung function she has. She might begin to experience her breathlessness as more anomalous and shameful than before. She may feel alienated from the physiological body that has let her down. The ways in which the subjective experience is shaped by the clinical gaze is another aspect of the experience of breathlessness that phenomenology can usefully illuminate. I therefore now turn to a phenomenology of breathlessness.

A Phenomenological Account of Breathlessness

A phenomenology of breathlessness can reveal the nature of the experience and its qualia. It can also structure the experience using phenomenological concepts, as I do below. The first distinction I would like to make as the foundation of this phenomenological description is between pathological and normal breathlessness. Normal breathlessness is the kind of breathlessness a healthy person experiences upon exertion. It may involve heavier, deeper breathing that is also speeded up. But regardless of the level of exertion, in a healthy person oxygen saturation levels remain above 97 percent; such exertion is not dangerous and does not lead to loss of control, such as fainting. Experientially, healthy breathlessness does not lead to feelings of panic, anxiety, or fear. It is not a total experience and does not remove its bearer from the familiar everyday sense of her body and of herself. In fact, normal breathlessness can be associated with enjoyable bodily exertion as well as with a sense of challenge and joy (e.g., in exercise, running, or dancing).

Pathological breathlessness, of the kind experienced by people with impaired lung or heart function, is entirely different. It, too, involves heavier, faster breathing, but unlike healthy breathlessness, it does not deliver the required amount of oxygen to support bodily exertion. The gap between the amount of oxygen required for the activity and the amount available determines the level of incapacitation and the acuteness of the breathlessness. A person with severe respiratory disease might not be able to walk or bend down to pick up a pen from the floor. At its worst, pathological breathlessness is debilitating and causes severe disability.

In pathological breathlessness, blood oxygen levels can drop severely, leading to dizziness, fainting, shaking, excessive sweating, and a sense of doom. It is a total and overwhelming experience of loss of control and is acutely unpleasant. It removes the breathless person from the normal course of events and can cause deep anxiety, panic attack, and trauma.

Such pathological breathlessness is characterized by several core features: it is an acute and extremely unpleasant experience that can lead to severe distress, but not pain (although evidence from brain-imaging studies shows that the same neural pathways are activated in breathlessness and in pain.¹⁰ It is an overwhelming, but as discussed above, invisible sensation. Unlike other, more dramatic, symptoms (e.g., bleeding, fainting, seizures) that can be easily observed, breathlessness is hard to see. This is in line with the characterization of breathlessness as an “invisible disability.”¹¹ We can add a third layer to Gysels and Higginson’s twofold view of breathlessness, saying that patients and disease are invisible. I suggest that the experience of breathlessness is also invisible. Although you might see a person standing and looking uncomfortable, often they are not panting, talking, or making any noise. It is therefore extremely hard to discern the extreme nature of this experience and how discomfiting and upsetting it is. In extreme cases, breathlessness and accompanying oxygen desaturation can lead to feelings of nausea, dizziness, faintness, and incontinence.

Some first-person articulations of pathological breathlessness include sufferers saying that they feel trapped, as if they are about to die, that they are suffocating or drowning, and that these feelings are intimately associated with feelings of panic and loss of control. Here is a first-person account of the experience of breathlessness:

Trapped. That is what breathlessness feels like. Trapped in the web of uncertainty, bodily doubt, practical obstacles, and fear. The deepest fear you can think of. The fear of suffocation, of being unable to breathe, the fear of collapsing, desaturated to the point of respiratory failure.¹²

Let us now ground this experience in a phenomenological framework, in order to flesh it out more fully and to orientate the experience to a rich phenomenological description.¹³ On a phenomenological account, embodiment determines possibilities. Merleau-Ponty famously draws on Heidegger’s notion of existence as “being able to be” [*Seinkönnen*], and formulates this ability as grounded in motility and embodied action.¹⁴ In breathlessness, these possibilities are truncated, curtailed, or altogether closed off. As a result, the world shrinks and becomes hostile, as the pathologically breathless person’s ability to freely navigate it, move within it, and experience it shrinks. These truncated possibilities restrict choices and freedom and often dictate what is and is not possible, and what is and is not worth the considerable additional effort that carrying out the choice entails for a person with

restricted mobility. As a result, projects that were previously open and executed with freedom become delimited by restriction.

For example, if I want to go for a walk after dinner to stretch my legs, I stroll until I am satisfied, and then I return home. In effect, I have walked without bounds. But for the respiratory patient, the walk must be carefully planned, with gradient, distance, and terrain considered, amount of ambulatory oxygen to be taken calculated, and frequent stops for rest built in. The very same activity—going for a walk—becomes restricted, narrowed, riddled with discomfort and worry, and of course this changes the nature of the experience. The shape of the walk has been entirely dictated by the illness, and is therefore not experienced as free.

As a result, a vicious cycle of self-limitation may ensue, leading to reduced fitness caused by deconditioning, which itself is caused by the reduced activity level. This cycle often leads to feelings of helplessness, despair, fear, anxiety, and depression. Any activity needs to be carefully planned, and during its execution, constant attention is paid to the breath: am I desaturating? Do I need to increase the oxygen flow? Will this walk be too exhausting for me? Will I be able to walk back? Will I have enough oxygen? The constant explicit consideration places the activity in the shadow of the breathing and the experience of breathlessness, and the way in which it is constantly managed and heeded changes the nature of any activity. It becomes secondary to the breath and the management of breathlessness.

In other words, the body loses the transparency it normally has in health. Thus, for example, Jean-Paul Sartre writes about the transparency of health; Drew Leder discusses the absent body in health; and Leriche speaks of health as a state lived in “the silence of the organs.”¹⁵ In respiratory illness, this putative transparency¹⁶ disappears, while the body, as Leder would put it, “dys-appears,” that is, it appears, but in a state of dysfunction, aberration, attracting negative attention and requiring treatment, strict regimentation, observation, and special measures.¹⁷

One way of characterizing the type of experiences that can occur in breathlessness is through the notion of bodily doubt.¹⁸ Normally we have a tacit underlying sense of bodily certainty that characterizes everyday embodied experience. But in illness this certainty breaks down and is replaced by bodily doubt. This sense of bodily doubt is the breakdown of this tacit certainty, and leads to a radically modified embodied experience. It does this in three ways: loss of continuity, loss of transparency, and loss of faith in one’s body.¹⁹ Breathlessness is a core example of this breakdown. In cases of pathological breathlessness there is a break from past ability to exert oneself and to perform actions freely. The body loses its transparency, as discussed above. And finally, bodily doubt is characterized by a loss of faith in one’s body. A body that has broken down, disappointed, or otherwise failed the ill person is likely to give rise to feelings of deep alienation, suspicion, and lack of trust.

Because of the breakdown of bodily trust, and the loss of certainty and transparency, in the presence of pathological breathlessness daily activities become

a problem. The sense of “I can,” which Husserl suggests characterizes our embodied stance toward the world, changes into a new stance, of “I no longer can,” or “I was once able to but am no longer.”²⁰ Our connection to the world “goes limp,” as Merleau-Ponty puts it.²¹

There are a few further ways in which the transparency (or relative transparency) of the body changes in pathological breathlessness. First, there now is artificial and conscious engagement with breath. The modulation of breath (and of oxygen flow, if used) becomes explicit, and the natural, tacit, way in which breath is normally modulated is lost. The habitual body described by Merleau-Ponty becomes habitually breathless.²² Habits are changed, bodily repertoires shrink, activities that were once enticing, even fun, are now passed over as too difficult or too tiring. Behavior is now modulated by both motor and psychological self-censorship: certain movements (e.g., bending) are avoided; exertion is carefully weighed and planned, so as to avoid overexertion; plans are made, then remade, changed, and often cancelled, if they require too much effort or lead to anxiety about keeping up, possible fatigue, and social embarrassment. This process takes place on both a motor and a conscious level. On the motor level, movements that were once easy and natural but have become difficult, challenging, or lead to severe breathlessness are avoided:

Every time I tried—and failed—to do something that was too strenuous, my body stoically registered the failure and thereafter avoided that action. The change was subtle, because this happened by stealth. The miraculous result created by my body’s adaptive abilities was that I stopped feeling so acutely all the things I could not do. They were quietly removed from my bodily repertoire, in a way so subtle I hardly noticed it.²³

To summarize, in pathological breathlessness, explicitness of action becomes second nature on both a motor and a conscious level. This creates a new terrain, in which freedom and obliviousness are replaced by hesitation and limitation. In this terrain, distances increase: it is full of barriers, disruption, and unanticipated obstacles. This leads to the breathless person being excluded from shared norms; concepts like “nearby” and “easy” no longer tally with the concepts used by healthy people. In this way illness disrupts meaning structures and sufferers must rebuild meaning and regain their foothold on the everyday. Of course, in cases of progressive breathlessness, that everyday shifts as disease progresses. The lost opportunities and relinquished activities require a continuous reworking of the boundaries of the possible.

I said above that everyday activities become a problem, something requiring explicit attention, planning, and thought. In a similar way, the body itself also becomes a problem, an obstacle, a stranger, because embodied normality

is disrupted. As philosopher S. Kay Toombs writes, illness is a series of losses. The losses she attributes to illness experiences in general are especially apt in the case of breathlessness, because breath is needed for any and all activities. So the loss of breath—being breath-less—results in the following losses: first, there is a loss of wholeness, a loss of bodily integrity, of a reflective sense of wellness. The awareness and anticipation of loss also cause distress. Second, there is a loss of certainty, which is pervasive and irreparable. Third, a loss of control. Breathlessness causes anxiety, dysautonomy, worry about and preoccupation with controlling one's body, one's breath, one's speech, and one's actions. Fourth, sufferers experience a loss of freedom to act; and fifth, a loss of the familiar world.²⁴

Let us now turn to the final section, in which I consider the implications of this analysis for the clinic, and suggest several ways in which a phenomenological analysis of breathlessness can be utilized in the clinic.

Phenomenology in the Clinic

There are several ways in which inviting the first-person phenomenological perspective into the clinic can be important and useful. I suggest that this is particularly the case for breathlessness, for several reasons. First, there is a noted discrepancy between objective and subjective measurements of lung function; this has been reported in the literature and causes physicians difficulties in predicting how patients will continue to cope with everyday living. Patients often over- or underperform, relative to their objective lung function measurement,²⁵ and this makes treatment and the allocation of resources such as social care difficult and inaccurate.

Second, as discussed above, breathlessness is an invisible symptom. Seeing someone stop to catch her breath tells you nothing of the internal turmoil, panic, and mounting discomfort she may be experiencing. Without patient reports about the experience, breathlessness will continue to be invisible and poorly understood. Making such accounts available and giving them prominence in public and patient fora, decision-making committees and other consultative process will contribute to reducing the invisibility of both symptom and patients, many of whom are housebound, or find leaving the house difficult, and are therefore less visible to both public and health professionals.

Another reason it is important to articulate the phenomenology of breathlessness is because it gives an opportunity to demonstrate the breadth and diversity of experiences of breathlessness. In particular, there are compelling accounts of well-being experienced within the constraints of ill health, and this opens the door to viewing wellness despite breathlessness as both achievable and significant.²⁶ Barbara Paterson proposes the “shifting perspectives model,” in which the illness (in this case the breathlessness) can shift from foreground to background during

periods of stable disease, and back to the foreground during disease progression or symptom exacerbation.²⁷ The important thing is to note the possibility of the breathlessness receding into the background and no longer affecting the breathless person's well-being, although she still has limited mobility and other restrictions.

Another reason to promote the presence of first-person accounts of breathlessness is that, like all illnesses, breathlessness is experienced very differently from the inside (first-person perspective) and from the outside (second- or third-person perspective). Health professionals might have an intimate acquaintance with the causes and process of a particular disease, or treatment options and prognosis, and of the symptoms, but they still lack the first-person knowledge of what it is like to experience a particular disease. This experience can be transformative in two ways: it can reveal to you what it is like to suffer from pathological breathlessness, and it can also transform you in deep ways through the experience of a serious illness.²⁸ The "insider" perspective on breathlessness can be instructive and edifying for the health professional who does not have first-hand experience of the disease, and hence remains an "outsider" to that experience. This can also help with the discrepancy between the perceived ease of task (for the health professional) and the challenge it presents to a patient.

Finally, phenomenological reflection has a positive force. It can help sufferers to order and discern confusing experiences, and can provide a reflective stance from which to think about the bewildering, painful, and sad experiences of illness and of breathlessness. I have developed a "patient toolkit" that uses philosophical ideas to support patients in making sense of their illness. The toolkit has three steps: (1) stripping away the sociocultural understanding of illness to make room for individual interpretations; (2) viewing illness from different perspectives (thematizing) to enable patients to understand it as a multidimensional process. Thematizing reveals illness as it may appear to the ill person, carer/s and health professionals; and (3) considering how illness changes the ill person's way of being.²⁹

To conclude, accounts of breathlessness can help overcome the gulf separating the healthy person's understanding of the term and the harsh reality of pathological breathlessness. As Elaine Scarry notes:

[. . .] when one speaks about "one's own physical pain" and about "another person's physical pain," one might almost appear to be speaking about two distinct orders of events. For the person whose pain it is, it is "effortlessly" grasped; while for the person outside the sufferer's body, what is "effortless" is *not* grasped it.³⁰

The unsharability of unique experiences such as extreme pain or pathological breathlessness undermines care and knowledge. Insofar as we do not attempt to reconcile the clinical perspective with that of the breathless patient, breathlessness remains opaque, invisible, and refractory. Health professionals are not exempt from

holding both unconscious and conscious biases and stereotypes and from falling prey to stigmatization of disease and to certain diseases in particular.³¹ Patients' invisibility and suffering can be exacerbated by this stigma and by their attempts to mask their symptoms, as they are trailed by tacit assumptions about their life and choices (e.g., that they were smokers, that they are contagious).

The feelings of pity, terror, and denial that many people experience when they encounter people with respiratory disease may also inflect health professionals' conduct and attitudes. Hence another reason for bringing them into close and sustained contact with sufferers' accounts of their experiences. The difficulties they experience are lived in the first person, and yet perceived by others via masking, miscommunication, and stigmatizing labeling. Patients' feelings of shame, self-consciousness, and objectification are common and often reported, and influence one's self-perception of oneself *as perceived by others*.³²

To conclude, I suggest that a phenomenology of breathlessness can account for the richness and diversity of breathlessness experiences, and articulate the positive and unintended consequences of suffering. These consequences include the ways in which breathless patients adapt to their limitations, their increased resilience in the face of everyday adversity, and what Jonathan Haidt terms "post-traumatic growth."³³ Breathlessness is a juncture of physiological, psychological, existential, spiritual, and cultural dimensions. It cannot be studied solely as a symptom but requires a rich phenomenological account that makes room for the possibility of wellness within the constraints of breathlessness. As I hope to have shown here, a phenomenological framework can provide the conceptual tools required to fill this need.

Acknowledgments

I am grateful to the Wellcome Trust for awarding me a Senior Investigator Award (grant number 103340), which enabled me to write this chapter.

Notes

1. Jane Macnaughton and Havi Carel, "Breathing and Breathlessness in Clinic and Culture: Using Critical Medical Humanities to Bridge an Epistemic Gap," in *Edinburgh Companion to Critical Medical Humanities*, ed. A. Whitehead and A. Woods (Edinburgh: Edinburgh University Press, 2016), 294–330.

2. For figures from improving and integrating respiratory services see <https://www.networks.nhs.uk/nhs-networks/impress-improving-and-integrating-respiratory> (accessed March 28, 2017).

3. Charlotte A. Roberts, "A Bioarcheological Study of Maxillary Sinusitis," *American Journal of Physical Anthropology* 133 (2007): 792–807.

4. Peter J. Barnes and Sabine Kleinert, "COPD—A Neglected Disease," *The Lancet* 364 (2014): 564–565.

5. British Lung Foundation, "Invisible Lives: Chronic Obstructive Pulmonary Disease (COPD)—Finding the Missing Millions" (London: British Lung Foundation, 2007), 3.
6. Marjolein Gysels and Irene J. Higginson, "Access to Services for Patients with Chronic Obstructive Pulmonary Disease: The Invisibility of Breathlessness," *Journal of Pain and Symptom Management* 36, no. 5 (2008): 451–460.
7. Ibid.
8. Miriam J. Johnson, David C. Currow, and Sara Booth, "Prevalence and Assessment of Breathlessness in the Clinical Setting," *Expert Review of Respiratory Medicine* 8, no. 2 (2014): 151–161.
9. Macnaughton and Carel, "Breathing and Breathlessness."
10. Mari Herigstad, Anja Hayen, Katja Wiech, and Kyle T.S. Pattinson, "Dyspnoea and the Brain," *Respiratory Medicine* 105, no. 6 (2011): 809–817.
11. Gysels and Higginson, "Access to Services."
12. Havi Carel, *Phenomenology of Illness* (Oxford: Oxford University Press, 2016), 109.
13. See also *ibid.*
14. Martin Heidegger, *Being and Time*, trans. John Macquarrie and Edward Robinson (London: Blackwell, 1962; first published in 1927); Maurice Merleau-Ponty, *Phenomenology of Perception*, trans. Donald A. Landes (London: Routledge, 2012).
15. Jean-Paul Sartre, *Being and Nothingness*, trans. Hazel E. Barnes (London and New York: Routledge, 2003; first published in 1943); Drew Leder, *The Absent Body* (Chicago: University of Chicago Press, 1990); Leriche as cited in Georges Canguilhem, *The Normal and the Pathological*, trans. Carolyn R. Fawcett (New York: Zone Books, 1991).
16. Although see Carel, *Phenomenology of Illness*, for a critique.
17. Leder, *The Absent Body*.
18. Havi Carel, "Bodily Doubt," *Journal of Consciousness Studies* 20, no. 7–8 (2013): 178–197.
19. Ibid.
20. Amy Kesserling, "The Experienced Body, When Taken-for-Grantedness Falts: A Phenomenological Study of Living with Breast Cancer," PhD diss., available via UMI, 1990.
21. Merleau-Ponty, *Phenomenology of Perception*.
22. Ibid.
23. Carel, "Bodily Doubt," 40–41.
24. S. Kay Toombs, "The Meaning of Illness: A Phenomenological Approach to the Patient–Physician Relationship," *Journal of Medicine and Philosophy* 12 (1987): 219–240; S. Kay Toombs, *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient* (Amsterdam: Kluwer, 1993).
25. P.W. Jones, "Health Status Measurement in Chronic Obstructive Pulmonary Disease," *Thorax* 56 (2001): 880–887.
26. O. Lindqvist, A. Widmark, and B. Rasmussen, "Reclaiming Wellness—Living with Bodily Problems as Narrated by Men with Advanced Prostate Cancer," *Cancer*

Nursing 29, no. 4 (2006): 327–337; E. Lindsey, “Health within Illness: Experiences of Chronically Ill/Disabled People,” *Journal of Advanced Nursing* 24 (1996): 465–472; M. Little, C. Jordens, K. Paul, K. Montgomery, and B. Philipson, “Liminality: A Major Category of the Experience of Cancer Illness,” *Social Science & Medicine* 47, no. 10 (1998): 1485–1494.

27. Barbara Paterson, “The Shifting Perspectives Model of Chronic Illness,” *Journal of Nursing Scholarship* 33, no. 1 (2001): 21–26.

28. Havi Carel, Ian James Kidd, and Richard Pettigrew, “Illness as Transformative Experience,” *The Lancet* 388, no. 10050 (2016): 1152–1153. doi:[http://dx.doi.org/10.1016/S0140-6736\(16\)31606-3](http://dx.doi.org/10.1016/S0140-6736(16)31606-3).

29. For a full description of the toolkit, see Havi Carel, “Phenomenology as a Resource for Patients,” *Journal of Medicine and Philosophy* 37, no. 2 (2012): 96–113. doi:10.1093/jmp/JHS008.

30. Elaine Scarry, *The Body in Pain* (Oxford: Oxford University Press, 1985), 4.

31. Ian James Kidd and Havi Carel, “Epistemic Injustice and Illness,” *Journal of Applied Philosophy* 34, no. 2 (2016): 172–190. doi:10.1111/japp.12172.

32. Luna Dolezal, “The Phenomenology of Shame in the Clinical Encounter,” *Medicine, Health Care and Philosophy*, 18, no. 4 (2015): 567–576.

33. Jonathan Haidt, *The Happiness Hypothesis* (London: William Heinemann, 2006).

Bibliography

Barnes, Peter J., and Sabine Kleinert. “COPD—A Neglected Disease.” *The Lancet* 364 (2014): 564–565.

British Lung Foundation. “Invisible Lives: Chronic Obstructive Pulmonary Disease (COPD)—Finding the Missing Millions.” London: British Lung Foundation, 2007.

Canguilhem, Georges. *The Normal and the Pathological*. Translated by Carolyn R. Fawcett. New York: Zone Books, 1991.

Carel, Havi. “Bodily Doubt.” *Journal of Consciousness Studies* 2, no. 7–8 (2013): 178–197.

Carel, Havi. “Phenomenology as a Resource for Patients.” *Journal of Medicine and Philosophy* 37, no. 2 (2012): 96–113. doi:10.1093/jmp/JHS008.

Carel, Havi. *Phenomenology of Illness*. Oxford: Oxford University Press, 2016.

Carel, Havi, Ian James Kidd, and Richard Pettigrew. “Illness as Transformative Experience.” *The Lancet* 388, no. 10050 (2016): 1152–1153. doi:[http://dx.doi.org/10.1016/S0140-6736\(16\)31606-3](http://dx.doi.org/10.1016/S0140-6736(16)31606-3).

Dolezal, Luna. “The Phenomenology of Shame in the Clinical Encounter.” *Medicine, Health Care and Philosophy* 18, no. 4 (2015): 567–576.

Gysels, Marjolain, and Irene J. Higginson. “Access to Services for Patients with Chronic Obstructive Pulmonary Disease: The Invisibility of Breathlessness.” *Journal of Pain and Symptom Management* 36, no. 5 (2008): 451–460.

Heidegger, Martin. *Being and Time*. Translated by John Macquarrie and Edward Robinson. London: Blackwell, 1962. First published in 1927.

- Haidt, Jonathan. *The Happiness Hypothesis*. London: William Heinemann, 2006.
- Herigstad, Mari, Anja Hayen, Katja Wiech, and Kyle T.S. Pattinson. "Dyspnoea and the Brain." *Respiratory Medicine* 105, no. 6 (2011): 809–817.
- Johnson, Miriam J., David C. Currow, and Sara Booth. "Prevalence and Assessment of Breathlessness in the Clinical Setting." *Expert Review of Respiratory Medicine* 8, no. 2 (2014): 151–161.
- Jones, P.W. "Health Status Measurement in Chronic Obstructive Pulmonary Disease." *Thorax* 56 (2001): 880–887.
- Kesslering, Amy. "The Experienced Body, When Taken-for-Grantedness Falts: A Phenomenological Study of Living with Breast Cancer." PhD diss. available via UMI, 1990.
- Kidd, Ian James, and Havi Carel. "Epistemic Injustice and Illness." *Journal of Applied Philosophy* 34, no. 2 (2016): 172–190. doi:10.1111/japp.12172.
- Leder, Drew. *The Absent Body*. Chicago: University of Chicago Press, 1990.
- Lindqvist, O., A. Widmark, and B. Rasmussen. "Reclaiming Wellness—Living with Bodily Problems as Narrated by Men with Advanced Prostate Cancer." *Cancer Nursing* 29, no. 4 (2006): 327–337.
- Lindsey, E. "Health within Illness: Experiences of Chronically Ill/Disabled People." *Journal of Advanced Nursing* 24 (1996): 465–472.
- Little, M., C. Jordens, K. Paul, K. Montgomery, and B. Philipson. "Liminality: A Major Category of the Experience of Cancer Illness." *Social Science & Medicine* 47, no. 10 (1998): 1485–1494.
- Macnaughton, Jane, and Havi Carel. "Breathing and Breathlessness in Clinic and Culture: Using Critical Medical Humanities to Bridge an Epistemic Gap." In *Edinburgh Companion to Critical Medical Humanities*, edited by A. Whitehead and A. Woods, 294–330. Edinburgh: Edinburgh University Press, 2016.
- Merleau-Ponty, Maurice. *Phenomenology of Perception*. Translated by Donald A. Landes. London: Routledge, 2012.
- Paterson, Barbara. "The Shifting Perspectives Model of Chronic Illness." *Journal of Nursing Scholarship* 33, no. 1 (2001): 21–26.
- Roberts, Charlotte A. "A Bioarcheological Study of Maxillary Sinusitis." *American Journal of Physical Anthropology* 133 (2007): 792–807.
- Sartre, Jean-Paul. *Being and Nothingness*. Translated by Hazel E. Barnes. London and New York: Routledge, 2003. First published 1943.
- Scarry, Elaine. *The Body in Pain*. Oxford: Oxford University Press, 1985.
- Toombs, S. Kay. *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient*. Amsterdam: Kluwer, 1993.
- Toombs, S. Kay. "The Meaning of Illness: A Phenomenological Approach to the Patient–Physician Relationship." *Journal of Medicine and Philosophy* 12 (1987): 219–240.

