
Essay review for studies in history and philosophy of biological and biomedical science

1. Illness

To experience illness, ageing, and dying is intrinsic to the human condition. This set of truths prompted Alasdair MacIntyre (1999), almost twenty years ago, to call for a radical reorientation of moral theory. We ought to start our reflections on the good life from our status as ‘vulnerable, dependent, afflicted’ creatures. A wider community of feminist and care ethicists and disability theorists had long made similar calls (see Jaggar, 1992; Silvers, 2016). Conceptions of the good life premised on autonomy, capacity, and freedom are a poor fit for the bodily and social realities of the majority of human beings.

A natural way to take forward such calls was to consider illness, but unfortunately philosophers were slow to do so. There is, these days, a growing body of excellent work in the philosophy of medicine, but its agenda and methods mainly reflect the philosophy of science, so concentrates on epistemological and metaphysical issues. As such, there is still a significant space for sustained philosophical reflection on the experience and value of illness—a space, that is, for the philosophy of illness. Such a discipline should explore and illuminate the ethical, epistemological, and existential issues latent in the diversity of ways that human beings experience and engage with illness.

With this new book by Havi Carel, we have a powerful contribution to the development of the philosophy of illness. Almost ten years ago, she published a short, rich book — nominated for the Wellcome Trust book prize - entitled Illness: The Cry of the Flesh (Carel, 2008). Now in its third edition, it is a moving reflection on her own experiences of the early years of her life with a life-limiting lung disease. It drew on personal anecdote, ancient Greek ethics, and phenomenology to offer a humane account of the lived experience of illness. As befits a book that appeared in a series entitled ‘The Art of Living’, it was, and remains, hugely influential among academics — philosophers, medical humanists, healthcare researchers - but also those experiencing, anticipating, or responding to illness.

Some critics protested Carel’s use of anecdote, autobiography, emotion, and subjective experience. Although conceding the book’s insights, these critics judged it too personal to class as ‘properly philosophical’, a charge rebutted by later commentators (see Burley, 2011; Kidd, 2017). Although not written to allay such critics, her new book — Phenomenology of Illness — offers a fuller, more systematic account of the phenomenological description of the lived experience of illness and its wider philosophical significance. Carel explores the complexities and possibilities that emerge when one develops an account of the good life that makes central our bodily vulnerability.

Carel provides us with a robust framework for describing what it is like to be ill and what philosophy can usefully say about this. It offers new ways to think philosophically about topics as diverse as embodiment, trust, and epistemic injustice and integrates existing work on illness and disability by S. Kay Toombs (1993), Fredrik Svenaeus (2001), and others. It will be of interest to ethicists, philosophers of medicine and illness, phenomenologists, medical humanists, and healthcare practitioners and researchers. It will also be welcomed by those who are personally or professionally concerned with understanding the possibility of ‘wellbeing within illness’.

Phenomenology of Illness has ten chapters that fall into roughly two parts. The first five chapters are devoted to the phenomenology of illness. Carel draws on Sartre, Heidegger, Husserl, and Merleau-Ponty to describe the ways our structures of experience change during chronic illness. The second half of the book — chapters six to ten — move onto a set of ethical and epistemological issues that include wellbeing, death, and epistemic injustice. The book ends by outlining the distinctive insights afforded by philosophising with and about illness.

2. Phenomenology, naturalism, and illness

The majority of contemporary philosophical work on somatic and psychiatric illness has drawn upon the phenomenological tradition. Its relevance lies in its capacity to describe the changes in the structure of lived experience caused by pathological...
experiences. Carel focuses on chronic somatic illness, though makes regular remarks on non-chronic and psychiatric illnesses (see Ratcliffe, 2014).

Carel characterises illness as ‘a complete transformation of one’s life’ that entails a set of radical disruptions to our typically tacit structures of experience, meaning, and possibility (pp.14–15). This points to an immediate distinction, too often occluded, between disease and illness. Within modern healthcare and much of philosophy of medicine, what has become entrenched are naturalistic or biomedical conceptions of disease as biological dysfunction. As such, describing and treating disease is a matter for naturalised biomedical science of a properly objective sort.

The best-known philosophical champion of a naturalistic conception of health and disease is Christopher Boorse. In a trio of influential papers published in the late 1970s (e.g. Boorse, 1977) he argued for a naturalistic conception that aspired to exclude axiological and subjective considerations from thinking about health and disease. Medicine should privilege the third-person perspective and the terminology, methods, and concepts of biomedical science. Naturalism about health and disease has been challenged and refined, but remains entrenched in modern healthcare systems (despite calls for ‘whole-person’ approaches) and central to philosophy of medicine (see Cooper, 2002).

Carel agrees that naturalistic conceptions of health and disease have, of course, been enormously intellectually and practically productive. But she also affirms the limits of those ways of thinking about and responding to health. Her main complaint is that they are too narrow, excluding the vital subjective, first-person experience of those biological dysfunctions. Illness is the lived experience of disease. Despite the power of naturalistic conceptions, they are not the whole story. Treating disease is a very different matter from coping with illness. Carel’s argument is that healthcare systems tend to be very good at the former, but not so good with the latter. Understanding the lived experience of illness requires an acute attention to the everyday realities of experiencing and responding to a biologically dysfunctional body. A phenomenological conception of illness adopts a first-personal stance that is sensitive to the existential and social dimensions of illness and this is what Carel provides.

The tradition and practice of phenomenology is described in chapter one. It argues that illness is the primary and fundamental phenomenon, with disease an aspect of it, abstracted from it for specific practical or theoretical purposes. A focus on disease is useful for specific purposes, but falls short of a fuller account of illness as what Merleau-Ponty called a ‘complete way of being’. Carel draws on both classical phenomenologists and also contemporary practitioners, such as Shaun Gallagher, Matthew Ratcliffe, and Dan Zahavi. Special attention is paid to Toombs — a pioneer in phenomenology of illness — and her search for the ‘eidetic features’ of illness: those common to all experiences of illness, regardless of the peculiarities of particular disease states. These features take the form of various ‘losses’ — of wholeness, certainty, control, freedom to act, and of a familiar world. Such losses entail what Svenaeus calls the ‘unhomeliness’ that characterises experience of illness. This is the erosion of a stable, confident sense of embodied existence within a world receptive to agency and purpose. Chronic illness makes the world ‘unhomelike’ — hostile, alienating, resistant to our efforts to create and maintain meaningful projects and a sense of belonging.

Although Carel adopts much of Toombs’ account, she argues, in chapter two, that the various losses have more diverse forms, and apply less uniformly to different cases. A loss of freedom, for instance, has multiple aspects, some bodily, some existential. Some involve a loss of freedom of bodily movement — to move, breathe, eat — but others take a different form. Carel describes losses of freedoms to plan for the future and to live confidently in the present and of trust in the world (pp.44–45). But if and how an ill person experiences these losses will vary. Some experience all of the losses, others only some of them, and cultural context also affects the sorts of losses that might be salient for a person — not all cultures valorise Prometheus virtues like autonomy and independence, for instance.

Such observations reiterate the irreducibly subjective character of experiences of illness and underscore the epistemic privilege enjoyed by an ill person. ‘The patient is the only one to whom the full subjective experience of illness is available’, says Carel, which gives them an ‘epistemic advantage’ (p.50). This advantage is worthy of incorporation into healthcare theory and practice. Although some cases of illness won’t require the patient’s active epistemic contributions, many will, especially those that involve chronic illness.

3. The body, world, and breathlessness

A distinctive reason for the epistemic significance of a first-person stance on the lived experience of illness is the central role of the body. Carel emphasises that chronic illness, especially, can ‘permanently and radically modify my bodily experiences’. She develops this theme using Sartre’s account of the ‘orders of the body’ and Heidegger’s account of ‘equipmental breakdown’ (p.59). Chapter three therefore focuses on ‘the body in illness’, honouring Merleau-Ponty’s celebrated remark that the body is ‘the vehicle of selfhood’.

Changes in one’s body situation affect our agency, identity, projects, and intersubjective capacities, reverberating through our ways of engaging with the world. Drawing on her own experiences, Carel describes how the world changes as one’s body changes — ‘things grow heavier and further away’, distances inflate, tasks magnify, projects shrink or retreat, movements are censored, and impulse and spontaneity are displaced by a forced need for rigid planning and calculated activity (pp.71–72).

The constraints imposed by a transforming body are amplified by what Carel calls the ‘social architecture of illness’. Sartre announced in Hui cios that Hell is other people; something similar could be said of illness. Pathographies are filled with testimonies — often bitter, frustrated, and angry — to the ways that the social world exacerbates the difficulties of being ill. People stop and stare, speak brusquely, ask brutal questions, and act without empathy. Cultural norms and ideals celebrate health, autonomy, and independence in ways that exclude ill persons from prevailing visions of ‘doing well at life’. This makes it difficult for people to try to answer honestly Carel’s question, ‘what happens to one’s life when one becomes restricted by illness’ (p.78).

The difficulties of honestly discussing illness are amplified by a tendency among philosophers to make ability central to human life. Heidegger’s account of Dasein—roughly, our ‘mode of being’—emphasises our ‘being able to be’, our status as agents who engage in activities, undertake tasks, and initiate projects. But Carel argues that this account has only limited purchase on human life. It refers mainly to adulthood, rather than vulnerable youth and aged dependence, and presupposes bodily and psychological health. ‘Inability-to-be’ should be built into our conception of our ‘mode of being’. In doing so, suggests Carel, we might be better able to identify effective processes for coming to terms with the many experiences of inability that are integral to a human life.

Carel’s project is to better enable us to anticipate and then experience the curtailment of our abilities in positive ways. In chapter four, this is illustrated in a discussion of the phenomenon of ‘bodily doubt’. This occurs after the erosion of our typically unrecognised and taken-for-granted sense of certainty in our...
bodily capacities. Sitting in this coffee shop, I can make this bodily certainty a conscious object of experience. I type rapidly, reach for my coffee cup, inhale and exhale — my body does these things automatically, effortlessly. That my body can realise such possibilities, offering capacities without caveats, is a basic certainty that underlies my life. A healthy body is, then, ‘a silent enabler of action’ (p.91).

Such bodily certainty will not last forever. It will be repeatedly ruptured, as the course of my life inevitably subjects me to accidents, ageing, and acute and chronic illness. Bodily doubt becomes the norm, whether totally or partially, and gradually or suddenly — the slow ache of ageing joints, or sudden chaos of illness. Bodily doubt, explains Carel, discloses the precariousness of our bodily situation and ‘invades the normal sense of things’. It reveals our vulnerability in ways that ‘overthrow our most basic assumptions about the regularity, predictability, and benevolence of the world’ (pp.93—94). To experience bodily doubt is to realise experientially the truth in MacIntyre’s triad of dependence, affiliation, and vulnerability.

Such experiences of bodily doubt will alter how we experience ourselves as embodied beings within the world. Suddenly one needs to pause, plan, and to prepare in advance for actions that were once automatic. Projects are quelled because ‘the possibility of catastrophic bodily failure is now part of one’s experiential horizons’. Some degree of bodily certainty may be restored, but even so, the initial experience of it ‘taints’ our existence, acting as a ‘constant reminder of the contingency and fallibility’ of our embodied existence (pp.95, 97).

Carel offers rich accounts of the shifts from bodily certainty to doubt in their practical, emotional, and existential dimensions. Her accounts will resonate with those familiar with them, but can inform those yet to experience them. They help us to ‘reckon with the possible’, as Merleau-Ponty puts it, as I did in my little coffee shop reverie. The hope is that pre-emptive reflection on lived experiences of pathology can disclose aspects of our being-in-the-world that we are apt to neglect but could learn to attend to. In so doing, we may learn how to appreciate and cope with the fragility of our mode of life.

Carel offers an exercise of this sort in chapter five’s sustained discussion of the phenomenology of breathlessness. It draws on her own experiences and is valuable for drawing together themes and ideas from the earlier chapters and presenting them within the context of a specific life. This chapter illustrates the universalising and particularising potential of phenomenology. It shows us how one might ‘account for the richness and diversity of the illness experience’, while also describing the particular form that experiences can take within the life of a person (p.126).

4. Wellbeing, death, and authenticity

The latter half of the book — chapters six to ten — is devoted to a wider set of ethical, epistemic, and metaphilosophical issues. It shows how phenomenology of illness can inform a range of topics of wider philosophical interest.

The theme of chapter six is the question of whether wellbeing is possible within illness. A negative answer may seem obvious, but the empirical evidence surprisingly shows that many ill persons argue the opposite. Chronic illness does not substantially diminish one’s wellbeing, a fact that poses the question of how to explain the ‘gulf between how... states of illness are experienced first-hand and how they are perceived by outsiders’ (p.136). Carel draws on psychological studies to offer explanations. Most healthy people have a very limited idea of what it would be like to live with illness and popular accounts of such lives are of very limited value. Healthy people also suppose that illness must be a defining feature of one’s life, and fail to imagine how people might adapt to their illnesses (pp.136—140). Not knowing what life in illness is like, the healthy struggle to imagine how they might cope, and tend to expect the worst.

The limited insight of healthy people into a life led with illness is coupled to a failure to appreciate its potentially positive fruits. As Jonathan Haidt (2006) argues, people tend to underestimate their capacity to cope with adversity. Such coping can reveal unrealised abilities, enhance relationships, and offer focus and peace of mind. Carel proposes that the possibility of positive responses to illness illustrates what Haidt calls ‘post-traumatic growth’, something evident not only in empirical psychology, but also a venerable tradition in philosophy. Epicureans and Stoics devised practical and spiritual exercises to enable people to achieve tranquillity and ataraxia amid the turmoil of life. ‘Wellbeing within illness’ will demand effort and concentration, of course, but that is partly constitutive of its status as an achievement (p.149).

Critics might protest that such claims are too optimistic. Many ill persons are deeply hostile to what Barbara Ehrenreich (2009) decries as the ‘bright-siding’ of experiences of adversity and suffering. ‘Post-traumatic growth’, ataraxia, and wellbeing are not universal, inevitable gifts of illness. But Carel does not say that they are — she does not ‘bright-side’ illness. Her purpose is to emphasise the too-often unrecognised or excluded possibility of such positive responses to illness. Moreover, to attain those goods depends on one’s having a suitably complex conception of the experience and value of illness, of a sort that phenomenology aspires to provide (see Kidd, 2012).

The idea of ‘post-traumatic growth’ may seem to reach its limit with the topic of chapter seven, which is death. Illness and death are natural bedfellows. Carel describes illness as ‘being-towards-death’ in its most intense form. ‘To die is the natural terminus of her conception of illness as ‘inability-to-be’. The first half of the chapter presents and revises Heidegger’s notion of death, while the second adds what Carel argues is a missing aspect of the concept of death, namely, the ‘dimension of finitude’. The anticipation of death is constitutive of Dasein as mortal, making our existence existentially, if not literally, a process of dying; indeed, the certainty of death is, says Heidegger, ‘the basic certainty’ (p.156). But propositional assertion of this certainty is, of course, quite distinct from its existential realisation. Life is constituted by activities and projects that we naturally ‘project’ into the future, such that we perpetually place our death at an indeterminate point in the future.

The articulation and discussion of Heidegger’s concept of death is complex and many readers will find the exegetical discussion heavy-going (pp.160—167). But the fruits are Carel’s amended concept of death, which builds in temporal finitude and finitude of possibility. Death is ‘a constant condition of every possibility’, yet ‘only ever impending’, since it cannot be experienced and therefore ‘actualised’. It is a possibility that is both constant and distinctive: its actualisation entails total inability to take up other possibilities. Once death is actualised, all other possibilities are nullified. To authentically cope with death is, argues Carel, to grasp that one is ‘mortal and finite’, embracing the ‘radical contingency of life’ (p.169). The chapter ends with discussion of authentic and inauthentic attitudes to death, mortality, and finitude (pp.172—178). Carel’s idea is that reflective coping with experiences of illness can be existentially preparatory for the development of authentic attitudes towards death — indeed, to life-as-a-whole.

5. Testimony, intelligibility, and epistemic injustice

Illness and death are difficult to talk about by virtue of their emotionally and personally demanding realities. Even if we set aside the complex analyses of ‘being-towards-death’, temporal
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6. Philosophy, illness, and life

Carel ends the book by identifying ways that philosophy can be enriched through a more robust engagement with illness. The enrichment lies not only in the novel means for ethical, epistemic, and axiological debate, but also in new conceptions about the aims and practices of philosophy. The tenth and final chapter, ‘The Philosophical Role of Illness’, offers a manifesto for future projects in philosophy of illness. Carel starts by outlining a range of ways that illness can enrich philosophy. First, philosophising about illness can afford new insights into such staple topics as embodiment, agency, virtue, empathy, and the good life. Second, reflecting on illness can expose tacit certainties and presuppositions, enabling us to ‘bracket’ them, with being ill akin to an enactment of Husserl’s epoché. Third, illness can shape the methods, aims, and agenda of philosophical enquiry. The distinctively personal and forceful character of experiences of illness can transform our sense of the sorts of values, literature, and cognitive styles necessary to authentic philosophising. It can also force one to philosophise, in ways wonder or curiosity might not, and to do so seriously, rather than as a trivial cognitive pastime.

The metaphilosophical defence of the value of illness to philosophy is best understood as a retrieval of an older recognition of that value. Carel notes that ‘reflective coping’ with illness has been a theme in the history of philosophy. Its neglect is therefore a recent and peculiar phenomena, not least when contrasted with the vast interest in health and illness in other areas of the arts, humanities, and social and biomedical sciences (think of ‘medical humanities’). This tradition of philosophical reflection on illness ought to be revived, not least since there is a ‘bilateral relationship’ between the two. Philosophy and illness can be mutually illuminating, but only if their relationship is structured by empathy, compassion, and openness to sources and methods to which some philosophers are averse. A philosophy of illness must use first-personal stances, autobiography, and literary narrative. It draws on diaries and poetry as well as psychological studies, relies on themes like authenticity and edification, and will talk of ‘being-towards-death’ and crass ‘bright-siding’ cultures. Some readers will no doubt want more on charged, topical issues of healthcare policy and practice, to which Carel does allude. But the aim of this book is to articulate a phenomenological conception of illness; tracing its lessons for policy and practice is work for another day.

The breadth and depth of these themes and methods is a testament both to the complexity of human experiences of illness, and of the richness of Carel’s investigations and reflections. Illness is a vast topic that opens up an immense variety of issues – virtue, justice, and the good life; dependence, vulnerability, and fragility; epistemic inclusion, testimony, and hermeneutic agency; the diversity and frailty of embodied existence; wellbeing, death, and dying; the existential arduors of mortality; the proper aims and practice of philosophy – to name but a few of Carel’s topics and themes. But it is crucial to appreciate that these themes do not converge simply in the abstract sense that one topic might be conceptually related to another – bodily fragility to death, death to the meaning of life, say. The unity of these themes has a deeper source, namely, their integration within the existential experience of a person of their life-as-a-whole.

Underlying the discussions of this book is a sense that the myriad aspects of the experience of illness find their ultimate unity in Life itself. A philosophy of illness is therefore a reflection on the meaning and nature of human life. It marks a welcome return to the ancient conception of philosophy, not as a mere set of cold doctrines or arguments, but as a ‘way of life’. It is a vision of philosophy as a vital practice aimed at the amelioration of human life, guided by wise insight into the deep truths about our situation within the wider order of things. These truths include our being essentially dependent, vulnerable, afflicted creatures – truths that we need to understand if we are to live with them and try to help others to. Understood in this way, Phenomenology of Illness is a contribution not only to an understanding of illness, medicine, and healthcare, but also to a philosophy of life.
References