

Body, death, self, and ethics: A phenomenological inquiry of bodily illness**Xi Chen¹****Abstract**

Objective: The author aims to create a phenomenological foundation for understanding the meanings of bodily illness and its ethical implications. Phenomenology focuses on subjective meanings and personal interpretations. It offers insight into the lived experiences under investigation. Bodily illness often brings vulnerability and a desire to avoid being objects of sympathy or attention. Although there are ethical frameworks for treating and coping with bodily illness, these can be rigid. They may not capture the full experiences and dignity of those affected.

Methods: This article uses a phenomenological conceptual approach to analyze the meanings of bodily illness, personal attitudes toward death, experiences of selfhood, and ethical reflection in treatment and coping.

Conclusions: Phenomenology lets us assign different meanings to physical illness. This approach changes how we understand the body, consciousness, self, suffering, and ethical reflection. Phenomenology gives ill people more agency and strengthens moral decision-making for those around them, including healthcare professionals.

Keywords: illness, phenomenology, body, physical illness, ethics

Introduction

When we become ill, we feel vulnerable and exposed as objects of attention and sympathy. Medical diagnosis and treatment render our bodies, thoughts, and values vulnerable. Given these objectifying experiences, the central question is: What is it really like to be physically ill? To answer this question, the article draws on phenomenological philosophy, which explores the relationship between consciousness and the world. Phenomenology relies on reflection and immersion to examine diverse human experiences, such as seeing art or listening to music. It provides a way to observe and describe subjective experience as it appears to us. Anthropological and psychological studies often focus on causal mechanisms, but phenomenology investigates the foundational conditions that make experience possible. It emphasizes the transcendental features of consciousness, as Kant highlighted.

Phenomenology also guides ethical decisions in medicine. Greenfield and Jensen (2010) see disability as an ongoing process of bodily, intellectual, and moral change. Their phenomenological approach adds context to moral decisions by revealing and interpreting patients' stories (Greenfield & Jensen, 2010, p. 1185). Phenomenology offers better ethical choices based on clear insight into patients' perspectives and values. Zeiler and De Boer (2020, p. 11) argue phenomenology strengthens bioethics by focusing on lived experience. Phenomenology uncovers rigid assumptions. It creates more subjective meanings—since humans are meaning-makers, our experiences shape our surroundings and vice versa (Zeiler & De Boer, 2020, pp. 12–13).

What is the meaning of being physically ill? What are the moral concerns of bodily illness in the context of phenomenology? These are the article's research questions. The author's central argument is that phenomenology, by examining existential experiences of illness, reveals new dimensions of body, self, and ethics. Bodily illness transforms our sense of self and consciousness and alters our attitudes toward death. The author maintains that phenomenological analysis not only clarifies these changes but also identifies ways to reduce the suffering of those affected by reconnecting ethical reflection with lived experience.

¹ Polish Academy of Sciences, Warsaw (Poland); email: xi.chen@gssr.edu.pl; ORCID: 0000-0001-6892-0725

Body and illness

This section examines our phenomenological experiences when we are bodily ill. The key argument is that understanding bodily illness requires acknowledging the complex unity of mind and body, as well as the subjective ways individuals experience their own illness. Consciousness is bound with perception and sensation. Unlike Descartes, who separates mind and body, Husserl proposes the genuine unity of the two (Husserl, 1989, p. 176). He distinguishes the *objective body* from the *lived body*. *The lived body is how we interact with and experience the world as persons*. The first-person aspect of experience shows how localized sensations belong to the subject's awareness. Sensitivities—touching, seeing, perceiving, and being perceived—combine to form the complexity of perception. Consciousness processes these sensations so we can know the world. Merleau-Ponty (2012, p. 147) states that human experience is rooted in perception. Bodily sensitivity expresses our personhood and subjectivity. Our body shows how our subjectivity comes to be. For example, we see through our eyes and touch through our hands (Merleau-Ponty, 2012, p. 147).

Sartre (2003) describes three views of the body. The objective body is material and measurable. The subjective body is lived from a first-person view. The intersubjective body emerges when we experience our body as others see it. For example, a shy person feels embarrassed by their body and avoids comparisons. They notice their body through others' eyes. Sartre says the gaze of others shapes our self-concept.

Sartre (2003, p. 354) says a healthy body is invisible: “consciousness of the body is lateral and retrospective; the body is neglected, passed by in silence”. When healthy, the body goes unnoticed by us and others. Illness and disorder draw attention and concern from both the ill person and those around them. Sartre's view of the unhealthy body reveals our intersubjectivity and how our bodies become objectified as ill and malfunctioning (Svenaeus, 2009, p. 55). The ill body faces daily challenges, obstacles, and environmental resistance. Illness changes how we live, restricts us, and becomes a concern. This leads to alienation, anxiety, and embarrassment.

According to Heidegger, entities are not just material objects but handy tools, or “equipmental totalities” (Heidegger, 1962, p. 96). We use these tools in daily projects. When writing with a pen, our focus is on our message, not the pen itself. The pen is a tool that blends into the background, only noticed if it stops working (Heidegger, 1962, in Carel, 2016, p. 61). Dysfunction draws attention to the tool. Similarly, an ill or disabled body is revealed as malfunctioning. We are accustomed to a healthy, transparent body. If a hand becomes paralyzed or dislocated, it is no longer a silent tool. Its failure becomes obvious. This disruption affects our being-in-the-world (Svenaeus, 2000, pp. 128–129). Sartre (2003, pp. 363–364) notes, “when my means of universalizing thought I tried to think of my body emptily as a pure instrument in the midst of the world, the immediate result was the collapse of the world as such”. Bodily dysfunction, as with tools ceasing to work, makes fragility and vulnerability clear. This can feel bizarre and alien (Svenaeus, 2011, p. 336). For example, a person with hearing impairment must know the world through other senses. Illness or disability may harm their sense of dignity. They may feel incompetent if they struggle with audio input.

Bioethics scholars Crisan and Copoeru (2020) discuss the lived body. It acts as a middle way between our experiences and our state of being. The live body helps connect us to the world and enables our existence (Crisan & Copoeru, 2020, p. 4). Bodily illness makes our lived bodiliness retreat from the world (Crisan & Copoeru, 2020, p. 4). Illness of the lived body causes suffering and vulnerability. This requires care and attention from others. Vulnerability places physically ill people in a community of empathy and care, but also of inter-dependency. Both the ill and those around them, such as healthcare professionals, depend on each other in unpredictable circumstances. Patients' agency is not based on rigid reasoning. Instead, phenomenological analysis of illness helps ill individuals reflect on and share their experiences

with caregivers. This process allows empathy and exchange of information. Phenomenology helps bodies interact, fosters ethical agency, and builds awareness of our inter-dependence (Murray, 2012, p. 292).

Death and illness

Heidegger conducts a detailed analysis of the tenets of death in *Being and Time*. We are temporal beings, yet we are disquieted by the present, formed by links between the past and the future. We anticipate the future, which constitutes anxieties regarding the possibility of the future. The future may progress into diseases, pains, terminal illnesses, and reach the ultimate secular destination of death. Heidegger's *Dasein* connotes 'to be', whereas death annihilates missions of 'to be' and substitutes 'to be' with a closure of all the existential possibilities. Furthermore, death constantly reminds us of the finite structure of existence. Finitude is "the fundamental way of being" (Heidegger, 1995, p. 5). Death is an absolute character of *Dasein*'s temporal finitude. Being gravely injured or being severely ill exacts a basic certainty of *Dasein*, and Heidegger terms a state of being gravely ill or wounded as "sum-moribundus" (Heidegger, 1995, p. 317). The *sum-moribundus* exhumes bodily senses that death is coming. Furthermore, Heidegger identifies three features of death: ownmost, non-relational, and not to be outstripped. First, a major characteristic of death is that it cannot be avoided by any individual and cannot be passed on to others. Second, non-relationality of death refers to death's individual entities to *Dasein*, which death links to *Dasein* with its own facets. Third, not to be outstripped typifies the certainty and indefiniteness of death: we must die one day, but we have no idea of the exact coming of death.

Being ill is different from death. Being sound and healthy formulates the opportunity to be, and, hence, death nullifies all the existential possibilities and puts an end to this opportunity to be. Apart from exceptional circumstances leading to accidental deaths and suicides, we are highly likely to go through illnesses, pains, emotional disturbances, agonies, before arriving at the end of life. Being ill bridges the gap between health and death. *Dasein* expects death: "*Dasein* constantly runs towards its death. It constantly anticipates death; death is always and only something that is yet to come" (Carel, 2016, p. 159). *Dasein*'s expectation of death designates nothing in association with waiting for actualization of death but denotes living with the full knowledge of how temporality and finitude construct our being. Serious illnesses often point to the end of life and suggest the finitude of human existence. Illness implies a transformation from being an existing person to termination of existence, and this transformation signifies our finitude (Carel, 2016, p. 151). In other words, illness breaks restriction, bondage, and unfreedom of living in and having the world, and marks them as striking and conspicuous aspects of finitude. Afflicted with illness, we are unable to function at a normal pace; our values, goals, and beliefs have to be changed to some extent and be adjusted in order to adapt to the circumstance that we are ill; These emotions may become common: feelings of being constrained, hardships due to greater physical and psychological bondage, and distress of feeling limited and not free. Another connection of illness with death pertains to the notion of individuating and indefinite orders. First, having and living with illness, like experiencing death, constitutes experiences immersed within an individual's particular values, goals, and beliefs. Second, being ill, especially in terms of severe illness, involves indefiniteness: we are not sure whether the illness aggravates, whether it would progress to the end of life, whether we would feel better and eventually recover, and how to manage and cope with difficulties in life of being ill.

We, being ill, inhabit a form of indifference unless we start to listen to and abide by our conscience. Neglect of and aloofness from answer to the call of conscience punctures authenticity of *Dasein* and draws close to *das man* – the depraved *Dasein* that endorses communication and sharing but is still interpreted against liberation of being. Our society,

infused with cultures and values, has taught us to foster an indifferent disposition to renounce death. Herein, the viewpoint is a good example of such indifference: “So death, the most frightening of all bad things, is nothing to us; since when we exist, death is not yet present and when death is present, then we do not exist. Therefore, it is relevant neither to the living nor to the dead, since it does not affect the former and the latter do not exist” (Carel, 2016, p. 152). Such an attitude, which Heidegger would address as existential inauthenticity, disengages *Dasein* from its mortality and finite temporality. Nevertheless, there is no dichotomous position between authenticity and inauthenticity. Inauthenticity and indifference integrate key components of our existence: 1) indifference subsumed in everydayness sparks transition from inauthenticity to authenticity; 2) authenticity arises out of inauthenticity of everydayness; and 3) authenticity does not leave out of *Dasein*’s sociality, being communicative, everydayness, averageness, and affinity to *das man*. *Dasein* relishes both authenticity and inauthenticity. In addition, authenticity should not be coupled with solitude, and inauthenticity with being-with-others (*Mitsein*). Heidegger (1962, p. 344) described genuine authenticity in connection with *Mitsein*: “Resoluteness, as authentic being-one’s-self, does not detach *Dasein* from its world, not does it isolate it so that it becomes a free-floating ‘I’”. Viewpoints cited above inspire a genuine, authentic reading of death and illness – “an authentic form of being-with-and full participation in the world” (Carel, 2016, p. 178). Death and illness can be approached and examined without detachment of *Dasein* from its relations. For instance, grief and mourning over death would render *Dasein* a community-based, relational understanding of authenticity (Aho, 2018, p. 11). To confront and to cope with illness and death involves less pain and anxiety when facing and accepting its presence (not refusing to acknowledge pain, loss, distress, and anxiety), for our existential questioning and interrogation of them do not solely rely on solitude but can go through via communication and being-with-others.

Communication and being-with-others as an ill person are about to die requires ethics of care and empathy for both the ill individuals and other people. Svenaeus (2017, p. 144) expounds the path of a person’s biological development: very early persons (weeks 22–24 gestational time), early persons (sense of psychology around 6 weeks), persons (personhood around 18 months), full articulate persons (around 4.5 years), biological sudden death or gradual progression towards dying (gradual collapse of biological organism), and coming through the possible phase of “late, very late, and post-personhood)” (Svenaeus, 2017, p. 144). A phenomenological examination of personhood signifies certain life values pointing to our human body as an essential construct of our very being: through this lived body, we grasp the feeling of being alive, we engage our self-expression, we respond to others’ expression, and we interact with others and share our existence in the world (Svenaeus, 2017, p. 144). During the time of a person’s late or very late personhood, as they are moving towards dying, we, empathic and caring, share their vulnerability and suffering, and take on a responsibility to take care of them while trying many ways to protect their dignity.

Self and social surroundings

It occurred to him that what had appeared utterly impossible before—that he had not lived life as he should have done—might after all be true [...] And his professional duties, and his ordering of his life, and his family, and all his social and official interests might all have been false. He tried to defend it all to himself. And suddenly he realized the weakness of what he was defending. There was nothing to defend (Tolstoy, 1995, pp. 83–84).

As Tolstoy’s Ivan Illyich learns about his gradually declining health, he starts to anticipate the closeness to the end of life, and more importantly, he realizes that dependence and humility play crucial parts when experiencing illness, pain, and loss. We are inclined to characterize the illness of self-loss regarding stability, familiarity, and liberty. It is interesting to note here that,

as health ceases to exist, we are forced to recognize and acknowledge the ill selves. This process is analogous to Heidegger's hammer in that the hammer is not visible until the hammering becomes awry (Aho, 2018, p. 206). The body is no longer in a harmonious and capable station, as one finds it hard to breathe and is unable to run as healthy individuals do; ulcers in the stomach grow and burn, thus one must be on a selective, strict diet, or one suffers from terminal cancer and has to take into consideration dying and the coming of death. Illness deranges one at different stages: the emergence of symptoms, the time of diagnosis, and the progression of illness. Concerns, worries, and anxious feelings may not occur consecutively and likely overlap during the three stages. The time of diagnosis, especially, marks a moment when a certain illness is recognized by the ill person and others as a disease, and the illness and the ill person suddenly become subjects of labeling and physiological arrangements (Carel, 2016, p. 69). This is a startling transition for the ill person, who displaces their subjective, private, and personal experience onto an objectified disease, "to which shared meanings and knowledge are attached" (Carel, 2016, p. 69). Progression of illness is not only a manifestation and reinforcement of the ill person's vulnerability and dependence but also a validation of both bodily and psychological finitude. Moreover, one's being ill is disclosed. That well-being is not in the condition of being noticed, of being open to many things, transforms being-ill into transparency (Gadamer, 2018). One who has been diagnosed with diabetes no longer enjoys transparency as they did when they were healthy. They must adhere to a strict daily routine under medical supervision. They would often encounter others expressing concerns about their health. They themselves receive constant reminders of their health condition and their being explicit due to their ill body.

Being ill also structures an architecture conglomerated with our social surroundings. Carel notes: "Ill and disabled people invent a myriad of strategies and coping mechanisms to override the constraints inflicted on them by the environment and by the invisible background norms that govern our lives. The demand to be autonomous, independent, self-sufficient, is often met by failure in cases of illness or disability" (Carel, 2016, p. 77). This further elaborates that ill persons' lives and dignity would not be that damaged if there existed lessened requirements of independence and self-sufficiency, for the requirements of being autonomous and independent could be troublesome for ill persons; coping and living with illness is difficult and ill persons are often in need of being cared for and supported by other resources; being ill also necessitates a need for building trust and respect between ill persons and others; also being ill results in fewer opportunities to actively participate in social interaction and communication, however, social life does not always demand a certain degree of autonomy and independence, and people with illnesses can also participate in some forms of socialization, especially when they are equipped with assistive technologies; hence if being independent and self-sufficient is not so much a premium for a person in spite of their health conditions, it is possible for ill individuals to have more self-esteem and dignity in common life activities (Carel, 2016, p. 77).

Phenomenology as a method

Ill persons often experience being epistemologically marginalized in accordance with bureaucracy and impersonal attributes of the healthcare professionalism: 1) ill people suffer from testimonial injustice for they are often regarded as cognitively unstable, emotionally disturbed, or existentially unreliable, hence how they interpret and testify regarding their own health conditions are placed under suspicion; 2) knowledge and skills of the medical professionals have been mechanized and verified as privileged and unwarranted epistemic priority "by virtue of their training, expertise, and third-person psychology" (Carel, 2016, p. 182); and 3) healthcare mechanisms at present further embolden epistemic injustice that only certain decorum of articulating testimonies, specific modes of evidence, and particular forms of presenting, and sharing medical knowledge are considered and privileged as impersonal and valid reports and are disabled as medical knowledge produced by virtue of hermeneutic

activities.

Many medical professionals struggle with a dilemma in which they find it difficult to balance a firm trust in and a steadfast reliance on medical *techne* with existential doubt and question about whether they should pay more attention to patients' perspectives. The medical anthropologist Kleinman (1988) considers it crucial to include patients' perspectives in healthcare, arguing that medical services that lack patients' agency and participation in diagnoses and treatments are purely technical and medical (Kleinman, 1988, p. 213). He insists on encouraging medical practitioners to come into patients' lives and to be emphatic to their pain and suffering, and, by switching to patients' perspectives, medical practitioners can develop a more comprehensive understanding of their diseases and are making finding better solutions for treatment and care more possible (Kleinman, 1988, p. 213; Aho & Aho, 2008, p. 148).

A prominent objective of phenomenology is to deconstruct the technicality and instrumentality of medical practices and knowledge, and in another aspect to construct and vitalize a new way of the healing arts (Aho & Aho, 2008, p. 149). The present paper argues that phenomenology should be used as a method in medicine and health care, that it not only counts in the perspectives of ill individuals and reduces the effects of paternalism in healthcare, but also endows a significant part for the ill persons to participate in healthcare policies and decision-making (Carel, 2016, p. 198). The present contribution concludes five advantages of inviting a phenomenological conceptualization and actualization of medicine. First, this approach will help patients reevaluate, revitalize, and eventually value their own voices and thoughts, and will help them better understand their medical conditions. Furthermore, patients, through a phenomenological understanding of medicine and illness, would be better able to perceive the impacts of illness on their lives and to cope with and live with it. In addition, it supplements traditional medical knowledge by no longer ignoring emotive and idiosyncratic illness experiences that, in fact, it "crucially interlaces with illuminates the medical facts" (Carel, 2016, p. 198). This also shifts the patient's position from passive receiver and speaker of medical information to an active role as a participant, through which a shared enterprise between patients and medical professionals is conceived and would flourish (Madeira, Leal, Filipe, Rodrigue & Figueira, 2019, p. 282). Lastly, it assists in resolving Kleinman's dilemma mentioned above, that a balanced interaction and exchange of information, including those that are more subtle, unlimited, and nuanced, would breed "an epistemic symmetry" between clinicians and the ill individuals (Carel, 2016, p. 199).

There are three steps of applying phenomenology as a method in coping with bodily illness. First, change attitudes and focus away from treating illness as an objective entity. Second, signifying illness as a specific consciousness and awareness through shifting its cognitive, emotional, ethical, or aesthetic phenomena. Third, using phenomenology as a toolkit to grasp the pervasive impacts of illness, as the one who has such an illness engages in epistemic and sensational interactions with their surroundings and with other people. In all, this phenomenological methodology helps the ill person capture meanings and norms and construct the world of knowledge and customs.

Conclusion

Illness triggers for us an experience of being bound and restricted, feeble and fickle, and more essentially an existential finitude and uncertainty. The present contribution encourages us to explore and reflect on this existential question. Inquiring into and pondering on being ill and feeling close to death is not a negative immersion in self-pity or morbid remorse. A phenomenological study and understanding of being ill is useful to alleviate the state of being ill to a conscious inquiry and is also feasible to extend our capacity of perceiving illness not merely as solitary suffering but also as an in-depth retrospection of illness being relational and

of being-with-others (Fernandez, 2020, p. 4411). Ethical implications arising from the phenomenological approach transform social relations not only for the ill persons but also for others, including caretakers, medical personnel, and those surrounding them. Phenomenology encourages and nurtures empathy and care ethics toward others, as well as interdependence between ill persons and others.

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