

Chapter 10

Breathlessness: From Bodily Symptom to Existential Experience

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Existentially, breathlessness is a constant reminder of impending mortality. Most of us want to die in our sleep with no knowledge of the event. Not only do patients with chronic, progressive lung disease know of their impending death months, years or decades ahead of the day, they fear how they will die, with the fear of suffocation always somewhere in their minds.

—Currow and Johnson, “Dyspnoea”

This chapter uses a phenomenological approach to investigate the philosophical significance of a common yet debilitating experience: the experience of severe and pathological breathlessness. Using two key examples of breathlessness in the case of respiratory disease (somatic) and in anxiety disorders (considered as mental disorder) we show why a phenomenological approach to the study of these experiences is needed and how the distinction between the somatic and the mental comes under pressure when considering a complex phenomenon like breathlessness.

We see the distinction between the somatic and the mental as emerging from a key problem in modern health care: a disproportionate commitment to a worldview that prioritizes the physiological over the holistic (Aho and Aho 2009). This worldview can be associated with problems in healthcare provision, communication between health professionals and ill persons, and in outcomes (see Carel 2013a; Toombs 1987; Department of Health 2011). This approach, we suggest, gives rise to a failure to adequately account for the alterations in the lifeworld of the respiratory patient. This approach also occludes the complex and shifting nature of breathlessness, which is a unique medical symptom, as we explain below.

As a result of the prioritization of the physiological, we suggest that patients are subject to unnecessary suffering, inappropriate treatments, increased failure rates in outcomes, and epistemic injustice (cf. Carel and Kidd 2014; Critchton et al. 2016). Moreover, we suggest that clinicians' knowledge, understanding, and treatment of comorbid mental health conditions in respiratory patients is lacking and further exacerbates an already complex and debilitating health concern.

Furthermore, research shows that the impact of patients' socioeconomic, cultural, and mental health status affects the development, treatment, and management of respiratory disorders, and so needs to be addressed in the context of respiratory medicine (Wilson 2006). For instance, studies show that patients with chronic obstructive pulmonary disorder (COPD) are often poor, working-class smokers (Pauwels and Rabe 2004). We thus argue that socioeconomic status is part of patients' life-world and therefore plays a constitutive role in their health and well-being (Department of Health 2008; Gysels and Higginson 2008; Marmot 2010).

In those with a mental health diagnosis, rates of respiratory disorders increase, as many patients with depression or anxiety (for example) also smoke to cope with their anxiety (Wilson 2006; van Manen et al. 2002). One study found anxiety and depression rates of 80 percent in COPD patients who smoke (Kunik et al. 2005). In prison populations, up to 90 percent are smokers, and many have smoking-related disorders as well as mental health conditions, both of which are underdiagnosed, alongside restricted access to pulmonary rehabilitation, an efficacious intervention for breathlessness discomfort (Turner and Jefford 2013). So it is also a health inequality issue (Department of Health 2010; Social Exclusion Task force 2010).

Focusing on phenomenological descriptions of the person as being-in-the-world can help us begin to address inadequate understandings of respiratory illness. This has been the focus of the *Life of Breath*, a Wellcome Trust-funded research project we are members of (www.lifeofbreath.org). Indeed, our work suggests that a phenomenological framework captures how the structures of experience and the possibilities of certain experiences are changed in patients with breathlessness and panic disorder (Carel, Dodd, and Macnaughton 2015). Moreover, this approach can help explicate the "problem of differentiation" whereby clinicians and patients alike struggle to distinguish breathlessness caused by respiratory illness from that caused by panic anxiety.

We argue that phenomenological description and explanation is indispensable to our understanding of the difficulties faced by patients. Attention to the life-world of the patient is essential to making their experience intelligible. It is also indispensable to medical understanding of the impact of breathlessness on conditions that challenge this dichotomous understanding, which, in turn,

results in compartmentalized treatment of these illnesses. We hope that the reconceptualization of breathlessness disorders in phenomenological terms will contribute to improved patient care, reduced misunderstandings and epistemic injustice, and improved ability to address the interrelated issues which arise from these illnesses.

Many studies show significant barriers in place for those with physical illnesses comorbid with mental health conditions; in this context, many physical symptoms are at risk of being dismissed due to the mental health diagnosis, resulting in integrated care obstacles (Gysels and Higginson 2008). This is a further reason to study these disorders. Detailing the experiences of such patients is important in order to understand how and why this happens, and suggest ways to address these troubling problems (Rethink Mental Illness 2012; Department of Health 2011; Hegarty 2011).

BREATHLESSNESS: FROM SYMPTOM TO EXPERIENCE

The ability to breathe underpins human life; it is vital to all we do. Not only do we unconsciously alter our breathing when talking and moving; we can also control our breath to dive, avoid inhaling toxic fumes around cities, and calm ourselves. In people with respiratory disease, the struggle to breathe is often a mortal threat.

Imagine sprinting up several flights of stairs and getting out of breath. Now imagine feeling like that *all the time*. When you cannot catch your breath terror, panic and a sense of suffocation overcome you. Thus anxiety often accompanies pathological breathlessness, due to a constant sense of threat and bodily betrayal (Smoller et al. 1996; Carel 2016). Importantly, this experience is largely invisible and difficult to describe, despite being one of the leading causes of suffering in the UK, and a significant cause of death that is on the rise (World Health Organization 2016). This invisibility stems in part from stigma attached to breathlessness (associated with smoking) and pronouncedly to mental illness, due to perceptions of responsibility and weakness of will (Crichton et al. 2017). This invisibility also has an embodied dimension: When the breath is stifled, talk is silenced, communication cut off and in its extreme manifestation, both panic and oxygen deprivation can significantly impact thinking itself (O'Donnell et al. 2007; LeDoux 2015).

However, can we sharply distinguish the physiological from the mental in the experience of breathlessness? Can we separate somatic sensations from how they are experienced, interpreted, and expressed? In our view, the answer is no. Breathlessness is a unique medical symptom and experience that of its essence involves sensation, cognition, and reasoning, none of which are reducible to the other. To think of it purely in physiological terms

is inadequate as the experience has significant emotional, cognitive, and interpretative dimensions. Thus we have a significant and common medical symptom that unsettles the distinction between somatic and mental symptoms and disorders.

How is breathlessness typically characterized in both medicine and lay knowledge? While the physiological components are bound to a wide variety of subjective and cultural ideas about breath, and thus may vary considerably, typical sensations include feeling short of breath, winded, difficulty in inhalation or exhalation, air hunger, chest tightness, and discomfort when breathing (Carel 2014). Not every experience of breathlessness includes every sensation, nor is it at the same intensity for different episodes and there is much felt variation between and within individuals (Abernathy and Wheeler 2008; Smoller et al. 1996; Lansing et al. 2009).

In terms of the etiology of pathological breathlessness, no two cases of underlying dysfunction will necessarily result in the same felt intensity or severity of the experience (Abernathy and Wheeler 2008; Haugdahl et al 2015). Apart from the varying subjective qualities of breathlessness, and a wide range of underlying causes, intensity can also be difficult to measure, rendering evaluation, treatment, and management difficult and sometimes ineffective (American Thoracic Society 1995). Diagnosing and assessing breathlessness typically follows the medical model, insofar as the pathophysiology is sought, via physical examination, patient history, and diagnostic tests. These include spirometry and lung function tests, as well as inventories such as the Chronic Respiratory Disease questionnaire (CRQ). If the condition is not traced to a cause, or if the breathlessness cannot be relieved, management of symptoms is sought to reduce intensity, distress, and any comorbid mental or physical conditions, but these do not necessarily address the shrinking world of the patient.

In many respiratory conditions, the dysfunctional breathlessness cannot be corrected and so the patient's abilities and lived experience are altered irrevocably (Gysels and Higginson 2008). In these cases, there will be varying levels of disability that are likely to worsen over time, but are often unlike other chronic disease progressions because of the impending and ever-present nature of episodic attacks (Eccleston 2016). For instance, acute exacerbations of respiratory infections can often result in death. As a patient put it, "If you can't breathe you don't live" (Nicholls 2003, 132). Understanding, managing, and attending to the patient experience—including their voice when they are not too breathless to talk—can be a matter of life and death. Without such study, high rates of suffering from the misdiagnosis, underdiagnosis, and undertreatment of breathlessness will continue (Currow and Johnson 2015).

The term *breathlessness* needs to be conceptually clarified to investigate whether it captures a common feature and so has corresponding clinical

utility, or if the experiences differ widely and require us to modify our conceptualization of pathological breathlessness and correlating clinical understanding. For example, in the case of pernicious anemia, a breathlessness symptom previously classed as “shortness of breath” has now been changed to be described as “the sighs” to capture the difference between these experiences. Patients who experience air hunger feel that they struggle to get the air in and out. Those with pernicious anemia describe the feeling of needing to gulp in air at a slow, steady pace when exerted but, importantly, do not encounter difficulty in doing this. Thus the term *breathlessness* in these two cases does not refer to the same type of experience (Haugdahl et al. 2017). Hence understanding, defining, and labeling different types of breathlessness is important so that clinician and patient can differentiate between different types of breathlessness to get to the correct diagnosis. Careful attention to such differences can aid our understanding of the lived experience of specific types of breathlessness, alongside improving clinician knowledge, which may help prevent misdiagnosis or unnecessary treatment for asthma, a common misdiagnosis in cases of pernicious anemia (Chanarin 1992).¹

ANXIETY AND BREATHLESSNESS

With the progressive and irreversible nature of COPD, differing rates of felt breathlessness, inflammation of the airways, sputum accumulation, and resultant cough, it is unsurprising that there is a higher prevalence of anxiety disorders in these patients compared to the general population. Studies suggest that anxiety disorders appear in approximately 50 percent of COPD patients (compared to about 6 percent in the general population). Other mental health conditions such as depression and agoraphobia are also more likely to appear in that population (Smoller et al. 1996). Effects such as restricted mobility, lower reported quality of life, worsening overall health, and functional disability are often consequences of anxiety, even in those without respiratory disorders. These issues are often underdiagnosed and undertreated in comorbid respiratory cases, worsening the impact of these disorders on the patient (McManus et al. 2016). Mental symptoms are often ignored or seen as an inevitable consequence of respiratory disease (Maurer et al. 2008).

Studying breathless and anxious experience can help us understand problems in the medical attitude to illness. One overarching problem is the reduction of the suffering person to biological processes; this ultimately separates the body from its subject (cf. Merleau-Ponty 1962; Aho and Aho 2009; Carel 2016; Ratcliffe 2015; Svenaeus 2000; Toombs 1987). Further, many mental disorders are not easy to differentiate from physical disorders (Ratcliffe 2015). Depression and anxiety disorders include physiological

distress such as breathlessness, rapid heart rate, gastro-intestinal upset, and other flu-like somatic symptoms (Kirkengen 2010; Ratcliffe et al. 2013). So how can we capture and address these varied illness experiences included in comorbid respiratory and anxiety disorders? This is what we call the problem of differentiation.

The definition of anxiety disorders, found in the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, *DSM-5* 2013a), relies on differentiating between fear and anxiety as an appropriate response to a real or impending threat, as opposed to an anticipatory state related to distressing distorted thoughts or irrational beliefs regarding certain situations, bodily feelings, and other perceived threats (cf. Esser et al. 2015). Anxiety often leads to avoidance behaviors that may temporarily reduce anxiety symptoms, yet increasingly result in hypervigilance, reduced activities, and maintaining the fight-or-flight response (*DSM-5* 2013a, 189).

As we are focusing on anxiety and its relationship to the lived world of the breathless person, an immediate difficulty arises because the anxiety response often arises from the fear of having an acute breathlessness episode, a potential threat to life experienced by the patient previously, and thus a realistic concern. Past events of acute breathlessness inform the present and arouse anxiety about the future. It is difficult for patients and clinicians to initially distinguish between the breathlessness caused by panic anxiety and the underlying respiratory illness. Moreover, anxiety is often experienced prior to breathing difficulties, as a warning that blood oxygen levels are low (see below). This, again, demonstrates that aspects of breathing disruption are nonreducible to discrete physiological, emotional, and psychological elements. Intense fearful thoughts, including thinking about death, fear of losing control, and feeling hopelessness and confusion, are also frequently reported (Willgoss et al. 2012).

We suggest, therefore, that three themes in the comorbidity of breathlessness and anxiety are revealed by a phenomenological analysis:

- a A problematic relationship with breathing: Anxiety is not only a cause of breathlessness, nor a separate symptom. On the one hand, anxiety can warn of low blood oxygen saturation prior to the experience of breathlessness, and thus predates the conscious somatic experience (Eccleston 2016). On the other, idiopathic anxiety episodes often occur in social situations such as visiting crowded spaces, and thus exacerbate physiologically caused breathlessness. This often results in a vicious cycle whereby anxiety and breathlessness trigger one another, and patterns of panic and fear of losing control lead one to reduced activities, social isolation, and resultant deconditioning that worsens health and increases the likelihood of depression (Willgoss et al. 2012; Eccleston 2016). As Willgoss notes:

“It’s like a vicious circle. Your breathing gets bad so you get anxious, then you get afraid, and your breathing gets worse, which makes you more afraid” (Willgoss et al. 2012, 565).

Such vicious cycles reinforce the “big five”: physiological, emotional, cognitive, behavioral, and situational binds that are triggered in anxiety and breathlessness, making it much harder for the patient to break free from the panic (Wells 1997; LeDoux 2015). Avoidant behavior and hypervigilance leave the patient exhausted and on constant high alert (LeDoux 2015, 17). Further, breathlessness conditions such as asthma are more common in those with comorbid anxiety and depressive symptoms, with a higher prevalence in women, pointing to gendered and social contributions to the development of these disorders (Kewalramani et al. 2008; Kirkengen 2010; cf. Hegarty 2011).

- b Anxiety, like severe breathlessness, is often experienced as uncontrollable, with an almost constant fight to regain control, as panic and helplessness are felt while trying to control the anxiety. One could attempt to regain control by practicing “self-talk” (Willgoss et al. 2012), or by employing safety behaviors such as sitting by exits. This may alleviate some of the stress in the short term but also creates an association between these behaviors and prevention of anxiety, which becomes distorted so that elements of magical thinking and further avoidance behaviors come into play. This maintains the anxiety or panic disorder as the patient does not challenge his or her beliefs about anxiety and its relationship to his or her condition (Wells 1997).
- c The life-changing and life-limiting nature of such experiences. Experiences of anxiety and severe breathlessness are often described as traumatic and isolating with some patients referring to them as “near-death experiences” (Willgoss et al. 2012). Feeling unable to breathe adequately, being smothered, or unable to escape often causes meta-worry (worry about worry) due to the fear of an uncontrollable panic attack. Furthermore, caregivers often underestimate the severity and intensity of breathing distress due to its terrifying yet subjective and silent nature (cf. Binks et al. 2016). Indeed, the persistent worry and sense of impending doom overlaps with another anxiety disorder, generalized anxiety disorder (GAD), and so multiple morbidities can interact and reinforce feelings of loss of control. Not even sleep can offer respite in some cases: Many respiratory patients suffer from nocturnal hypoxemia. A consequence of this is startled awakening and disturbed sleep, described as feeling suffocated, choking, and terrified of dying “making anxiety as a 24-hour ongoing disorder” (Alkhuja 2013, 82).

When the triggers to the occurrence of panic attacks and anxiety are vague and the episodes idiopathic, the patient does not know when the next attack will occur. This can be understood in terms of the world itself becoming an object of fear for the patient and explains why some anxiety patients become housebound even when their breathlessness is not caused by an underlying physiological pathology. Here, panic anxiety is not just due to bodily betrayal; the threat of breathlessness can be viewed as a threat with both an internal and external source. Internally, the body is experienced as a source of threat with breathlessness causing the fear of choking, suffocation, and loss of control. Panic attacks thereby alienate the patients from their usual being at home in the world, with the threat posed by one's own self felt as a bodily or brain betrayal as the fear and anxiety take over despite no discernible underlying pathology (Svenaeus 2000). Externally, the world can be viewed as a threat with cognitions of not feeling safe due to the world's hostility and potential source of the onset of another attack: for instance, when pollen sets off an asthma attack, or when a panic attack has previously occurred in a supermarket or other public place under the stigmatizing gaze of others in the world. Others, too, can be perceived as sources of danger to the anxious person, whether it is through worry of judgment when undergoing a breathless, panicked episode to medical stereotyping of a mental health diagnosis. Further avoidance and withdrawal from social, medical, and everyday situations can lead to agoraphobia and becoming housebound, restricting patients' lives and future experiences.

We suggest that psychiatric and psychological conceptualization and treatment for anxiety present difficulties related to separating symptoms into cognitive, affective, physiological, and temporal categorizations, which we contrast with the lived experience of these conditions as arising out of and affecting the life-world of the patient. These are experiences that, when studied, reveal the primordial, interrelated, and mutually impacting features of these disorders. Reducing anxiety to faulty information processing leading to false beliefs and negative thinking cuts off the potential revelatory power of these experiences (cf. Wells 1997; LeDoux 2015). We suggest that this is where phenomenology can supplement medical accounts.

Anxiety already has a complex history in philosophical thought; thinkers such as Kierkegaard and Heidegger argued for the power of anxiety in creatively shaping human existence. The focus on the productive role of anxious feelings in providing an opportunity for reflection, has, we argue, been stripped away from the perspective of clinical psychology and psychiatry, which view anxiety as a dysfunctional condition that must be treated rapidly with little consideration of its existential meanings and its impact on the patient's agency and self-understanding (cf. NICE 2011; Haugdahl et al. 2015). In other words, the potential revelatory power of anxious experience

lies in the experience telling us that something is wrong in how we live; that only “I” can take responsibility for my facticity and use this opportunity to choose who I want to be (Heidegger 1962, 304).

O. van den Bergh (2016) argues that interpretation, subjective certainty, past experiences, fear of bodily sensations, and interoceptive bias have an important role in the perception of breathlessness. Developing disambiguation strategies for dealing with the fear of bodily sensations and ambiguity in decision making would help patients cope with their comorbid symptoms and increase feelings of agency; but this is possible only through exploring these experiences in terms of their lived world and subjective interpretation. This is a world that includes environmental and socioeconomic factors and how these affect autonomous agents, who understand how their illness alters their life. They can then reflect on the transformations to their experience and take a stance on their existence, instead of feeling powerless and isolated by the alienating, depersonalized, and controlling features of the illness and the healthcare setting. However, anxiety is often dismissed as an irrational experience to be treated by cognitive restructuring, pharmacological interventions, or behavioral therapies (Teachman et al. 2010). Again, the physiological focus means that the symptoms are to be treated while the existential meaning and social or environmental factors often remain unaddressed.

The potential meaning and intelligibility of these disorders in the context of individual human existence, discourse, and social structures impacting self-understanding and potential positive aspects of anxiety is therefore closed off. Perhaps attending to the anxious experience in relation to the insidious increase of respiratory disease in the current climate can tell us more about modern vulnerabilities and concerns in an era of environmental and political instability. At the very least more should be done to recognize the relationship between anxiety and respiratory illnesses, the consequences of undertreatment and underdiagnosis, and finally the lack of treatment options in integrating these areas of illness into the patient’s healing (Department of Health 2008).

A PHENOMENOLOGY OF ANXIOUS BREATHLESSNESS

We now turn to phenomenology to reveal the experiential features of anxious and breathless experiences (Carel 2008, 42). Studying breathlessness via a phenomenological lens uncovers the normal, pre-reflective ways of existing in the world, providing opportunities for self-reflection and understanding. Carel’s (2013b) analysis of illness as a limit case of embodied experience describes how illness pulls us out of our everyday taken-for-granted existence (the “natural attitude”). It can be philosophically productive in that it

can show us how we normally exist in the world and provide us with deeper self-understanding (Carel 2013b, 346). Tacit areas of our existence such as bodily freedom, the habitual body, intentionality, and motility are uncovered and altered by attention to these breathless experiences (cf. Merleau-Ponty 1962). In fact, the phenomenological reduction and bracketing of the natural attitude is analogous to the distancing effect that illness creates (Carel 2013b). We step back from our everyday absorption in the world through breathless experiences and can reflect on the structures of embodied experience through this distancing. Like Heidegger's (1962) notion of angst, possibilities, projects, and our everyday living become radically inaccessible when meaningful existence collapses.

Disclosive affectivity thus implicates the central significance of the body in human experience despite the noted absence in Heidegger of an explicit analysis of the body. Mood, or attunement, is not a mental intentional state accessible only to the conscious subject. Moods color our interactions within the world and shape how things appear and matter to us (Heidegger 1962, 227; Ratcliffe 2008).

Can this phenomenological notion of the collapse of intelligibility in angst map onto anxiety as defined in psychiatric classification manuals such as the *DSM*? We suggest so. Certainly cases of specific phobias are more akin to the ontic descriptions of fleeing from owning up to one's own self and of misinterpreting the self in terms of *das Man* (Heidegger 1962, 164–165). However, the loss of significance and looming threat can cause momentary or enduring collapses into the angst that Heidegger described. Indeed, the anxiety and panic in these anxious experiences may arguably also be ontic versions of angst where the self is covered over and fear displaced onto an undefined threat. However, we believe that there is still a utility to exploring these experiences. This is because they shed light on human freedom and our reflexive natures which enable us to utilize anxious experience to reflect on who we are. In other words, while gripped by angst, the understanding of what it means to be, or existence as a whole, can come into view (Carel 2013a).

In both experiences (of breathlessness and of angst) what remains most vivid even after the collapse of intelligibility and the ensuing practical paralysis is the confrontation with our own death. Studying these experiences reveals that one day I will no longer exist. That nothingness can overwhelm me at any time. Once I face this, embracing the full awareness of my own death, I can reclaim my existence and stop it being governed by the demands and interpretations of others (Heidegger 1962, 308).

This account fits with the changes to body image, self-identity, and self-understanding frequently reported by patients with dyspnea and panic disorder (Carel 2013b; Carel 2016). As previously described, rather than the body being in the background while people are going about their daily activities,

they now become aware of new limitations: Breathlessness and a tight chest bring their awareness back to the body and how they can no longer live care-free, but rather exist under the constant threat of mortality. Their body image is altered through changes to embodiment and existential threat via breathlessness (Carel 2016; Haugdahl et al. 2017). They may no longer understand themselves as healthy, or identify as an athlete, as illness progresses and restricts these possibilities.

Breathlessness and anxiety experiences thus cause a shift in the life-world and embodied experience of the patient. They must find new ways of coping with changes in their habitual repertoire, due to the closing down of certain possibilities (Carel 2016). Indeed, the initial crisis of symptom appearance or diagnosis often causes grief and so it is important that clinicians are aware of emotional needs the patients may have by considering their experiences as illuminated by phenomenology (cf. Merleau-Ponty 1962, 189). Evidence shows that phenomenological descriptions match qualitative research and patient descriptions of their disorders and so reflect the reality of the patient experience (Ratcliffe and Broome 2012).

We suggest that in cases of common but severe mental disorders such as panic disorder comorbid with respiratory illness, the pre-anxious, pre-breathless body is often hard to re-access. Knowledge of the habitual body performing certain roles and actions becomes so remote that the memory of them almost takes on a “dream-like quality” (Ratcliffe 2013). This can in part account for the insidious character of these disorders: Not only are these routines and possible ways of being closed off to me, I cannot remember taking them up and enacting them nor imagine doing so in the future. Their significance and meaning have been suspended and no longer show up as something that I could do, nor that I want to any longer (Carel 2011). In chronic illness, the habitual body often adapts to the losses in motor habits and previously enjoyed activities, but these lost abilities still hold significance and meaning for the sufferer that may begin to diminish as time passes. They must adapt to the new limitations by carefully attending to their new embodied situation:

It may be said that the body is “the hidden form of being our self,” or on the other hand, that personal existence is “the taking up and manifestation of a being in a given situation.” (Merleau-Ponty 1962, 192)

However, there are potential positive aspects to these experiences. The loss of significance described here as caused by these comorbid illnesses can be recovered whence the body is opened once again

to others or to the past, when it opens the way to co-existence and once more (in the active sense) acquires significance beyond itself. Moreover, even when cut off from the circuit of existence, the body never quite falls back onto itself.

Even if I become absorbed in the experience of my body and in the solitude of sensations, I do not succeed in abolishing all reference of my life to a world. (Merleau-Ponty 1962, 191)

The world is always calling to me to respond in addition to the intentionality directed toward the vista in front of me, or of consideration of my next task. Anxiety is thus a temporary experience, but still one with the power to disrupt this return. Healthcare practitioners can help aid an incorporation of these experiences into the life of the patient to return him or her to the world of concern, pointedly by the concepts of leaping ahead of the patient, rather than leaping in and removing his or her agency (Heidegger 1962, 159). Exploring the life-world of the patient and the impact of these complex syndromes on his or her ability-to-be is thus imperative.

This focus may also prevent hermeneutical injustice, a subtype of epistemic injustice, defined as “the injustice of having some significant area of one’s social experience obscured from collective understanding owing to hermeneutical marginalization” (Fricker 2007, 158). The lack of shared hermeneutical resources specifically catering to anxious respiratory patients may be attributable to testimonial injustice, with patient knowledge of the severity of their breathlessness silenced or discounted by clinicians who instead focus on their prior mental health diagnosis, socioeconomic status, and prejudices stemming from smoking status (Crichton et al. 2017). The consequences of breathlessness, from struggling to talk to increasing rates of physical disability, possibly leading one to become housebound, contribute to these already-significant barriers in communicating suffering to clinicians due to being too breathless and exhausted to talk or access appropriate treatment for mental and somatic symptoms, for example, to be able to attend various clinics for treatment, and even to think.

The lack of appropriate contact between the patient and clinician is “insufficient to be able to truly understand the challenges that people face in the attempt to integrate a chronic illness into their lives” (Fraser, Kee, and Minick 2006, 550). Indeed, we suggest that phenomenological exploration reveals there should be a refocusing on their lived experience rather than on treating the symptoms in isolation from one another. For instance, addressing breathlessness symptoms or fatigue as discrete fails to capture the wider picture of the debilitating effects of chronic respiratory illnesses, aspects that include social isolation, difficulty in attending outpatient facilities due to fluctuating symptoms, reduced mobility, and so on. The picture can be disjointed, and knowledge and treatment lacking.

As phenomenology reveals, we are active agents in the world, skillfully coping with encountered entities; that skillful coping is disrupted in chronic illness. We can therefore see why medical treatment can be alienating:

Agency is handed over to those assumed to have the best knowledge and skills. A clinician may further alienate a patient when frustration with their failure to attend a pulmonary rehabilitation session or complete homework, for instance, shows their lack of understanding or appreciation of the impact the disorder has on the person and fails to appreciate how intrusive biomedicine can be to patients' personal lives.

CONCLUSION

Within biomedical practice, large differences exist between how practitioners think about disease and illness and how patients experience their illness (Toombs 1987, 1993; Carel 2013a). For example, medical practitioners often thematize illness in terms of patterns of symptoms that persist over time. The symptoms are measured, tested, and form part of the constitution of a functional abnormality, a disease. Yet for the patient, the illness is experienced as a way of being, to be lived through and coped with (Carel 2013a).

How these experiences affect patients' understanding of their disorders is often overlooked. The patients respond to their diagnosis and illness experience, reflecting on what these experiences mean to their current and future ways of living (Jutel 2011). With a diagnosis of a chronic illness, the patients may understandably respond with despair, or the realization of the transience of life and an opportunity to take control of their remaining health (*ibid.*). Other patients struggle to make sense of their experiences through medical narratives alone (Svenaesus 2000). Such a reductive view fails to capture human existence as an embodied, self-interpreting agency in a world with others, who can also take a stand on the patient's illness.² Although an objective medical focus on disease has its place in managing the disorder and alleviating suffering, this view is incomplete (Svenaesus 2000; Kirkengen 2010).

Biomedicine neither prioritizes nor fully utilizes patient experience of medical care despite medicine's stated commitment to patient-centered care (NICE 2011). The consequences of this range from failing to meet patient needs comprehensively to lacking a complete, adequate picture of the effects of illness and medical intervention on the patient. Indeed, the patients' experience of their disorder in the clinical encounter and management of their disorders often reveals injustices committed against them (Carel and Kidd 2014). We suggest that phenomenological description, for example, the patient toolkit developed by Carel (2012b, 2013a), can thematize patient experiences and provide deeper knowledge and understanding of these human ways of being and experiences of medical care.

Phenomenology is free of naturalistic or scientific commitment to ways of ordering experience and entities in the world. Diverse experiences of

illness across episodes, individuals, and even cultures are not subsumed under preexisting categories or epistemological frameworks. Instead patient experiences are listened to and described, with shared themes and features of illness appearing without any dogmatic structuring from the listener. This allows the patients to be heard, and a study of alterations in their existence through their experiences to be attended to. Attending to illness phenomenologically discloses the shared world of meaning whereby features of illness experiences are described in order for the patient and those around him or her to understand the changes brought about through illness. Practically, this knowledge can be used in practitioner training to redress issues such as communication difficulties.

Ultimately, phenomenology provides a framework to describe the closing down of possibilities and human ways of existing. In contrast to phenomenological description, then, naturalistic or biomedical accounts continue to fail in accounting for these differences. Phenomenology hence provides a descriptive and interpretive framework to describe these transformations to lived experiences and personhood, which can complement medical understanding of illness experiences. It also offers freedom from certain metaphysical or epistemological commitments that underpin reductive accounts of human existence. For example, Nicholls argues that chronic breathlessness can be viewed as “a product of a person’s life experience rather than as a patho-physiological entity” (Nicholls 2003, 124). In contrast to seeing illness as a manifestation of an underlying disease process, he argues for the importance of the personal meaning of illness in qualitative research, underscoring a move from biomedical traditional focus on symptom descriptions to an account that captures a fluid, complex set of experiences that evidence-based medicine (EBM) fails to appreciate (Nicholls 2003, 125).

As we have described here, breathlessness conditions often have subjective multidimensional phenomena at their heart: personal, interpersonal, social, cultural, emotional, and metaphysical. Indeed, sometimes only the patients can interpret these experiences and so a phenomenological analysis is indispensable (Nicholls 2003; Carel 2013b; Ratcliffe 2012).

Furthermore, the interaction between these varied elements is often underplayed in healthcare research (Nicholls 2003, 123). Rather than explaining illness responses as emerging rational narratives incorporated into the ill person’s bodily schema or identity, “chronic illness is a more complex, fluid, dynamic phenomenon that current biomedicine would have us believe” (ibid.).

Analogously, depression and anxiety disorders are not easily predictable in this manner either: spontaneous remission, worsening, and “good days/bad days,” for instance, show up the relational characteristics of illness experiences. In other words, embodied existence is not *partes extra partes*. It is unified and modified both by the body as constitutive for experience, and

perception and the world shaping this experience, including the stance that the patient takes upon his or her illness.

Finally, we have seen how anxiety and breath are deeply related: The onset of anxiety can reveal oxygen deprivation. Episodes of breathlessness due to either “cause” are difficult to differentiate at first, and subjective variances that do not match objective measurements occur. Dualistic thinking underlies physical and mental clinical practice which causes many problems in understanding and treating certain illnesses. For instance, patients referred often struggled at first with their diagnosis of anxiety disorder; after many tests and referrals, they felt sure their symptoms (shortness of breath or heart palpitations) were due to a somatic disease. This demonstrates the implicit dualistic thinking that underlies conceptions of mental disorders being in the mind, and physical symptoms as caused by a somatic disease and this is what patients have inherited from our social and medical milieu.

A potential remedy to these problems has been suggested by attending to the lived experiences of the anxious respiratory patient to understand the meaning and significance of these complex conditions. Such attention can aid the development of truly patient-centered integrated health care that evidence demands in such complex cases.

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NOTES

1. Another example of how phenomenological description can help distinguish between two conditions is that of breathlessness in asthma and in COPD (Simon et al. 1990; cf. Lansing et al. 2009). It seems that the term *breathlessness* may not describe the same type of experience in every case. We claim that it is important to have conceptually clear accounts not only for clinical purposes, for example, to avoid misdiagnosis but also to understand what we mean by the term in order to understand the lived experiences of those who suffer from breathlessness and to reduce the alienation patient reportedly experience in the medical encounter (Toombs 1987). Unfortunately mental health practitioners are only just getting training on chronic illness integrated health care in the UK, so this was a tentative process.

2. The invitation to reflection and to philosophize, to reexamine and reinterpret one’s life alongside modifying movements and goals uncovers edifying possibilities that illness presents (Carel 2011, 2016; Kidd 2012).

References

- AARP. 2017. About the AARP Purpose Prize Award. <http://www.aarp.org/about-aarp/purpose-prize/>. Accessed on July 11, 2017.
- Abecassis, M., Adams, M., Adams, P., Arnold, R. M., Atkins, C. R., Barr, M. L., Bennett, W. M. et al., Live Organ Donor Consensus Group. 2000. Consensus statement on the live organ donor. *JAMA* 284(22): 2919–2926.
- Abernathy, A., Wheeler, J. 2008. Total dyspnoea. *Current Opinion in Supportive and Palliative Care* 2: 110–113.
- Agar, N. 2013. *Truly human enhancement: A philosophical defense of limits*. Cambridge, MA: MIT Press.
- Ahmed, S. 2004. Collective feelings, or the impression left by others. *Theory, Culture & Society* 21(2): 25–42.
- . 2006. *Queer phenomenology: Orientations, objects, others*. Durham and London: Duke University Press.
- Aho, J., Aho, K. 2009. *Body matters: A phenomenology of sickness, disease, and illness*. Lanham, MD: Lexington Books.
- Aho, K. 2003. Why Heidegger is not an existentialist: Interpreting authenticity and historicity in *Being and Time*. *Florida Philosophical Review* 3(2): 5–22.
- . 2008. Medicalizing mental health: A phenomenological alternative. *Journal of Medical Humanities* 29(4): 243–259.
- . 2016. Heidegger, ontological death, and the healing professions. *Medicine, Health Care and Philosophy* 19(1): 55–63.
- Aho, K., Guignon, C. 2011. Medicalized psychiatry and the talking cure: A hermeneutic intervention. *Human Studies* 34(3): 293–308.
- Alderman, H. 1978. Heidegger's critique of science and technology. In M. Murray (ed.), *Heidegger and modern philosophy* (35–50). New Haven, CT: Yale University Press.
- Alkhuja, S. 2013. Anxiety Disorders in Patients with COPD. *Respiratory Care*. 58(10) e131; DOI: <https://doi.org/10.4187/respcare.02716>

- Ambagtsheer, F., Zaitch, D., Weimar, W. 2013. The battle for human organs: Trafficking and transplant tourism in a global context. *Global Crime* 14(1): 1–14.
- American Psychiatric Association (APA). 1994. *Diagnostic and statistical manual of mental disorders: DSM-4*. 4th edition. Washington, DC: American Psychiatric Press.
- . 2013a. *Diagnostic and statistical manual of mental disorders: DSM-5*. 5th edition. Washington, DC: American Psychiatric Press.
- . 2013b. Major depressive disorder and the “bereavement exclusion.” https://www.psychiatry.org/2FFile%2520Library%2FPsychiatrists%2FPractice%2FDSM%2FAPA_DSM-5-Depression-Bereavement-Exclusion.pdf
- American Thoracic Society. 1995. Standards for the diagnosis and care of patients with chronic obstructive pulmonary disease. *American Journal of Respiratory Critical Care Medicine* 152: S77–S121.
- Améry, J. 1999. *At the mind's limits: Contemplations by a survivor on Auschwitz and its realities*. S. Rosenfeld and S.P. Rosenfeld (trans.) London: Granta Books.
- Anderson, E. 1999. *The code of the street: Decency, violence, and the moral life of the inner city*. New York: Norton.
- Aouizerate, B., Cuny, E., Martin-Guehl, C., Guehl, D., Amieva, H., Benazzouz, A. et al. 2004. Deep brain stimulation of the ventral caudate nucleus in the treatment of obsessive-compulsive disorder and major depression: Case report. *Journal of Neurosurgery* 101(4): 682–686.
- Atwood, G. E. 2011. *The abyss of madness*. New York: Routledge.
- Atwood, G. E., Stolorow, R. D. 2014. *Structures of subjectivity: Explorations in psychoanalytic phenomenology and contextualism*, Second edition. London and New York: Routledge.
- Averill, J. 1968. Grief: Its nature and significance. *Psychological Bulletin* 70(6): 721–748.
- Aydede, M. (ed.). 2005. *Pain: New essays on its nature and the methodology of its study*. Cambridge, MA: MIT Press.
- Bachelard, Gaston. 1987. *The psychoanalysis of fire*. A. C. M. Ross (trans.) Boston: Beacon Press.
- . 2014. *The poetics of space*. M. Jolas (trans.) Harmondsworth: Penguin.
- Bain, D. 2013. What makes pains unpleasant? *Philosophical Studies* 166: S69–S89.
- Bartky, S. 1990. Foucault, femininity, and the modernization of patriarchal power. In *Femininity and domination: Studies in the phenomenology of oppression* (63–82). New York: Routledge.
- Beauchamp, T. L., Childress, J. F. 2001. *Principles of biomedical ethics*, 5th edition. Oxford: Oxford University Press.
- Biller-Andorno, N. 2011. Voluntariness in living-related organ donation. *Transplantation* 92(6): 617–619.
- Binks, A., Desjardin, S., Riker, R. 2016. A preliminary study shows ICU clinicians under-estimate breathing discomfort in ventilated patients. *Respiratory Care*. 62(2): 150–155. DOI: <https://doi.org/10.4187/respcare.04927>
- Binswanger, L. 1958a. The case of Ellen West: An anthropological-clinical study. In R. May, E. Angel, and H. F. Ellenberger (eds.), *Existence: A new dimension in*

- psychology and psychiatry*. W. M. Mendel and J. Lyons (trans.) (237–364). New York: Basic Books.
- . 1958b. The existential analysis school of thought. In R. May, E. Angel, and H.F. Ellenberger (eds.), *Existence: A new dimension in psychology and psychiatry*. E. Angel (trans.) (191–213). New York: Basic Books.
- . 1962. *Grundformen und Erkenntnis menschlichen Daseins*. Munich, Germany: Ernst Reinhardt Verlag.
- Borgmann, A. 2005. Technology. In H. Dreyfus and M. Wrathall (eds.), *A companion to Heidegger* (420–432). Oxford: Blackwell Publishing.
- Boyar, J. I. 1964. The construction and partial validation of a scale for the measurement of the fear of death. *Dissertation Abstracts International* 25: 20–21.
- Boym, Svetlana. 2001. *The future of nostalgia*. New York: Basic Books.
- Bremer, S. 2011. *Kroppslinjer: kön, transsexualism och kropp i berättelser om köns-korrigering*. Göteborg: Makadam.
- Buber, M. 1972. *I and thou*. R. G. Smith (trans.) New York: Scribners.
- Buchbinder, E., Eisikovits, Z. 2003. Battered women's entrapment in shame: A phenomenological study. *American Journal of Orthopsychiatry* 73: 355–366.
- Bullington, J. 2013. *The expression of the psychosomatic body from a phenomenological perspective*. Berlin and Heidelberg: Springer.
- Burnell, P., Hulton, S.-A., Draper, H. 2015. Coercion and choice in parent–child live kidney donation. *Journal of Medical Ethics* 41: 304–309.
- Call, L. 2013. *BDSM in American science fiction and fantasy*. Basingstoke: Palgrave Macmillan.
- Camus, A. 1989. *The stranger*. M. Ward (trans.) New York: Vintage International.
- Canguilhem, G. 1991. *The normal and the pathological*. C. R. Fawcett and R. S. Cohen (trans.) New York: Zone Books.
- Carel, H. 2007. Can I be ill and happy? *Philosophia* 35(2): 95–110.
- . 2008. *Illness. The cry of the flesh*. Durham: Acumen.
- . 2011. Phenomenology and its application in medicine. *Theoretical Medicine and Bioethics* 32(1): 33–46.
- . 2012a. Nursing and medicine. In S. Luft and S. Overgaard (eds.), *The Routledge companion to phenomenology* (623–632). London: Routledge.
- . 2012b. Phenomenology as a resource for patients. *Journal of Medicine and Philosophy* 37(2): 96–113.
- . 2013a. Illness, phenomenology, and the philosophical method. *Theoretical Medicine and Bioethics* 34(4): 345–357.
- . 2013b. Bodily doubt. *Journal of Consciousness Studies* 20(7–8): 178–197.
- . 2014. Ill, but well: A phenomenology of well-being in chronic illness. In J. Bickenbach, F. Felder, and B. Schmitz (eds.) *Disability and the good life* (243–270) Cambridge: Cambridge University Press.
- . 2016. *Phenomenology of illness*. Oxford: Oxford University Press.
- Carel, H., Dodd, J., Macnaughton, J. 2015. Invisible suffering: Breathlessness in and beyond the clinic. *The Lancet Respiratory Medicine* 3(4): 278–279.
- Carel, H. H., Kidd, I. J. 2014. Epistemic injustice in healthcare: A philosophical analysis. *Medicine, Health Care and Philosophy* 17(4): 529–540. DOI: 10.1007/s11019-014-9560-2

- Carson, R. A., Burns, C. R., Cole, T. R. (eds.). 2003. Introduction. In *Practicing the medical humanities: Engaging physicians and patients*. Hagerstown, MD: University Publishing Group.
- Casey, Edward. 1987. The world of nostalgia. *Man and World* 20(4): 361–384.
- Chanarin, I. 1992. Pernicious anaemia. Diagnosis should be certain before treatment is begun. *British Medical Journal* 304: 1584–1585.
- Chappell, T. 2007. Infinity goes up on trial: Must immortality be meaningless? *European Journal of Philosophy* 17(1): 30–44.
- Christman, J. 2004. Relational autonomy, liberal individualism and the social constitution of the selves. *Philosophical Studies* 117: 143–164.
- Cole, J. 2004. *Still lives: Narratives of spinal cord injury*. Cambridge, MA: MIT Press.
- Conrad, P. 2007. *The medicalization of society: On the transformation of human conditions into treatable disorders*. Baltimore, MD: The Johns Hopkins University Press.
- Corns, J. 2014a. The inadequacy of unitary characterizations of pain. *Philosophical Studies* 169: 355–378.
- . 2014b. Unpleasantness, motivational oomph, and painfulness. *Mind & Language* 29: 238–254.
- . 2015. The social pain posit. *Australasian Journal of Philosophy* 93: 561–582.
- Crichton, P., H. Carel and I. J. Kidd. 2016. Epistemic Injustice in Psychiatry. *British Journal of Psych Bulletin* 41(2): 65–70. <http://pb.rcpsych.org/content/pbrpsych/early/2016/08/18/pb.bp.115.050682.full.pdf>. DOI: 10.1192/pb.bp.115.050682
- Crichton, P., Carel, H., Kidd, I. J. 2017. Epistemic injustice in psychiatry. *British Journal of Psychiatry* 41(2): 65–70.
- Crossley, N. 2001. The phenomenological habitus and its construction. *Theory and Society* 30(1): 81–120.
- Crouch, R. A., Elliot, C. 1999. Moral agency and the family: The case of living related organ transplantation. *Cambridge Quarterly of Healthcare Ethics* 8: 275–287.
- Crowther, M. R., Parker, M. W., Achenbaum, W. A., Larimore, W. L., Koenig, H. G. 2002. Rowe and Kahn’s model of successful aging revisited: Positive spirituality—the forgotten factor. *Gerontologist* 42: 613–620.
- Culbertson, C. 2016. The omnipotent word of medical diagnosis and the silence of depression. *IJFAB: International Journal of Feminist Approaches to Bioethics* 9 (1): 1–26.
- Currow, D. C., Johnson, M. J. 2015. Dyspnoea. Distilling the essence of breathlessness: The first vital symptom. *European Respiratory Journal* 45: 1526–1528.
- Dallmayr, F. 2000. The enigma of health: Gadamer at century’s end. In L. K. Schmidt (ed.), *Language and linguisticality in Gadamer’s hermeneutics* (155–169). Lanham, MD: Lexington.
- Dass, R. 2001. *Still here: Embracing aging, changing, and dying*. New York: Riverhead Books.
- Dass, R., Gorman, P. 1985. *How can I help?: Stories and reflections on service*. New York: Alfred A. Knopf.
- Dastur, F. 2012. *How are we to confront death?: An introduction to philosophy*. R. Vallier (trans.) New York: Fordham University Press.
- Del Carmen, M. G., Joffe, S. 2005. Informed consent for medical treatment and research: A review. *The Oncologist* 10(8): 636–641.

- Department of Health. 2008. *Commissioning IAPT for the whole community: Improving access to psychological therapies*. DH Publications: London.
- Department of Health. 2010. *Inclusion health: Improving primary care for socially excluded people*. DH Publications: London.
- . 2011. *No health without mental health*. UK: Department of Health.
- Social Exclusion Task Force. (2010). *Inclusion health: Improving the way we meet the primary health care needs of the socially excluded*. London.
- Descartes, R. 1989. *Meditations on first philosophy*. J. Veitch (trans.) Buffalo, NY: Prometheus Books.
- Deutsch, H. 1937. Absence of grief. *The Psychoanalytic Quarterly* 6: 12–22.
- Devisch, I. 2010. Oughtonomy in healthcare. A deconstructive reading of Kantian autonomy. *Medicine, Health Care and Philosophy* 13(4): 303–312.
- . 2012. Co-responsibility: A new horizon for today's health care? *Health Care Analysis* 20(2): 139–151.
- Devisch, I., Vanheule, S. 2014. Singularity and medicine: Is there a place for heteronomy in medical ethics? *Journal of Evaluation in Clinical Practice* 20(6): 965–969.
- Dibley, L., Coggrave, M., McClurg, D., Woodward, S., Norton, C. 2017. “It’s just horrible”: A qualitative study of patients’ and carers’ experiences of bowel dysfunction in Multiple Sclerosis. *Journal of Neurology* 264(7): 1354–1361.
- Donchin, A. 2001. Understanding autonomy relationally: Toward a reconfiguration of bioethical principles. *Journal of Philosophy and Medicine* 26: 365–386.
- Dreyfus, H. L. 1991. *Being-in-the-world*. Cambridge, MA: MIT Press.
- . 2005. Foreword. In C. J. White (ed.), *Time and death*. Aldershot: Ashgate.
- . 2009. *On the internet*. New York: Routledge.
- Eccleston, C. 2016. *Embodied: The psychology of physical sensation*. Oxford: Oxford University Press.
- Ekstrom, M. P., Abernethy, A., Currow, D. C. 2015. The management of chronic breathlessness in patients with advanced and terminal illness. *British Medical Journal* 349: 1–7. DOI: <http://dx.doi.org/10.1136/bmj.g7617>
- Elliott, C., Chambers, T. (eds.). 2004. *Prozac as a way of life*. Chapel Hill: University of North Carolina Press.
- Engel, G. L. 1961. Is grief a disease? *Psychosomatic Medicine* 23: 18–22.
- Engelberg, M. 2006. *Cancer made me a shallower person: A memoir in comics*. New York: Harper Perennial.
- Engelhardt, H. T. 1982. Illnesses, diseases, and sicknesses. In V. Kestenbaum (ed.), *The humanity of the ill: Phenomenological perspectives* (142–156). Knoxville: University of Tennessee Press.
- Epicurus. 1994. Letter to Menoeceus. In B. Inwood and L. P. Gerson (trans. and eds.), *The Epicurus reader*. Indianapolis, IN: Hackett.
- Esser, R.W., Stoeckel, M.C., Kirsten, A., Watz, H., Lehmann, K., Taube, K., Büchel, C., Magnussen, H., Von Leupoldt, A. 2015. Neural correlates of dyspnea in COPD. *European Respiratory Journal*. 46. DOI: 10.1183/13993003.congress-2015.OA4954
- Fairfield, P. 2014. *Death: A philosophical inquiry*. London: Routledge.
- Falk, G. 2001. *Stigma: How we treat outsiders*. Amherst, NY: Prometheus Books.

- Fernandez, A. V. 2014a. Depression as existential feeling or de-situatedness? Distinguishing structure from mode in psychopathology. *Phenomenology and the Cognitive Sciences* 13(4): 595–612.
- Fernandez, A. V. 2014b. Reconsidering the affective dimension of depression and mania: Towards a phenomenological dissolution of the paradox of mixed states. *Journal of Psychopathology* 20(4): 414–420.
- Fernandez, A. V. 2017. The subject matter of phenomenological research: Existentials, modes, and prejudices. *Synthese* 194(9): 3543–3562. <https://doi.org/10.1007/s11229-016-1106-0>
- Fischer, J. M. 2009. *Our stories: Essays on life, death, and free will*. Oxford: Oxford University Press.
- . 2013. Immortality. In B. Bradley, F. Feldman, and J. Johansson (eds.), *The Oxford handbook of philosophy of death* (336–354). Oxford: Oxford University Press.
- Fisher, H., Aron, A., Brown, L. L. 2005. Romantic love: An fMRI study of a neural mechanism for mate choice. *Journal of Comparative Neurology* 493: 58–62.
- Fisher, T. 2010. Heidegger and the narrativity debate. *Continental Philosophy Review* 43: 241–265.
- Forsberg, A., Nilsson, M., Krantz, M., Olausson, M. 2004. The essence of living parental liver donation—donors’ lived experience of donation to their children. *Pediatric Transplantation* 8: 372–380.
- Foucault, M. 1984. Dream, imagination, and existence: An introduction to Ludwig Binswanger’s “Dream and Existence.” *Review of Existential Psychology & Psychiatry* 19(1): 31–78.
- . 1990. *A history of sexuality. Volume 1: An introduction*. R. Hurley (trans.) New York: Random House.
- Fowler, N. 2014. *AIDS: Don’t die of prejudice*. London: Biteback Publishing.
- Frances, A. 2013. The new crisis of confidence in psychiatric diagnosis. *Annals of Internal Medicine* 159(3): 221–222.
- Frank, A. W. 1991. *At the will of the body*. Boston: Houghton Mifflin.
- Frank, A. W. 1997. *The wounded storyteller: Body, Illness, and Ethics*. Chicago: University of Chicago Press.
- Frankfurt, H. 1998. *The importance of what we care about*. Cambridge: Cambridge University Press.
- Fraser, D; Kee, C., Minik, P. 2006. Living with Chronic Obstructive pulmonary Disease: Insiders’ Perspectives. *Journal of Advanced Nursing* 55: 550–558.
- Freeman, L. 2011. Reconsidering relational autonomy: A feminist approach to selfhood and the other in the thinking of Martin Heidegger. *Inquiry* 54: 361–383.
- Fricke, M. 2007. *Epistemic injustice. Power and the ethics of knowing*. Oxford: Oxford University Press.
- Frie, R. 1997. *Subjectivity and intersubjectivity in modern philosophy and psychoanalysis*. New York: Rowman & Littlefield.
- . 1999. Interpreting a misinterpretation: Ludwig Binswanger and Martin Heidegger. *Journal of the British Society for Phenomenology* 30(3): 244–257.

- Friedman, M. 1997. Autonomy and social relationships: Rethinking the feminist critique. In D. Meyers (ed.), *Feminists rethink the self* (40–61). Boulder and Oxford: Westview Press.
- Frohlich, D. O. 2014. Support often outweighs stigma for people with inflammatory bowel disease. *Gastroenterology Nursing* 37: 126–136.
- Fuchs, T. 2000. *Psychopathologie von Leib und Raum: Phänomenologisch-empirische Untersuchungen zu depressiven und paranoiden Erkrankungen*. Darmstadt: Steinkopff.
- . 2013. Depression, intercorporeality, and interaffectivity. *Journal of Consciousness Studies* 20(7–8): 219–238.
- . 2016. Intercorporeality and interaffectivity. *Phenomenology and Mind* 11:194–209.
- Fujita, M., Slingsby, B. T., Akabayashi, A. 2004. Three patterns of voluntary consent in the case of adult-to-adult living related liver transplantation in Japan. *Transplant Proceedings* 36(5): 1425–1428.
- Fulford, K. W. M. 1989. *Moral theory and medical practice*. Cambridge: Cambridge University Press.
- Gabara, S., Schön, S., Stendahl, S. 2015. Epidemiologi. *Svenskt Njurregister, Årsrapport*. <http://www.medscinet.net/snr/rapporterdocs/Svenskt%20Njurregister%20%C3%85rsrapport%202015.pdf>. Accessed June 3, 2017.
- Gadamer, H. -G. 1996. *The enigma of health*. J. Gaiger and N. Walker (trans.) Stanford, CT: Stanford University Press.
- . 2004. *A century in philosophy: Hans-Georg Gadamer in conversation with Riccardo Dottori*. New York: Continuum.
- Gallagher, S., Jacobson, R. 2012. Heidegger and social cognition. In J. Kiverstein and M. Wheeler (eds.), *Heidegger and cognitive science* (213–245). London: Palgrave-Macmillan.
- Gallagher, S., Morgan, B., Rokotnitz, N. 2017. Relational authenticity. In O. Flanagan and G. Caruso (eds.), *Neuroexistentialism: Meaning, morals, and purpose in the age of neuroscience*. New York: Oxford University Press.
- Gawande, A. 2014. *Being mortal: Medicine and what matters in the end*. New York: Metropolitan Books.
- Geniušas, S. 2015. The pathos of time: Chronic pain and temporality. *Dialogue and Universalism* 3: 25–38.
- Gilhousen, R. 2017. *The lived experience of individuals living with human immunodeficiency virus (HIV) and acquired immune deficiency (AIDS) while residing in a rural region of Northern Appalachia*, Doctoral Dissertation, Duquesne University School of Nursing.
- Goffman, E. 1974. *Stigma: Notes on the management of spoiled identity*. New York: Jason Aronson.
- Goldie, P. 2011. Grief: A narrative account. *Ratio* 24(2): 119–137.
- Goodman, P. 1969. Can technology be humane? *New York Review of Books* 13(9). <http://www.nybooks.com/issues/1969/11/20/>
- Grahek, N. 2007. *Feeling pain and being in pain*, 2nd edition. Cambridge, MA: MIT Press.

- Guignon, C. 1983. *Heidegger and the problem of knowledge*. Indianapolis, IN: Hackett.
- . 2011. Heidegger and Kierkegaard on death: The existentiell and the Existential. In P. Stokes and A. Buben (eds.), *Kierkegaard and death* (184–203). Bloomington: Indiana University Press.
- Gunnarson, M. 2016. *Please be patient. A cultural phenomenological study of haemodialysis and kidney transplantation care*. Lund: Lund University Press.
- Gysels, M. Higginson, I.J. 2008. Access to services for patients with chronic obstructive pulmonary disease: The invisibility of breathlessness. *Journal of Pain and Symptom Management* 36(5): 451–460.
- Hart, J. 1973. Toward a phenomenology of nostalgia. *Man and World* 6(4): 397–420.
- Haugdahl, H. S., Dahlberg, H., Klepstad, P., Storli, S. L. 2017. The breath of life. Patients' experiences of breathing during and after mechanical ventilation. *Intensive Critical Care Nursing* 40: 85–93.
- Haugdahl, H. S., Storli, S. L., Meland, B., Dybwik, K., Romild, U., Klepstad, P. 2015. Underestimation of patient breathlessness by nurses and physicians during a spontaneous breathing trial. *American Journal of Respiratory and Critical Care Medicine* 192(12): 1440–1448.
- Hauskeller, M. 2014. *Better humans? Understanding the enhancement project*. London: Routledge.
- Hawley, K. 2015. Trust and distrust between patient and doctor. *Journal of Evaluation in Clinical Practice* 21: 798–801.
- Hayden, E. C. 2016. Tomorrow's children: What would genome editing really mean for future generations? *Nature* 530: 402–405.
- Healy, D. 1999. *The antidepressant era*. Cambridge: Cambridge University Press.
- Hegarty, K. 2011. Domestic violence: The hidden epidemic associated with mental illness. *The British Journal of Psychiatry* 198: 169–170. <http://bjp.rcpsych.org/content/198/3/169.full>. Accessed May 19, 2014.
- . 1962. *Being and time*. J. Macquarrie and E. Robinson (trans.) New York: Harper and Row.
- . 1966. Memorial address. *Discourse on thinking*. J. Anderson and H. Freund (trans.) New York: Harper and Row.
- . 1967. *What is a thing?* W. B. Barton, Jr., and V. Deutsch (trans.) Chicago: Henry Regnery.
- . 1977. *The question concerning technology and other essays*. W. Lovitt (trans.) New York: Harper and Row.
- . 1978. Das Ding. In *Vorträge und Aufsätze*. Pfullingen: Neske.
- . 1985. *History of the concept of time: Prolegomena*. T. Kisiel (trans.) Bloomington: Indiana University Press.
- . 1986. *Seminare*. Gesamtausgabe Band 15. Frankfurt am Main: Vittorio Klostermann.
- . 1993a. Letter on humanism. In D. F. Krell (ed.), *Basic writings*. New York: HarperCollins.
- . 1993b. The origin of a work of art. In D. F. Krell (ed.), *Basic writings*. New York: HarperCollins.
- . 1993c. The question concerning technology. In D. F. Krell (ed.), *Basic writings*. New York: HarperCollins.

- . 1993d. *Sein und Zeit*. Tübingen: Max Niemeyer.
- . 1996. *Being and time*. J. Stambaugh (trans.) Albany: State University of New York Press.
- . 2001a. *Zollikon seminars: Protocols-conversations-letters*. F. Mayr and R. Askay (trans.) Evanston, IL: Northwestern University Press.
- . 2001b. Building dwelling thinking. In A. Hofstadter (ed.), *Poetry, language, thought*. New York: Harper and Row.
- . 2001c. The origin of the work of art. In A. Hofstadter (ed.), *Poetry, language, thought*. New York: Harper and Row.
- . 2005. *Introduction to phenomenological research*. D. Dahlstrom (trans.) Bloomington: Indiana University Press.
- . 2006. Letter on humanism. In W. McNeill (ed.), *Pathmarks*. New York: Cambridge University Press.
- . 2008. *Phenomenological interpretations of Aristotle: Initiation into phenomenological research*. R. Rojcewicz (trans.) Bloomington: Indiana University Press.
- Hillman, James. 2000. *The force of character and the lasting life*. New York: Ballantine Books.
- Hofer, Johannes. 1934. Medical dissertation on nostalgia or homesickness. *Bulletin of the Institute of the History of Medicine* 2: 376–391.
- Hoffman, P. 1983. *The human self and the life and death struggle*. Gainesville: University Press of Florida.
- Hutchinson, P., Dhairyawan, R. 2017a. Shame and HIV: Strategies for addressing the negative impact shame has on public health and diagnosis and treatment of HIV. *Bioethics* 32(1): 68–76.
- Hutchinson, P., Dhairyawan, R. 2017b. Shame, stigma, HIV: Philosophical reflections. *Medical Humanities* 43(4): 225–230.
- Ihde, D. 1979. *Technics and praxis*. Dordrecht: Riedel.
- Illbruck, Helmut. 2012. *Nostalgia: Origins and ends of an unenlightened disease*. Evanston, IL: Northwestern University Press.
- Inwood, M. J. 1997. *Heidegger*. New York: Oxford University Press.
- Jacobson, K. 2011. Embodied domestics, embodied politics: Women, home, and agoraphobia. *Human Studies* 34(1): 1–21.
- . 2016. Waiting to speak: A phenomenological perspective on our silence around dying. In S. K. George and P. G. Jung (eds.), *Cultural ontology: The self in pain* (75–92). New Delhi: Springer India.
- James, I. 2006. *The fragmentary demand: An introduction to the philosophy of Jean-Luc Nancy*. Stanford, CA: Stanford University Press.
- Jaspers, K. 1963. *General psychopathology*. Chicago: University of Chicago Press, 1963.
- Johnson, Sandy. 1994. *The book of elders: The life stories and wisdom of great American Indians*. San Francisco, CA: HarperSanFrancisco.
- Jones, M. P., Keefer, L., Bratten, J., Taft, T. H., Crowell, M. D., Levy, R., Palsson, O. 2009. Development and initial validation of a measure of perceived stigma in irritable bowel syndrome. *Psychology, Health and Medicine* 14: 367–374.
- Joseph, Jenny. 1992. *Selected poems*. London: Bloodaxe.
- Joy, B. 2000. Why the future doesn't need us. *Wired*. <https://www.wired.com/2000/04/joy-2/>

- Jung, C. G. 1933. *Modern man in search of a soul*. New York: Harcourt, Brace.
- Jutel, A. M. 2011. *Putting a name to it: Diagnosis in contemporary society*. Baltimore, MD: Johns Hopkins University Press.
- Kay, L. 2015. Stories are difficult like that (unpublished doctoral research), University of Central Lancashire, UK.
- Kewalramani, A., Bollinger, M.E., Postolache, T.T. 2008. Asthma and Mood Disorders. *International Journal of Child Health and Human Development*. 1(2): 115–123.
- Kidd, I. J. 2012. Can illness be edifying? *Inquiry*: 55(5), 496–520.
- Kim, Y., Wininger, K. M., Tye, S. J. 2016. Deep brain stimulation for treatment-resistant depression. In K. H. Lee, P. S. Duffy, and A. J. Bieber (eds.), *Deep brain stimulation: Indications and applications* (197–214). Oxford and New York: Pan Stanford Publishing.
- Kirkengen, A. L. 2010. *The lived experience of violation. How abused children become unhealthy adults*. Bucharest, Romania: Zeta Books.
- Klein, H. S. 2004. *A population history of the United States*. Cambridge: Cambridge University Press.
- Kochanek, K. D., Murphy, S. L., Xu, J. Q., Tejada-Vera, B. 2016. Deaths: Final data for 2014. *National Vital Statistics Reports* 65(4). Hyattsville, MD: National Center for Health Statistics.
- Kolodny, N. 2013. That I should die and others live. In S. Scheffler (ed.), *Death and the afterlife* (159–173) Oxford: Oxford University Press.
- Konnopka, A., Schaefert, R., Heinrich, S., Kaufmann, C., Lupp, M., Herzog, W., König, H.-H. 2012. Economics of medically unexplained symptoms: A systematic review of the literature. *Psychotherapy and Psychosomatics* 81(5): 265–275.
- Kouba, P. 2015. *The phenomenon of mental disorder: Perspectives of Heidegger's thought in psychopathology*. Dordrecht: Springer.
- Knibbe, M. E., Maeckelberghe, E. L. M., Verkerk, M. A. 2007. Confounders in voluntary consent about living parental liver donation: No choice and emotions. *Medicine, Health Care and Philosophy* 10(4): 433–440.
- Kraemer, F. 2013. Me, myself and my brain implant: Deep brain stimulation raises questions of personal authenticity and alienation. *Neuroethics* 6: 483–497.
- Kramer, P. 1994. *Listening to Prozac*. London: Fourth Estate.
- Kraus, A. 2003. How can the phenomenological-anthropological approach contribute to diagnosis and classification in psychiatry? In B. Fulford, K. Morris, J. Z. Sadler, and G. Stanghellini (eds.), *Nature and narrative* (199–216). Oxford: Oxford University Press.
- Kunik, M. E., Roundy, K., Veazey, C., et al. 2005. Surprisingly high prevalence of anxiety and depression in chronic breathing disorders. *Chest* 127: 1205–1211.
- Kusch, M. 2017. Analysing Holocaust survivor testimony: Certainties, scepticism, relativism. In S. Krämer and S. Weigel (eds.), *Testimony/bearing witness: Epistemology, ethics, history and culture*. London: Rowman and Littlefield International.
- Kurzweil, R. 2001. Promise and peril. <http://www.kurzweilai.net/promise-and-peril>
- Käll, L. F. 2009. Expression between self and other. *Idealistic Studies* 39: 71–86.
- . 2013. Intercorporeality and the shareability of pain. In L. F. Käll (ed.), *Dimensions of pain* (27–40). New York: Routledge.

- . 2014. Intercorporeality and the constitution of the body schemata. In R. F. Fox and N. M. Monteiro (eds.), *Pain without boundaries: Inquiries across cultures* (51–62). Oxford: Inter-Disciplinary Press.
- Käll, L. F., Zeiler, K. 2014. Bodily relational autonomy. *Journal of Consciousness Studies* 21(9–10): 100–120.
- Kärrfelt, H. M. E., Berg, U. B., Lindblad, F. I. E. 2000. Renal transplantation in children: Psychological and donation-related aspects from the parental perspective. *Pediatric Transplantation* 4: 305–312.
- Lansing, R. W., Gracely, R. H., and Banzett, R. B. 2009. The multiple dimensions of dyspnea: Review and hypothesis. *Respiratory Physiology and Neurobiology* 167(1): 53–60.
- Leder, D. 1990. *The absent body*. Chicago, IL: University of Chicago Press.
- . 1992. A tale of two bodies: The Cartesian corpse and the lived body. In D. Leder (ed.), *The body in medical thought and practice* (17–35). Dordrecht: Kluwer Academic Publishers.
- . 1997. *Spiritual passages: Embracing life's sacred journey*. New York: Tarcher/Putnam.
- . 1998. The trouble with successful aging. *The Park Ridge Center Bulletin* October/November: 10–11.
- LeDoux, J. 2015. *Anxious: The modern mind in the age of anxiety*. London: Oneworld Publications.
- Lennerling, A., Forsberg, A., Nyberg, G. 2003. Becoming a living kidney donor. *Transplantation* 76(8): 1243–1247.
- Loeser, J. D., Melzack, R. 1999. Pain: An overview. *The Lancet* 353: 1607–1609.
- Löwith, K. 1928. *Das Individuum in der Rolle des Mitmenschen*. In K. Stichweh (ed.), *Sämtliche Schriften* 1: 9–197. Stuttgart: J. B. Metzler.
- Lyons, O. 1980. An Iroquois perspective. In C. Vescey and R. Venables (eds.), *American Indian environments: Ecological issues in Native American history* (202–205). Syracuse, NY: Syracuse University Press.
- Ma, P., Mumper, R. J. 2013. Paclitaxel nano-delivery systems: A comprehensive review. *Journal of Nanomedicine and Nanotechnology* 4(2): 1000164.
- Mackenzie, C., Stoljar, N. (eds.). 2000. *Relational autonomy: Feminist perspectives on autonomy, agency, and the social self*. Oxford: Oxford University Press.
- Madison, G. B. 2013. *On suffering: Philosophical reflections on what it means to be human*. Hamilton: McMaster Innovation Press.
- Malmqvist, E., Zeiler, K. 2010. Cultural norms, the phenomenology of incorporation and the experience of having a child born with ambiguous sex. *Social Theory and Practice* 36(1): 157–164.
- Malpas, J. 1998. Death and the unity of a life. In J. Malpas and R. C. Solomon (eds.), *Death and philosophy* (120–134). London: Routledge.
- Marmot, M. 2010. Fair society, healthy lives. The Marmot Review: Strategic review of health inequalities in England post-2010. Available at <https://www.local.gov.uk/marmot-review-report-fair-society-healthy-lives>
- Marrato, S. L. 2012. *The intercorporeal self: Merleau-Ponty on subjectivity*. Albany: State University of New York Press.

- Marx, W. 1987. *Is there a measure on Earth? Foundations for a nonmetaphysical ethics*. T. J. Nenon and R. Lilly (trans.) Chicago, IL: University of Chicago Press.
- Matas, A. J. 2004. The case for living kidney sales: Rationale, objections and concerns. *American Journal of Transplantation* 4(12): 2007–2017.
- Maurer, J., Rebbapragada, V., Borson, S., Goldstein, R., Kunik, M. E., Yohannes, A. M., Hanania, N. A. 2008. Anxiety and depression in COPD: Current understanding, unanswered questions, and research needs. *Chest* 134 (4 Suppl.): 43S–56S.
- Maxwell, J. A. 2013. *Qualitative research design: An interactive approach*, 3rd edition. Los Angeles, CA: Sage.
- May, T. 2009. *Death*. Stocksfield: Acumen.
- McManus, S., Bebbington, P., Jenkins, R., Brugha, T. (eds.). 2016. *Mental health and wellbeing in England: Adult Psychiatric Morbidity Survey 2014*. Leeds: NHS Digital.
- McQuellon, R. P., Cowan, M. A. 2000. Turning toward death together: Conversation in mortal time. *The American Journal of Hospice & Palliative Care* 17(5): 312–318.
- Merleau-Ponty, M. 1962. *The phenomenology of perception*. C. Smith (trans.) London: Routledge.
- . 1963. The philosopher and his shadow. *Signs*. R. McCleary (trans.) Evanston, IL: Northwestern University Press.
- . 1964. *The primacy of perception*. Evanston, IL: Northwestern University Press.
- . 1968. *The visible and the invisible*. Evanston, IL: Northwestern University Press.
- . 2006. *The phenomenology of perception*. C. Smith (trans.) London: Routledge.
- . 2012. *The phenomenology of perception*. D. Landes (trans.) London: Routledge.
- Minkowski, E. 1958. Findings in a case of schizophrenic depression. B. Blis (trans.) In R. May, E. Angel, and H. Ellenberger (eds.), *Existence* (127–138). New York: Simon and Schuster.
- . 1970. *Lived time: Phenomenological and psychopathological studies*. N. Metzler (trans.) Evanston, IL: Northwestern University Press.
- Monaco, A. 2007. Is there a rationale for the kidney shortage? *Medicine and Health, Rhode Island* 90(3): 89–90.
- Moore, A. W. 2006. Williams, Nietzsche, and the meaninglessness of immortality. *Mind* 115: 311–330.
- More, M. 2001. Embrace, don't relinquish, the future. Available at <http://www.kurzweilai.net/embrace-dont-relinquish-the-future>
- More, M., Vitra-More, N. (eds.). 2013. *The transhumanist reader*. Malden, MA: Wiley-Blackwell.
- Morin, M. -E. 2016. Corps propre or corpus corporum: Unity and dislocation in the theories of embodiment of Merleau-Ponty and Jean-Luc Nancy. *Chiasmi* 18: 333–351.
- Morris, K. J. 2013. Chronic pain in phenomenological /anthropological perspective. In R. T. Jensen and D. Moran (eds.), *The phenomenology of embodied subjectivity* (167–184). Dordrecht: Springer.

- Nancy, J. -L. 1993. *The sense of the world*. J. S. Librett (trans.) Minneapolis: University of Minnesota Press.
- . 2000. *Being singular plural*. R. Richardson and A. O’Byrne (trans.) Stanford, CA: Stanford University Press.
- Nancy, J. -L. 2008a. *Corpus*. R. E. Rand (trans.) New York: Fordham University Press
- . 2008b. *Dis-enclosure: The deconstruction of Christianity*. New York: Fordham University Press.
- . 2016. *Ego sum: Corpus, anima, fabula*. M.-E. Morin (trans.) New York: Fordham University Press.
- National Institute for Health and Clinical Excellence. 2011. *Common mental health disorders: Identification and pathways to care*. London: Nice.
- Nicholls, D. A. 2003. The experience of breathlessness. *Physiotherapy Theory and Practice* 19: 123–136.
- Nietzsche, F. 1966. *Beyond good and evil: Prelude to a philosophy of the future*. W. Kauffman (trans.) New York: Random House.
- Norton, C., Dibley, L. B., Bassett, P. 2013. Faecal incontinence in inflammatory bowel disease: Associations and effect on quality of life. *Journal of Crohn’s and Colitis* 7: e302–e31.
- Nussbaum, M. 1994. *The therapy of desire*. Princeton, NJ: Princeton University Press.
- O’Donnell, D. E., Banzett, R. B., Carrieri-Kohlman V., Casaburi R., Davenport P.W., Gandevia S.C., Gelb A.F., Mahler D.A., Webb K.A. 2007. Pathophysiology of dyspnea in chronic obstructive pulmonary disease: A roundtable. *Proceedings of the American Thoracic Society* 4: 145–168.
- Olde Hartman, T., Blankenstein, N., Molenaar, B., van den Berg, D. B., van der Horst, H., Arnold, I. et al. 2013. NHG guideline on medically unexplained symptoms (MUS). *Huisarts & Wefenschap* 56(5): 222–230.
- Omar, F., Tufveson, G., Welin, S. 2010. Compensated living kidney donation: A plea for pragmatism. *Health Care Analysis* 18(1): 85–101.
- Packard, M. G., McGaugh, J. L. 1992. Double dissociation of fornix and caudate nucleus lesions on acquisition of two water maze tasks: Further evidence for multiple memory systems. *Behavioral Neuroscience* 106: 439–446.
- Parens, E. 2015. *Shaping our selves: On technology, flourishing, and a habit of thinking*. Oxford: Oxford University Press.
- Parker, R., Aggleton, P. 2003. HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. *Social Science and Medicine* 57: 13–24.
- Pauwels, R. A., Rabe, K. F. 2004. Burden and clinical features of chronic obstructive pulmonary disease (COPD). *Lancet* 364: 613–620.
- Perper, R. 2013. Grief, depression and the *DSM-5*. *San Diego Psychologist* 28(4): 5–8.
- Phillips, C. 2003. Who’s who in the pecking order: Aggression and “normal violence” in the lives of girls and boys. *The British Journal of Criminology* 43(4): 710–728.
- Pies, R. 2014. The bereavement exclusion and *DSM-5*: An update and commentary. *Innovations in Clinical Neuroscience* 11(7–8): 19–22.
- Plaut, W. G. (ed.). 1981. *The Torah: A modern commentary*. New York: Union of American Hebrew Congregations.

- Pöggeler, O. 1989. *Martin Heidegger's path of being*. D. Magurshak and S. Barber (trans.) Atlantic Highlands, NJ: Humanities Press.
- Price, D. M. 2000. Psychological and neural mechanisms of the affective dimension of pain. *Science* 288: 1769–1772.
- Proust, Marcel. 1970. *The past recaptured*. A. Mayor (trans.) New York: Vintage Books.
- Quirin, M., Loktyushin, A., Arndt, J., Küstermann, E., Lo, Y. Y., Kuhl, J., Eggert, L. 2011. Existential neuroscience: A functional magnetic resonance imaging investigation of neural responses to reminders of one's mortality. *Social Cognitive and Affective Neuroscience* 7(2): 193–198.
- Radcliff-Richards, J. A. S., Daar, R. D., Guttman, R., Hoffenberg, R., Kennedy, U., Lock, M., Sells, R. A., Tilney, N. 1998. The case for allowing kidney sales. *The Lancet* 351(9120): 1950–1952.
- Radden, J. 2009. *Moody minds distempered: Essays on melancholy and depression*. Oxford: Oxford University Press.
- Ramsey, R. E. 1998. *The long path to nearness: A contribution to a corporeal philosophy of communication*. Atlantic Highlands, NJ: Humanity Books.
- Ratcliffe, M. 2008. *Feelings of being*. Oxford: Oxford University Press.
- . 2013. Why mood matters. In M. Wrathall (ed.), *Cambridge companion to Being and time* (157–176). Cambridge: Cambridge University Press.
- . 2015. *Experiences of depression: A study in phenomenology*. Oxford: Oxford University Press.
- . 2017. Grief and the unity of emotion. *Midwest Studies in Philosophy* 41: 154–174.
- Ratcliffe, M., Broome, M. 2012. Existential phenomenology, psychiatric illness and the death of possibilities. In S. Crowell (ed.), *Cambridge companion to existentialism* (361–382). Cambridge: Cambridge University Press.
- Ratcliffe, M., Broome, M., Smith, B., Bowden, H. 2013. A bad case of the flu? The comparative phenomenology of depression and somatic illness. *Journal of Consciousness Studies* 20(7–8): 198–218.
- Reiser, S. J. 2009. *Technological medicine: The changing world of doctors and patients*. Cambridge: Cambridge University Press.
- Rethink Mental Illness. 2012. 20 years too soon. *Physical health: The experiences of people affected by mental illness*. https://www.rethink.org/media/511826/20_Years_Too_Soon_FINAL.pdf
- Ricoeur, P. 1992. *Oneself as another*. Chicago, IL: University of Chicago Press.
- Rosati, C. S. 2013. The Makropulos case revisited: Reflections on immortality and agency. In B. Bradley, F. Feldman, and J. Johansson (eds.), *The Oxford handbook of philosophy of death* (335–390). Oxford: Oxford University Press.
- Rose, N., Abi-Rached, J. M. 2013. *Neuro: The new brain sciences and the management of the mind*. Princeton, NJ: Princeton University Press.
- Roszak, Theodore. 2009. *The making of an elder culture: Reflections on the future of America's most audacious generation*. Gabriola Island, BC, Canada: New Society Publishers.
- Routledge, Clay. 2015. *Nostalgia: A psychological resource*. London: Routledge.

- Routledge, Clay, et al., 2010. A blast from the past: The terror management function of nostalgia. *Journal of Experimental Social Psychology* 44: 132–140.
- Rowe, J. W., Kahn, R. L. 1998. *Successful aging*. New York: Pantheon/Random House.
- Rowling, J. K. 2000. *Harry Potter and the goblet of fire*. New York: Scholastic Press.
- Russ, A. J., Shim, J. K., Kaufman, S. R. 2005. “Is there life on dialysis?”: Time and aging in clinically sustained existence. *Medical Anthropology* 24(4): 297–324.
- Russon, J. 2014. Between two intimacies: The formative contexts of adult individuality. *Emotion, Space, and Society* 13: 64–70.
- . 2016a. Self and suffering in Buddhism and phenomenology: Existential pain, compassion and the problems of institutional healthcare. In S. K. George and P. G. Jung (eds.), *Cultural ontology of the self in pain* (181–195). New Delhi: Springer India.
- . 2016b. The body as site of action and intersubjectivity in Fichte’s *Foundations of Natural Right*. In G. Gottlieb (ed.), *Fichte’s foundations of natural right* (138–156). Cambridge: Cambridge University Press.
- . 2017. *Sites of exposure: Art, politics, and the nature of experience*. Bloomington and Indianapolis: Indiana University Press.
- Ryder, J. G., Holtzheimer, P. E. 2016. Deep brain stimulation for depression: An update. *Current Behavioral Neuroscience Reports* 3(2): 102–108.
- Ryle, G. 1949. *The concept of mind*. Hammondsworth: Penguin.
- Sacks, O. 2015. Oliver Sacks on learning he has terminal cancer. *The New York Times*. <http://www.nytimes.com/2015/02/19/opinion/oliver-sacks-on-learning-he-has-terminal-cancer.html>
- Salmon, P. 2007. Conflict, collusion or collaboration in consultations about medically unexplained symptoms: The need for a curriculum of medical explanation. *Patient Education and Counseling* 67(3): 246–254.
- Sandel, M. J. 2007. *The case against perfection: Ethics in the age of genetic engineering*. Cambridge, MA: Harvard University Press.
- Sartre, J.-P. 1956. *Being and nothingness*. H. E. Barnes (trans.) New York: Washington Square Press.
- . 1998. *Being and nothingness*. H. E. Barnes (trans.) New York: Routledge.
- Sass, L. A., Parnas, J. 2003. Schizophrenia, consciousness, and the self. *Schizophrenia Bulletin* 29(3): 427–444.
- Saul, R. 2014. *ADHD does not exist: The truth about attention deficit and hyperactivity disorder*. New York: HarperCollins.
- Savulescu, J., ter Meulen, R., Kahane, G. 2011. *Enhancing human capacities*. Malden, MA: Wiley-Blackwell.
- Scarry, E. 1985. *The body in pain: The making and unmaking of the world*. Oxford: Oxford University Press.
- Schalow, F. 1994. The Kantian schema of Heidegger’s late Marburg period. In T. Kisiel and J. van Buren (eds.), *Reading Heidegger from the start* (309–323). Albany, NY: SUNY Press.
- Schachter-Shalomi, Z., Miller, R. 1995. *From age-ing to sage-ing: A revolutionary approach to growing older*. New York: Time Warner Books.

- Scheffler, S. 2013. *Death and the afterlife*. Oxford: Oxford University Press.
- Schüpbach, M., Gargiulo, M., Welter, M. L., Mallet, C., Béhar, C., Houeto, J. L. 2006. Neurosurgery in Parkinson disease: A distressed mind in a repaired body? *Neurology* 66: 1811–1816.
- SFS 1995:831. Lag (1995:831) om transplantation m.m.
- Shildrick, M. 2002. *Embodying the monster: Encounters with the vulnerable self*. London, Thousand Oaks, New Delhi: Sage Publications.
- . 2008. Contesting normative embodiment: Some reflections on the psycho-social. *Perspectives: International Postgraduate Journal of Philosophy* 1: 12–22.
- Shusterman, R. 2005. The silent, limping body of philosophy. In T. Carman and M. Hansen (eds.), *The Cambridge companion to Merleau-Ponty* (151–180). New York: Cambridge University Press.
- Simon, P. M., Schwartzstein, R. M., Weiss, J. W., Fencl, V., Teghtsoonian, M., Weinberger, S. E. 1990. Distinguishable types of dyspnea in patients with shortness of breath. *American Review of Respiratory Disease* 142: 1009–1014.
- Singer, L. 1981. Merleau-Ponty on the concept of style. *Man and World* 14(2): 153–163.
- Slatman, J. 2014. *Our strange body. Philosophical reflections on identity and medical interventions*. Amsterdam: Amsterdam University Press.
- Slatman, J., Zeiler, K., DeVisch, I. 2016. Can you restore your “own” body? A phenomenological analysis of relational autonomy. *American Journal of Bioethics* 16(8): 18–20.
- Sloterdijk, P., Huyssen, A. 1988. *Critique of cynical reason*. Minneapolis: University of Minnesota Press.
- Smith, D. M., Loewenstein, G., Rozin, P., Sherriff, R. L., Ubel, P. A. 2007. Sensitivity to disgust, stigma, and adjustment to life with a colostomy. *Journal of Research in Personality* 41: 787–803.
- Smoller, J. W., Pollack, M. H., Otto, M. W., Rosenbaum, J. F., Kradin, R. L. 1996. Panic, anxiety and dyspnoea. *American Journal of Respiratory and Critical Care Medicine* 154: 6–17.
- Smuts, A. 2011. Immortality and significance. *Philosophy and Literature* 35(1): 134–149.
- Smyth, B. 2011. Foucault and Binswanger: Beyond the dream. *Philosophy Today* 55(Supplement): 92–101.
- Snethen, J. A., Broome, M. E., Bartels, J., Warady, B. A. 2001. Adolescents’ perception of living with end stage renal disease. *Pediatric Nursing* 27(2): 159–167.
- Socialstyrelsen. 2017. Antal transplanterade organ 2000–2016. <http://www.livs.viktigt.se/SiteCollectionDocuments/ Antal%20transplanterade%20organ%202000-2016%20%28f%20c3%b6r%20webben%29.pdf>. Accessed March 5 2017.
- Solomon, A. 2001. *The noonday demon*. London: Vintage.
- Sontag, S. 1978. *Illness as metaphor*. New York: Farrar, Straus and Giroux.
- SOU 2015:84. *Organdonation. En livsviktig verksamhet*. Fritzes: Stockholm.
- Spital, A. 2001. Ethical issues in living organ donation: Donor autonomy and beyond. *American Journal of Kidney Diseases* 38(1): 189–195.

- . 2005. More on parental living liver donation for children with fulminant hepatic failure: Addressing concerns about competing interests, coercion, consent and balancing acts. *American Journal of Transplantation* 5(11): 2619–2622.
- Steinbrecher, N., Koerber, S., Frieser, D., Hiller, W. 2011. The prevalence of medically unexplained symptoms in primary care. *Psychosomatics* 52(3): 263–271.
- Stempsey, W. E. 2006. Emerging medical technologies and emerging conceptions of health. *Theoretical Medicine and Bioethics* 27: 227–243.
- Stolorow, R. D. 2007. *Trauma and human existence: Autobiographical, psychoanalytic, and philosophical reflections*. New York: Routledge.
- . 2011. *World, affectivity, trauma: Heidegger and post-Cartesian psychoanalysis*. New York: Routledge.
- Stolorow, R. D., Atwood, G. E. 2017. The phenomenology of language and the metaphysicalizing of the real. *Language and Psychoanalysis* 6(1): 4–9.
- Stanghellini, G., Aragona, M. (eds.). 2016. *An experiential approach to psychopathology: What is it like to suffer from mental disorders?* Switzerland: Springer.
- Sullivan, D. 2001. *Cosmetic surgery: The cutting edge of medicine in America*. New York: Rutgers University Press.
- Svenaesus, F. 2000. *The hermeneutics of medicine and the phenomenology of health: Steps towards a philosophy of medical practice*. Dordrecht: Kluwer.
- . 2007. Do antidepressants affect the self? A phenomenological approach. *Medicine, Health Care and Philosophy* 10: 153–166.
- . 2009. The phenomenology of falling ill. An explication, critique and improvement of Sartre's theory of embodiment and alienation. *Human Studies* 32(1): 53–66.
- . 2010. The body as gift, resource, or commodity: Heidegger and the ethics of organ transplantation. *Journal of Bioethical Inquiry* 7(2): 163–172.
- . 2011. Illness as unhomelike being-in-the-world: Heidegger and the phenomenology of medicine. *Medicine, Healthcare and Philosophy* 14: 333–343.
- . 2013. The relevance of Heidegger's philosophy of technology for biomedical ethics. *Theoretical Medicine and Bioethics* 34(1): 1–16.
- . 2015. The phenomenology of chronic pain: Embodiment and alienation. *Continental Philosophy Review* 48: 107–122.
- Talero, M. 2005. Perception, normativity, and selfhood in Merleau-Ponty: The spatial "level" and existential space. *The Southern Journal of Philosophy* 43(3): 443–461.
- Teachman, B. A., Make, C. D., Clerkin, E. M. 2010. Catastrophic misinterpretations as a predictor of symptom change during treatment for panic disorder. *Journal of Consulting and Clinical Psychology* 78(6): 964–973.
- Theunissen, M. 1984. *The other*. C. Macann (trans.) Cambridge, MA: MIT Press.
- Thomson, I. 2005. *Heidegger on ontotheology: Technology and the politics of education*. New York: Cambridge University Press.
- . 2011. *Heidegger, art, and postmodernity*. New York: Cambridge University Press.
- Thoreau, H. D. 1983. *Walden and civil disobedience*. New York: Penguin Books.
- Tong, T., Morton, R., Howard, K., Craig, J. C. 2009. Adolescent experiences following organ transplantation: A systematic review of qualitative studies. *The Journal of Pediatrics* 155(4): 542–549.

- Toombs, S. K. 1987. The meaning of illness: A phenomenological approach to the patient-physician relationship. *The Journal of Medicine and Philosophy* 12: 219–240.
- Toombs, S. K. 1993. *The meaning of illness: A phenomenological account of the different perspectives of physician and patient*. Dordrecht: Kluwer.
- . 1995. The lived experience of disability. *Human Studies* 18(1): 9–23.
- . 2001. Reflections of bodily change. The lived experience of disability. In S. K. Toombs (ed.), *Handbook of phenomenology and medicine* (247–261). Dordrecht: Kluwer Academic Publishers.
- Trevarthen, C. 1979. Communication and cooperation in early infancy: A description of primary intersubjectivity. In M. Bullowa (ed.), *Before speech* (321–347). Cambridge: Cambridge University Press.
- Trigg, Dylan. 2006. *The aesthetics of decay: Nothingness, nostalgia, and the absence of reason*. New York: Peter Lang.
- . 2012. *The memory of place: A phenomenology of the uncanny*. Athens: Ohio University Press.
- . 2016. *Topophobia: A phenomenology of anxiety*. London: Bloomsbury.
- . 2017. Chronophobe. *Etc Media* 110: 74–77.
- Tugendhat, E. 1986. *Self-consciousness and self-determination*. P. Stern (trans.) Cambridge, MA: MIT Press.
- Turner, N., Jefford, H. 2013. *Pulmonary rehabilitation in prisons*. Oxleas NHS Foundation. http://oxleas.nhs.uk/site-media/cms-downloads/Oxleas_COPD_GUIDE_for_web.pdf. Accessed August 2016.
- Twitchell, C. 2001. Toys in the attic: An Ars Poetica under the influence. In N. Casey (ed.), *Unholy ghost: Writers on depression* (21–28). New York: Perennial.
- van den Bergh, O. 2016. The benefit of doubt: The role of subjective certainty in the perception of dyspnea and pain. *International Dyspnea Society*. <http://www.dyspnea2016inparis.fr/program/poster-sessions/>
- van Manen, J. G., Bindels, P. J., Dekker, F. W. 2002. Risk of depression in patients with chronic obstructive pulmonary disease and its determinants. *Thorax* 57: 412–416.
- van Manen, M. 1997. *Researching lived experience: Human science for an action sensitive pedagogy*, 2nd edition. London and Ontario: Althouse Press.
- Varga S. 2012. *Authenticity as an ethical ideal*. New York: Routledge.
- Villablanca, J. 2010. Why do we have a caudate nucleus? *Acta Neurobiologiae Experimentalis* 70(1): 95–105.
- Vogel, L. 1994. *The fragile “we”*: Ethical implications of Heidegger’s Being and Time. Evanston, IL: Northwestern University Press.
- Waldenfels, B. 1989. Körper—Leib. In J. Leenhardt and R. Picht (eds.), *Esprit/Geist. 100 Schlüsselbegriffe für Deutsche und Franzosen* (342–345). München: Piper.
- Watts, M. 2011. *The philosophy of Heidegger*. Stocksfield: Acumen.
- Wei, H., Bruns, O. T., Kaul, M. G., Hansen, E. C., Barch, M., Wisniewska, A., et al. 2017. Exceedingly small iron oxide nanoparticles as positive MRI contrast agents. *Proceedings of the National Academy of Sciences of the United States of America (PNAS)* 14(9): 2325–2330.

- Weiss, G. 1999. *Body images: Embodiment as intercorporeality*. New York: Routledge.
- Wells, A. 1997. *Cognitive therapy of anxiety disorders*. Wiley: Chichester.
- Wikström, B., Fored, M., Eichleay, M. A., Jacobson, S. A. 2007 The financing and organization of medical care for patients with end-stage renal disease in Sweden. *International Journal of Health Economics and Management* 7: 269–281.
- Wileman, L., May, C., Chew-Graham, C. A. 2002. Medically unexplained symptoms and the problem of power in the primary care consultation: A qualitative study. *Family Practice* 19(2): 178–182.
- Willgoss, T. G., Yohannes, A. M., Goldbart, J., Fatoye, F. 2012. “Everything was spiraling out of control”: Experiences of anxiety in people with chronic obstructive pulmonary disease. *Heart Lung* 41: 562–571.
- Williams, B. 1973. *Problems of the self*. Cambridge: Cambridge University Press.
- Wilson, E. A. 2004. *Psychosomatic. Feminism and the neurological body*. Durham and London: Duke University Press.
- Wilson, I. 2006. Depression in the patient with COPD. *International Journal of Chronic Obstructive Pulmonary Disease* 1(1): 61–64.
- Wittgenstein, L. 1953. *Philosophical investigations*. Malden, MA: Blackwell Publishing.
- . 1975. *On certainty*. D. Paul and G. E. M. Anscombe (trans.) Oxford: Blackwell.
- Wolf, N. 2002. *The beauty myth: How images of beauty are used against women*. New York: HarperCollins.
- World Health Organization. 2016. *Chronic Obstructive Pulmonary Disease (COPD)*. Available at <http://www.who.int/mediacentre/factsheets/fs315/en/>. Accessed January 2017.
- Zahavi, D. 2001. Beyond empathy: Phenomenological approaches to intersubjectivity. *Journal of Consciousness Studies* 8:151–167.
- Zeiler, K. 2010. A phenomenological analysis of bodily self-awareness in the experience of pain and pleasure: On bodily dys-appearance and eu-appearance. *Medicine, Health Care and Philosophy* 13(4): 333–342.
- . 2013. A phenomenology of excorporation, bodily alienation, and resistance: Rethinking sexed and racialized embodiment. *Hypatia. A Journal of Feminist Philosophy* 28(1): 69–84.
- . 2014a. A philosophical defense of the idea that we can hold each other in personhood: Intercorporeal personhood in dementia care. *Medicine, Health Care and Philosophy* 17: 131–141.
- . 2014b. A phenomenological approach to the ethics of transplantation medicine: Sociality and sharing when living-with and dying-with-others. *Theoretical Medicine and Bioethics* 35: 369–388.
- Zeiler, K., and Guntram, L. 2014. Sexed embodiment in atypical pubertal development: Intersubjectivity, excorporation, and the importance of making space for difference. In K. Zeiler, and L. Folkmarson Käll. (141–160) *Feminist Phenomenology and Medicine*. Albany, NY: State University of New York Press.
- Zeiler, K., Guntram, L., Lennerling, A. 2010. Moral tales of parental living kidney donation: A parenthood moral imperative and its relevance for decision-making. *Medicine, Health Care and Philosophy* 13(3): 225–236.

- Zeiler, K., Lennerling, A. 2014. Organdonation från förälder till barn: Starka känslor behöver inte vara hinder för autonomt beslut. *Läkartidningen* 55–56: 109–110.
- Zeiler, K., Wickström, A. 2009. Why do “we” perform surgery on newborn intersexed children? The phenomenology of the parental experience of having a child with intersex anatomies. *Feminist Theory* 10(3): 355–374.
- Ziegert, K., Fridlund, B., Linell, E. 2009. “Time for dialysis as time to live.” Experiences of time in everyday life of the Swedish next of kin of hemodialysis patients. *Nursing and Health Sciences* 11: 45–50.
- Zygon, J. 2007. Moral breakdown and the ethical demand: A theoretical framework for an anthropology of moralities. *Anthropological Theory* 7(2): 131–150.