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# Can I Be Ill and Happy?

Havi Carel

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**Abstract** Can one be ill and happy? I use a phenomenological approach to provide an answer to this question, using Merleau-Ponty's distinction between the biological and the lived body. I begin by discussing the rift between the biological body and the ill person's lived experience, which occurs in illness. The transparent and taken for granted biological body is problematised by illness, which exposes it as different from the lived experience of this body. I argue that because of this rift, the experience of illness cannot be captured within a naturalistic view and propose to supplant this view with a phenomenological approach. The latter approach accounts for changes in the ill person's relationship to her social and physical world. These changes, I argue, cannot be captured by a naturalistic perspective. I then propose the notion of health within illness as a useful concept for capturing the experience of well-being reported by some ill people. I present empirical evidence for this phenomenon and assess its philosophical significance. Finally, I suggest that adaptability and creativity are two common positive responses to illness, demonstrating that health within illness is possible. The three elements combined – the transformed body, health within illness and adaptability and creativity – serve as the basis for a positive answer to the question posed above.

**Keywords** Happiness · Illness · Well-being · Phenomenology · Naturalism · Disease · Boorse · Fulford · Health within illness · Chronic illness · Medicine

## Introduction

When we think about the good life, whether within an Aristotelian, liberal or other framework, we often try to spell out the conditions for such a life. These are freedom, health, access to social goods, self-fulfilment and so on. Although health is, of course,

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taken to be an essential element of the good life and a necessary condition for happiness, a particular issue seems to be insufficiently discussed in such accounts. This is the question: what happens to the good life or to happiness when health is permanently absent? This, I claim, is not a tangential or secondary issue but a fundamental one. It is fundamental because ultimately the vast majority of people die of some kind of illness and some spend a large portion of their lives chronically ill or disabled. So surely, any account of the good life or of happiness must consider the inevitable decline of the body and its consequences. But how should it do so?

Surprisingly perhaps, little attention has been paid to this issue. Overall, it seems that the questions and challenges arising from states of illness and disability are often overlooked in discussions of the good life and happiness. In this paper I raise this issue and consider the following question: when seriously constrained by ill health, be that of chronic illness, terminal illness or disability, can one still be happy?

In the first part of the paper I provide a definition of illness that encompasses the aspects relevant to a discussion of happiness and the good life. For this purpose I propose a phenomenological approach. On this approach, illness is not just an impairment of a certain organ or physiological function. Rather, it affects the entire person and her relationship with both physical and social environment.

In the second part of the paper I turn to the notion of health within illness and demonstrate, both empirically and conceptually, how it is possible. Examining recent healthcare literature and qualitative studies informed by a phenomenological approach, I develop the notion of health within illness and discuss the results of studies looking at reactions ill and disabled people have to their illness and how this affects their well being. Rather than measuring the experience of the ill person in objective parameters, i.e. how far from the norm she is, I focus on the experience of personal growth, adaptability and health within illness. I argue that a phenomenological methodology can enable the expression of these experiences, in order to give a more complete description of the altered relationship of the ill person to her world and develop a better understanding of her lived experience.

This approach does not entail a rejection of the naturalistic view.<sup>1</sup> This view provides us with a coherent and useful account of the biological body, which is appropriate in basic science and laboratory work. But in clinical medicine, where medical practitioners encounter ill people rather than biological processes, the naturalistic view should be augmented by a phenomenological perspective. This perspective encompasses both the objective biological body and the lived body, the body as it is subjectively experienced. Given this novel relationship between the biological and lived body found in illness, I will show how illness could elicit creative philosophical and personal responses.

Finally, I answer positively the question posed at the beginning of the paper: can seriously ill or disabled people have a good life? I develop the idea of illness as a limit case of the relationship between the biological and the lived body. Having lost the habitual relationship between the two, the ill person must form a new one, and this, in turn, requires significant adaptability and creativity. These two central ideas – that

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<sup>1</sup> I would like to thank Eran Dorfman and Samir Okasha for helpful discussions of the relationship between naturalism and phenomenology.

illness induces adaptability and that adversity is the source of creative responses to it – serve as the basis for this positive reply.

### The Cost of Naturalism

What is disease? The naturalistic approach put forward by Christopher Boorse and others sees disease as a value-free objective concept. They view disease as a biological dysfunction of a body part or system. Boorse defines disease as statistically species-subnormal biological part-function, while health is conformity to species design. Ultimately, argues Boorse, states of health and disease are “an objective matter to be read off biological facts” (1997, p.4). This is the prevailing conceptual model used by medical practitioners to think about their practice.

But this view does not tell us anything about the experience of illness. What is it like to live as ill or disabled? What is the experience of someone who is no longer able to walk, or talk, or perform tasks such as writing or cooking? What impact does illness have on the world of the ill person, on her interactions with her environment and with other people? What happens to goals, plans and temporality in the face of medical uncertainty? What is the nature of our relationship with our bodies and how does this relationship change when our bodies betray us? These types of questions, crucial to any account of the good life, are excluded by the naturalistic approach. The impact of illness on the ill person remains unaccounted for in this view.

Some naturalists defend their view by claiming that it is not the aim of their approach to encompass the changes to the life and world of the ill person as these changes (which some naturalists call ‘illness’) are secondary and derived from the primary concept, that of biological dysfunction (‘disease’). But is this claim true? Is disease primarily the failure of a physiological system and only secondarily does it affect the life of the ill person?

I claim that for both conceptual and practical reasons the answer to this question is no and therefore the naturalistic account is incomplete. Many have presented counter-examples of illness without disease (migraine, depression) which on Boorse’s account would not count as physiological dysfunction. Additional examples are states that fall under the category of disease under the naturalistic view, but that we would find odd calling disease (ageing, pregnancy). This led many authors to claim that “no biological account of disease can be provided because this class of conditions is by its nature anthropocentric and corresponds to no natural class of conditions in the world” (Cooper 2002, p.271)

More importantly for our purposes, biological dysfunction is only one aspect of illness. The breakdown of an essentially unified phenomenon into a biological vs. social/psychological elements relies itself on the naturalistic view, and as such is question begging. It relies on a putative distinction between body and person, biological fact and its interpretation. The phenomenological approach rejects these distinctions both in its general metaphysical view and more concretely in its approach to illness.

Naturalism comes at a cost. Naturalistic theories neglect the loss of agency or incapacity characterising the experience of illness. This is because of the disease/illness distinction, which sees disease as primary and illness as derivative. But as

Fulford (1993) argues, illness is not secondary to disease. On Fulford's account a value-free definition of illness is insufficient to capture the full meaning of the term.<sup>2</sup> He writes: "illness sits between bodily/mental parts (which become diseased) and social structures (within the values of which standards of health are defined)" (p. 308).

After showing that disease cannot be a value-free concept, Fulford suggests an account that would encompass both disease and illness. While for Boorse illness is an evaluative sub-category of disease, Fulford regards disease as a sub-category of illness. "The more value-laden concept of illness would encompass any condition that may be evaluated as an illness; but disease (with its more factual connotations) would be restricted to that sub-category of these conditions which are so evaluated by most people most of the time" (p.310).

I agree with Fulford's criticism of Boorse, but I believe that his account is incomplete. It perceives the debate as taking place between naturalism and normativism (or value theory). But neither view takes into account the experience of illness and the first-person perspective on its meaning and impact. In order to provide such an account, a philosophical approach that rejects the distinction between mental and bodily properties in favour of an embodied approach, sees embodiment as an essential feature of action and takes the first-person description of experience as its building block, is needed. The phenomenological approach of Merleau-Ponty provides these, as I explain below.

These are conceptual reasons for augmenting the naturalistic account with a phenomenological approach. There are also pragmatic reasons for doing so. These reasons are clearest when looking at chronic or currently untreatable illness, which make explicit the need for an altogether different approach. If an illness has a medical treatment leading to restoration of previous function, then the course of action is simple and in some respects the naturalistic account is sufficient. But in many cases eradicating the disease is impossible. Under conditions of chronic or untreatable ill health, focusing on the physiological condition is unhelpful. What is helpful, and this is where medicine's embrace of the naturalistic approach becomes tragic, is trying to reduce the impact of illness or disability on the person's life.

In order to do this, a different account is required. What is needed but absent from clinical medicine is a relational account of the ill person, which includes her daily activities, goals and interaction with the environment and social world. Once the change in these is understood vis-à-vis the illness, a remedy can be sought. But a view that enables a complete description of these elements is required (cf. Charmaz 1983). Such a view can be found in phenomenology.

The introduction of a phenomenological approach to illness is not intended to displace but augment the naturalistic approach. Phenomenology distinguishes the lived from the biological body, but does not reject the latter (Merleau-Ponty 1962). Of course the biological body is central to any conception of illness. What I am contesting is the possibility of understanding illness only through the biological body, while ignoring lived experience.

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<sup>2</sup>Fulford (1993) shows how Boorse himself slips into value-laden language.

In illness the danger of objectification is exacerbated by naturalist language, objectifying attitudes of medical practitioners and tests and procedures which support an objective view of the body. But this danger has a creative aspect, as I show below, for illness also provides a rare opportunity to perceive the gap between the biological body and the experience of the lived body, a gap that remains hidden in health (Merleau-Ponty 1962). In illness the body becomes, perhaps for the first time, my own: a body appropriated by confronting the challenges it now poses.

On the other hand, the body remains an object, a biological body, not only for the medical team, but also for the ill person herself. We observe our naked flesh under the glare of the lamp at the doctor's office; we check our test results to see if we are within the normal range; we are weighed and probed like any object.

Illness splits apart the biological and the lived body. Instead of the flawless correspondence between our objective body and our lived experience of it, in illness the biological body behaves oddly; it exhibits strange symptoms and becomes unpredictable. The transparent silent function of the biological body is gone and the biological body is now the subject of anxious attention and medical scrutiny. The otherness of this body is brought to the fore; it may behave strangely or become unrecognisable. Objective facts about the biological body cease to tally with lived experience. For example, in the case of anorexia, one could be underweight (objectively weigh six stone) but the lived experienced is that of an overweight person ('I feel fat. I need to lose weight').

Illness distances us from the biological body, which becomes alienated and erratic, the source of pain and disability. This distance is not normally available to us while we are healthy. But illness removes the body's transparency and problematises it. The body becomes the focus of concern, a source of pain and fear, and thus becomes a problematised body in two senses. It is the source of practical problems and concern, as well as metaphysically unstable because its pervious position and relationship with lived experience are no longer valid.

The movement between the biological and lived body has a creative potential. Ultimately a new relationship between the two can emerge. This new relationship would reflect not only the practical complexities of illness but also the philosophical complexities of the body-subject: the body that is both a material object and the seat of subjectivity. Phenomenology, to which we now turn, gives us the tools to think about this relationship between the lived and biological body, between the body as subject and the body as object.

## **A Phenomenological Approach to Illness**

On the phenomenological approach of Merleau-Ponty, the body is not a vehicle of the person, but the embodied person herself. Consciousness is not separate from the body and therefore disease can no longer be understood as a mere physiological process that affects the person only secondarily. This is not just the trivial view that our lives and subjective experiences are affected by disease, but a much stronger conceptual shift. On the phenomenological view, disease cannot be taken as a mere biological dysfunction, because there is nothing in human existence that is merely biological. We are embodied consciousness, so consciousness is inseparable, both

conceptually and empirically, from the body. Therefore the concept of disease – and also of health – must be reconceived taking into account this mental-bodily unity.

The phenomenological view distinguishes between the lived body and the biological body. The lived body is the medium through which I apprehend the world and interact with it. This lived body exhibits a bodily intentionality that reveals a dynamic relationship between body and world. Thus my lived body always aims at achieving a goal by directing itself towards an object (Merleau-Ponty 1962). The body is thus not a container for the mind, as the Cartesian view has it, but “our general medium for having a world” and playing out the various dimensions of human existence (ibid., p.146). In short, the person is *being in the world*, an embodied, worlded human being (Heidegger 1962). As such, being in the world is not a matter of an ‘I think’ but an ‘I can’ (Merleau-Ponty 1962, p.137).

From within this general view, we can now see how illness is not simply a problem of an isolated physiological component, but a problem with the whole embodied person and her relationship to her environment (Toombs 2001, p.6). Because the lived body is not just the biological body but one’s contextual being in the world, a disruption of bodily capacities has a significance that far exceeds that of simple biological dysfunction (Toombs 1995).

This view captures the important relationship between agency and the body. A change in the body and in physical and perceptual possibility transforms subjectivity itself (Merleau-Ponty 1962; Young 1990). The possibility of agency is inherently linked to the ability to assert oneself, perform actions and carry out activities that promote one’s goals. The loss of physical ability entails a reduction in one’s agency, because even the most abstract goal requires bodily action. Whereas it is normally taken for granted that the body is a healthy functioning element contributing silently to the execution of projects (with the body perceived as transparent and inconspicuous), in illness the body comes to the fore and its pain and incapacity directly affect the agency of the person.

The phenomenological view gives a full account of the existing and modified world of the ill person. By contrasting the old healthy world with the new world we can see what was taken away by illness. For example, if an ill person enjoyed sports which are now impossible because of a spinal injury or multiple sclerosis, the lost activities and the empty space left in her world become obvious within a holistic account. On the naturalistic view an account of this loss is impossible, unless an additional concept to that of disease is introduced.<sup>3</sup>

The phenomenological concept of illness contains the relation of the ill person to her world. This includes spatial, temporal and social relations. The geography and spatial relations of someone in a wheelchair are entirely different from those of the able-bodied person. Subjective notions of distance, difficulty and so on are modified as bodily abilities change. While an able-bodied person perceives stairs as a means

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<sup>3</sup>This has been proposed by Boorse (1997), who suggests a distinction between disease, the biological dysfunction, and illness, the normative and social effect of disease. The problem with this approach is that it, again, splits a unified phenomenon into two. It treats different aspects of illness as belonging to two domains, the physical and the social. Seeing the various areas of impact as separate serves to further objectify disease. The phenomenological approach rejects the mind/body dichotomy and therefore rejects the split between disease and illness, and instead offers a unified account.

for getting somewhere, for a person in a wheelchair the same stairs represent an insurmountable obstacle. This is not just a local disturbance of the disabled person's activity, but a fundamental alteration of the way she engages with her world.<sup>4</sup>

Similar changes can be seen with respect to inclines, visibility and so on, depending on the particular condition affecting a person's interaction with her environment (cf. Amundson 1992). The world of the ill person is changed, and notions of distance, time and level of difficulty go through a fundamental transformation. This transformation must be considered in order to give a complete account of illness. It is also needed practically, in order to seek remedies for these changes.

Similarly, the social world is transformed. Many disabled and ill people report difficulties maintaining their social world, because they are no longer able to participate in shared activities such as work, trips and sports. Reciprocity is lost if the ill person is housebound and ill people sometimes voluntarily withdraw from social situations which may compromise or embarrass them (Charmaz 1983, p.177). Relationships come under new kinds of pressure when the autonomy and independence of the ill person are modified. Old friendships must adapt and change to accommodate the illness or eventually wane. New friendships are now formed under the stigma of illness or disability. The ability to interact naturally within a social context is lost. The illness or disability becomes a social issue as much as a personal one (Goffman 1963). For example, this is apparent in the work of many mental health charities, whose goal is to reduce stigmatising of mental illness. Physical disabilities are stigmatised in a different way but create social difficulties nonetheless.

In the case of chronic illness, a further exacerbation is created by the naturalistic approach. On this view, chronic illness is perceived as a physiological problem and therefore only physical suffering is taken into account. The loss of agency, productive function, social participation and financial status are not recognised as part of the illness and are not addressed by the medical care team. Moreover, because chronic illness is treated within a framework of care designed for acute illness, the result is fragmented care, incomplete information, overburdened caregivers and isolation (Charmaz 1983, pp.168–169).

We normally think of illness as a temporary abnormal condition that should be rectified so as to return the ill person to normal life. But in chronic illness and disability this aim cannot be achieved. Chronic illness is often misconceived within the framework of acute care, with its assumption of illness as causing a temporary disruption of self, rather than causing continuous losses (ibid.). What is called for in the case of chronic illness is attention to the transformed world of the ill person. This world, with its altered dimensions and limitations, can be accurately captured and theoretically anchored in phenomenology.

Long-term illness or disability redefines the relationship of the person to her world, and moreover transforms this world by altering and limiting it. As embodied persons we experience illness primarily as a disruption of lived body rather than as a dysfunction of biological body (Toombs 1988). But medicine has traditionally focused on returning the biological body to normal functioning, and has therefore

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<sup>4</sup>For a detailed phenomenological account of daily life with multiple sclerosis see Toombs (1995).



worked from within a problem-focused, deficit perspective that ignores the lived body. Within this approach, the experience of the ill person is measured in negative objective parameters, i.e. how ill or impaired she is, while the lived experience of illness, which varies tremendously from one person to another, is overlooked (Lindsey 1996).

As I showed, a phenomenological approach can provide a framework for incorporating the experience of illness into an account of the good life by providing a rich description of the altered relationship of the ill person to her world. This altered relationship is a natural part of the life cycle and as such must be part of any account of the good life. Such a description takes illness to be a relational concept, one that must include the ill person, her physical and social world. Equipped with a phenomenological methodology, we can now ask: “what happens to the well being of people who are seriously ill?” Are they less capable of having a good life?

### Health Within Illness

The second part of the paper discusses the relevant literature on these questions. It takes the notion of health within illness as central to its claims and demonstrates how the experience of health is possible even within the context of severe illness. Examining recent healthcare literature informed by a phenomenological approach, I discuss the results of studies examining the well being of ill and disabled people and their reactions to their illness. Rather than measuring the experience of the ill person in objective parameters, i.e. how far from the norm she is, I focus on the experience of personal growth, adaptability and health within illness (Lindsey 1996). I also argue that a phenomenological methodology allows the expression of these experiences and enables us to develop a better understanding of the experience of illness.

Health within illness is a concept developed in the nursing literature in the 90s. This concept was developed by Lindsey, Moch and others, and expresses the diversity of illness experiences (Lindsey 1996; Moch 1989). Using a phenomenological approach and its emphasis on first-person experience, Lindsey and others interviewed patients with chronic illness to assess the impact of illness on their lives and how they respond to it.

Different studies show large variation in the meaning and impact of illness and in the coping mechanisms developed in response to it. Some authors, such as Moch, claim that the experience of illness can promote personal growth through awareness and transformational change (Moch 1989, p.24). Charmaz notes that for some chronically ill people “illness became a tool of self-discovery and a fundamental source of later self-development” (1983, p.176). Nordeson et al. (1998) suggest that chronically ill people experience health subjectively and individually. Others have taken health to be a process of unfolding that can be created by each individual, rather than prescribed by social norms. On this view, health is “co-created through the human-environment interaction” (Parse 1990, p.137). And Amundson (1992) sees handicap as the result of a particular environment rather than an intrinsic property of the disabled person.

These views acknowledge the possibility of health within illness, regardless of the person’s physiological condition. And these views seem to mirror accurately

chronically ill or disabled people's self-reports. As Kempen (1997) notes: "subjective well-being is by far the domain least affected by chronic medical conditions". Similarly, Sherbourne et al. (1992) write: "there is substantial evidence of individual variation in health-related quality of life measures that is not accounted for by age or disease condition". Nordeson et al. (1998) report that ill people's experience of quality of life is subjective and individual.

In a study by Stuifbergen et al. (1990), 73% of interviewees, all of whom were living with a disability, rated their health as good or excellent. Moreover, the individual definitions of health varied considerably among interviewees. While some defined health as 'never to be sick or taking medication', others used 'being able to take care of myself', or 'enjoy life each day', revealing the multidimensionality of the concept. Similarly, in a survey conducted in Canada 60% of respondents suffering from health problems rated their health between good and excellent (cited in Lindsey 1996).

This requires a shift in the way we think about health and illness from seeing them as mutually exclusive opposites, towards a continuum or a blend of the two, allowing for health within illness in persons who seem objectively ill or disabled. A second shift is required, away from an objective deficit-centred health assessment towards giving more weight to subjective first-person reports. Both shifts are achieved through changing the view of health and illness from a purely naturalistic to one combined with a phenomenological approach.

This shift has also been expressed in the change "from cure to care", moving away from a model of disease and cure, to a model of care which promotes health and healing for people with chronic illness or disability (Lindsey 1996, p.467). Ultimately the aim is to change health care practices by reconceptualising the health/illness distinction and by offering more holistic perspectives on health and health experience.

As Lindsey reports, the phenomenon of health within illness emerged through the explication of themes such as: honouring the self, creating opportunities, celebrating life and transcending the self. These themes were developed from participants' own words and therefore accurately reflect their illness experience. As one interviewee said: "I can live life to the fullest, even if I have no physical ability, I can still live life to the fullest because where I am living, life is from within" (Lindsey 1996, p.469).

As Lindsey admits, other studies present very different findings. Many qualitative studies report feelings of loss, chronic sorrow, frustration, guilt, anger, loss of connectedness and struggling with change (Michael 1996). Charmaz (1983) and Matson and Brooks (1977) found negative attitudes, a diminished sense of self-identity and a process that is likened to grieving. Lindsey's study, on the other hand, focused on the experience of health within illness, rather than on the experience of illness, and the different research question led to the incongruent results (Lindsey 1996, p.470).

This brings to light another limitation of the medical approach. Because the focus is on disease and a negative deficit approach is applied, the positive experience of health within illness remains unacknowledged within medical practice. For example, many medical test results are presented as a normal range with one's place within it. Lung function is expressed as percentage of predicted capacity, but is not matched to a subjective sense of functionality or well-being, i.e. what the individual can do with this lung function. The actual function – how active the individual is; what sort of

physical activity she does or would be suitable for her etc. – is left out of medical records, despite a well-documented discrepancy between objective parameters and actual functionality.

Studies have repeatedly found that chronically ill people's experience of quality of life is subjective and individual (Nordeson et al. 1998; Kempen 1997; Sherbourne et al. 1992). Many people with chronic conditions find the current objectivist approach oppressive and lacking (Benner 1990), because it does not emphasise their capacities, or attempt to maximise or enhance these. Rather, medicine takes a deficit-focused approach, which provides little help to chronically ill people.

Similar comments are found in a large metastudy of qualitative studies of the experience of illness (Thorne et al. 2002). The authors analysed the findings of 292 qualitative studies of the experience of chronic illness. Although the authors criticise the studies as question begging in theory, method and data analysis, some interesting commonalities can be found. While the metastudy showed that the researchers' philosophical orientation to the meaning of disease created a significant discrepancy in their data analysis, the philosophical value of this diversity is not discussed in the paper. For example, the authors lament the emerging inconsistency between the various studies. Some researchers articulate chronic illness experience through terms such as spoiled identity, biographical disruption and chronic sorrow, while others depict chronic illness as an exemplar of courage or transcendence (Thorne et al. 2002, p.447).

But these findings are not surprising given the breadth of chronic illnesses looked at (from herpes to cancer) and the diversity of emotions present in each individual's life due to the nature of chronic illness. Chronic illness stretches over long periods of time, possibly decades, and it would be surprising if a monotonous meaning were attached to chronic illness in all cases.

The philosophical value I see emerging from the metastudy is the plurality of responses and attitudes between individual cases and also within each case. Perhaps a genuine ambiguity attaches to the meaning of chronic illness and the concept should be regarded as too broad to be stable. The point made by Lindsey remains valid. When studies ask about illness, the interviewees' responses focus on illness. But if they ask about health within illness, new and more positive dimensions of chronic illness emerge.

### **Adaptability and Creativity**

In the last section I began to answer positively the question posed in the beginning of the paper: can seriously ill or disabled people have a good life? In order to complete my answer, I now develop the idea of illness as a limit case of lived experience, one in which the usual transparency of the biological body is replaced by its constant negative presence. In this situation, a gap opens between the biological and the lived body and normal types of interaction with the social and physical world require significant adjustment and creativity. These two ideas: that illness induces adaptability and that adversity is the source of creative responses to it, serve as part of this positive reply.

In general, adaptation denotes successful adjustment to an environment, or a modification to fit a changed environment (an environment could be either physical or social).<sup>5</sup> The term ‘adaptation’ has come to acquire a specific meaning in evolutionary biology, where it denotes an alteration in the structure or function of an organism or any of its parts that results from natural selection (West-Eberhard 1992, p.12). To avoid confusion, I will use the term ‘adaptability’ to denote the phenotypic and behavioural plasticity of ill or disabled people who need to adjust their behaviour in response to their condition.

In the case of illness and disability, we find two notable features. Firstly, the adjustment is to a change not within the environment but within one’s body. The change is experienced immediately and unpredictably, leading to an experience of alienation from one’s suddenly uncanny body. This makes the change unmediated and more intimate than any environmental change. Secondly, the introduction of tools and instruments to overcome bodily limitations could be thought of as a hybrid of body and tool, which bears an interesting relationship to exaptation (the utilisation of a structure or feature for a function other than the one for which it was selected).

The literature on chronic illness mostly uses adaptation to denote psychological adjustment and the term is often applied vaguely and interchangeably with ‘adjustment’, ‘coming to terms’ and ‘acceptance’ (Michael 1996, pp.252–253). But in fact, adaptability in the case of illness or disability is much more diverse. Adaptability takes place on several levels: physical, psychological, social and temporal. It is important to note that this division is for descriptive purposes only. In reality the changes in the different dimensions occur simultaneously and often blend into each other. The most notable feature of these types of adaptability is that they arise as a response to changes in one’s own body rather than to a novel environment. This endows adaptability with a highly personal dialectic nature, one of disruption followed by rapid response. Another feature is that the change is not neutral but always negative. The change reflects deterioration in some bodily capacity.

The point I wish to focus on is not the negativity of the change but the highly personal and creative dimension of adaptability. This focus, I claim, goes hand in hand with the notion of health within illness discussed earlier.

In face of a diminished bodily capacity, physical solutions to novel problems and challenges must be found. The ill person may need to adapt her walking speed, gait, time allocation, level of physical activity and so on, depending on the limitation created by the illness or disability. For example, in the case of respiratory illness, the ill person may find circuitous ways to the shop to avoid walking up-hill; she may pause several times while climbing up a flight of stairs and allocate more time for everyday tasks such as gardening or having a shower. Additionally, she may become more aware of the physical aspect of minor tasks and of her body’s novel responses to exertion.

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<sup>5</sup>This is, of course, a very different use of the term than in its more usual milieu, in evolutionary biology. I am using the term here in the general colloquial sense. Interesting questions about function that may overlap with the biological debate can arise in some cases. For example, the use of hands to propel a wheelchair may be seen as an exaptation, where hands and tool combined replace the function of walking.

These types of adaptability can be viewed as automatic or subconscious. For example, the physiological response to breathlessness and oxygen desaturation is panting, dizziness and chest tightness. These responses are not controllable and may lead to a sense of loss of control over one's body, an experience of alienation from one's own body (cf. Svenaeus 2000a,b). The transparency and taken-for-grantedness of the body are now replaced with an acute sensitivity to the body's demands and the limitations it places on the ill person.

Although they are responses to a negative change in one's body, these kinds of adaptability also have a creative element. Finding a new way of performing an old task, given an altered set of capacities is also challenging and successful performance leads to a sense of achievement. For example, a physiotherapist told me that patients who completed a course of physiotherapy and regained some of their lost capacities report a high level of satisfaction and improvement in quality of life (personal communication). Being able to improvise and create new ways of compensating for a lost capacity demonstrates the plasticity of behaviour and the human capacity to adjust to change.

Psychological adaptability is of a significantly different nature. Firstly, it is mostly conscious and secondly it contains an emotional dimension. Some have described illness in terms of biographical disruption (Williams 1999, 2003; Bury 1982). The disruption is of taken for granted assumptions and behaviours (especially focusing on the body which no longer 'passes us by in silence' as Sartre says) and of the explanatory framework (raising questions such as 'why me?'). The response to the disruption comes as mobilisation of resources (medical, financial, cultural; Williams 2003, pp.96–7).

Several themes emerge from this framework for understanding illness: a new meaning must be found for the new narrative; the ill person seeks an explanation for her suffering and limitations; a new approach to one's future must be created. The mechanisms of coping, normalisation, strategic mobilisation of resources, accommodation and denial have been noted (ibid., p.98). Changes to one's sense of self and identity have also been observed (Charmaz 1983) and concepts such as enduring, struggling and disruption are often used to describe the experience of illness by both patients and researchers (Ohman et al. 2003; Michael 1996).<sup>6</sup>

Within this negative context, some positive adaptive responses have been noted. For example, Michael (1996) reports a theme of gaining control of an altered life direction as one of the themes raised by the chronically ill people she interviewed. Other adaptive themes include confronting loss, struggling for normalcy (Ohman et al. 2003), reformulation of the self, transcending suffering and courage in the face of adversity. These adaptive themes demonstrate the continued exploration of self and creation of meaning against an adverse background.

Adaptability is also expressed on a social level. Here examples of patient advocacy groups, patient activism and patient-driven research demonstrate a positive adaptive response. Other types of social adaptation may be finding new activities the ill person

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<sup>6</sup>An interesting exception is a study of East-End Londoners' attitude to illness, which notes their cheerful stoicism and pragmatism towards illness (Cornwell 1984). The author provides a social explanation. These people view illness as a normal part of life, and use terms such as 'normal illness' and 'health problems which are not illness'. In this sense, biographical disruption carries particular class- and age- related connotations (Williams 2003, p.103).

can share with others to replace activities that are no longer feasible in light of the illness. For example, a woman with a chronic respiratory condition who could no longer go on long hill-walks has replaced this group activity with Tai-Chi, a more gentle form of physical activity that can be done in a group (personal communication).

Finally, temporal change is notable and phenomenologically significant. Following Sartre's analysis of illness and Husserl's notion of inner time-consciousness Toombs describes four temporal levels of illness. Illness is experienced on a pre-reflective sensory level. On this level pain, for example, is experienced as a temporal object through the synthesising activity of inner time-consciousness. Pain is experienced as a continuum; it is endured, lived through. Through retention and protention each moment of pain is connected to ones that preceded it and future ones. For this reason patients find it difficult to describe the duration of pain in terms of an objective time scale (Toombs 1990, p.232).

On a second level, the suffered illness becomes reified and separate from the body. The stomach painfully lived becomes a separate entity located in the stomach.<sup>7</sup> Patients often refer to the pain as 'it', describing its progress and movement from one location to another (*ibid.*). At this level the pain is given meaning by constituting the painful experience as 'illness'.

On a third level illness is constituted as 'disease'. Disease introduces an objective dimension, turning one's body from being for-itself to in-itself, the body for others (Sartre 1956). The body is now experienced as an object, and the disease as an alien entity residing in but still distinct from the body. Thus a lump in the breast may be experienced as possible cancer. The ill person relies on information gleaned from external sources, and when asked to describe her experiences, these are now recalled rather than lived through, further contributing to the objectification.

The events are also reported within an objective time scale (Toombs 1990, p.234). But this conflicts with what Scarry calls the 'unsharability' of pain (Scarry 1985). Toombs sees the unsharability as partly arising from the incommensurability of inner and outer time. Disease is now constituted as a temporal process set along an objective time scale.

The final temporal level is that of disease state. This represents the medical practitioner's conceptualisation of the illness as physiological or anatomical dysfunction, which is in itself an objective fact. As such it is now constituted entirely objectively, as a causal process. While the patient does not experience her illness directly as a disease state (e.g. multiple sclerosis), the medical practitioner constitutes the illness directly as such. For the medical practitioner, the fundamental entity is a lesion in the central nervous system, while for the ill person the fundamental entity remains the suffered illness (inability to walk) secondarily understood as a symptom of multiple sclerosis (Toombs 1990, p.236).

As a result, the medical team and the ill person constitute the temporality of illness differently. This contributes to the fundamental disparity between the objectively perceived, naturalistic model of disease and the lived experience of illness. Again, introducing a phenomenological approach could reduce the disparity and may assist the physician and ill person to co-define the temporal dimension of illness.

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<sup>7</sup>A friend told me her 4 years old son once said to her: "Mummy, I've got a headache in my tummy".

More concrete temporal changes are also noted. More time is given to each activity, which in turn may cause that person to begin experiencing herself as older than her years, as ‘useless’ or as more disabled than she is (cf. Merleau-Ponty 1962; Toombs 1988). The unpredictability of the course of illness leads some to adopt a perspective of living in the present and refraining from looking towards the future, making long-term plans or having rigid goals (Michael 1996, p.261). Illness restricts the ability to imagine future scenarios, causing a further shrinking of the ill person’s world.

Within these restrictions, an ability to live in the present is often developed in response. The capacity to understand the fragility and transience of life and nonetheless appreciate it is often reported by seriously ill people. This rare insight is another creative dimension that is available through the experience of illness. As Freud writes: “a flower that blossoms only for a single night does not seem to us on that account less lovely” (Freud 1985, p.288).

A final point about adaptability and creative responses to illness and disability is that of the extended body. As Merleau-Ponty points out, external props such as a walking stick can become an integral part of one’s lived body. When a tool such as a car or a musical instrument becomes intimately familiar and incorporated into everyday practices, it is no longer an external object but becomes part of the lived body. If we apply this idea to medical tools, we can point to the use of a wheelchair as novel in two senses. First, in the use of one body part to compensate for the loss of function in another (using the hands instead of the legs for forwards movement). This use can be seen as a kind of exaptation and as expressing phenotypic plasticity.

The second sense in which the use of a wheelchair is novel is in the use of an external artefact to compensate for some loss of function. On Merleau-Ponty’s account, the wheelchair would become incorporated into the lived body schema and would no longer be experienced as an external addition. As he writes: “the blind man’s stick has ceased to be an object for him, and is no longer perceived for itself; its point has become an area of sensitivity, extending the scope and active radius of touch, and providing a parallel to sight” (Merleau-Ponty 1962, p.143).

## Conclusion

I have shown that the experience of illness cannot be adequately captured within a naturalistic view. I therefore proposed to augment naturalism with a phenomenological approach and explained the advantages of this view. I then proposed the notion of health within illness as a theoretical tool for capturing the positive experience of well being experienced by ill people, and finally used the notions of adaptability and creativity to demonstrate how health within illness is possible. These ideas were presented within the context of the rift between the biological and lived body. The two bodies are torn apart, and the gap between them is acutely experienced in illness. It is now time to show that it can also be reconciled.

I explained how illness creates a gap between the biological and lived body. But a second, reconciliatory stage is possible. Illness can also reconcile the two bodies when the biological body that was transformed by illness is now reunited with the lived body. I reconcile the two by appropriating this transformed body and integrating it into

my experience of illness. This synthesis may take many years to achieve, but this reconciliation is a creative achievement made possible in illness.

Happiness and a good life are possible even within the constraints of illness. But their uncovering requires a new set of conceptual tools (health within illness, adaptability) and a metaphysical framework that gives precedence to the experience of illness and to the embodied nature of human existence (the phenomenological approach of Merleau-Ponty).

A final comment on the impact of this approach is in order. The take-home message is that medical practitioners would do well to adopt a broader, less exclusively naturalistic approach if they want to assist their chronically ill and disabled patients maintain their life-world. The naturalistic approach will provide only a limited, biological picture of the illness and will therefore fail to provide the concepts and ideas essential to understanding the experience of illness.

As physicians themselves report, the phenomenological approach is threatening to many healthcare practitioners' outlook (Gunderman 2000). This outlook requires strict separation between their and their patients' lives, an objective, sanitised language, and lack of engagement with social and relational aspects of illness. The naturalistic approach provides protection from the personal, whilst the phenomenological approach requires precisely such engagement.

If physicians want to help their chronically ill and disabled patients, the questions they should ask are: how has illness changed your life? What are the aspects of it that affect you the most? How can those effects be compensated for? These kinds of phenomenologically informed questions will open a space for the creative adaptability that can enable a good life even within a context of illness. They would give due place to the context, experience and relations of the ill person and may assist in maintaining a modified but nonetheless rich texture of life even without a medical resolution of the disease.

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