

Havi Carel

Phenomenology of Illness

Oxford: Oxford University Press, 2016 (ISBN 978-0199669653)

Christine Wieseler

Christine Wieseler completed her PhD in philosophy and a graduate certificate in women's and gender studies at the University of South Florida. Her current position is Postdoctoral Research Fellow, McGovern Center for Humanities and Ethics, University of Texas Health Science Center at Houston, McGovern Medical School. Wieseler's dissertation demonstrates that if disabled people's experiences are to be taken seriously, then philosophical inquiry must be radically transformed. Her research interests include biomedical ethics, feminist philosophy, phenomenology, and philosophy of disability.

Christine.Wieseler@uth.tmc.edu

According to Havi Carel, philosophers have typically not considered it to be worthwhile to engage with experiences of illness. She claims that philosophers have tended to think of illness as belonging in the domain of science rather than the humanities. As a result, philosophers have paid much more attention to the philosophical significance of death than of illness. Carel suggests that in this way, philosophers are at odds with the general public, which expresses interest in experiences of illness. She focuses specifically on serious chronic illness, which she contends may serve as an impetus for philosophical reflection, in part due to its ability to lead us to call into question our "beliefs, expectations, and values" (3). Illness disrupts habitual ways of thinking about and being in the world, preventing us from having the ability to take our bodies, projects, relationships, and our very existence as givens. Carel has two central aims in *Phenomenology of Illness*: first, to show that philosophy (phenomenology in particular) has unique contributions for understanding illness, and second, to show that attending to illness can enrich philosophers' thinking in areas such as ethics and political philosophy.

Carel combines a phenomenological approach to illness grounded in the work of philosophers, including Edmund Husserl, Martin Heidegger, Drew Leder, Maurice Merleau-Ponty, Jean-Paul Sartre, and S. Kay Toombs, with empirical work on well-being within psychology. This enables her to engage in careful description of illness and to evaluate the relationship between illness and well-being. Carel positions her project as being influenced more by existential phenomenology than by transcendental phenomenology. She characterizes existential phenomenology as being "concerned with pre-reflective everyday life, human subjective experience, and existential themes such as freedom and authenticity" (23). Carel advocates phenomenology as a method for describing illness because it is able to attend to the lived experiences of individuals with multifarious conditions while also enabling identification of commonalities between them.

Those who understand philosophy as essentially engaged in abstraction and formulation of universal rules may object to Carel's call for philosophers to take the personal and anecdotal seriously. She responds to this potential objection by noting that philosophy is grounded in

personal experience. (Whether this is acknowledged or not is another question.) In Carel's words: "Whenever we abstract, we abstract from a prior concrete experiential totality: the world as lived or 'being in the world.' The purpose of abstraction is to understand the world and then return to it with new sensibilities" (6). She explicitly takes this approach in applying the conceptual tools of philosophy to illness as well as the insights gained through experiences of illness to philosophy. Indeed, Carel seeks to go beyond academic philosophy in developing a "phenomenological toolkit" meant to help patients to carefully describe and reflect upon their experiences of illness. I will provide an overview of each of the chapters followed by a brief evaluation of the text as a whole.

Chapter 1 differentiates between disease and illness, provides a brief introduction to phenomenology, and explains the features of phenomenology that make it a useful method for describing experiences of illness. Carel characterizes disease as physiological dysfunction; it can be observed and measured. Roughly, illness is the experience a person has of disease. She does note that not all diseases are experienced, and not all illnesses have a known etiology. Since Carel takes an approach to phenomenology that centers embodiment, her discussion focuses primarily on the work of Merleau-Ponty and, to a lesser extent, Husserl and Heidegger. Merleau-Ponty's insight that "the inseparability of embodiment, perception, action, and subjectivity" entails that "changes to one's body often lead to changes in one's sense of self and in one's way of being in the world" is fundamental for understanding the significance of illness for being (27). It also reveals why his approach to phenomenology is a useful starting point for examining illness.

Chapters 2 and 3 focus on phenomenological features of the body and the ways illness affects them. Toombs's five "typical features" of illness are central to this discussion. They are: loss of wholeness, loss of certainty, loss of control, loss of freedom to act, and loss of familiar world (41-43). Toombs initially calls them "essential features," but in later work she refers to them as "typical features" of illness (Toombs 1987; 1992). Carel builds on this framework, but qualifies the scope further to "conscious adults with a certain degree of self-awareness, in Western societies" (45). Carel also draws on the distinction between the objective body and the body as lived developed by Husserl and Merleau-Ponty, Sartre's three orders of the body, and Leder's notion of "dysappearance." Illness requires that one pay explicit attention to one's body in a way that is not otherwise necessary. The bodily changes of illness may necessitate planning for contingencies and adoption of strategies to manage the reactions of friends and strangers alike to visible (or invisible) difficulties. Combined, these consequences of illness may lead one to feel a sense of alienation from one's body, projects, and world.

Carel argues in chapter 4 that healthy subjects typically have a tacit bodily certainty; this is discovered, in part, through contrast with the experience of bodily doubt within illness or impairment. She claims that bodily certainty and doubt are of an existential nature: the former grounds and the latter undermines our ability to engage in meaningful projects and focus on thinking and doing. Bodily doubt compels those who experience it to attend to the constraints imposed by their bodies. In her words: "Bodily doubt is not just a disruption of belief, but a disturbance on a bodily level. It is a disruption of one's most fundamental sense of being in the world" (92). The following chapter draws on Carel's own experience of living with Lymphangioliomyomatosis (LAM) in order to provide a detailed example of how bodily doubt can affect being in the world.

Carel formulates a preliminary phenomenological account of breathlessness in chapter 5. She notes that there are numerous reasons one may experience pathological breathlessness (as opposed to types of breathlessness experienced by healthy individuals) and that future work may reveal important differences among those instances. The type of breathlessness Carel describes is of a chronic nature punctuated by acute episodes. All of her bodily movements and plans--whether they involve a trip out of town or to the library--are informed by an explicit concern for being able to breathe. She highlights the significance of articulating what it is like to live with breathlessness for the individual as well as for adequate communication to health-care professionals and others lacking this lived experience. Carel succeeds in providing a vivid account of this phenomenon, which is all-consuming and yet largely invisible to the observer.

Exploring the positive aspects of illness, chapter 6 focuses on two questions. The first is whether it is possible for well-being to be part of the experience of illness. Carel states, "well-being in this context denotes subjectively measured well-being, or level of happiness" (134, n. 3). Given that several empirical studies indicate that the answer is "yes," the follow-up question is why we tend to regard illness as "one of the most terrifying events that can befall a person" (132). Having considered three perspectives on how well-being is possible within illness, Carel nonetheless emphasizes that it is far from automatic. She appeals to Julia Annas's claim that happiness is "an achievement that requires thought, planning, and work" (132). Turning to the second question posed in this chapter, Carel argues that, in general, there is a significant difference between the views of people experiencing illnesses and impairments and those who are only imagining what it would be like. Without sustained engagement with people with chronic illnesses and impairments, most people lack a solid epistemic basis upon which to make judgments about experiences of illness.

In chapter 7, Carel seeks to flesh out the relationship between illness and death by drawing on Heidegger's notion of being-toward-death. Much ink has been spilled on the meaning of "death" and Heidegger's characterization of death as the impossibility of possibilities in *Being and Time* (Heidegger 1962). Carel devotes the bulk of her discussion to the interpretations of William Blattner and Hubert Dreyfus (she condenses them and refers to the "Dreyfus/Blattner interpretation"), which maintain that death prevents Dasein from entering into possibilities due to extreme anxiety about the groundlessness of existence. In her words: "Although Dasein still is in the thin sense, it is unable to be in the thick sense" (164). She contends that this view omits temporal finitude--the sine qua non for making sense of key ideas within *Being and Time*--and thus needs to be supplemented with this aspect of death. In sum, Carel conceives of death as referring to finitude of possibility and temporal finitude. She concludes by turning to the relationship among illness, death, and authenticity. Contra Heidegger, Carel argues that individuation is not an essential condition of death; she advocates a "more relational understanding of death" and illness (179).

Chapter 8 advances the claim that ill people face epistemic injustice in clinical settings. Miranda Fricker coined this term to refer to injustice done to a person "in their capacity as a knower" (180). On Fricker's account, epistemic injustice may take the form of testimonial injustice wherein "prejudice causes a hearer to assign a deflated level of credibility to a speaker's testimony" and hermeneutical injustice in which "a gap in collective interpretative resources puts

a speaker at a disadvantage when trying to make sense of their social experiences" (183). Importantly, epistemic injustice need not be enacted maliciously or even intentionally (186).

Carel suggests that clinicians may believe that "listening for medically relevant information precludes listening to other information conveyed in patient speech, such as existential concerns, need for empathy, or emotional content" (181). Rather than being tangential, these aspects of patient testimony may be crucial for understanding illness, determining treatment options, and improving patients' lives. Testimonial justice in the context of health care involves soliciting patient testimonies and recognizing when they are epistemically authoritative (188). Carel contends that developing a phenomenological toolkit for patients may contribute to hermeneutical justice by providing patients with a way to make sense of their experiences of illness. To apply this phenomenological toolkit, patients would take the following steps: bracket the natural attitude, thematize illness, and construct a new understanding of illness (200-01).

Although Carel does expand on earlier remarks, chapter 9 is largely a review and synthesis of the previous chapters. Drawing on the work of Arthur Frank and Fredrik Svenaeus, among others, she develops ways that illness can create a "rift" between the objective body and the lived body, which may lead to objectification and uncanniness. Focusing on the processes and effects of disease requires ill people to understand their bodies as medical objects: a perspective that is only temporarily tenable (220). According to Carel: "[u]ncanniness arises from a new, negative focus on one's body, a sense of this body becoming an alien destructive force, or even the threat of annihilation" (222). She asserts that the body acquires these characteristics "instead of" [emphasis added] being "my home, a familiar place I inhabit" (221). I would suggest that uncanniness occurs insofar as the body is simultaneously familiar and unfamiliar. The familiarity of one's body is juxtaposed with new limitations, ways of accomplishing tasks, and/or pain, which are, at least initially, unfamiliar and disorienting. In conclusion, Carel reiterates the claim that, in addition to being a "compulsive invitation" to engage in philosophical reflection, illness is relevant to philosophical concerns related to character, identity, and what it means to live a good life (225).

Phenomenology of Illness makes a significant, original contribution to philosophy, and will, no doubt, spur much-needed conversation about ways both philosophy and health care must change if the experiences of people with illnesses and impairments are to be taken seriously. Carel grounds her accounts of illness in phenomenology in a way that many using the term *phenomenology* do not. She brings together philosophy and medical humanities and deftly moves between phenomenology and feminist epistemology. Carel centers the experiences of people living with chronic illness and demonstrates ways that health-care providers provide inadequate care when they focus on disease to the exclusion of illness.

Although I enthusiastically recommend this book, I do have a few critiques. Chapter 7 seemed out of place in this book. I found Carel's contribution to the ongoing discussion of how to interpret Heidegger's notion of "death" interesting, but the topic, technical level, and presumed target audience were different enough from the other chapters that it was a bit jarring to encounter it here. I would definitely recommend *Being and Time* (at a bare minimum) as a prerequisite for reading this chapter.

References to feminist philosophers were surprisingly few and far between. Although Carel does build on the work of Toombs and Fricker, I believe her project would be enriched through engagement with the insights of feminist theorists whose work draws on phenomenology, including Sara Ahmed, Linda Martín Alcoff, Linda Fisher, Emily Lee, Mariana Ortega, Gail Weiss, and Iris Marion Young, to name a few (Alcoff 2000; Fisher 2000; Young 2005; Alcoff 2006; Ahmed 2007; Lee 2014; Weiss 2015; Ortega 2016). If there was any discussion of race at all, I missed it. Carel does not address the importance of social categories such as race and gender for lived experiences of health and illness (Wieseler 2016). Although she recognizes that the boundaries between illness and impairment are blurry (in some cases, nonexistent), she does not reference the work of philosophers of disability or disability theorists from other disciplines (such as Diedrich 2001; Scully 2008; Siebers 2008; Wendell 2008; Hall 2011; Wendell 2013).

In setting up the book, Carel says that she has two aims: "to contribute to the understanding of illness through the use of philosophy, and to demonstrate the importance of illness for philosophy" (2). She fully addresses the first aim, but I would have liked more development of the second. Engagement with the work of feminist philosophers would be beneficial here as well (for example, Mackenzie and Stoljar 2000; Kittay and Feder 2002). I hope this is a topic she will continue to explore.

Carel seems to have written *Phenomenology of Illness* with multiple audiences in mind: philosophers, health-care professionals and students, and people who have chronic illnesses. She has much to say to philosophers, but her writing is clear and accessible to readers without a philosophy background as well, with the aforementioned exception of chapter 7. I was fortunate enough to have the opportunity to test and validate this claim with the help of medical students and nursing PhD students this semester. This text was an extremely valuable resource for helping students to develop a greater understanding of the ways illness drastically changes a person's life as a whole. I have high hopes that these students will be more attuned to their patients' concerns as a result of their engagement with this book.

Most portrayals of illness and impairment in the media take the form of tragic or heroic narratives rather than capturing everyday experiences of illness and impairment (Clare 1999; Wendell 2008; Kafer 2013). Carel accomplishes quite the feat in sharing both the difficulties and losses associated with chronic illness as well as the positive aspects, which are usually overshadowed in our thinking about illness. She neither evokes pity nor suggests that she has triumphed over her condition. Her narrative is one of living with a significant chronic illness rather than a tragic or heroic narrative. *Phenomenology of Illness* closes with a vignette in which Carel is walking her dog and comes across a mother playing in the autumn leaves with her two sons. Although participation in this type of activity would require more oxygen than she can afford, Carel shares in their joy and walks away with a smile.

Acknowledgments

I would like to thank Alina Bennett and Alex Levine for reading a draft of this review and providing numerous helpful suggestions. I am also grateful students in my Spring 2017 course, "Lived Experiences of Illness," for reading *Phenomenology of Illness* with me and sharing their thoughts.

References

- Ahmed, Sara. 2007. A phenomenology of whiteness. *Feminist Theory* 8 (2): 149-68.
- Alcoff, Linda Martín. 2000. Merleau-Ponty and feminist theory on experience. In *Chiasms: Merleau-Ponty's notion of the flesh*, ed. Fred Evans. Albany: State University of New York Press.
- , 2006. *Visible identities: Race, gender, and the self*. Oxford: Oxford University Press.
- Clare, Eli. 1999. *Exile and pride: Disability, queerness, and liberation*. New York: South End Press.
- Diedrich, Lisa. 2001. Breaking down: A phenomenology of disability. *Literature and Medicine* 20 (2): 209-30.
- Fisher, Linda. 2000. Feminist phenomenology. In *Feminist phenomenology*, ed. Lester Embree and Linda Fisher. Dordrecht: Kluwer.
- Hall, Kim. 2011. *Feminist disability studies*. Bloomington: Indiana University Press.
- Heidegger, Martin. 1962. *Being and time*. Trans. John Macquarrie and Edward Robinson. New York: Harper & Row.
- Kafer, Alison. 2013. *Feminist, queer, crip*. Bloomington: Indiana University Press.
- Kittay, Eva Feder, and Ellen Feder. 2002. *The subject of care: Feminist perspectives on dependency*. Lanham, Md.: Rowman and Littlefield.
- Lee, Emily. 2014. Introduction. In *Living alterities: Phenomenology, embodiment, and race*, ed. Emily Lee. Albany: State University of New York Press.
- Mackenzie, Catriona, and Natalie Stoljar. 2000. *Relational autonomy: Feminist perspectives on autonomy, agency, and the social self*. Oxford: Oxford University Press.
- Ortega, Mariana. 2016. *In-between: Latina feminist phenomenology, multiplicity, and the self*. Albany: State University of New York Press.
- Scully, Jackie Leach. 2008. *Disability bioethics: Moral bodies, moral difference*. Lanham, Md.: Rowman and Littlefield.
- Siebers, Tobin. 2008. *Disability theory*. Ann Arbor: University of Michigan Press.

Toombs, S. Kay. 1987. The meaning of illness: A phenomenological approach to the patient-physician relationship. *Journal of Medicine and Philosophy* 12 (3): 219-40.

----- . 1992. *The meaning of illness: A phenomenological account of the different perspectives of physician and patient*. Amsterdam: Kluwer.

Weiss, Gail. 2015. The normal, the natural, and the normative: A Merleau-Pontian legacy to feminist theory, critical race theory, and disability studies. *Continental Philosophy Review* 48: 77-93.

Wendell, Susan. 2008. Toward a feminist theory of disability. In *The feminist philosophy reader*, ed. Alison Bailey and Chris Cuomo. New York: McGraw-Hill.

----- . 2013. Unhealthy disabled: Treating chronic illnesses and disabilities. In *The disability studies reader*, 4th ed., ed. Lennard Davis. New York: Routledge.

Wieseler, Christine. 2016. "A feminist contestation of ableist norms: Implications for biomedical ethics, disability theory, and phenomenology." Dissertation. University of South Florida. <http://scholarcommons.usf.edu/etd/6433>.

Young, Iris Marion. 2005. Lived body vs. gender: Reflections on social structure and subjectivity. In *Throwing like a girl and other essays in feminist philosophy and social theory*. Oxford: Oxford University Press.