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INVISIBLE EXPERIENCES: A PHILOSOPHICAL EXPLORATION OF BREATHLESSNESS

by

Tina Maria Tanya Williams

A dissertation submitted to the University of Bristol in accordance with the requirements
for award of the degree of Doctor of Philosophy in the Faculty of Arts,
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Abstract

This thesis attempts to redress what has been lacking in the Western philosophical tradition: an analysis of the significance of breath, breathing, and pathological breathlessness in the context of philosophy of medicine. This is conducted alongside research into its impact on the lives of those that suffer from this invisible illness, including transformations to fundamental structures of existence such as embodiment, affectivity, sociality, and meaning and intelligibility. Transformations often unexamined nor adequately explored in current knowledge and understandings of these illness experiences. Phenomenological analysis will be shown to be an invaluable methodology for exploring these changes. This is a pressing need when we further consider the rising rates of illnesses with breathlessness at their core are predicted to be one of the three greatest causes of morbidity and mortality in the future.

Inclusive of a substantive historical presentation, I confront the neglect of Western philosophical study, arguing that there has been an over-reliance of reductive worldviews dominating how the world and human experience are described and explained. I show that this is both inadequate and detrimental to our understanding of what it means *to be*. Ancient Greek emphases on breath are recovered through phenomenological methodology to redress this: breath and breathing are revealed as meaningful beyond traditional spiritual and physiological conceptions. Existential accounts of anxiety complement this move from the unhelpful dichotomous severing between mind and body.

Utilising thought of key phenomenologists, an ethics of co-breathing emerges that captures existential facets of the significance of breathing and breathlessness to both our lives and to philosophical thought. Ultimately, this thesis illustrates what is latent in chronically breathless experience to better understand human existence. Concluding with policy recommendations, my analysis poses challenges to how we not only treat the breathless: socio-economic structural changes regarding environmental treatment and continuing health inequalities are demanded.

Dedication

For my family, for keeping the faith.

Acknowledgements

This thesis was undertaken as part of the Wellcome Trust funded 'Life of Breath' Project, based at Bristol and Durham Universities. I would like to thank them for their generous scholarship, and training and support throughout the years. I was based in Bristol at the Philosophy department, to which I owe a debt of gratitude for their support and providing a stimulating environment. The 'Life of Breath' team, all scattered across the country and within different disciplines, were helpful. I am thankful and deeply appreciative of being part of such a brilliant group of people. Peers, students, and colleagues across the entire University were fantastic, it is an outstanding place to be because of them all.

My supervisor, Professor Havi Carel, has been an inspiration and so encouraging academically and personally. There are no words that could ever express the respect and admiration I have for her, from my prior undergraduate days being taught Merleau-Ponty and Heidegger, to our meetings in the Lido discussing philosophy, politics, our children. It has always been a privilege working with her.

Team members are far too numerous to list, so I will have to thank them personally. Jess Farr-Cox's superb proof-reading and editing skills deserve a special thanks. Thank you to Coreen McGuire for reading through previous drafts of chapters.

Finally, thankyou too to my boys and husband. Your energy and encouragement are appreciated more than you will ever know. Well, 'proximally and for the most part'!

Author’s Declaration

I declare that the work in this dissertation was carried out in accordance with the requirements of the University's Regulations and Code of Practice for Research Degree Programmes and that it has not been submitted for any other academic award. Except where indicated by specific reference in the text, the work is the candidate's own work. Work done in collaboration with, or with the assistance of, others, is indicated as such. Any views expressed in the dissertation are those of the author.

SIGNED: ....Tina Williams............................ DATE:..17/12/2019..................

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INTRODUCTION

> Dum Spiro, Spero [While I breathe, I hope] – *Proverb*

> What patients seek is not scientific knowledge doctors hide, but existential authenticity each must find on her own. Getting too deep into statistics is like trying to quench a thirst with salty water. The angst of facing mortality has no remedy in probability.
>
> *Paul Kalanithi, 2015, My Last Day As A Surgeon* [1]

This dissertation takes the Heideggerian (1962) insight that human existence cannot be reduced to *what* we are materially (the fleshy, measurable, biological entity homo-sapiens) and applies it to chronic breathlessness. *How* we are, and how this 'being as existence' manifests itself in terms of 'affective, situated, and embodied activity' must be considered when thinking about what it means to be human (Aho, 2018: *xii*). This includes the philosophically under-investigated phenomenon of breathing, and of breathlessness. The latter, in its pathological form (medically termed *dyspnoea*), is itself a much understudied and misunderstood phenomena, as I will uncover (Hui *et al*., 2013). In doing so, I present a detailed case of how the significance of providing a philosophical illumination of these experiences goes beyond typical functional or spiritual presentations. This will not entail an abandonment of the contributions that science or modern medicine has made, rather a careful 'critique regarding the prevailing lack of reflection of itself by science' (Heidegger, 2001: 95).

Our ability *to be* anything at all is underpinned by breath. Lived experience can be radically altered by obstructions to this mostly autonomous function, as seen through

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[1] Website address: http://stanmed.stanford.edu/2015spring/before-i-go.html. Retrieved 14th December, 2015. Kalanithi's book *When Breath Becomes Air* (2016) provides a first-person account of the transformations to embodiment and experience via his illness (metastatic lung cancer), alongside the shift between being the physician (he was a practicing neurologist) and becoming the patient. His work captures the differences that physician and patient embody with regards to their existential experiences, knowledge of disease and illness, and metaphysical worldviews; offering philosophical insights pertinent to this project (as noted by Carel (2008, 2016) in her discussion of the gaps between physician and patient perspectives of illness and disease). His scientific perspective as a physician who is trained to see disease and health in scientific terms is radically altered, to one of a lived experience of the processes of disease and illness, and what matters to the terminally ill patient. He also utilises philosophical concepts to describe transformations in the structures of meaning and experience. First-person accounts of physician-breathless patient, and philosopher-breathless patient by Kalanithi and Carel will be explored throughout.

studies of the increasing prevalence of chronic respiratory disorders (World Health Organisation, 2012; Carel, 2018). As I will argue, these transformations do not just impact the health of the individual concerned. From the emotional, cognitive, inter-personal, geographical, and social levels, profound changes to understandings of illness, self, and society co-occur.

Without such consideration, I argue, we are left with the mere brute facts of what we are composed of, telling us nothing about how people live their lives, relate to one another, and engage with the world. In medicine, it may be quite appropriate to examine the facts of our biological make-up in diagnosing and planning treatment for disease. Lung function tests, blood tests, and other diagnostic tests are thus undeniably important, specifically in tracking any deterioration.[2] Yet medicine that restricts itself to only such a reductive standpoint fails to account for the impact of disease on the lived experience of the patient, (understandably) resulting in, for example, the problem of 'symptom discordance': a conundrum for physicians when faced with two patients with the same objective lung function measurements but very different reports of felt symptom severity, reported changes to structures of experience, and responses to treatment (Aho, 2018: *xii*).

In short, such a view of illness as disease falls painfully short when describing, understanding, and explaining such experiences. It is also unable to account for its own discursive impact on how it shapes a patient's understanding and experience of their illness:

> The methodologies of natural science are unable to address the experience of illness and the ways in which the experience disrupts and modifies how we interpret ourselves. Indeed, the affective experience and personal meanings of illness are deemed to be largely irrelevant to the object and technical concerns of medical science. (Aho, 2018: *xii*).

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[2] Although these measurements are not without their own problematic: often they do not reflect how breathless or in how much distress the patient is in, rendering their existential meaning to patients' lives incompatible with objective measures and scales. They also can cause distress as the pathological breathless patient is given a result that deviates from the 'norm.' They are thus abnormal, a perjorative and harmful self-understanding that can cause distress and upset as their self-identity and identity to others is perceived to be judged as deficient. Finally, the statistical significance of normal lung functions themselves can be called into account, as variations in lung function across sex and race, for example, are often not considered. Priv. comms. Coreen McGuire, James Dodd, Kate Binnie, and Alice Malpass.

This dissertation takes up this challenge and applies it directly to breathlessness and related experiences by using insights from philosophy. In doing so I consider notions of *angst* and anxiety disorder to highlight the problems in splitting the mind and body both in epistemological terms and within the purviews of healthcare intervention. This will highlight how other persons, the social world, and our environment emerge as transformations to knowledge, understanding, and existence are radically revealed. These transformations occur where else, 'but in the air?' (Irigaray, 1999). In short, I show that not only does the air underpin respiration; language, gesture, and our ability to express our situation as an individual and collectively, relies on this. As I examine, any changes to the air, to the respiratory apparatus, and to blood oxygen levels necessitate modifications to embodiment, cognition, social structures, health, and wellbeing. It also can fundamentally affect our interpersonal relationships. Thus, the increasing rates of air pollution, respiratory conditions and co-morbid mental health issues require philosophical consideration due to the lack of western philosophical study in addition to the mounting prevalence of these experiences and their situatedness in our unequal socio-economic environments.[3] I shall now describe how this will be done.

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[3] That is, inequalities effect the risk of poor health overall, both as a consequence of the higher risk of developing respiratory related illnesses due to living in poor, deprived, and marginalised areas as well as the unequal access to health-care to those from areas of social deprivation.

Methodology

> I can’t go on. I’ll go on.
>
> *Samuel Beckett (2010), The Unnameable.*

Phenomenological concepts and methods developed by Edmund Husserl (2012), Martin Heidegger (1945), Maurice Merleau-Ponty (1962) and Jean-Paul Sartre (2003) alongside contemporary phenomenological accounts such as those of Richard Zaner (1981), Drew Leder (1990), S. Kay Toombs (1989), Frederik Svenaeus (2000), Havi Carel (2012) and Matthew Ratcliffe (2012) are used throughout this dissertation to explore the issues described above. Concepts such as the lived body and the biological body, embodiment, perception, sociality, intersubjectivity, and the lifeworld are elucidated and used to support my arguments. Carel’s work on the philosophical roles of illness and her detailed work on the phenomenology of illness, particularly her modification of Heidegger’s notion ‘ability to be’ (*Seinkönnen*) and her descriptions of bodily doubt, are therefore indispensable to this work and as such are examined within Chapter 1 (Carel, 2008; 2014; 2015).[4]

Contextually, in the history of philosophy, there is a paucity of investigation into breathing and breathlessness, which contributes to the need for such an examination. This is particularly timely considering the current rise of respiratory illnesses and correlative rates of suffering. I therefore return to the ancient Greeks, specifically Aristotle and his concept of *pneuma,* which articulates his influence on philosophical thought regarding respiration. This also reveals how his work contributed to the neglect of studies within later philosophical thought. I will then move to the few remaining philosophers who have written on these topics. Other philosophers who have studied breathing include Levinas (1981) on breathing, and Irigaray (1999) on ‘The Forgetting of Air in Martin Heidegger’. These both feature throughout this work, beginning within the historical chapters (2 and 3). I will bring out these uncovered central insights deemed useful for a philosophy of breathlessness. These are then incorporated into later chapters, tying historical themes to

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[4] *Seinkönnen* is translated as both ‘ability to be’ and ‘potentiality for being’, depending on the author and translation (Blattner, 1999; Macquarrie and Robinson, 1962). Both attempts to capture Heidegger’s description of the human being, and so for our purposes I utilize ‘ability to be’.

the present-day pressing need for further philosophical examination. In doing so, I will argue that the significance of the air and breath demand a new focus on the power of breathing to awaken what Levinas called an ethics of the breath, one that I interpret in terms of co-breathing at the end of life (Levinas, 1998). The philosophical salience of the air and breath in the Pre-Socratics that was forgotten for centuries is born anew and adapted in recognition of the importance of pathological breathlessness to the experience of living and dying, I argue.

As I am describing first person experiences, I must integrate research outside of pure philosophy to enrich this work. Interdisciplinary research, which considers interpersonal, social, cultural, economic, and historical aspects of scientific knowledge and policy, in addition to embodied existence, can fruitfully investigate the experiences, and meanings, of illness and health. They will thus be considered when philosophically salient, particularly when philosophical and health-care interrogation has been deficient, as I will argue has often been the case (via both understudy, misunderstanding and lack of attention to the lived experience of breathlessness). Further, this type of research can consider such issues without being bound to a naturalistic or scientific worldview.[5] This enables a deeper understanding of human existence in both healthy and ill variants impacted by breathlessness. As my dissertation emerged from work undertaken as part of the Life of Breath Project (funded by the Wellcome Trust), an interdisciplinary project encompassing the aforementioned areas of study, I utilise pertinent findings from a number of disciplines, including medical history, medical anthropology, qualitative healthcare research, and literature, to illuminate this philosophical examination of breathing and breathlessness.

Being part of the project has supported my investigation into wide-ranging breathlessness experiences, viewing them as changes to the *being-in-the-world* of the patient, rather than a discrete symptom (Chapter 4). Indeed, I explore the claim that pathological breathlessness (*dyspnoea*) might be better thought of as an umbrella term that incorporates different breathless experiences. The term ‘breathlessness’ will be shown to

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[5] I discuss what I mean by the use of naturalistic worldviews in the section ‘naturalism’ below, before further elaboration of the naturalistic problematic throughout the thesis.

be needed to be clarified to investigate whether the term captures a common feature of breathlessness and so has corresponding clinical utility; or if the experiences differ widely and so our conceptualisation of pathological breathlessness and correlating clinical understanding needs to be modified. For example, in the case of pernicious anaemia, a breathless symptom previously classed as ‘shortage of breath’ has been modified. It is now described as ‘the sighs’ to capture the particular nuance of this disease presentation. In this case, the differing phenomenology of struggling to breathe (whether through oxygen saturation problems or the narrowing of the windpipe) described by patients who experience shortage of air, and the feeling of needing to gulp in air at a slow, steady pace (but without encountering difficulty in performing this, as described by those with pernicious anaemia), can aid our understanding of their lived experience of the illness. How it affects their lives, the meaning of being breathless to the patient, but also how understanding it through the biomedical gaze impacts how it is lived and managed. Paying attention to the lived experiences of patients in this way could also improve clinician’s knowledge. This may help prevent misdiagnosis or unnecessary treatment. (Chanarin, 1987).

Another salient example is the acute breathlessness of an asthmatic individual in comparison with the progressive breathlessness of an individual with chronic obstructive pulmonary disorder (Simon *et al.*, 1990; cf. Lansing *et al.*, 2009). This lends evidence to my claim that the term ‘breathlessness’ may not describe the same type of experience in every case. This is problematic: it is important to have conceptually clear accounts for clinical purposes, for example to avoid misdiagnosis, and to understand what we mean by the term ‘breathlessness’ in order to understand the lived experiences of those who suffer and the alienation reported in the medical encounter (Toombs, 1989). This is why I will argue for utilizing phenomenology. It enables us to describe breathlessness experiences and provides us with the much-needed tools to achieve that free from assumptions and a naturalistic worldview where the real is often collapsed into what is measurable (see Chapters 3 & 4):

> The core idea of phenomenology is pertinent here. If health-care practitioners devoted more time to understanding the experience of illness, much of the misunderstanding, bad communication and sense of alienation that patients report would be alleviated. (Carel, 2008: 42)

Breathlessness in co-morbid physical and mental health conditions

This dissertation also addresses mental health conditions comorbid with respiratory illnesses, as well anxiety *eo ipso*. Breathing and breathlessness experiences are often involved within the so called ‘mental’ disorders: panic and anxiety are often experienced as a struggle to get enough air (air hunger). For example, the short, shallow breaths when hyperventilating, or the more positive experiences of breathing exercises to calm panic and associated anxious feelings. Depression, too, has an important role to play within comorbid respiratory conditions beyond the obvious higher risk of smoking or substance misuse (as stress relief), particularly in worsening disability:

> Depression has been found to predict fatigue, shortness of breath, and disability in patients with heart disease or COPD [chronic obstructive pulmonary disease] even after adjusting for severity of illness. (Maurer *et al*., 2008: 44)

These breathless and depressive experiences can be present in those with and without chronic health conditions but are highly prevalent in the latter (Hui *et al*. 2013). Contrary to the symptom-counting and scientism that current psychiatry focuses upon, in Chapter 5 I argue that facets of panic disorder, depression, and anxiety disorder can be elucidated through philosophical analysis (Frances, 2013; Wakefield, 2007; Pickersgill, 2012; 2013; Kupfer, 2002; *cf*., Spitzer et al, 2012). This is important in exposing important and neglected aspects of these experiences that continue to cause distress for the patient and a lack of understanding and knowledge of the impact of these conditions (Smoller *et al.*, 1996). For example, the problem of splitting the mind from the body, or the mental symptoms from the physical correspondingly treated by psychiatry and medicine separately (and, I argue, insufficiently) can leave many respiratory patient’s mental health conditions under-diagnosed and untreated (Gysels & Higginson, 2008). It also highlights the problematic way of seeing the patient as suffering a disease process or dysfunction. A disordered mind plus a diseased body. This is alienating and demoralising, I argue. It is also a misunderstanding of what it means to exist as human.

Many so-called ‘mental’ disorders, including depression and panic, involve physiological symptoms such as rapid heartbeat, chest pain, gastro-intestinal upset and so forth, and so are not so easily differentiable (Ratcliffe, 2014; cf. Kirkengen, 2006). Adding medically unexplained disorders, or so-called ‘psychosomatic’ illnesses such as chronic back pain, or chronic fatigue syndrome with its links to co-morbid respiratory distress, further reveals such problems inherent in separating the mental from the physical (Bullington, 2014). I suggest that these problems can be accounted for through phenomenological description: we are embodied subjectivities (mind-body unities) bound to a meaningful world that structures and is structured by our perceptual abilities, our history, and our social settings (see 456 Chapter 5). Importantly, this also includes our health, or lack thereof. *Angst,* as described by Heidegger, Merleau-Ponty, and Levinas, will be examined with reference to these. A phenomenological framework, I argue, enables us to see that the whole person as a mind-body-world unity (that is, being-in-the-world) is affected by illness in these cases, and so make sense of phenomena that medicine can struggle to accommodate.[6]

Once the person’s experience of their illness and interpretation of their life and current situation is attended to, meanings and alternate explanations of their conditions can emerge. Anxiety disorders co-occurring with breathing difficulties are, therefore, not entirely reducible to ‘irrational’, dysfunctional or abnormal behaviours and cognitions, nor are they to be couched solely in those terms.[7] Meanings and intelligibility are not merely making sense of mental ill health; rather, the occurrence of these disorders (panic and anxiety) is intelligible to the self and to others through the person’s account of their illness. Such intelligibility is seen in multiple descriptions of the experience of depression or anxiety in those with comorbid chronic health conditions. For example, *severe* or clinical depression with a prevalence rate of 40 per cent in COPD patients (Stage *et al.,* 2006) is described by a patient:

> That day my life changed forever. In a blink of an eye, I went from an independent, energetic newspaper editor with a bright future to a disabled, chronically ill patient, who had to rely on oxygen at night and medications by day to breathe more easily... I took a leave of absence from work and fell into a deep depression. I felt like I had become my illness. I had no life of my own—merely a life of survival—racing from

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[6] Of course, some acute illnesses such as influenza can be seen as experienced purely ‘bodily’ (see Ratcliffe and Broome, 2014). This is not contentious, as I am exploring chronic conditions.

[7] As the Diagnostic and Statistical Manual of Mental Disorders-V [2015] or the National Institute for Mental Health’s new Research Domain Criteria project would have it.

> doctor to doctor only to confirm what I already knew: at age 54, I had end-stage COPD caused by more than 30 years of smoking. I suffered in silence, wondering how long I had to live. 3 years? 5 years? I didn't know and was too afraid to ask…. I joined an online support group, where members shared their experiences on living with COPD. I learned that quitting smoking was the best thing I could do to slow the progression of my disease and that exercise was the key to keeping my energy levels up. I developed an attitude of gratitude, as many members were sicker than I was. When depressed, I spent time in the chat rooms with people who knew exactly how I was feeling. …. life is no longer a race to be endured, but a journey to be enjoyed—one breath at a time. (Bowers, 2004)[8]

This description reveals that her *inability* to continue with her life projects and status as an active agent resulted in a depression that, for a time, made her feel *reduced to* her illness, and threatened by her impending death (cf. Carel, 2008). Depending on the patient's personal life history and current situation, then, depression or anxiety can be understood and described through attention to more than functional or biological impairments. Perhaps it arose through the perception of the meaningless of life when trying to make sense of a world and existence dogged by pain and suffering, or through the knowledge and experience of breathlessness that is likely to get progressively more limiting.

In her case, despite her 'abilities to be' being undoubtedly radically and painfully altered, she was able to respond to these changes and adapt, finding different projects and ways of interacting with the environment, world, and others (revealing our embodied active existence as human beings). The description above shows that ultimately the patient wasn't reducible to her illness and was able to enjoy life 'one breath at a time' despite her suffering and depressive experiences (*ibid*.). In what follows, I examine how such meaning and intelligibility is constituted through embodied subjectivity, as well as their intersubjective nature and socio-historical embedding, to offer a phenomenological alternative to the division of a person into *partes extra partes,* or psyche and soma.

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[8] This first-person account also reveals how diagnosis dramatically changes the individual's sense of self and agency, and her altered embodiment and 'ability to be' (cf. 456 Carel, 2008). I therefore apply the phenomenological framework laid out in Chapter 1 to an analysis of this, along with other examples, in later chapters to demonstrate the utility of philosophical dialogue with illness experiences.

Indeed, returning to the point that the quotation above revealed (that the patient, for a time, viewed herself only as her illness), highlights the problem with taking such a reductionist view of patients: it fails to capture their human existence as an embodied, self-understanding agent in a world with others *who can take a stand* on their illness.[9] I suggest that the current emphasis on biological dysfunction and the search for pathological causes have translated into clinical encounters that do not consider the entire person and their social status in medical practice and study, alienating the patient in the process (Carel, 2008; Svenaeus, 2013; Toombs, 1989). This includes curtailing and limiting their own understandings and responses to these illness experiences.

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 (Wilson, 2006). For instance, studies show that patients with chronic obstructive pulmonary disorder (hereafter COPD) are often poor, working-class smokers (Pauwels and Rabe, 2004). I therefore argue that socioeconomic status is part of patients' lifeworld and plays a constitutive role in their health and wellbeing (Department of Health, 2010). When a mental health diagnosis is added, rates of respiratory disorder increase, as many patients with depression or anxiety smoke to cope with their anxiety (Wilson, 2006; van Manen *et al.*, 2002). One study found anxiety and depression rates of 80 per cent in COPD patients who smoke (Kunik *et al.*, 2005).

In prison populations, up to 90 per cent smoke and many have smoking-related disorders and mental health conditions, that are under-diagnosed, alongside restricted access to pulmonary rehabilitation (Turner and Jefford, 2013). Studying these socially excluded groups and their experiences (see Chapter 6) will not only address links between social exclusion, invisible suffering, and the risks of respiratory disease, but also provide an account of shame, stigma, and social exclusion. This will facilitate possible explanation of the under-diagnosis of some respiratory diseases, as well as the difficulty of respiratory

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[9] The invitation to reflection and to philosophize, to re-examine and re-interpret one's life alongside modifying movements and goals, will be considered in later chapters. This will reveal the edifying possibilities that illness presents. It will also allow for a critical engagement with what Havi Carel calls the philosophical role of illness; both what philosophy can learn from examining illness and how philosophy can be useful to those suffering a chronic illness (2012; 2013; 2014).

patients in adhering to their treatment and giving up smoking (*ibid.*). It will also give these stigmatised and under-represented populations a voice, something that is often literally prevented through smoking-related disorders via breathlessness that make it difficult for them to speak, but also through the shame of feeling responsible for their illness (Kvangarnes, 2013).[10]

In sum, my research intends to investigate the experiences of breathing and breathlessness in respiratory illness, mental health conditions, and socially excluded groups. Patient-centred care requires information on treatment options and the specific condition in question to be evidence based and provided in a clear manner that considers reading age, language and culture, and mental capacity (NICE, 2009). Yet the language used by medical professionals can be difficult to understand or relate to and thus contribute to epistemic injustice (Fricker, 2007; Carel and Kidd, 2013), as well as reducing embodied, meaningful experience to lists of symptoms and disease entities.

Apart from the problems these issues already present for those with breathless conditions, it is pertinent to consider the impact of retaining such a problematic view when faced with the predicted rise in the prevalence of respiratory conditions (WHO, 2012). That is, a narrow focus on dysfunction and disease without a study of the lived experiences of the patients could be particularly damaging for those with a high risk of developing respiratory illnesses due to the risk factors of a mental health diagnosis, their socio-economic group, and adverse upbringing when such people may already be marginalised and alienated in society. Using phenomenological methodology and analysis, the reduction of these experiences to impersonal medical language, understanding and treatment can be avoided and a space for improved communication opened. Following Carel and Macnaughton's (2012) call for an interdisciplinary approach, incorporating literary studies, anthropology, medicine and philosophy, I aim to tackle these issues to provide descriptions of the experiences bound up with breathing and breathlessness,

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[10] Social and cultural factors will be shown to play a constitutive role in the development of feelings of shame and exclusion, in particular as society provides the background or horizon of intelligibility for which behaviours can be blamed for causing a condition and when one is 'responsible' for one's illness.

highlighting gaps in our knowledge and understanding of these issues, and identifying further research areas that philosophy can both contribute to and be informed by.

Naturalism

When I discuss the problems with naturalism, I am for the most part engaging with the problems specifically arising from the biomedical understanding and explanation of illness, disease, and human experience more generally. A scientific worldview that, (I will argue), uncritically accepts naturalistic features including metaphysical and epistemological concepts that it takes for granted when describing and explaining the world (Carel, 2008; Gallagher and Zahavi, 2008). This target is analysed and critiqued in the majority of my chapters, sometimes the term scientism is used, other times biomedicine (see chapters 1 , 4, 5 for comparison). I must therefore discuss how I am using this term for clarity, and so as not to appear to be creating a straw-man.

Naturalism is not a singular doctrine. Instead, the term refers to a wide range of doctrines that nonetheless have many shared themes and overlapping features (Gallagher and Zahavi, 2008). Materialism (or physicalism) is the exemplar of naturalism, further carved into variations including eliminative materialism, Cartesian materialism, identity theory, computational theories of mind, and so on. The list of variations ostensibly endless. It is not useful nor relevant to this study to discuss all of these. Instead I will give a brief account of naturalism and why I will be arguing for phenomenological analysis to both challenge and supplement accounts informed by naturalistic thought.

As Gallagher and Zahavi point out, naturalism 'is by no means an unequivocal term' (2008: 4). Regardless of this, it is one adopted by science (and thus medicine). So what is meant by this term? Simplifying somewhat, naturalism comprises the view that all that is real is what is natural. Everything that is real is thus reducible with reference to such description (Moran, 2000: 142). What is wrong with this? Doesn't Merleau-Ponty advocate the centrality of embodiment and the world to our understanding of what constitutes existence? (Moran, 2000: 403; Ratcliffe, 2008: 250). This is not problematic *per se.* Rather, it's the concomitant beliefs that uncover serious issues, issues that alinate the constitutive first-person experience of understand and knowledge of the world. These include (but are in no means exhausted by):

1. Events, the world, and everything within it can be explained by science and scientific method
2. As nothing else exists outside of the natural, alternate descriptions are superfluous
3. Third-person, objective description of people, events, and the world are more reliable than first-person accounts.
4. A tacit belief in a mind independent reality discoverable by science (the ‘natural attitude’).[11]

As I deal with these objections in detail in the thesis, I will give a brief sketch of why these are problematic. As for the naturalist any account of reality can only include the natural, any descriptions must only be given with reference to the scientific worldview. The objective, third-person account trumps any introspective, first-person descriptions of phenomena. The latter are irrelevant to the provision of knowledge. Not only do these accounts assume the very thing for which they are trying to explain (the assumption that reality is entirely mind-independent, somehow out there in the world), they reduce human experience to brute physical facts. This ‘betrays the internal meaning of perceptual experience’ (Moran, 2000: 332). Perceptual experience is stripped of meaning and content, with naturalism taking for granted one of the very things it needs to account for! (for further detail, the natural attitude that Husserl and Merleau-Ponty malign is critiqued in chapter 1).

This may not seem so problematic until we further draw out its implications. Consider the disorder depression. If we only describe it with reference to the physiological features and causes, the very subjective experience is completely disregarded and unaccounted for (Carel, 2008: 9). Recourse to neurotransmitters, chemical imbalances, lesions on the brain, and dysfunction in the (again, hypothesised) limbic system tell us nothing about the loss of pleasure in activities (anhedonia), the misery, depersonalisation and myriad other experiences that first-person accounts reveal.

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[11] I discuss Husserl’s conception of the natural attitude and why it is problematic at length in later chapters.

Furthermore, (and relevant to our concerns), when examining respiratory experiences, lung function, blood-oxygen levels and other symptoms and their measurements do not tell us how these experiences are lived and perceived by the patient, their loved ones, and health-care workers caring for them. Expressing the tensions between the universality of illness, and its unique variations that individuals painfully experience bring to light features of human existence that purely naturalistic accounts cannot describe. Nor can they understand as they remain committed to third person, objective accounts.

The predominance of defining the human subject in reductive terms, whether as man as the *animal rationale,* or even the Cartesian *cogito* also shares features with naturalism in so far as the mind and body are categorised in third-person, objective terms. The body is matter: extended in space and subject to the laws of physics. The mind as the seat of the self somehow interacts with this physical stuff. Dominating the fleshy part of our existence as if it obeys like a machine. Mechanistic, reductive, and unthinking.

Naturalism of course has its merits, but crucially for us what is missing is the (first-person) embodied experience of illness. The phenomenology of these experiences. How they feel, how we perceive them and interact with our understandings of science, medicine, and self. It is these that are attended to and what I examine within my critique in the subsequent chapters.

Thesis Structure

This dissertation argues that by attending to patients first-most as persons, we can uncover the changes to experience that alter their lived experiences in ways that healthcare fails to consider. This will offer the opportunity to understand the impact of these illnesses on the person, their families, carers, medicine, and society. Phenomenology, with its methodological utility as a descriptive endeavour, will guide us here. In the first chapter, I offer a phenomenology of illness, arguing that utilizing phenomenology as a methodology for describing the lived experience of illness reveals important underlying structures of human existence that are usually ignored in clinical medicine and traditional philosophical accounts. Phenomenological study will elucidate how such structures are experienced and transformed by chronic ill health, and I will argue that incorporating the tacit structures of human existence and resultant changes to experience are vital for understanding and making intelligible human existence in both its healthy and ill variations.

I begin with a brief analysis of how the biomedical adherence to naturalism creates the need to pay attention to lived experience of illness, before offering a phenomenological critique. I then explore the interrelated subjects: what a phenomenology of illness includes; what a phenomenology of illness has to offer to patients and to clinical medicine; and how paying attention to the lived experience of illness provides greater clarity and knowledge to traditional philosophical conceptions of agency, embodiment, health and wellbeing. It will be argued that studies of chronic illness allow the patients to be heard; their experiences to be made intelligible. It will also disclose what it is to exist as a human being: a perceiving, self-interpreting embodied agent absorbed in the world.

Chapters 2 & 3 focus on philosophical studies of breathing and breathlessness from the Ancients to the present. Starting with the early formulations and descriptions of breathing in ancient Greek philosophy through to contemporary philosophical accounts, I address the historical conceptions of breathing and breathlessness in the philosophical tradition, noting the lack of study of this vital human function and experience. This includes Western philosophical conceptions of respiration throughout the ages, and their significance to modern breathing practices in medical treatment alongside everyday usage, such as how mindfulness practice with the emphasis on the breath has developed out of Buddhist teachings.

Consideration will be paid to ancient Greek thought on air, breath and metabolism, and I will offer an analysis to show how the Aristotelian account of *pneuma* influenced Western knowledge on the function and significance of breathing to the mediaeval period and beyond (Chapter 2, specifically). I will compare this to contemporary accounts of breathing in both philosophy and medicine to highlight these findings, and critically appraise them in light of such interdisciplinary knowledge and understanding (Chapter 3). In sum, this will uncover the neglect of the breath in philosophy and trace the philosophical story of this neglect and alternative focusing from the Pre-Socratics to the present day. It is here where I begin to build upon the idea of an ethics of the breath (Levinas, 1997; Škof, 2018).

Chapter 4 presents a phenomenology of breathlessness. Following Carel (2013), I will describe those areas of our existence that are revealed by chronic illness. The phenomenological reduction and bracketing of the natural attitude will be shown to be analogous to the distancing effect that illness creates (*ibid*.). Ordinary, meaningful existence is collapsed and transformed. I will argue that illnesses such as respiratory and anxiety conditions that have breathlessness as a major symptom show how our normal modes of being and existing are radically changed. The closing down of possibilities, bodily, social, physical, economical require the ill person to find new ways of existing with illness, finding new meaning and intelligibility in the world and her place in it (Carel, 2013b: 348). I argue that Carel's modification of the Heideggerian conception of human existence as 'ability to be' (*Seinkönnen*) to incorporate more inclusive ways of being revealed by illness provides an *ideal* framework to interpret breathlessness through. Indeed, this framework will be explored throughout the dissertation in order to enrich the phenomenology of breathing and breathlessness.

Chapter 5 then expands this focus to look at the case of anxiety, angst, and panic disorder. It examines anxiety as it is viewed in philosophy, in psychiatry, and in medicine. The 'differentiation problem' is my term for the problem of distinguishing between breathlessness caused by anxiety, and breathlessness caused by an acute exacerbation of a respiratory illness.[12] I do not suggest that philosophy can solve this problem. Rather, conceptions such as Heidegger's *angst* and the uncanny (loss of meaningfulness or unhomelike being-in-the-world) become pertinent (Svenaeus, 2000). For example, Ratcliffe's 2012 studies of depression (the shift in the sense of reality, of significance and connection with the world and others), and competing psychiatric and psychological construal's of anxiety allow us, I argue, to unpick the differences between existential threat embodied in panic and anxiety attacks and exacerbations of asthma, for example. This enables a clearer understanding and uncovering of these experiences.

Such distinctions can also help us to see the links between mental and physical disorders. That is, such explorations attempt to bridge the gap between the mind-body split in mental health to present a clearer picture of the experiences contributing to anxiety disorders; and whether there are any shared features that may aid in distinguishing between breathlessness due to anxiety or physical disorders. This entails an excursion into more traditional notions of death, dying and existential threat as described by phenomenology, stoicism, and philosophy more generally to get a clearer picture of anxiety in comparison to mortal threat.[13]

Finally, Chapter 6 examines social meaning and intelligibility through the concepts of intersubjectivity and Being-with (*Mitsein)* applied to everyday life, as well as the modification of these existential structures of human existence within the patient-physician encounter (Kirkengen, 2005). A description and analysis of these merges with themes of shame, stigma, and social exclusion in relation to the clinical gaze, suggesting that a situated gaze informed by Heideggerian insights may be more productive. I argue that a patient-centred approach would need to take account of the fact that our

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[12] Plenty of articles in medicine, nursing, psychiatry and psychology cite these problems, which consequently lead to many patients being unnecessarily admitted to A & E in the UK (leading to unnecessary visits and treatment, NHS costs, longer hospital stays and so forth: see Smoller *et al.*, 1996). Clinicians participating in the Life of Breath project, and psychiatrists and primary care mental health practitioners have voiced this problematic, hoping that work can be done to shed light on these issues.

[13] Notions of death traditionally given in phenomenology will not be covered. So much has already been written on angst and being-towards-death, that I will instead be specifically relating the connection between anxiety and death to the experience of severe and pathological breathlessness. This is not to deny the importance of Heidegger's idea of being-towards-death and its relationship to angst See Moran, 2001 or Carel, 2008, for further reading.

understanding of disability and illness is formed not only by our embodiment. Interpersonal, socio-economic, and public ideas and epistemologies shape them alongside our notions of normal and pathological. Thus, engaging with person- rather than patient-centred theories alongside attention to patient narratives that incorporate philosophical and the inter-disciplinary research can redress these issues.

Ultimately, I suggest that the call for an ethics of the breath can more modestly be unpicked via the development and conceptualisation of the term *co-breathing* to capture these issues. Such a step, I argue, will offer a reconsidering of philosophical ideas of existence. Specifically, it will open a framework with which to rethink our conceptualisations of what it means *to be*. I will also attempt to offer an application of these research findings: drawing them together within the Conclusion to offer policy recommendations and possibilities for further research.

Summary and conclusion

Disease and illness, although related, differ.[14] Illness is the experience of disease and as such differs greatly from disease (see Chapter one). One’s illness experience may be a direct symptom of the disease such as sputum accumulation and subsequent coughing, or one may experience changes to motility as pernicious anaemia indirectly causes inhibited movement that is often mistaken for lack of fitness, ‘coming down with something’ and so forth. The experience of illness can thus be a direct or indirect consequence of the disease. Studying first-person experiences of illness reveal such complexity. Chronic illnesses that include breathlessness as a main feature also reveal how interpersonal, social, healthcare, and institutional facets enter into the experience of the illness and its treatment and management when we focus on the lifeworld of the patient.

Anxiety, fear, stress, and panic often immediately appear upon diagnosis of a disease, a mental disorder, or a psychosomatic disorder of unknown cause. Suffering is thus compounded, often unintentionally, when the individual feels that others, society,

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[14] Although not always necessarily so; one can be ill without a locatable disease (e.g. fibromyalgia) or diseased without being ill (e.g. being HIV positive).

and medicine are judging them for their diagnosis. Shame, stigma, and social exclusion thus must be considered. A full account of illness experiences in the area of breathlessness disorders cannot be provided without consideration of these areas.

CHAPTER 1: Phenomenology and Illness

> It is not a matter of denying or limiting the extent of scientific knowledge, but rather of establishing whether it is entitled to deny or rule out as illusory all forms of inquiry that do not start out from measurements and comparisons.
>
> *Merleau-Ponty, 2004: 43*

> For science the domain of objects is already pregiven. Research goes forward in the same direction in which the respective areas have already been talked about prescientifically. These areas belong to the everyday world… However it is not the same with *being* [human existence]…Being cannot be glimpsed by science…[15]There is no abandonment of science, but on the contrary, it means arriving at a thoughtful, knowing relationship to science and truly thinking through its limitations.
>
> *Heidegger, 2001: 17*

In this chapter I argue that utilizing phenomenology as a methodology for describing the lived experience of illness reveals important underlying structures of human existence that are usually ignored in clinical medicine. Phenomenological study will highlight how these structures are experienced and transformed by chronic ill health. In other words, incorporating the tacit structures of human existence and the changes brought about to lived experience by illness are posited as vital for understanding and making intelligible human existence in both its healthy and ill variants.

I begin with situating this chapter in the overall thesis. This requires an excursion into the concepts of health, disease, and illness. A brief description of how the biomedical adherence to naturalism creates the need to pay attention to lived experience of illness follows, before offering a phenomenological supplement.[16] It is thus argued that examining chronic illnesses from a first-person perspective enriches the third-person perspective of medicine (Toombs, 1987; Bishop, 2011; Svenaeus, 2015).

I then explore the following inter-related subjects: firstly, what a phenomenology of illness includes; secondly, what a phenomenology of illness has to offer to patients and to clinical medicine; and thirdly, how paying attention to the lived experience of illness

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[15] It will be argued that science cannot capture this lived experience, nor does it examine its own prescientific metaphysical assumptions.

[16] It is taken as undeniable that medicine is, in the words of Roy Porter (1999), ‘the greatest benefit to mankind’. That is why I offer a measured critique with a suggested phenomenological augmentation.

provides greater clarity in and knowledge of philosophical conceptions of agency, embodiment, and self-understanding.

Studies of experiences of illness not only offer the benefit of allowing patients to be heard and their experiences to be made intelligible; they also reveal what it is to exist as a human being: a perceiving, self-interpreting, embodied agent (Merleau-Ponty, 1962; Heidegger, 2011; Carel, 2018). The transformations that take place in embodiment and perception due to illness can cause the loss of the patient's ordinary practical engagement with the world, and her ability to take up future roles and activities. I argue that this closing down of possibilities (bodily, social, physical, and economical) require the ill person to find new ways of existing with illness, finding new meaning and intelligibility of the world and her place in it (Carel, 2013b: 348).

Further, I suggest that a patient-centred approach would need to take account of the fact that our understanding of disability and illness is constituted not only through our embodiment. Whilst the body is undoubtedly the 'medium for having a world' (Merleau-Ponty, 1962), the meaning and intelligibility of illness is derived from our social, cultural and historical embedding in a world with others (as the background or 'horizon' of understanding and interpretation). For instance, the language and concepts that are used to describe and explain disability are taken up and used by the ill person (Cooper, 2005). The patient is disabled or depressed due to a physical pathology, impairment, or dysfunction according to medical terminology. Understandably such a reductive account may alienate her. This reveals the disjunction between the medical take on the illness, and the existential lived experience of it (see Chapter 4 for detail on Carel's suggestions of how to bridge this gap). These concepts can be eschewed in favour of other ways of thinking found in, for example, patient groups, medical humanities discussions and so forth (see Chapter 5 in particular). For instance, the concept 'disabled' is viewed from a social constructionist point of view as attitudes of *others*, including social institutions towards the ill person, and not the physical or mental impairment that they have (Griffiths, 2012: 11).

As the traditional biologically-based explanatory models in medicine are reductive and often reliant on scientific naturalism by virtue of the focus on the dysfunctional biological body, separated from the lived, experiencing subjectivity, they can fail to account for social norms that affect the patient's self-understanding.[17] Nor can these models account for such social constructionist variances (Kirkengen *et al.,* 2015). Separating *psyche* and *soma*, and subject and object is therefore inherently problematic. I conclude that phenomenology can address these issues through disclosing the meaning of illness that is constituted by the embodied, socially situated patient (Toombs, 1987; Carel, 2011).

1.1 Respiratory illness, health, and the lived body

> Why can't there be something real that is not susceptible to exact measurement? Why not sorrow, for example?
>
> *Heidegger, 2001: 7*

Philosophical studies of breathing and breathlessness in respiratory disorders are few and far between (Carel, 2013; 2018). Western philosophy lacks a coherent and detailed account of breathing and its pathological derivative (breathlessness) in both physical and mental conditions, as well as in everyday 'normal' functioning (see Chapters 2 and 3 for a detailed historical account of this). This thesis attempts to examine what is at stake through such a lack, offering a novel account of what philosophy can contribute to the everyday and clinical picture of breathlessness, or dyspnoea; and what breathlessness reveals about our embodied existence. To this end, we must start with a brief examination of health, disease, and illness in philosophical thought.

1.2 Health and Illness

As philosophers such as Martin Heidegger (1962), Hans-Georg Gadamer (1996) and Lennart Nordenfelt (2007) have argued, we cannot examine illness without a conception of health:

> The nature of being sick cannot be adequately grasped without a sufficient determination of being healthy ... It is an ontological

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[17] Biomedical accounts are undoubtedly useful in clinical medicine, and more nuanced accounts attempt to address the reductionism inherent in the system. I do not question this utility. However, for the reasons given above, phenomenological description can capture what naturalistic accounts often miss out: the lived experience of illness.

> phenomenon, that is, it refers to a possibility of being and not merely to the logic of a propositional negation. (Heidegger, 2001: 18)

What, then, is health? It is beyond the scope of this chapter to examine conceptions of health in all philosophical or medical approaches (see Svenaeus, 2000). However, an account of health can be given from contemporary naturalistic thought on health, disease, and illness. Christopher Boorse (1977) presents the influential biological-statistical theory of health (BST), which holds that 'health is statistically normal function in a reference class, and "health" and "disease" are empirical, objective and value-free concepts' (Kingma, 2008: 128).[19] Disease occurs, then, when a bodily state or process inhibits part of the body from carrying out its normal function. Without any such dysfunction, the body is taken to be healthy. Thus, health is defined by the 'absence' of disease.

This naturalistic account is problematic in its overly mechanistic and reductive presentation of a person. There is no reference to the harm that is experienced through the dysfunction or disease processes. Within this language of biomedicine they are reduced to bodily states and functions, their personhood unaccounted for nor addressed. This is doubly alienating as they are objectified; treated as an object rather than a subject with the complex levels of harm conferred on them by the disease seemingly stripped away. That is, when the illness is understood as disease and dysfunction in discrete areas of the body, the existential dimensions of the illness and how it affects the experience and self-understanding of the person in a harmful manner is ignored. Harm is simply not featured in these naturalistic accounts. In other words, they ignore the fact that the ill person responds to a disease diagnosis or experience, and diseases and ill experiences are evaluated by the patient as harmful. We can contrast these with other accounts of health and illness. Nordenfelt (1987) presents a holistic account of health whereby the 'ability to

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[18] The Zollikon Seminars in their entirety reveal problems with the prevailing medical models more generally: 'Heidegger's profound explorations of the relation between *being* and *bodyhood* undermined the very notion that the *human being* could be divided into a 'holistic' assemblage of separate entities labelled 'mind', 'body' and 'spirit' – or *psyche* and *soma*. Yet the deeper questions that Heidegger raised in the Zollikon Seminars are still consistently sidestepped in the fields of brain science and genetics, 'psycho-neuro-immunology' and 'psychosomatics'. Indeed *all* medical-scientific 'explanations' of illness have so far avoided the far more fundamental question of what illness itself essentially *is* – reducing it to a biological, behavioural or neurological 'disorder' and ignoring the intimate connection between individual health and the health of human social relations' (Wilberg, 2003).

[19] Normative and hybrid accounts of disease and psychiatric illness based on concepts such as harm are covered by Wakefield, 1992 & 2007 (see bibliography).

act', to choose goals and achieve them, is taken to be constitutive of health. Hybrid accounts such as Wakefield's conception of a disorder (although he is discussing mental disorders) as conditional on 'whether it is negatively valued ("harmful") and due to a failure of some internal mechanism to perform a function for which it was biologically designed (e.g. naturally selected)' (Wakefield, 2007: 149) is another response to the naturalistic accounts (although is still subject to naturalism insofar as the disorder is explained in third person, scientific terminology).

Noting the quote from Heidegger above, then, I suggest that deriving a conception of health from the lack of disease is insufficient in capturing the differing ways that human beings experience these concepts of health, disease, and illness. It also excludes the possibility of health within illness (Carel, 2008). Before returning to a more positive construal of health and illness in later sections, it will be sufficient here to continue with the naturalistic problematic in order to reveal an alternative presentation of the experience of illness. Such accounts describe illness in impoverished and sometimes inadequate language by virtue of their failure to include first person, lived experiences of illness, and the alterations to these experiences and life-world in their accounts, instead relying on physical objective facts and scientific explanation, alone (Carel, 2008: 8; Aho, 20008: xii).

Indeed, epistemological issues arise from the over-emphasis on scientific naturalism present in medical terminology:

> The language of disease [has] replaced that of health and justice. Discourses that are identified with knowledge claims and institutions seen as powerful replaced the voice of suffering… So now almost any human difficulty is subsumed in functional terms (Heaton, 2006: 58).

These implicit naturalistic assumptions underlying medical conceptions of illness limit our knowledge of illness experiences, then. When the vocabulary of medicine revolves around terminology such as patient, disease, diagnosis and prognosis; and when 'language shapes the way we think, and hence the way we act', it becomes natural for the knowledge and understanding of illness to be subsumed under a medical framework that fails to account for the lived experiences of patients (Johnstone, 2006: 81). Therefore, the assumption that science is the foundation to discovering and investigating reality uncritically becomes part of the language and concepts that we use in circumscribing illness.[20] In turn, the assertion of epistemological primacy of such scientific naturalism to the detriment of other construal of illness obliviously *presupposes the meaning giving background that gives rise to, and sustains such an outlook* (Merleau-Ponty, 1962). This is the world that is already there prior to any theoretical reflection upon it, constituted by human perceptual abilities and a socio-historical setting from which science and naturalism inherit meanings and intelligibility owing to this very situatedness (*ibid*.).

Moreover, the reduction of the person to biological facts and processes separates the body from its subject, the *soma* from the *psyche*. This problematic is exemplified by the phenomena categorised as psychosomatic, or somatoform, illnesses. For example, medically unexplained symptoms (MUPS), such as chronic fatigue syndrome, or chronic backache with no known cause, present an anomaly for medicine's typical materialistic characterization of illness and disease (Bullington, 2013; Kirkengen, 2015). This is because there is no identifiable bodily dysfunction or discoverable disease state, perhaps evidence of the 'mind inform[ing] bodily matter' and the problems inherent in dichotomous characterisations of human existence (Kirkengen, 2005: 23). Intertwined and inextricably linked. That is, the intractable nature here is due to them being two aspects of the same thing: the embodied subject (see below for detail). Further, many mental disorders are not easily differentiable from physical disorders (Ratcliffe, 2015). Depression and anxiety disorders include physiological distress such as breathlessness, rapid heartbeat, gastro-intestinal upset and other somatic symptoms (see Chapter 5). So how can we explain these varied illness experiences? I argue that twentieth-century methodology of phenomenology equips us with the conceptual framework and tools necessary for this undertaking.

1.3 The Lived Body

The Merleau-Pontian conception of the 'lived body', central to a phenomenology of

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[20] I continue this line of critique in Chapters 4-7, arguing that as much of what is natural 'includes much that is social' (Bolton, 2008: xix), attention to biological facts is not enough. That is, focusing on biological abnormalities in cases of health, disease and illness divorced from norms instead of a multi-factorial consideration of these lived experiences inadequately attends to the social impact of illness on the patient; socio-economic factors that contribute to the onset of certain disorders; and the impact of illness on social structures.

illness, can be used to compliment the naturalistic picture and bridge the gap between mind and body, *psyche*, and *soma*. This lived body (*Leib*) is not the same as the biological body of science (*Körper*). Instead, the lived body is an embodied subjectivity that ‘lives and breathes’ (Leder, 1990). The *Körper* is an aspect of *Leib* that is inseparable. It is useful to apply the metaphor of the Janus face: two aspects of the same existence (Dreyfus, 1991). To be a lived body, then, is to be a physical being. The ‘body’ can be diseased, but the patient as a lived body responds to their disease as a lived state of illness. Hence, this is not a new form of dualism whereby the lived body is pitted against the physical body (Aho and Aho, 2008). The concept body-subject encapsulates this perfectly. It is at once both a subject and an object to itself and to the external gaze of others as a visible being (Sartre, 1962). Even so-called psychological states such as our moods and emotions are directly available to the other through gesture, expression, and tone of voice, and the others can respond directly to these (Heidegger, 1927; Ratcliffe, 2008). For example, the sadness of a patient embodied through slumped shoulders, a tear, or a wavering voice often calls for a compassionate or caring response from clinicians or carers prior to theorizing about how we can tell that they are upset, or assessing whether they are malingering (see Chapter 5). Whilst the body can be explained objectively as a biological entity, then, this is never the ‘last word’ (Leder, 1990).

To elaborate, these insights from philosophy and the social sciences can support my argument for a phenomenological supplement to biomedical accounts of both respiratory disorders and related mental health conditions that are insufficient for several inter-related reasons. These include, firstly, the failure of biomedicine to capture the rich and varied experience of the embodied, socio-culturally embedded breathless individual. Enormous differences exist between how practitioners think about disease and illness, and how patients experience their illness (Toombs, 1989; 2001; Carel, 2008; Kalanithi, 2016). 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 (disease). Yet for the patient, the illness is experienced as a way of being, to be lived through and coped with (Carel, 2008):

> I felt like I had become my illness. I had no life of my own—merely a life of survival… Today my lifestyle does not revolve around my illness. I have adjusted to the fact that I have physical limitations and spend my precious energy wisely doing the things that are important and meaningful to me. I am grateful for what I can do—even on the

> days when I must slow down and rest because my breathing is more labored than usual…. life is no longer a race to be endured, but a journey to be enjoyed—one breath at a time. (Bowers, 2004).

Secondly, how these experiences affect patients' understanding and the intelligibility of their disorders is often overlooked. The patient is not reducible to their biological dysfunction or diagnosis. They respond to their diagnosis and illness experience, reflecting on what these experiences mean to their current and future ways of living. With a diagnosis of a chronic illness, the patient may understandably respond with despair and depression, or the realisation of the transience of life and an opportunity to take control of their remaining health, by giving up smoking, for example (*ibid.*). Other patients often struggle to make sense of their experiences through medical narratives or language alone (Svenaeus, 2012). This highlights the problem with taking such a reductionist view of patients: Bowers's (2004) inability to continue with her life projects and status as an active agent resulted in a depressingly deficient conception of herself that made her feel *reduced* to her illness and bodily limitation (*cf*. Carel, 2008). Such reductivism failed to capture her human existence as an embodied, self-interpreting agent in a world with others who can take a viewpoint on her illness.[21] That is, although an objective medical focus on the disease has its proper place in managing the disorder, this focus is not the whole story (Svenaeus, 2012; Kirkengen, 2015).

Thirdly, biomedicine neither prioritises, nor fully utilises patient experience of medical care despite medicine's supposed commitment to patient-centred care (NICE, 2009). The consequences of this range from failing to meet patient needs comprehensively, to provision of a complete, adequate picture of the effects of illness and medical intervention on the patient. Indeed, the patient experience of their disorder within the clinical encounter and management of their disorders often reveals types of injustices committed against them, as we shall explore in later chapters (Carel and Kidd, 2014). I argue that phenomenological description, for example the patient 'toolkit' developed by Carel

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[21] The invitation to reflection and to philosophize, to re-examine and re-interpret one's life alongside modifying movements and goals, will be considered in later chapters. This will reveal the edifying possibilities that illness presents. It will also allow for a critical engagement with what Carel (2012; 2013; 2014) calls the philosophical role of illness: both what philosophy can learn from examining illness and how philosophy can be useful to those suffering from a chronic illness.

(2010; 2012; 2013a), can thematize patient experiences of their illness by attending to their first-person accounts to provide deeper knowledge and understanding of these human ways of being and experiences of medical care.

For the most part, I am focusing on chronic illnesses[22], particularly disorders characterised by dyspnoea, including 'physical' illnesses such as respiratory diseases, and 'mental' disorders such as panic disorder, generalised anxiety disorder and depressive disorders that have more than the symptom of breathlessness at their heart. Apart from the aforementioned ubiquity of breathlessness experiences, paucity of philosophical research, and increasing prevalence of these illnesses, this focus is also because physical and mental respiratory issues are often both invisible (there are often no exterior tell-tale signs, or fear of judgment causes the patient to conceal them) and related to themes and experiences of stigma, shame, responsibility and social injustice (Dolezal, 2015; Ratcliffe and Broome, 2012). I therefore examine conditions such as chronic obstructive pulmonary disease (hereafter COPD) and comorbid depression and anxiety disorders, to fully elucidate the impact of shame, stigma, responsibility, and socio-economic status on patients' experiences and the onset and maintenance of their illness. I will explore the link between these illnesses and the impact of the socio-economic architecture of society and medicine on the person, their self-understanding and identity in Chapter 6.

Of course, chronic illnesses share certain universal features that are not always distinguishable from acute illness (Carel, 2014). For instance, we all get ill, and we all have been ill at some point in our lives (*ibid*.). Chronic illnesses also reveal our mortality; not just the fact that death can loom closer, but our underlying attitudes to dying and death which are revealed when reflecting on the transformative experiences undergone through chronic illnesses (Gawande, 2014; Bishop, 2011).[23] These reflections would not ordinarily be experienced with an acute illness such as a cold, for example. Moreover, with chronic illnesses physical limitations and transformations to the lived body usually persist for long

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[22] Acute illnesses can reveal structures of human existence, but, as Toombs (2002) and Carel (2013) argue, chronic illnesses reveal deeper transformations to our existence via concepts such as loss. These include loss of wholeness, loss of certainty, control, freedom and familiarity (see Toombs, 1987; *cf*. Carel, 2016).

[23] See Chapter 5 and 6 for examinations of conceptions of dying and death in respiratory disease, mental health conditions, and philosophy.

periods of time, in some cases worsening as the illness progresses (Toombs, 1987). The shrinking of aspects of human existence such as motility, spatiality, and inter-subjectivity alters the relationship to the immediate environment, family, community, and world of work, as we shall see below. In acute illness, on the other hand, any bodily changes are usually short and once recovered, life returns to ‘normal’ (Carel, 2018). There is thus a temporal as well as spatial distinction to be made then as acute illnesses are short and time limited, with worsening of the impact of the condition lacking the progression and continuation that are a feature of chronic conditions.

In sum, to reach an adequate and accurate model of how disorders with breathlessness at their core affect the patient, I use phenomenology as a methodology to redress the aforementioned criticisms. I will now present a phenomenological preamble, prior to presenting a phenomenological framework of illness that will be utilised in later chapters for the elucidation of breathing and breathlessness.

1.4 Phenomenological description

> The Essence of Dasein lies in its existence. Accordingly those characteristics which can be exhibited in this entity are not ‘properties’ present-at-hand of some entity which ‘looks’ so and so and is itself present-at-hand; they are in each case possible ways for it to be, and no more than that.
>
> *Heidegger, 1962: 42*

> Dasein *is* its possibility
>
> *Heidegger, 1962: 42*

Phenomenology is concerned with the study of phenomena as we encounter them through experience.[24] There are differing forms of phenomenology (for example, existential and hermeneutic), which are derived from the phenomenological pioneers Edmund Husserl (2001), Martin Heidegger (1927), Jean-Paul Sartre (1962) and Maurice Merleau-Ponty (1962). Due to the different stances of each phenomenologist, it is more useful to see phenomenology as a style of thinking rather than a system (Moran, 2000). As a

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[24] Rather convolutedly, Heidegger formally defines it thusly: ‘…"phenomenology" means αποφαινεσθαι τα φαινομενα -- to let that which shows itself be seen from itself in the very way in which it shows itself from itself.’ (1962: 32).

philosophical movement, phenomenology claims to study the first-person structures of consciousness in experience (how we experience), and is often used by researchers as a methodology that can supplement medical knowledge through its independence from any pre-received notions of reality or adherence to 'best' practice in scientific communities (Van Manen, 2014: 16).[25]

This form of investigation is a way of inquiring into areas such as existence, encountered objects, and world experience, rather than positing an ontological account of what exists (Heidegger, 1927; Merleau-Ponty, 1962). Husserl, the founder of this movement, called for such a return to phenomena, often formulated as the battle cry 'to the things themselves' without any ontological presuppositions (Husserl, 1960; 1988). The 'transcendental' characterisation of phenomenology means to hold back from our everyday 'natural attitude'; the taken-for-granted nature of everyday thinking; of believing in an independent world separate from human existence; and of commitment to certain assumptions, assertions and metaphysical postulations regarding the world and phenomena (Husserl, 2001). This is to perform the phenomenological reduction. To quote Merleau-Ponty: 'to place in abeyance the assertions arising out of the natural attitude" (Merleau-Ponty, 1962: *xi*). This includes bracketing off our scientific stance as 'all my knowledge of the world, even my scientific knowledge, is gained from my own particular point of view, or from some experience of the world without which the symbols of science would be meaningless' (Merleau-Ponty, 1962: ix).

Such metaphysical modesty requires that we start from our own experience of *Being* (*Sein*), or of existing as embodied subjects located in a particular location, culture, and historical period (or, as it is often called, our being-in-the-world: [*in-der-Welt-Sein*]). As human beings we are part of this world and our consciousness cannot be separated from the body or objects of our experience: perception directly connects us to an already meaningful world of entities, objects, and experiences (*ibid*.). This is not a repetition of Cartesian (mind-body) dualism, as consciousness is not separable from embodiment or world (Merleau-Ponty, 1962). Indeed, this methodology returns us to the 'life-world'

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[25] It would be impossible to give a full account of the movement since its beginnings in Brentano (*Psychology*,1988) and Husserl (2001). For useful accounts of this, see Moran (2001), and Zahavi (2018).

(*Lebenswelt*): the underlying source of our experiences, including our scientific presuppositions. It requires a rediscovery of the world we inhabit, despite being ‘prone to forget’ (Merleau-Ponty, 2009: 31).

In short, this world is the pre-reflective world of perception and experience, a return to the perceived world that grounds or operates as the foundation of our knowledge (Merleau-Ponty, 1962: ix). ‘Pre-reflective’ denotes our ordinary, absorbed engagement with our world and projects prior to reflective practice. We make a sandwich, read medical texts or philosophical journals in our everyday existence with a view to meeting our desires, needs, and purposes and without a need to attend consciously to how we accomplish these tasks. Our experience is lived through prior to theorising, then. Before taking up a reflective stance we are influenced by lived experience and this experience influences language, thought and society (Sartre, 2003).

Heidegger called this form of human existence *Dasein* (being-there); Merleau-Ponty preferred the term ‘body-subject’ to express the constitutive nature of our embodiment (1962: 42).[26] Rather than assuming the philosophical tradition of notions of self as consciousness independent from the body and world, these concepts capture how we inhabit, question, interpret and make sense of our world and own existence. Further, the *Da* (there) of human existence does not refer to a particular location as an object in Euclidean space. Instead, ‘to exist as Da-sein means to hold open a domain through its capacity to receive-perceive the significance of the things that are given to it’ (Heidegger, 2001: 4; *cf.* 1962). As Merleau-Ponty suggests, our ability to perceive is taken as vital in examining human existence, along with the world: that from which we receive perceptual experience is the ‘natural setting’ and ‘grounding’ of perception (Merleau-Ponty, 1962: xii). Thus, perception is ‘the background from which all acts stand out, and is presupposed by them’ (Merleau-Ponty, 1962: xi).

This opening for ‘receiving – perceiving’ is not to be construed as a ‘present at hand’ object amenable to scientific measurements. It can never be objectified ‘under any

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[26] In later work, Merleau-Ponty preferred to use the term ‘flesh’ (*la chair*).

circumstance' (Heidegger, 2001: 17). Only biological facts about the body can be objectified, whereas our form of existing is necessarily experienced as subjective and can be disclosed through phenomenological investigation. This presentation of our body as lived, which grounds and shapes our perceptual experience, can reveal how in illness our experiences are altered as the body loses its typical transparency through failures of smooth activity and the inability to carry out projects.

Breathlessness experiences, for example, capture this fundamental perceptual connection between the world and our existence through opening up an arena for reflection on our altered embodiment, offering strength to arguing for a phenomenology of breathing and breathlessness. As Leder (1990) points out, our embodied experience might be enabled by perception and motility, but these rely on the invisible aspects of our body such as 'the autonomous rhythms of breathing and circulation, the stilled body of sleep, the mystery of the corpse' (Leder, 1990: 2). To have a full understanding of human existence, of the self, we need to pay attention to these ordinarily absent horizons, particularly as they show up to us in a bodily breakdown. Indeed, Leder suggests that these automatic processes are often ignored by philosophers due to their 'experiential absence' (*ibid.*). That is, these processes are so close to us, making possible our fluid engagement with our environments and projects, they are for the most part absent in daily, 'healthy' existence.

When this autonomous/automatic rhythm is disrupted through illness we have to attend to the breakdown in our usual bodily transparency, enabling reflection on both what it means to be human, and what these alterations mean for the self as an individual as well as a social being bound to a world that calls on us constantly to respond. For example, consider Heidegger's emphasis on our active engagement with the world and our relationship with others. Dasein is thrown into an already meaningful world that shapes our possibilities. That is, we are actively engaged with projects and take up certain roles – possibilities or ways of being – when we become teachers, parents, cyclists, smokers, and so forth (*cf.* Carel, 2013b). These 'abilities to be' (*Seinkönnen*) are made possible through *perceptual engagement* with the world, underpinned by automatic processes such as respiration, and are therefore changed by chronic breathlessness. The alterations may start gradually – cycling becoming harder, then perhaps impossible; I can no longer fulfil my role as a teacher as talking becomes exhausting, and so forth. Or, the disruption may be violent: an acute respiratory event that forces us to pay attention to respiration and altered bodily movement to fight for survival. As Heidegger did not provide an account of embodiment, it is useful to turn to an examination of intentionality and motility to further draw this out.

1.5 Intentionality, embodiment, and the world

In philosophy, intentionality denotes the characteristic of consciousness that is called *aboutness*: that consciousness is directed towards something, whether an object, an idea, or an abstract concept. Brentano (1995) first suggested that mental phenomena are intentionally directed: our experience is directed towards things i.e. consciousness is always intentional. To explain, the meaning or content of consciousness is structured by intentionality: I understand *p*, I see that *p*, I desire that *p*. This consciousness is lived through experience – I experience shortness of breath, I feel a sense of impending doom, I desire the panic to cease. In chronic respiratory illness, pathological breathlessness (dyspnoea) often takes over this intentionality; it colours my vision of what I must focus on and frightens me (*cf.* Ratcliffe, 2012). I have to address what could be a life-threatening episode rather than continuing with my current task. Previous embodied experience may equip me with the tools to calm my breathing, or to differentiate between panic and an asthma attack. However, the illness removes me from my usual absorbed relationship with the world and my intentionality manifests this change.

To reiterate, intentionality does not lead to another mind/body split. These thoughts and experiences are conscious thoughts *about this,* or about *that,* which are *embodied*. I can reach for my inhaler; I direct my attention to deeper breathing, and so on. Indeed, the appearance of the inhaler as significant to my asthma (as an intentional object) shows up via previous bodily experiences with an inhaler: I have used one before and it shows up as ready-to-hand (*zuhanden*) for me to use again.[27] Intentionality, then, is ever-present in the

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[27] As we will explore, Heidegger uses ready-to-hand (*zuhanden*) to denote how we are already absorbed in the world in terms of practical engagement and activities. A hammer is something we use without theorizing about it; it is there and ready for us to use in order to achieve an end. So too is our inhaler. These objects have significance and meaning as part of the larger world, showing that we care or are concerned about something (known as the ‘tool analysis’). In contrast, present-at-hand (*vorhanden*) denotes an object which

structures of consciousness and experience: in thought, perception, memory, embodiment, inter-subjectivity, language, and emotion. We direct our attention towards things in the world, then, and this basic form of intentionality reveals further inter-related structures of experience: for example, temporality. We intend towards things within a temporal framework – I must write a talk by a specific date; I must make a doctor's appointment, and so forth. My consciousness and experience are structured by time and thus intentionality is bound to temporality (to which we return to below).

Before examining another form of bodily intentionality, it is useful to focus on the basic structures of embodiment. In the third chapter of *The Phenomenology of Perception*, Merleau-Ponty presents the notion of the spatiality of the body – of how we understand our body in terms of its connection with the space that the body inhabits. Rather than the parts of the body 'spread out side by side' (Merleau-Ponty, 1962: 112), they are enveloped within each other. This envelopment signifies the totality of the body as a whole entity that is not split into differing parts with differing functions. Indeed, the 'whole body for me is not an assemblage of organs juxtaposed in space. I am in undivided possession of it and I know where each of my limbs is through a body image in which all are included' (Merleau-Ponty, 1962: 68). This body image (which can be changed by illness) orientates me in my environment, and I am able to move around without checking where my legs are, for example.

The spatiality of the body is thus a lived space that is directly connected to the world. 'Up', 'down', 'near', 'far', 'left', and 'right' capture the connection between the body and the world, along with the inter-relatedness of bodily organs. Indeed, orientations such as 'near' or 'far' are not dependent on objective space, but on the body image as reflective of the spatiality of the body. What does this mean? Whilst it is proper to describe distance with reference to measurement in some instances, a new signification and intelligibility transforms our everyday understanding of the concepts themselves. This is because as we understand our capacities and ourselves in terms of our body image, our understanding of

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we view in a detached, theoretical manner, or when a tool breaks and so is no longer ready-to-hand but instead conspicuous, obstinate or obtrusive (BT: 104). These concepts will be returned to in later chapters.

what is near or far can be depend on our embodiment. What is near to me can be ‘too far’ for a patient with multiple sclerosis, for example (Toombs, 1989).

This spatiality of the body is constitutive of the lived body, the first-person experience of the body. Such attention to the lived body further discloses the habitual nature of embodiment, accounting for the significance and knowledge of how to use the inhaler, for example. That is, the body is for the most part habitual, and this ‘habitual body’ underpins our experiences by providing the framework from which we can experience things and undertake projects (Merleau-Ponty, 1962: 130). For example, when driving my car, I do not need to consciously focus on changing gear, or how to manoeuvre around a cyclist. Nor when I swim do I need to instruct one arm to move in front of the other. I perform these movements and activities smoothly by the prior sedimentation of these actions from previous experience and practice; they become part of my bodily repertoire that I can engage in when I want to, or when the world solicits me to act (Dreyfus, 1991). I have used an inhaler to control my asthma, and instinctively reach for it when I feel sensations indicative of the onset of dyspnoea. Thus, the present experience of my body utilizes this tacit knowledge and responds accordingly.

However, two conditions necessary here are bodily continuity and integrity: I can count on my body to carry out projects so long as it is for the most part unchanged or uninhibited. When something goes wrong, when the harmony between the lived body and the biological body is ruptured, the knowledge of how to carry out a project (knowing how) remains: I know how to drive, how to swim, how to run. Yet the biological body becomes obstructive and prevents these habitual movements from taking place. The loss of lung capacity prevents athletic endeavours, running for the bus even. The way that I understand myself, my body image, may be altered by the changes to spatiality as the connection between the body and environment. I am no longer an athlete; I have to choose new possibilities, new projects. Indeed, the adaptable nature of the body allows for new habits to be created, of modifications to movement to occur; with practice, these habits become sedimented and part of the habitual body (Carel, 2008). The world still solicits me to act, then; the intimate connection remains although the performance of my activities and self-understanding may change.

The relationship between the body and the world therefore constitute the meaning-giving background for my activities. These themes of embodiment, being-in-the-world, motility, intentionality, and temporality are captured by Merleau-Ponty’s conceptualization of the intentional arc:

> The life of consciousness—cognitive life, the life of desire or perceptual life—is subtended by an ‘intentional arc’ which projects round about us our past, our future, our human setting, our physical, ideological and moral situation […] It is this intentional arc which brings about the unity of the senses, of intelligence, of sensibility and motility. And it is this which ‘goes limp’ in illness. (Merleau-Ponty, 1962: 136)

As we have seen, chronic illness with breathlessness as a main feature can cause this disruption, or, in the language of Heidegger, cause the collapse of meaning and thus allow an examination of these structures of experience. It can show us how the world is altered for the ill person, providing rich description of how they have to readjust and cope with these changes (*cf.* Svenaeus and illness as ‘unhomelike being-in-the-world’, 2000). A basic structure of the intentional and world unity is given by Merleau-Ponty’s detailed account of the perceiving embodied subject related to its world through purposive orientation to the environment and its objects. This ‘motor-intentionality’ underlies our relation to objects in our environment. Our environment solicits our body to respond skilfully – and without conscious intent in many cases (Merleau-Ponty, 1962; Dreyfus, 1992). This body-world unity is the meaning-giving background to our activity. Motor (and other) habits we have formed in accomplishing certain feats are easily employed in new tasks. For example, coping with a new activity, responding to a change in environment e.g. a long ferry journey between Plymouth and France requires one to make subtle bodily adjustments in order to walk around the ship, carry objects, chase unruly children, and so on, whilst the ship rocks. As the ship constantly responding to the movement and flow of the water, and the water to tides, channels, and weather moment by moment, so too, does the body-subject constantly respond and adapts. These responses are not conscious (unless the sea is so rough that our usual tasks are interrupted, or maybe if one is an anxious or sick sailor). The situation that we find ourselves in calls for a response and we respond though movement and action (motor intentionality) that is spontaneous and for the most part unconscious.

When the body breaks down in such a way as to be unable to carry out tasks, projects, and movements that the environment solicits us to react to, both bodily freedom and concrete liberty can be removed. These changes are not just personal; they impact our social being and interpersonal relationships. Armed with these concepts and descriptions of phenomenology and illness, we can move to the provision of a framework for a phenomenology of respiratory distress.

1.6 Framework for a Phenomenology of illness

> The real is a closely woven fabric.
>
> *Merleau-Ponty, 1962: xx*

Phenomenological studies into the transformations to experience mediated by illness have provided a rich source of description thus far. I now present a framework for a phenomenology of illness that will be utilised in later chapters for examining breathing and breathlessness in physical and mental disorders. In contemporary phenomenological studies, there exists a recent proliferation of variants of phenomenology of illness, with four main types that are often inter-related. These include a phenomenology of illness as dis-ability (Carel, 2008); of illness as breakdown (Carel, 2014; Ratcliffe, 2015); of illness as unhomelike-being in the world (Svenaeus, 2000);[28] and finally, of illness as loss (Toombs, 1987; Carel, 2013b).

Keeping with the phenomenological methodology of description as a system of thought rather than dogmatic adherence to a particular theory, I will use insights from these variations in the creation and application of the framework in later chapters (Aho, 2012; Carel, 2016; Ratcliffe, 2015, Toombs, 1987, Levinas 1998). Many of these presentations of a phenomenology of illness intersect and share core phenomenological concepts and

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[28] Illness for Svenaeus is ‘being not at home’, an uncanniness, or unhomelike being in the world. Health, then, is a homelike-being-in-the-world. This world isn’t separate from me; I am my own world, immersed in it within the roles and activities I partake in, connected to others and the environment in a meaningful way (Svenaeus, 2000). Health in illness is also possible under his account; to gain a sense of being homelike despite the experience of unhomelikeness (Svenaeus, 2012). The role of the physician is to establish a connection between the medical, scientific gaze and the perspective of the patient as undergoing the experiences of an ill person (*ibid*.).

descriptions of shared structures of human existence thus far discussed. Recall that for phenomenologists, embodiment is the background condition for subjectivity to exist. We do not need to locate various body parts and then use our mind to order them to move. Proprioception and kinaesthetic powers are synthesised and underpin our usual pre-reflective habitual movements, revealing the intelligence and goal orientation of our embodiment (Merleau-Ponty, 1962). This background allows us to consciously focus on the task at hand, whether it is studying the Aristotelian concept of *pneuma*, for example, or playing 'Basin Street Blues' on the saxophone. These abilities to carry out meaningful activities reveal that such movements are meaning constitutive themselves because of their goal orientation. This is why Merleau-Ponty writes that the body is more than an instrument or means for the performance of practical or theoretical activities. Instead, the body is 'our expression in the world, the visible form of our intentions' (Merleau-Ponty, 1962: 5).

If in health we ordinarily perform meaningful, goal orientated movements through the lived body as a body-subject, what happens when our lived body is split from the biological body as seen in the bodily breakdown of illness? Are dualism or naturalism correct after all? That is, is the body subject comprised of two substances, psyche and soma, matter and mind? No. The mind-body unity still underpins human subjectivity; what instead occurs is the appearance of the ambiguity of the body, the body as both a subject and an object for ourselves and others, a lived body and a biological body. This is an alteration of our normal experience. Carel characterises the alignment of these aspects of embodiment in health as harmonization: transparent and taken for granted (Carel, 2008; *cf*. Carel, 2016). This is thus changed by illness, with the body becoming the focus of our attention rather than the usual background to our activities. When this connection breaks down, then, the body becomes conspicuous. Carel draws on Heidegger's tool analysis as an analogous case of such a breakdown (Carel, 2016). Ordinarily, we encounter entities in the world in the context of our projects and activities. A hammer is grasped as ready-to-hand (*zuhanden*) in order to fulfil a job. We already know what it is without needing to take up a theoretical stance. When it breaks, it becomes an object of our awareness as unready-to-hand or present-at-hand (*vorhanden*). This is through its conspicuous, obstructive, or obstinate appearance (Heidegger, 1962). Just as the hammer breaks and no longer is inconspicuous as we carry out our projects, radical changes to embodiment through the breakdown of bodily transparency and certainty (for example) can disable us, pulling us out of our everyday absorption in our projects and in the world.

We are forced to attend to the sudden onset of breathlessness, or obstructive back pain, or chest pain: the pain or inability to breathe brings our attention back to our body. Of course our body cannot be replaced like the hammer, but this doesn't detract from the analogy: rather, illness reveals our *essential* embodied nature through its violent and abrupt alterations to our existence, alterations that we have to live and cope with (Carel, 2008:27). Thus, the body 'embodies my situation as an ill person' (Carel, 2008: 51).

As illness is a thus a form of disruption of the lived body, physical changes to embodiment and possible ways of being create transformations in subjectivity and self-understanding. This is because illness disrupts the body's transparency and integrity, causing it to break down. What does this mean? The healthy body is (for the most part) in the background: transparent, whole, and taken for granted. This does not exclude the ability to shift our focus to it and make it the object of awareness in certain circumstances or in periods of reflection: for example, when feeling pain, or on hearing the rumbling of the stomach signifying hunger. However, the healthy body is able to enact our existence as 'ability to be'. That is, '[a]s long as it is, Dasein always has understood itself and always will understand itself in terms of possibilities' (Heidegger, 1962: 185). As we have seen above, Heidegger characterizes human existence as 'being able to be' (*Seinkönnen*). One can take up certain roles or potential projects dependent on physical, social, and cultural norms. For instance, *being* a student, *being* a physician, *being* a runner. One can also understand oneself in these terms (although as potentiality-for-being, cannot be reduced to these roles, as we shall see). For instance, one is a mother, a teacher, and a singer. As a Western woman in the twenty-first century, I can take up these various roles, although this freedom can be inhibited. I couldn't be a samurai swordfighter, for example (Dreyfus, 1991).

Therefore, human existence is structured by *thrown* projection (*geworfen Entwurf*). I am thrown into a particular historical period and cultural setting, and I project myself accordingly into the possibilities opened to me through these. Temporality again is part of this structure; my present role as a PhD student connects the present with the future project of becoming a philosopher, and my past as an undergraduate and as a Masters student. These processes of becoming are responsive to the environment and changes in my self-understanding and projects (Merleau-Ponty, 1962). I can choose to retrain in psychology, for instance, if I decide that my previous career in mental health is my true calling. Thus, people can change, develop, and grow, attaining further abilities and experience. However, Carel describes how for those who live long enough to grow old or encounter radical changes to existence through physical illness or mental disorder, these abilities (and potentialities) are curtailed (Carel, 2013b). Inability to be – and chronic illness is inarguably a state of 'inability' – should therefore be included in the characterization of human existence as ability to be (which Heidegger failed to do).

Inability to be, then, occurs via changes to embodiment through processes of ageing, illness, and mental disorder. The *I can* of practical comportment in the world, becomes *I can't*. Not only is the transparency of the body changed, with habitual movements transformed into explicit achievements, but changes to *bodily certainty* entail what Carel calls *bodily doubt* (2013b). Bodily certainty is the inductive tacit certainty that we have regarding our bodies. This includes the assumptions that we 'will be able to digest our lunch, that our hearts will carry on beating, that our legs will carry us' (2013b: 146). This bodily certainty is inductive in so far as it cannot be justified rationally (*à la* the Humean critique of induction), and yet it constitutes a 'powerful faith [that] underlies our relationship with our bodies' (*ibid*.). This form of certainty is not the same as holding a propositional belief subject to philosophical scrutiny, although it is a (unjustified) belief. Rather, it is a bodily feeling that 'makes its bearer present in a world by offering her a meaningful horizon in which things and projects can appear' (2013b: 147). That is, bodily certainty underpins our *abilities to be* as seen by our assumptions that we can do *this* or *that* thing.[29] It is both a bodily feeling and a feeling of the connection with entities outside of the body.

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[29] Matthew Ratcliffe's (2008) unique work on existential feelings is explored further in Chapters 4 and 5, particularly in accordance with the changes in the sense of reality brought about through depression and anxiety comorbid with respiratory distress.

Bodily feelings are therefore also the existential feelings Ratcliffe describes (2008). They disclose how we find ourselves in the world (see also *Befindlichkeit* and *Stimmung* in Chapter 5 for elaboration). Bodily certainty, however, makes possible the background for things to appear as meaningful, and hence underpins existential feelings (Carel, 2013b). We assume, without conscious reflection for the most part, that just as the sun has risen every day, so too our body will function in its prior fashion. Plans to drive to work in the morning, to throw a birthday party for our child, to attend a boxing class, exemplify the habitual body's implicit sedimentation of these abilities, my trust that *I can* perform *x* or *y* pre-reflectively in the background as a horizon for activity (although again, like Heidegger's notion of thrown projection, this *I can* is limited).

This tacit belief in bodily certainty is writ large in cases of bodily doubt. Bodily doubt is the experience of betrayal, alienation and detachment from one's body and the world (Carel, 2013b: 150). It is brought about by the loss in confidence in our bodies through the bodily breakdown that illness confers upon us and affects the entire being-in-the-world of the chronically ill patient. Possibilities, the ability to be, spatiality, motility and the intentional arc are radically changed (see below). Therefore, the belief in bodily certainty is not only transformed: the attachment to the world, the ordinary home like quality or comfortableness inhabiting the world is removed (*cf*. Ratcliffe, 2008; Svenaeus, 2000).

This doubt includes three components of bodily loss: loss of continuity, loss of transparency (as previously discussed), and loss of faith in one's body (Toombs, 1987; 2007). Continuity expresses the ordinary connection of both experience and of purposive action (Carel, 2013b: 154), modified through illness to bring action and self-awareness to consciousness as the usual transparent connection breaks down. Once this continuity is lost, it can be regained, dependent on the severity of the illness.

Loss of faith in one's body is a loss of the 'tacit set of beliefs we hold about our bodies' (*ibid*.: 158). These beliefs function as supporting our actions, goals, and our projects. When we begin to doubt that we can carry these out due to bodily breakdown, we are no longer certain we can go about our daily business in the world. Instead, we become alienated and estranged from our body and from the world, as we can no longer respond to its solicitations to act. This doubt may be temporary, as in illness experiences that are acute and short lived; or it may transform the relationship to one's body and world irrevocably, as in severe, progressive illnesses. With these concepts and descriptions in mind, I argue in later chapters that studying illness can reveal the reality of the ill person, in addition to unearthing our ordinary ways of existing as embodied subjectivities.

As we have seen, illnesses are thus various 'ways of being' that can prevent one from either choosing or taking up certain possibilities (Carel, 2016). Chronic illnesses also can inhibit our freedom in self-interpretation as an agent: instead of the pre-reflective *I can* of the habitual body, limitations may initially cause the experience of alienation from one's own body and environment, seeing the self in terms of *I cannot*. The smooth habitual actions are inhibited: instead of the body tacitly orientating one towards these projects, it becomes a conspicuous object to my awareness. The capacity to interact with the world, to find significance in projects and activities, is thereby changed, although these can be mitigated by new bodily habits, goals, and rehabilitation. These altered abilities can be both conscious and unconscious. On the one hand, joining support groups and creating a role for oneself as a spokesperson for COPD, for example. On the other, damage to lung tissue can cause the body to unconsciously and automatically 'increase the number of oxygen binding red blood cells… the heart works harder, pumping the blood even faster through the lungs in an attempt to absorb more oxygen from a reduced surface area' (Carel, 2016: 34).

Hence, studying chronic illness such as those with breathlessness as a core feature via a phenomenological lens reveals our normal pre-reflective ways of existing in the world, providing opportunities for self-reflection and understanding. One example, mentioned above, is Carel's (2013b) analysis of illness as a 'limit case' of embodied experience. Her account shows that as illness pulls us out of our everyday taken-for-granted existence (the 'natural attitude'), it can show 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, for example, have been uncovered by illness. In fact, the phenomenological reduction and bracketing of the natural attitude is analogous to the distancing effect that illness creates (*ibid.*). 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. Just as with Heidegger's (1962) *Angst*, possibilities, projects, and our everyday living are radically altered and meaningful existence collapses.

This descriptive account fits with the changes to body image, self-identity and self-understanding frequently reported by patients (Carel, 2013b; 2016). Rather than the body being in the background whilst the person is going about their daily activities, they now become aware of their new limitations: breathlessness and a tight chest bring their awareness back to the body and how they can no longer live carefree. In short, their body image is altered through changes to embodiment such as, for example, having to use a mobility scooter as one can no longer walk for more than twenty yards (Fuchs, 2012). They may no longer understand themselves as a fit and healthy person or identify as an athlete once the illness progresses and restricts these possibilities.

Further, it is important to note that mobility inhibition and its effects on bodily certainty (the taken-for-granted confidence in our bodily abilities) also alter the person's existential and social interactions. The shrinking of the social world and physical activities via the illnesses' effect on the body also has psychological, social, and interpersonal impacts that act upon one another (Smoller *et al.*, 1996). For example, anxiety and fear of moving around too much may limit physical and social activities such as attending one's regular exercise class or visiting friends. This fear of exacerbating the condition leads the patient to avoid going out so often, and to socially isolate herself. This can lead to depression and make the anxiety worse via not challenging their fear that going out will cause physical harm, and thus becoming a harmful coping mechanism known as 'safety behaviour' (Wells, 2007).

These transformations also effect intimate and social relationships. Interpersonal relationships are altered as the person's independence and motility is changed and they need help doing daily activities that heretofore they managed independently (Carel, 2016). Their loved ones may take up the role of carer, and so the ill person's agency is radically changed (See Chapter 4 for more detail). Rather than projecting oneself into roles and possibilities that one could do with ease before, the opportunities may now disappear (analogous to Heidegger on anxiety and death). In short, for the ill person, the illness affects all aspects of life, not just pulmonary function and suffering caused by shortness of breath. Moreover, awareness of their own mortality is commonly reported in people who have suffered a medical crisis: their altered sense of self as an active agent is disrupted through the experienced threat to life, further changing their sense of temporality in addition to the shrinking of experiences of spatiality (Toombs, 1987; Carel, 2013a). The past may hold significance as the time ‘before I got ill’, and measurements of the future may come in terms of what the body can manage in the next twenty-four hours, rather than planning for next year.

As I later question whether there is potential for growth and edification in these transformed experiences, this account thus far appears quite negative. However, it is only a sketch to be enriched as the study deepens. Here I wanted to capture what is at stake in such disrupted experience: in sum, as our body is constitutive for having knowledge and experiences, that is, for *opening* a world to us, it should not be surprising that in illness our meaningful connection and everyday movements are altered. When walking upstairs can cause panic and anxiety, these experiences reveal the usual way that we unreflectively move around and engage with our environment. It should also point to how insidious invisible yet life-threatening breathlessness can impact lived experience. In contrast to the biological body that science investigates, then, our habitual body, as Merleau-Ponty calls it, is disrupted, and so the task at hand (to draw positive or creative responses) may seem impossible. As we will explore in Chapter 4, the patient can take a stance on these changes, and adapt creatively (*ibid*.).

1.9 Conclusion

Phenomenology provides detailed description and language suitable for explicating alterations in experience caused by chronic illnesses. Its utility consists in many factors. These include freedom from traditional assumptions and metaphysical commitments. This allows a return to ‘the things themselves’: shifting focus onto the experiences as lived and describing these rather than explaining them. Nor searching for underlying causes (a remit of medical science). Ultimately, such an approach sheds light on often invisible, yet surprisingly common, experiences.

Secondly, as we have seen, limitations of medicine include neglecting aspects of suffering that patients encounter in their day-to-day living (it is undeniable that medical data is vital, but so is focusing on the ill person). Recognising this and moving forward by virtue of the provision of descriptions of altered life world can help these patients cope, address symptom management, improve daily functioning, and quality of life, wellbeing within illness, and physical and mental health symptoms (Nicholls, 2003: 123; Carel, 2013).

Third, with under-researched experiences such as breathlessness, we see that it is intelligible to and interpretable by the patient with the subjective symptom. Like pain and depression, dyspnoea is a subjective experience difficult to quantify due to its subjective nature. However, unlike pain, whereby neural networks involved in the experience of pain can be mapped or elucidated, no such simple mapping is discoverable in breathlessness experiences (Nichols, 2003). To discover the experience and how it is lived, we therefore need to enquire into the perspective and understanding of the patient (Chapters 4 & 5). Finally, a phenomenology of illness highlights the isolation and alienation experienced by a patient, not just from physical difficulties caused by the illness, but also the social stigma of these traditionally marginalised groups. For example, in COPD and some mental health conditions the patient is stigmatised by self and others as responsible for their disorder. Phenomenological description thus reveals how we ordinarily live in the world as a social, self-interpreting agent, and provides language and tools to describe the changes to these structures brought about by ill health. Therefore, phenomenological studies of illness, in this case breathlessness conditions, offer many benefits. These benefits could be translated to further research and understanding of the impact of breathlessness (and its close relationship to socio-economic and health inequalities). Apart from reducing distress, managing the condition, socio-economic savings and fostering a greater understanding and knowledge of dyspnoea for both patients and clinicians and so improving communication and better diagnosis (e.g. is this attack anxiety-related, or because of an underlying condition?),[30] selection and funding of the appropriate clinical

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[30] Work done, for instance, by qualitative healthcare researchers (Malpass *et al.*, 2014), highlights that pulmonary rehabilitation and mindfulness can reduce A&E visits, manage dyspnoea and discomfort, and therefore improve the patient’s life (research from the ATS affirms this).

interventions would be ensured. The NHS aims for the right intervention to be accessible at the right time, rather than the issues currently prevalent as evidenced in worsening symptoms and distress from undiagnosed panic disorder, depression, respiratory disorders, or other causes. In short, the millions of people suffering could have their lives improved through more accurate knowledge and understanding of certain illness experiences.

Keeping in mind the distinctions made previously between the biological body (objective body) from the physician's point of view, and the body as lived (body subject) from the point of view of the patient, the diseased body and illness experienced by the patient remain separate. How do these two perspectives meet? The removal of our absorption in the everyday world through transformations to the transparency of the body provides an opportunity to see the gap between these two different perspectives, and invites the use of phenomenology to discover how illness is not an object subject to explicit scientific formulation. Rather, just as body subjects 'constitute the meaning of their experiences' (Carel, 2014), illness is constituted by the experiences and dialogic relationship of patient and physician, society and world. It is to these claims we later return to once we establish the historical development of these ideas.

CHAPTER 2: Reinjecting life into breath. A History of Breath in Western Philosophical Thought: Pre-Socratics to Avicenna

> The difficulties of the climb [to reach *beyond essence*], as well as its failures and renewed attempts, are marked in the writing, which no doubt also shows the breathlessness of the author.
>
> *Levinas, 2016: xlviii*

2.1 Introduction

Detailed philosophical study of the experience of breathing and breathlessness is lacking, aside from Aristotelian and Stoical accounts of *pneuma* related to the elements of fire, air and aether and the roles that these play in the structure of body, soul and cosmos. This natural philosophy (*phusis*) took precedence over the *experience* of breath and its meaning outside of functional utility. Focus was instead on the structure and constitution of the respiratory apparatus, with the role of air frequently reduced to elemental theories of matter. Human existence and the universe were regularly explained by objective, observational and theoretical analysis, with respiration often split between purely materialistic accounts on the one hand, and those that emphasized the material and spiritual elements of the functional task of keeping one alive to nourish and trap the soul (for example) on the other.

This chapter will demonstrate that these Hellenistic accounts were influential until the early modern period, informing medical thought on anatomical structures in the ancient and classical period and Christian[1] thought on the soul. This was prior to a renewal in the medieval period due to the increasing spread of, and reverence for, ancient Greek philosophy.[2] Indeed, physics as natural philosophy grounded in the four elements (with the fifth, Empedoclean 'aither' occasionally included) posited as the basic building blocks of matter influenced science up to the period of Antoine Lavoisier (1743). Indeed, an

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[1] In Christianity this was known as *pneumatology*: the study of the Holy Spirit.

[2] This is demonstrated in the works of thinkers such as Abu al-Walid Muhammad ibn Ahmad ibn Rushd (1112-1198), known as Averroes in the Latin West; Thomas Aquinas (1225-1274), and Pietro Pomponazzi (1462-1525). See Carel, 2012; Routledge Encyclopaedia of Philosophy, 2015.

association with solid, liquid, gas and plasma continue to this day.[3] This focus on elemental theory resulted in a narrow conception of the air, breath and breathing. In particular, the adoption of Aristotelianism and the Platonic ladder of being in Christianity dominated philosophical thought for a thousand years. These were later merged with *pneumatology* and the association of breath with spirit (as the breath of God) to explain human existence and its relationship to God and the universe. Plainly, breath is tied to God, life, soul and spirituality in all the major religions and cultures: there is reference to the 'breath of life' (Genesis, 2:7; Quran, 32:9), the *ruah* (Hebrew), the *prana* (Hindu), *ch'i* (Chinese), and the *hu* (Sufi).[4]

This chapter argues that the importance of breath to human experience, health and vitality has largely been overlooked in the West since Galen (130AD), a neglect that extended to the role of air quality in causing disease until relatively recently. This is in contrast to the Eastern philosophical and medical tradition: from the sixteenth century, there was strong evidence for the relationship between air quality and respiratory disorders, a fact first recognised by the ancients (e.g. in descriptions of silicosis), but this was quickly dismissed or forgotten, as were the air and the breath themselves.[5]

Breathing, an automatic, pre-personal experience, is rooted in the body. It can also be categorized as a subjective experience (despite being influenced by the 'outer' environment), one which we can consciously control within certain limits and, I argue, worthy of philosophical attention. Despite this, or perhaps because subjective, sensual experience was often deemed unworthy of serious philosophical study, there are many objective studies of the physiological processes of breathing, respiration and respiratory diseases throughout empirical studies, yet first-person, lived experiences of breathing and breathlessness are largely unexplored (*cf*. Carel, Dodd and Macnaughton, 2015).

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[3] M. Kikuchi, *Frontiers in Fusion Research: Physics and Fusion* (London: Springer Science and Business Media, 2011).

[4] The spiritual tie of breath to religious *pneumatology,* and the translation of *psyche* to spirit, *Geist,* and soul cannot be covered in this chapter, which instead intends to provide a history of breath in philosophy.

[5] It is beyond the remit of this thesis to address breath and breathing within the Eastern tradition. There exist multitudes of studies of these and my purpose here is to address the neglect in the Western tradition (See Irigaray, 1999; & Škof, 2015). This, I argue, is a lack tied to the development of Western philosophy post pre-Socratics. One that informs Western thought not only about the proper areas and topics of studies for philosophy, but also one that excludes breath as being more appropriate for spiritual or medical study.

Starting with the early formulations and descriptions of breathing in ancient Greek philosophy, I address historical conceptions of breath and breathing in the philosophical tradition, noting the paucity of philosophical analysis of this vital human function and experience outside these mainly physiological descriptions as found in Plato, for example. Yet breathing is an experience that not only keeps one alive: it connects us to the world and to others within the world. Heretofore, despite the traditional emphasis on metaphysical, objective, and scientific thought in relation to the breath, we must retrieve the dealings philosophy has had with breath over the centuries to uncover and address potential sources of neglect.

Thus the focus is on Western philosophical conceptions of the breath throughout the ages, due to a paucity of study of the breath in this tradition (in contrast to the rich conceptions of breath as *prãna*, *chi* and so forth found in the Eastern traditions and covered in detail by writers such as Luce Irigaray (1999) and Lenart Škof (2015)).[6] It will be shown that air, breath and respiration have indeed played a part in cosmologies, metaphysical systems, epistemological concerns, feminist philosophy and finally, ethics, morality and philosophy of medicine. Often these roles have been indirect, obscure and taken for granted. Such an investigation will reveal themes emerging around consciousness, knowledge, subjectivity and intercorporeality that begin with the ancients, and are touched upon in the medieval and modern period before being taken up in contemporary thought.

In the first section, we consider ancient Greek thought on air, breath, and metabolism, with focus on the pre-Socratic philosopher Anaximenes of Miletus. Next, Plato's physiological account of respiration is described, before moving to the Aristotelian account of *pneuma* and its central role in shaping body and soul, including how this influenced Western knowledge on the function and significance of breathing from the Stoics through to the mediaeval period and modernity. I will then compare these insights

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[6] Although Eastern philosophical treatments of the breath and their significance to modern day breathing practices in medical treatment alongside everyday usage will not be covered in this chapter, where overlap exists with the Western canon, my final chapters on philosophical contributions to practice will include, for example, mindfulness to address the panic of anxious, breathless patients.

to both modern and contemporary accounts of breathing in both philosophy and medicine (specifically chapter 3) and critically appraise them.

The results of this historical recovery of breath will tie in with the next chapter, specifically the thought of Levinas (1906-1995) and Irigaray (1930) so that the 'forgetting of air' in the philosophical canon can be recovered (Irigaray, 1999: 7).[7] With a proper consideration of the breath, the predominance of the categorisation of the human subject as fundamentally the rational animal or the Cartesian *cogito* will be questioned, with the phenomenological focus on human existence as active, embodied agents (I am, therefore I think) *which has also neglected the breath,* complemented by 'I breathe, therefore I am'. I suggest that focusing on the importance of the breath can lead to an ethics of co-breathing, revealing shared values and norms in the context of health and illness.

Whence the philosophy of breath is thus historically contextualised, I then argue that the importance of the air, breath and breathing in structuring human experience and existence has a larger role to play than hitherto thought (Levinas, 1998; Irigaray, 1999; Škof, 2015). This history of breath in Western philosophy can then inform the chapter on the phenomenology of breathing and breathlessness, alongside later chapters on anxiety, human existence as Being-with (*Mitsein*), and on medical implications, to form a coherent structure via hermeneutical methodology. Ultimately, the individual '*I breathe, therefore I am',* becomes a shared *'we breathe, therefore we are'.* Responding to the needs of breathless patients through to considering the socio-economic and environmental contributions to the onset of respiratory difficulties, such as health inequalities and deprivation in communities with high rates of air pollution, requires rethinking how we approach breathlessness and the concomitant anxious and vulnerable status of human ways of being. Recognising the subtle meanings of the breath via philosophical study can attest to such a need and assist in the re-evaluation of our thinking about air, breath and breathing beyond purely physiological or scientific concerns. With increasing rates of respiratory illness and mental health problems, such studies are imperative.

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[7] Again, I am not giving a spiritual or Eastern account, and as Irigaray does both in addition to a phenomenological, feminist and ethics of love and non-violence reading, I must limit my studies to a philosophical (particularly phenomenological) account, as outlined in the introduction.

2.2 Anaximenes: Aer, Breath & Pneuma

This section describes how the earliest existing emphasis on air in the West begins with the pre-Socratics.[8] Pre-Socratic philosophers asked: where does everything originate from? What Being or substance (*ousia*) determines entities? How is the variety and difference of natural things explained? How can we use mathematics and science to describe and account for things? Pertinent to our concerns are the three Milesian natural philosophers, Thales (624-546 BCE), Anaximander (610-546 BCE) and Anaximenes (585-525 BCE), who sought the material principle, the *arche*, as that from which everything originates. These material monists posited different *archai* as founding, encompassing and unifying entities, fundamental to human existence, matter, and the construction of the world. These cosmologies not only investigated the origin of the universe, but also the structures and purpose of the soul, knowledge, morality, and the unseen forces and laws acting on phenomena. Thales saw water as the material principle, the basis of all that exists. Anaximander posited an undifferentiated, unlimited substance without qualities, the *apeiron*, analogous to the atom, which was then differentiated into hot, cold, moist, and dry. Anaximenes, however, proposed air as the *arche*: 'Just as our soul [*psychē*], being air [*aēr*], holds us together, so do breath [*pneuma*] and air [*aēr*] encompass the whole world' (Anaximenes of Miletus, 1911, *The public domain, Encyclopaedia Britannica*).

Regrettably, this is one of only two fragments of Anaximenes's corpus remaining, and it is unclear as to whether it is quoted from the original material and whether it has been modified (Benso, 2006).[9] His thought, though, undeniably heavily influenced the philosophical tradition. Theophrastus composed a whole treatise on Anaximenes, signifying the impact of the latter's thought regarding air on his peers and later thinkers

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[8] Empedocles (495-430 BC) was taken by Aristotle and Theophrastus as the progenitor of the theory of elements constituting the universe and everything in it.

[9] However, enough secondary evidence exists and is discussed by Aristotle's pupil Theophrastus (371-287 AD) and the biographer Diogenes of Laertius (180-240 AD) that the meaning of this statement remains unquestioned.

(Benso, 2006: 17). This alignment of breath, air, *pneuma* and *psychē* certainly influenced how breath and the soul were regarded in philosophy, Christianity, and medical thought up to the medieval period, specifically in *pneumatology.* Anaximenes was the first philosopher to undertake a systematic philosophical treatment of these notions, building a system that posited congruence and synonymy between them.[10] We must deal with the above quote in parts. Firstly, what does Anaximenes mean by positing air as the foundation of the world and everything in it? Secondly, what exactly is meant by *pneuma,* and what is its relationship to air and the soul*?* Finally, what does this contribute to understanding breath?

Firstly, for Anaximenes, air is the original substance, infinite, and everywhere. Yet it is not immaterial: 'Air is the nearest to an immaterial thing; for since we are generated in the flow of air, it is necessary that it should be infinite and abundant, because it is never exhausted' (Anaximenes, debated fragment). What can this 'nearest to an immaterial thing' mean? Foucault says that breathing is temporal and (dis)continuous, for when we breathe

> we give up a little of our *pneuma* and take a little of another *pneuma*, so that the *pneuma* is never the same … As body, even as *pneuma*, we are always something discontinuous in comparison to our being. (Foucault, 2006: 303-4).

We cannot be reduced to a moment in time, a bodily state nor a breath whilst we are created from this abundance of the air, the *pneuma*. There is constant flux even while my identity remains. I can thus breathe in the air (as *pneuma*) as well as breathe it out, but I can never exhaust, nor fully own, this air. Breath therefore partakes in both the material and immaterial realm, metaphorically speaking. Its nature is hard to grasp, as the act of breathing takes in the outside air as well as 'gives up' the inside air (Foucauldian *pneuma*). Thus, we can see that Anaximenes states that air is not 'no-thing' (immaterial). We may not be able to grasp it physically due to its (dis)continuous, constantly moving nature, but it is the founding principle of all that exists and as such partakes in the

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[10] Note that Empedocles also saw the air or aether (aither) as the 'life giving Hera' (Shaw, 2014: 172). However, there is debate regarding the synonymy of air and aether in his work. Aristotle was guilty of making this reduction with regards to Empedoclean thought, but there is evidence that Empedocles treated them as wholly different, with aether aligned to the upper atmospheric air and the heavens (Homeric air) and air referring to that which surrounds us on Earth and is breathed by us (*ibid.*).

material realm. How can this be? How can something that appears immaterial in fact be material, as his material monism requires?

Using observation and scientific deduction, Anaximenes observed that breathing was vital to living beings and concluded from this that air was thus a life-sustaining force. It is everywhere and in everything; even other elements come to being through the differentiation of the air. That is, by altering the state of air, the physical universe was formed:

> Anaximenes of Miletos, son of Eurystratos, a companion of Anaximandros, agrees … that the essential nature of things is one and infinite, but he regards it as […] determinate, and calls it air; the air differs in rarity and in density as the nature of things is different; when very attenuated it becomes fire, when more condensed wind, and then cloud, and when still more condensed water and earth and stone, and all other things are composed of these; and he regards motion as eternal, and by this changes are produced. (Theophrastus, Physics: 6r 24, 26)

So, via condensation, Anaximenes pointed to how air becomes water, arguing that condensing the water further led to the formation of earth and stone:

> But he [Anaximenes] went further than his predecessors by suggesting how this transformation might happen. He used the example of felt, which is made by squeezing together soggy fibres and drying them out. Thus the Earth formed as fibrous congealed water was forced together. The heavens were formed in the same way, making a felt cap that shrouded the world. (Bouman, 2014)[11]

The air is thus ‘almost’ immaterial, as it is everywhere, but it is still some-*thing* as it flows around us as the wind or is breathed in and out of our body. Moreover, it makes up that body. It is material, found in earth, rocks, rivers as well as animated entities such as our selves. The Anaximenean disciple Diogenes of Apollonia (fifth century BCE) also saw air as the *arche*:

> that which possessed thought is what people call air, and that by this everyone both is governed and has power over everything. For it is this which seems to me to be god and to have reached everything and to arrange everything and to be in everything. And there is not a single thing which does not share in it. (Frag. B 5. Simplicius, Commentary on the Physics, 152).

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[11] Bouman, 2014: https://philosophynow.org/issues/104/Philosophys_Roots_and_Branches

Again, only fragments of Diogenes's thought remain, but it is interesting to note that his reduction of thought to air will be echoed by James in the nineteenth century (see chapter 3). Air is thus infinite and 'a God' (as creator or *demiurge*), but also associated with finite beings such as human beings. Our souls and bodies partake in this god-like stuff, from both being constituted by rarefied and condensed air and breathing in the air that governs our continued existence.

Secondly, air, breath (physiologically speaking, warm air), the psyche and *pneuma* are all taken as co-extensive with one another. The latter three are made from the material principle air, yet what do they mean individually? Breath (*pneuma)* is the warm air exhaled by the body, but also, like air, it encompasses 'the whole world' (Anaximenes, 1911). Air and breath are therefore synonymous. *Pneuma,* the ancient Greek word for breath, differs in meaning from *psyche* (soul or spirit), despite being sometimes confused in antiquity. For the pre-Socratics, *pneuma* refers to breath, vital wind, and air in motion, whereas the *psyche* (soul or intellect) is comprised of both air and *pneuma.* This makes sense when we recall that *pneuma* 'enlivens the soul, makes it mobile, pulsating, active, verbal and not substantive' (Benso, 2006: 18). Thus, the *psyche* (soul) is made from the air but sustained by the *pneuma* via the latter's tie to embodiment, specifically respiration. *Pneuma,* the warm breath imbued with a vital, life-sustaining force only exists while I breathe. In this way, inspiration and expiration and

> not simple air […] individualized the human being, that gives him or her subjectivity, and that ultimately constitutes his or her soul. Such an activity of breathing provides physiological as well as psychological, physical as well as spiritual life. (Benso, 2006: 19)

Pneuma is thus 'a life force' as well as a life-sustaining force (*ibid*.). In short, the *psyche* (soul) is natural (as it is made from air), but it is the *pneuma* that animates the soul through respiration, as breathing takes the outside air inside and feeds the soul.[12]

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[12] This account is adapted by Democritus, who maintains that the soul 'holds' the body or the individual human being together insofar as it is sustained via breathing. Due to ageing, disease or violent death, respiration stops and the soul departs.

Breathing is thus accorded a vital role in human experience for the first time. The breath, as warm air, sustains human existence via breathing. The air is the natural foundation to all existence and thought: it *is* breath, it is thought, and it *is* spirit. Breathing thus crosses the boundaries of inside and outside, of objective and subjective by bringing in the outside air, temporarily partaking of it, and then expelling part of our *pneuma* into the world. There is thus a continued exchange between ourselves and the world.

Breathing, then, is our connection to the world, and breath the conduit for animating the soul and nourishing our existence. The spiritual breath is the natural, and the natural breath is the spiritual in this regard, for the first and last time in Western philosophy (until contemporary thinkers recover this, as below). This is significant because the two were later separated, with dualistic thought taking over. A split between breath as spirit and breath as natural, arising from the domains of religion and natural philosophy (science) became the norm/our inherited wisdom. With Anaximenes, however, his material monism does not split the soul (*psyche*) and the body, the breath, and the soul, nor the self and the world into differing substances. All is natural. There is no hierarchy of soul or intellect over the body because breath (*pneuma*) and air underpin life and the world. It is this emphasis that I will incorporate throughout to complement a rationale for returning breath to philosophical attention.

2.3 Plato, Aristotle & The Stoics: The significance of breath in the Ancients and their influence on later medical and philosophical thought

This section begins with Plato's discussion of air, breath, and respiration in the *Timaeus* and its relevance to our concerns. We then move onto the concept of air and the connate *pneuma* in Aristotle, comparing this stance to that of the Stoics. It is useful to note that medical thinkers during this period inherited some of Anaximenes's ideas on the breath, but with a physiological reduction evident: describing *pneuma* as air that circulates throughout the body to enable the functioning of the vital organs, balancing the body and cooling the heart. *Pneuma* is moved around the body through the arteries, and so is necessary for sustaining life, thought and action, notions that influence Plato, Aristotle, and later thinkers, as we will see.

2.4 Respiration in the *Timaeus*

Plato offers an interesting account of the breath and respiration in the *Timaeus*. The dialogue considers the creation of the cosmos by a *demiurge*, covering being and becoming, the constitution of and persistence of the human body, and how the intelligent creator forges these and enables balance through the principle of movement (necessity) in relation to divine intelligence. As breath is our concern here, I therefore move straight to the relevant sections before contrasting them with Aristotle's account and how this contributes to understanding how these issues were dealt with by key philosophers in the Hellenistic period.

In sections 69a to 92c of the *Timaeus*, Plato merges his prior discussion of the interplay between divine Intelligence and material Necessity (laws of movement) with how they co-operate. This cooperation is framed by investigating anatomy and the processes of the living body, specifically 'irrigation' (roughly, the circulatory system), digestion and respiration. We are only concerned with his thoughts on respiration, air, and the 'fish' or 'lobster-trap'[13] organs involved in breathing. Anatomically speaking, Plato is providing a physiological account of the soul and where it resides (in the organs of the thorax and abdomen) before moving on to how the rest of the body functions. Nourishment, digestion, respiration, and the movement of the blood (irrigation) inform his account of bodily processes involved in health and disease, and in growth, ageing and death (Pelavski, 2014: 61). He argues that respiration sustains life and cools the body to keep it in balance.

As established, from the time of the pre-Socratics, the four elements (fire, air, water, and earth) played a pivotal role in the creation of the world and reality. Anaximenes saw air as the *arche*, whereas Plato, even whilst moving towards the doctrine of the forms, posited

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[13] The use of the fish/lobster trap metaphor is employed to describe how the respiratory apparatus, specifically the mechanism (epiglottis) for separating the windpipe from the oesophagus, operates.

that while all four elements were important, fire and air play the fundamental roles in the constitution of the human body, soul and of life (78b2–c1):[14]

> The god […] wove a mesh of air and fire, something like a fish-trap, with dual access-points at its entrance, one of which he knitted with a further bifurcation. And from these access-points he stretched something resembling reeds around the mesh all the way through to its extremities. The inner parts of this plaited structure he composed in their entirety of fire, whereas the access-points and the hollow cavity he composed of air.[15]

The digestive system is aligned with fire, whereas the hollow cavity is the lungs for the cool air to enter via the ‘access-points’ (nose and mouth). The joining of these in the pharynx then splits into the respiratory and digestive branches of the system, with the ‘fish trap’ acting as a functional analogy (Pelavski, 2014) representing the hollow compartments of the contiguous system, a system of the separate processes sharing the same entrance. The organs thus comprise a united system that is also connected to the environment (Pelavski, 2014). The function of this ‘fish-trap’ is to take the life-sustaining elements (air, food, water, fire) into the body where they are processed via digestion and respiration and taken into the bloodstream. The air cools the fire in the *belly*, ‘cutting up’ the food, and distributing the digested food and the soul around the body via the blood. This is where Aristotle departs from Plato, as Aristotle emphasized the role of the air cooling the *heart* and maintaining the ‘vital heat’ necessary for growth and health, as well as being present in the semen as connate *pneuma*. Thus, the role of breath and respiration for Plato is *purely* mechanistic. Respiration allows air into the body to ‘penetrate the porous flesh. When in turn the air is turned back and passes outwards through the body, it thrusts the inhaled air around, back inwards through the passage of the mouth and nostrils’ (79c2-8).

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[14] Aristotle also maintains an emphasis on air and fire in terms of reproduction, growth, health, disease and dying, as does the contemporary philosopher Luce Irigaray, refocusing philosophy on the importance of air.

[15] [ὁ θεὸς] … **πλέγμα** ἐξ ἀέρος καὶ πυρὸς οἷον οἱ κύρτοι συνυφηνάμενος, διπλᾶ κατὰ τὴν εἴσοδον **ἐγκύρτια** ἔχον, ὧν θάτερον αὖ πάλιν διέπλεξε δίκρουν· καὶ ἀπὸ τῶν ἐγκυρτίων δὴ διετείνατο οἷον σχοίνους κύκλῳ διὰ παντὸς πρὸς τὰ ἔσχατα τοῦ πλέγματος. τὰ μὲν οὖν ἔνδον ἐκ πυρὸς συνεστήσατο τοῦ πλοκάνου ἅπαντα, τὰ δ᾽ ἐγκύρτια καὶ τὸ **κύτος** ἀεροειδῆ.

So, the pores of the skin also absorb the outside air (Pelavski, 2014). With this, there appears to be ‘cutaneous respiration’ (porous respiration) in addition to the respiratory function of the lungs, so that air can cool the body in multiple ways. This was because the balance between the elements was seen as vitally important in maintaining health and the integrity of the body, with too much heat and not enough air burning up the body and resulting in death (and the release of the soul): ‘Thus, we see what the human body actually is: it is a portion of the world body consisting of the four elements and organized in such a way as to harbour temporarily the human soul’ (Karfík, 2012: 172). Here we can see a connection between the role of the four elements in the cosmos (macrocosm) and within the human body (microcosm) supporting the holding of the soul within a healthy body. The soul, for Plato, is posited to inhere in the bone-marrow, yet it animates the entire human body. It is released via death as the body is unable to regenerate and retain the structural integrity necessary to keep it inside. The body breaks down due to the constant flux of elements passing in and out of it, particularly the forces of the vital elements air and fire that ‘melt’ and ‘deplete’ it (Karfík, 2012: 173).

The air and respiration are life-giving, then. The body must restore its depleted energy and elements to balance out degeneration and decay via digestion and circulation, which is dependent on the air, breath, and respiration. The air draws in the fire, and aids digestion so that food can be distributed to the body as energy via the veins. In other words, there is an obfuscation of breathing and respiration (gas exchange): the two are taken as one and the same. Of course, the Greeks weren’t aware of gas exchange in the lungs, but we can see the elemental exchange between the air cooling the vital heat as analogous. The exchange between the air outside the body, and the processes of the breath in respiration ensure that the body is nourished and animated via the notions of ‘cooling’ and ‘heating’; the air cools the heat of the heart and stomach, but such a continual exchange eventually leads to imbalance and decay, for example as the lungs harden with age (Plato, *Timaeus*: 58a4–b4). Although the body depends on the elements, their continual movement inside and outside us damages the tissues and organs, leading eventually to death by ‘natural causes’. The positive role of the air is thereby downgraded.

Unnatural deaths, whether by injury or disease, are painful as the soul is ejected from the body. Here we can see that Plato is splitting body and soul into two separate substances (material and immaterial), in contrast to Anaximenes's corporeality or naturalizing (as air via breathing) of the soul. The air has a role to play in animating the soul and body and contributing to decay, yet for Plato the primary element for the cosmos (macrocosm) is fire, related to the fire or 'vital heat' of the body, with air having secondary importance and certainly not united with the intellect, as with Anaximenes:

> [r]espiration and blood circulation is a microcosmic counterpart of the everlasting movement of the elements within the body of the world and even a causal response of the innate heat of the animal body to the heavenly fire of the body of the universe. (Karfík, 2012: 178-9)

This emphasis on fire over air remains in Aristotle. Its influence cannot be underestimated. As we shall see, it is taken up by the Stoics and persists in the later ideas of medieval thinkers. However, the role of air in health and disease vanishes from philosophical thought until twentieth-century French phenomenologists and philosophers remedy this 'forgetting' (Levinas, 1998).

The expansion of scientific knowledge of the body and environment in relation to air, oxygen and respiration no longer relies on elemental theories from antiquity. Thus, natural philosophy was eventually made redundant. Relatedly, philosophers (excepting Heidegger and his discussions of earth within the Fourfold) and their interests expanded and developed into a multitude of disciplines and sub-disciplines independent of elemental theory. So, although the elements were important in Western philosophy for the ancient Greeks (and later Christianity and the sciences), philosophers continued the pursuit of the 'good life', of truth, epistemological foundations, ethical systems, metaphysical and ontological concerns, favouring these subjects over theorizing on the elemental structure of objects. Matter was taken over by science and (eventually) stripped of its reliance on the four elements. Whilst interest in Aristotle's hylomorphism persisted into the medieval period, as we will see, in thinkers such as Avicenna, it is understandable that theories of matter would fall under the remit of science.[16]

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[16] Hylomorphism is the theory of composition of objects via form and matter, and matter comprised of the four elements.

In summary, Plato saw an important role for air in his philosophy, and yet respiration remained a primarily physiological concern, even when related to sustaining life and the soul. Unlike Anaximenes or Levinas (for example), breath and breathing are only significant for him insofar as they sustain life. The act of breathing and of connecting the subjective to the outer world is forgotten. Aristotle disagreed with Plato's account of respiration, and we will now investigate his stance and that of the Stoics, and why it is relevant to our study here.

2.5 Aristotle and the purpose of respiration

> Thus the material constitution of anything corresponds in fact to its environment; in water live wet things, in earth dry, and in air hot.
>
> *Aristotle, 1984: 467*

Aristotle wrote about respiration in the *Parva naturalia*, specifically *On Respiration* and *On Breath*.[17] He begins by criticising prior notions of respiration in animals and fish (such as Democritus's account) before outlining his own theoretical account.[18] As established, prior to Aristotle, respiration was supposed to be to do with nutrition, trapping the soul, and cooling the stomach (Polansky, 2007: 67). The skin was thought to breathe also, as discussed above. Aristotle incorporates some of these themes in his account, yet expresses frustration that the *purpose* of respiration is not considered by his forbears, excepting the physiological focus demonstrated when, for example, Democritus states that respiration serves a certain purpose in animals or that respiration prevents the soul from being crushed out, yet still maintaining this as a 'coincidental' feature. Aristotle states that these accounts appear to give a

> purpose for which animals are equipped with these functions (I mean inhalation and exhalation), but merely describe them as something coincidental. And yet we see that they control life and death; for when

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[17] Although there is some disputed authorship, the Aristotelian ideas around breath and respiration are consistent.

[18] Soul and life are first linked explicitly to respiration by Democritus, with the active soul atoms of the element fire being taken into the body during breathing to sustain life (404a10–16). The atoms that make up the soul and cause movement tend to escape the body and are 'squeezed' from bodies by atmospheric pressure, so respiration sucks back in more soul atoms to restore the balance and trap the soul (De resp. 471b30–472a26; *cf*. Polansky, 2007: 68).

> respiring creatures can no longer respire, then destruction comes to them. (Aristotle, 1984: 473)

Breathing is thus *essential* to maintaining life, he asserts. Aristotle also appears to retain a physiological focus when he emphasizes vital heat and the importance of the heart (as generating the vital heat) in continuing human existence. The lungs are crucial insofar as they cool the heart and the body 'by means of the breath' (*ibid*.: 457). The cool air taken into the body by inhalation is transported from the lungs to the heart, and then reaches the other organs via the veins and arteries (respiration), before being exhaled as warm air. He also ties in the soul in his account when he argues that,

> all living creatures that have lungs breathe. But two questions remain: why some creatures have this organ, and why those that have it need to breathe. The answer to the first is that animals higher in the scale of creation have more heat; for they must at the same time have a higher form of soul; for they have a higher nature than that of fishes. So the animals which have a lung with the most blood and heat are greater in size, and that whose blood is purest and in the greatest quantity of all living creatures is the most erect, that is to say man; "up" in his case corresponds to "up" in the whole universe just because he has such a lung. (*ibid*.: 463)

The possession of vital heat (the generative principle) and the lung in man, the highest animal, keeps him erect, pointing towards the heavens. Without the lungs, then, we are nothing: when the heat is no longer cooled by taking the air into one's body, 'a crisis is reached and the fire dies out' (*ibid*.: 473). This crisis (death) can be caused by external forces injurious to the chest, lungs, or other vital areas of the body, as well as internal forces that harden the lungs such as 'tumours, secretions, or excess of morbid heat' from fevers that prevent the lung from expanding or contracting adequately (*ibid*.: 475). Aristotle asserts that death by hardening of the lungs is more likely when one reaches old age, as the vital heat has been '*breathed away'* over a long life, thus making the lungs more susceptible to the effects of infections, illnesses and so on (*ibid.*). Yet this *breathing away* of the inner life force suggests an openness to the outside world, transporting part of ourselves out into it. Indeed, the opposite must be the case too: the inner life force is supported by taking internally the outside *as air*. Thus, although not explicitly stated, remnants of Anaximenes's thought on the significance of air do appear to influence Aristotle.

The lungs too have *purpose*: the function of the spongey, blood-rich lung is to store and process air. In doing so, the warm breath can be processed to reach all the organs of the body as well as cooling the heart. Lungs are thus the ‘primary refrigerative organ’ (*ibid*.: 475). This is similar to Plato’s account. One significant area of difference is that for Aristotle soul and body are two aspects of one thing (the living organism), whereas Plato splits body and soul into two substances. Form (*morphe*, *eidos*) and matter (*hyle*) are inseparable (distinguished in thought and speech only) for Aristotle, and so breathing is fundamental in sustaining these aspects of an individual: ‘life depends upon inhalation and exhalation’ (*ibid*.: 481).

What of *pneuma*? Recall that *pneuma* is the warm mobile air (breath), the air in motion that maintains the vital heat during respiration. *Pneuma* is also important for Aristotle, then, playing a unique role by way of his conception of the *connate pneuma* as that which causes movement (locomotion) and the transmission of the soul of the father to the child via the *pneuma* in semen (Aristotle: *GA* 2. 3, 736b30 ff). He does not have a consistent or full theory of this form of *pneuma* and so discussion of its significance continues (Nussbaum, 1976: 163; Freudenthal, 1999). To begin to understand this form of *pneuma*, we must see it in the context of his proposals regarding the generation of animals. Creatures are generated, according to Aristotle, when the sperm of the male acts upon the female’s menstrual fluid (Freudenthal, 1999). The sperm is always hotter than the product of menstruation, despite both originating in the blood; the blood of the male is always hotter (and imbued with more intellect) and so this is where the *pneuma* must reside. Essentially, the vital heat and the *pneuma* converge to transmit the soul, intellect and power of locomotion and sensation to the infant (Freudenthal, 1999: 112).

How they interact is not properly described by Aristotle in extant works.[19] Ancient Greek medical thinkers certainly had theories of *pneuma* inherited from Anaximenes and others. Aristotle likely inherited elements of these pneumatic doctrines, as demonstrated by the work of Theophrastus, for example. Certainly, his concern with physiology was contiguous with much of the medical knowledge of his day. For our purposes, this

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[19] Nonetheless, he may have had a coherent theory laid out in one of the many works that were lost or destroyed, although I cannot speculate on this.

connection between *connate pneuma* and vital heat is one of an inter-relationship whereby the former carries the latter into all the organs and into offspring. The heart produces a constant process of 'pneumatization' that pulses around the blood as moisture (the blood) (Aristotle, 1984: 480).

Pneuma therefore has a double significance for Aristotle: the mobile air of the breath as *pneuma* cooling the heart and sustaining life, and the transmission of powers and forces of movement and the soul combined with the vital heat. This also explains the quotation at the beginning of this section in which he asserts that hot creatures live in the air: as higher beings, we are hotter and participate in the heavenly fire and air (air as aether). As we are so intelligent (and hot), we need the outer air to keep our internal and external heat in equilibrium. In sum, for Aristotle, the outside air cools the body once it is inhaled, cooling the heart through the air being pushed into blood, whereas the connate *pneuma* is an 'aeriform' substance made in the heart. The warm air participates in the formation of the soul, but the heat of the connate *pneuma* is (once again) the primary source for this. Nevertheless, air and breath and breathing, despite the incorrect description of respiration and gas exchange, underpin life.

Air and breath, then, do have a role to play in the generation of life and the structure of the body, inherited from the pre-Socratics and passed to the Stoics through the concept of *pneuma*. Although we have seen that pneuma functions variously throughout ancient Greek philosophy, the main elements of 'mobile warm air' sustaining life, the intellect, movement and so on, show that respiration, specifically the act of breathing and the analogous energy/gas exchange, has significance for the Greeks outside purely physiological concerns. Breathing connects the inner to the outer as the air is breathed in and the inner *life force* is exhaled into the world. I have attempted to draw out these points despite the standard focus on the doctrine of *pneuma*, theories of vital heat and the inaccurate theories of respiration. There is thus more to learn about the breath in these philosophers than might first appear.

By contrast, the Stoic philosophers and their ideas about *pneuma* have been studied in detail. They of course inherited these ideas from Anaximenes to Aristotle, and despite a shift in meaning,[20] created a doctrine of *pneuma* that many scholars have considered (and thus will only be briefly touched on here) (Sellars, 2006). For the Stoics, *pneuma* is the ‘breath of life’, similar to the term *psyche* used by the pre-Socratics. This is a generative principle that structures human existence, the cosmos, and unifies objects. There are different levels of *pneuma* corresponding to different roles in the cosmos. For example, the human soul is made from the *pneuma* of the soul of God (Zeus), but it also exists in objects because it structures matter (thus linking Anaximenes and Aristotle). It is an intelligent spirit, but also a substance made up of warm air or breath. Accordingly, air, breath and breathing become conflated under cosmological and ontological concerns related to the creation of the world, the soul and God, and hence are influential in later religious thought.

So, while *pneuma* meant many things to the ancients, as time progressed it became synonymous with the spirit or soul. A key point to draw out of my historical summary thus far is that the life *of the breath* became stripped of its experiential dimensions and thus unimportant to philosophical study. The hints that breathing broke down barriers between inner and the outer and that the natural and spiritual were united were gradually lost in favour of positing two distinct substances. Breathing was treated as undeniably important to health and life, but breathlessness was considered in purely physiological and medical terms, focused on ageing, disease, and illness. The gap between the material and immaterial realms remained, finding ultimate expression in the dualism of Descartes (Chapter 3). Even when breath is posited as essential to life, the breath itself, in all its variation and glory, has been ignored (see below).

2.6 Avicenna’s thought on respiration, bridging ancient Greek philosophy and medical thought through to medieval philosophy and current knowledge

Ibi Sibn, known as Avicenna in Latin (980CE), was a Persian Islamic physician and polymath and the author of *The Canon of Medicine,* an encyclopaedic five-volume text that influenced European medicine for 700 years and returned Aristotle and Galen’s

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[20] That is, aligning *pneuma* with *psyche,* soul and spirit more than breath and air.

thought to the West.[21] The four elements as the substratum of matter, in addition to the correlative four humours, were retrieved when explaining health, illness and disease. Morality, too, was related to his notions of medical practice, developing the idea of medicine as an art-form to be practised to help the sick (Hashemi and Raza, 2009). Whereas in Christian thought the ill were seen as responsible for their illnesses and as such often left untreated, or as a product of demonic possession, Avicenna defined medicine as

> the science by which we learn the various states of the human body in health and when not in health, and the means by which health is likely to be lost, and when lost, is likely to be restored. In other words, medicine is the art whereby health is conserved and the art whereby it is restored after being lost. (Avicenna, 1999: 11)

Avicenna dedicates a substantial amount of time to respiration. In particular, *On Breath* covered the role of breath in healing, health and medicine. This includes theorizing on the purpose of breathing, detailed descriptions of asthma, the diagnosis and treatment of respiratory distress (for example with opioids, which are still used today), stridor and cases of suffocation (Hashemi and Raza, 2009). Breath was also given spiritual, psychological, and emotional significance, with cultivation of the breath important in strengthening the will and sharpening the intellect. It had a role to play in maintaining health alongside the drug treatments he recommended for various breathing problems (Avicenna, 1999). Avicenna was also the first to describe endotracheal intubation and tracheostomy.

> There is no harm in inserting something such as a cane/reed or it's like around which some cotton is wound, to clear the airway and dilate it. One might also insert a tube made from gold or silver or their like into the pharynx to assist breathing […] (if this fails) […] And so, if the suffocation continues, and treatments are unsuccessful, then it will be beneficial to incise the trachea. The head is extended back and the skin is gripped and stretched back with hooks before the incision is made. The trachea is then exposed, and an incision is made in the middle between the two tracheal rings, whilst avoiding cutting the (cricoid) cartilage. The edges of the cut skin are turned outwards and stitched without damaging the underlying tissue. (Avicenna, 1911)

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[21] He also translated ancient texts to the extent that he is said to be the reason some of Aristotle's work was not lost forever (Hashemi & Raza, 2009: 1-10).

Avicenna’s ideas on the origins of dyspnoea, types of respiratory disease, asthma and its changes, and tuberculosis and its incidence in autumn and winter (Rıos *et al.*, 2000) have merit even under the framework of modern medicine (Hashemi and Raza, 2009).

Of course, Avicenna was limited by the science of his time. Nonetheless, he acts as a bridge between Anaximenes, Aristotle, Galen and the breath to philosophy and medicine in Europe from the eleventh century to the eighteenth. His focus on the scientific approach to classification, diagnosis and medical practice can also be seen to re-orientate medicine towards a modern, scientifically rigorous, objective framework. Despite his retrieval of the significance of the breath from the ancients, his emphasis on the nuance of the meaning of breath, including its cognitive, psychological, emotional, and spiritual features was largely forgotten. In short, philosophically salient questions around the breath’s role in the development and maintenance of, for example, the intellect, fits with our current knowledge of how breathlessness can cause cognitive problems. Avicenna’s thought certainly was a precursor to these ‘new’ discoveries.

2.7 Conclusion

Within this chapter, I have traced the history of air, breath, and breathing from the pre-Socratic philosophers to Avicenna’s thought in the medieval period. This incorporated an analysis of the concept *pnuema*, and its many formulations. We thus have seen the movement from an all-encompassing notion that places great significance on the breath and air to existence, to a more natural philosophy and medical conception.

Indeed, breathing and respiration are today defined in physiological terms, even whilst lay people obfuscate them. Breathing is now defined as the act of taking oxygen into the lungs and expelling carbon dioxide (ventilation, more properly). Respiration is defined as the ‘process in living organisms involving the production of energy, typically with the intake of oxygen and the release of carbon dioxide from the oxidation of complex organic substances’ (Oxford Living Dictionaries Online, 2017). In medical practice, respiration is often viewed contextually in the process of monitoring a patient, and thus functionally defined similarly to what the Ancients and medics such as Avicenna described. Whatever their differences, all these theories have the life-sustaining role of the air, breath, breathing and respiration at their core.

Yet we can still ask, what *is* the significance of breath and of breathing? Just warm air? Oxygen and carbon dioxide with other small particulates and gases caught in the mix? Is it mere inhalation and exhalation? Can it play any role outside of the remit of science and medical knowledge? Does breathing as an experience have philosophical significance outside functional and biological concerns? It is likely that we find these questions, particularly regarding the significance of the breath, hard to understand as we are so used to the scientific worldview. That is, understanding what significance the breath and breathing has traditionally been obscured by the scientific worldview. To even pose the question requires a new way of thinking about these. I have laid out how thinking about breath and breathing has developed alongside Western philosophical treatment of these experiences. Although the scientific worldview of respiration now dominates, we already have seen that there have been more nuanced accounts of breath and breathing possible, specifically with Anaximenes. In the next chapter, we return to the questions posed above via continuing a historical examination from Descartes to modern philosophy.

CHAPTER 3: Towards a Phenomenology of the Breath & Breathlessness

3.1 Introduction

As established in Chapter 2, there has been little philosophical study (outside pneumatology) of the breath and breathing in medieval or modern philosophy. Aristotelian metaphysics, the widening split between philosophy and medical science, and the framing of the human being as essentially soul, spirit and mind (as in the Christian and rationalist traditions), or purely material beings reliant on sense experience (as in the empiricist tradition) all contribute to overlooking the breath.[1] Respiration is examined through the sciences, physiology and medicine, whereas (Western) philosophy now focuses on epistemology, metaphysics and ethics. Even empiricists who held that knowledge is based on sense experience and observation neglected the breath. I will now briefly examine the neglect of the breath in philosophy in these periods, suggesting that due to the *animal rationale* or the Cartesian *cogito* as the main focus of human knowledge and our knowledge of reality, embodiment and breathing are taken for granted.

Such essentialist thinking dominated thinking about breath and breathlessness to the detriment of philosophy, as well as to understanding these lived experiences, I argue. As Levinas tells us, getting *beyond* essence, beyond substance dualism and the language of essences, is a continual battle (Levinas, 1997). Perhaps our language, philosophical traditions and conceptual apparatus are either not up to the job or are inhibited by being rooted in a metaphysical and epistemological framework that operates as a conceptual prison of esotericism and ineffability. It is therefore doubly difficult when it comes to talking about a traditionally physiologically framed phenomenon such as breathing, which requires new ways of thinking and describing both the phenomenon and the related subjective experiences. These difficulties have caused both metaphorical and literal breathlessness in the work of philosophers and their theories, as I elaborate below.

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[1] A further barrier was that to step outside Aristotelianism in ecclesiastical thought was heresy.

3.2 Breath in modern philosophy: Descartes, James, and Nietzsche

There are few mentions of breathing in relation to philosophical concerns during the modern period. Descartes (1596) briefly engaged with the breath in relation to his famous proclamation ‘je pense, donc je suis’, Latinized as *cogito ergo sum* (Descartes, 1911 [1641]). At first glance, he does not appear to offer any role for breathing; indeed, he denies that inference from perceiving that one is breathing as the foundation to one’s existence is adequate. Rather, *I think* that I am breathing, the *cogito,* takes precedence:

> For the thought of breathing is present to our mind before the thought of our existing, and we cannot doubt that we have it while we have it. To say: “I am breathing therefore I exist” in this sense, is simply to say “I think, therefore I exist.” If you pay attention, you will find that all the other propositions from which we can thus prove our existence, reduce to this same one… (Descartes Letter to X; 1638: 37-8).

As Descartes is attempting to establish the foundation to human knowledge on the *cogito* whilst arguing that the senses and perception are prone to error and thus insufficient, it is understandable that he dismisses respiration so quickly. Thinking that I am breathing always takes precedence, since to say ‘I breathe, therefore I exist’ is just a way of expressing that I am *thinking* about breathing. Thus ‘I breathe’ is redundant: the *cogito* is already there before such an observation. Substance dualism also plays a part: the self is a thinking, immaterial thing, with the body a material, extended substance commanded by the ‘ghost in the machine’. Respiration is a function of this fleshy being, but not the true ‘self’, the *cogito*.[2]

It thus appears that Descartes’s commitment to the word of God (which in Catholicism is always followed by breath), the breath of life and the Holy Spirit are treated as separate to the breath of man (in breathing and respiration) and so is not part of the spirit or soul of man. However, for Descartes the perfection of God and His relationship to human spirit

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[2] It may seem surprising that the breath of spirit common to religious thought at this time is not part of his epistemological foundationalism, considering his ontological argument for the proof of God (Descartes, 1911). However, as he is focusing on the basis of human knowledge and proof of existence, anything related to the body that can be prone to error cannot serve as that basis, including respiration.

and existence as indubitable does not entail that the body is infallible. The body *is not* perfect, he maintains. Nerves may be damaged, sense data may be misinterpreted, our cognitions can be incorrect. God may be perfect, but we are not. Therefore, we can see that the importance of breath to human existence is not explicitly denied. Rather, that we *think* we breathe therefore we exist is *a priori* to inferring that we exist because we breathe, and thus our existence is established, once again, by the *cogito*. In short, breath and thought are intimately related: 'I breathe' is expanded to 'I think I breathe'. The act of breathing is subsumed under the *cogito* and not completely stripped of significance, then.[3] The breath of life given to man via God can still animate human existence in this way.

In a purely epistemological sense, however, we cannot (for Descartes) infer our existence from the breath. Given the Cartesian commitment to substance dualism, it is false to say that breath can have such a role in establishing existence. Of course, for Descartes the *res extensa* cannot have thoughts, only the *res cogitans*. Thus, we can infer that he would not accord such significance to the breath. Perhaps it would be more useful to move away from the relationship of the cogito and ontological certainty, and towards the relationship of the cogito to existence through breath via the Kantian unity of apperception.

William James (1842) appears to have taken this step. When considering the role of the '*I think'* in philosophy and consciousness, James argues against reducing the breath to the *cogito* as demonstrated by Descartes. The significance of *I* think to existence via breath is instead turned on its head: 'The "I think" which Kant said must be able to accompany all my objects, is the "I breathe" which actually does accompany them' (James, 1976: 19). Notwithstanding criticism of the supposed error that James makes of equating breath (specifically the sensation of exhalation) with knowledge and action (to proclaim that consciousness is therefore underpinned by the breath), thereby reducing knowledge to

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[3] In sleep, however, respiration is automatic and unconscious and thus stripped of any ties to thinking and consciousness for Descartes. Breathing is reduced to the mechanical function of the body akin to a machine: 'Now a very large number of the motions occurring inside us do not depend in any way on the mind. These include heartbeat, digestion, nutrition, respiration when we are asleep, and also such waking actions as walking, singing, and the like, when these occur without the mind attending to them. When people take a fall, and stick out their hands so as to protect their head, it is not reason that instructs them to do this; it is simply that the sight of the impending fall reaches the brain and sends the animal spirits into the nerves in the manner necessary to produce this movement even without any mental volition, just as it would be produced in a machine' (Descartes, 1979: 229-30).

‘mere’ respiratory movements (Shushterman, 2008), there is some merit to James’s contention.[4] Firstly, I argue that it is not correct to say that James is reducing knowledge or consciousness to purely respiratory *movements*. I suggest that James is pointing to the limits of thought and the idea of a transcendental consciousness as vital to human knowledge, behaviour, and action. It is a fact that we breathe; lack of oxygen quickly leads to unconsciousness, which prohibits any knowledge. Moreover, our movements in the world, as demonstrated by acquisition of habits (‘knowing how’) do not need an ‘I think’ constantly narrating what we are doing, and do not need an independent observer supervening our experience (Merleau-Ponty, 1962; Dreyfus, 1991). We often move or behave ‘thoughtlessly’, without explicit intent or thought about what we are responding to or acting upon (see Chapter 1). However, our breath is always present, accompanying and enabling all thought and action. Secondly, James is not reducing all knowledge acquisition to the breath. He is merely pointing to the limits of thought, and although breath may be privileged in accompanying all our acts, behaviour, or knowledge, is it just that: *accompanying*, rather than controlling what we think, know and do (although we will see how breathlessness limits our cognitive and physical abilities in later chapters).

Shusterman’s criticism does have some merit, however. James flips Descartes’s characterisation of the relationship of breath to the *cogito*, to knowledge of our own existence. The ‘I think’ now depends on ‘I breathe’ and *not* on mere respiratory movements. That ‘I think’ depends on the ‘I breathe’ requires these respiratory moments, but clearly points to a layer of significance imbued in this power: the perception of breath and the experience of breath enables knowledge. Yet James obscurely asserts that whilst consciousness, the stream of thinking, inheres in breathing, consciousness as an entity is fictitious:

> I am as confident as I am of anything that, in myself, the stream of thinking (which I recognize emphatically as a phenomenon) is only a careless name for what, when scrutinized, reveals itself to consist chiefly of the stream of my breathing. The 'I think' which Kant said must be able to accompany all my objects, is the 'I breathe' which actually does accompany them. There are other internal facts besides breathing (intracephalic muscular adjustments, etc., of which I have said a word in my larger Psychology), and these increase the assets of

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[4] Indeed, Shusterman makes this charge without convincingly showing that this is what James was actually arguing (Shusterman, 2008; *cf*. Škof, 2015: 7).

> 'consciousness,' so far as the latter is subject to immediate perception; but breath, which was ever the original of 'spirit,' breath moving outwards, between the glottis and the nostrils, is, I am persuaded, the essence out of which philosophers have constructed the entity known to them as consciousness. That entity is fictitious, while thoughts in the concrete are fully real. But thoughts in the concrete are made of the same stuff as things are. (James, 1904; 1976)

It is beyond the scope of this thesis to examine James's philosophical treatment of consciousness.[5] I will remark only that such a rare privileging of the breath over a thinking, immaterial substance (the *cogito*), or over existence and knowledge revealed via consciousness, echoes Anaximenes's emphasis on the air and breath to founding human existence, knowledge and reality. The 'stream of breathing' can be interpreted as an expression of the constancy of both an individual's continued existence and that which underpins and gathers together all experience and knowledge (empiricism is at play here), both conscious and otherwise (*cf*. Kant). James also recognises the connection of the breath to the origin of the term 'spirit'. Breath thus has a larger role to play in thought and action than Descartes suggests. Crucially, it appears that James is saying that philosophers have mistaken consciousness with the continuity and constancy of breath for all thought and existence. Breath, and other 'internal facts' underpin and sustain life, grounding thought (as Leder argues much later, see Chapters 1 & 4). Consciousness incarnated as embodiment or incorporeality means that we should no longer separate mind from body. The body 'thinks', as they are aspects of the same thing (prefiguring eliminative thought and phenomenological attention to embodiment).[6]

Finally, air appears in nineteenth-century philosophy, tied to health and wellbeing. As the causes of respiratory conditions and illness were discovered with emphasis on poor air

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[5] It is clear that James treats consciousness as a function rather than dismissing it as without conceptual utility. His point is rather that consciousness is not a separate entity as dualistic thought posits. Knowledge does not depend on such an immaterial notion (James, 1904).

[6] These ideas are important when we return to contemporary philosophers such as Irigaray and Škof taking up the mantra 'I breathe, therefore I am' over the privileging of consciousness. All these themes connect with the philosophy of breath, but do not make a significant appearance in philosophy in the modern period. Although some philosophers of this period such as Jean-Jacques Rousseau (1712) touch upon the breath, brief mentions have been excluded from this chapter for reasons of space.

quality, so too were mental health difficulties and morality tied to the air (Cannon, 2010).[7] For example, Friedrich Nietzsche exalted the higher air of the mountains to maintain health and aid recovery (Nietzsche, 1998). He also tied "bad air" and bad breath to the vulgar, vengeful ascetic men of religion and the 'last man' of herd morality. "Bad air! Bad air!" he laments, as if breathing the breath of such people could infect our intellect (Nietzsche, 1998: 21). For Nietzsche, the stench of their breath results from the tranquilizing lies that the ascetic ideal and values of these people have on their indifference to life and one's own potential. They claim that these values have metaphysical and holy foundations, but they *'fabricate ideals* – it seems to me they stink of pure lies' (Nietzsche, 1998: 21). This, (for him) is a collective madness and Christianity a mental illness that spreads sickness and digestive problems, differing from 'normal sicknesses' as it comes from the life-denying ideals of Judeo-Christian morality. Air can thus be infected by dangerous moral systems of thought and practice arising from both religion and the scientific paradigm of a 'will to truth' at all costs (*ibid.*).[8]

The air, smell and breath are thus given meaning that transcends the purely physical. Or, more correctly, the physical, mental, and moral are part of the same reality and as such the interrelation of the body and mind with the shared world of others can cause illnesses to arise from systems of thought as well as polluted air.[9] Physically, intellectually and emotionally one becomes stunted and unwell. Nietzsche, ever the sardonic polemicist, equates the fresh air of the Upper Engadin with his own intelligence:

> He who knows how to breathe the air of my writings knows that it is an air of the heights, a bracing air. One must be made for it, otherwise the danger is no small one of catching cold in it. The ice is near, the

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[7] In medical thought, too, the ties between air, mental and physical health were at play in the works of the Pneumatic Institute clinician Thomas Beddoes (e.g. *Hygia*), and in the work of John Haslam (e.g. *Observations of Madness and Melancholy)*. Indeed, Aristotle's ideas of the pneuma passed into the sperm was still discussed and seen to play a role in passing the spirit to the offspring, with the air causing delusion and depression.

[8] Heidegger's ideas of Das Man certainly resonate, borrowing heavily from Nietzsche.

[9] Air and mental health were thought to be related in the nineteenth century: too much air in the veins, heart or brain was posited to cause madness. Paranoid delusions, intrusive thoughts and delusions centred around harmful or magical air that invaded patients (Haslam, 1809; Porter, 2005; Connor, 2010). The delusion was thus thought of as the accidentally constituted 'accurate self-representation of the physical deficit of the organ of thought' (Connor, 2010: 58).

> loneliness is tremendous — but how peacefully all things lie in the light! How freely one breathes! (Nietzsche, 1993).[10]

Whether or not we agree with Nietzsche's estimation of his own brilliance, studies show that when the air is significantly polluted, or when respiration is disrupted, cognition, memory and decision-making are seriously impaired (Dodd, 2015). The implications of this in a world of increasing air pollution and rising morbidly and mortality rates due to air pollution are obvious. The climate is thus essential to the development and maintenance of the intellect:

> List the places where there are or have been intellectual people, where wit, refinement, and malice are part of happiness, where genius is almost necessarily at home: they all have an excellent dry atmosphere. Paris, Provence, Florence, Jerusalem, Athens — these names prove something: genius is conditioned by dry air, by pure skies — that means by rapid metabolism, by the possibility of supplying oneself over and over again with large, even enormous amounts of strength (Nietzsche, 1993: 21).

3.3 Phenomenology and contemporary philosophy: Breath & Being, health and illness

> An openness of the self to the other...breathing is transcendence in the form of opening up.
>
> *Levinas, 2016: 181*

This section will tie together what we have learned about the breath, breathing and respiration with more recent philosophy. Recovering the meaning of air, breath(ing) and breathlessness in contemporary thought serves multiple purposes. Through the ideas of Levinas, Irigaray and Škof, a dialogue is opened from the ancients through to Heidegger's 'forgetting' of the air, breath and bodily being. Epistemic concerns, morality, subjectivity, and embodiment reveal themselves. How this relates to health and illness, including psychological and emotional health, is built upon, as is its relevance to philosophy more

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[10] As a colleague pointed out, this can be linked with Aristotle's notion that "air is fundamentally cooling, too. Good air is thin, high, cold and not to be shared with others" (pers. comm. with Jess Farr-Cox).

generally. Finally, there is an implication for an ethics of care based on the breath, which will be developed more fully within the final chapters.

Our investigations thus far have shown that breath is largely forgotten in philosophy, apart from the multifarious meanings of *pneuma* in the ancients and a few references here and there in the intervening period. Within the last hundred years, Heidegger discussed the relationship of anxiety in ‘stifling the breath’ whilst opening the potential for existential authentic change (see Chapter 5). As his focus was on recovering the forgetting of the meaning of Being by examining the ontological structures of human existence rather than embodied experience, he does not discuss breathing in *Being and Time*. Irigaray engages with this forgetting, but we must first consider Emmanuel Levinas, because his engagement with Heidegger, as well as his own interpretation of breath as *inspiration* tie to an ethics of proximity that bridges Heidegger and Irigaray, in turn informing her work. Lenart Škof brings all these thinkers together. Through examining his work on an ethics of the breath we can draw themes that are salient to a phenomenology of breathlessness and healthcare. These ultimately enable me to make a case for a philosophy of co-breathing.

3.4 Levinas: air, breath, and lung

In *Otherwise than Being* (1998) Levinas calls on us to step beyond essences and substance dualism. We must embark upon a demystification of inner and outer, of being closed off, of commitment to bifurcations of activity and passivity, freedom and non-freedom, subject and object. Focusing on ‘beyond essence’ in this way, on the space between us and the Other, he tells us, is vital. For achieving this openness to the outside will provide us with meanings ‘deeper and broader’ than mere notions of freedom (Levinas, 1998; Škof, 2016). Levinas suggests that it is the outside space of air taken inwards animates our narrow concepts of freedom, activity, subject and object. It gives them life, returning the breath of life to humanity.

Indeed, ‘[f]reedom is animation itself, breath, the breathing of outside air, where inwardness frees itself from itself, and is exposed to all the winds’ (Levinas, 1998: 180). That is, the act of inspiration, of unconsciously exposing ourselves to the air (no matter its condition) frees us from ‘closedness’. This ‘closedness’ expresses our prior thinking and theorising about respiration when taking in air. Through focusing on essences and searching for epistemological foundations, philosophers in the West have lost sight of what lies beyond essences. ‘The emptiness of space’, he continues,

> would be filled with invisible air, hidden from perception, save in the caress of the wind or the threat of storms, non-perceived but penetrating me even in the retreats of my inwardness, that this invisibility or this emptiness would be breathable or horrible, that this invisibility is non-indifferent and obsesses me before all thematization, that the simple ambiance is imposed as an atmosphere to which the subject gives himself and exposes himself in his lungs, without intention and aims, that the subject could be a lung at the bottom of its substance – all this signifies a subjectivity that suffers and offers itself before taking a foothold in being. (Levinas, 2016: 180)

This passivity in its unconscious form is not an expression of an in-itself; that is an organ closed off performing its function. Its significance extends to reveal a tenuous existence that opens and spans the gulf between us: the space filled with the dichotomies of inner and outer, subject and object:

> The restlessness of respiration, the exile in oneself, the in-itself without rest, is not an impossibility of inhabiting that would already become a movement from here to yonder; it is a panting, a trembling of substantiality, a hither side of the here. (Levinas, 1998: 180)

Moreover, the very act of breathing reveals our responsibility to the Other; or rather (for Levinas) our subjection to their needs and their wants. Levinas is suggesting something very urgent and ground-breaking here. Attending to the breath in this way becomes a demand writ large as an ethics of the breath (see Chapter 6). Refocusing on breathing in this way steps up his ethical project as it opens up ontology, ethics and medicine freed from philosophical and scientific bifurcation. Breath brings them back together, and it does so via co-breathing with others within the world. That is, it is no longer just the call of the face of an ‘Other’ that binds us in a reciprocal relationship as he argued in prior work (e.g. Totality & Infinity, 1969). The nature of our respiration, our sharing of the air, creates an ethical demand to attend to the suffering of others (Levinas, 1998: 181). One created by the breath. The barriers between self and Other are thus broken down, even though the very

> breathing by which entities seem to affirm themselves triumphantly in their vital space would be a consummation, a coring out of my substantiality, that in breathing I already open myself to my subjection

> to the whole of the invisible other, that the beyond or the liberation would be the supporting charge, is to be sure surprising. (Levinas, 1998: 181)

The personal act of respiration, then, may appear to be an ego asserting its sphere of individual existence through its private breath, and yet this is not the case, he says. Rather, the Other is always implicated when I breathe, and as such an ethics of alterity is born. How can he make such a strong claim? Why should I attend to your desires just because I breathe? Or, to put it another way, why should I attend to your needs and wants just because you breathe? Of course, a clinician should attend to the respirations of a patient, but is this applicable to everyday living? Moreover, isn't this possibly a new form of mythologising the inner and outer and our connection to others via focus upon the air and the breath? This would make Levinas guilty of his own charge on the one hand, and obfuscating air and respiration so as to be clinically and ethically empty, on the other.

Such an interpretation would be a simplistic reduction of his thought and would do Levinas a disservice. It is quite proper to see the biological function of respiration on its own terms (Levinas, 1998). Our 'need for energy', the oxygenation of the blood and tissue with the elimination of carbon dioxide, can be discussed and examined quite apart from any ethical significance, *yet there is more to the breath than this.* Indeed, even the Aristotelian quest in presenting the function of the lungs as cooling the heart and providing nutrition can be seen as combined with concerns of the power of the breath in relation to our interconnection with others. 'Breathing away' my *pneuma*, passing your *pneuma* to me through exhalation (and/or via semen) connects us. This hints at what the East has known all along: the breath, the air and the lungs provide us with an intimate connection to other people, creatures, the environment, and the world.[11] Levinas, I propose, is therefore suggesting that scientific accounts do not tell the whole story.

Moreover, he insists, we must be careful to avoid scientific accounts of air, breath and breathing becoming scientifically reductive and stripped from their fundamental

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[11] Disappointingly, Levinas does not discuss the breath of animals. Derrida finds this surprising considering Levinas's experiences in a prisoner of war camp, where he wrote of a dog recognising the humanity of the emaciated men.

relationship to our existence. This is as such thinking can lead to commodification. For example, he cautions that healthy or unhealthy air (air carried in tanks by an astronaut or diver) does not mean that air is a commodity. That is, the use of air carried in tanks by the astronaut or the diver does not mean that air is a commodity to be objectified and stripped of all *meaning*. Whilst the air, respiration and the breath can be spoken of in biological terms or used in human experience, this does not denote an experience in itself (*ibid*.: 181). Levinas appears to be saying that just because we can talk of our relationship to the experience of the air in biological or commodified terms does not mean that we can reduce the air and experience of breathing to 'what is said' (*ibid*.). The philosophical tendency to reify the significance of what is said in language about phenomena or an experience often overtakes the prior meanings, significations of events and experiences that are ineffable, 'unsayable'. Just like James's suggestion that I breathe underpins the 'I think', the breath and air underpins all experience and knowledge in the first place.

Philosophy then becomes this 'exaltation' when it translates the said into meanings taken up by 'religions, sciences and technologies'. It must be careful with its propensity to label things, not to cut off prior meanings and areas of ineffable experience in the process. Breathing is in fact 'a transcendence'. It opens spaces for contact, communication, and connection: a foundation for experiencing anything at all (this is elaborated in Chapters 5 & 6). The warning is clear. Strip the breath and the air from its unshakeable ties to life and we risk air quality. Our duty to others, to the environment, is fractured from capitalisation of the air that ignores its ethical and existential primacy. Pollution is one such result: a right for some to have access to clean air (ostensibly, the rich), and others not to.

3.5 Pneumatology of the Other: beginnings

The pneumatology of the *Other* is thus born. In breathing, the meaning of the breath is shown only through the relationship to the other, and this proximity of breath shared with a neighbour elicits the recognition that we owe a debt of care to the Other:

> To open oneself as space, to free oneself by breathing from closure in oneself already presupposes thus beyond: my responsibility for the other and my aspiration by the other, the crushing charge, the beyond, of alterity. (ibid.: 180-181)

So, breath reveals our immanence, our embodiment, but it also connects us to others, our community and environment. As Irigaray (1999) says, ‘where else does man reside other than in air?’ We hear what the other is saying through their own use of the air in respiration and the mechanics behind vocal gestures. Air carries the sound to our ears and auditory processing is conditional on the medium of air.[12] It is constitutive of inter-subjectivity or of being-with-one-another (see Chapter 1). We share the air with others, co-breathing yet never fully owning the air. The environment (the oxygen-rich air of Nietzsche’s Sils Maria, for example, or the toxic fumes of the inner city) thus plays an important role in both our health and our ways of being-with-one-another. We must therefore attend to the breath in all settings, particularly medical settings:

> It should not be forgotten that this is also a task, for us to learn how to ethically respond to the call of another human being […] and their breathing, since breathing means staying alive and sensing everything and everyone that is alive around us. (Škof, 2015: 8)[13]

The breath is located as a space beyond essence and shown to connect human existence in a way that allows an ethical demand to be raised, a responsibility that grounds our subjectivity as intersubjectivity. Through this ‘responsibility’ to the other, the lungs can be posited as an ‘ethical organ’: respiration both precludes and grounds theoretical and ontological discourse by virtue of the fact that breathing enables and structures intelligible discourse (Levinas, 2016). The lungs, of course, enable and ensures this.

Levinas also argues that responsibility itself grounds subjectivity and ethics (2016; Škof, 2018). It is a bond that gives the imperative command that in order for the self (subjectivity) *to be*, it must first subject itself to the needs and the wants of the other, and the most important of these is their breathing. Although he situates this ethics of alterity in the face of the other, his emphasis on the breath and lungs is suggestive of an ethics of the breath, I argue (*cf*. Škof, 2018). It is not the face as suffering, inquiring, or demanding that motivates a response. In the clinic, it is the very breath itself that urges action. Perhaps the face is unable to express discomfort due to intense swelling (oedema) from medication. The voice may be silenced as sputum accumulation is too severe. Breathing must be

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[12] This is not to suggest that other forms of communication are not possible, but rather noting the importance of the air and breath in verbal communication.

[13] We will return to an ethics of the breath in the final chapter of this thesis.

attended to and thus we must take a position on how to react to the inaudible call of the other's distress. How one responds reveals the recognition of the Self as subject. It is to be answerable to one's own projects, as well as the unique demands of the situation revealed by the subordinate relationship to the other. Thus, he says, the relationship brought forth grounds and sustains life. To understand this further, we move onto Irigaray, before further reengagement with his ideas in later chapters to start to unpick and apply these ideas.

3.6 Breath and Being

> No wonder philosophy dies – without air
>
> *Irigaray, 1999: 5*

Despite her respect for the phenomenological insights of Martin Heidegger, Irigaray devotes an entire book to how Heidegger has 'forgotten the air' through his preoccupation with Being (*Sein*), and later, the privileging of Earth in the fourfold (*das Geviert*), analogous to the forgetting of Being that he charges Western philosophy with.[14] 'What is the meaning of Being?' and 'what is breath?' are thus two questions that have been taken for granted. This is because the air is invisible. Breath, like Being, as that which is 'closest to us', is also the 'farthest away' (Heidegger, 1962). That is, as we have neglected the meaning of Being, so too with breath.

With the former, Heidegger argued that over the centuries, philosophers have claimed that Being is many things, and no-thing. Being is a universal, indefinable, obvious, forgotten, meaningless concept or idea (Heidegger, 1962). Phenomenologists, by investigating the meanings of our human experiences as lived, pre-reflectively and prior to thematisation and scientific deduction (see Chapter 1), can unfold the meaning of Being through human

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[14] This does not mean that Irigaray was against Heidegger. Rather, she expanded his phenomenology to include sexual difference as well as the forgetting of air and the breath to 'celebrate the work of Martin Heidegger. To succeed in this gesture implied not appropriating his thought, but respecting it in its difference. To pay homage to Martin Heidegger in his relationship to the earth, to the sky, to the divinities and to the mortals presupposed for me the unveiling and the affirmation of another possible relation to this fourfold' (Irigaray 2001, p.315).

language, disclosing the openness to Being, available in our self-understandings of Being. This includes our relationships with others; objects; and the world.

Yet according to Irigaray, Heidegger and phenomenology are still bound to the metaphysical tradition through the obsession with Being and the earth, ultimately forgetting the 'clearing of the opening'. That is, forgetting the air, the groundless foundation of metaphysics (Irigaray, 1999: 5). Heidegger forgets that, 'to breathe also means to be. This does not occur to him. Is it because there is still and always too much air that he has not yet reached the point of conserving it?' (*ibid*.: 62). To reiterate, the emphasis that Heidegger puts on forgetting Being because 'that which is closest, is also farthest away', unhappily remains examined in relation to air and the breath for Irigaray.

For her, this limitless, taken-for-granted air grounds being. Air is the 'origin of the power of thinking, without air, without breathing, we could not think, could not exist' (*ibid*.: 7):

> Is not air the whole of our habitation as mortals? Is there a dwelling more vast, more spacious, or even more generally peaceful than that of air? Can man live elsewhere than in air? Neither in earth, nor in fire, nor in water is any habitation possible for him. No other element can take the place of place. No other element carries with it – or lets itself be passed through by – light or shadow, voice or silence. No other element is to this extent opening itself – to one who would not have forgotten its nature there is no need for it to open or reopen. No other element is as light, as free, and as much in the 'fundamental' mode of permanent, available, "there is". (Irigaray, 1999: 8)

As humans, phenomenologists have argued that we have a unique access to Being through human existence, *being-here* (*Dasein*). To get at Being, we must look to our own experience to raise anew the question of what it means *to be*. So, instead of focusing on intellectual, rationalist notions of Being as substance, consciousness, and so on, Irigaray suggests we look at air and respiration to shed light on what it means to be (*ibid*.). This is in part because questions of appearance and reality, Being and non-Being cannot be posed without breath, or without air constituting the very 'place of place' (*ibid*.). Air creates the 'there is'. It is so present to us that it is always in the background and does not 'compel' us to notice it: 'Always there, it allows itself to be forgotten' (*ibid*.: 9). The philosopher takes this invisible presence as an absence through the lack of its self-announcement.

However, the air is also ‘the clearing’ for presence and absence, for appearance and disappearance. By its very nature, then, the constant presence of air and its necessity for life fades into the background (like the transparent nature of the body). We use up the air, without having to consciously attend to it as a being or substance. Thus, its very nature rules it out of philosophical concerns. This is why Irigaray calls air the ‘*a priori* condition of all his *a prioris’* (Irigaray, 1999:13). Irigaray suggests that air is easy to forget because, whilst thinking is dependent on air, ‘air does not show itself. As such, it escapes appearing as being. It allows itself to be forgotten’ (Irigaray, 1999). The ubiquity and invisibility of air lead to ‘oblivion’, she says. The presence and absence of air is also the presence and absence of breath.

Echoing Anaximenes and James, I suggest, culminates in Irigaray arguing that we draw the power of thought from the air. Other elements have their place, but the ancients were wrong to posit fire as the most important element: fire *needs* air, as Anaximenes knew. James’s emphasis on the ‘stream of breathing’ as thought can be further seen as an extension of a refocus on the fundamental resource that is air (James, 1962: 208). Yet the passive air plays an active role in human existence, experience and thought, via *breathing*: something which we must *do* to live. Indeed, *to be* at all is to breathe:

> To air he owes his life’s beginning, his birth and death; on air, he nourishes himself; in air, he is housed; thanks to air, he can move about, can exercise a faculty for action, can manifest himself, can see and speak. (Irigaray, 1999: 12).

From our first breath through to our last, then, there can be no Being (for us individually) without air. Breathing is enacted, not a mere passive function of respiration. Undeniably, we are engaged in skilfully coping with our self-imposed projects and goals, but respiration makes possible the sensuousness and ethical metaphysical call of the other that Levinas sees as primary to human existence, the care and concern of Heidegger, and the primacy of perception that Merleau-Ponty emphasizes. All this is dependent on air, on that which has been forgotten in philosophy, temporarily inside us, outside us, sustaining us, yet never owned fully by us (*ibid*.: 5). Irigaray therefore reunites interest in the ideas of the Pre-Socratics on the significance of the air *and* the breath.

Thus, excepting Anaximenes and Theophrastus, air has been forgotten unless something goes wrong. Irigaray argues that philosophers have created a void in knowledge and understanding by ‘using up the air for telling without ever telling of air itself’ (*ibid.*: 7). The resultant philosophies of two millennia are philosophies of forgetting. To offset this, we must create a philosophy of breathing, based on air as relational, rather than of individual ownership, echoing Levinas on the initial conception of the individuality and personal nature of breathing that connects people turned on its head: subjectivity is constituted by the Other. Thus, the ubiquitous, immaterial nature of the air appears: we can never fully own or appropriate it.

So, echoing Anaximenes, and Aristotle, the air is where we exist. It is where we draw the sustenance for thought, embodiment, and spirituality. It is where we exist with others, with breathing both enabling my individualization, my subjectivity. At the same time, this breath is Levinasian: it constitutes my proximity to others, the intercorporeal structure of human being (which leads to the ethical demand). Focus on the air and the breath in this way can transcend the split between the mind and body, inner and outer, the masculine and feminine, Self and Other: it unites them all. ‘Breathing corresponds to the first autonomous gesture of the living human being. To come into the world supposes inhaling and exhaling by oneself’ (Irigaray, 2002: 81). Irigaray borrows from Eastern philosophy to focus on the importance of the body, with the breath akin to the vital heat. By cultivating breathing, the body can again become aligned with spirit for her, without needing to perform philosophical reductions to rationality or appeals to observation to expand understanding and knowledge. Awareness of breathing bridges any gaps that exist between the body and consciousness, immanence, and transcendence. Indeed, for Irigaray, knowing oneself, exploring existence, overcoming bifurcations in philosophy can be achieved through breath awareness.

Indeed, the usual stereotypes of women as bodied, beholden to their emotions and sensations and men as rational and connected to spirit and consciousness can be overcome by focus on the breath, for her. As the Greeks held it, breath bridged the divide between body and spirit. If the body is aligned with the female, and the spirit the male, the breath binds male and female together: through the mother, the male child breathes with her, until it is born. ‘She gives first. She gives the possibility of that beginning from which the whole of man will be constituted. This gift is received with no possibility of a return. He cannot pay her back in kind’ (*ibid.*: 28). Thus, the mother gives the first air via her blood (echoing Aristotle's connate *pneuma* travelling through the blood, but through the blood of the female, and not the semen of the male). The possibility of agency, experience, reason, language, and speech begins in the body of the mother.

> To breathe is to separate from [the mother or nature], to be reborn, and to give back to her a share of breath: through air, through praise, through work of life and of living spirit. To breathe is to leave prenatal passivity, to leave the infantile state, dependent or mimetic, to leave simple contiguity with the natural universe, in order to maintain and cultivate a status as an autonomous living being (Irigaray, 2001: 309).

Irigaray, then, returns to the divine, the spiritual facet of human reality (albeit divorced from God as an independent reality). It is more a recovery of the feminine divine, revealed to us through the female body, specifically through the breath (165).

For the purposes of this thesis, I cannot comment on her philosophy of difference, but point the reader to the bibliography for further reading. Essentially, her refocus on the air and the breath attempts to reawaken the feminine divine (amongst other aims). What is pertinent for this historical account is the re-emergence of the power of the air, breath, and breathing. In short, the idea that the breath of life that 'we each receive and share with one another' can reawaken humanity to embrace differences on the one hand, but to open up new ethical spaces, on the other (Škof & Holmes, 2013: 12). What is contained in these new ethical spaces cannot be determined beforehand. Nor can I attempt here speculation on a new ethical framework based on sexual or gendered difference. Instead, I will take these insightful philosophical analyses in order to tie them to my project of rethinking breathlessness, both in clinical settings and interpersonally. I take them forward as a philosophical call to attending to the breath.

One final point relevant here to our bodily being is Irigaray's refocus on the relationship between movements and embodiment, ostensibly overlooked due to the invisible nature of this relation and how we take it for granted. Air supports our movements, delineating certain bodily boundaries: once we are born, we attempt to move within a world 'new' to us that moderates certain possibilities of movement (Irigaray, 2001). This in turn shapes our 'conceptual apparatus' (*ibid*.). Just as we have to learn how to move our bodies when we start to swim, exposure to the invisible air supports our freedom of movement. Unlike water when swimming, however, we need to take the outer air inside us for survival. That is, we don’t need to take in the outside water in order to swim. We thus ‘borrow’ the air, sharing it with other living beings.

Air has further significant powers. Studying it further, we can see how air also connects us to loss, mourning and absence. These experiences are not just known to us through the death of a loved one: when we run out of air during breathlessness we connect with loss directly; a loss of our abilities, capacities for movement and thought resulting in the loss of opportunities and possibilities open to us before (*cf*. Carel, 2016; Lorde, 1980). Such an uncovering of the significance of the air can encourage us to reflect on and recalibrate our values, behaviour, and lives, I suggest. We thus begin to care for our own lives and cultivate breathing to align our natural breath (corporeal automatic breathing) with our spiritual breathing. If we recognize air as life itself, never fully appropriated by us but rather shared, then air can bring us closer to others.

> If breathing estranges me from the other, this gesture also signifies a sharing with the world that surrounds me and with the community that inhabits it. Food and even speech can be assimilated, partially become mine. It is not the same for air. I can breathe in my own way, but the air will never simply be mine (Irigaray, 2001: 309).

Life and death are thus bound by the breath, with our experiences of health and illness altered by the temporal structure of our breathing as well as our lives: ‘death and dying are connected to breath in visible ways’ (Jaworski, 2014: 71). Breath therefore also has a temporal dimension – signalling not only the start and end of our lives, it also carries with it the ex-stases of the past, present and future. The temporal flow of the breath is fluid, but, for example, the in-breath implicates all three temporalities. If I run for the train, a ‘future-projection’ of a goal and its manifestation is created; I gulp in breaths to meet the needs of my body. I cough and splutter, due to the past and present state of the body; its present asthma, for instance, with past smoking, and unfitness for the task taking over and bringing me to a stop as I try to navigate the demands of my breath and body with the activities I must complete. The status of the air quality, situational demands, the fitness of my respiratory and cardio-vascular system is constantly feeding back and mingling with the past, present and future needs of the life-sustaining function, breathing. These themes relate directly to the role of the breath in health: cultivating breathing techniques can calm the rapid breathing in panic and hyperventilation. Equally, studies show the positive effect of breathing exercises such as yoga and mindfulness on those with respiratory conditions, panic, depression, and anxiety (Malpass *et al.*, 2014).

Hence, attending to the air and breath opens up new areas to explore in health, wellbeing and subjectivity. This focus also implicates the other for Levinas and Irigaray. Intersubjectivity, responsibility, care, and compassion reveal themselves. Lenart Škof (2015) proposes opening a *mesocosm;* a space between the body and Self (microcosmic) lifeworld and the world of the other, of nature, and the world (macrocosmic). Ethics based on the breath as the 'life-energy' (*ibid*.: 8), he proposes, will enable an ethics based on the gestures found in compassion, care, and tenderness. Rather than intersubjectivity, this study is more about intercorporeality and the spaces 'in-between us', hence mesocosmic. The use of intercorporeality captures the bodied connections between one person and another. It is not a mere connecting of the selves as subjects and minds. The embodied nature of sensing, perceiving, breathing bodies is implied. I touch on his work briefly, returning to his ethics of proximity in later chapters. To make sense of the concept of intercorporeality, we can read Merleau-Ponty:

> In perceiving the other, my body and his are coupled, resulting in a sort of action which pairs them. This conduct which I am able only to see, I live somehow from a distance. I make it mine; I recover it or comprehend it. Reciprocally I know that the gestures I make myself can be the objects of another's intention. (Merleau-Ponty, 1951/1964: 118.)

The unconscious perception of the gesture (e.g. yawning) of the other and the 'prompting' of that action in ourselves are supported in neuroscientific studies. When observing one breathe rapidly, whether the cause is panic or a life-threatening illness, we find ourselves reacting physiologically, with an elevated heart rate, sweating or gastrointestinal disturbances and a demand to act. We *embody their distress* by seeing and hearing their respiratory distress. It is direct and pre-cognitive, prior to reflection. Indeed, health practitioners often try to calm the patients' breathing to decrease their physiological symptoms (Binnie, *forthcoming*). This, I suggest in later chapters, can be done by co-breathing, allowing the patient to unconsciously mirror the breathing of a calm nurse or doctor.

This will be of salience in applications to that which has been overlooked the most in philosophy, breathlessness. Whilst we have been able to explore air, breath, and breathing in the history of philosophy, this is still missing. This is unfortunate. Breathlessness is not just characteristic of respiratory disorders or mental health conditions such as anxiety and panic disorder. Breathlessness is also common in cardiac disease, cancer and often present at the end of life in both hospital and palliative care settings. Terminal, or ‘agonal’ breathing is an often misunderstood but common occurrence at the end of life for patients with a wide range of diseases. How can such a common experience be glossed over via philosophical and phenomenological concerns with existence, embodiment, and experience? Levinas’s ethics of proximity and an ethics of the breath (as interpreted by Irigaray and Škof) are invaluable here, for both my philosophical study, and clinical understandings, I argue. For the neglect of knowledge and understanding of this prior to terminal breathing, whilst no fault of healthcare practitioners, leads both clinicians inexperienced in the recognition of these breaths at the end of life and families and loved ones to express horror at what they may perceive as gasping for breath, indicative of suffering. There is much to be revealed, then, through analysis of the significance of the air and breath to life, health, illness, and medicine (see Chapter 6 for detail).

3.7 Conclusion

Ultimately, this study builds on and contributes to ideas regarding the philosophy of breath in Western thought. Although studies in medicine typically deal with respiration, philosophy has much to contribute, particularly in terms of providing a phenomenology of breathlessness relevant to medical understanding of this as heterogeneous experience, rather than the typical concern with the symptom. Western philosophy, however, has forgotten the breath, and thus this chapter sought to rectify that. This is on an individual basis, socially, and in terms of an ethics of breath and air. The analytic focus on unpicking ideas of breath, *pneuma*, air and breathing contributes to medical ways of thinking of respiratory disorders and comorbid mental health issues, issues that are typically separated into discrete categories of the *psyche* and soma. Studies on these issues are very few, but I hope to contribute a particular focus on the inter-relationship between mental health and physical health. This chapter ties into the rest of the thesis whereby we analyse patients’ breathless experiences from both ‘causes’, as well as the history of breath in philosophy in order to illuminate the relationships between air, physical health, mental health and communities.

This chapter has examined the history of the breath in Western philosophy to show that *to be* is to breathe. We have moved from the limitations of the Cartesian *cogito* through to the existential ‘I am, therefore I exist’ to retrieve a philosophy of the breath. Of course, we do not deny the centrality of skilful coping, sensuousness, perception, and so on, but respiration makes these possible. We must recover air and the breath as the requisite to life and move away from the Western focus on thinking. Air does not show itself. As such, it escapes appearing as being (Irigaray, 1999: 14). It also provides the ‘there is’, the place of the *there*. As such, this ‘air’ space is infinite openness (*ibid*.). Such an abyss as an ever-present absence (since it is invisible) is always ‘passing from outside to inside, inside to outside’ (*ibid*.: 41). The air allows itself to be forgotten even whilst it constitutes the *there is* of existence. *There is* anything for us only insofar as there is air. It opens up spaces and makes place possible. Phenomenology is defined as that which shows itself from itself, allows itself to appear (Heidegger, 1962; Moran, 2000). Yet air doesn’t appear. How is a phenomenology of the air possible? It is via its transcendental, structuring nature that constructs and structures experience of breath and breathing, of existing. We can attend to that which is invisible via examining our experiences as human being, and it is to this we turn in the next chapters.

CHAPTER 4: Invisible Populations and Breathlessness

> To reduce breathlessness to a unidimensional clinical sign like peak expiratory flow or respiratory rate diminishes the person who lives with its debilitating effects and the fear that it engenders.
>
> *Currow and Johnson, 2015: 1527*

> 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. This is as frightening as life can be.
>
> *Currow and Johnson, 2015: 1527*

4.1 Introduction

As previous chapters have established, there is a paucity of philosophical study of the experience of breathing and breathlessness. Even the exceptions of the pre-Socratics, and the Aristotelian and Stoical studies of pneuma that were revived briefly in the mediaeval period due to the influence of Greek philosophy were more focused upon the anatomical and spiritual features divorced from human experience. Quite apart from prior thinkers already covered, this propensity was writ large in the work of thinkers such as Abu al-Walid Muhammad ibn Ahmad ibn Rushd, known as Averroes in the Latin West; Thomas Aquinas; and Pietro Pomponazzi, for instance (Carel, 2012; Routledge Encyclopaedia of Philosophy, 2015).[66]

It is therefore undeniable that philosophical investigations into the relationship between health, poor air quality, disease, and sickness demand attention. I contend that this is pressing in relation to the subject that is missing from philosophical accounts: the lived experience of the embodied subject. As the ancient philosophers offered the foundation for much of our scientific and objective approach to the anatomy of the body, perhaps we should not be too surprised that first-person subjective accounts have been eschewed

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[66] Due to the remit of this chapter, I do not have time to discuss these thinkers.

(Baron, 1985). Hence the existence of many studies of the physiological processes of respiration and respiratory diseases. In this chapter I will directly address this lack, expanding upon my justifications as to why undertaking a study of breathlessness experiences is so important and meeting this need by providing an interdisciplinary and phenomenologically informed account of breathlessness in physical disorders.

Breathlessness in chronic or life-limiting illness is reported as one of the most distressing symptoms and life-changing experiences, and the most common reason for admission to accident and emergency (Abernathy and Wheeler, 2008). What does this frequent source of suffering comprise? Historically, it was generally held that 'the sense of effort was the primary component of breathing discomfort', although other qualitative elements were sometimes mentioned (American Thoracic Society, 1996). Now the sensations encompassed by this term are beginning to become more nuanced (as I discuss below), and so patient and clinician dialogue and interpersonal understanding of patients' experience are improving. Still, there is much work to be done. Physiological discoveries have certainly broadened our knowledge and understanding, and neuroscientific discoveries via technological advancement have localized areas in the brain thought to be related to respiratory sensation processing and with some correlation with areas related to hunger, thirst and pain (Herigstad, 2011; American Thoracic Society, 1996). Yet there are still gaps in our knowledge and understanding of this distressing symptom. Increased knowledge of the neural processing of respiratory sensations is undoubtedly important but does not tell us much about the patient's perceptual experience (Ekstrom *et al.*, 2015). That is, evidence shows that their breathlessness experience doesn't just rely on the stimulation of receptors: the patients' attention to their symptoms, their prior experiences and memories, understanding, cultural and social experiences; in short, their *being-in-the world* (*In-der-welt-sein*) shapes their experience of breathlessness, and their suffering.

In this chapter, I will thus use phenomenological concepts such as intentionality, embodiment and *being-in-the-world* to describe these alterations, and the experience of breathlessness in COPD as a case study.[67] This is in order to describe these experiences and reveal pre-reflective structures of our everyday normal existence. Although the biomedical model is critiqued for leaving out the first-person perspective through its over-reliance on science and a naturalistic worldview, I argue for a phenomenological supplementation to these forms of knowledge. This is in order to provide a more accurate picture of this form of hidden suffering. That is, science undeniably has its proper role in investigating these diseases, but it can benefit from interdisciplinary study that does not privilege third-person, etiologically-based explanations when dealing with symptoms that are inherently bound to this subjective variation in human experience.

This approach can fit with medicine's own inconsistent use of many different subjective measurements (for instance, the Chronic Respiratory Questionnaire dyspnoea subscale – CRQ-D) in cases of breathlessness. Anxiety, depression, and breathlessness levels are often identified with reference to the experiences of the individual (subjective lived experience), rather than pure third-person observation or physical measurements (objective) that medical science holds as the gold standard (Goldberg and Goodyer, 2005). Indeed, diagnoses of mental or physical disorders often depend on diagnostic criteria that attempt to capture some of the typical qualities or symptoms of these conditions. Obviously understanding these symptoms and deciding which symptoms or experiences 'count' clinically is very important (not least for diagnosis and treatment), but it is also important to provide an accurate account (whether descriptive or explanatory) of these disorders, and to use such accounts reliably (Goldberg, 1995). What is missing is consistency in terms of which measurements to use, whether they capture what breathlessness means to each patient and the impact of their illness on their lived experiences, and certainty as to whether they capture the realities of living with dyspnoea, which we will now turn to. The under-recognition, diagnosis, and treatment of anxiety disorders in patients with long-term lung conditions suggests they do not (Clark, 2017; NHS England, 2016).

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[67] Studying breathlessness in COPD offers clinical utility. It presents the opportunity to foster greater understanding and awareness of one of the most prevalent diseases in the UK, a disease with high rates of mortality and morbidity, both here and globally (NICE, 2014; British Lung Foundation, 2016).

4.2 Breathlessness, dyspnoea, and urgency of study

The American Thoracic Society (1998) states that, '[R]espiration, the act of breathing, is unique in that, of all the vital functions, it alone is regulated not only by automatic centres located in the brainstem but also by voluntary signals initiated in the cortex'. In other words, we have a level of control over our breathing, and this control is unique for an indispensable condition of living. We cannot directly control other vital automatic processes, such as metabolic rate, digestion or brain function; yet, quite apart from being able to consciously alter our breathing (for example, by holding our breath, practicing meditation, smoking, sports training and so forth), our rate of breathing is also affected by sensations made manifest through respiratory activity (American Thoracic Society, 1996). What we experience through these feedback sensations can affect *how* we breathe. When something goes wrong or is perceived as such[68] and these sensations change (regardless of the exact cause), individuals can experience uncomfortable breathing sensations, anxious and panicked breathing, and sometimes hyperventilation (Abernathy & Wheeler, 2008). For the most part, these experiences are not under our control (American Thoracic Society, 1996).

Dyspnoea, the medical term for breathlessness is defined here (following the ATS) as,

> A term used to characterize a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity. The experience derives from interactions among multiple physiological, psychological, social, and environmental factors, and may induce secondary physiological and behavio[u]ral responses. (*ibid.*)

Breathlessness, then, is not just *a* feeling or sensation; the experience is more complex and implies feedback loops pertaining to responses from cognitive-affective, bodily and social interactions in a temporal framework, much like Merleau-Ponty's (1962) intentional arc outlined in Chapter 1. I suggest that these features of breathlessness have the power to reveal our sensorial embodied experience and 'being-in-the-world' in what initially appears to be a symptom of a change in, or dysfunction of, our respiratory

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[68] See Chapter 5 for detail on how perceptions impact breathlessness experiences.

system. This altered experience is, in part, why studying breathlessness can open philosophical reflection about our ways of existing in the world, including revealing pre-reflective fundamental structures of embodiment and the life world, as I will argue below. This complexity in subjective experience may explain why breathlessness studies are lacking in philosophy, and why objective third-person accounts in medicine focus on pathophysiology instead, despite the American Thoracic Society recognising inter-related phenomena and impacting experiences. Put simply, these complex interacting areas and the role of perceptual experience are often ignored in medicine despite their importance, do not fit with the scientific worldview outlined in Chapter 1. Hence, they have not been pursued philosophically since the dominance of materialist and rationalist metaphysics that have sought to study objective reality and knowledge over subjective experiences of embodiment (see Chapter 2).

However, what do we know of this complex experience encompassed by the term breathlessness? How is it typically characterized in both medicine and folk knowledge? Whilst the physiological components are bound to a wide variety of subjective components, typical felt sensations involve include feeling short of breath, winded, difficulty with inhalation or exhalation, not receiving enough air (resulting in low oxygen saturation), air hunger, chest tightness, muscle fatigue, and discomfort when breathing (Carel, 2014). Not every experience of dyspnoea includes every sensation, nor is it at the same intensity for different episodes and there is much felt variation across individuals (Abernathy and Wheeler, 2008; Smoller *et al.*, 1996).

Causally, in terms of the aetiology of dyspnoea, no two cases of underlying dysfunction will necessarily result in the same felt intensity or severity of the experience (Smoller *et al.*, 1996). Of course, due to the myriad causes of dyspnoea, there are multiple well-documented ways of correcting the underlying pathophysiology or successfully managing the condition, for example in cases of mild asthma using bronchodilators to relax the muscles in the airways and widen the bronchi (Lancet Editorial, 2015; NHS England 2014). However, in complex cases such as refractory breathlessness, such management is complicated and palliative treatments often unsuccessful (Booth *et al.*, 2009). Further, apart from dyspnoea’s varying subjective qualities, with many underlying mechanisms and causes, intensity can also be difficult to *measure*, rendering evaluation, treatment, and management difficult and sometimes ineffective (ATS, 2006).

Diagnosing and assessing dyspnoea 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. If the condition is not easily traced to an exact cause, or if the dyspnoea cannot be relieved, management of symptoms is tackled to reduce intensity, distress, any comorbid mental or physical conditions, and to address the shrinking world of the patients (Ellison *et al.*, 2012).

Crucially, in certain conditions, such as the increasingly prevalent chronic obstructive pulmonary disease (hereafter COPD), or with refractory respiratory diseases, these dysfunctional mechanisms cannot be corrected and so the patient’s daily physical abilities and lived experiences are altered irrevocably (Bailey, 1994). In these cases, there will be varying levels of disability that are likely to worsen over time but are often unlike many other chronic illness progressions (e.g. arthritis) because of the impending and ever-present nature and dangerous consequences of episodic attacks. For instance, acute exacerbations of respiratory infections can result in death. As one patient put it, “If you can’t breathe, you don’t live” (Nicholls, 2003: 132). Understanding, managing and attending to the patient’s experience – including their voice when they are not too breathless to talk – is therefore often a matter of life or death (see Chapters 5 and 6 for stigma and COPD; patient responsibilities; and clinician assumptions of ‘poor people’s disease’). In other words, understanding and investigating their experiences can aid the development of self-management techniques through clinician training and education.

In 1996, the Thoracic Society recognized these problems, stating;

> [A] better understanding of the mechanisms, assessment and treatment of dyspnoea is necessary if clinicians are to improve their ability to monitor and treat patients with shortness of breath (ATS, 1996: 1).

With COPD predicted to be the third-biggest cause of mortality Worldwide by 2020, the need for this ‘better understanding’ is becoming more pressing (WHO, 2016). I intend to go one step further here, attending to the subjective experience of dyspnoea in both respiratory disorders such as COPD and asthma, and in anxiety disorders such as panic disorder. This approach has multiple purposes. Briefly, these purposes and the underlying reasoning are as follows:

1. Illumination of these experiences to foster greater knowledge of dyspnoea and the understanding of its impact on those with these disorders, with a view to lessening the impact of related comorbidity (for example, the high rates of depression or anxiety in these cases).
2. Achieving a deeper understanding of the impact of stigmatisation, social isolation, and deprived populations as a result of the current lack of integrated care for these patients to allow clinicians to treat the co-morbid mental health issues better, arriving at the right therapeutic intervention the first time and thus fulfilling the NHS criteria of right treatment, at the right level, at the right time (NICE, 2009; Improving Access to Psychological Therapies, 2016; NHS England, 2016).
3. To help practitioners and patients to differentiate whether functional disabilities (e.g. reduced activity and changes in behaviour) are due to the underlying breathlessness or another disorder (e.g. depression or anxiety), and to differentiate between the emotional, behavioural and cognitive consequences of dyspnoea for efficacious treatment. This will also aid disclosure of the meanings and significance of patient experiences, often left out by clinical interventions and medical studies (Hasson *et al*., 2008; Nguyen *et al*., 2013).
4. Addressing the need for a more detailed account of the subjective structures of dyspnoea than currently being used by clinicians and researchers in contemporary medical practice (Ekstrom *et al*., 2015).
5. Examination of the high rates of the occurrence of anxiety disorders and shared phenomenology, elucidating how these experiences share features.

In part, such philosophical and interdisciplinary analysis will address the fact that, despite mounting evidence for the prevalence of mental health problems and the efficacy of mental health interventions in comorbid cases of breathlessness, they are ‘rarely treated’ (IAPT, 2008: 19). I suggest this is in part due to the failure of so-called ‘collaborative care’, which results in a lack of communication between mental health services and general medicine. Referral services are insufficient in tracking patients’ progress and treatment adherence if they are not operating under holistic practices (NHS England, 2016). In most cases, people are referred to outside services for their ‘mental health’ or social issues and only treatment for their disease or dysfunction is deemed appropriate in medicine (see below). This suggests fragmented, depersonalized medical care in which the patient is treated as an objective body, separated from their emotional, cognitive, and experiential life world (Aho and Aho, 2012). Even more startlingly, those respiratory patients with under-diagnosed and under-treated mental health problems have higher rates of suffering, health inequalities, and mortality (NICE, 2014).

4.3 Chronic Obstructive Pulmonary Disorder and Breathlessness

Breathlessness is the main (and least understood) symptom in COPD and one of the most distressing symptoms reported in illness experiences (Nichols, 2003). COPD, a chronic disease for the most part caused by smoking, is ‘characterized by airflow obstruction that is not fully reversible’ (NICE, 2010; Hansen *et al.*, 2007: 321). Due to the noted levels of subjectivity and variations in the experience of breathlessness in COPD patients, limited research exists exploring this extremely distressing symptom and its correlates (Barnett, 2004; Wilgoss *et al.*, 2012; Hui *et al.*, 2013). As medicine seeks to understand diseases, disorders and symptoms via empirical studies and trials that are objective, repeatable and generally quantitative, we can see how the subjective experience of breathlessness (one that is affected by patients’ perception of their experience and not easily amenable to objective measurement) poses difficulty for future research in the area.

Beginning with this physical disorder, exploration of the *lived* experience of COPD is necessary for the following inter-related reasons. Firstly, pathological breathlessness is physically, interpersonally, and socially disabling, resulting in distress and fatigue; social isolation via smoking stigma; limited energy to carry out everyday tasks; alienation of body and world; changes in interpersonal relationships when intimate relationships become those of caring and dependence; inability to work; and so on. The list of embodied and interpersonal changes is long and in dire need of further description and study to be fully understood (Carel, 2012; Yorke *et al.*, 2008).

COPD causes further symptoms such as anxiety, panic, depression, confusion, and fear. Of course, these so-called mental components are felt and experienced as embodied, and not so easily differentiated (see Chapter 4). Imagine that you have a condition that makes it difficult to draw breath. Recently, you suffered an attack during which you felt you were suffocating and required hospital admission. This was followed by another attack that felt exactly the same, with the same level of suffocation, dread and palpitations with the same result (i.e. hospital admission); however, subsequently you were discharged with a diagnosis of a panic attack. The two attacks *felt* the same, despite differing underlying mechanisms. In short, breathlessness is not only debilitating in and of itself: it incorporates many facets of life and involves many severe comorbid conditions that are not easily differentiated (Smoller *et al.*, 1996). Furthermore, as lung capacity is thought to vary up to 20% a day, measuring breathlessness via an objective measurement on two separate occasions may show the same FEV1 (forced expiratory volume in the first second), despite the patient reporting one being worse than the other. It is still not clear whether perception, variation, or some unknown mechanism is involved in these experiences and how useful such measurements are in tracking these felt variables.

As mentioned, currently there is no cure or for COPD and treatment varies across the country. These problems add weight to the need to examine pathological breathlessness so that it is understood more clearly. It is hoped that appreciation of the insidious nature of this disorder through sharing knowledge can aid better coping through examining patient accounts of their experiences. Identifying common themes for more effective treatment and management. As Carel argues, and qualitative studies confirm (Nicholls *et al.,* 2003), it is possible for wellbeing to exist within illness experiences (Carel, 2016). The patient becomes an expert in finding coping strategies, managing their symptoms, and living within their modified body image. Yet with these individuals so often isolated (and stigmatised as responsible for their illness in the case of smokers), there is little sense of a community of COPD patients who can share their expert knowledge-by-experience. For example, when adequate psychosocial support was put into place, a ‘fairly good’ quality of life was reported by half of participants in one COPD study (Barnett, 2004: 805). In contrast, those who didn’t receive any support reported their quality of life was severely compromised (*ibid*.). Furthermore, there is qualitative evidence that treating COPD with pulmonary rehabilitation and mindfulness is helpful in addressing subjective experience, physical sensation and cognitive, emotional and behavioural factors that impact upon the patient and their experience of COPD (Malpass *et al.*, 2015; Ellison *et al.*, 2012).

Barriers to such help are not limited to knowledge structures or support networks: in respiratory illnesses, a hierarchy appears to exist in terms of who is more deserving of sympathy and clinical time related to responsibility for their conditions, which may contribute to stigma perceptions and attempting to self-manage, rather than seeking professional help before the illness becomes life-limiting (Guillick and Stainton, 2007). Shame, stigma, and blame can have additional consequences for the management of the disorder and further isolate and alienate the patient, as outlined in Chapter 6 (Goffman, 1963; Johnson, 2007).

There are thus many reasons to study breathlessness in conditions such as the under-diagnosed and yet highly prevalent COPD. Diminished life expectancy, reduced quality of life, morbidity, healthcare costs, disability burdens, familial issues, economic burden, and complex needs that progressively worsen over time in and of themselves deserve philosophical attention. When taken together, the value of studying under-researched breathless experiences is demonstrable.[69] Despite these issues, research into breathlessness has tended to focus on functional achievement (airflow) and pathophysiological mechanisms underlying the experience or sensation of dyspnoea. Such mechanistic or explanatory phenomena cannot explain the variations of breathlessness across patients who objectively have the same airflow output, but report varying levels of severity and distress. Nor is the experience discoverable via a focus on pathological or physiological processes alone: Chapter 1 revealed how psychology, culture, and society impact on the body and the experience and significance of diseases or suffering. It cannot be assumed to exist independently of the person and their lifeworld.

This lack of knowledge, understanding and adequate studies of the experience of breathlessness are not the consequence of the failure of any particular discipline alone. My contribution here to insist on attending to patients' experience through phenomenological description (free from metaphysical assumptions or explanatory frameworks) to redress such paucity of language and knowledge (Carel, 2016). Otherwise, this current lack of knowledge and understanding (and the demonstration of subjective difficulty) trickles down to patients.[70] That is, breathlessness accounts given by patients usually take the form of metaphors or narratives indicative of these problems (Nicholls, 2003; Ratcliffe, 2010). Appeal to imagery may thus reflect a gap in language

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[69] I will also look at breathless experiences in other respiratory disorders, alongside mental health conditions, to elucidate these invisible experiences (see also Chapter 5).

[70] Indeed, stigmatising and defeatist language can affect self-identification with labels that further alienate isolated patients, as I discuss below in relation to 'heart-sink' cases, 'blue bloaters', and 'pink puffers'.

use and description utilised by medical and folk knowledge. It is here that this research, particularly phenomenological contributions, can begin to address these inadequacies.

4.4 Phenomenology of breathlessness

> A physician is obligated to consider more than a diseased organ, more even than the whole man – he must view the man in his world.
> *Harvey Williams Cushing, 1895*

We all experience breathlessness at some point in our lives. From the fleeting sensation of needing to take a deep breath and fill our lungs after exercise, to the final breaths of a dying person, the range of causes and the felt experiences of breathlessness are vast. As argued above, I am focusing on pathological breathlessness (dyspnoea) to redress the lack of study of the experiences of the often preventable yet increasingly prevalent disorders afflicting a large proportion of the world's population (ATS, 2013). The seriousness and significance of being breathless, from acute respiratory events, through the psychological and emotional consequences of strangulation in intimate partner violence, to panic attacks, is irrefutable. We all have to breathe. Within minutes of the lack of oxygen, permanent cellular destruction and finally, death would result. This study is not about merely being breathless after exertion: it is about breathlessness as a threat to our very existence.

So, as essentially breathing beings who require oxygen to function within the world, the impact of pathological breathlessness will profoundly alter the life of those who suffer (Dodd *et al,* 2011; NHS England, 2016). With the tens of millions of the UK population suffering from a form of respiratory difficulty, from asthma to cystic fibrosis, studies of the nature and phenomenology of these experiences are essential. Significantly, the UK has one of the highest lung disease mortality rates throughout Europe and lung diseases are also more prevalent in deprived areas, reflected in the very high rates of health inequalities in the UK (British Lung Foundation, 2016). Examining the respiratory patient and their changed lifeworld is thus vital to understanding why this may be so, as well as highlighting the impact these disorders have upon their lives, the lives of their families, the community, and the wider population. Furthermore, rates of cardiovascular disease and non-respiratory cancers have dropped in the past decade, with significant investment in the study and treatment of those conditions (*ibid.*). With respiratory disease, rates have broadly stayed the same and so significant resources need to devoted to examining these disorders to understand why this is so, and to alleviate suffering from 'one of the most distressing symptoms' of illness: breathlessness (ATS, 1996; Nicholls, 2003; Abernathy and Wheeler, 1996).

The following builds upon the phenomenologically-guided idea that experiences of breathlessness do not purely rely on the stimulation or triggering of receptors; the patients' attention to their symptoms, their prior experiences and memories, self-understanding, cultural and social experiences as active agents skilfully coping in the world shape their experience of breathlessness and their suffering and distress (Dreyfus, 2014). The human being, as a body-subject who fundamentally engages with care towards entities in the world to realise certain projects or possible ways of being (*Seinkönnen*) will therefore have more than their embodiment altered by pathological breathlessness. Their entire world will be shattered and transformed as a result of the deterioration of their abilities. Possible projects, changed relationships to others, and the perceived hostility of medical practices, society, and the environment to seeking help are all hurdles to overcome within a world often unaccommodating to disability.

Yet, in the first instance we must ask, how do we arrive at a phenomenology of breathlessness? What can philosophy contribute to our understanding of the experiences of dyspnoea? One simple answer is that paying attention to the lived experiences of breathlessness discloses that pathological breathlessness differs vastly from normal breathlessness created by activity and exercise, with phenomenological description able to capture and disclose the impact of these experiences on the person and their world (Carel, 2015; 2016). The phenomenological method of suspending our preconceptions about the world, viewing the person as an embodied subjectivity within a connected network of meaning and significance with others in a shared world (*being-in-the-world*) overcomes any disease/illness, subject/object divide. As breathlessness experience can shatter this primordial connection to the world, to others, and to our sense of self through alterations to our embodiment, I'd suggest there can be a double benefit. This would be via opening an engagement can that can offer nuance to philosophy, and hopefully shed light on these transformations to experience that can improve our understanding and treatment of them.

4.5 Describing Breathlessness: The challenge

How does one first experience breathlessness at the onset of a severe respiratory illness? Initially, it may be gradual, feeling slightly breathless, wheezy, a tight chest perhaps (*cf.* Carel, 2008; Kalanathi, 2016). Running up the stairs becomes tiring, rest is needed to catch the breath, and then gradually lighter activities seem to trigger a cough, a struggle to breathe, inexplicable fatigue (Carel, 2008). Or the first breathlessness attack may be severe – an asthma attack that feels as if the airways are closing and one is suffocating. There are thus many ways that pathological breathlessness may announce itself. These seem to omit simple categorisation. However, philosophical analysis, I argue, reveals shared features of pathological breathlessness. Rather than the fleeting and uncomfortable feeling of needing to pause or draw a deep breath after a long run, first person descriptions of episodes of pathological breathlessness experience all share one distressing feature: the *on-going struggle to breathe*, whether triggered by minor movement, temperature or environmental changes, anxiety-inducing situations or a multitude of other factors. Even more troubling, is the fact that it can assail one at any moment, is difficult to control, and is never freely chosen (Guillick and Stainton, 2007; Ellison *et al.*, 2012). Lack of control looms large (Toombs, 1987; Carel, 2018).

For example, in cases where oxygen desaturation is severe, there are terrifying feelings of suffocating, losing control, dizziness and sometimes incontinence (Carel, 2016: 106). Experiences of such severe episodes of dyspnoea are often associated with dying: ‘it is not like running for the bus; it is not hiking in high altitude; it’s more what I imagine dying would be like’ (Carel, 2016: 110). These experiences, which are for the most part invisible to the outsider, when described phenomenologically contextualise and make intelligible to those who do not suffer from dyspnoea the content of these experiences and how they impact one’s entire bodily, interpersonal and world experience. The relationship between breathlessness and panic, for instance, becomes entirely understandable when we consider these facets of the patient’s experience.[71] One is literally fearful for one’s

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[71] Lobbying by the British Lung Foundation, researchers, clinicians and other organisations has contributed to new policies around integrating care for patients with long-term conditions and mental health problems

existence. Indeed, awareness of these experiences via first-person description can reveal to healthcare practitioners how the lack of integrated care lets down respiratory patients who struggle with untreated fatigue and panic. How can they meet all the various appointments in different localities when they struggle to travel distances between appointments, especially with the added barrier of not understanding that said distances may appear insignificant to those without such existential and mortal threat conditioning their experiences? Learning from their experiences can draw attention to the need to address their mental and social needs as well as the physical difficulties that they face, improving their overall quality of life and rates of comorbidity (Clark, 2017).

In short, the differing experiences of respiratory illnesses impact one's *being-in-the-world* differently to other illnesses, and thus demand different treatment. Integrated person-centred care is more appropriate for those with respiratory disease, for instance, as the patient is often too fatigued to attend various healthcare appointments in different locations and the fear of an attack often causes them to become housebound (see Chapter 6). Distances navigated alter their meaning and intelligibility for the patient as the lungs and bodily abilities are restricted and damaged. An appointment at the local hospital that was once 'near' can become 'too far' (Carel, 2016). Although the transformation of experience and difficulty reaching multiple locations may be shared in other illness experiences, such as with those who are wheelchair-bound, the close relationship between panic, anxiety and breathlessness experiences benefit from analysis to elucidate shared and differing features of respiratory illness and illness more generally.

Utilising philosophical methods of investigation also shines a light on the problems with aligning breathlessness experiences with other debilitating illness experiences. Pain and breathlessness are often seen as analogous, as both are distressing and share some felt elements alongside their negative impacts on the lifeworld of a person. For instance, 'total pain' and 'total dyspnoea' models incorporate a framework that categorises these

(BLF, 2016; NHS England, 2016; IAPT, 2016). However, many of these programmes are yet to be established and at a recent commissioning event many clinical leads expressed dismay at the shortage of knowledge in these areas for their staff, particularly in psychological help for respiratory patients (IAPT, 2016; 2017). The few existing programmes are being extended and new courses for practitioners begin in March 2017, although these are tailored to diabetes, COPD and other long-term conditions rather than purely respiratory diseases.

experiences: physiological, spiritual-existential, emotional, cognitive-psychological, and social (Saunders, 1964; Abernathy and Wheeler, 2008). Yet despite shared brain pathways activated in experiences of pain and breathlessness, feeling breathless isn't the same as being in pain, just as being in pain is not the same as being hungry or thirsty (Carel, 2016: 107). Analysing descriptions of the lived experience of these cases explicitly show us the limitations of such an alignment. To be breathless is distressing and frightening, but it isn't the same as having lower back pain, or a headache. It is a constant reminder of the threat of that if it gets worse, you could die (Williams & Carel, 2018).

So, we must return to the task at hand by beginning with what it *means* to be pathologically breathless. Drawing upon existing research on conditions such as COPD and various lung diseases, in the following I analyse the complex nature of breathlessness to supplement the accounts discussed above.

4.6 Embodiment

The Merleau-Pontian presentation of the body *as lived*, as that which grounds and shapes our perceptual experience, revealed in the first chapter how in illness our experiences are altered as the body loses its typical transparency through failures of smooth activity and the inability to carry out projects (Merleau-Ponty, 1962; Leder, 2016). Breathless experiences capture this fundamental perceptual connection between the world and our existence through opening up reflection on our altered embodiment, offering strength to arguing for a phenomenology of breathing and breathlessness. Our embodied experience, whilst mediated by perception and motility relies upon on the invisible features of our body: 'the autonomous rhythms of breathing and circulation, the stilled body of sleep, the mystery of the corpse' (Leder, 1990: 2). Hence to understand notions of self and existence we need to attend to these 'absent' horizons, particularly as they show up to us in a bodily breakdown. Indeed, Leder suggests that these automatic processes are often ignored by philosophers due to the involvement of respirations experiential absence in embodiment and experience (*ibid.*). That is, these processes are so close to us, making possible our fluid engagement with our environments and projects possible, that they are for the most part absent in daily, healthy existence (as argued in Chapter 1). Breathlessness stops one in their tracks as it threatens their very existence. It thus inhibits our lives, and so makes the absent horizons of the body readily apparent. The body stands out as an ‘I cannot’, something that is obstinate, conspicuous, in our way. The tool analysis of Heidegger, and the ability-to-be Carel discusses, is starkly revealed.

Furthermore, an adequate understanding of these patients must recognise their continual anticipation of more suffering, more pain, the fear of a collapsed lung or blocked airway, of not being able to take a breath, haunting every movement, even every anticipated activity. In short, the usual ability of the body to transform ideas and desires into actuality shifts: no longer can the body move to the background, ‘discarding itself’ to realize projects or possibilities in the here and now (Merleau-Ponty, 1962: 190). The body becomes present as the focus of attention. For instance, in cases of severe COPD, the relation between the past, present and future is altered to a series of recurrent ‘now’s; communication with others is cut off and one becomes imprisoned in one’s body. Merleau-Ponty quotes Binswanger, saying that the body becomes ‘the place that life hides away’ (*ibid.).* Illness becomes the ‘complete form of existence’ (Merleau-Ponty, 1962).

As Chapter 1 discussed, the body has an anonymous life that one can return to in reflection, leaving the personal life behind temporarily to attend to breathing or heart rate. This anonymous life underpins the personal life: ‘[t]he momentum of existence towards others, towards the future, towards the world can be restored as a river unfreezes’ (*ibid*.: 191). This is so even with the chronically ill or anxious patient, to some extent.[72] There are times when breathlessness and anxiety call one out of one’s absorption in one’s plans to instead return to this anonymous life of the body, paying attention to the breathing, taking deep and calming breaths to assess the severity or cause of the symptom (is it an anxiety attack? Is it due to exertion? Is it dangerous?).[73]

This temporary loss of significance due to pathological breathlessness can, however, be recovered when the body is opened once again

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[72] Chapter 5 analyses this relationship between breathlessness and *angst* in detail. The ‘violent disruption’ and removal of the person from their everyday roles and intelligibility is linked to the ‘call of the body’ and the ‘call of conscience’ respectively. Both produce a distancing effect, an awakening that one must attend to, and both can bring us to an authentic understanding of Being-towards-death (Carel, pers. comm.).

[73] This is analogous to anxiety as the call of conscience, and breathlessness the call of the body (see Chapter 5).

> 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 through the distancing effect that illness produces, the body never quite falls back on to 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 therefore always calling to me to respond and cope with things that currently present themselves to me. Bodily intentionality, for example, is directed towards the vista in front of me, or of consideration of my next task. This can lead to sorrow for the respiratory patient as the world shrinks, with increasing bouts of fatigue from a lack of oxygen that lead to less activity and engagement in the world (Guillick and Stainton, 2007). The freedom to act, and the ability to be called forth (solicited) to respond to the call of the world is gradually changed and in some cases, cut off.[74] This alteration to one's embodiment is always situational, but there is less control over what the respiratory patient can do and when they can do it, unlike in the healthy person :

> I may very well take myself away from the human world and set aside personal existence, but only to rediscover in my body the same power, this time unnamed, by which I am condemned to being. It may be said that the body is 'the hidden form of being ourself', 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)

With severe breathlessness, then, the possible situations open to the patient reduce as embodiment alters. These losses in potential abilities deepen when we consider that the body possesses its own form of intentionality, the motor intentionality outlined in Chapter 1, which is unified in the body schema and body image (Merleau-Ponty, 1962). So, the body schema, which orients me in my environment and enables me to move around without checking where my legs are (for example), changes with pathological breathlessness. The spatiality of the body, the lived space that is directly connected to the world capturing the connection between the body and the world, along with the inter-relatedness of bodily organs, shifts. We have previously seen how orientations such as 'near' or 'far' were not dependent on objective space. Instead, we used the Merleau-Pontian concept of body image as more reflective of the spatiality of the body. This

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[74] This shrinking is analogous to 'dying a social death' before their demise, and is explored in Chapter 5.

means that it is perfectly correct to describe distance in terms of objective measurement, but our understanding of our capacities and ourselves is framed in terms of our body image, and thus our understanding of what is near or far can be dependent on our embodiment. A journey to a pulmonary rehabilitation clinic appears easily accessible to the physician but can be too difficult for a patient who can no longer navigate a ‘small’ hill, or walk more than two hundred yards (Carel, 2016). Importantly, it is not just the perception of distance that is changed. The meaning of what is ‘near’ or ‘too far’ has altered. Two hundred yards becomes unintelligible as a short distance to the respiratory patient (*cf.* Toombs, 1987). With these changes to meaning, we see that perceptual changes, changes to social and linguistic norms, all therefore result from the illness.

Thus, perceptual experience, intimately bound up with intentionality, are significantly transformed. Recall that spatial awareness and movements show up to me through my directedness, intending towards objects and tasks in the world. So too with self-awareness, awareness of others, embodiment, the life world around us as shown up in culture, social norms, shared language and so forth; these are all imbued with intentionality. For example, the intentional structure of consciousness is related to our everyday, absorbed activities that take place in a surrounding world. This is the world of a specific culture, with gender expectations perhaps, or limitations on sexuality, a world that the patient intends towards/acts within: indeed, a world that in part shapes our possibilities.

As we saw in previous chapters, this spatiality of the body is constitutive of the first-person experience of the body. Such attention to the lived body further disclosed the habitual nature of embodiment, accounting for the significance and knowledge of how to use the inhaler, for example. However, two conditions necessary here are bodily continuity and integrity: I can count on my body to carry out projects so long as it is for the most part unchanged or uninhibited (Toombs, 1987). When the harmony between the lived body and the biological body is ruptured, the knowledge of how to carry out a project remains: I still know how to drive, swim, or run. Yet the biological body becomes obstructive and prevents these habitual movements from taking place. The loss of lung capacity prevents athletic endeavours, including running for the bus. The way that I understand myself, my body image, may be altered by the changes to spatiality (as the connection between the body and environment). My ability-to-be no longer includes being a hiker; the mountain no longer solicits me to be a mountaineer; I have to choose new possibilities, new projects.

Of course, the adaptable nature of the body allows for new habits to be created, of modifications to movement to occur; with practice, these habits become sedimented and part of the habitual body (Carel, 2008). For example, in pregnancy, I learn how to navigate the world with a larger, heavier frame so as not to walk into a table, or tire myself out going upstairs (*cf.* Young, 2002). In this case, the world still solicits me to act; the intimate connection remains although the performance of my activities and self-understanding may change. Breathlessness, however, shows a more violent disruption to taking up new possibilities, limiting day-to-day tasks such as washing, walking, and talking, navigating a flight of stairs (Guillion and Stainton, 2012; Carel 2013a).

Breathlessness in illness thus reveals this fundamental structure of embodiment. When motor intentionality breaks down in illness, our movements become conscious as we attempt and fail to complete those tasks we were habitually able to do. These motor intentions are 'inseparable unities of intentions and movements' (Merleau-Ponty, 1962). The *significance* of motor intentionality, of movement to human existence, is shown clearly through the breakdown of smooth actions often caused by dyspnoea. As discussed, our possibilities do not simply change (the ability to spontaneously go for a walk, or walk to the kitchen to make a cup of tea): simple movements are disrupted and brought to our attention, with the environment constricted by our altered embodiment. Our ordinary embodied freedom is revealed by our capacity to walk, to move freely. Thus, walking is not just functional: it is significant and meaningful through its links to freedom, independence, normality, and spontaneity. The ability to partake in such activities relies on the bodily capacity to be free to respond to the situation (bodily freedom), and the freedom to be solicited to act (concrete liberty) that is changed by disruptions brought forth by illness (Carel, 2016).

With disrupted embodiment that limits our ability to carry on our daily routines and movements that the reaction to environment solicitation was previously able to invoke, bodily freedom and concrete liberty can be removed. Depending on the severity of the breathlessness, this could cause temporary alterations to our habitual body, or in more serious cases, the habitual repertoire may shrink vastly. Thus phenomenological description, breathlessness reveals these meaningful relationships and our ordinary freedom, further displayed by the restriction of movement in social interactions whereby we cannot get out to work, meet people, or engage socially without help (Nicholls, 2003: 133). Indeed, the impact of the loss of control over one's body is often profound. These changes or losses are not just personal; they impact our social being and interpersonal relationships (Toombs, 1989). *Not* being able to calm my breathing, to control my bowels, to stop the spread of cancer (Lorde, 1980); fear others will see my panic, anxiety, hear the raspy breathing; the body betraying me in the most important bodily functions exposes my vulnerability and mortality to all.

This loss of control over one's body can be overwhelming: the sense that at any moment it could *not only* defy you, for example by the fatigue that overcomes you if you overdo things, *but also* expose this loss of control to other people. This 'exposure' may result from gasping for air, or an uncontrollable coughing fit that leads to the need to expel phlegm, despite this being socially unacceptable (Guillick and Stainton, 2007). The invisibility of the illness then becomes public in a way that causes reports of shame and stigmatisation, of losing the capacity to define oneself under the gaze of others who now can see and hear some small part of the illness experience (Sartre, 1965). Alienation from one's own self can thus appear (Dolezal, 2014; Ratcliffe, 2012; Svenaeus, 2012).

Further, the described alterations in being able to do things spontaneously, taking up past activities or new projects is also experienced as losing control over the body coupled with the resultant shift in others' perceptions, and can lead to a change in mood, temperament and connection to others. For example, one patient describes a loss of effectiveness that is harmful to their self-identification as capable and masculine (Guillick and Stainton, 2007). This often results in anger at the inability to do what they could do before or wanted to accomplish presently (*ibid.*). Another patient describes a change in identity and the onset of depression due to the stigmatising gaze of others witnessing episodes of breathlessness (Ellison *et al.*, 2012). This perceived objectification was reported to break down the connection they felt to others (see Chapter 5). Ultimately, changes to both the patients' lifeworld in terms of the shrinking of their social world and the alienating gaze of the other compound each other when potential action is curtailed, and the habitual body loses another smooth action, automatic and unconscious movement in order to fulfil some goal. This in turn alters the conceptualisation of the self, the experience as a person who can do this or that spontaneously (recall Merleau-Ponty's *I can*, or Heidegger's ready-to-hand analysis).

Wheezing, persistent cough, difficulty in drawing breath, chest tightness and shortness of breath are all experiences produced by asthma, the narrowing and inflammation of the airways (bronchi). The felt experience of asthmatics varies depending on the severity of the attack, subjective conditions such as whether the patient feels that they can manage the attack and have a sense of control (for example, with the successful and repeated use of medication in previous exacerbations), their current psychological state, the rapidity of the onset of fatigue from the struggle to breathe that may reduce their perception of control, and their current physical health. Thus, the unassailable onset of an attack, the struggle to draw breath, is shared across many breathless conditions. Exacerbations of COPD, lung cancer, and other respiratory disorders can be managed to a degree, by avoiding certain triggers. Control is a repeated theme across these disorders, and often feelings of control over the self are further stripped away by the stigmatising gaze of others, including those who care for them professionally (Guillion and Stainton, 2012).

For instance, COPD patients are often split into categories of 'pink puffers' or 'blue bloaters' depending on whether emphysema or bronchitis is the primary cause of their condition. These coarse descriptions have value insofar as they capture the physicality of the condition as it appears to others. The 'pink puffer' (emphysema) often has a pink or reddish complexion and 'puffs' whilst breathing. The extra exertion needed to get enough oxygen leaves them with significant weight loss and a barrel-chest shape, due to the muscles in the chest becoming larger in the fight for breath. The 'blue bloater' (chronic bronchitis) will have a slightly blue tinge to their lips or skin as the gas exchange increasingly is impaired, and the volume of the lung increases, thus appearing bloated. Although clinicians would not refer to the patients directly in this manner, a quick internet search brings up dozens of pages using these terms, including patient resources (see Chapter 5). To perceive oneself through the gaze of others in this way, particularly healthcare practitioners, is damaging to prevention, treatment, and patient distress.

4.7 Shared features: loss of control through breathlessness in COPD

In terms of experiences of respiratory illnesses, shortness of breath, difficulty breathing, wheezing, coughing, breathing difficulties with minor exertion, fatigue, and potential cyanosis from the inability to get enough oxygen and the inhibition of gas exchange are shared across patients of both pink and blue varieties. Dyspnoea has many shared features (also across different conditions) that strip the person of control over their breathing, and the stress and fatigue that are a consequence of the struggle to breathe can confound their ability to regain control. When one of the most important bodily functions for life is under threat, the vulnerability of patients who may have lost their energy, their voice, their ability to resist stigma, as well as the inadequate study and understanding of pathological breathlessness become obvious, and in serious need of attention.

Loss of control is particularly damaging to the lived experience of the breathless person and is linked to anxiety and panic attacks, or the vicious cycle of dyspnoea-panic-dyspnoea whereby fear of an episode of breathlessness can increase the sensation of breathlessness, in turn increasing the fear and anxiety with muscle deconditioning and further reduced mobility and increased isolation as a consequence (Bailey, 2004; Willgoss *et al.*, 2012; Howard and Dupont, 2014; Coventry and Hind 2007; NHS England, 2016). Further, the loss of some basic, fundamental abilities described phenomenologically as the sense of *I can* impact the breathless patient in complex ways that have repercussions for the visibility of patients both in medical care and wider society. For example, with the loss of voice due to severe breathlessness, or in the case of intubated patients in intensive care, communication is hindered and hence alienates the person further from the world of the other (Karlsson *et al.*, 2012). Ordinarily, with the power of speech intact, simple communication of our needs, wants and thoughts is taken for granted. With the loss of the power of speech, the relationship to others fundamentally creates a shift in the connection between what one can do, what shows up as meaningful and significant. The other

> no longer exists for me as an interlocutor, sought after or rejected; what collapses is the whole field of possibilities. I cut myself off even from that mode of communication which silence provides. (Merleau-Ponty, 1962: 188)

Silence is therefore not appropriately assignable to those with such severe breathlessness. They *cannot* speak, which magnifies their social invisibility (*cf.* Lorde, 1980). Indeed, as our identity is often shaped and dependent on the others with whom we share a meaningful relationship in the world, and as more and more possibilities are closed off, the ill person's identity as an embodied self, an agent in the world, is frustrated. Considering the breakdown of meaning and significance due to breathlessness, and the amplification of invisibility shown through these examples, we can make sense of the damage to the self through the non-recognition from others:

> A person or group of people can suffer real damage, real distortion, if the people or society around them mirror back to them a confining or demeaning or contemptible picture of themselves. Non-recognition or misrecognition can inflict harm, can be a form of oppression, imprisoning someone in a false, distorted, and reduced mode of being. (Taylor ,1994: 25)

Labelling people as responsible for their breathlessness, reinforcing stereotypes of poor, uneducated COPD patients from socially deprived backgrounds with no chance of recovery is thus to be rooted out through dialogue and the provision of compassionate and integrated care (see Chapter 6).

4.8 Invisibility through altered significance of objects

As explored, diagnosis of chronic or life-threatening illness often causes a sense of profound despair, loss, and meaninglessness. Experiences of anxiety and depression share these emotional features, felt at the core of one's being (see Chapter 5). The embodied interconnected relationship to the world, to others, to the sense of reality has changed through these life-threatening conditions, colouring everything from one's perception of the present and future to a bodied heaviness and ache of the heart. Interconnectedness is not merely one of me to you, or me to the world. My existence shows up in the world via objects that reveal my identity as a philosophy student, as a mother, as a therapist, even when I am not physically in my department, home, or therapy centre.

Heidegger captured how the presence of others in the world is often visible through the objects left behind that implicate a significance and connection to another *Dasein*:

> The structure of the world's worldhood is such that Others are not proximally present-at-hand as free-floating subjects along with other Things, but show themselves in the world in their special environmental Being, and do so in terms of what is ready-to-hand in that world. (Heidegger, 1962: 160)

We may here pause to ask that if this significance (*worldhood*) of other things is tied to the way the environment shows the existence of others to us through how they matter as objects or tools to be utilised, what could this mean for human identity for the housebound? Is the existence of the breathless patient damaged, their social presence seemingly eradicated when they are unable to participate in the cultural world of objects? That is, does chronically ill Dasein become invisible as the tools and equipment in the world that ordinarily relate to their existence evaporate, once these significations are no longer useful for the ill person? If I am no longer visible in the department or the therapy centre through the significant objects I use, what happens? This is complex to answer, but very important in identifying how social institutions can fail people who are unable to participate in the world of work, or typical social activities.

Heidegger's analysis of how the other shows up in the world as quoted above suggests a useful way of explaining why and how medicine and society fail to recognise the other who no longer takes part in the world: not just as a social being, but as meaningfully connected to significant entities in the world – tools and equipment that are intelligible for them (see Chapter 6 for further elucidation). When one can no longer participate in (for example) marathons, hiking or skiing, not only do these projects and the equipment used when partaking in them (the runner's gear and the fundraising motive, the hiking boots and the trails, the skis and the slopes) cease to be open to them: the people themselves become invisible by their absence. When this absence isn't just a case of John no longer running the Bristol half marathon, or attending any training, but spreads to John becoming housebound through increasing disability, it is as if he himself has become invisible, in his perception erased by the perception of society. This suggests a twofold impact: the activities *no longer can* elicit the action, so ultimately the breathless person's involvement is curtailed for good. This compounds the isolation and marginalisation through no longer being visible in the social world and the world of significant ready-to-hand objects that point to their existence.

4.9 Transformation

Illness, borrowing Merleau-Ponty's phrase, is a 'complete form of existence' that can have positive, edifying features. For instance, Nietzsche tells us that:

> I discovered life as if it were anew, myself included, I tasted all good and even petty things in a way that others could not easily taste them – I made out of my will to health, to life, my philosophy […] for pay heed to this: it was in the years of my lowest vitality that I ceased to be a pessimist: the instinct for self-recovery forbade to me a philosophy of indigence and discouragement. (Nietzsche, 1970: 10).

So, illness for him had transformative powers that were positive: in essence, inviting him to respond and reflect on not only his ill health, but more widely about life and meaning. He saw life anew, became more positive about it, re-valued it, in spite of his worsening sicknesses.

Carel's account of illness as a mode of 'ability to be' explores the positive elements that can come out of chronic illness: specifically, adaptability and creativity (2016). Indeed, I would suggest that *adapt*-ability is a fundamental feature of human existence; that is, for the most part people share the ability to respond to adverse circumstances in ways that enable them to skilfully cope with changes to embodiment (although see Chapter 5 for examples of mental disorders such as borderline personality disorder features that move from a coping mechanism to a maladaptive schema).

New ways of being that the ill person adaptively and creatively responds to in living with their illness bring forth their freedom to find new meaning and intelligibility with regards to the world and their place in it (Carel, 2013b: 348). For example, Paul Kalanithi (2016), a neurosurgeon diagnosed with metastatic lung cancer, has written about the changes to time and temporal experience he experienced due to the tiredness and reduced energy levels caused by his illness. 'I plod, I ponder. Some days I simply persist' (2015; *cf*. Carel, 2008). He has to modify his movements and speed with respect to relieving the severity of his breathlessness and does so by altering his habits and movements. Indeed, lived time may be experienced as slowing down; patients often report being trapped in the present, the future taken away (Carel, 2008). However, he can respond to these alterations: the knowledge of the time Kalanithi has left takes on new meaning and significance.[75] How much time is left to spend with family? Do I have enough time left to pursue certain goals? Indeed, a prognosis of three months in comparison to three years alters the salience of values and different goals (*ibid.*).[76] Both Kalanithi and Carel write in detail about how their prior goals and the values and goods previously pursued are changed by lung disease, with the meaning and significance attached to money and status lost in the face of one's fragile mortality, the threat of sudden finitude (*ibid.*; Carel, 2008). With three months, one may choose to spend time with friends or family. With a year, one may choose to travel, or finally write the book they always planned.

Taking up new goals and revaluations are further modified in terms of wellbeing in illness, of good days/bad days, and of relapse, which means for Kalanithi 'finding a way of getting back in the world' (2016). Thus, the individual has a certain level of freedom to respond to limitations placed upon them, further disclosing transcendental structures of human experience, including temporality, openness, self-interpretation, and embodiment, brought forth through the disruption that illness can cause. The ability to initiate action for the most part remains as long as the freedom to respond to the situation (bodily freedom), and the freedom to be solicited to act (concrete liberty) are in place (Heidegger, 1962). However, this is only until the illness, in this case pathological breathlessness, has become too severe. The patient as a self-reflecting agent bound to a meaningful world to respond to in terms of projects, activities and roles is inhibited and radically brought back to their embodied nature as the body restricts their prior ways of being-in-the-world (Carel, 2016). Even then, this inability to be, as a modification of 'ability to be', can invite philosophical reflection of what matters, of what other possible roles they can take up and inhabit; in essence, revealing the nature of human existence as able to respond to their facticity and take a stance on their existence, adapt creatively to limitations.

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[75] Further revealing the shift in the horizon of knowledge and understanding of disease as a physician becoming the lived experience of a patient, as I examine in Chapters 5 and 6.

[76] Carel also details how the time of diagnosis radically changes these experiences (2008; 2014).

As the lifeworld shrinks when the breathlessness gets too severe, for example in the later stages of COPD, goals can still be attained but via a conscious and pre-planned route to be able to monitor one's rates of breathing and check for any potential environmental triggers or issues that may exacerbate the condition. This 'conscious body management' is often used by patients in order to complete tasks and go about one's routines whilst undertaking breath control to mitigate against significant motor loss and the subsequent susceptibility to despair and depressive experiences reported in studies of severe breathing difficulties (Guillick and Stainton, 2007). Equipment such as inhalers, oxygen tanks and mobility scooters may be incorporated into the bodily schema of the patient to aid their abilities to act in the world.

However, not all experiences of breathlessness, nor illness in general, will have these positive elements as people respond differently to their illness, as well as some cases worsened by unaddressed mental health or other comorbid conditions. For example, feelings of unreality and perceiving the modified body somehow as a temporary imposter are often reported (Lorde, 1980). The 'real me' is sensed as located in the past, in the well individual prior to the pathological breathlessness. If I didn't have this condition, I would be free to be dynamic and authentic. This new 'me' is not real: it is corrupted, a 'shadow of my former self': 'I'm so tired of all this. I want to be the person I used to be, the real me. I feel sometimes that it's a dream and surely I'm about to wake now' (Lorde, 1980*:* 17). Thus, the subjective interpretation of one's condition is bound to the perception of severity, of extent of the damaged lungs, and of the social impact through marginalisation or isolation.

4.10 Impact of Altered Embodiment

We have seen how breathlessness experiences cause a shift in the lifeworld and embodied experience of the patient. They must find new ways of coping with their changes in their habitual repertoire and the closing down of certain possibilities e.g. no longer being a swimmer, dancer, or athlete. Indeed, the initial crisis of the condition often causes grief and loss and so it is important that clinicians are aware of the emotional needs that the patient may have by considering the experiences of these conditions illuminated by philosophical descriptions. This is not mere speculation; evidence shows that these descriptions match qualitative research and patient descriptions of their disorders patient's experience of illness and should be taken into consideration by medicine (Ratcliffe and Broome, 2013). Such a claim does not mean that doctors and nurses need to be trained as counsellors. However, they should know the therapeutic services that they can refer their patients to. This would not only alleviate suffering of the patient and help them process the catastrophic changes that they are undergoing; it would also have economic and social benefits (Smoller *et al.*, 1996).

The interplay between these varied elements is often underplayed or neglected in healthcare research (Nicholls, 2003: 123). Rather than illness responses explicable as emerging rational narratives (or trajectories) 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*.). This is evident in conditions such as chronic obstructive pulmonary disease: whilst illness generally progresses into worsening symptoms and further difficulties in living, day by day (even hour by hour in some cases), it is experienced differently in each patient.

Embodiment 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 their illness (as thrown projection). I now turn to experiences of comorbid mental health conditions, deepening the understanding of breathlessness experiences through phenomenological description of attunement, mood and *angst*.

CHAPTER 5: Breathlessness in Respiratory and Anxiety Disorders: The Problem of Differentiation & Comorbidity

> Fear and anxiety are not the same at all. One is an appropriate response to a real situation which I can accept and learn to work through just as I work through semi-blindness. But the other, anxiety, is an immobilizing yield to things that go bump in the night, a surrender to namelessness, formlessness, voicelessness, and silence.
>
> *Lorde, 1980: 6*

5.1 Introduction

This chapter applies a phenomenological approach to symptoms of breathlessness and panic anxiety in respiratory illnesses.[77] This is to unpick the philosophical significance of this common yet debilitating experience: pathological breathlessness. Using the key examples of respiratory disease (somatic) in conjunction with panic disorder (considered a mental disorder), I show why a phenomenological approach to the study of these experiences is needed. Moreover, this will highlight how the distinction between the somatic and mental realm comes under pressure when we consider the complexity of breathlessness experiences. This emerges from a considerable problem in contemporary healthcare: the disproportionate commitment to scientism in modern medical practice gives rise to a failure to adequately describe or account for the alterations in the lifeworld that the patient experiences. The physiological is thus prioritized over the holistic (Aho & Aho, 2008; Bishop, 2011). As a result, not only is the patient subject to unnecessary suffering, inappropriate treatments, increased failure rates in outcomes, and epistemic injustice, but also clinicians' knowledge, understanding, and treatment of co-morbid mental health conditions in respiratory patients is lacking and thus problematic (Carel, 2013: Toombs, 1987; Department of Health, 2010).

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[77] Please note that the majority of this chapter was published in the edited collection 'Existential Medicine' (Kevin Aho ed, 2018) in a slightly different format for which I was the first author (Williams, T., & Carel, H., 2018. Breathlessness: From Bodily Symptom to Existential Experience. In: Aho K, editor. *Existential Medicine*. London: Rowman & Littlefield International; Chapter 10). Some repetition may therefore be present from previous sections as this published piece came out of the research of this thesis. Thankyou to my co-author, Havi Carel, for permission to use this.

Such a worldview also contributes to communication problems between patients and healthcare practitioners, with structural, socio-economic, and institutional barriers reinforcing alienation and stigmatization (Bishop, 2011; Mahler & Harver, 2000; Johnson *et al.,* 2014). It also occludes the complex, shifting nature of breathlessness. This causes its features and temporal, multisensorial nature to be overlooked. Such oversight contributes to misunderstanding and intelligibility of these illnesses in the context of socio-economic and institutional power imbalances. These negatively impact the patient, their relatives, and the perception of quality of life.

As a result of the prioritisation of the physiological, I suggest that patients are subject to unnecessary suffering, inappropriate treatments, increased failure rates in outcomes, and epistemic injustice (Kidd & Carel, 2014; Critchton *et al.,* 2016). In their study of epistemic injustices in healthcare, Carel and Kidd explore how first-person first experiences are regarded by those in positions of power and authority (Carel & Kidd, 2014). This of course includes clinicians, but also the government, policymakers and those within economic decision-making that allocate funding and resources to tackle illness and disease. Are patients believed and trusted, they ask? Or are their descriptions and testimony disbelieved? The results are a sad indictment of systematic failures: '[e]vidence from social psychology, health economics, patients organisations, and healthcare research show that what patients say is more likely to be misunderstood, ignored, or rejected than reports from other people' (Carel & Kidd, 2014).

When clinicians' knowledge, understanding, and treatment of co-morbid mental health conditions in respiratory patients is inadequate, it is not surprising that we see exacerbation of already complex and debilitating health concerns. Research shows that patients' socio-economic, 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). I thus argue that socioeconomic status is part of patients' lifeworld and therefore plays a constitutive role in their wellbeing (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 as a coping mechanism (Wilson, 2006; van Manen *et al.*, 2002). One study found anxiety and depression rates of 80 per cent in COPD patients who smoke (Kunik *et al.*, 2005). As stated in the introduction many prisoners suffer from smoking-related disorders as well as mental health conditions, both of which are under-diagnosed, alongside restricted access to pulmonary rehabilitation, an efficacious intervention for breathlessness discomfort (Turner and Jefford, 2013; Department of Health, 2010; Social Exclusion Task force, 2010). Paradoxically self-reported justifications of smoking often centre around stress and anxiety relief, when smoking infact exacerbates these conditions through its negative effects on the body and to health.

Focusing on phenomenological descriptions of the person as *being-in-the-world* redresses such an atomistic, inadequate presentation of chronic illness in all their complexity. Indeed, this framework captures how the structures of experience and the possibilities of certain experiences are changed in patients with these symptoms and illnesses (Carel, 2018; Ratcliffe, 2016). Analysis here will be aided by examined existential notions of anxiety alongside clinical and psychological (mis)understandings. Moreover, this approach can help explain the ‘problem of differentiation’ whereby clinicians and patients both struggle to distinguish between dyspnoea caused by respiratory illness and dyspnoea caused by anxiety. The shifting nature of the experience thus incorporates much more than discrete physiological or mental components, as I illustrate below.

Ultimately, I show that phenomenological description and explanation is indispensable to our understanding of the difficulties faced by patients beyond diagnostic lists of symptoms and aetiology. Attention to the lifeworld of the patient is essential to understand patient experiences of breathlessness, and to make their experiences of breathlessness and of healthcare a focus of research from which to glean potential improvements (as I outline in policy recommendations below). These claims are not based on purely theoretical considerations. Drawing on case studies and prior clinical experience from IAPT Primary Care Mental Health practice in a charitable setting, I highlight the problems in short-term, evidence-based interventions that are delivered in standard Primary Care practice. This will be compared to the resources that the holistically focused charity offered to patients via attempts to treat the whole anxious person: that is, also addressing patients' health and socio-economic needs and their understanding of their illness.

With this, I offer evidence for that claim that the reconceptualization of breathlessness disorders in phenomenological terms will contribute to improved patient care, reducing misunderstandings and epistemic injustice, and improving the ability to address the interrelated issues that arise from these illnesses. This is important. Many studies show significant barriers in place for those with physical illnesses co-morbid 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 & Higginson, 2008). 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, 2014). In short, I argue that a phenomenological framework can be supplementary to the provision of medical knowledge and understanding of the impact of breathlessness on physical and mental conditions that go beyond present dichotomous presentations. This is to avoid the compartmentalized treatment of these illnesses in specific healthcare fields that do not offer holistic care, leaving many features of their illness untreated. Without the reconceptualization of breathlessness disorders in phenomenological terms, patient suffering, reported misunderstandings and injustices, and missed opportunities to address the inter-related issues that arise from these illnesses will continue.

5.2 Breathlessness in medicine and mental health, from symptom to experience

We all become unwell during our lifetimes, and in cases of 'physical' and 'mental' illnesses, breathing is often disrupted, sometimes irrevocably so. The ability to breathe underpins human life and is vital in all our activities. Not only do we unconsciously alter our breathing when talking, moving, but we can attempt to control our breath to dive, avoid inhaling the toxic fumes around cities, *and* to calm our panic when we become anxious. In people with asthma, lung diseases, and cystic fibrosis, this struggle to get air can be a mortal threat.

Imagine sprinting up a few flights of stairs and getting out of breath. Now imagine feeling that *all the time*. When you can't catch your breath; terror, panic and suffocation overcome you. Therefore, anxiety often co-occurs due to this constant threat of 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 (World Health Organisation, 2016). This invisibility stems in part from stigma attached to breathlessness (associated with smoking) and to mental illness, due to perceptions of responsibility and weakness of will (Crichton *et al.,* 2016). 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).

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? The answer is no. Breathlessness is a unique medical symptom and experience that 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.

When a mental health diagnosis and a physical disorder co-exist in the same patient, things become even more complicated, with failures to diagnose or treat at the first instance of particular note, as a consequence of the notion that patients with mental health issues cannot speak with authority about physical ailments:

> I ruptured my ankle tendon and couldn't walk as a result. On a visit to hospital, the nurse looked at my medical history, and then refused to medically examine my ankle, saying I should see my Community Psychiatric Nurse. I then had to visit another doctor to get my ankle treated. This is another example of medical staff assuming my physical health problems aren't really there and are just manifestations of anxiety. (Anonymous, Rethink Mental Health Summit, 2017).

Such reactions are instances of epistemic injustice (as first studied by Miranda Fricker). When such harm is caused to the patient in terms of their 'capacity as a knower' via testimonial or hermeneutical injustice, 'epistemic injustice' is appropriately labelled. This includes testimony that is ignored, disbelieved, and discounted. Despite the explosion of work done in this area, these biases persist, and consequences include patient marginalization, misdiagnosis, and stigmatization. For patients with comorbid breathlessness and mental health diagnoses, it is thus vital that considerations of their silencing and marginalisation is acknowledged in the clinical encounter.

For example, health anxiety, a common anxiety disorder previously known as hypochondria, often includes experiences of breathlessness, and is notoriously difficult to treat on the one hand; and on the other, medics must be aware that patients with poor mental health are still capable of suffering from (and describing) physical problems. This understanding and acknowledgement would help remove epistemic injustice as well as barriers for diagnosis and treatment. Again, I suggest that the problem lies with the theoretical underpinnings of mental disorders carving nature into psyche and soma. The patient with health anxiety 1. finds the source of threat as within one's own body whether cognitive or affectively misinterpreted rather than as a fear of something outside the body; and 2. due to the body 'being the medium for having a world', they cannot escape from their embodiment and focus is continually brought to the perceived bodily breakdown and betrayal which reveals our fundamental nature as embodied subjectivities. To help these patients to make sense of these experiences, and to make them intelligible to us as thinkers, we must follow the phenomenologist. A 'return to the things themselves' of how the anxious and fearful phenomena shows up for the patient. In doing so we would discover three common features:

1. *Threat from one' own body*, comparable to the bodily doubt of Carel discussed in Chapter 1 (2008; 2018)
2. *Threat of and from others* in the form of judgement, shame, and stigma but also from the environment, smog, pollution (see Chapter 6)
3. *Threat of and from a passive, meaningless world* characterised by unhomelike being in the world (Ratcliffe, 2018; Svenaeus, 2000)

Breaking it down in this way shows that here, as in panic anxiety, the threat of breathlessness can be viewed as a threat with both an internal and external source, and that panic attacks thereby alienate the patient from their usual being at home in the world, with the threat of the one's own self felt as a bodily or brain (as neurochemical) betrayal. Even when the experience has been dismissed by the practitioner as a misinterpretation by the health anxious, we can make sense of these experiences and come to a shared understanding of what is going on for the patient, thereby breaking down communication barriers and avoiding injustices and misdiagnosis.

Thus, breathlessness is a significant and common medical symptom that unsettles the distinction between somatic and mental symptoms and disorders. Utilising phenomenology, then, I want to give voice to these silenced experiences, looking at the impact of respiratory illness and anxiety on our personal lives and self-identity. This focus reveals insights into these life-changing ways of existing. I suggest that the shockingly low rates of diagnosis and treatment are related to inadequate clinical and public understanding of these disorders, knowledge of symptoms, the impact of social deprivation, and poor air quality in our cities.

Treating the mind and the body as separate entities medically is an antiquated form of healthcare and indeed a failure to these patients who often suffer from both anxious and respiratory symptoms that are not easily distinguishable (Smoller *et al.*, 1996). These cases demonstrate that the whole person, not a body or a mind, is affected. As I have argued in previous chapters, we *are* our bodies, and the massive rates of co-occurrence of breathlessness in respiratory and anxious experience reveal this. Indeed, I further suggest that there is a potential power to the illness and anxiety experience to awaken an awareness that maybe the way we are living is damaging to us (see also Chapters 3, 6 and 7). For example, air pollution, distorted work/life balance and so forth are making people ill, disrupting their usual habits and daily life, and this might invite philosophical reflection into ways of existing (Irigaray, 1999; Carel, 2012; Škof, 2018). Confronting and working through this can give us an opportunity to grow as people. Attention is demanded to the importance of clean air, the breath, caring for our lungs, wellbeing, others, and the environment, leaving a healthy legacy for future generations. Respiratory diseases can be prevented and de-stigmatised if we chose to recognise and explore this silent invisible suffering and its significance in revealing what it is to be a human being. The seriousness and significance of being breathless, as argued in Chapter 4, is thus irrefutable.

As we have seen, oxygen starvation leads very quickly to irreversible cellular damage and ultimately, death. Thus, this study is not about merely being breathless after exertion; it is about breathlessness as a threat to existence. As Carel says, ‘it is not like running for the bus … it’s more what I imagine dying would be like’ (2016: 110). Further, I show below that the high rates of co-morbid respiratory illnesses and anxiety disorders offer powerful evidence of the failure of medicine, psychiatry and psychological practice to not only adequately understand, explain and treat these illnesses, but also the problems in differentiating attacks of dyspnoea (episodes of pathological breathlessness) are unveiled. They hint that treating anxiety disorders as ‘mental’ phenomena and respiratory diseases as ‘physical’ belies an inadequate understanding of what it is to be human, and what illness experience *is*.

We have seen how breathlessness is typically characterized in both medicine and lay knowledge. As argued above, physiological components are bound to a wide variety of subjective and cultural ideas about breath, and thus may vary considerably. Although characteristic sensations included shortness of breath, wheezing, struggle inhaling/and exhaling, and a struggle to breathe, leaving a hunger for more air (Carel, 2014). Not every episode had the intensity or included every sensation, demonstrating the complex and shifting nature of these life-changing experiences (Abernathy and Wheeler, 2002; Smoller *et al.*, 1996; Lansing, 2009). Categorisation of breathlessness in terms of symptoms is therefore inadequate: breathlessness is more properly understand and explained as an experience with a range of overlapping features. Chapter 4 in particular, detailed the fluctuations and temporal factors, and complexities of these breathless experiences, further lending evidence to this move.

It was why I argued that ‘breathlessness’ needed to be clarified conceptually and through phenomenological analysis. These types of investigation can assess whether the term captures a common feature (for corresponding clinical utility), or if the experiences differ so much that we must revise and rework our conceptualisation of breathlessness and the clinical understanding of this. Understanding, defining, and labelling different types of breathlessness is important so that clinician and patient can differentiate between different types of breathlessness to prevent misdiagnosis, unnecessary treatment, and to further our knowledge to match reality (Chanarin, 1987). Seeing it as a symptom is inadequate. The picture is further complicated with co-morbidity with anxiety. As I show, it changing experience informed by, and informing anxiety.

5.3 Anxiety and Breathlessness

Studying breathless and anxious experience exposes the problem of medicine's, psychiatry and psychology's attitude to a person's illness that currently often results in the reduction of that person to biological facts and processes that split the body from its subject, the soma from the psyche (see Chapter 1). This is demonstrated clearly within the phenomena categorised as psychosomatic illnesses, as noted above. To recap, medically unexplained symptoms, such as chronic fatigue syndrome confound medicine's typical characterization of illness and disease because there is no discernible pathophysiological entity or bodily dysfunction (Bullington, 2013). Additionally, many mental disorders themselves are neither fully distinguishable from physical illnesses as they may include symptoms such as breathlessness, rapid heartbeat and so forth (Ratcliffe, 2015). Does this mean that the separated psychiatric, psychological, and medical domains are founded on a mistaken conception of the human being? I have suggested so.

Indeed, psychiatric descriptions of mental disorders, specifically anxiety disorders, continue this separation of the mental from brain states that cause 'faulty' thinking and maladaptive behaviours due to neurochemical misfiring, or imbalances. However, the official definition of anxiety disorders, from the Diagnostic and statistical manual of mental disorders (DSM V TR, 2013) remains quite vague (until one looks through the extensive symptom lists):

> Anxiety disorders include disorders that share features of excessive fear and anxiety and related behavio[u]ral disturbances. *Fear* is the emotional response to real or perceived imminent threat, whereas *anxiety* is anticipation of future threat (DSM V, 2014).

Psychological theories, conceptualisations, and treatment for anxiety fare no better. Here, anxiety is characterized as being caused by faulty information processing, leading to false beliefs, negative thinking, cognitive distortions, and biases. These lead to thinking patterns becoming sedimented, maintaining both the anxiety experience and avoidance behaviours (Wells, 1997; Beck, 1967; LeDoux, 2015). Reductive, alienating, and far too simplistic, where is the lived experience of the person that undergoes such disturbances? Indeed, where is their subjectivity and personhood?

I suggest philosophy can help further our understandings and thus help out here. Undoubtedly, anxiety already has a complex history in philosophical thought; thinkers such as Kierkegaard (1813-1855) and Heidegger (1899-1976) have written extensively on the power of anxiety in shaping human existence. The focus on the utility of anxious feelings in providing an opportunity to pause and reflect on our lives, on how our lives *could* be, has, I argue, been stripped away in favour of scientific explanations and classifications of types of anxiety and how to treat them efficiently. It alienates the person from their experience, from being able to understand, comes to terms with, and take a stance upon their anxiety. In other words, the potentially revealing aspects of anxious experiences in telling us something is wrong in the way that we live, rather than ‘a catastrophic misinterpretation’ of bodily events or outside events, has been lost. In this way, I suggest that analysing anxiety phenomenologically is thus an important step to awakening a detailed understanding of the co-morbid effects on the human being and their way of existing. Helping to understand why it may have occurred rather than present it as an irrational force out of one’s control. Again, this doesn’t mean disengaging from science: psychiatric, psychological and pharmacological interventions all still have their place. It is about augmenting our understandings to ensure adequate knowledge. Offering alternative supplementary descriptive tools when dealing with explanatory gaps in our understanding.

To be clear, this chapter is not only about breathlessness in physical or mental disorders. It includes these studies, but also picks up on the presence of intertwining features in co-morbidity. Shared characteristics between anxiety and breathlessness include variations under the proposed umbrella term mentioned above: shortness of breath, chest tightness, air hunger, feelings of suffocation, fear of dying. Intense fear of death and of losing control, hopelessness and confusion when experiencing a panic attack also are frequently reported (Willgoss *et al.,* 2012). With the progressive and irreversible nature of COPD and with 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 in these patients (around 50 per cent) compared to the general population (around 6 per cent). Conditions such as depression and agoraphobia are more likely (Smoller *et al.*, 1996). Effects range from restricted mobility, lower reported quality of life, worsening over-all health and functional disability, often as consequences of anxiety, even in those without respiratory disorders.

Through this, we can thus reveal four major themes in co-morbidity. Firstly, a problematic relationship with breathing: anxiety is not only a cause of breathlessness, nor just a symptom. Anxiety can sometimes warn of low oxygen prior to the experience of breathlessness, in addition to causing episodes. It can thus prefigure the somatic conscious experience (Eccleston, 2016). On the other hand, idiopathic anxiety episodes often occur in social situations such as visiting crowded spaces, worries about lateness or being lost, and so on. This often leads to 'the vicious cycle' whereby anxiety and breathlessness trigger one another and patterns of panic and fear lead one to reduce activity, social isolation, and resultant muscle and lung deconditioning that worsens health and increases the likelihood of episodes of depression (Willgoss *et al.*, 2012; Eccleston, 2016): '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. The COPD feeds the anxiety and the anxiety feeds the fear' (Willgoss, 2012: 565). These vicious cycles indeed reinforce the 'big five': physiological, emotional, cognitive, behavioural, and situational binds, making it much harder for the patient to break free (Clark, 2016). Behaviour and states such as hypervigilance the patient exhausted and vulnerable (Bailey, 2004). Furthermore, breathlessness conditions such as asthma are more common in those with co-morbid anxiety and depressive symptoms, with a higher prevalence in women, pointing to gendered and social contributions to the risks and development of these disorders (Kewalramani *et al.,* 2008; Kirkengen, 2010; Hegarty, 2014).

Secondly, anxiety, like severe breathlessness, is often experienced as uncontrollable, with an almost constant fight to regain control. One might attempt to regain control by sitting quietly and practicing 'self-talk' (Willgoss et al., 2012), employing coping mechanisms such as carrying water to sip when the mouth becomes dry, carrying spare medication, sitting close to exits, and so on. These behaviours may alleviate some of the stress in the short-term, but associations between the strategies and the actual prevention occurrence of the event become distorted, so that elements of magical thinking come into play: 'the water prevented an attack', or 'sitting close to the fire exit allowed me to enjoy the play'. This maintains the anxiety or panic disorder, as the patient is never able to challenge the beliefs they have about their anxiety and its relationship to their condition and the relative power of their coping mechanisms (Wells, 1997). Of course, treating panic disorder is more likely to be successful when one can employ evidence-based treatments such as cognitive behavioural therapies. However, in patients with chronic lung conditions this can be harder as care is often short-term and not easily accessible, due to the barriers between clinical domains (see policy recommendations in the Conclusion) has its own specific location and expertise (NHS England, 2016). The challenge, then, is to not only change current legislation, bridging the divide between 'mental' and physical clinical practice and redress the lack of training; it is also to develop clinical knowledge of the intimate relationship between these illnesses and how they impact the person as a whole, not as parts. That is, failure to treat anxiety as co-morbid shows the problematic of healthcare in failing to provide holistic, integrated care.

Thirdly, the life-changing and life-limiting nature of these experiences. Both breathlessness and panic anxiety attacks are often experienced as traumatic and isolating, with some patients referring to them as 'near-death experiences' (Willgoss *et al.*, 2012). The feelings of being unable to breathe adequately, being smothered or unable to escape often caused meta-worry (worry about worry). Indeed, the persistent worry and sense of impending doom overlaps with another anxiety disorder, generalized-anxiety-disorder (GAD), and so multiple morbidities can once again feed on one another and reinforce feelings of loss of control. Not even sleep can offer a respite in some cases: those patients with overlap syndrome (sleep apnoea and COPD) suffer from nocturnal hypoxemia. A consequence of this startled awakening (and disturbed sleep) is described as feeling suffocated, choking, and terrified that they may die. As Alkhuja notes, these episodes 'may carry daytime anxiety to night-time, making anxiety as a 24-h ongoing disorder' (Alkhuja, 2013: 82).

Additionally, there is also the perceived threat of the world, heightening fear and reinforcing withdrawal from the world. When the triggers of panic attacks and anxiety are vague and the episodes idiopathic, the patient does not know when the next attack will occur, and we can understand this in terms of the world itself becoming an object of fear. This makes sense of why some anxiety patients become housebound even when their breathlessness is not due to 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 patient 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 takes over despite no discernible underlying pathology (Svenaeus, 2001). Externally, the world can be viewed as a threat with connotation of feeling unsafe due to the world's hostility and as a potential trigger for 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 stigmatising 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 judgement when undergoing a breathless, panicked episode through to medical stereotyping of having a mental health diagnosis. Further avoidance and withdrawal from social, medical, and everyday situations can lead to agoraphobia and becoming housebound, changing, and restricting lives and future experiences.

The implications here should be apparent. Psychiatric and psychological conceptualisation of and treatment for anxiety represent difficulties related to separating symptoms into cognitive, affective, physiological and temporal categorisations, which I contrast with the lived experience of these conditions as arising from, and affecting the lifeworld of, the patient. Studying these experiences reveals the interrelated 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). I suggest that this is where phenomenology can supplement medical accounts.

The focus on the productive role of anxious feelings in providing an opportunity for reflection on how our lives could be has been stripped away from the perspective of clinical psychology and psychiatry, which view anxiety as a dysfunctional condition that must be treated, with little consideration of its existential meanings and its impact on the patient's agency and self-understanding (*cf*. NICE, 2011; Haugdahl *et al.*, 2016). 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 for reflection on 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 all play 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 co-morbid symptoms and increase feelings of agency, but this is only possible through exploring these experiences in terms of their lived world and subjective interpretation. This is a world that includes environmental and socio-economic factors and how these affect an autonomous agent who understands how their illness alters their life. They can then reflect on the transformation of 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 behavioural therapies (Teachman *et al.,* 2010). Again, the physiological focus means that the symptoms are to be treated whilst the existential meaning remains 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, social and political instability. More should be done to recognise 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).

5.4 Mood & Anxiety in phenomenology

> Arguably, Heidegger's most important contribution to the history of philosophy, in addition to entrenching the subject in its world and thereby overcoming the subject/object dualism, is the primacy that he accords to mood in his analysis of human existence. Through mood humans gain access to their world, to themselves and to their relations with others in the world in a manner that is prereflective and unthematic.... [M]ood, especially the mood of *Angst*, has the power to reveal the whole: the whole of how one is in the world and the whole of the world at large.
>
> *(Elkholy, 2008: 4)*

In this section, I will detail Heidegger's concept of *angst*, because it is extremely relevant to a phenomenology of breathlessness, and because it is central to studies of philosophical studies of anxiety. As one philosopher put it, 'when I read the passages in *Being and Time* devoted to Heidegger's existential analysis of *Angst,* I nearly fell off my chair!' (Stolorow, 2016: 14). We have seen above in Chapters 1 & 4, in Heidegger's presentation of *angst*, possibilities, projects and our everyday living are radically altered and meaningful existence collapses. This is not a disembodied experience: rather, Heidegger's conception of *Befindlichkeit,* (i.e. how 'one finds ones-self in the world' as revealed by *Stimmung*) is the way that being-in-the-world is disclosed in Dasein.[78]

Stimmung, mood, or disclosive affectivity, thus implies the central significance of the body in human experience despite the lack of analysis of various appendages and bodily capacity within Heidegger's work. This is writ large in the experience of ontological *angst* that can also be revealed, for our purposes, by ontic manifestations as examples of fleeing from the ontological experience. These moods, or attunements, are not mental intentional states accessible only to the conscious subject (Heidegger, 1962; Ratcliffe, 2016; Moran 2000). They colour our interactions within the world and shape how things show up for us, how things matter to us. Thus *Befindlichkeit* reveals that, as humans, we are always already thrown into a situation amongst meaningful objects, and projects, with

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[78] *Stimmung* is often translated as mood but might more accurately be thought of as attunement or disclosive affectivity.

an understanding of who we are derived from enculturation, which reveals our skilful coping in a referential totality *with others* (Heidegger, 1962: Stolorow, 2016).

I want to avoid a charge of reifying anxiety disorders as something that may be better be thought of as ‘problems in living’, thereby inappropriately interpreting the existential conceptual power of *angst*. For instance, Robert Stolorow charges Matthew Ratcliffe with providing a phenomenology of depression that makes the mistake of ‘traditional psychiatric diagnosing (Stolorow, 2015: 2-3). Stolorow suggests that,

> Ratcliffe does with psychiatry’s Diagnostic and Statistical Manual (DSM) something similar to what he does with Husserl’s term bracketing; after commenting on its inadequacy and questionable validity, he proceeds to use two of its categories—‘‘major depressive episode’’ and ‘‘major depressive disorder’’—as the organizing psychiatric framework for his studies. Recent research has called into question the most recent DSM’s creation of new diagnostic entities and categories that are scientifically unsubstantiated and that over-pathologize vulnerable populations such as young children, the elderly, and the traumatically bereaved. (*ibid*.)

Stolorow’s charges seem unfair: he takes great offence at the title of Ratcliffe’s book invoking depression, interpreting it as conflating a complex and wide-ranging horizon of experiences into a reductive category. I cannot offer a full defence here, but needless to say, this attack misunderstands Ratcliffe’s project. Perhaps Stolorow is as guilty of narrowing an understanding of a rich and nuanced account of depressive experiences as he suggests Ratcliffe to be.

However, I do agree with Stolorow that,

> fundamentally, the DSM is a pseudo-scientific manual for diagnosing sick Cartesian isolated minds. As such, it completely overlooks the exquisite context-sensitivity and radical context-dependence of human emotional life and of all forms of emotional disturbance. Against the DSM, Atwood and I (Atwood and Stolorow 2014) have contended that all emotional disturbances are constituted in a context of human interrelatedness. One such traumatizing context is characterized by relentless invalidation of emotional experience, coupled with an objectification of the child as being intrinsically defective. (Stolorow, 2015: 3).

We might see in both the child of Stolorow's example, and a COPD patient with co-occurring anxiety – a smoker from a poor, socially marginalised population, struggling to articulate their experiences of both physical and mental conditions that both overlap and interact. So we *can* give a description that doesn't have to pit the ontic and the ontological, the particular manifestation and the existential structure, against one another. It is therefore instead sensible to exercise caution in my analysis of anxiety disorders. However, the co-occurrence of anxiety, panic disorder, and breathlessness is not subject for debate. Rather than debate its ontological status, we should look to its epistemic and ontic/existential impacts to do the relationship justice.

With this in consideration, we can return to an analysis of existential notions of anxiety. *Angst* is differentiated from fear, an experience that is related but distinct for Heidegger, as it is for some contemporary accounts of anxiety (Heidegger, 1962; DSM V-TR, 2013; Wells, 2007). Fear is fear of *something in the world.* With phobias, the fear has the structure of aboutness or intentionality – I am fearful of being in a small space, of flying, of others in the world. In contrast, anxiety does not have a definite correlating object or fear. It is a general feeling or mood unique to the *Dasein*. If asked what one is frightened of, an anxious person might reply 'nothing', despite being gripped by a pervasive feeling of dread. This is because the affective experience of *angst* reveals our encounter with the nothingness at the root of our existence, providing us with an opportunity to examine what it is to be a human (Heidegger, 1962).

Heidegger's ontological conception of anxiety brings to light important phenomenological features that map onto anxiety disorders as psychology and psychiatry circumscribe them, but in a deeper and more far reaching way than normally considered. For instance, the collapse of meaningfulness or of practical significance is accompanied by the feelings of not being at home in the world, of uncanniness (Heidegger, 1962; Sveneaus, 2000; Stolorow, 2014). For Heidegger, such a collapse is related to authentic Being-towards-death. This conception of death, as previously defined, is not the passing of a physical organism. It is the 'distinctive possibility that is constitutive of our existence – of our intelligibility to ourselves in our futurity and our finitude' (Stolorow, 2014: 4). Death then shapes our life, and the experience of anxiety brings us close to this ultimate 'impossibility of possibilities' through the collapse of *anything* being able to matter to us at all. In this state, we are brought face-to-face with our death. The anxiety of the breathless patient is horror of being, but also of non-being. Paralysed by *angst* as well as gripped by de-personalisation, the threat of death is mixed with *having to* exist, fighting both being and the threat of non-being as a double expression of anxiety. This is similar to Stolorow's account of trauma and death: the 'illusion of everyday life that evade and cover up the finitude, contingency, and embeddedness of our existence and the indefiniteness of its certain extinction' is revealed by the threat of death posed by pathological breathlessness and its bedfellow, anxiety (Stolorow, 2014: 4).

Phenomenological conceptions of anxiety as angst can therefore be useful. This is twofold. Firstly, they offer a nuanced account of angst as disclosing 'the horror of being' and the loss of practical significance of the everyday world (like Ratcliffe's existential hopelessness in depressive experiences). This also gives justice to unique situation of the individual that considers socio-economic and structural contributory factors to these experiences. That is, these accounts offer descriptive effectiveness by revealing the context and historicity of the person and their situation. Secondly, these conceptions of anxiety can also allow for pathological accounts that are not subject to a simplified psyche/soma split. This matter because breathlessness and the incidence of anxiety disorders are tightly bound together (as argued above). Anxiety is not a discrete mental condition that can be easily separated from the emotional, physiological, spiritual, existential, and psychological realms. In short, the embodied subject, the entire person and their embedding in the world, is affected.

Debate exists around how exactly to define the 'nothingness' that the experience of anxiety confronts us with (Moran, 2000; Svenaeus, 2000; cf. Levinas, 1997). Remaining within the remit of exploring anxiety in medical and philosophical examinations, I will describe it in the context of an experience of *angst*. During an experience of anxiety, the world as a totality 'slips away'. Dread overcomes one, as everything in the world becomes alien and strange and one's attention to and concern with familiar objects and environment is replaced by indifference:

> [I]n the very drawing away from us as such, things turn toward us. This drawing away of everything in its totality, which in angst is happening all around us, haunts us. There is nothing to hold on to. The only thing

> that remains and comes over us—in this drawing away of everything – is this ‘nothingness’. (Heidegger, 1962)

Just as in the dark we see nothing, but are still seized by dread due to the awareness of things ‘out there’ in the world that could pose a threat, in anxiety the entire world is still present even though it has been stripped of its meaningfulness and significance. Thus, the nothingness or void that has been revealed is not located in physical space, but in making sense of the significance of the world. The appearance of *unheimlich*, the uncanny, elaborated upon by thinkers such as Svenaeus (2000) dislodges us from our world of concern, social roles, or current projects. Can such experiences as a phenomenological notion map onto anxiety as defined in the DSM or other classification manuals? I suggest so. Certainly, cases of specific phobias or of social anxiety for example are excluded here and are more akin to the ontic descriptions of fleeing from owning up to one’s self out of absorption in the world and interpreting the self in terms of *das man* (Heidegger, 1962: 164-5). However, the loss of significance and looming threat of the others and/or the world can cause momentary or enduring lapses into the sense of *angst* that Heidegger describes. Indeed, GAD and panic disorder may be ontic versions of *angst* in which the self is covered over, and fear displaced onto a undefined threat. We can still see the utility of exploring these experiences, however, because they shed light on human freedom and our reflexive natures that enables us to understand our *Being* and utilise anxious experience to reflect on who we are. In other words, whilst gripped by *angst*, an understanding of what it means *to be* (of being) can come into view. The ordinary, everyday ways of understanding, knowing and interacting with objects and others in the world sink back, suspended, whilst the ‘being-there’ of everything as existing indifferently provokes the ontological question of ‘why is there anything at all, rather than nothing’?

I am not claiming that each person with GAD or panic disorder considers this question. Rather, I suggest that in the grip of anxiety the pervasive sense of dread indeed does cause feelings of unfamiliarity and alienation in the world and offers a way into questioning what it means to *be*, and specifically, what it means to *be me*. Importantly, in the grip of anxiety when the world draws away and feelings of unreality, detachment, derealisation and depersonalisation occur, the freedom and potentiality for choosing authentic ways of existing, of roles to choose from, or else to fall back into the roles and self-interpretations provided by the public way of thinking, become possible. In short, this form of anxiety reveals the radical freedom and responsibility Kierkegaard discussed (Kierkegaard, 2014). This state of dread, of being faced with the nothingness of the world and my freedom to choose my own path resolutely (standing out into nothingness) awakens me out of my fascination and identification with the world to make a new start, or to choose to become who I am consciously and to own that decision, rather than go along with what 'one' does. We cope with *angst* by covering it over and identifying with the roles conferred on us, or want the healthcare practitioner to leap in for us so we don't have to respond to call of the self (see chapter 7 for expansion on this).[79]

Can this form of angst connect with experiences beyond generalised anxiety? Can it have any relationship to respiratory disorders? Indeed, it can. Heidegger's notion of facing the possibility of the impossibility of existing, of encountering nothingness by facing one's death, gives us the feeling of dread through *angst* that reveals death as *my* particular death, the non-being of *me* that only *I* can die. In this way, *angst* individuates me to my very existence. If I am to live authentically, I must resolutely anticipate my death to reveal that my life is my own to define, to live in accordance with who I am. As we have seen, respiratory disorders co-morbid with anxiety are commonplace. Once severe asthma attacks or exacerbations of COPD become a frequent source of confrontation with one's mortality, it is understandable that one would become anxious and thus more prone to panic attacks. Indeed, the initial difficulty of differentiating between breathlessness due to anxiety and breathlessness due to a physiological cause reveals that we are consciousness incarnate and not a mind plus a body. In both experiences (dyspnoea and *angst*), what remains is the confrontation with our own, personal death – the loss of possibilities and ways of being. Studying these experiences reveal that, one day, 'I' will no longer exist. Nothingness can, at any time, overcome me. Once we embrace the full awareness of our own death, we can reclaim our own lives, rather than being over-run by the demands and interpretations of others.

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[79] We might also consider how ontic angst is akin to fleeing from the essential uncertainty of the world and the ungrounding of our being, but this is beyond the scope of this chapter.

Breathlessness and anxiety experiences thus cause a shift in the lifeworld and embodied experience of the patient. They must find new ways to cope with changes to their usual repertoire caused by the closing down of certain possibilities (e.g. no longer being able to swim, dance or run). Indeed, the initial crisis of the condition often causes feelings of grief and loss, which the clinicians should be mindful of, and which can be illuminated by philosophical descriptions. Evidence shows that these descriptions match qualitative research and patients' descriptions of their disorders (Ratcliffe and Broome, 2013). To re-iterate, this does not mean that health-care workers must become trained counsellors. Only that they should be aware of relevant therapeutic services for referral.

This loss of significance due to co-morbid conditions can be recovered when the body is opened once again

> 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 on to itself. … 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 towards 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.

I suggest that in cases of common but severe mental disorders such as depression or panic disorder, the pre-depressed or pre-anxious bodies are often hard to access. This is similar to how the healthy body can be hard to recall by those severely unwell. The habitual knowledge of the body in performing and enjoying activities has become so remote that the memory of these activities can take on a dream-like quality. This may in part account for the insidious character of these disorders: not only are these routines and possible ways of being closed off to me, but I cannot remember taking them up and enacting them, nor can I imagine doing so in my future. Their significance and meaning have been suspended and no longer show up as something that I could (or wish to) do. In diagnosing depression or anxiety, typical symptoms include sluggish movements, bodily heaviness, and a lack of interest in things once enjoyed (DSM V, 2013). In chronic illnesses, often the habitual body eventually adapts to losses in motor habits and previously enjoyed activities, but these lost abilities still hold significance and meaning to the sufferer that may begin to diminish as time passes or with the onset of co-morbidity of depressive or anxious disorders. These phenomenologically informed descriptions and concepts therefore deepen our understanding of these experiences, and in this way can help us draw out themes that previously were ignored to be able to see what is at stake.

5.5 Regaining a voice: The future of clinical contact

> What are the words you do not yet have? What do you need to say? What are the tyrannies you swallow day by day and attempt to make your own, until one day you will sicken and die of them, still in silence?
>
> *(Lorde, 1980: 13)*

Long-term conditions affect some 17 million people in the UK each year, with over 30 per cent of these suffering from a common mental health disorder (NHS England: National Collaborating Centre for Mental Health, 2016). Having a co-morbid mental health condition leads to slower recovery, can worsen the physical ailment and lead to an early death, as well as creating barriers in getting help:

> We should have fewer cases where people are unable to get physical care due to mental health problems affecting engagement and attendance (and vice versa). And we need [the] provision of mental health support in physical health care settings – especially primary care. (The Five Year Forward View for Mental Health).

A continued commitment to naturalism in the biomedical model underlies clinical knowledge and practice and disseminates knowledge to trainees and professionals alike. These clinicians have the knowledge and power over the resources that the chronically ill patient needs (Nicholls, 2003: 131). The language used in many interpersonal dialogues between patient and doctor is structured by medicine and often taken up by the patient, as demonstrated by repeated descriptions of symptoms shaped by what the doctor dictates as useful or relevant. Patients report becoming frustrated and exhausted by repeating their stories and difficulties to different healthcare practitioners (Nichols, 2003:130) and may confine themselves to a few bare details, phrased in clinical language and thus potentially missing wider, holistic picture, other important details and nuances of their case (*ibid.*).

Conversely, when a relationship is established (what is called a ‘therapeutic alliance’ in primary care mental health practice) and the practitioner shows they have heard and understood the suffering patient, their needs and concerns, not only are patients more likely to follow guidelines and treatment, but outcomes are more efficacious. Patients are more relaxed, more likely to share, be open and honest (Nicholls, 2003: 131). However, brief contact is prevalent in medical practice and often the alliance cannot be established. This 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). I suggest that phenomenological exploration indicates that there should be a refocusing on their lived experience, rather than just on treating the symptoms in isolation from one another. For instance, addressing the breathlessness symptoms or fatigue as discrete symptoms fails to capture the wider picture of the debilitating effects of chronic respiratory illnesses, aspects which include social isolation, difficulty in attending outpatient facilities and so forth. The picture is fractured and therefore knowledge and treatment are compromised.

As phenomenology has revealed, we are active agents in the world, skilfully coping with encountered entities that are modified and disrupted by chronic illness. We can therefore see why medical treatment can be alienating: agency is handed over to those assumed to have the best knowledge, skill set and presumed motivation of working in their best interests. A clinician may further alienate a patient when expressing frustration at their failure to attend a pulmonary rehabilitation session or complete exposure homework in CBT, for instance, which shows their lack of understanding of the impact the disorder has on the person and fails to appreciate how intrusive biomedicine can be into a person’s personal life, habits and abilities. Patients may begin to feel powerless in accessing appropriate care for their needs, as if they were handing over their autonomy to the medical gaze (Nicholls, 2003).Their anxiety regarding their illness can spread to become an anxiety of healthcare and related interactions.

To summarise, I have claimed that respiratory and anxiety conditions have shown how our ‘normal’ modes of being and existing are radically changed. The closing down of possibilities, bodily, socially and economically, means that we have to find new ways of existing with our illnesses, finding new meaning and intelligibility of the world and our place in it (Carel, 2013b: 348).

As illness creates a distancing affect analogous to the phenomenological reduction, so too can anxiety. *Angst*, in individuating me down to myself, reveals the ungrounding of my being; the world appears uncanny, strange, unhomelike (*Umheimlich*). Treating anxiety as a discrete mental disorder needing psychological intervention in order to restore one to the world is no longer a matter of covering over the experience and its intelligibility in order to offer a quick fix.

Whilst it is quite proper to alleviate suffering, we can learn from Heidegger and phenomenology: providing a return to the world authentically enabled by engaging with anxiety experience, not fleeing in the face of it. For example, in my previous clinical practice in a mental health service, I ran therapeutic groups attending to the complex needs of patients with multi-morbidities (COPD and panic disorder, specifically) outside of the standard short term psycho-education.[80] Being mindful of social and cultural realms that shaped patients' understandings of themselves, the relationship between smoking and their physical and mental health, it was possible to tease out unique difficulties that limited their way of life, which was particularly important in such a diverse and deprived demographic.

Exploration of how they were *able* to act and the self-interpretations open to them was enabled through phenomenologically informed practice. This was achieved through listened to their interpretations of their anxious and breathless experience and working together to find meaning. Practically speaking, this was through tailored groups or individual therapy. For instance, transgendered groups, therapeutic sessions for abuse survivors, therapist awareness training, and delivery of personalised therapy to accommodate the needs of religious or ethnic minorities. The life world and patients' intentionality, backgrounds and self-understanding were all considered. Unfortunately, no protocol on treating those with chronic illnesses was stated and is only just now being put into practice. Thus, careful research had to be done by the practitioner with support from

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[80] Regrettably mental health practitioners are only just getting training on chronic illness integrated healthcare in the UK, so this was a tentative process. Results showed improved efficacy, and the IAPT service are now rolling out training in comorbidity, but sadly with reduced funding and so still short term only.

the clinical team that would not have been available under the NHS at that time (Clark, 2017).

5.6 A phenomenology of anxious breathlessness

Phenomenology, I have argued, can reveal the existential features of anxious and breathless experiences (Carel, 2008: 42). Studying breathlessness through a phenomenological lens uncovered our pre-reflective ways of existing in the world, providing opportunities for self-reflection and understanding. Carel's (2013b) analysis of illness as a limiting case of embodied experience described how illness pulls us out of our everyday existence (the 'natural attitude'). This was shown to 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, and movement were uncovered and seen to be altered by attention to these breathless experiences (*cf.* Merleau-Ponty, 1962). In fact, the phenomenological reduction and bracketing of the natural attitude was shown to be analogous to the distancing effect that illness creates (Carel, 2013b). Stepping back from our everyday absorption in the world through breathless experiences, reflecting upon the structures of embodied experience through this distancing. Analogously with Heidegger's (1962) notion of *angst*; possibilities, projects and our everyday living become cut away when meaningful existence collapses. Disclosive affectivity implicates the central significance of the body in human experience despite the noted absence, in Heidegger, of explicit analysis of the body. Mood or attunement was shown not to be a mental intentional state accessible only to the conscious subject. Rather, mood colours our interactions within the world and shapes how things matter to us (Heidegger, 1962: 227; Ratcliffe 2008).

This account fits with the changes to body image, self-identity and self-understanding frequently reported by patients with dyspnoea and panic disorder (Barnett, 2004; Carel, 2013b; Carel, 2016; Gysells & Higginson, 2011). As previously described, rather than the body being in the background whilst the person is going about their daily activities, they now become aware of their new limitations. Their body image is altered through changes to embodiment and existential threat via breathlessness (Carel, 2016; Haugdahl *et al.*, 2016).

Hence breathlessness and anxiety experiences both can cause a shift in the lifeworld and embodied experience of the patient. They must find new ways of coping with their changes in their habitual repertoire, due to the closing down of certain possibilities (Carel, 2016).

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 to the sufferer that may begin to diminish as time passes, or with the onset of co-morbidity of depressed or anxious disorders. They must adapt to the new limitations by carefully attending to their new embodied situation: '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.'

Healthcare practitioners can help aid an incorporation of these experiences into the life of the patient to return them to the world of concern, pointedly by the concepts of leaping ahead of the patient, rather than leaping in and removing their agency (Heidegger, 1962: 159). Such a 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 is a case in point that 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, socio-economic status, and prejudices stemming from smoking status (Crichton *et al.*, 2017). The prior consideration of health anxiety and breathlessness (above) bears this out.

5.7 Anxious breath in the clinic

Levinas has much to say on angst, too. Responsibility, anxiety, and existence are all interlinked for him in a much more fundamental way that implicates ethics. He tells us, like Heidegger and Sartre, we are always responsible for taking over the being that is my own to be, owning the 'burden' of my own being. Why is this a burden? Being responsible for one's actions, choices, decisions, errors, and mistakes is a challenge. Consider addiction. Smoking, substance misuse, gambling, and many other compulsive behaviours can be seen as related to the fleeing and falling phenomenologists discuss.[81] With Levinas, such behaviours are in fact an escape from 'the horror of Being'. Illness, then, like existential angst provides an opportunity to face up to this horror of always having ultimate responsibility over one's essential having *to be*. In short, no-one else can live your life for you (cf. Heidegger, 1962).

This 'bare fact of presence is oppressive'- anxiety inducing, Levinas argues, because one is held accountable by Being for one's own being (Levinas, 1997: 65). This means that like anxiety and being-towards-death (*Sein-de-tode*), one is ripped out of absorption in the world, detached from objects and others, and still 'there is presence' (*ibid*.,). Presence here signifying 'the universal fact of the *there is'* with anxiety expressing this horror of always having one's being *to be* (Levinas, 1997: 65). Death *is* coming, but life is here right *now*. The meaning of anxiety arguably deepens here as it is no longer tied to uncanniness nor death (as finitude of possibilities in addition to mortality).
Anxiety, life, and death are interwoven, then. Anxiety is inextricably tied to having to exist, of the constancy of the 'there is'. This recognition of the '*there is'* is thus

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[81] This also relates to responsibility, without minimising complex risk factors nor trying to blame or shame people. Addicts often talk about how they have no control over the need to use, to drink, to smoke. Whilst there is truth to this, many alcoholics, for example, choose to take responsibility for this lack of control and commit to abstinence without contradiction. How is admitting having no control over the need to smoke, drink, misuse drugs, and taking responsibility for this part of one's constitution not inherently contradictive? Simply because one recognises that need, takes responsibility for it by accepting that if one gives in, one is choosing to decide to once again exercise no control. Undoubtedly giving up requires much more support that an existential decision to be authentic; support groups, family support, good healthcare, therapy and so all, all contribute. The point is that even with such devastating, harmful impulses and patterns of behaviour, responsibility for one's decisions and actions is still possible. The scales fall from one's eyes: I am an addict. I am under no illusion that my freedom will continue to be curtailed if I do not take responsibility for this, whether I am ready for recovery or not. This is an extreme example, but one that I hope highlights how even in the grips of 'irrational' or harmful modes of existing we can recover our own responsibility for our lives, individually.

horrifying. You cannot escape the fact that at some point you will again face this certainty, even if you attempt to flee, tranquilise oneself via distraction or addiction, denial, and so forth.

How is this anxiety at the horror of being tied to responsibility? Our 'simplest gestures' leave manifold, unintended traces of our actions and goals. Levinas famously describes pulling a chair out to sit. Scratches in the floor are left, flecks of cigarette ash are dropped, and by doing what he 'willed to do, I did a thousand and one things I hadn't willed to do' (Levinas, 1998: 3). These gestures always implicate a responsibility that reaches out beyond any intentional action we have, and so we must act carefully and own up to this full responsibility or risk unintended harmful consequences (see also chapter 6). For example, consider:

> 'an animal fleeing in a straight line across the snow before the sound of the hunters, this leaving the very traces that will lead to its death (Levinas, 1998: 3)'.

The animal, panicked by threat, attempts to flee and yet such a reactive impulse ensures (unintended) destruction. Analogically, fleeing from the horror of existence leads to many unintended consequences which brings one right back to that very threat: the ever-present presence that reveals itself in anxiety. You have to choose your possibilities, take ownership of your life. Responsibility lies *with you only*.

This responsibility was even more radical for Levinas than a 'mere' responsibility over one's life and actions. Indeed, Levinas provided phenomenology with a description of the nature of the ethical relationship between self and other in contrast to Heidegger's avoidance of ethics (Levinas, 1998; Heidegger, 1962). Ethics precedes metaphysics, ontology, and epistemology. It is the one 'first philosophy'. So, this responsibility naturally incorporates such a blossoming from the inner to the outer. Or better, a breakdown between such dichotomies that lead to the usual problems of other minds. Through his phenomenology of alterity (literally, the Other as from the Latin *alterite),* he puts 'concern for the other at the centre of ethics' (Moran, 2000: 320). This a profoundly different ethical endeavour than heretofore seen. It is not concerned with the multifarious ethical systems historically presented. Nor with ethical justifications. He steps beyond such ego-centric frameworks. Instead, one's responsibility to the other is always the primordial, or fundamental structure that enables sociality, culture, and intersubjective relationships.

So, this new way of presenting ethics entails a rethinking of ethics divorced from prior assumptions and theoretical posturing's. It is nothing less than a restraint on the behaviour and prior liberties previously enjoyed and enacted to ensure an openness to the needs of the other (Levinas, 1998; Moran, 2000: 321). Hence, this is a calling to fully attend to the other. The question of being thus moves from the ontological to the ethical: the reason of one's being is bound to the other. This, of course, becomes a prescriptive demand, entirely appropriate to the remit of healthcare. After all, what else is about the needs of the other than (in this case specifically) attending to the breathlessness and experience of the patient?

Stepping away from the problematical clinical gaze (charged by Sartre, Foucault, and Bishop), requires a refocussing upon the Levinasian demand of how we should behave, rather than what or how we (or, pertinently in this case, clinicians) do behave. This move from description to prescription is not without potential detractors due to its exchange from the phenomenological emphasis on description of first-person structuring to a seemingly more prescriptive endeavour. After all, the 'is' and 'ought' problematic is still a powerful philosophical enquiry. However, not only can we not get side-tracked with such a debate here, we need to consider this move in relation to Levinas' phenomenological position. He is not presenting an ethical framework or theory. It is more a pre-ontological positioning: the ethical dimension presented is a primordial feature. A structure of human existence that is both descriptively honest and so prescriptively implicating. That is, we can derive prescriptive import from this description of human being. That is why Moran states that Levinas is presenting a 'humanism of the other': one that is to 'speak of the other, not objectively in the third person, but addressing the other directly, in the vocative sense, invoking his or her 'proper name' (Moran, 2000: 321).

This will ensure that the egoism inherent in ethics and philosophy is continually subverted by the other, according to Levinas. The other in their very existing prohibits totalising and global explanations (Moran, 2000: 320). Like with Bishop, totalising explanations that don’t respond to the nuance of the situation and persons circumstances are not just incorrect, they are harmful. For instance, in medicine, the ‘ideal body’ is that of a corpse (Bishop, 2011). The human is lost in such a clinical gaze. Levinas too, characterizes the entire Western ethical endeavour as one that focuses upon the relation of the self to its - self (i.e. egoism writ large), to the detriment of others. In cases of breathlessness and anxiety, the distress, the continuation of epistemic injustice, mortality and morbidity rates thus go properly unchallenged as power relations, or, the Heideggerian notion of leaping in instead of ahead, even with best intentions, is seem as the proper way to behave in these situations. For Levinas, to build an ethics is to thus to step away from prior conceptions of ethics and the relation with the other. If we couple this with the thought of Bishop ending totalising care in addition to Heidegger’s authentic care as leaping ahead, we can approach the other in a way that is more solicitous, kind, and ultimately open to the agency and nuanced situation of the ill person.

Thus, I claim that Levinas’ version of phenomenology is a philosophy that overcomes ‘previous forms of totalising philosophy’ that can be useful to analysis of the anxious breathless person (Moran, 2000: 327). To be clear, totalising types of philosophy are those that close off the potential understandings and openings that can be achieved if we instead look at what makes us human. At recognizing the absolute centrality of the other to our existence that steps beyond interior monologues on the self in relation to self that extrapolates the existence of others from such a standpoint. His usage of phenomenology, too, differs. He steps away from the Husserlian reduction to instead free phenomenology to describe human experience in ways that don’t have to be thematized. Afterall, when we *actually do phenomenology* we often are surprised by structures, experiences, and meanings that come forth yet differ person to person. With anxious breathlessness then, we can use phenomenology to thematize changes to structures in experience; but we can also utilise it to describe and therefore account in the variations of breathlessness experiences across different individuals. To be non-dogmatic phenomenology lends itself to this fundamental principle. It is fluid and allows for development:

> ‘My method is phenomenological: it consists in restoring that which is given, which bears a name, which is objective, to its background of intention, not only that intention which is directed towards the object, but to everything which calls it to concreteness, to the horizon. I’ve often said that it is research into the staging [*mise en scene*] of that which is the object; the object, which left to itself, is clarified, as much

> as it closes off the gaze – as if the giving was like an eyelid which lowers itself as an object appears, and consequently as if the objective is always abstract. Concreteness is the ensemble of what is lived, of intentionality, which is not entirely heuristic; it includes the axiological and the affective. Consequently, meaning is given in the concreteness, and there can be surprises here over the general role of thematization (Levinas, quoted in Moran, 2000: 327).'[82]

Levinas' project of ethics as first philosophy and of phenomenology as a descriptive enterprise thereby fully eschews totalising philosophical theories, then. So, his ethics is not one of rules, duties, virtues, or any number of prior conceptions we have of ethical theories. It is one embedded in phenomenological description that exists in both the description of and the interpretation of the actual event of encountering the other (Levinas, 1997). Within this face to face encounter, one is called to subjugate to the needs of the other: this is enacted and unfolded in the actual event of the encounter. Our embodied sensibility reveals this to us, albeit through a pre-cognitive level that is uncovered via phenomenological attention to the encounter. Such an intersubjective responsibility is thus a first philosophy in that our descriptive and interpretative reflection reconstructs pre-cognitive experience that enables and underpins our agency and practical activity (Levinas, 1997; Škof, 2015).

We can now fully come to understand transcendence. It is not just being out-there, pushing into possibilities nor consciousness stretching towards things out there in the world (Heidegger, 1962; Husserl, 1960). It includes these but is instead aligned with exteriority: that which lies outside me, the other person that can never fully be known. I can see and touch the other as something outside of myself, but this encounter is not just one with a physical object. In this encounter, the other speaks, commands me to listen to them. To respond to them, for Levinas, is to uncover the responsibility I have to them. This is his ethical ground: the lived origin within the face-to-face-encounter that is prior

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[82] 'No one combatted the dehumanisation of the Real better than Husserl, the dehumanisation which is produced when one extends the categories proper to mathematised matter to the totality of our experience, when on elevates scientism to absolute knowledge… Husserl's phenomenology has furnished the principal intellectual means for substituting a human world for the world as physicomathematical science represents it (Levinas, 1998: 131).'

to utilitarian, deontological, or virtuous theories. As we saw in Chapter 3, it is a transcendence through breath (as I elaborate in Chapter 6).

It is also responsive to the situational context, and therefore, I suggest, it is useful for considering in clinical encounters with the breathless patient. Regardless of the physical or mental cause. Attention to each individual encounter can utilise prior knowledge, understandings or thematization of breathlessness. But it can do more than this: it can overcome the questions of the mismatch between objective measurements and subjective distress. Not that these do not matter. Only that the doubt, testimonial injustices, the gaps in trust and communication can be put aside in a receptive, non-judgmental, and attentive manner. Whether one smokes, or is deemed as neurotic or panicking, their distress should be validated by approaching them compassionately and with care. He gives us a deep basis for reconsidering and thus recalibrating our relations to other beings.

This also includes with empathy (we will return to this in relation to proximity, see below). What is crucial here is that the embodied, pre-cognitive levels are those that impose the ability to share meanings and intelligibility, knowledge and understanding. In effect, there is both a normative and ethical dimension. For without the intersubjective relationship forged through the face of the other, perceptual experience would not offer any objectivity whatsoever (and thus clinical encounters would be totally useless). In other words, there has to be a grounding to normativity and shared knowledge and understandings, and this is revealed in the face of the other calling into question my experience. With this, the “sense of the normative, of standards against which the validity of my experiences can be judged” (Crowell 2015: 574). In the potentially life-threatening cases of breathlessness, this is writ large. The gasping of the other person, their blue face, their struggle for breath reveals this fundamental relationship. It can become an ethics of the breath.

How? Recall that the normativity herein described is thus to do with sensibility, or more precisely, affect. The very first normativity that the I ever experiences (for Levinas), is dependent on an awakening in the face-to-face encounter with another person that appears as an affect prior to reflection or judgment (Levinas, 1969: 294). Our verbal response, or gestural communication, contains this and the recognition of the others exteriority:

> ‘Language makes possible the objectivity of objects and their thematization. Already Husserl argued that the objectivity of thought consists in being valid for everyone. To know objectively is therefore to constitute my thought in such a way that it already contain[s] a reference to the thought of others. What I communicate therefore is already constituted in function of others’ (Levinas, 1969: 210).

Subjectivity always therefore contains primordial dimensions always already conditioned by intersubjectivity. Harking back to Heidegger, our response is mediated by our being-with (*Mitsein*) others. As Škof develops these, the demands of the other impose a calling for the ethics of the breath, one that I will develop as a co-breathing (Chapter 6).

5.8 Conclusion

Within biomedical practice, significant differences exist between how practitioners think about disease and illness and how patients experience their illness (Toombs, 1989; 1999; Carel, 2013). As argued in Chapter 1, medical practitioners often thematize illness in terms of patterns of symptoms that persist over time, whereas for the patient, the illness is experienced as a way of being, albeit one that has been radically transformed (Carel, 2013). How these experiences affect patients’ understanding and the intelligibility of their disorders is often overlooked. The patient responds 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 patient may respond with despair, or the realisation of the transience of life and an opportunity to take control of their remaining health (*ibid.*). Such a reductive view fails to capture human existence as an embodied, self-interpreting agency in a world with others who can take a stand on her illness. Although an objective medical focus on disease has its place in managing the disorder and alleviating suffering, this focus is not the whole story (Svenaeus 2001; Kirkengen 2010).

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 pre-existing 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 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 with which 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 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). Breathlessness conditions, I have argued, 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 the provision of phenomenological analysis can be indispensable (Nichols, 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 their 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 occur that do not match objective measurements. Dualistic thinking underlies physical and mental clinical practice which causes many problems in understanding and treating certain illnesses. For instance, patients often struggle with their diagnosis of anxiety disorder; after many tests and referrals, they feel sure their symptoms of shortness of breath, or heart palpitations were due to a disease of the body. 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 a truly patient centred integrated healthcare that evidence demands in such complex cases. Levinas breath as transcendence and the ethical underpinnings of human existence was built upon. These insights lay the foundation of a call for the ethics of co-breathing in the next chapter.

CHAPTER 6: Shame, Stigma, and the Other: Breathlessness and the Social World

> In discussing my illness with physicians, it has often seemed to me that we have been somehow talking at cross purposes, discussing different things, never quite reaching one another.
>
> *S.K. Toombs (1993)*

> The dilemma for government is this: it is simply not possible to promote healthier lifestyles through Whitehall diktat and nannying about the way people should live. Recent years have proved that one-size-fits-all solutions are no good when public health challenges vary from one neighbourhood to the next. But we cannot sit back while, in spite of all this, so many people are suffering such severe lifestyle-driven ill health and such acute health inequalities.
>
> *The White Paper (2010)*

6.1 Introduction

This chapter is split into three parts. Part 1 examines social meaning and intelligibility through the concepts of intersubjectivity and Being-with (*Mitsein*) applied to everyday life. It also looks at the modification of these existential structures of human existence within the patient-physician encounter, mediated by breathless and anxious experience (Toombs, 1989; Kirkengen, 2005; Baron, 1985; Bishop, 2011). This analysis dovetails with the co-occurring themes of shame, stigma and social exclusion that are so common to breathless and anxious experience (Part 2). Epistemic injustice will therefore warrant re-examination. Such an uncovering of these harmful experiences and their detrimental effects to both patient healthcare outcomes and on wider human relationships, demands philosophical and medical attention (see policy recommendations in the Conclusion). Finally, I suggest bringing together all these insights in relation to the call for ‘an ethics of the breath’ (Part 3), thereby building upon Chapter 3.

I argue that a truly integrated person-centred approach would need to take account of the fact that our understanding of disability and illness is constituted not only by our embodiment, as illuminated in earlier chapters. Whilst the body is undoubtedly the ‘medium for having a world’ (Merleau Ponty, 1962: xi), meaning and intelligibility of illness is given to us through our social, cultural and historical embedding in a world with others (Sartre, 1943; Merleau-Ponty, 1962).

This builds upon my argument that these types of concepts can be informed by other models and descriptions of human existence freed from the individualistic, naturalistic worldview. One example given in Chapter 1 was disability. The concept 'disabled' is viewed from a social constructionist point of view as attitudes of others towards the ill person, and *not* the physical or mental impairment that they have (Griffiths, 2012: 11). The onus is not placed upon the shamed patient (e.g. a smoker 'responsible' for their condition) alone. Smoking did not happen in vacuum. It was advocated as attractive, cool; good for health, even, in times gone by (Gardner & Brandt, 2006). The changes in embodiment and resultant mobility problems can be seen as a responsibility for communities and society to help with, rather than excluding the already suffering, marginalised, individual.

Increasing air pollution is not the fault of the individual patient, either. As the traditional biologically-based explanatory models in medicine have been shown to be individualistic, reductive and excessively reliant on scientism, they were unsuccessful in accounting for such economic and cultural pressures, social norms and wider contributory factors, which we have seen affect patient's self-understanding and wellbeing. Nor, as we have established, do these models account for such social constructionist variances (Chapters 1, 4, and 5). Nuance is lost, which in turn shows these models to be outdated and empirically and ontologically deficient when it comes to understanding and explaining human existence. Belonging in a world of others is fundamental to our being-in-the-world, our lived experience, our identities.

6.2 Recapitulation

As I have argued throughout, phenomenology can address these issues through disclosing the meaning of illness that is constituted by the embodied, socially situated patient (Toombs, 1987; Carel, 2011). Building upon the concepts of embodiment, and the lived and biological body discussed in previous chapters, I explore the structures of intersubjectivity, being-in-the-world as being-with, or sociality, to further this framework for investigating breathless experiences (Heidegger, 1962; Merleau-Ponty, 1962; Dolezal, 2015; Slatman, 2014). I suggest that investigating these elements may help to explain (for example) why many asthmatics fail to adhere to preventative medication regimes: patients' perceptions and beliefs regarding the necessity of the medication and concerns using it over a longer temporal period, in particular, stand out. Exposing these socially scaffolded values and concerns about pharmacology and medicine on the one hand, and addressing the real problems patients report with following treatment on the other, can be explained and accommodated by attending to patients' embodied, social and cultural setting. Focus upon the interpersonal relationships between patient and practitioner, and improved communication on the individual, familial, and social levels via education and training, is required (Kirkengen, 2010).

Thus, emphasis on the individual as a rational actor divorced from others (inherited from Aristotelian and Cartesian views of the human being) must be examined and ultimately overcome to promote better health as an interpersonal, socially embedded enterprise. Heideggerian notions of authentic care (*Solicitude*) as 'leaping-ahead', rather than 'leaping-in', are pertinent here (Heidegger, 1962: 158). This in turn highlights how we are not isolated subjects but depend on one another. Thus, we can begin to promote better health and lifestyle choices, healthcare policies, and environmental protections.
This also complements the other challenging issue already highlighted within this thesis, and in the discipline philosophy of medicine more widely: the failure of the language of biomedicine to convey the importance of treatment adherence to patients (Horne and Weinman, 1999).

Something goes wrong within the patient-physician dialogue/relationship in this case, and the fault does not lie simply with either of the two parties (cf. Toombs, 1993: *xi*). The entire socio-economic situating, including the disjoint between clinicians' expectations of patients' understanding of these issues; the individual wanting to be a 'good patient'; lack of consultation time; wider suspicion of medication; and so on, means that we need to look at the 'bigger picture'. We must call for changing social knowledge and understanding of these issues when making proposals remedying these life-threatening problems. This hammers home Toombs' suggestion that there appear to be two distinct realities present in patient-healthcare interactions: realities that result in not only disempowerment and worsening morbidity on the part of the patient, but of the two groups talking at cross purposes (*ibid*.). When communication is inhibited, it is not surprising that progress is slow and patient complaints so prevalent (Toombs, 1993: 155).

I will elaborate on the role of shame, stigma, and social exclusion in the breathlessness experience, utilizing the example of COPD diagnosis and treatment adherence. This includes a discussion of pertinent issues surrounding mental health problems, rates of social exclusion ranging from isolation and alienation, through to criminality risks that often go hand-in-hand with worsening respiratory and mental health, as seen in socially deprived groups (ONS, 2019; cf. Leder, 2015).

Finally, considerations of the breath at the end of life will be examined. Studies show that breathlessness is a reliable predictor for mortality (Johnson *et al.,* 2016). This is not exclusive to diseases caused by respiratory problems. Heart failure, cancer, and many other diseases cause prolonged episodes of distressing breathlessness towards the end of life. Yet these ‘clues’ (sustained struggle for breath and reported rates of being breathless) have often not been adequately attended to by healthcare practitioners (*ibid*.). Drawing together insights from researchers and practitioners, I build a Levinasian call for attention to the breath in the context of the face-to-face encounter. This is not a demand to train clinicians and patients in a course of (Levinasian) philosophy. Rather, I utilize his philosophical insights to build upon my argument concerning the importance of exploring breathlessness to supplement our understanding of both this human experience, and the philosophical and clinical implications borne throughout. Drew Leder’s reconfiguration of healthcare practice as compassionate healing that reintegrates the alienated patient with their powers of agency, lived experience as embodied, and the wider world, will be shown to fill the between-space of the clinician-patient encounter (Leder, 2015; Aho & Aho, 2005). Person-centred care, then, must consider the lived experience of the patient, inclusive of these features.

Part One: Being-With, Intersubjectivity, Sociality

> Being-with is an existential characteristic of Dasein even when factically no Other is present-at-hand or perceived. Even Dasein's Being-alone is Being-with in the world.
>
> *Heidegger (1962: 158)*

6.3 The Significance of Being-With

Within this thesis, I have discussed the human way of being as open: embodied as opposed to the standard Cartesian mind/body split, and yet equally importantly as interpersonally, socially, and environmentally, situated. We live within a 'we' world: a world inextricably bound with others (Merleau-Ponty, 1962). Our singular existence, even as a hermit, is never fully alone (Heidegger, 1962; Merleau-Ponty, 2005: 65). It has always been shaped by a human world even if we decide to cut off contact from others (Heidegger, 1962: 156). This decision, after all, is a privative mode of a primordial structure that must exist first (Heidegger, 1962; Merleau-Ponty, 1962). I now will elaborate what this interpersonal Being-with entails.

As Szanto and Moran (2016) ask, what do we mean by invoking this 'we' that we belong to? Who are the members of this group? What shared knowledge, understanding, and forms of relationship comprises this membership? (Szanto and Moran, 2016: 1) More importantly for the purposes of this thesis, what does this membership suggest with regards to breathless, anxious co-existence? Heidegger tells us that 'as Being-with, Dasein "is" essentially for the sake of Others' (1962: 160). This is not an ethical demand to subjugate our needs and wants to those of the Other (cf. Levinas, 1997). It is not even to call for a reciprocal ethical relationship (cf. Olafson, 1987). Heidegger here means it in an ontological sense to be understood as how our very being, the significance of things, and our understanding of self and world, is already shaped by the primordial structure of living in a shared world that derives its very possibilities from our Being-with.[83]

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[83] Heidegger named this being-in-the-world-together-with-one-another *Mitsein*, which translates as Being-there. This is not the same as being in the world alongside objects and other entities. Being-with plays a

As he goes on to discuss care as concern and solicitude as the meaning of Being, we can question his denial of an ethical stance and examine whether Being-with as solicitude calls us to attend to the needs of others. For example, he tells us that forbearance and consideration are positive modes of solicitude: the type of being-towards others that we possess (Heidegger, 1962: 158-159). Indeed, the everyday, deficient modes of solicitude, of Being-with, are '[b]eing for, against, or without one another, passing one another by, not mattering' are indicative of a normative evaluation (Heidegger, 1962: 158). Particularly given his argument that these not only inhibit the being-able-to-be oneself of the other, they also trap our own freedoms and possibilities (Heidegger, 1962: 161). This is the freedom to know oneself. 'Hiding oneself away', 'aloofness' towards the other, appears to cause harm to one's very own self and access to self-knowledge and understanding, then (Heidegger, 1962: 161). This seriously challenges his position that he does not mean anything ethical when it comes to describing one's Being-with others (cf. Olafson, 1987). Here, it is enough to say that although he claims he is not presenting an ethics of Being-with others, the centrality he places upon being in a world shaped by others for our self-understandings, knowledge, and possibilities, makes such a claim contentious.

Bracketing the question of ethics for now, if our relationship is one of Being-with, positively construed as solicitude towards the other, what comprises this relationship? For Heidegger, this is not a relationship based on empathy. Instead, empathy is made possible by our fundamental constitution of being with others, a relationship that structures such possible relationships:

> Not only is Being towards Others an autonomous, irreducible relationship of Being: this relationship, as Being-with, is one which, which Dasein's Being, already is […] 'Empathy' does not first

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constitutive role to each and every individual Dasein (Heidegger, 1962:; Olafson, 1998:4). Being-with other people is not reducible to traditional notions of empathy when we try to describe how we interact with another person. Our relation to the other is shaped by care as solicitude (*Fursorge);* one human being caring for another human being, to the extent that the various differentiated modes of this concept suggestively imply that we exist "for the sake of others", although Heidegger doesn't fully flesh this out (Heidegger, 1962: 344). It is important to define these two concepts. Being-in-the-world was not a structure later pieced together. Instead, it was shown to be a structure permanently and constantly whole (Heidegger, 1962: 39). The world in its worldliness, being a self, being with others, and being-in as such revealed that Dasein's existential meaning is care. We are concernfully engaged in the world of non-human things, and we care about others as shown by our dealings with them.

> constitute Being-with; only on the basis of Being-with does ‘empathy’ become possible: it gets its motivation from the unsociability of the dominant modes of Being-with. (162)

The other, for Heidegger, is thus there before any requirement of me positing their existence. We have already seen how the other is disclosed in the cultural artefacts around us: tools and equipment, social roles, and institutions. Merleau-Ponty builds on this with his description of subjectivity emerging from intersubjectivity (Merleau-Ponty, 1962: 475; see also 2005). It may be more proper to say that intersubjectivity arises from intercorporeality, as the body of the other shapes and structures one’s own embodiment prior to shaping one’s subjectivity (Merleau-Ponty, 1962: 405). Such consciousness of the self comes much later but is seamlessly interwoven into our bodily being. Indeed, our self-understanding and knowledge of the other is based upon the body of the other, whether as the anonymous other (cultural world), or the corporeity of an existent other. The infant mirrors its mother, not only learning how to speak and understand, but how to gesture and express oneself bodily (Merleau-Ponty, 2005: 65). The other makes possible my self-understanding, directly affecting my embodiment and subjectivity:

> I never become aware of my own existence until I already have made contact with others; my reflection always brings me back to myself, yet for all that it owes much to my contact with other people. (Merleau-Ponty, 2005: 65)

For example, the university library is full of the anonymous lives of others. The way that we understand what a library is, how it is accessible, all shows up the bodies of others in a with-world prior to a cogito having to posit their existence: the books on the shelves are handy, within reach. Our involvement with others thus permeates every chair that we sit upon, every computer that we use (Merleau-Ponty, 1962).

So how does this relationship between self and others show up explicitly via phenomenological attention? As we saw in previous chapters, Heidegger told us that the meaning of Being-in-the-world is care (*Sorge*). In being-alongside-others, ahead-of-ourselves, and already-in a world we are absorbed in; care is the way that we approach things, others, the environment. We look after our garden, we approach our tools circumspectly, we are concerned about the environment. Care thus structures our existence through and through (Heidegger, 1962: 243). We are always thrown into a world already alongside others. We may act indifferently, or even cruelly towards them, yet we have the power to more authentically be-with other people. If we understand ourselves as primarily caring creatures, we can free ourselves to foster more authentic relations to others as our self-understanding changes through these insights. This can apply directly to clinical contacts, bridging the two realities discussed by Toombs (see Chapters 1 & 4). Our interactions with them thus should incorporate listening to them, attending to their needs, holding open the space between us for authentic dialogue rather than ignoring them, speaking over them, passing them by (Leder, 2015). We thereby see ourselves and our responsibilities to others in a new light.

However, even if we recover these ways of understanding, interpreting oneself, and interacting with others, they can be radically altered when undergoing chronic respiratory illness or mental distress. This is compounded by social marginalisation and shame and stigma, frequently reported as experienced with these types of illnesses. The social world is itself altered and both affects and is affected by increasing rates of isolation and alienation. It is to this we now turn.

6.4 Illness, identity, and Being-with

> By taking up a present, I draw together and transform my past, altering its significance, freeing and detaching myself from it. But I do so only by committing myself somewhere else.
>
> *(Merleau-Ponty, 1962: 528)*

Transformations to social intelligibility and self-reflection are deeply connected. Breathless experiences, experienced as alterations to embodiment that in the present alter my interpretation of who I am by looking to who I was, are perfectly valid when considering self-identity and intersubjectivity *(ibid.*). They do not obliterate that I was a gymnast in a certain social club with others. What is altered I only that I am unable to be an active gymnast *now* considering my present rates of breathlessness. Yet I can *still* be part of that club (as a coach, for example). Or perhaps I can take my knowledge and understanding of these activities and their social structuring, funding and sponsorship requirements, organisation affiliation, and so forth, to become a yoga teacher, or a fundraiser. Resilience, creative responses to physical alteration, can restore our loss of control and agency (Toombs, 1993). My facticity may limit or curtail certain possibilities, but with help, I can take this experience and share them elsewhere to create new meaning making experiences within my purview (Malpass *et al.*, 2018; Pattinson *et al.,* 2018). The significance of the breath to existence, to making communication possible at all, is thus obvious, even though changes to breathing directly resulting in altered social relationships may not be at first sight. However, I hold that the breath has even more ontological substance.

As Sartre argues, saying that man is a sexual being because he has genitals is the wrong way around; he has genitals because he is a sexual being, just as he has sense organs because he is a sensing being (Sartre, 2003: 405). It is part of our ontological existential structure. I would extend this to the emphasis discussed in Chapters 2 & 3. We are not respiring beings because we possess lungs, airways, and so on: we have lungs because we are breathing beings. Breathing, sensing, and sexuality are not additions placed upon our being because we have lungs, sense organs, genitals. We possess the physiological organs as part of our originary relationship with others in the world, and as part of being-in-the-world itself.

Breathing, perceiving, and sexuality are made possible (at birth) in the world with others; are limited when we get sick; end when we die. It is true that sexuality can be frustrated, the sense organs can be damaged and close off seeing, smelling, or hearing, but the possibilities of sexuality and sensing as fundamental structures remain (Sartre, 2003: 406). What about breath? We know that even with damage to the airways, problems with the gas exchange in the lungs, tumorous growths, and so forth, we will always continue to be respiring beings (cf. Levinas, 1997; Škof, 2015). For, if we can no longer breathe, we are no longer. I would suggest that in this way, being breathing beings is our primary connection to the world and to others (cf. James, 1962).

This may sound obscure. To clarify, I'm positioning breath and breathing at the centre of our existence. It grounds human existence, as underpinning our capacity for thought and action, communication and expression. This may sound obvious. Of course breathing connects us to the world, and to others. That is hardly interesting. I would say that the emphasis here requires a closer look. It is rather a primordial structuring that has been obscured and overlooked. Just as Heidegger pointed out the forgetting of Being as too universal, indefinable, obscure, and so forth, and Irigaray sought the re-engagement with air (again as something forgotten as it is used up by philosophers, but too close to be made visible) as worthy of philosophical attention, breathing needs such treatment (Heidegger, 1962; Irigaray, 1999).

As I have argued, recovering the pre-Socratic significance of breath and breathing alongside phenomenological description of its pathological mode has given us insights into what it is to exist. Of what it is to be human. Breath, breathing, and breathlessness shape our very connection to the world. Our very ability to communicate and to engage in the world is structured by fundamentally being respiring creatures, with any threat to the breath a very threat to these capabilities, as well as to existence itself. The significance and importance of the availability for clean air to not only ensure health but maintain our existence is not to be overlooked. Each chapter has discussed the problems with seeing breathing in purely mechanistic, or physiological terms, recovering the dimensions of breath such as its interlinked and intractable impact upon thought and action, the *I breathe, therefore I am* more adequately described as *we breathe*. For example, with regards to respiratory conditions such as COPD (examined in chapter 4), it was demonstrated that the disruptions to breath permeate and alter existence at the levels of not just embodiment. Cognition such as decision making powers can be extremely interrupted by small changes to oxygen desaturation. Interpersonal, social, temporal, political, and institutional elements were also shown to be affected, just as they too can stifle the breath with their oppressive, stigmatising glares and alienating practices. Further, with anxiety, we see that our affectivity can also be unsettled and transformed by panicked breathing, or by the more positive breaths of mindfulness to regain control. In the next two chapters, I take this claim further to expand it to the understanding of our relationships with other people and how putting breathing on a pedestal demands a rethinking of our approach to clinical contact, specifically at the end of life. Breath underpins and shapes every moment of our lives, and its derivative is more than likely to be experienced for many of us who go on to die of chronic diseases and age related illnesses, as we shall see.

To say that being breathing-beings or entities is our primary connection to the world and to others is to say that breathing opens up the very capacities to experience the world and to interact with others, to engage in thinking, reflection, philosophy. It 'perpetually intertwines the self, the body, and the world' (Skof & Berndtson, 2018: *xiii*). Re-examining breathing and breathlessness closely can uncover the forgotten foundations of epistemology and metaphysics that started with the Pre-Socratics. The foundations of our understandings of the world and experience of existing as human that no longer dismisses the breath to spiritual or medical domains of study. Looking at the world anew through disclosing the significance of the breath from the perspective of the breathless.

For now, it suffices to point out that within the context of healthcare, we can acutely see that attending to breathlessness in the clinic recognises the significance of the breath and breathing beyond mere diagnostic utility. The changes to social intelligibility and meaning making become powerfully present (Malpass *et al.*, 2016). When attending to a person with chronic breathlessness, we recognise that such responsiveness brings us into contact with the person in a way we can term 'embodied proximity' with ensuing revelatory powers (Škof, 2015). We see their discomfort and acknowledge it, rather than fleeing from something that frightens us with our powerlessness to cure it and the way in which it reveals our own mortality (Leder, 2015). The 'between' space that mediates the contact among clinician and patient can thus be bridged (Toombs, 1993; Leder, 2015). How is this so? What are these powers? We shall return to these questions later in the chapter, but firstly we consider what can happen when such an approach is not taken.

As we have seen, selfhood is constituted by our relations to and with others. Changes in these structures' can lead to changes in how we interpret our self and our world and how we relate to others. The link between respiratory disease, diseases of age (e.g. dementia, cognitive decline, impaired decision-making) are horrifying examples of what happens when embodied proximity, and the covering up of one's selfhood, occurs. A deficient mode of Heideggerian care [*Sorge*], whereby the patient is ignored, talked over, their illness seen as a natural part of their lifestyle or age, for example, leads to infantilizing, stigmatizing, and objectification in care settings (Kitwood, 1997). If communication fails, dialogic breakdown occurs. This results in not only the patient not being heard, but potential for misdiagnosis and unnecessary treatment. Moreover, even with correct diagnosis and treatment plans, without skilled communication there is a large risk of failure to adhere to treatment as the patient doesn't yet see themselves as asthmatic, for example (Leder, 2015: 99).

As social beings whose identity often hinges on our social interactions and status, when healthcare treats us in this way, our subjectivity and personhood is ignored. Our condition deteriorates when one is stripped of personhood in this way. Such 'malignant social psychology', that is, 'interactions that tend to depersonalize the sufferer of Alzheimer's disease', for example, result in depersonalising effects of healthcare (Kontos, 2005: 555). This results in healthcare that is not actually person-centred, or at least, that claims that it is whilst treating the (for example) COPD patient as a 'hopeless case'.

Selfhood, then, has many layers of sedimented being, inclusive of Being-with others both as intersubjectivities and the bodily basis of this relationship, that is, intercorporeality. It also includes the 'bodily sources of agency, grounded in the pre-reflective level of experience, [which] are fundamental to the constitution and manifestation of selfhood' (Kontos, 2005: 555). Our body, after all, is the foundation for having a world, for engaging with things, with others, and with institutions such as healthcare. My argument has been that breathlessness certainly reveals these structures that underpin human existence and ways of being with one another. However, as the bodily sources of agency are altered, both our relationships with others and the world change, as does our ability to communicate with the wider world. To attend to the breath of the patient is to be truly responsive to not only their distress and immediate need, but to their very identity as a person, recognising their humanity in the face-to-face encounter, as I further elucidate below (Levinas, 1997).

As we have seen, the activity and behaviour or comportment of the body reveals how the body has a meaningful hold on the world. The current horizons opened by perception constitute this meaningfulness. This is not a pure passive material realm; the movements and activity (comportment and motor power as bodily intentionality) actively participate in revealing the meaning and significance of the present situation as well as playing a constitutive role in opening and transcending the current field of possibilities to open new horizons (Merleau-Ponty, 1962). Speech, too, is a lived act that uncovers my hold on the world. Intelligibility, significance, and meaning shine forth in speech acts (Merleau-Ponty, 1962). This would not be possible if there was not already a cultural world, a unity between the perceiving embodied subject, the other, and the world. Language and gestures are already there at my disposal in the world I am thrown into, and I can organise the meanings through speech. This relationship too, is my situational hold on the world, and this ability to express oneself, to be heard, or be recognised, can be severed through the limits illness places on the individual on the one hand, and the lack of recognition of these changes by clinical medical practice on the other.

So, as phenomenologists have argued, sharing a language, socio-cultural environment, history, and intercorporeal reality all matter when considering what it is to be human (Heidegger, 1962; Merleau-Ponty, 1962; Toombs, 1997). No-one does it alone (cf. facticity and historicity in Chapter 4). That is, we are not isolated egos creating our own selves before we infer that others must be like us. The with-world itself shapes our possibilities, the projects and roles and self-interpretations we can project into. This is not just on the individual or familial level: social structures inclusive of political and religious structuring, as well as medical roles and the concomitant understandings of one's identity as healthcare-practitioner, patient, carer, socially responsible citizen, all have implications when we focus on breathlessness. To properly attend to the person, these facets must be considered.

Thus, philosophical attention to the breath, breathlessness and air illuminate issues pertaining to agency, autonomy, social and intersubjective concerns outside of purely theoretical, biological, or scientific study. Studying the philosophical neglect of the breath, of poor air quality and the damaged breath in respiratory diseases has (I argue) revealed significant changes to decision-making, cognition, embodiment, being-with others, and society, with consequences beyond patients' ill-health. The medical understanding of these illness experiences alongside policy changes at the social, political, national, and global health levels and infrastructure can be informed by such consideration. People are mostly encountered in our lives through what they do, the roles that they have within society (Heidegger, 1962:163). Power relationships, where they exist, thus are part of, and disruptive to, our daily lives (Heidegger, 1962: 164; cf. Bishop, 2011). We can translate this to the clinic. If the vulnerable, breathless patient has experienced social stigma, shame, and exclusion already, the power dynamics in healthcare can worsen their likelihood of adequate care and compassion, be this through epistemic injustice, boundaries to care, communication breakdowns, as we examine below.

Part Two: Shame, stigma, and social exclusion

6.5 Shame

Shame is not, as the general philosophical consensus has often argued, a self-reflective or evaluative emotion that causes the ashamed to experience anxiety at the thought of being judged negatively by others (Velleman 2001: 28–29n; cf. Dolezal, 2017). Whilst these elements comprise part of the story, such a definition falls short considerably: ‘Shame has ontological significance in that it has the power to reveal the self to its-self via the ‘look’ of another’ (Sartre, 1962: section x).[84] Whilst anxiety around how I might look to another comprises a shameful experience, it doesn’t constitute the entire experience (Sartre, 1962; Dolezal, 2017). Shame disrupts the ordinary flow of experience so that one has the opportunity to come face-to-face with one’s very own selfhood: in this case, the self as something to be ashamed of ‘I am ashamed of what *I am.* Shame therefore realizes an intimate relation of myself to myself’ (Sartre, 2003:245).

Although shame is a variable experience related to an umbrella of related emotions and feelings from embarrassment to mortification, it is distinguishable from guilt. The latter arises when one feels disgusted with oneself over something they have done or caused and is not integral to their sense of self. The former, however, is about the self, the person that I am. My identity, my very self is the source of shame that causes others to think less of me (Dolezal, 2017). A ‘triangular’ framework thus comes into play. Me, the other, my self-consciousness of how the other perceives me in view of my transgression or flaw

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[84] For a discussion of Sartre’s three orders of the body, see (Sartre, 2003). Simply put, these include the objective, subjective and intersubjective levels. For our purposes, we are concerned with how intersubjectivity, or, to be precise, my observation of others observing my breathless body can worsen my illness as well as curtail my ordinary unthinking connection to others. Of course, Shame has an intentional structure in that ‘it is a shameful apprehension *of* something, and this something is *me*’ (Sartre, 2003: 245). It therefore rips me out of the present as I live it, absorbed in spying on somebody, uttering a question and immediately regretting it, picking one’s nose. As suddenly, ‘somebody was there and has seen me’ (Sartre, 2003: 245). This other becomes the ‘indispensable mediator between myself and me. I am ashamed of myself *as* I *appear* to the other’ (Sartre, 2003: 246). This results in the self now judged as reduced to an object once one recognizes that the other has seen them and found them lacking. They judge their self as an object for the others evaluation. It is not to merely appear as shameful to the other then. It is an affective, immediate recognition that I am ashamed; that I am that which the other sees me as: ‘shame is an immediate shudder which reins through me from head to foot without any discursive preparation’ (*ibid*.,).

(being ill, being breathless, being anxious) constitute this framework as a shame as a ‘triangular experience’ (ibid.). It is structured by our interdependence with another person, and others more widely.

Why should this be so? How is so much power held in the shameful look of another? This is because how we view ourselves is bound to a deep-rooted sense of belonging:

> Sartre’s account does in fact reveal something essential to the structure of human existence: the vulnerability at the core of our existence and the concomitant human need for connection to others, or belonging. (Dolezal, 2017: 423).

Being-with thus permeates every element of our lives, from the affective to our ideas of self-identity. As I have argued, identity is altered via breathless and anxious experience. This ‘self-conscious’ evaluative emotion is often reported by patients, and thus its negative consequences for patient experiences and treatment adherence and outcomes are unsurprising. They are ashamed of themselves for being dependent, worrying that they are being seen as shameful by medicine and society and so do not voice their concerns that they have heard negative things about long-term steroid usage, or how the medication inhibits their sex life, for example. Shame prevents such communication.

As we are trying to capture what it means to be breathless, we must explore shame and stigma in society and medicine and healthcare, then. In the case of illness, shame causes anxiety as we perceive ourselves as guilty of some transgression (smoking, being unhealthy, and so on) in the eyes of the doctor and of society (Leder, 2015). Becoming aware of how others regard my breathless body makes me painfully aware of my sick body. In this way, I suggest, shame related to respiratory conditions and related mental health conditions worsens anxiety as it disrupts the connection to others, increasing suffering and inhibiting treatment outcomes as our bodily vulnerability is seen as ‘our own fault’. We did not lead a healthy lifestyle, we cannot control our bouts of panic, and so on. Marked as deficient and blamed by others for not being somehow good enough, we are burdensome to others.

Rates of anxiety and depression thereby increase, and a feedback loop is created (see Chapter 5; cf. Leder, 2015). The breathlessness feeds the anxiety, and the anxiety feeds the breathlessness. Patients may become housebound as they fear an acute exacerbation event and do not want to feel judged by others as they become short of breath (Guillick & Stainton, 2007). Muscular deconditioning occurs as the muscles are used less and less, causing the patient to become further unfit, isolated, trapped in a shrinking life-world (Ekstrom *et al.*, 2015). When vulnerable, feelings of helplessness interact with the physical illness to worsen our resilience and our suffering. Social withdrawal, the widening gap between the self and others, alters our relationship to others from an idealised status of equality to one of reliance on others for our wellbeing. Intimate relationships may change as important intimate partner bonding activities, such as sex, are disrupted (Johnson, 2016). Shame at feeling unable to perform or being too embarrassed to discuss sex with the doctor may mean that another important area of human existence is closed off to patients and their lovers.

Research shows that sex and sexual activity is fundamentally important to people, including older adults, but decreases with the onset and progression of breathlessness (Hanson, 1982). Lack of research and understanding contributes to clinicians overlooking or addressing this with patients. It also results in worse perceptions of health: 'breathlessness contributes to sexual inactivity and worse perceived health in older adults, which calls for improved assessment and management' (Ekstrom *et al.*, 2018). Thus, if feelings of shame continue and the underlying cause is not addressed, the gap in communication between the ill person and the healthcare provider widens. This can lead to further isolation and once again, increasing rates of mortality, morbidity, and suffering. It is a perfect example of the consequences that can arise as described in Toombs' two differing realities in medical and patient discourse (Toombs, 1987; 2001).

However, can shame provide an opportunity to forge new relationships, new ways of being-with? As Dolezal argues, '[s]hame originates from our embodied vulnerability and serves to help us maintain the social bonds necessary for our (physical, emotional, psychological and social) survival' (2017: 422). If Dolezal is right, then a realm of possibility can be opened. Shame caused by breathless experiences may mean that, rather than a maintenance of social bonds, there is a transformation occurring within those bonds. Our relationships with others can become more honest and authentic, as one no longer has time or strength to waste on pursuing bonds that are inauthentic. For example, 'fair weather' friends may disappear, but the patient will discover that other relationships are strong (cf. Carel, 2011). New opportunities for forging relationships may occur when joining patient groups, such as pulmonary rehabilitation. Here, patients and carers can meet people in similar positions who understand the unique challenges that they each face, and share these experiences without judgement. One's identity and social belonging can thus be reclaimed (Leder, 2015).

However, for these opportunities to exist, there needs to be more support from healthcare institutions, community groups and society more widely. Government funding in the UK is still lacking, despite rising rates of chronic breathlessness in the population. Charitable organisations can only do so much. With regards to shame, normalising these feelings and emotions can be made possible by compassionate attention from the healthcare practitioners (known as socialisation in the psychological literature). Mental health services too can utilise therapeutic interventions, such as acceptance and commitment therapy (ACT), or psychoeducation in cognitive behavioural-based interventions. Mindfulness cognitive behavioural therapy in conjunction with pulmonary rehabilitation, too, can lead to resilience to overcome shame (cf. Malpass *et al.*, 2018).

In short, shame reveals the essential nature of being-with (*Mitsein*). For as soon as it arises, it is not referring to an isolated ego ashamed of their own behaviour. Rather, it has arisen from the relationship to another person. So shamefulness, like boredom or angst, appear as potentialities of one's being in relation to both the self but also to others: 'for they are meanings and as such they surpass the body and at the same time refer to a witness capable of understanding them and to the totality of my human reality' (Sartre, 2003: 246).

6.6 Stigma

Whilst shame, then, has the ability to damage, it also may positively affect our lives through pressurising us to give up smoking, or in seeking new friendships. Can we say the same of stigma? Shame and stigma are both related to low self-esteem as well as a cleaving of social connectedness in general. For Zahavi, shame entails a decrease in one’s self-esteem as well as being a social emotion that is ‘essentially characterized by the way it affects and alters our relationship to and connectedness with others in general’ (Zahavi, 2015: 223). This is starkly present in David Lean’s 1970 film ‘Ryan’s Daughter’. In one scene, Sarah Miles’ character Rosy Ryan is humiliated by the Irish Catholic community. They tar and feather her to try to evoke the shame they feel she should have for not only cheating on her passionless, much older husband, but for doing so with a British soldier. The viewer is alongside her in her humiliation, perhaps even experiencing this bodily as our heart rate quickens. The stripping away of Rosy’s subjectivity is clear in the culmination of the scene, through the act of stripping her naked, shaving off her beloved hair, and tarring and feathering her. She has become a thing. Rosy refuses to continue to be shamed, and leaves the community with her head held high. However, although she recovers from the shameful experience, she is still stigmatised, marginalised by the community: some heckle her, some ignore her, but almost all cast her out as a ‘thing’. The temporal dimension thus matters shame is transient, while stigma has the power to further disrupt being-with others for longer. It thereby has much longer lasting effects on the person, their self-identity, and the feeling of connection to others. In this way, it is much more damaging than shame, as we see below.

6.7 Stigma and social exclusion

Many of the experiences and illnesses discussed throughout this thesis have, for the most part, been typically thought of as reflective of the ‘socially abnormal’, deviating from our often-unconscious norms and construal’s of what it is to be a healthy agent (Leder, 2015): the mentally ill, the COPD patient, the disabled. Erving Goffman (1963) was interested in the separation between the normal and abnormal in addition to how the stigmatized abnormal person ‘can shore up his precarious, social and personal identity’ (Goffman, 1963: 63). To be stigmatized is to be stereotyped and excluded.

We are all subjected to unconscious social expectations and norms that mediate social encounters. When we deviate from these, we can be labelled as ‘deviant’ or ‘abnormal’. Goffman offers a far-reaching account of stigma (1963). For our purposes, to be stigmatised is to be deemed to have disagreeable qualities from the point of view of our social grouping, seen as abnormal and/or disgraceful (Leder, 2015). These unconscious biases then act as arbiters when we interact with one another. You are poor? You have been to prison? You have a smoking-related lung disease? You are mentally unwell? Sadly, these cases often result in stigmatisation, which in turn damages social standing, a person’s identity, and self-esteem (Goffman, 1963). Access to social justice and healthcare diminishes as more opportunities are closed off from the perceived abnormal, testimonial unreliable, patient. This is not mere supposition: there is plenty of evidence to show that poor, socially excluded groups are often those with higher rates of smoking, poor health, unemployment, and risks of criminality (WHO, 2012; 2016).

Once one is stigmatised, the effects can last a lifetime. One may further cut oneself off from society as shameful experiences become the norm. A key difference from shame is that stigma comes from others in the world. Social exclusion and marginalisation thus result in a person being less likely to visit the doctor, less able to afford prescriptions, and less likely to feel included in the social world, eroding their sense of belonging and community (Leder, 2015).

In the case of prison, rates of smoking, mental health problems, and respiratory illness are much higher than the non-prison population (Turner and Jefford, 2014; Leder, 2015). Yet pulmonary rehabilitation, smoking cessation programmes and good mental healthcare are rarely offered (Glover, 2012). The prisoner is objectified and subject to all manners of depersonalisation, including being separated from loved ones and stigmatised when they are eventually released. It is perhaps no wonder that this population suffer some of the worst quality of life. The beliefs and judgement of non-prison populations often characterise their illnesses as ‘moral failure’, or deserved (Ehrenreich, 2009; Leder, 2015). This results in the loss of the sense of self and a person may punish themselves, as well as being punished by society and other institutions. In short, categorising people of the basis of their socio-economic status, their health, and/or their past actions, fundamentally harms them as they are excluded from society.

Thus, stigmatisation has insidious effects on the lived world of the stigmatised. Isolation from others imprisons them within a shrinking world devoid of opportunity and access to adequate care (Leder, 2015). Thus, we can see that social exclusion and marginalisation contributes to respiratory conditions, and untold suffering that must be addressed.

6.8 Epistemic injustice revisited: considering socially excluded groups

Stigmatisation is inherently damaging to patient, to the clinical encounter, as well as within larger society. Yet in cases of respiratory disease such as COPD or within severe mental disorders, it is often left unaddressed. Could philosophical thought have a part to play in this problematic? I suggest yes. As argued previously, the primacy of the Cogito still informs our thought and judgment, the value that we place in the perceptions of others. Merleau-Ponty writes that:

> The Cogito has, up until our present day, devalued the perception of other; it has taught me that the I is only accessible to itself, since it has defined *me* through the thought that I have of myself, which I am clearly alone in having, at least in the ultimate sense. In order for the word “other” not to be meaningless, existence must never reduce itself to the consciousness that I have of existing; it must in fact encompass the consciousness that *one* might have of it, and so encompass my embodiment in a nature and at least the possibility of an historical situation. The Cogito must find me in a situation, and it is on this condition alone that transcendental subjectivity will, as Husserl says, *be* an intersubjectivity (Merleau-Ponty, 2012: Preface Ixxvi).

We can reconcile this Cartesian primacy alongside the judgment of healthcare practitioners who ‘know best’, who disregard the perception of the patient as an other, forgetting that we share this historical setting along with their perspective and experience of their illness (Bishop, 2011).85 Epistemic and hermeneutical injustices are therefore quite likely to result with each person in the position of power over the patient ending up

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[85] Jeffrey Bishop call this the totalising gaze of medicine, that both treats the ideal body as a corpse theoretically, whilst trying to help but ultimately harmfully ‘penetrating’ every facet of the patients’ lives (Bishop, 2011: 283). They are thus categorised, prodded, managed and subject to a biopolitical power that takes for granted its inherited metaphysical worldview that is structured by splitting the bdy and the subject. In short, depersonalising the care that they intend to make personal.

framing their interactions with the patient as an inaccessible and unknowable other. Such a way of seeing ourselves and the othering of other persons forgets the unity of perception-body-world and other that Merleau-Ponty’s descriptive phenomenology uncovers. The consequences of this leads to misunderstanding and lack of understanding the experiences of the other, attributing value only to what the expert judges as relevant in the medical encounter. Feeling devalued, alienated, judged can cause a patient to not only disengage from treatment adherence, for example; pertinent information that may be relevant is discounted as their testimony is ignored (Baron, 1985; Fricker, 2007; Bishop, 2011). Stigmatisation only deepens this then.

This is why I have made a case for the using phenomenology to describe the transformations in experience brought about by breathlessness and anxiety. Discussing social marginalization and exclusion via the example of prisoners and high rates of comorbid respiratory and mental health conditions additionally demonstrates that the unique experiences and circumstances of the patient matter when we consider the rising rates of these problems, and the impact on the self and others.

Social disadvantage, marginalization, and epistemic injustice are further compounded by stigmatisation; with the low status of sufferers, blame for poor life choices and lifestyles, and for failing to attend appointments, adhere to treatment and co-operate with pulmonary rehabilitation and mental health interventions all linked together (Leder, 2015: 176). What we have here uncovered is how the already marginalized may be further silenced and stigmatized by society, governmental institutions, and healthcare organizations (Turner and Jefford, 2014). When one is rendered breathless and disempowered, one is often rendered literally speechless, with no-one to speak up on our behalf.

Ultimately, hermeneutical and testimonial injustice is therefore increased. For example, a former convict may not only be unable to access specialist healthcare such as smoking cessation and pulmonary rehabilitation whilst in prison, but studies suggest that he is unlikely to access these when out (*ibid*.). Why? We have seen how powerful shame and stigma are, and how they are linked to those that have been excluded from normal society, cast out like Philoctetes (Leder, 2015: 18). It is not hard to see how testimonial and hermeneutical injustice results from layers of silencing (Crichton *et al.*, 2017). I suggest that the lived world must be attended to in such circumstances. Holistic healthcare that focuses upon factors such as socio-economic status, unique needs, social care, and so forth, would provide better care for marginalized individuals, as well as for patients more generally. In the next part, I will make suggestions for this via Levinas and building upon the idea of an ethics of the breath.

6.9 Generality, individuality, and overflowing

A caveat: in order to think about or present a philosophy of breathlessness, specifically in relation to chronic illness, I now underscore that it will more useful to conceptualise such experience in terms that capture the reality of how they are lived existentially. This is with an emphasis on how specific cases 'overflow any ideas' we have of these (Dolezal, 2017: 319). That is, the non-reducibility of these variations to lists of symptoms, in addition to the clinically recorded difficulty in felt symptom severity across conditions, then make sense, particularly when utilising a phenomenological framework. Eschewing naturalistic and Cartesian accounts of body and mind, *psyche* and *soma* to map onto our presupposed scientific (and hence 'proper') ways of describing breathlessness is thus demanded. These accounts have failed and will continue to fail because they cannot account for the generality across human experiences of breathlessness, in addition to their specificity: their unique expressions. This is where phenomenological description steps in.

This doesn't preclude acknowledging the danger of generalising. Generalisations, categorizations & stereotyping are also performed by political, governmental, medical, and social structures and institutions. Yet these forms of generalisation are harmful without such attention to specificity of a person's unique situation and experience. They extend stigmatisation. This is also harmful, as they perform a type of *symbolic* violence through process of exclusion and erasure of 'non-normal' populations (Bishop, 2011). That is, the alterity of others, that 'unknowable difference and value of particular persons' is ignored completely (Diprose, 2017: 22; Levinas, 2016). The violence is symbolic as rather than inflicted physical violence on the person; it instead causes harm to the persons status as a person as 'fear, divisiveness, social conflict, and/or indifference to difference and to the plight of the less fortunate' is promoted (Diprose, 2017: 21). This includes a failure to protect their rights and inciting violence through this status as 'other', as not-normal (Canguilhem, 1991; Eccleston, 2016).

The body of the other is deemed as not-normal, as deviating from the norm and thus not considered in, for example, health and social welfare decisions and policy making. Apart from the obvious issues surrounding epistemic injustice (see above), health inequalities then continue to grow and the vicious circle of underdiagnosis, undertreatment, worsening morbidity and mortality, and multi-morbidities, are the consequence. If lack of consideration and funding when making important health policies to redress social exclusion continues, then the gulf between the health of the have and have nots, widens. For injustices do not occur only at the epistemic, or physical, level. Selves, embodied knowers, are integral for and interrelated in political and healthcare levels. Indeed, even the gaps – the spaces – between people implicitly implicate the body-subject. With regards to self-perceptions of blame with respiratory illnesses and mental health stigma, we can contextualise how sociality, or Being-with has structured these self-understandings and identifications. Consequently, projecting the blame of what we believe others think of us (whether correctly or incorrectly judged) impacts not only our feelings of responsibility and self-worth, but also shapes how we relate to others, including healthcare interactions (Bishop, 2011, cf. with Heidegger's notion of the anonymous other, *das man*):[86]

> 'All of us grow up in and draw our first understandings of things from the average explanation of being and beings "published" by everyday hearsay. Much that is useful is learned from hearsay, the common basis on which, and from which, and against which, all genuine

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[86] Das man is the anonymous and public mode of Dasein's selfhood whereby norms, values and individual conduct is decided by the oppressive commands that 'One does this', 'One says this', 'One expects this' and so on, delimit our own potential abilities and activities. It thereby covers up our not only our individuality; the 'ontological character' of Dasein, or the body-subject, is silenced (Olafson, 1998: 3). Our potential for authentic, original self-understanding, behaviour and existence by owning up to our self-interpreting nature and freedom (within the limits of our factical constitution) cannot be claimed if we think of our own self in terms of what we think 'One' should do. The tyranny of the 'They' or the 'One' substitutes our Being for a levelled out and anonymous way of Being where we throw off the difficult and sometimes threatening responsibility of taking control of our lives. 'One teaches', 'One stays at home to look after the children', 'One plays the part of the good patient', dictate who we are and who we can be if we do not recover our own responsibility. Of course, this anonymised way of living is not always wholly negative; within our everyday lives we often fall back on public ways of thinking and behaving to complete certain tasks and social transactions without constantly having to worry whether we are truly free or responsible for all that we do. This would be likely impossible. That is not Heidegger's, nor existential and phenomenological thinkers point when discussing the dangers of losing one's identity and selfhood by always interpreting and comparing the self to others. It is to gain new insights into who one is, or can be, and to own up to one's own responsibility for one's own self. I cannot substitute my responsibility for finishing my studies in a timely manner, or parenting my children, for quitting smoking, for somebody else's. It is my choices in life, and only mine, that I can choose to take to responsibility for.

understanding and communicating and rediscovering take place….It decides in advance even the possibilities of attunement- that is, of the basic way in which Da-Sein lets the world touch him, concern him. “They have always already prescribed what one sees and how one feels about the world and oneself’ (King, 2001: 86).

Part 3: Levinas and co-breathing.

6.10 Levinas: Summary & Beyond

As we saw in Chapter 3.4, Levinas called for a demythization of myths; of inner and outer. Instead, focusing on 'beyond essence', on the space between us and the others and the openness to the outside allows a rebirth of meanings 'deeper and broader' than freedom or individuality (Levinas, 2016; Škof, 2016). The very outside space of air taken inwards animates our notions of freedom, subject and object. Epistemology, ontology, and the naturalism underpinning the medical framework is also nourished by the air. Recall, '[f]reedom is animation itself, breath, the breathing of outside air, where inwardness frees itself from itself, and is exposed to all the winds' (Levinas, 1998: 180). To paraphrase, he tells us that the act of inspiration, of unconsciously exposing ourselves to the air – no matter its condition – frees us from 'closedness'; the prior theorising about respiration and the participation in co-breathing the air. 'The emptiness of space'. Attending to this unconscious passivity of participating in the air reveals its significance hitherto largely ignored by philosophers. This significance was revealed to be an opening, or more precisely a bridging, connecting the self and the other by breaking down the gulf that Cartesian (individualistic) thought dominated (Levinas, 2016).

The very act of breathing uncovered our responsibility to the other. Not just the demand in the face obliging us into a reciprocal relationship: the very nature of our respiration, our (co) sharing of the air, generates an ethical demand to respond to the suffering of the other (Levinas, 2016: 181). This responsibility is created by the unconsciousness of breathing prior to a decision between, for example, clinician and patient, mother, and son. It is within the very:

> breathing by which entities seem to affirm themselves triumphantly in their vital space… a coring out of my substantiality, that in breathing I already open myself to my subjection to the whole of the invisible other,. (Levinas, 2016: 181)

There is no *personal* breath split from the co-breathing of the air, then. The other is always implicated for him. The ethics of alterity, now become an ethics of the co-breath here, I suggest.

Breathing is thus ‘a transcendence’. It underpins the spaces for contact, interaction, and connections. The pneumatology of the other is born through this. Just as air opens our connection, the breath connects us, and co-breathing is the necessary element for our dialogue and communication. Such a refocussing on the significance of the powers of the proximity of breath makes explicit we owe the others a debt of care: ‘…to free oneself by breathing from closure in oneself already presupposes thus beyond: my responsibility for the other and my aspiration by the other, the crushing charge, the beyond, of alterity’ (Levinas, 2016: 180-181).

What can this tell us about shame, stigma, and taking personal responsibility? What can this mean in the clinic? I already covered how responsibility grounds subjectivity and ethics for Levinas (Chapters 3 & 5). This is that the very breath itself demands attention, a co-breathing in that we all partake in. Personal responsibility of all parties involved in the clinical encounter of breathlessness fits here. Philosophically speaking, Levinas can only partially absolve us the blame and shame caught up in many of these interactions. For him, we must dispense with seeing the agent in any of these situations as always intentionally acting. This can release all parties of elements of blame, shame, and stigma alongside drawing out how such non-intentional yet harmful consequences, come about. His philosophy gives us a deeper understanding into the complexity of human thought and action, which when we operate in the natural attitude, we cover over. What do I mean by attending to this ‘non-intentional’? Levinas tells us:

> To understand a tool is not to see it, but to know how to use it; to understand our situation in reality is not to define it, but to be in an effective state. To understand being is to exist. (Levinas, 1991: 3 cf. Heidegger, 1962; Merleau-Ponty, 1962)

We see that lots of acts are therefore not intentional, but traces left by other aims and actions. For example, in pulling out a chair, Levinas told us,

> I have folded the arm of my jacket, scratched the floor, and dropped my cigarette ash. In doing what I willed to do, I did a thousand and one things I hadn’t willed to do. The act was not pure; I left traces. (Levinas, 1997: 3)

These traces implicate our responsibilities ‘beyond our intentions’ (*ibid.*). Our relationship, with the world, with others, is therefore not exhausted in reality by our mere conscious intentions. Levinas gives the example of how, in trying not to fulfil a prophecy, Lauis still brings about the step's requisite for their fulfilment (Levinas, 1998). Similarly, the witches' predictions come to be through Macbeth's attempts to act out the favourable elements, but to also take steps to prevent the unfavourable; he thereby seals his fate. As a man born in the 1920s, I may have smoked, unaware of its destructive consequences. I did not know that the tobacco industry used unscrupulous medics to advertise the health benefits of smoking, or how its popularity in films and society belied its harmful nature. Now I have given up smoking, I'm still chronically unwell. The intentional and non-intentional acts (for I didn't knowingly cause my illness) imply others: the tobacco and advertising industries, healthcare, government policies, and so on. So although there can be a partial absolution of blame, it is still necessary to take responsibility for our actions and lives by considering how we may affect others.

Yet is it feasible to expect these issues to be considered when we make healthcare decisions for ourselves and for others? It must be, if we are to improve patient outcomes and prevent the increasing spread of respiratory conditions; if we are to improve global health; understand the impact of breathlessness on both individuals and wider society; and alleviate suffering and worsening mental health and the decline in cognitive ability. Indeed, increasing links between good mental health and physical wellbeing on the one hand, and air pollution, the rise of respiratory conditions and cognitive and psychological problems, on the other, suggest two things. One, the rise of anxiety in the population is due in part to the rise in ill health, specifically for my purposes from (but not limited to) environmental and social structures caused by air pollution and inequalities. Two, respiratory illness cannot be treated fully without consideration of mental health needs, or social and environmental considerations. These can be as obvious as considering the transformations to experiences of distance as mobility decreases (Chapter 4), but also includes honest conversations between clinicians and patients, carers and institutional organisations of the responsibilities that each bear in alleviating the wide-ranging symptom impacts, and their causes. In short, considerations of what we owe the other in terms of our responsibilities to the suffering, breathless individual:

> Courage consists in being reliant on oneself and others to the extent that, irrespective of differences in physical and social circumstance, all manifest in their behaviour and their relationships that very same spark which makes us recognize them, which makes us crave their assent or their criticism, the spark which means we *share a common fate.* (Merleau-Ponty, 2005: 67).

6.11Totality and Medicine

The philosophical tradition’s obsession with rationality belies an ‘all-consuming force which absorbs everything into itself’ (Moran, 2000: 329). This is what Levinas means by totality, and what we can apply to Jeffrey Bishop’s charge that medicine, borrowing Western metaphysics and epistemology, is the totalising focus that attempts to represent everything, to control the body and see it as an object (or corpse devoid of life) for science (Levinas, 1997; Bishop, 2011). As Moran puts it:

> ‘In trying to break through the stranglehold of ‘totality’, Levinas evokes experiences of the unbounded and indeed infinite nature of the ‘other’. For Levinas, that which challenges the sphere of totality may be understood as ‘transcendence’, the ‘other’, and the ‘infinite’; and Levinas may be seen as trying to open up phenomenology to describe this transcendent dimension of human experience’ (Moran, 2011; 329).

Moreover, all knowledge in a sense reduces being and thought as representation, objectification of that which is sought. This is why Levinas charges that ‘knowledge seizes hold of its object. It possesses it. Possession denies the independence of being’ (Levinas,1963: 8). Such a framework is comparable, once again, to Bishop’s criticism of the totality present in medical thought as a ‘biopolitical realm’ that seizes the bodies of mankind (Bishop, 2011: 285). For both, there is violence present. Violence as a ‘man [who] does not move out of himself. He takes, he possesses. Possession denies independent existence. To have is to refuse to be…. To know how to perceive, to seize an object – be it a man or group of men – is to seize a thing’ (Levinas, 1963: 9).

For Bishop’s part, the violence is akin to Foucault’s criticism of the medical gaze, but furthered with technological medicine that reifies scientism as the way to come to know the patient. Applying such a totalising gaze to the patient is thus to harm him, and so to commit violence, I suggest. For every moment of their lives and care become penetrated, perhaps inappropriately so. There must always thus be an uneasy relation between doing the what is perceived to be the most helpful guidelines to the person and their family, with the respect of their wishes and privacy.

For Bishop, and for me, the caring motivations of health care practitioners are not under interrogation. Here too, we recognise the importance of practitioners to caring for the ill and distressed. Rather, the metaphysical worldviews and epistemological subscriptions are under attack: it is these unexamined commitments to a totalising philosophical regimen that must be revised to alleviate the problems heretofore discussed. All that can be done here is to expose such a problematic and suggest potential ways to overcome (an admittedly small, yet undoubtedly important) area: care and socio-economic relations related to breathless experiences. Perhaps this is no more evident in the care of the dying as well as the breathless. These two are not mutually exclusive: for breathlessness is present in so many cases of respiratory and non-respiratory related illnesses as at the end of life.

6.12 Breathing at the end of life

Breathlessness is not just characteristic of respiratory disorders or mental health conditions such as panic attacks, anxiety, or panic disorder. As intimated in Chapter 3, breathlessness is also frequent in cardiac disease and cancer, and commonly occurring at end of life in both hospital and palliative care settings to an extent that reliably predicts impending mortality (Gruffydd-Jones *et al.* 2017). In effect, even though it is considered an invisible experience, it is extremely widespread to an extent that demands addressing. Terminal, or ‘agonal’ is the name for such breathlessness at the end of life (Johnson et al., 2016). It is here where I am would like to give an interpretation of Levinas’ ideas around an ethics of proximity & an ethics of the co-breath. This is because the neglect of knowledge and understanding of the link between breathlessness and impending mortality as a predictive indicator prior to terminal breathing (whilst no fault of healthcare practitioners), leads both clinicians inexperienced in the recognition of these types of breathing, through to families and loved ones; to feel horror at what they may perceive as gasping for breath, indicating terrible suffering. If we can describe breathlessness in all forms, even at the absolute limits of life, we can begin to appreciate the significance of an ethics of co-breathing at the end of life. I think Levinas ideas can complement these needs.

Agonal breathing refers to the struggle to breathe at the end of life, or due to a life-threatening medical emergency. It is not ‘true breathing’, but a reflex instigated by the brainstem. Gasping for breath comes from a lack of oxygen, due to either the lungs being unable to get enough air, or the heart failing to circulate oxygen-rich blood. It signals a threat to life or the dying process and can cause immense suffering and horror for the friends, relatives, and carers of the dying who witness this without being aware of what is happening. It is called ‘agonal’ because the gasping, moaning, jerking movements, rasping, snorts, and laboured breathing seem to indicate horrific suffering (Perkin and Resnik, 2002). Lasting anywhere from a few minutes to several hours, the struggle for breath can look as though the person is suffering terribly, even though a lot of the time they may already be unconscious (Perkin and Resnik, 2002: 164).

This differs from what is commonly known as a death rattle: when mucus or saliva is caught in the chest of a dying person, a gurgling noise is heard. Marie Curie offer advice for both health professionals and loved ones when faced with this part of the care of the dying, but such advice is sparse, and the communication of breathing types not often imparted to those around the patient. This can cause unnecessary trauma on witnessing an already distressing event. For example, after a teenager passed away surrounded by family and friends, her mother witnessed her undergoing agonal breathing and reported that ‘she wished she that she had not had to see her daughter gasping. The mother is convinced that her daughter suffered and has frequent dreams where she revisits her daughter's last agonal breaths’ (Perkin and Resnik, 2002: 165). This is not only anecdotal:

> There is no question that these agonal breaths are distressing for both family and medical staff to observe… Many parents report that watching their children gasp at the end of life is among the worst experiences of their children's illness. Many parents can graphically describe the horror they felt when their child appeared to be struggling to breathe at the end of life; they perceived the child to be distressed. (Perkin and Resnik, 2002: 166)

So breath towards the end of life, I argue, is related to immediate embodied understanding, akin to existential feelings in those witnessing these events. By existential feelings, Ratcliffe defined these as a ‘felt sense of being rooted in a shared world, which shapes all experience and thought' (Ratcliffe, 2014: 1).[87] The body can be transparent, taken for granted (as in simple cases of autonomous functioning such as breathing, for example). Yet, as we have seen, it can also be brought to our immediate awareness, as in cases of breathlessness, chest pain, and air hunger. For the most part though, there lies an intermediate state (Ratcliffe, 2014: 4). This is where the 'body is often phenomenologically accessible in its noetic role, as that through which something else is experienced', *and* 'where The same feeling is sometimes both noematic and noetic, a content of experience and – at the same time - a way of experiencing something else' (Ratcliffe, 2014: 4). In short, the body exists within the two extreme states (in this specific case, but not limited to) when witnessing pathological breathlessness.

This is shown through the ability to have empathy (feelings directed to or from the other) and world-directed feelings and backed up through neurobiological research which shows experiences of the world and the body are inextricable (*ibid.,*). With breathlessness experiences, the non-breathless person can immediately sense the danger, the distress, the threat that takes over the breathless person. The sound of their disrupted breathing, the panic in their face, the entire embodied relationship triggers an immediate response in the embodied experience of the Other. They feel there needs to be an urgent and instant response to alleviate this suffering even when sadly, nothing can be done.

Levinas, I argue, was right, even though this part of his first philosophy went undeveloped. The demand that we attend to the other is nowhere more apparent than by seeing them struggle to breathe. The concept co-breathing thereby identifies a primordial structure of human existence. In emphasising this relation and making it explicit, we can appreciate how fundamental this aspect of human experience is. It is intrinsically related

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[87] Ratcliffe's groundbreaking account of existential feelings is the subject of many books and papers that I cannot do it justice here: "People sometimes talk of feeling alive, dead, distant, detached, dislodged, estranged, isolated, otherworldly, indifferent to everything, overwhelmed, suffocated, cut off, lost, disconnected, out of sorts, not oneself, out of touch with things, out of it, not quite with it, separate, in harmony with things, at peace with things or part of things. There are references to feelings of unreality, heightened existence, surreality, familiarity, unfamiliarity, strangeness, isolation, emptiness, belonging, being at home in the world, being at one with things, significance, insignificance, and the list goes on. People also sometimes report that 'things just don't feel right', 'I'm not with it today', 'I just feel a bit removed from it all at the moment', 'I feel out of it' or 'it feels strange'." (Ratcliffe, 2008: p.68). For further reference, see the bibliography.

to others: The intercorporeal relationship between human beings (via the co-breath) being more profound & accurate than individualistic philosophical conceptions of human agency have presented. In the clinic, in society, at home, we need to recognise these important yet often overlooked and taken for granted facts of life. By doing so, we may thereby avoid the tortuous experiences reported by patients' loved ones, and the healthcare practitioners who experience fear and trauma when witnessing severe breathlessness at the end of life. A common feature of many deaths, as we have seen. As these parents testified:

> '"When she was struggling (to breathe) that was the worst bit…the noise she was making it was like you were killing her or something—a horrible noise." (P13: father of baby with cardiac anomaly) "He was coughing, spluttering, gasping . . .the minute he (the doctor) was coming over (to check that his heart had stopped) he started again. I was just not looking...My arm was numb. They were saying, 'Go and have a lie down, this could go on for hours.' But I couldn't even move. I was just so damned scared. I think it was more his noises that haunt me than the colour of his blue hand. It was going on forever . . .It was two and a half hours." (P20: mother of severely asphyxiated baby) (McHaffie *et al.*, 2001: 85).

Breathing at the end of life, whilst extremely distressing for the patient and their loved ones, also poses challenges to health-care practitioners. It is not my place to suggest exactly what can be done to meet all of these complex and sensitive issues. Much more modestly, I suggest that incorporating phenomenological insight to the importance of attending to these first-person experiences can raise the general features shared throughout breathlessness as an intercorporeal experience that affects us all in this situation, alongside the specific situational demands that demand a more person-centred approach. Phenomenological concepts such as care, co-breathing, intersubjectivity, embodiment, and being-with help structure and articulate these. Nowhere is this more apparent than severe and pathological breathlessness, especially at the end of life. As Škof summarised:

> '[T]he death of a person has a double meaning for Lévinas (2000, 105): it is a person's departure and, for the other of the deceased—"What we call, by a somewhat corrupted term, love, is par excellence the fact that the death of the other affects me more than my own"—,but it is also "a halting of those movements and [: : :] an immobilisation"; that is the end of what animates a man; and the move(ment) of life par excellence is, of course, the very breathing. Lévinas (9) adds: "We meet death in the face of the Other." This

> relationship between life and death is where we should look for the meaning that breath has for the ethics of Lévinas" (Škof, 134).

Attention to different forms of breathlessness and the reliability of worsening breathlessness in predicting the end of life thus needs to be addressed. Healthcare practitioners must be trained to recognise such signs. We will now turn to the challenges that breathlessness brings to philosophy, and how philosophy can respond.

6.13 Breathlessness and air pollution: a building crisis for health and medicine

We have seen that personal, moral, existential, and ethical concerns are altered through respiratory and mental illnesses. These transformations occur where else, 'but in the air?' (Irigaray, 1997). That is, the air underpins respiration and our ability to talk, gesture and express our situation as an individual. Any changes to the air, to the respiratory apparatus, to blood oxygen levels mean changes to not only embodiment, but to cognition. Social structures, health and wellbeing, and our interpersonal relationships are altered when communication is altered, when being-with is modified and limited, as it is in chronic breathless experience. So, it cannot be a surprise (indeed, it is more of a logical consequence) that the increasing rates of air pollution, respiratory conditions and co-morbid mental health have risen. These issues thus required philosophical consideration due to the lack of Western philosophical study, the increasing prevalence of these experiences, and their situational causes in our socio-economic environments.

This tendency to ignore the air, the breath, respiratory conditions, and their related mental and social difficulties can be understood in many ways. Breathless and mental conditions are invisible and therefore taken for granted: silenced, difficult to articulate and stigmatising (see Chapter 2). Philosophy becomes salient, indeed necessary, when we uncover how such pathologies and chronic conditions distance the patient from their usual bodily transparency when accomplishing goals, habits and daily activities that otherwise 'go unnoticed' (Carel, 2016: 5) and hence why such illness becomes a 'violent call to philosophise' (Carel, 2012). As we have seen in previous chapters, this occurs through Toombs' 'loss cycle' and our tendency to be absorbed in a world of things and others

(Dasein-with), whereby fleeing from our own-most potentiality-for-being (*Seinkönnen*) is the default (Heidegger, 1962).

Studying pathological cases such as respiratory and comorbid mental health conditions can provide knowledge of these normal and 'abnormal' human ways of being in a similar way to how developmental psychology studies maternal depression and its effects on the infant's psychological capabilities and wellbeing in later life (cf. Carel, 2016: 5), or how dementia alters the self-identity and understanding of sufferers. Rather than just exploring the symptoms and their impact on the individual, the entire social world (being-with) must be considered. There is therefore much to be learned from focussing on the breath, the air, and on breathlessness. It can take on the role of a heuristic device, similar to the way that the phenomenological study of illness functions (in part) as a 'philosophical tool' in Carel's 2016 study, or how depression sheds light on our being-in-the-world and disruption to existential feelings as seen in Ratcliffe's (2012) work, for example.

In light of the structures of existence changed through breathless experience, the increasing choking nature of our cities and our towns, and higher rates of respiratory distress predicted within the next decades, with little effort made by governments to make adequate changes, is the future bleak? I have argued that it is not enough to make personal changes (for example, embarking upon a healthy diet, exercising more, quitting vaping). We can build resilience, adapt our responses to breathlessness, alter our healthcare institutions, and practice yoga, mindfulness, or any other therapeutic intervention that we want. However, collectively, at the socio-political level too, there must be change:

> Environmental toxins and carcinogens, a food system slanted by government subsidies towards unhealthy calories, chronic unemployment, racism, the lack of accessible day and healthcare – these causes of disease can be understood and addressed only on the collective level. (Leder, 2015: 66)

We see that the onus for change is not on the individual or clinician alone. If we attend to the increasing suffering in, and high rates of, respiratory illness, looking at the present and futures (and informed by our past experiences as historicity), we must campaign for change at the socio-political and economic levels. Co-breathing structures health just as it structures illness.

6.14 Practical suggestions and policy recommendations

> The task for medicine is not to go backward but to better integrate new discoveries with an age-old awareness of humanistic care, spiritual meaning, and healing environments.
>
> *(Leder, 2015: 70)*

Accepting that our lived experience and our very existence is reliant on the Other, with reciprocal calls to care for them (at the very limit, within healthcare practice), what could an ethics of the breath incorporate? Through Dewey's description of human experience as a 'rhythm of intakings and outgivings', Lenart Škof builds upon Levinas' breath focus. He argues here for a correlation with the breath (Dewey, 1987: 62; Škof, 2015: 2). Thus, human existence, experience, and being-in-the-world is *preserved* via the motion of this 'stream of interpersonal experience… [that] resembles the stream of breath' (Škof, 2015: 2). Each breath connects us with the environment, with others, with the world. It is lived through and carries expression and signification as it is enacted. For example, our distress is immediately visible to others in our ragged breath at the end of a race, during an asthma attack or when we are choking. Such disruption to the often autonomous, quiet, unobtrusive life supporting and life sustaining function demands immediate attention to those outside the breathless person. It is here that an ethics of proximity, and ethics of breath, can be furthered in terms of praxis. Hence, Škof argues that:

> To be connected with every breath we take denotes our connection with every- thing and everyone. This process does not contain anything metaphysical; on the contrary, the (new) cosmology, epistemology and ethics are mirrored in it. This is the space of new spiritual energies that feed the impulses, wishes and hopes that guide our actions. Through that, the world of the inter-subjective and the ethics and politics stemming from it, are connected to the most essential aspect of human lives—our breathing in and out and their role within nature and the community culture that are our breath's living spaces. (Škof, 2015: 2).

An ethics of breath is to thus be constituted by the 'mild gestures' of care, compassion and of patience (Škof, 2015: 5). What does he mean? He calls for us to stop suffocating other, the environment and the world through our endless acquisition of 'stuff' as a cost to the lives, the breath of the world and all that resides within it. By attending to our habitual gestures, our connection with others, he argues that we can become more 'receptive' to the breath of others, and thereby to their very lives (Škof: 2015: 6).

Although Škof's focus is upon building a larger radical ethics intersubjectivity based upon non-violence (an admirable and fascinating philosophical pursuit), for my purposes I will be only attending to the breath-based material. However, such a new ethics of the breath has not yet been fully spelled out, in part because it requires a new way of relating to one another:

> It should not be forgotten that this is also a task, for us to learn how to ethically respond to the call of another human being or of a non-human species and their breathing, since breathing means staying alive and sensing everything and everyone that is alive around us (Škof, 2015: 8).

Škof notes that 'Levinas has fully developed his idiosyncratic thought of breath(ing)—of soufflé, air and vent, but also of lungs as an ethical organ of breathing, an organ being there for the other, (co)breathing with her' (Škof, 2015: 14; Levinas, 1997). However, a full ethics of breathing has not followed, and it is beyond the possibilities of this thesis to build one here. Rather, we can build upon these ideas with help from other phenomenologists to suggest how one could orient themselves to the breathless patient, as outlined below and in Policy recommendations within the Conclusion.

6.15 Conclusion: Authentic healthcare

Illness often 'sever[s] the patients' habitual trust in his or her own body, community, and universe of belief' (Leder, 2015: 77). Caring authentically, whether through the therapeutic alliance, the compassionate touch, the face-to-face encounter, and so forth, can help bring back the patients' being-in-the-world, creativity, and adaptability. Even if it is an altered world due to the physical constraints of breathlessness, care that focuses on the patient as a whole person can restore their sense of belonging to a community, to a world. Depersonalised medicine, the depersonalisation of anxiety and panic, can be overcome. One's body is different, yes. However, with proper understanding, empathy, and communication the healing process can restore one's power and some control of the heretofore betraying and betrayed body. The two separate realities of the clinician and patient can come together within this between-world that is bridged by authentic person-centred care.[88]

Such practice can re-orient the lived experience of the patient and their family. Instead of being a passive object, prodded and prescribed treatment by the clinician, they regain their agency through shared decision-making, feeling heard, their suffering acknowledged and experience validated (Kirkengen, 2005). Evidence of the healing effects of the therapeutic alliance abounds (Leder, 2015; Aho & Aho, 2005). This is not a suggestion to unseat all the objectifying, necessary elements of medicines, but rather, to augment these with a return to the patient's unique needs and personhood to restore their dignity and sense of self. The alienation of the illness that causes splits from one's own body, sense of self, others, and from the world, can thus be redressed. So too, can the unhomelike being-in-the-world caused by depersonalised healthcare, be overcome (Sveneaus, 2001).

Hospitality in healthcare can therefore be restorative: care as being-alongside an-other in their distress and responding with solicitude rather than fleeing, avoiding, or dismissing, opens up an honest, trusting space. We must recognise our fleshy, vulnerable being and how is it bound up to the lives and the fates of Others. For, '[o]ur living flesh is the vehicle whereby we perceive our surroundings, move towards desired goals, and interact with others, resonating with their moods and intentions' (Leder, 2015: 75). Tying together the themes and findings from phenomenology and research in the wider medical humanities, we have seen how our relationships with others can positively or negatively impact our health, self-understanding, and sense of belonging to a society. Care as solicitude and responsiveness to the ethical demand of the breath can be accomplished by the following (not exhaustive) list:

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[88] Discussing authenticity in relation to illness can leave a bad taste in the mouth. Who is to say whether your response to your bodily transformations or limitations is authentic or inauthentic? This is why I steered clear of using this in terms of a value judgment and instead focussed on its relationship to individual human existence in the context of freedom and responsibility. I will not be discussing authenticity in such a normative way. However, that doesn't mean that phenomenology has nothing to offer in terms of authentic and inauthentic ways of Being-with one another when one is ill. In other words, to rectify the underdiagnosis of the illnesses that this thesis has focused upon, to help avoid further suffering, misdiagnosis, various injustices suffered by patients, it is necessary to focus upon other ways that we can be together in the medical and indeed within general social encounters.

1. Removing shame, stigma, and reclaiming one’s sense of self damaged by breathlessness, stigmatisation, and diagnosis.
2. Attending to the patient as person, inclusive of fostering, for example, Heideggarian care as ‘leaping ahead’ instead of ‘leaping in’.
3. Development of an ethics of breath, a recognition of our duties to Others in their distress and their humanity.

With regards to the first case, we have seen how ‘healthy individuals are formed and recognised within healthy community’ (Leder, 2015: 192). When shamed and stigmatised, the self can be lost. We must help return this loss of self, of control, of wholeness, through removing stigma and building resilience in the formation of a new, albeit transformed self. Rather than the Foucauldian ‘docile body’ that has been subjected to disciplinary clinical procedures, self-harm, social punishment (e.g. ostracization), we can offer care and compassion to the self (if we are the patient), or to others (if we are the practitioner). Agency can thus be reclaimed if, rather than ‘doing what we are told’, like a thing or object is commanded, our relational existence is acknowledged and changed accordingly to reflect this. This can only be through empathic caring that non-judgmentally attends to the unique needs of the person and their situation. It must be holistic, as we have seen, the physical, mental, spiritual, and socio-economic features of a person cannot be treated in isolation as they are bound together. Secondly, authentic care as leaping ahead rather than in frees both the patient from being a docile body, as well as the practitioner from dominance and its harmful consequences.

Thus care [*Sorge*] is the very meaning of Being-in-the-world: it structures our lived experience through and through. With regards to others, Heidegger tells us that the authentic way of being-with others is care as solicitude [*Fursorge*]. This was split into ‘leaping in’, whereby one leaps in for the other, thereby taking over their burden of existing (Heidegger, 1962), thus taking away the opportunity for the reclamation of self, of being able to exercise one’s agency and face personal responsibilities; and ‘leaping ahead’, which offers caring for the other in such a way ‘as to enable her to perceive and take up this burden in the right way’ (Koo, 2016: 96). For one to heal, to reclaim one’s life and a sense of control, the clinician can return the patient from their exile of illness and stigma.

Finally, utilising Levinasian insights into the fundamental centrality of breath as bridging the ‘between’ I and thou can refocus the relationship between self and other. Instead of the ordinary body/mind, self-other, master-slave tendencies to categorise and carve up reality, we open a space for reflection, but also for embodied proximity. Healing can begin with a more authentic appreciation of the importance of the air, the breath, and nurturing relationships to both maintain health, and to help restore or manage it when it has been damaged.

These features of person-centred healthcare are not easily separated, nor are they exhaustive of what comprises person-centred care. However, they stand out as vitally important with regards to breathlessness, shame, and stigma. I argue that they begin an ethics of the breath in relation to rising rates of breathlessness, and the binding of our lived experiences to one another both within and without healthcare, to socio-economic factors, and environmental concerns. In short, our fates are inextricably linked via the importance of the air, the breath, and social equality.

CHAPTER 7: Conclusion

> Breathing, which is the biological foundation of breath as a cosmological (in ancient mythologies) and anthropological or philosophical category, can therefore be explained by means of an inner movement of an animated being; it is the pulsation of a being, transmitted and externalised through a sequence of inspirations and expirations…And the transition into the spiritual dimension is where ethics enters the philosophy of the breath. The breathing subject…is inspired by the other and linked to the breath emanated from them.
>
> *Škof, 2015: 14*

At the end of her book *Phenomenology of Illness,* Carel describes a scene in her local park of a mother chasing her children with handfuls of leaves. It is a powerful expression of joy and laughter, but always mediated by her own struggle for air, her alteration in her ability-to-be:

> So much air is needed for this, I think. I walk behind them, slowly, observing their playfulness, their physical joy. I share in their joy second-hand, but I am not able to join in anymore. I smile as I trudge up the hill, slowly, slowly, ever mindful of the oxygen so freely available in the air around us and so invisible to those who can have as much of it as they want. (Carel, 2016: 228)

Breathlessness in chronic conditions is always present, as the background of bodily existence that shapes and colours the world and our possible ways of being in it. For the chronically ill person, the air, which is as plentiful as it is invisible, is painfully remote when breathlessness takes over. As fellow travellers in this shared world, we should recognise and understand these invisible lived experiences in the clinic because of their distress and deep levels of alterations to the sufferers lived world. Our health-care policies must be able to offer more effective care for chronically breathless and anxious patients, attending to psycho-social effects, social inequalities, and barriers to communication. But we too, as individuals as well as a society, should ensure that we understand these invisible threats to life require empathy and compassion. Air quality, pollution, socially-deprived lifestyles, and poor health that are the result of health inequities must be battled at the socio-political levels too, to confront these issues and mitigate their devastating effects to all.

Within this thesis, then, I have looked at air and the breath, starting with the beginning of written Western philosophy and its significance to life and thought, through to the contemporary arena, and breathlessness at the end of life. Due to a lack of philosophical attention to breathlessness, I presented a phenomenological framework with which to explore and thematise a life-changing human experience that can teach us much about so-called normal and pathological embodiment, and how these uncovered meanings and intelligibility can be philosophically salient for studying both philosophy of medicine and chronic illness.

This study included empirical studies in addition to utilising philosophical methods and analysis to unpick these intractable and intertwined issues. Breath and breathing are not purely physiologically states with concomitant subjective phenomena. The world of others, social structures, culture, economic features and so forth were shown to interact and interplay, even as our air is contaminated by toxic chemicals and other harmful pollutants. Via a tour of philosophical studies on air, breath, and breathlessness from the ancients to the present day, I argued for a refocussing on the centrality of the breath to human knowledge, experience, and co-existence. A co-breathing of being human.

Phenomenological notions and thought informed my account throughout. This included the body as lived, as ability-to-be and subsequent breathless and anxious modifications to this. As we saw in earlier chapters, there is a deficit in thought about the human being as object present in scientific thought and everyday ways of conceiving human existence. Using the Husserlian distinction between *leib* and *korper* captures this. *Korper* referred to the corporeal body, the body as physiologically described in science and medicine. *Leib* referred to the experience of the body, *my* body as lived and whereby I comport myself to the surrounding environment experienced in movement, action, sensing. Heidegger termed this ‘bodying forth’ (Heidegger, 2001; Aho & Aho, 2009). Whilst it is undeniable that scientific description and explanation has its remit in many fields, including medicine and healthcare, it was argued that too narrow an account of human existence failed to consider the ‘actual lived experience of embodiment’ (Aho & Aho, 2009: 2). Indeed, such limitations are unavoidable in a reductive metaphysical worldview. For instance, we saw that measuring lung capacity is a valuable method of predicting and recording lung function and yet it fails to measure the subjective experience of breathlessness. Human experiences of illness are not reducible to such anato-physiological descriptions and scientific applications. There was therefore so much more to consider in capturing and understanding these experiences. The underlying ontological and epistemological underpinnings of naturalistic accounts were unable to do this.

Instead, this thesis considered how philosophical thought, informed by phenomenology, could help here. The lived body, or ‘my own body’ (*le corps propre)* was presented as a way in which I inhabit the world: ‘a way of living that tacitly understands the world in terms of practical movement and orientation’ (Aho & Aho, 2008: 3). Navigating the world so seamlessly is revelatory once we attend to this experience (as illness invites us to): being embodied is to be part of a world, irrevocably bound to it (Merleau-Ponty, 1962: 148). When certain abilities are cut off and limited, this fact is uncovered. One example would be when a person becomes breathless to the point of no longer being able to speak, gesture, or move. The attempt to talk, move, communicate, or reach out, the inhibiting of our ordinary fundamental connection between self, other and world springs forth in a painful and distressing way. I can no longer be who I was or do what I once did. My ability-to-be is curtailed (Carel, 2018). In short, the fundamental connectedness to body, self, other, and the world becomes apparent through pathological breathlessness. The spatiality of my body as part of the world is thereby altered via a ‘violent disruption’ of its usual habits and pursuit of everyday projects.

Thus, through illuminating breathlessness in chronic illness, we have seen how the body becomes an object, and how (unintentionally) medical practitioners and the patients themselves can view it as a ‘thing’. The self is thereby altered as the transparent, taken-for-granted healthy body cannot do what it used to be able to do, what I need it to be able to do. It disobeys my commands (*cf*. Carel, 2012). The self becomes alienated and the person’s agency changed as embodiment is brought to one’s attention. This includes alterations to knowledge through perceptual changes: recall that Merleau-Ponty said ‘all knowledge takes its place within the horizons opened up by perception’ (Merleau-Ponty, 1962: 241). As knowledge is grounded on perception (and, as I have argued previously, respiration), changes to these entail changes to how we experience, what we can know, and how we can know things. When chronically ill, we can discover the hidden, underlying structures of human existence that underpin our experience. This is not just because we need to breathe for our heart to beat and our blood to circulate, but also because breathing presents us with a ‘special’ embodied knowledge uncovered by breathlessness. It is the opportunity and invitation to philosophise, as Carel suggested (2008). It also reveals our co-breathing with others, with things, and with the environment (Levinas, 1997; Irigaray, 2001; Škof, 2018). It is a primordial experience, in every sense of the word.

Of course, these changes are not always philosophically revealing in a positive manner, or able to uncover tacit primordial structures for one to reflect upon and incorporate into one’s knowledge. That would be a crude analysis. Lack of oxygen can cause cognitive decline and severe debilitating perceptual changes and so inhibit knowledge formation (Dodd, 2015). It can thus hinder life, possibilities (as abilities-to-be), and shrink experience and thus potential sources of knowledge. As we have seen, chronic illnesses with breathlessness at their core often prohibit perception and knowledge due to the obvious, and fundamental extreme: death itself. What I have tried to suggest is that ‘special’ potential for knowledge that is opened includes the truth that we are mutually dependent as human beings. On both the world as we are with the others that share the air. Co-breathing is not to sit meditating in a yoga class or practicing mindfulness in a research meeting (although it can be part of these things). It is something that we all do, even when alone (cf. Heidegger, 1962). When the air is heavily polluted, the increasing rates of mortality and suffering imply a sense of responsibility that we all must attend to those others surrounding us, whether it is helping our neighbour or fighting the government to meet agreed environmental standards. In the UK alone an estimated 28,000-36,000 people die each year due to diseases caused by poor air quality (Public Health England, 2019). That is more than deaths due to smoking (*ibid*.). Studies show that mental health is impacted too, both directly (through ‘affect[ing] the human brain via neuroinflammatory pathways’ (Khan *et al.*, 2019:1) and indirectly (as comorbidity is often linked with another chronic illness that exacerbates mental wellbeing)

Alongside lifestyle risk factors, complicating psychiatric factors inhibiting medication compliance, health and social inequalities, healthcare can contribute to the failure to properly address the healthcare needs of those with mental illness:

> there is now strong evidence that people with mental illness receive worse treatment for physical disorders (‘diagnostic overshadowing’).

> This takes place because general healthcare staff are poorly informed or mis-attribute physical symptoms to a mental disorder…It seems clear, therefore, that medical staff, guided by negative stereotypes, tend to systematically treat the physical illnesses of people with mental illness less thoroughly and less effectively (Thornicroft, 2011: 441).

This is a form of structural discrimination so harmful and widespread that researchers call it a violation of the 'right to health' (Article 12 'The right to the highest attainable standard of health' of the International Covenant on Economic, Social and Cultural Rights). The twenty-year difference in life expectancy between those with mental health diagnoses comorbid with physical illnesses and those without has been acknowledged for over two decades and yet is unaddressed. Psychiatrist Graham Thornicroft calls this a 'cynical disregard for these lost lives', due to stigmatisation and discrimination that reflects 'how much people with mental illness are categorically valued less than others in our society' (Thornicroft, 2011: 442). As he points out, any other large segment of the population that suffered in this way would lead to a public outcry. Add to this the stigmatisation of respiratory conditions such as COPD, a disease found predominantly among the poor and working classes due to smoking, and the structural discrimination is furthered.

Additionally, we have seen how both breathlessness and mental health conditions are characterized by invisibility. This is due to the literal invisibility of the conditions (i.e. the lack of a locatable visible physical impairment) and the withdrawal of those individuals from the public realm as ill health, stigmatisation and anxiety cause them to become housebound or less active in the community. They are rendered voiceless literally and figuratively, as they are robbed of their breath, their dignity, and the ability to be active in their healthcare treatments and management, dismissed as 'hopeless' cases responsible for their condition, or as lost causes who will never return to health:

> For many patients and clinicians, the presence of the symptom is simply accepted as part of the illness, with no thought that the symptom and its impact could and should be specifically assessed and treated. Many patients with… breathlessness will silently adapt to its limitations and suffering, omitting to volunteer to health professionals the presence and severity of the breathlessness they experience or the consequent impairment of activities of daily living. For those whose breathlessness is induced or worsened by lifestyle choices such as smoking, this failure to report may be contributed to by the notion that chronic breathlessness and the associated suffering is in some way self-inflicted. A major

> reason why physicians may fail adequately to enquire about or explore chronic breathlessness and its treatments is because of a poor understanding of what can now be achieved in terms of symptomatic relief. (Currow *et al.*, 2017: 393)

This does not need to continue. Rethinking our engagement with one another in healthcare and within society is possible. As Levinas argued, mutual recognition is part of human being-with (*Mitsein*). In illness, the skills and unique contributions of each person may be curtailed as they become less mobile and more reliant on others. This can damage their connection to others and sense of self-esteem (Chapter 6). When the concept of socially-constructed pathology is considered (i.e. stigmatised 'weakness of will' illnesses such as obesity, COPD, lung cancer, diabetes, substance misuse, mental health problems and so on), we have seen that the shame and stigma comes from three places: the self, others and society. When one is reliant on others for care, as those under the care of respiratory teams are, epistemic injustice and miscommunication are in some cases the result. This is not to blame healthcare practitioners: often these problems are part of the structure of healthcare institutions, which are normalised and dictated by social norms. Sometimes they operate from the perspective of the patient who feels ashamed and so does not reach out to voice their worries and needs to their care providers. Restoring their sense of self and respect through care, empathy, and compassion is thus vital. Recognising the co-dependence of us all within the concept of co-breathing, I suggest, can provide a useful framework for us to articulate this and work this out. I have only been able to provide a sketch here but hope to extend this further in later work.

This is also important, as I have argued, as a form of social death occurs when humiliation and social shaming occurs, and this is in part due to the way we have come to mis-recognise fellow humans, thinking of them in terms of their function rather than our emotional connection with them as fellow affective beings. This is certainly a pattern of thought that has been normalised in the West. How much one is worth, what one contributes to society, what one costs and so forth are ideas that have contributed to what is classed as normal and pathological, with the rich, healthy, strong as the idealised person (Goffman, 1963; Canguilhem, 1989; Bishop, 2011). Social injustice, health inequality, poverty and chronic illnesses are then considered to be due to a defective, abnormal body and nothing to do with the rest of society. Such an individualistic, egotistical worldview is a natural result of uncontrolled capitalism and must be challenged. Within the purposes of this thesis, I suggested that philosophical examination of being-with, co-breathing and of refocusing on the importance of the air to human life, can overcome this.

7.1 Policy recommendations

In the following sections I suggest policy recommendations that have emerged from the work within this thesis, and from the rich research of others that has emerged when considering breathlessness, anxiety disorders and chronic illness. As I am no longer a healthcare practitioner, these are sketches and themes that have arisen from such studies, guided by the expertise of clinicians, psychiatrists and psychologists, philosophers, and many others whose proficiency overlap with these concerns. They are ordered by themes that have emerged throughout the thesis, and thus conclude the thesis with a future orientation for further research.

7.3 Authentic healthcare [89]

As previously argued, illness often ‘sever[s] the patients’ habitual trust in his or her own body, community, and universe of belief’ (Leder, 2015: 77). This is why I have argued that caring authentically, whether through the therapeutic alliance, the compassionate touch, the face-to-face encounter and framework of a co-breathing with patients and love ones, helps to restore the patient’s agency and sense of self. This removes the unhomelike, alien character of the world so passionately described in patient testimonies. Regardless of whether the world is transformed due to the physical constraints of breathlessness or the anticipatory affective features of panic anxiety, care that focuses on the patient as a whole person can restore their sense of belonging to a community, to a world. Depersonalised medicine, and the depersonalisation and derealization of anxiety and panic, can thus be overcome. One’s body (and hence selfhood) is acknowledged different, mostly painfully so. However, with proper understanding, empathy, and communication the healing process can restore one’s power and some control of the here-to-fore betraying body. The

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[89] A longer, more detailed version of this appears in chapter 6, thus this is a summary.

two separate realities of the clinician and patient can come together in this between-world via co-breathing that is bridged by authentic person-centred care.

In this way, such practice can re-orient the patients’ and their families’ lived experience. Instead of being a passive object prodded and treated by the clinician, they regain their agency through shared decision-making, feeling heard, their suffering acknowledged, and experience validated (Kirkengen, 2005). Evidence of the healing effects of the therapeutic alliance abounds in empowering the patient and improving outcomes (Leder, 2015; Aho & Aho, 2007). This is not a suggestion to supplant all the objectifying, necessary elements of medicine, but rather to supplement these with a return to the patient’s unique needs and personhood to restore their dignity and sense of self. The alienation of the illness that causes splits from one’s own body, sense of self, others, and from the world, can thus be redressed. So too can the unhomelike being-in-the-world, caused by depersonalised healthcare, be overcome (Sveneaus, 2001). Hospitality in health-care is therefore restorative: care as being-alongside an-other in their distress and responding with solicitude rather than fleeing, avoiding, or dismissing, opens up an honest, trusting space. Within chapter 6, I have detailed how this might be accomplished specifically regarding breathlessness: incorporating phenomenological description, training that attends to the agency and social-affective world of the person, with a suggestion for an ethics of the breath. Training for health-care practitioners would thus be important to help better meet the needs and concerns of those who experience breathlessness either first or second hand.

7.4 Agonal breathing, dying, and Being-with (*Mitsein*)

Agonal breathing referred to the struggle to breathe at the end of life, or due to a life-threatening medical emergency. Witnessing it could cause distress and vicarious traumatisation in loved ones and health care practitioners. As various hospices and hospitals have different policies on discussing the dying process with families and friends, I suggest that a single, coherent policy or set of guidelines on educating and communicating this form of breathing needs to be put in force to ensure that such trauma can be mitigated (Gruffydd-Jones *et al.* 2017).. This would fulfil Levinas’s demand to attend to the breath of the other, to their suffering, extending this from the patient to include those surrounding them (Levinas, 1997). After all, being-with is not a relationship between just one person and another: others are caught in this web and their personhood needs to be considered. This can be done by including information on the dying process, and especially terminal breathing to reassure those surrounding the patient that they are not in any distress. Training around empathy, Socratic questioning, attentive listening and psycho-education from clinicians to patients is already given in psychological therapies. To extend this to those caring for the dying will improve communication between practitioner and the patients' loved ones, ensuring a therapeutic alliance respects the autonomy of these others so that they are well informed.

Specific factors that loved ones find distressing when witnessing a loved one day have been identified (McHaffie *et al.,* 2001). They include:

1. Unpleasant noises and sights such as appearing to struggle for breath, turning blue, and jerking movements.
2. Lack of information. In one study, a fifth of families reported that they had received far too little information about the dying process and so were inhibited in their ability to make informed decisions (McHaffie *et al.*, 2001: 85).
3. Staff unavailability and staff shortages that lead to a delay in treatment and thus more stress and anxiety for loved ones worried about the suffering of the dying.
4. Failure of clinicians to conform to pre-agreed procedures. Families felt let down and powerless (*ibid.).*

Such problems can be avoided if these concerns are addressed via an agreed policy that outlines recommendations for training staff in the ways suggested above (and that, as per point 4 above, clinicians abide by). As I am no longer a healthcare practitioner, it is not appropriate for me to say exactly what would need to be included, but I suggest that incorporating existing evidence-based training and therapies alongside specialist training within dealing with breath at the end of life, listening to the concerns of loved ones of what distresses them, and psycho-education so that they are appropriately informed, would avoid these problems. As breathlessness is present in most cases of those dying (from whatever cause), this must be attended to (Johnson *et al.,* 2016).

7.5 Integrated care in respiratory healthcare

As the NHS is facing increasing challenges in service delivery when treating increasing numbers of patients with chronic illnesses, such as chronic obstructive pulmonary disease in ageing and deprived populations, it is recommended that models of integrated care 'are tailored to local populations' but still person-centred (Baxter *et al.*, 2018: 5). Focus on integrated care in general, whilst posing many challenges, can enhance patient satisfaction and further research is being undertaken to see what benefits to health outcomes there may be (Baxter *et al.*, 2018: 6). However, within respiratory care, findings are already promising (Roberts *et al.*, 2010). Collaboration between clinicians, patients, loved ones, and social and psychological services can ensure this by removing barriers between GP practices, hospitals, community services and social care when dealing with patients and across organisations. Better communication can be established through creation of 'a collective leadership across all… for the benefit of the whole', alongside 'tackling the broader determinants of population health (Timmins, 2019: 2).

7.6 Shame and stigma: a consideration for clinical encounters

We have also seen the (largely) harmful power of shame and stigma. In the clinical encounter, shame can be crippling without such recognition of its complex nature. Sartre argued that in our concrete relations with others, that 'the Other *looks* at me' gives this other a privilege in appearing to 'know what I *am'* (Sartre, 2003: 385). In this way the meaning of my being is always outside of myself, 'imprisoned in an absence' through the other (*ibid.*). This is an absence as I can never see myself as I appear to another, and, moreover, the appearance of the other in part constitutes an area or structure of my being that I would be unable to access without his presence first of all opening this opportunity. I am an object-for them, and they are an object for me amidst-the-world, even as for myself I can never be this object-thing that they apprehend. Through the look (*le regarde)*, or gaze as that which first reveals the other, and me to that other, 'we experience our inapprehensible being-for-others in the form of possession. I am possessed by the Other; the Others look fashions my body in its nakedness, causes it to be born, sculptures it, produces it as it is, sees it as I shall never see it. The other holds a secret – the secret of what I am (Sartre, 2003: 386).

In the clinical encounter, the Other sees me as sick, diseased, unable to be, left wanting; needing to be acted upon to be fixed or treated. As an object to be repaired. I would suggest in this way medicine can be guilty of, per Sartre, the conflictual by nature 'look' writ large (*cf*. Bishop, 2011). The power and judgment of medical science and its practitioners already in their very status and claim to be experts ensures that the clinical encounter is dominated by their look, their judgment on who I am and what I am. If they see me as guilty of my illness because I smoked, of responsible for my own situation, I can see that everything else that I am – mother, teacher, charity worker, poet, is ripped away. All that I am for them is this object before them; diseased, at their disposal. This is why Sartre said that 'conflict is the original meaning of being-for-others' (Sartre, 2003).

It is true that in this way I have a certain amount of responsibility for how I appear to others (responsibility for my being-for-others, as he calls it). But I have limited control over this as I am not the 'foundation' of this appearance: they can be wrong about why I have a certain illness, or why I appear to them in a certain way, for example. In this way, I can attempt to reclaim my being as it is for these others. It will always be limited as I can never transcend the freedom that the other possesses in their estimation of me. That is why in trying to recover my being I have to 'assimilate the Other's freedom' so that I can gain control of my-being-looked-at (Sartre, 20003: 386-7). Clinicians do not need to be taught the merits of a Sartrean analysis of shame. I do suggest that the powerful consequences be considered in future guidelines when dealing with such a complex experience as pathological breathlessness.

7.7. Anxious philosophy and healthcare

As I have argued, anxiety disorders are often misdiagnosed, and in the case of those with respiratory illnesses, the rates of misdiagnosis or underdiagnosis are high. On the other hand, when patients' complaining of a physical health complaint have previously been diagnosed with a mental disorder, their testimony is often in doubt, leading to delay in diagnosis and treatment of underlying illnesses that results in worsening symptoms and disease progress. Many respiratory illnesses comorbid with anxiety disorders are prevalent in already marginalized populations, who suffer great deprivation and stigmatization that can render them voiceless and invisible.

Multiple false dichotomies are thus operating in both the epistemological and ontological realms, between *psyche* and *soma*, subjective and objective, normal and pathological. These unexamined and chiefly implicit ways of categorizing the world are extremely damaging to those that are unwell, especially in those with breathlessness as a common experience – from whatever cause. Symptoms do not necessarily correlate with measured lung function. The subjective/objective divide is inadequate in these circumstances, as is the split between the psyche and the soma. As we have seen, it is hard to differentiate between breathlessness due to anxiety and breathlessness due to the underlying condition. In both cases, too, breathlessness and anxiety each impact the other in feedback loops that worsen cognitive, psychological, emotional, and physical symptoms. A neat divide between the normal and pathological is thus not possible nor helpful in such cases.

Focusing upon the experiences of anxious breathlessness as described in first-person accounts and through the application of phenomenological description can bring these difficulties and problems in conceptualization out. This can also help overcome the omissions present in, for example, the American Thoracic Society's definition of dyspnoea. Where it elides experience and sensation without investigating such a merge or how other factors such as anxiety, experiences of healthcare objectification, and so forth informs both the experience and the felt sensation. Studies in interoception and expectation reveal how problematic overlooking such factors (and perhaps making a category mistake) can be: more unnecessary suffering, less effective treatment outcomes, and a failure to understand the complexity of breathlessness and related phenomena more adequately (Faull & Pattinson, 2017; Herigstad *et al.*, 2011). Overlooking these is now inexcusable when we know how hypervigilance often leads to avoidance behaviours, increased low tolerance to intensity, and reduced activity. This means that patients are reluctant to take up proven interventions that can help decrease distress and manage intolerance, such as pulmonary rehabilitation and talking therapies (Herigstad *et al.*, 2011). Suffering, worsening health, development of panic and health anxiety are the consequences.

Research has shown that falls suffered by patients with chronic respiratory diseases such as COPD reliably predict mortality (Higginson *et al.*, 2017; Oliveira *et al*, 2015). Yet such studies do not consider mental disorders. Increasingly the relationship between falls and mortality is being considered, with cognitive decline linked to breathlessness, changes to embodiment, and social isolation due to becoming housebound all getting attention. Yet the fear and anxiety compounding becoming housebound, or contributing to difficulties making decisions, accessing help, and worries of becoming burdensome, are lacking. Mental illnesses, whilst seen as understandable in cases of the chronically ill, need attention to bring out the nuance and impact of affectivity on perceptions of breathlessness and healthcare, and realistic access to interventions that remove barriers to the uptake of these. Such attention can reveal safety behaviours, for example, so that they can be addressed and challenged to enable the patient to live a life as from discomfort as possible. Without challenging cognitive distortions, unhelpful thinking patterns and maladaptive coping behaviours, the fear and anxiety (and thus the underlying illness) cannot be addressed fully.[90]

7.8 Clinical encounters and communication

Lung cancer is the second-leading cause of death in palliative care. Increasing breathlessness itself is often present prior to death, whatever the disease. Unfortunately, despite more calls for integrated care, often information-sharing and decision-making do not overlap. This is very worrying, as communication errors occur prior to patient and clinical encounters. Attending a palliative and end-of-life healthcare research group between south-western universities (based at Bristol University) gave countless examples of the barriers between and among patients and various sorts of clinicians. These clinicians genuinely care and are often frustrated by lack of government funding. Researchers are attempting a ‘patient reconstruction’: an integration of technical information regarding the patient alongside situating the patient in real life. This would be

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[90] As we have seen, the limitations of short-term CBT and other mental health interventions are not holistic, nor appropriate in the case of chronic respiratory conditions comorbid with panic anxiety. The sensation of breathlessness, and its discomfort, is informed by prior experiences and the nature of those experiences over time and changes in health status (Faull & Pattinson, 2017). For after an acute respiratory event, critical illness, or further progression of a respiratory illness, we know that people begin to avoid certain situations lest they exacerbate or trigger an attack.

inclusive of considering one's own relationship, as a healthcare practitioner, with the patient and how the power imbalance may affect the clinical encounter (Chapter 6).

Time and time again, communication difficulties across the healthcare spectrum and with the patients and their loved ones are identified as significant barriers to diagnosis, effective treatment uptake and maintenance, and reduction of suffering. In cases of lung cancer in palliative care, for example, barriers identified included:

> Communication failures
> Accommodating the perceptions of healthcare and expectations of patients and family
> A lack of clear and consistent use of terminology
> Care pathways in palliative care in terminal lung cancer cases are often vague (hence my suggestion that a coherent policy and strategy is needed)
> Patient priorities are not always discussed and realistically implemented
> A lack of consideration for family expectations
> Treatment aims and the reality of interventions in expediting death must be openly and honestly brought forth, even when uncertainty remains.
> The uncertainty must be discussed clearly and realistically: palliation does not mean cure and the patient and loved ones need to be told this
> A lack of support for patients adjusting to increasing limitation
> (McHaffie *et al.,* 2001; Bishop 2011)

When it becomes clear that nothing more can be done other than palliative care, considerations of how to break the news, whether patients relatives are able to be involved, and how to give information clearly, empathically, and honestly need to be considered. This would help avoid the charge of 'totalizing care' described in Chapters 5 & 6 (Bishop, 2010).

The conversations described above also need to include an honest discussion of the likely impact of treatment on everyday quality of life. Without this, there is a danger that the patient will withdraw from treatment. Palliation doesn't mean imminent death. As Chapters 4 and 5 argued, progressive lung diseases such as COPD entail limitations and moderations to one's lifeworld and ability-to-be (*Seinkonnen*). So, mindful of uncertainty and the notion of good-days/bad-days, hope, however realistic, can be fostered. Information is crucial at this point, but information overload without appropriate consideration of temporality when one is in shock and gripped by fear and anxiety after diagnosis or prognosis, must be avoided so as not to overwhelm and further alienate the patient. This has led to calls for a 'culture change' targeted at clinicians. This is not because they aren't working hard in their already stressful jobs, but to get away from another alienating and objectifying proforma. By modelling good-practice to medical students, training and furthering knowledge of these increasing prevalent illnesses will improve.

7.9 The Use of Phenomenology in lived experience of breathlessness

'Phenomenology puts essences back into existence', Merleau-Ponty explained (1962: *vii*). Whether we practice it as a 'manner or style of thinking' that thematizes breathless experiences, or a more Levinasian movement towards helping us 'say the unsaid', bringing out generality and specificity in the experiences of breathlessness, I argue that I have shown its importance for both understanding breathlessness, and for challenging philosophical inattention to the breath. This is because phenomenology studies lived experience and what it means to exist as an *embodied subject* actively engaged with the world. This dissertation thus elaborates on the contributions that phenomenology make to studies of illness and applies it to the breath. Indeed, experiences of wellbeing, suffering, health, illness, and disorder are often the subject matter of phenomenological studies (Carel, 2014). It was thus useful methodology for studying these, as it doesn't assume a physical or dysfunctional causal entity behind illness expression. As I have shown, this causally neutral stance can allow for the fact that each experience of what can be classed as the same disease can differ significantly e.g. you and I both have the same *objective* lung function, but you are able to go out in the world and do not become distressed by your reduced lung function, while I suffer panic attacks and isolate myself from others. Even if the patho-physiological basis is the same in two cases, the illness experiences certainly are not.

This was done by attending to patient experiences of changes to embodiment and thematizing the structures revealed by illness that can provide patients and clinicians with shared language and concepts. Patients are body-subjects: splitting them into mind and body neglects this. Attending to illness *itself* revealed special features common to chronic illnesses that can capture the importance of treating the whole person. For example, as

Carel (2016) points out, there are two key dimensions of chronic illness: its global and its fluctuating nature. Continuing with our example, depression in respiratory disorders may vary with the timeframe (progression) and severity of breathlessness events. For instance, a patient who manages their illness may undergo an acute respiratory event that leads to hospitalisation and further restriction to their lifeworld. Their anhedonia and motor retardation may be taken as a consequence of their worsening condition, rather than the global impact of their illness on every facet of their lived experience. Indeed, these physical symptoms may express the onset of depression that is dismissed as a normal response, and so not diagnosed and treated (Prescott and Iwashyna, 2014: 342). Once they are out of hospital and begin to adapt to bodily changes, or when the fluctuating nature of breathlessness becomes manageable, it is important to attend to their mental health.

Providing accounts of illness experiences, whether through patient toolkits or philosophical, anthropological, or nursing studies, can capture these important elements and compliment clinicians' knowledge, giving patients an opportunity to engage with conceptualisations of illness that reflect their own experiences. Phenomenology enables this. It provides the openness to capture the unique, varying illness experiences across individuals, which nevertheless expose certain shared features that are useful when attempting to understand illness.

Further, using phenomenological methodology to describe lived experience often shows how the changing nature of embodiment and human existence is imbued with uncertainty and ambiguity that cannot be collapsed into a one size fits all categorisation of what it means *to be*. In this way the acceptance of the uncertainty and ambiguity of chronic, progressive diseases that are prevalent in aging populations may help bridge the gap described by clinicians such as Atul Gawande. In his book *Being Mortal,* he notes that medical school trains students to save lives rather than facilitate them towards the end of life: 'Our textbooks had almost nothing on aging or frailty or dying. How the process unfolds, how people experience the end of their lives, and how it affects those around seemed beside the point' (Gawande, 2015: 1). Breathlessness is a common symptom at the end of life, so much so that it is often a reliable predictor of death. Yet, as I have argued, not enough training nor attention is given to this important and distressing experience. Perhaps this is understandable as clinicians are trained to prevent death: as

Gawande notes, his medical knowledge and training given did not prepare him or his peers to respond comfortably to patients facing the end of their lives. Even when treating patients facing death, honest conversations about the futility of possible treatments were difficult (Gawande, 2015: 5).

What happens to the increasingly breathless patient and their loved ones? How can they make an informed decision if these conversations are not broached? As Gawande notes, the responsibility for making difficult end-of-life decisions is ultimately that patients', even when the clinician recognises that the treatment option chosen would likely lead to a painful and prolonged end or weaken the patient to a degree that hastens the end. This is no fault of the clinician: they are trying to ameliorate the patient's suffering whilst giving them the best information and decision-making ability:

> We could never bring ourselves to discuss the larger truth about his condition or the ultimate limits of our capabilities, let alone what might matter the most to him as he neared the end of his life. If he was pursuing a delusion, so were we. Here he was in the hospital, partially paralysed from a cancer that had spread throughout his body. The chances that he could return to anything like the life he had even a few weeks earlier was zero. *But admitting this and helping him cope with it seemed beyond us*. We offered no acknowledgement or comfort or guidance [emphasis mine] (Gawande, 2015:7).

In this specific case, another painful treatment option was offered, which failed and caused more suffering. I suggest that this is indicative of the 'leaping in' that Heidegger warns us against, rather than the 'leaping ahead' that is more authentic (see Chapter). There are many reasons for this. To paraphrase Gawande, the rise of technological advancement in healthcare means that people are living longer. With the development of treatment options, there has been a shift away from dying at home towards dying in hospitals, nursing homes and hospices (Gawande, 2015: 6). Hence, there has been a loss of knowledge and praxis surrounding death and dying that previous generations of doctors and nurses (and even ordinary family members) had. We have become alienated from the processes of dying and death, and the resultant care, communicative skills, and knowledge of what to expect. Futility in healthcare interventions need to be communicated openly and honestly with patients and carers, then (Forbes, *forthcoming*).

As Felix Silverstone comments, ‘Old age is a continuous series of losses’ (Gawande, 2015: 55). The gradual decline of the mind and body in aging is exacerbated by breathlessness, as chronic breathlessness and aging share many deteriorating and co-occurring similarities. These losses were described by Toombs (1987), but also further elucidated by phenomenological research on breathlessness, including transformations to embodied experience described by patients (Carel, 2011: 2018); clinical and neuroscientific results showing cognitive decline due to hypoxia, reduced mobility, markedly worse mental health, difficulty making healthcare decisions; in short, a shrinking lifeworld. I argue that applying phenomenological insights to our knowledge and understanding of breathlessness can aid us here. Utilising insights on the co-breath and care [*Sorge*], we can develop more honest dialogue by approaching one another with forbearance, considerateness, and empathy in the face-to-face encounter. Specifically utilising phenomenological thinkers such as Heidegger and Levinas, we can frame austerity, shame, blame and stigma, and homelessness as deficient modes of passing by those in need. This can be overcome by asking *what do we owe the other*, both socially and in the medical encounter? I conclude by suggesting that access to clean air, respect, and equal access to holistic healthcare that removes exclusionary barriers is needed to combat the prolific and deepening rates of respiratory-related suffering.

We live in unpredictable times. The current rapid rise and fall of previously stable political parties being threatened and, in some cases, replaced by national populist movements, coupled with economic uncertainty and threats to the climate irrefutably attest to this. Unpredictability leads to angst (Chapter 5), as studies have proved time and time again. What is unnerving is the lack of Worldwide commitment to tackling climate change, reducing carbon emissions, and ensuring cleaner air (at of time of writing, the US has recently pulled out of the G7 alliance and the Paris accord). These pose a threat to life and health, directly through polluted air, water, rising sea levels and temperature; and indirectly through anxiety disorders and stress on the other. Taken together, each impact upon one another. A vicious feedback cycle is created and maintained that affects all levels of social and economic life. The consequences are profound. It is time to study these connections through the lens of breathlessness in lived experience. Only then we can clearly understand the harm caused to persons as patients and to their families, and to investigate potential remedies. This may or may not result in an ethical reawakening as set out in this thesis. If anything, it would be useful to ameliorate suffering by expanding our knowledge and understanding of these invisible yet common experiences. Maybe then we can address the threats that contribute to the risks of developing these conditions, combatting risk factors, and preventing the spread of respiratory conditions.

To summarise, within this thesis I have argued that we are not merely in object – subject relationships to one another (contra naturalistic attitudes). We sense, feel, communicate in an inter-relational and intercorporeal realm. These in turn shape our knowledge and understanding, impacting our self-awareness and even own understandings of illness and related experience. Thus, changing our knowledge, understanding, and approach to breathlessness via phenomenological research and expansion of training could better suit the needs of patients, carers, clinicians, and wider society. Paying attention to our embodied, intercorporeal structuring and the holistic changes that all the variations of breathlessness incur provides a deeper understanding of the unique challenges of these illnesses. Of how they affect the patient as person, not just as 'disease' vessel. The possibility of seeing all the alterations to the person's lived experience is opened with such a re-focussing. Co-morbid experiences of anxiety, panic, and depression can hereby be properly addressed, not to restore the person to their old ways of being (chronic, progressive lung disease often rules this out), but to open new ways of existing, and co-existing, in the world.

Without such an opening, the shrinking lifeworld described by patients and philosophers in such illness experiences may remain. The 'I can', or 'ability-to-be', remains curtailed (Heidegger, 1962: Carel, 2011). The stairs: no longer for climbing. The Lake can no longer be encountered as where I swim. My career as teacher, is rendered meaningless. Being a lover, loses its invitation as intimacy is ruled out as it incurs acute breathlessness. Possibility becomes impossibility (*cf*. Heidegger on death, 1962). These losses are not just due to a bodily limitation. In chapter 5, we saw how episodes of anxiety, whether clinically or existentially construed, can contain a disconnection from reality. A depersonalization, de-realization, or 'unhomelike-being-in-the-world' (Sveneaus, 2000a; 2000b). Positively, then, person-centred medicine, aided by phenomenological insights to breath and being both can describe these experiences, and also utilize our openness to being to foster new ways of thinking about these illnesses and how to be with the sick.

With phenomenological emphasis and attention to lived experiences of illness as structured through interpersonal, intercorporeal, and social ways of being, we can now properly return to the conundrum of how two people with the same disease report different felt severity. Essentially, experience is too diverse and temporally and experientially structured to admit only one response to breathlessness. We have also unveiled the complex factors that may be inhibiting treatment adherence, uptake of pulmonary rehabilitation, communication failures between clinicians and patients, and so on. Our philosophical and therefore scientific worldviews have been far too limited and dominated by scientism. Therefore, I hold that only via a holistic view the opportunity to build a greater understanding of the many factors that shape our understanding of illness, medicine, and epistemologically orientated worldviews, can be provided. Armed with such knowledge, we will be better equipped with addressing root problems that contribute to problems patients, their loved ones, clinicians, and society face when addressing lung diseases. For example, a Doctor may become frustrated at a patient who may not utilize pulmonary rehabilitation, thereby undergoing worsening distress and intolerance to exercise because they are terrified it will cause an acute attack. Their fear becomes panic disorder, and is unchallenged by many as ‘who wouldn’t be terrified’ of becoming breathless? The breakdown in communication between medicine and patient may further be exacerbated if this patient is compared against others who may have a similar (or even worse) objective lung function result than other who successfully partake in the schemes on offer. This is unhelpful, as it blames the patient as one who won’t help themselves, rather than explores (leading to removing) barriers in place of uptake.[91] As argued, a skilful and empathic response by health care practitioners would include listening to the patients concerns, gently challenging these, and offering help or referral for psycho-education and mindfulness cognitive interventions to help address these real concerns.

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[91] Of course, that is not to say that this is all the fault of medicine. Despite the power imbalance seemingly inherent in the clinician-patient relationship by virtue of the extensive medical knowledge and training undertaken by the former, the patient as person still has a responsibility over their own choosing to partake. What matters is that the full information is given, as crucially, the patient is vulnerable and by virtue of not being a clinician, needs to be fully informed and compassionately treated. Breathlessness is undoubtably terrifying, and his understanding can be accommodated by medicine to ‘leap ahead’ to liberate the patient.

Listening to the patient, as person, thus becomes a required and important endeavour. Eliciting their testimony to see how their engagement with the world, any loss of practical significations e.g. no longer partaking in their hobbies or prior roles, perhaps, can reveal how far their illness has permeated and disrupted their life and connection to the world and to others. Indeed, such focus can help diagnose and conceivably prevent any co-morbid mental health problems. For instance, descriptions of loss of connection to the world and a resulting 'lethargic body' can hint at the onset of psychiatric illness (cf. Ratcliffe, 2015: 5). Disengaging from the world, hypervigilance to bodily cues such as a tight chest, may not only suggest panic disorder or depression; it may be preventing the patient from pulmonary rehabilitation. Moreover, due to high rates of reported shame and stigma that go hand in hand with both chronic lung diseases and mental health conditions, in addition to social marginalization, the smoker may not want to reveal their current smoking status to the Doctor (Nykvist et al. 2014). This further aggravates the problem, leading to worse outcomes and rates of suffering.

I have shown that the transformation of the body as breathless, anxious, depressed, thus curtails not only bodily experience and engagement in the world, but our social relationship to others. Distressing sensations and the fears that they elicit, embody threat that has the person on constant alert to track whether they are about to have an attack, in turn heightening stress and anxiety -directly triggering rapid breathing and increasing the potential likelihood of breathlessness. It thus demanded consideration, and, as we have seen, first person accounts and phenomenological description can aid these issues, in turn helping us draw out insights and thematize transformations to experience. The concept of co-breath as a primordial structuring of human co-existence tied these insights together, and is something I would like to explore in future research.

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