

# Illness and Disease, a new Perspective

## Reflections on *Phenomenology of Illness*

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### Abstract

In this thesis, illness and its different aspects will be described, following Havi Carel's book *Phenomenology of Illness*, which offers a detailed account on the influence illness can have on the patient's life and thoughts. Illness can change the way the patient thinks of his or her body, and can give rise to thoughts such as doubt and anxiety. Providing an outline of *Phenomenology of Illness*, I will elaborate on illness and disease, and the perspectives that can be taken towards illness. Illness and disease form a continuum, and are present at the same time. The physician must not only focus on treating the disease of a patient, but also on treating the illness.

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## Introduction

When I started studying medicine, I expected that illness would play a major role in the curriculum. Surprisingly, it does not. During the study of medicine, we only get taught about diseases, symptoms and possible treatments, for a large part forgoing to take the experience of the patient into account. Diseases, the actual medical conditions that cause symptoms and bodily decline, are profoundly elaborated on, whereas illness, the experience of this decline and loss of function, has gained far too little attention. Naturally, there are some disciplines of medicine (such as general practice and geriatrics) that acquire awareness of the social and personal aspects of diseases. But even in these disciplines, the emphasis laid on the experience of the patient does not encompass the whole experience, it just zooms in on a few features. We, medical students, are taught to ask questions such as 'Are you still able to work?' or 'How do your complaints affect your social life?', but these questions are only aimed at estimating the severity of the symptoms, for example. The aim of the study of medicine is to create physicians who are able to cure patients, who can treat diseases at the best of their knowledge and who can enhance the quality of life of their patients. However, during this endeavour, we forget to see the patients as more than just their functioning (or malfunctioning) body. The patient and his or her experience, doubt and changing world are neglected. In this thesis, I want to provide insight in the phenomenon illness, stating its importance as counterpart of disease (for the patient as well as the physician) and finding possible ways for physicians to address the experience of patients.

As a student of philosophy, elaborating on illness is relevant, to get better insight in a different way of being-in-the-world, a way of changed perception and experience. In philosophy, the topic of illness and all the changes that accompany it could be elaborated on more thoroughly, for it plays a major role in our lives. We all know the experience of being ill, be it through ourselves or through someone close to us. We can all try to imagine what it is like to be ill and more importantly, when thinking about it, we all fear being ill. During our lives, we generally act to avoid illness, to ensure we never have to endure hospitalisation and above all to maintain health. We exhibit a constant fear of illness, but what is the reason for this anxiety?

I will provide insight in the possible experience of patients by first giving an outline of the book: *Phenomenology of Illness* written by Havi Carel<sup>1</sup>. She offers a description of illness as the experience of disease, giving a detailed account on how illness changes the patient and the way he or she lives and thinks. Using this outline, I will elaborate on the difference between illness and disease, and the way they relate to the state of health we constantly strive for. I will describe how illness changes the healthy person. Usually, this change is felt and perceived of as negative and frightening, but I will also try to take some positive aspects of disease into account. Lastly, I will address the role of the physician in treating the illness of the patient, in addition to only treating the disease. The experience of the patient has been neglected, and it is the task of doctors (and doctors to come) to start perceiving illness as equally important to the patient as the disease.

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<sup>1</sup> Havi Carel, *Phenomenology of Illness* (Oxford: Oxford University Press, 2016).

## Chapter 1. Brief outline of Carel's *Phenomenology of illness*

### 1.1 Introduction

In the following chapter, I will expand on the book that serves as the starting point of this thesis. In 2016, Carel's *Phenomenology of Illness* was published. Havi Carel is a professor of philosophy at the University of Bristol, teaching students of philosophy as well as medicine. She teaches for the unit Death, Dying and Disease.<sup>2</sup> After reading *Phenomenology of Illness*, I rather think that in this unit's name 'Illness' should be added, or 'Disease' should be changed to 'Illness' altogether, for Carel proposes that the latter is the more philosophical counterpart of the former. Carel argues that disease belongs to the realm of the empirical sciences (PhI, 17).<sup>3</sup> A disease is the actual medical condition or pathology that underlies symptoms, risks and is the factor that necessitates treatment. Carel focuses on illness, which is how the person affected by a disease experiences this disease and all that accompanies it. The most important difference between disease and illness is the difference in perspective between the two. Disease involves a third-person perspective, for it is diagnosed and followed by measuring, describing and looking at the body. Illness, on the other hand, involves a first-person experience. Illness is the answer to the question "what is it like?". It is experienced and therefore highly subjective and dependent on the consciousness. This feature makes illness very suited for a phenomenological approach, Carel argues (PhI, 40). In her book, Carel focuses only on a chronic, severe and life-altering state of ill health. Needless to say, a person with a short period of minor flu presumably does not feel well, but will give a very different answer to the question "what is it like?" compared to a patient with a person suffering from a life-threatening disease, accompanied by pain or other symptoms. These severe illnesses are the subject of study in this book, for they evoke the most profound existential changes in the patient's life.

### 1.2 Phenomenology and the body

As becomes clear from the title "Phenomenology of Illness", a phenomenological method is used to study illness. 'Phenomenology' consists of the Greek *φαινόμενον* (phainomenon) and *λόγος* (logos). Logos means theory or science and phainomenon originally comes from the verb *φαίνω*, which means 'I show'.<sup>4</sup> Thus, etymologically speaking, phenomenology is the study of the things that are shown to me, which are appearances. It is not of interest what there is in reality, but how I come into contact with the world, how I am related to the world. Notably, the suffix '-logy' implies that phenomenology is primarily a body of knowledge, whereas, at least in the book of Carel, it is more employed as a method. Phenomenology is put into practice and functions as a way to describe how something appears from a certain point of view. Over the course of the book, Carel provides us with a few examples of phenomenologists and some of their ideas, applicable to illness or the experience of the body.

Heidegger made a distinction between three modes of dysfunction of tools: conspicuousness, when the tool ceases to work, obtrusiveness, when the tool is absent, and obstinacy, when the tool is unsuitable for the task. Carel offers an analogy between healthy bodies and well-functioning tools. In this analogy, illness equates the state of dysfunction of

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<sup>2</sup> "Professor Havi Carel," University of Bristol, School of Arts, accessed June 11, 2019, <http://www.bristol.ac.uk/school-of-arts/people/havi-h-carel/about.html>.

<sup>3</sup> From now on I will use this abbreviation followed by a number to refer to certain pages in "Phenomenology of Illness." The number that is stated is the number of the page present in the 2018 paperback version.

<sup>4</sup> P.A.F. van Veen and N. van der Sijs, *Etymologisch Woordenboek: De Herkomst Van Onze Woorden* (Utrecht/Antwerpen: Van Dale Lexicografie, 1997).

the bodily tool. We can be conspicuous about our body, when one of our body parts ceases to function, for example due to paralysis. The body can be obtrusive after amputation, or obstinate when we cannot longer use the body part as we did before (for example if, following a stroke, you lose the ability to write). Nevertheless, perceiving our body as a mere tool is not realistic. We can cast away a tool that is broken or malfunctioning, but we cannot replace our body. Repairing our body is fundamentally different from repairing a broken tool (PhI, 61-62).

Husserl, a phenomenologist who wanted to enable a study of consciousness that is free of assumptions, through suspending our usual beliefs and understandings, distinguishes between the objective body (*Körper*) and the lived body (*Leib*). Consciousness is related to the lived body, which we experience from a first-person perspective (PhI, 24-26). The distinction between the objective body and the lived body is highly applicable in the context of illness, for the objective body is the body that is studied by physicians, which can be inflicted by disease and treated. Sartre calls this *le corps d'autrui* (the body of others), for it is other people who gaze upon your body. A typical situation arises in disease. Maybe then we could call one's body 'the body of the physician', for it is the physician who views the body in a particular way. Illness, on the other hand, affects the lived body, for it is experienced by me in the first-person perspective. The distinction between the objective and lived body is helpful, for not every instance of disease is experienced by the patient. To elaborate on this Carel provides elevated blood pressure (hypertension) as an example: hypertension is a disease, for it is the cause and consequence of dysfunctioning of particular parts of the body (e.g. the arteries or the kidneys), but it does not at all have to be felt as such by the patient. The objective body is affected, whereas the lived body remains unaltered. From the moment of diagnosis on, the patient may experience being ill, for the physician will most likely prescribe medication and talk about lifestyle changes. However, if no symptoms have occurred, the patient still does not *feel* the disease. Oppositely, not all illnesses are at the same time a disease. Some symptoms are experienced before the patient is diagnosed with a disease and there are symptoms and complaints that cannot be attributed to a detected disease. This poses a problem for physicians as well as patients. Most often, the endpoint of treatment or study is a restoration of objectively measured values of bodily functioning (such as lung-volume, blood-pressure or serum level of certain hormones), whilst the height of these values does not correspond with the experience of the patient at all. Treatment may only be directed at the objective body, leaving the lived body still feeling ill (PhI, 46-48).

Sartre, in addition to the above, made a distinction between three orders of the body. These are the objective, the subjective and the intersubjective order. The first two orders, objective and subjective, are related to the objective and lived body respectively. The latter however, the intersubjective order, is my body as I experience it as reflected in the experience of it by others. This gives rise to experiences such as embarrassment and shyness. These can only arise in experiencing my body as it is for others. Another example of such an experience is empathy: I perceive another as a body, but at the same time I am aware that I am perceived by that other as a body that is similar to his or hers, thus evoking the experience of empathy. Empathy can arise as the consequence of a second-person perspective. When watching a loved one suffer, I do not just gaze upon him or her from an objective third-person perspective. I do not only see the experiencing of symptoms, like pain, but I feel related to a 'you' and I recognize your suffering, through imagination, memory or being-together. The patient, the 'you', will experience this relationship and recognition through the intersubjective order: the 'you' experiences that I (as the other) experience his or her body and that I feel related (PhI, 51-54).

### *1.3 Experiencing illness*

Normally, I am not aware of my body being healthy, it is an everyday state of harmony, control and predictability. Carel therefore, following Sartre, describes the healthy body as being transparent, taken for granted. It is the tool through which we experience, but not the thematic focus of our experience. In illness, the body disappears no longer, but as Carel terms, it is now a dys-appearance. The body appears to us as the object of experience, but in a *dys* state, being ill. There arises a kind of urgency to do something, for example to take away the pain or discomfort that is felt (PhI 55-57).

When using phenomenology to study illness, we do not seek for causal explanations or other answers to questions asked by empirical sciences, but we must return to experience itself. Thus, what is to be said about illness and the experience of it? Carel describes phenomenologist Toombs' analysis of illness and the typical characteristics Toombs found, which are elementary to the experience of illness. She distinguishes between the perception of loss of wholeness, loss of certainty, loss of control, loss of freedom to act and loss of the familiar world. These losses are the consequence of the perception of the body as impaired: the body is no longer under control of the patient. The patient is forced to experience his or her vulnerability, and the shocking insight that medical science may fail to sustain a healthy state will dawn upon him or her. It is important to make a distinction between different experiences of these losses. For example, when a loss is expected to be temporary (like a fracture), it is experienced differently than a loss that is thought to endure. However, illness does not only involve losses. On the contrary, illness can also involve gains, such as personal, emotional and spiritual growth and insight, as well as the ability to focus on the things that are most important. The distribution between gains and losses that are experienced as a consequence of illness vary among persons and can amongst other things be attributed to cultural and historical differences (PhI 41-43, 66).

### *1.4 Stages of illness*

To describe how these losses can be experienced in illness, Carel names four stages of illness, noting that these are only aspects of illness and not intended to determine the consecutive phases of all illnesses. They are the symptoms, diagnosis, progression and prognosis of the illness. In most instances, illness starts with the appearance of symptoms that pose a reason for the patient to go and see a doctor. Exceptions can be found in diseases that can be detected by screening, such as breast cancer. In those cases patients did not experience any (noteworthy) symptoms before they visited a doctor. Sometimes, such patients can be treated before they experience any symptoms at all. Normally, however, diagnosis is preceded by the appearance and increase of symptoms, possibly leading to an experience of loss of freedom or certainty already, which can cause anxiety. Specific symptoms, such as incontinence, fainting or even just weakness and fatigue can cause the patient to have a feeling of loss of control. Symptoms can cause the patient to have fewer possibilities and opportunities, for some actions may not be physically executable anymore.

At the moment of diagnosis, some things change. The illness changes in a more predictable pattern of symptoms and an explanation is found for the, until then, subjectively experienced symptoms, making them 'more' than just complaints. At this moment, the illness becomes also a disease: objective and accessible to others. Progression of disease results in diminishment of capacities, dependence on medical aids and loss of one's freedom to plan and to act. But, Carel adds, the patient also loses his or her desire to act. Disease can result in a loss of positive affective response. This phase of disease is absolutely frightening. Progression of the disease reminds us most directly of our finitude and vulnerability (PhI, 67-70).

Due to illness, even the world around us changes in our perception. Objects that were once easily portable are now tremendously heavy, and things once close to us are now far away. As Carel, who herself suffers from lymphangioleiomyomatosis<sup>5</sup>, expresses: "My world, and the world of those who are close to me, has shrunk. For me, the trap is permanent. There is no release from it. Every movement requires oxygen." (PhI, 71). Spontaneity is lost, for everything needs to be planned beforehand. Illness can take away creativity in two different fashions: either by removing the capacity to fantasize or by abating the capacity to execute (PhI, 73).

In addition to a change in embodiment and perception of the body illness also changes our social interactions. How others (friends, family and even strangers) see the ill person will shape how they themselves experience their illness. Due to illness, a person cannot participate in social events as she or he had before, there may be a feeling of awkwardness and due to this, the ill person may fall in a situation of social isolation. Moreover, friends (and strangers for that matter) will often not mention illness, feeling that it would be impolite to ask or draw attention to it. However, the illness has such a major impact on the patient's life, that it is almost impossible not to mention it. People often feel embarrassed and do not know what to say. This way, social barriers are sustained and enlarged. Carel describes: "It is not only physical possibility that suffers at the hands of illness. It is ways of being and ways of being-with." (PhI, 75-78).

### *1.5 Bodily doubt*

One of the experiences most fundamental to illness is doubt. Needless to say, we all experience a feeling of doubt from time to time. Nevertheless, this common doubt is always directed only at particular facts, abilities and psychological features and never pervasive. We may question a certain decision we have made, but we never doubt our ability to make decisions in general. In health, we have a tacit, yet unjustified, belief of certainty that our bodies will function as they should and as they always have. This is a feeling of possibilities, openness, familiarity and trust. The tacitness of the feeling of bodily certainty characterizes our body as taken-for-granted: there is no reflection. In illness, this certainty changes in a feeling of bodily doubt. This is not only a disruption of belief, but moreover a disruption of one's being in the world, resulting in estrangement and anxiety. The patient's connection to the world is lost. Bodily doubt may come at any moment and disrupt the normal sense of being in the world. It reveals the vulnerability of the body, without it being possible to return to the naïve state of confidence that accompanied bodily certainty. Bodily doubt is however not directly related to bodily incapacity. Some disabilities are not experienced in bodily doubt, such as congenital disorders, whereas bodily doubt can also be experienced without any decline of bodily capacities, such as in depression (PhI, 88-95).

Normally, we experience continuity in our cognition and our actions, we live and think in patterns and habits. In bodily doubt, this continuity is lost: in its place comes a modified awareness of ourselves and the world around us. This is most eminently noticeable in our daily routine: everyday habits cannot be performed as before and are now under conscious attention. Due to doubt transparency is lost and replaced by anxiety. The body is viewed negatively by the patient: the body is the problem and the patient has lost his or her faith in it (PhI, 98-101). Heidegger speaks of *Angst* (anxiety) when purposefulness and thus the meaning of entities is taken away. Objects turn from being ready-to-hand to being present-at-hand, as which they confront us as being purposeless, without meaning. In illness, this change in perspective not only befalls the objects around the patients, but also the body itself. Carel offers an interpretation of the thoughts of Heidegger, describing human existence as *Being-*

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<sup>5</sup> A severe and progressive disease affecting the lungs.

*able-to-be*. As opposed to life, death is defined as the complete inability to be. This view focuses on the potential and ability humans have: we can choose what we want to become and then become what we want through decisions and actions. Of course, not everything is possible, due to our physical and temporal limitations (which is called *thrownness/Geworfenheit*). The present has meaning because it is part of a project that is aimed at the future. Actions have to be taken to become something, which Heidegger calls *projection*. Pursuing projects to become what we want, gives us freedom and responsibility. However, an ill person cannot pursue specific projects or the number of projects that can be pursued is limited. These projects may not coincide with the person's values, interests and hopes. Carel argues that Heidegger's analysis of humans as *being-able-to-be* seems to miss these important aspects of human life, namely the periods of decline and inability. She states that the ability to be should be broadened: also 'other' abilities should be included, such as projects that arise in a context of limitations. *Being-able-to-be* should account for the diverse possibilities and abilities that vary among humans. We should not see the ability to be and inability to be as a dichotomy, but as a spectrum of abilities<sup>6</sup> (PhI, 79-82).

The past and future play an important role in illness. In the past we were healthy and thinking of this may give rise to grief. In the future, all is uncertain. Anxiety may arise, especially in the prospect of progression of disease, which may ultimately lead to death. Carel states that all deaths are preceded by illnesses, with the exception of suicide and traumatic accidents (PhI, 150). She therefore wants to elaborate on the relationship between illness and death. We are able to form a phenomenology of the relationship we, during life, have with death. Our existence is severely influenced by death, which shapes our finitude. Heidegger calls this *being-towards-death*. He claims that we can face death both authentically and inauthentically. When you follow the view of death that the society (*das Man/the They*) provides, you '*flee in the face of death*'. However, you can also view death authentically, by freeing yourself from the tranquilization of the They. You must be anticipating death, understanding that life is temporal. To anticipate is something else than to expect, which would mean waiting for the actualization of death. However, death can never be actualized, for death means annihilation. Anticipation of death can illuminate all possibilities we have in the context of finitude. This means seeing yourself as a whole. In Heidegger's book *Being and Time* death can be understood as the end of one's life, but also as anxiety in the face of death. Carel argues that this results in a short inability to be, where understanding and familiarity of the world and oneself recede. Anxiety can be part of authenticity, for I still perceive the world and myself as a whole. Anxiety is however non-genuine, for it leaves me unable to act. For a moment, I cannot participate in the world. Genuine being-towards-death would be resoluteness, having a sight of transparency, an attitude aiming at new possibilities. It means being with others, fully participating in the world. Carel convinces that this attitude towards death should also be used as an attitude towards illness, accepting and living with it. We should focus on the possibilities of being-in-the-world that are offered to us in illness (PhI, 150-153, 177-178).

### 1.6 Positive experiences

Carel explores the positive aspects of illness, claiming that illness does not necessarily have to exclude well-being. Carel quotes a number of scientific researches that have examined the

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<sup>6</sup> However, the original term presented by Heidegger, which Carel translates as *being-able-to-be* is *Seinkönnen*. Closer reading of Heidegger shows that *Seinkönnen* should not be understood as an ability, but as an attitude towards being. It can be seen as the way you interpret your life, the specific way in which you are. *Seinkönnen* is non-hierarchical. This understanding of *Seinkönnen* would render the comments of Carel on the thoughts of Heidegger futile.



relation between illness (objectively or subjectively measured) and happiness or well-being. They all approximately point to the same: well-being is not (or sometimes only a little bit) affected by illness. One explanation Carel offers is that of 'hedonic adaptation'. We tend to adapt to changes in our lives, even if these changes have a negative impact, such as illness. It is important to note that this only counts for chronic illnesses, where adaptation is possible over a longer period of time. We live in a culture where pathophobia reigns, for we normally only focus on the negative aspects of the experience of illness. Why do healthy people see illness as such a disastrous state of living? Most healthy people have no idea of what it is like to be ill. They think the illness will become the defining feature of life, and as a consequence they will attribute a too large role to it. They fail to see the ability of the patients to cope with and adapt to the illness. It is foremost a problem of limited imagination. The person in good health is an outsider to the experience of an ill person, and fails to imagine what it is like. In addition, if a person presently healthy has ever been ill, he will most likely not recall that event rightly. Our memory recalls only the core of past experience, and confabulating makes up a large part of remembering. Moreover, we tend to be better in memorizing successful events, in contrast to defeats (such as illness) (PhI, 134-139).

Illness can also give rise to 'post-traumatic growth', a term coined by Haidt. Carel uses his 'adversity hypothesis' that people are in need of setbacks to achieve physical and personal development. Illness can be seen as an example of such a setback. It can reveal abilities that were formerly hidden, it can improve relationships between people and lastly it provides new focus on the things that really matter to the patient. Illness may lead the patient to focus on the present, appreciate it and diminish their worries. Illness also gives us opportunity for thought and reflection (PhI, 140-142).

Illness offers other dimensions of human life than can be seen and experienced in health. Healthy, normal experience can be revealed. It has become clear that the body plays a central role in how we are in the world. Illness, a change in bodily functioning, alters this way of being in the world, affecting our experience. It can reveal new abilities, such as adaptation, but at the same time it can lead to a loss of meaning, a loss of purposefulness. However, it may also result in a change of meaning, which is reflected in one's entire interaction with the world around him or her. The disruption of normal, everyday life that is the effect of severe illness provides a certain distance from this normal situation, and offers a shift in point of view. The concepts of distance and time are altered. Illness changes one's life dramatically and thus invites the patient and the persons close to him or her to philosophize. 'Invitation' implies a free choice, but that is not the case in illness. Illness is unchosen and violent and the philosophical reflection that may be its consequence is terrifying and all-consuming, but also more intense, focussed and non-elusive (PhI, 224).

### *1.7 A phenomenology of illness*

I want to end this brief outline of "Phenomenology of Illness" with a description of the phenomenology of breathlessness that Carel offers in her book. We now put her phenomenological method into practice, through a description of an illness, from the first person perspective. Breathlessness is an important symptom belonging to a wide range of diseases and Carel first describes the underlying pathophysiological mechanism. She notes that the term breathlessness is not a strictly defined symptom: the experience of breathlessness during an asthma attack can be different from breathlessness in heart failure. It is important to note that breathlessness can also occur as the consequence of physical exertion, or without an underlying physical cause. That is called breathlessness *e causa ignota* (of unknown origin); based on measurements and diagnostics it seems as if the patient is healthy, but he or she reports breathlessness nonetheless. This is phenomenologically interesting, for this

'unexplained breathlessness' only manifests itself in the experience of the patient. A phenomenological approach may enlighten the symptom of breathlessness and reveal new aspects that have been concealed by the physiological approach.

Carel describes breathlessness and her own experiences of it in a very telling way, giving an impressive description of what it is like to feel as if "you've held your breath for far too long and feel your chest is about to explode. But you cannot raise your head above the water and take a deep and gratifying breath. All you can do is gasp and pant and hope that eventually the breathlessness will recede, even a little, and a glimmer of hope of recovery will emerge from the dense clouds of dyspnea" (PhI, 110). She talks about her experiences and about the way illness (and in particular breathlessness) has changed her life. "The world shrinks and becomes hostile. The sense of possibility that accompanies objects disappears. A bicycle is not an invitation for an afternoon of fresh air and freedom. It is a relic of days bygone" (PhI, 111). "Breathlessness creates a new world, a new terrain to be navigated. Where freedom and obliviousness once ruled, hesitation and limitation now dictate my movements" (PhI, 113). Carel describes how uncertainty and destabilisation crept up on her. Interestingly, she adds that even during the time her physical condition was not yet very severe, she experienced fear and doubt, due to a sense of forceful fragility. In addition she mentions the discrepancy between objectively measured respiratory function and the subjectively experienced function of breathing. "The loss of transparency of the objective body and the tense relation between it and the lived habitual body came to the fore" (PhI, 119). During progression of symptoms denial and realization were at odds. Carel elaborates on the losses of illness described by Toombs which accompanied her breathlessness. However, she adds, "despite being so common, breathlessness remains invisible, opaque, or refractory. This opacity poses a particular challenge to health professionals, as the subjective experience of symptoms like pain and breathlessness is largely invisible" (PhI, 124). Carel concludes with an expression of hope that her phenomenology of breathlessness can illustrate the richness of her experience and that it may serve as a way of better understanding breathlessness. I am certain that she succeeded.

## Chapter 2. Reflections on illness and disease

### 2.1 Introduction

In what follows I will elaborate on some of the concepts presented in the previous chapter. As mentioned above, there is a distinction between the terms disease and illness. Disease is the third person medical condition, whereas illness is the first person experience of what that condition feels like. This is a very important distinction for the patient and the physician, although they often will not be aware of this. The patient will approach the disease and all that accompanies it (including the doctor) from the perspective of the illness, being his or her experiences, feelings, losses and gains. The physician will encounter the patient and his or her illness, but from the viewpoint of the disease. He or she has a different approach when reviewing test results, objectified symptoms and for example the X-rays. This may lead to problems in the communication between the physician and the patient. I will address this later on.

### 2.2 The first and third person perspective revisited

What exactly is the distinction between illness and disease? Carel offers two major points of distinction between the two. Firstly, she argues that we can perceive of disease as the pathophysiological mechanism of bodily breakdown. Disease is the process that causes our body to cease functioning. The precise mechanism can be diverse, also in the case of one diagnosis (there are for example numerous different mechanisms that can cause heart failure), or even unknown, for example in the case of mental disorders.<sup>7</sup> Illness is the effect the disease has on how you feel, what you do and what you can. Illness is the way in which the disease affects your life. Secondly, illness and disease can be distinguished on the basis of the first and third person perspective. The first person perspective offers the direct experience of the illness by the patient: "what is it like to be ill?"<sup>8</sup> whereas the third person perspective gives us a description of the disease (which belongs to the realm of the empirical sciences, Carel argues (Phl, 17)). There are different ways of understanding these perspectives. In literature, the first person perspective or narrative denotes the situation in which we read and experience the story from the point of view of the protagonist. We look, so to say, through his or her eyes and we are in his or her head. The first person perspective in phenomenology can amount to roughly the same. This perspective of the illness is the experience that I, being the patient,

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<sup>7</sup> In the case of mental disorders the underlying mechanism of disease, the pathogenesis, is not always known. It may be the case that we are just not yet able to uncover this causing process, or it may be that there is no underlying pathophysiological mechanism in the brain, in which case the disease arises as the consequence of psychological factors or imbalances. However, in my opinion this does not affect the statement that illness is the experience of disease, for also psychiatric disorders are experienced by patients (although these experiences are even further away from the normal experience of 'ordinary' diseases). That we do not know everything about a disease does not mean it cannot cause the feeling of illness. However, to be able to speak of illness, the presence of a disease has to be presumed, for disease and illness go hand in hand. I do not think that disease necessarily has to be present exactly at the same time as the illness, or that the disease has to be exclusively somatic, but I do believe there has to be some link between disease and the experience of discomfort to be able to speak of illness.

<sup>8</sup> We can also use the question "what is it like?" to address other, more abstract situations of experience. Compare this to Nagel's notion of "what is it like to be a bat?" We may try to imagine what it is like to be a bat and have perception mediated by sonar, and we can understand what sonar is and how sonar functions, and how bats live and behave, but we can never actually have any idea of what it is like to be a bat. Can we make an analogy between bats and persons experiencing illness?

Thomas Nagel, "What Is It Like to Be a Bat?," *Philosophical Review* 83, no. 4 (1974).

have. I perceive the illness through my eyes, and I experience it as it is in my head and body. Pronouns can be used to make the distinction between first and third person perspective. It is *my* illness, I have knowledge about *me*. The doctor, on the other hand, knows about *his* or *her* disease. The doctor has knowledge about a *him* or *her*, the patient. Following Choifer, who wrote about the distinction between the first and third person perspective, I believe that the distinction between the two perspectives is not about who is experiencing or perceiving (me, the ill person, versus he or she, the doctor). In contrast we should make a distinction between the point of view that is taken. We can have an 'origin' point of view, in which something is directly, unreflectively given to us and we can have an 'outside' point of view, when we reflect on our thinking or experiencing. The distinction between the first and third person perspective is thus based on the reflectiveness of our consciousness.<sup>9</sup> The first person perspective is the perspective in which an experience is unreflective, it is directly given. In the case of disease an example could be found in the sensation of pain, breathlessness or panic. Such sensations affect a person immediately, without mediation of thought and contemplation first. A third person perspective is a more reflective consciousness, in which, in case of the illness, the experiences of the patient are viewed from the outside, they are contemplated on. This reflective perspective or contemplation on illness can be viewed as an addition to the objective view on disease, which has a more material and measurable basis. It does not necessarily have to be a doctor who takes a third person perspective towards a patient's illness. Even the patient (or especially the patient) can deliberate over illness and thus take a reflective point of view (an 'outside' or third person perspective). Of course, the patient cannot view his or her sensations objectively or impartially. Nevertheless, the patient is able to ponder over these sensations and think about what they mean and how they affect his or her life. In the first person perspective, the patient experiences the illness directly, without reflection, experiencing all its losses and anxiety. In the third person perspective, however, the patient thinks about these experiences, and talks about them. In *Phenomenology of Illness* numerous examples of these reflective experiences are presented, such as the losses described by Toombs. The first and third person perspective presented here thus offer an extension to the distinction between illness and disease offered by Carel. The third person perspective of the patient, which is the reflection on the illness, can serve as crucial connection between the illness and the disease. A physician who wants to acknowledge the impact a disease has on the patient's life has to take a third person perspective<sup>10</sup> of the illness as well as the disease. This forms the key towards proper communication about illness (and not only disease) by the physician and the patient.

### 2.3 Illness and disease, a continuum

Distinguishing illness from disease is harder than it seems. The first distinction offered above (disease being the mechanism that causes bodily malfunctioning and illness being the experience of that) is not completely satisfactory. Disease does not have to involve illness, and vice versa. Someone may have a disease without having an experience of it. For example, a person may suffer from cancer without being aware of it. When there is no trace of the neoplasia, when it does not hurt or affect processes in the body, the affected person will most likely not feel ill, until the moment symptoms arise or until a doctor discovers the cancer coincidentally. Conversely, a person who has had cancer, has been treated and has been cured, will most likely still feel ill, even when the tumour is completely eradicated and bodily processes are no longer influenced. Doubt and anxiety will take long to resolve. During this

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<sup>9</sup> Alla Choifer, "A New Understanding of the First-Person and Third-Person Perspectives," *Philosophical Papers* 47, no. 3 (2018).

<sup>10</sup> He cannot truly reach the first person perspective of the patient's illness.

time the person does not 'truly' have a disease, yet he or she will still feel ill. Other situations in which illness occurs without disease are the condition which is called hypochondria and all disorders that can be ranked as somatically unexplainable or idiopathic.<sup>11</sup> In addition to the above, having a certain disease will not necessarily cause a certain experience of illness. Every patient has his or her own way of coping and undergoing bodily malfunctioning, and every patient experiences a disease in a unique way. It has been demonstrated that the response to and experience of a pain stimulus differs widely among persons.<sup>1213</sup> The role of genetics, sociological and psychological factors and neural mechanisms is uncertain and ambiguous. It is clear however, that the relation between the body (that receives the stimuli) and the experience of these impulses is not straightforward. This does point to some sort of distinction between disease and illness, but it only further indicates that the boundaries and relation between the two concept are uncertain.

I propose that illness and disease are not two completely different concepts that can be separated and distinguished on the basis of some criteria. I believe illness and disease must be viewed as a continuum. This continuum is the way in which the patient experiences the disease: only as bodily malfunctioning, only as feeling of a changed way of being in the world or as a combination of these two. When someone has a disease he or she has a certain medical condition, some sort of bodily process or malfunctioning, which may or may not cause symptoms. The person with a disease may experience this disease as disease or as illness or as something in between. To experience the disease as a disease is to know that you have a condition or a diagnosis, to experience symptoms to a certain extent, without the disease having a major influence on your life and your way of thinking and being in the world. The experience of illness is largely in the background. When the disease has impact on your life, when you must give up on habits and activities you like, when the disease starts to change your way of thinking, you become ill. The more this change takes place, the more ill you become, but that does not necessarily have to coincide with the disease becoming more severe. A mild disease does not have to correspond with a mild feeling of illness, and a severe disease does not necessarily make you feel very ill. The continuum I propose is the extent to which the bodily malfunctioning has an impact on the patient's life as well as body, and the way the patient perceives of this impact. When you experience the disease, you are aware of the symptoms and bodily changes, but you experience it as a change of your body, not as a change of your identity. An example of this could be found in a patient suffering from heart failure. He or she may experience a bodily change over time, for example when failing to walk distances once easily walkable. Experiencing the heart failure as disease is experiencing this inability as a bodily malfunctioning. Severe illness on the other hand can change your way of thinking and being in the world, and due to that it alters your identity. The patient with heart failure who became unable to walk the same distances as before may experience this as illness, for example when he or she does not feel in control, when he or she experiences crushing doubt over future activities or perceives objects and concepts as irreversibly changed. The continuum presented here means that for the patient illness and disease are present simultaneously. It is just a matter of which of the two is predominant in the experience of the patient. Whether illness or disease prevails, or whether they are equally pervasive or not can

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<sup>11</sup> In Dutch a helpful term is coined for these unexplainable disorders: *SOLK, somatisch onverklaarbare lichamelijke klachten*.

<sup>12</sup> R. C. Coghill, "Individual Differences in the Subjective Experience of Pain: New Insights into Mechanisms and Models," *Headache* 50, no. 9 (2010).

<sup>13</sup> R. C. Coghill, J. G. McHaffie, and Y. F. Yen, "Neural Correlates of Interindividual Differences in the Subjective Experience of Pain," *Proceedings of the National Academy of Sciences of the United States of America* 100, no. 14 (2003).

change over time. The continuum that exist in the experience of the patient ensures that the disease is not only knowable to the doctor. It is also recognized by the patient, but it simply is not paramount. The same goes for the illness, which can be sensed and understood by the doctor. As I will later discuss, it is the task of the doctor to focus also on illness in addition to disease, instead of neglecting it and forgoing to help the patient in the improvement of his or her experience.

## 2.4 Health and illness

Carel has given a very extensive description of the concept of illness and all that it encompasses. However, after reading *Phenomenology of Illness*, there is one aspect of illness that she has not often mentioned: health. I call health an aspect of illness, for without illness health would not be experienced by us. Only when we have a severe sinusitis that constipates our nasal airway we are aware of the ease with which we normally tend to breath. Illness confronts us with a malfunctioning which in health is not felt. In addition to that, if there would be no (ideal) state of health to which we strive, the importance or impact of illness would not be so great. What is the relation between health and illness? The official definition of health as stated by the World Health Organisation since 1948 is: "*Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.*"<sup>14</sup> Thus, being healthy requires more than just being not-diseased. Illness (which has more impact on the social and mental aspects of well-being) must also be absent to be able to speak of health. Health is thus a state of mind, body and interaction with others which must be characterised as a state of well-being. Life must be, the WHO argues, comfortable, enjoyable, safe and to a high degree also limitless. However wonderful this ideal state of health may be, the definition offered by the WHO is nowadays seen as overdrawn and inadequate to describe health, particularly in the light of the rise of chronic diseases.<sup>15</sup> The WHO definition of health makes health a subjective concept. I am the only one who can 'decide' if I feel healthy, and I am the only one who can feel ill and thus conclude that the state of complete wellbeing has faded. This renders health as something that can only be felt by the person in question, and never be established objectively by, for example, a physician.<sup>16</sup> However, *feeling* healthy is no guarantee for *being* healthy at all, for I may have a disease which I am not aware of. In that case, only the doctor can tell me that I am not healthy anymore, although it may feel as if I am. This situation of abrupt ending of the state of health is even more shocking than the lingering increase of symptoms and accumulation of precursors of illness that may precede a severe diagnosis. The different states of health, being the subjective experience of being healthy and the objective determination of a healthy body can be seen as the counterpart of the continuum I proposed above. Not only disease and illness form a continuum, but also the experience of subjective and objective health. When a person is healthy, subjective and objective health are present simultaneously. For some, the feeling of being healthy may be predominant, whereas for others, more emphasis is laid upon the reliable functioning of the body. This, of course, can also shift in different situations and contexts.

Health, or the state of being without illness or disease present, has become more than just an aspect of life. Nowadays, with the advance of the knowledge and abilities of medicine, being healthy has gained top-priority. One has only to look on Facebook or in the media to acknowledge the vast popularity health and all that is related to health has gained. In the

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<sup>14</sup> WHO, "Constitution of the World Health Organization," in *International Health Conference* (New York 1948).

<sup>15</sup> Other definitions are offered, for example by Machteld Huber.

Machteld Huber et al., "How Should We Define Health?," *British Medical Journal* 343 (2011).

<sup>16</sup> Note that the same goes for illness.

Netherlands, the number of gym memberships is increasing,<sup>17</sup> and the usage of non-prescription medication has approximately doubled since 1990,<sup>18</sup> to name a few examples.

In the medical practice, almost everything is possible. We are not only able to treat diseases that were once untreatable, we are not only able to cure disease that were once incurable, but in the past decades, we have learned to prevent diseases (and illnesses) from even coming into people's lives. The knowledge regarding risk factors and facilitating influences is rising, and with it the feeling of urgency to do something about it. A paradox can be perceived. On the one hand people do anything to avoid becoming ill. They purchase powerfoods, take yoga-classes, start drinking tomato juice with cayenne pepper,<sup>19</sup> and participate in the mass hysteria and dogmatism that surrounds the endeavour of staying healthy. On the other hand, in Western societies we can observe a process that can be described as medicalisation. We can view a rising tendency to medicalise aspects of life that were not within reach of the doctor before. The medical practice tends to expand to parts of life that were, until now, not seen as medical issues. More and more women choose to give birth in a hospital instead of at home.<sup>20</sup> There are numerous other examples, such as obesity, infertility and even the menopausal transition. This is not only the consequence of doctors redefining certain biological states as pathological, but also of changing societal values and standards.<sup>21</sup> It appears that people are strangely obsessed by health and its counterparts, disease and illness. We could perceive of health as a temporary religion. It even appears that, after analysis, the concept of health and the place it has in modern society meets ten characteristics of religion.<sup>22</sup> This once more indicates the profound relationship we have with health and staying healthy.

### 2.5 Well-being in illness

Illness alters our way of being-in-the-world. As Carel argues, our ways of thinking about objects and concepts changes. Objects once useful are no longer workable and may altogether fade into the background of perception. Only severe, action altering illnesses can cause a change in perception. In this context, Heidegger's notion of present-at-hand and ready-at-hand is applicable. When a tool breaks down, or (as in illness' situation) can no longer be utilised, we become aware of it. A turn in perception takes place. However, not only the perception of tools and objects around the patient change, but also the way the patient views him- or herself. When we follow the analogy between the body and a tool, we can call illness the functional breakdown of the bodily tool. If the patient is no longer able to control his or her limbs, or if he or she is bound to the bed, the way in which the ill body is viewed will change completely. This loss of bodily function will eventually lead to a modification of the goals and intentions the patient has, for it will become clear that not everything that was once within

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<sup>17</sup> Statline, "Fitnesscentra; Klanten, Abonnementsprijzen En Voorzieningen," CBS, accessed June 12, 2019, <https://opendata.cbs.nl/statline/#/CBS/nl/dataset/83822NED/table?ts=1542633113199>

<sup>18</sup> "Gezondheid, Leefstijl, Zorggebruik En -Aanbod, Doodsoorzaken; Vanaf 1900," CBS, accessed June 12, 2019, <https://opendata.cbs.nl/statline/#/CBS/nl/dataset/37852/table?ts=1547549029555>.

<sup>19</sup> This is a curious habit of my father, who is frightened to death by doctors in white coats.

<sup>20</sup> Statline, "Bevallig En Geboorte: 1989-2013," CBS, accessed June 12, 2019, <https://statline.cbs.nl/StatWeb/publication/?DM=SLNL&PA=37302&D1=0-2&D2=a&VW=T>.

<sup>21</sup> George L. Blackburn, "Medicalizing Obesity: Individual, Economic and Medical Consequences," *American Medical Association Journal of Ethics* 13, no. 12 (2011).

<sup>22</sup> The ten characteristics are: The sacred, a comprehensive worldview, moral values, a protective screen, salvation/liberation, symbols, rituals, certain moods and emotions, a conviction of trueness and community.

Britta Pelters and Barbro Wijma, "Neither a Sinner nor a Saint: Health as a Present-Day Religion in the Age of Healthism," *Social Theory & Health* 14, no. 1 (2016).

reach can now be achieved. This shift in aims and plans, and thus the shift in purpose, may altogether give rise to a shift in identity. The ill person changes as a person.

Needless to say, almost everyone feels at least discomfort when thinking about becoming ill, and most of us feel outright anxiety. The suffering that accompanies the progression of symptoms is terrifying. We fear that illness and disease will impinge on our lives, changing our loved way of being in the world. However, illness need not only be terrible, terrifying and negative to us, as Carel argues. She offers a few studies that show that well-being is possible, even though a patient may suffer from a disease or disability. She concludes that there is almost no correlation between well-being and objective health. Levels of well-being mostly drop only directly after diagnosis, but thereafter tend to stabilise at baseline level (PhI, 134-135). This raises the question of how this is possible. In my view, there are multiple explanations to be thought of. Carel appeals to the concept of hedonic adaptation, through which the perception of the ill patient changes. Events and objects previously viewed as positive or negative are now seen as merely neutral. Due to this shift the patient adapts to the new situation, although this of course will take some time. The shift in perception that occurs due to hedonic adaptation is distinct from the shift that arises due to so called desensitization, by which an overall decrease in affective response to a stimulus is caused.<sup>23</sup> Carel does not delineate the possibility of desensitization as explanation for the perceived high levels of well-being in ill patients, yet I agree that it is unlikely that a decrease in affective reaction (if caused by illness) would result in an equally high level of happiness, for I think that the ability to have an affective reaction is to a certain degree a prerequisite for being happy. However, in my opinion, the explanations offered above only show how well-being is possible in disease, not how well-being is possible in illness. Although it is unsure if and how the severity of illness could be measured, I suspect that subjectively measured health (thus the patient's experience of his or her health) could be a possible way to assess illness' severity. One of the studies that Carel cites, by Angner et al., shows no correlation between objective health<sup>24</sup> and well-being, but does find a correlation between subjective health<sup>25</sup> and well-being.<sup>26</sup> This would mean that the severity of a disease does not influence well-being (presumably due to hedonic adaptation), but that the severity of illness may indeed have an effect on the levels of well-being. This, for me, is contradictory to the possibility of well-being in illness. For if poor subjective health (and thus, I think, more severe illness), does result in lower levels of happiness, and if good or excellent subjective health does result in higher levels of happiness, as Angner et al. shows, I think well-being in (severe) illness may be impossible, or at least very hard. As discussed, hedonic adaptation may explain why a patient can again achieve well-being: the way the patient experiences the disease gradually alters from negatively to neutrally. One could argue that the objective health of the patient remains poor, for the disease is still present, whilst the experience of the patient, arguably the subjective health, improves. I would say that to improve the levels of well-being of the patient, it is not only required to diminish the severity of the disease, but also, and maybe even to a larger extent, to

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<sup>23</sup> Christina Armenta et al., "Is Lasting Change Possible? Lessons from the Hedonic Adaptation Prevention Model," in *Stability of Happiness*, ed. Kennon M. Sheldon and Richard E. Lucas (Academic Press, 2014).

<sup>24</sup> The objective health was measured by asking patients how much pain they experienced and if they had certain comorbidities. It is highly debatable whether this measurement really is sufficient to achieve a good impression of the objective health of a patient, for it was still self-reported by the patient.

<sup>25</sup> The subjective health was measured by asking patients how they rated their health.

<sup>26</sup> E. Angner et al., "Health and Happiness among Older Adults: A Community-Based Study," *Journal of Health Psychology* 14, no. 4 (2009).



fight and abate the illness of the patient. This is, at least partially, the responsibility of the physician and other healthcare professionals.

## 2.6 Helping the patient

I have now reached the practical implications of what I have discussed in the previous reflections. In the eighth chapter of *Phenomenology of Illness* Carel describes the possible reception of first person reports of patients. How do, for example, doctors react to the patient's report of his or her illness? When doctors do not respond, or are dismissive and show disbelief, a situation of epistemic injustice may arise. Epistemic injustice is caused by stereotypes and biases that negatively influence the conception of illness. The patient knows things, about his or her body and illness, but this knowledge is neglected as such by the doctor. This is a situation that has to be prevented, so that all testimonies and interpretations of patients are considered, sought out and judged based on relevancy (PhI, 188-189). In what Carel depicts as 'the situation of epistemic injustice', the physician is epistemically privileged and indifferent to the words of the patient. However, the introduction of terms such as 'patient centred-care' and 'shared decision making' and the notion of the 'patient expert' may provide ways of diminishing the distinction between epistemic injustice and privilege. Carel suggests that phenomenology may serve the goal of overcoming epistemic injustice by contributing to the clarification of the patient's experience of illness. For this purpose, she developed a toolkit. This toolkit may be helpful to patients as well as health professionals, using philosophical concepts to talk and make sense of illness, interpreting experiences and the impact that illness may have on the patient. It may serve as a supplement to medical knowledge. The toolkit consists, shortly, of a descriptive method to draw attention to the experience of illness, focusing on certain aspects of it and considering how a new understanding of illness may alter the ill person's life (PhI, 197-201). As I have discussed, I think it is paramount that physicians do not forgo to invest in caring for the illness of the patient. The illness is of equal importance as the disease, and has a wide and violent effect on the patient's life. Both illness and disease are present in the experience of the patient, and both will determine how the patient feels and functions. It is vital that the patient is able to think and talk about the illness, separately from the disease. This way, the patient is hopefully better able to find a way to deal with severe illness.

In this endeavour, the physician must provide help. For the patient is the 'expert' when it involves the illness and its experience, but the doctor is the authority when the disease is concerned. In my view, it is the task of the physician to try to connect the experience of illness with the impact of disease, together with the patient. For as we have seen, the level of well-being the patient experiences is influenced more thoroughly by the absence of illness than the absence of disease. If a physician aims to cure a patient (which he hopefully does) it is necessary that not only the disease is treated. This will, as I believe, only solve part of the problem, leaving the patient to deal with the different negative aspects of illness. Thus, the physician and patient should deliberate on the facets of illness that the patient faces, and search for possible solutions if needed. But how is proper communication on illness attainable? If the patient is the expert concerning his or her experience, how can the physician try to reach an adequate level of understanding of the patient's illness? I think there are two possible and supplemental approaches that the health professional can apply. The first method is to start with the experience of the patient. He or she has a first person perspective on his or her illness, directly feeling and suffering from it. The physician can ask questions about the life, feelings and perceptions of the patients, inviting him or her to talk. When the physician confronts the patient to speak about this illness, the patient may take a reflective, 'outsider' point of view, enabling the doctor and the patient to talk about a third person

perspective on the illness. This way, the physician may be able to familiarize with the experience of the patient, and help alleviate the feelings the illness may cause. It is absolutely paramount that the physician does not forsake to talk about the experiences of the patient, for that would be an expression of carelessness to the patient, and a failure to provide necessary assistance. The second approach that the doctor may use to come to understand the illness of the patient is trying to consider what illness would feel like from his or her own point of view. This goes further than empathy, which, at least in my view, has been misused in the medical sector to evoke a feeling of genuine compassion in the patient whenever needed, but is, often, deprived of complete sincerity. I therefore propose another method which would require that one writes or composes a phenomenology of an illness for oneself. So called pathographies have been shown to provide medical students with better insight in the experience of patients, indicating to these students what is of importance for ill patients.<sup>27</sup> I believe this will also be the case for other health professionals that wish to attain a better understanding of possible experiences of illness. Physicians are challenged to formulate an answer to the question “what is it like?” and can accordingly gain insight in the life and experiences of the ill, especially when combining this insight with the individual answers and experiences of their patients.

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<sup>27</sup> K. Hwang, H. Fan, and S. W. Hwang, "Writing About an Experience of Illness in Medical Students," *Advances in Medical Education and Practice* 4 (2013).

## Conclusion

Phenomenology provides a fitting method to examine and describe illness and the experiences of patients that suffer from it. The work of Carel concerning this field of study offers a detailed account of possible ways to perceive of the body and bodily breakdown, as well as different aspects of the experience that can arise due to severe illness. Changes, losses, anxiety and bodily doubt can thoroughly change the patient's life. Illness is the philosophical counterpart of disease, which is the objective pathophysiological malfunctioning of the body. Disease and illness disclose a continuum, for they are present at the same time, but not equally predominant. The illness is accessible to the patient, who experiences the illness directly from a first person perspective, whereas the disease is easier comprehensible to the physician. This discrepancy poses a problem, for it may result in a failure of the physician to address all the concerns of the patient: the disease as well as the illness should be attended to. It is therefore paramount that the physician tries to access the patient's experience of illness. I hope this thesis will provide insight in the phenomenon illness, offering a way for physicians, medical students, patients and others to better understand the experiences of ill patients. This way, I hope, illness will attain its rightful place in medical care, being equally important as its counterpart disease.

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