Med Health Care and Philos (2017) 20:405–412
DOI 10.1007/s11019-017-9763-4

SCIENTIFC CONTRIBUTION

# Some thoughts on phenomenology and medicine

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**Abstract** Phenomenology in medicine's main contribution is to present a first-person narrative of illness, in an effort to aid medicine in reaching an accurate disease diagnosis and establishing a personal relationship with patients whose lived experience changes dramatically when severe disease and disabling condition is confirmed. Once disease is diagnosed, the lived experience of illness is reconstructed into a living-with-disease narrative that medicine's biological approach has widely neglected. Key concepts like health, sickness, illness, disease and the clinical encounter are being diversely and ambiguously used, leading to distortions in socio-medical practices such as medicalization, pharmaceuticalization, emphasis on surveillance medicine. Current definitions of these concepts as employed in phenomenology of medicine are revised, concluding that more stringent semantics ought to reinforce an empirical phenomenological or postphenomenological approach.

**Keywords** Lived body · Living body · Phenomenology · Health · Sickness · Illness · Disease

## Introduction

Body awareness as the experience of our own body in health and disorder has been one of phenomenology´s primary concerns, mainly based on Merleau-Ponty´s studies of clinical cases such as phantom limb, where an amputee painfully feels the presence of the missing limb, or patients with anosognosia who do not acknowledge their neurological anomalies and dysfunctions. *Le corps propre*, our own body according to Merleau-Ponty, has an inner image, the lived body, presented to the world as an objectively perceivable living body, a distinction Sartre had mentioned in *Being and nothingness* first published in 1943. The clinical provenience of phenomenology's early analyses helped develop a productive branch of thought linking phenomenology and medicine.

From its very beginning, phenomenology availed itself of the semantic distinction between *Leib* and *Körper: Leib* is the body as experienced, aware of itself, perceiving the world and acting in it by means of its organic, living *Körper*. These somewhat polysemic philosophical concepts were promptly applied to medical practice engaged in psychosomatics, anthropological medicine, and clinical neurology (Plügge 1967). Translations into English wavered between "physical body", "body as lived", "animated organism", or "simply "Body"" (Toombs 2001a). Whereas lived body became the accepted term for *Leib*, the living body or *Körpe*r is diversely referred to as thingly, cagastric, organic, physical, material body (Spicker 1976). Despite such semantic vagaries, phenomenology has insisted that these are aspects, or facets, of the human body, decidedly not the two distinct primary substances—a rational or *res cogitans* and a mechanical part or *res extensa-* as postulated by Descartes. Phenomenology consistently dismisses mind/body duality, and yet, "modern medicine is profoundly Cartesian in spirit" (Leder 1992), unyielding to critical non-naturalistic perspectives provided by phenomenology, bioethics, narrative approaches, and patient-centered practices.

Major publications presented in this field for the past two decades, have especially focused on clarifying notions of health/illness, the conceptual distinction between illness and disease, the experiences of patients with chronic conditions and severe bodily malfunctions,

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and the interactions of patients and therapists in the clinical encounter. Nonetheless, "a great deal of phenomenological work consequently remains to be done on core experiences and concepts of medical practice and science" (Svenaeus 2009).

Acknowledging the need for ongoing major debates, this article purports to illustrate how the ambiguous use of core concepts referring to health, illness and disease have created misunderstandings and mutual mistrust between phenomenology and medicine, instead of easing the way for a complementary and fruitful interplay between first-person narrative of bodily experiences, and medicine's quest for the objective identification, classification and management of disease entities (Hucklenbroich 2014). The purpose of reviewing the key concepts involved is to briefly discuss the negative, even harmful consequences that accrue when pervading socio-medical practices neglect semantic stringency.

## Minding the gap

Definitions should hopefully help bridge the "separate worlds of physician and patient" (Toombs 1992, p. 1), although a thorough disambiguation is next to impossible. Opinions oscillate between proposing that conceptual definitions of health and disease are pointless (Heslow 1993), alternatively suggesting a renewal of the debate agenda (Khushf 2007), or insisting on philosophically precise definitions related to ordinary language and medical practice (Nordenfeld 2007a). The variety of phenomenological concepts regarding the body and its disorders nourishes a vivid philosophical discussion without having fulfilled the predicament that the "strongest, soundest, most urgent role for phenomenology in medicine is to inform clinical decision-making" (Baron 1992, p. 46). Medicine evolves into biomedicine—understood as "the interaction between different professional bodies…symbolizing the alliance of medicine, biology and also industry" (Sebag 2007, p. 20), causing uncertainties in distinguishing clinical practice and surveillance from evidence-based research (Sherman and Campione-Piccardo 2007). Considering that phenomenology focuses on the experience of illness, whereas the discipline and the practice of medicine refer to diseases as nosologic entities supporting objective diagnosis and evidence-based treatment, it should be rewarding to take a look at the conceptual conundrum resulting from the diversity of approaches employed to define health, sickness, illness, disease, and the clinical encounter.

## Exploring healthcare related concepts

### Health

Inspired by Leriche's dictum that health is the silence of the organs, Canguilhem (1974) sees health as a state of organic innocence. To be healthy means to rely on a range of physiological *normativities* capable of adapting to environmental challenges. Its experiential transparency would make health an unfit object for the phenomenological study of experience, since health appears to be a narratively silent non-experience.

In the view of Gadamer, health is a state of equilibrium, a "condition of inner accord" and harmony with oneself, an enigma: "Health does not actually present itself to us"; and yet, health is "harmony", a lived "form of protected composure, of *Geborgenheit"* that is positively felt as such rather than being transparent (Gadamer 1996, pp. 107, 116).

Health "effaces itself in an enigmatic way" (Svenaeus 2001, p. 88); "health is something we live *through* rather than *towards*" (Ibid. p. 89). Based on Heidegger, Svenaeus presents health as "a being at home that keeps the not being at home in the world from becoming apparent" (Ibid. 94), suggesting that to be healthy is not to be ill.

Phenomenology sways between the silent unobtrusiveness of healthy bodies, and the purportedly mindful experience of bodily awareness of wellbeing and the feeling of vital competence. Defining health as a state of complete physical, mental and social wellbeing and not merely as the absence of disease or infirmity is a roundabout way of admitting that health is an important component of wellbeing or happiness, though neither necessary nor sufficient.

In the intent to render a precise definition of health, Nordenfelt (2007b, p. 7) asserts: "A is completely healthy if, and only if, A has the ability, given standard circumstances, to reach all his or her vital goals". Goal-oriented concepts of health may confuse the difference between health, always related to the body, and wellbeing that is dependent on social conditions that facilitate or obstruct reaching vital goals.

According to Whitbeck, health depends on the capacity of responding "appropriately to a wide variety of situations" so that "to be happy, a person needs to be able to act in ways that serve *many goals, aspirations, and projects simultaneously*"" (Whitbeck 1981, p. 613). Failure may cause unhappiness, yet does not necessarily compromise health, just as suffering from disease does in no way preclude having, pursuing and fulfilling a life project. Of course, people with chronic diseases often live a content life: "there can be health within illness, joy within difficult circumstances, and emotional freedom within the adversity of disability" (Carel 2007b).

Contrariwise, a person may be healthy but miserable due to personal, social or financial loss: healthy but unhappy.

Phenomenology's concern with health has often been plagued by such confusing terms as ill health, non-health, full health, being unhealthy, having reduced, compromised or excellent health, or the notion of "health within illness" (Carel 2007a). But it is also Carel (2013, p. 98)) who writes about "the narrative of health that has now been disrupted by illness." Summing up positively lived embodiment of an organic disorder as being healthy may be confusing as it leads health concepts to expand beyond first-person experience to receive medical, political and social meanings. Health is, and should remain, a condition that is essentially a first-person lived experience of the body in harmony with itself, engaged in mastering adaptive challenges with its usual normativity range.

## Sickness

In spite of its ubiquitous and somewhat slovenly use, the concept of sickness is best captured by common thought and daily experience, which differs from the idea that "sickness is a social identity as *defined by others with reference to the social activity of that individual*" (Twaddle 1993, 11 italics in original). Such a sociological view, initially advocated by T. Parsons when describing the role of the patient, has been criticized as "a modernistic narrative of social control" in need of "displacement" since, although it represents a powerful narrative of medical expectations, it does not adequately describe the "*experience* of being ill" (Frank 1995, 2016).

Daily parlance refers to motion-sickness, morning-sickness, the sick feeling of having drank too much or suffering a bout of flu, and "feeling under the weather", all unpleasant but transient conditions of little social consequence: one would not expect a woman feeling unwell during her menstrual period, or an individual feeling miserable after last night's bachelor party, to fail in performing their next-day tasks. The common sense view of sickness is acceptable as a first-person experience of transient corporeal uneasiness that lacks social presence, for social responses tend to employ medical nosology in dealing with work absenteeism, rehabilitation programs, and the certification of disability or impediment.

The ambiguity of its use and meaning makes sickness an imprecise and misleading term too freely employed in phenomenology, whereas it is of restricted use when medicine resorts to nosology—classification of diseases—for diagnostic and therapeutic purposes.

## Illness

The first-person experience of illness is the awareness that an unwellness—the body becoming opaque—prevails beyond the unpleasant but transient and easily accounted for disarrangement of sickness. Phenomenologists have stressed the primary experience of the lived body suffering unwellness and disjointedness in facing routine tasks. Restlessness and loss of bodily control unleash fear, despondency, insecurity and helplessness, resulting in rich and complex "first-person narratives of illness" (Frank 2001). Feeling ill is the experience of losing control over what is happening to the living body, of being irritated by a deranged state of health. The illness experience feels the body becoming opaque, unyielding and uncontrollable beyond the unpleasant but transient and easily accounted for disarrangement of sickness.

Illness is the lived condition of having lost adaptability to one's own environment, a condition of failing to live up to one's usual standards of behavior and function; it is the disorder of one's previous ordered performance (Goldstein 1995). Feeling ill is a lived experience that precedes and prompts seeking diagnostic and therapeutic assistance: it is a "*pre-scientific denomination*" (Rothschuh 1975). "The real essence of being ill is *distress* leading to a solicitation for help" (Weizsäcker 1975, p. 218). Illness is an internal experience of the body that is lived as a process of alienation, an unhomelike being in the world (Svenaeus 2000, 2011), which cannot be controlled nor is self-limited, being "the very reason for going to the doctor" in order to detect or discard a disease state (Svenaeus 2009, p. 63). Because illness is a disjointing experience, it demands objective appraisal in order to explain, care and hopefully cure the body´s ill feeling. First person narrative of illness precedes medical intervention and is expected to assists physicians in planning diagnosis, envisioning prognosis and suggesting therapy.

*Pars pro toto*, philosopher Kay Toombs has developed a meticulous narrative about the embodiment of illness and disability, drawing from her long experience of "living with multiple sclerosis, an incurable, progressively disabling disease", adding that "[A]t one time or another my illness has affected my ability to see, to feel, to move…" (Toombs 2001b, p. 247). Havi Carel (2008, p. 37), a philosopher suffering from a progressive, disabling and eventually fatal disease (lymphangioleiomyomatosis, or LAM), describes the "many terrible things about illness". Dramatic and vibrant as their narratives read, they clearly constitute a mixed first-person account of illness, disease, severe disability and ominous prognosis. For clarity's sake, Toombs' description of "ill-as-lived" might more accurately be understood as "disease-as-lived".

The richness of first-person narratives of the ill who have been diagnosed with severe disease, contributes to a reconstructed narrative of the "individual model of disability or the social model of impairment" (Oliver 2004, p. 285). Reconstructed narratives are mostly presented by persons who have gone through, or live with, the experience of chronic and/or severe and disabling disease with foreseeable poor prognosis. Their singular narratives have moved beyond pristine illness experience, now describing disorders causing serious functional impediments, or a succession of severe maladies (Frank 1995), that are lived as disruptions of time, space, and social interactions. The formidable organic breakdown of disease leads to reassessment of the existential meaning of a "lived diseased body", or refer to illness plus, in analogy to Boorse's concept of disease plus, also viewed as the modified embodiment of the diseased subject (Kottow & Kottow 2007).

Diseases amenable to treatment leading to cure or stable compensation, may lead to transient modifications but hardly cause fatal changes of the self. The feeling of being diagnosed as "critically ill" leading to the diagnosis of an autoimmune disease is paradigmatic for alienation and the experience of "self as another" (Cohen 2004), but is not a general feature of falling ill. Both phenomenology and medicine are better served if the distinction between "falling ill" and "living with disease" is upheld.

Alienation experienced by falling-ill is not "always accompanied by a fatal change in the meaning-structure of the self", unless and until the disease diagnosis is ominous and will severely impact on the self and be reported, as in Toombs' and Havel's work, as lived disease aggravated by continued and progressive suffering and disability as described by their experiences. Once disease is diagnosed, the illness experiences will be transformed in view of prognosis, effectiveness and availability of treatment, the patient's biographical, familial and social contexts. The lived experience of illness becomes living with disease, upholding the distinction between illness as "a lived experience" and "disease as a physiological dysfunction giving rise to the illness" (Carel 2012, p. 111). Thus, two essential features of illness experience ought to be preserved: its prescientific status, and the decision to relinquish body control to external therapeutic interventions.

## Disease

"In our view, *nothing exists in science that has not also shown itself in* consciousness", Canguilhem states and adds: "medicine only exists because there are individuals that feel ill" (1974, p. 59). According to Nordenfelt (2007a, p. 29), "[D]iseases are…such physiological or psychological states or processes as tend to lead to suffering and/or disability". Although perfectible, this definition does fill an important purpose, for it speaks of diseases in the plural as processes, which is how medicine approaches the consulting individual, now patient: diagnoses aim at labeling a condition in order to initiate therapy, venture prognosis and officially classify the patient for records, social responses, and cognitive purposes. Furthermore, it confirms that diseases are entities—whether ontological or physiological, normativist or naturalist—that medicine operatively deals with, disregarding philosophy of medicine's circumambulations about the concept of disease. It comes as no surprise that, since medicine "consists in the application of state of the art", physicians try to excel in treating diseases and applying scientific facts to their *metier* (Baron 1992). The distinction between normal and abnormal is in permanent reconstruction, subject to conceptual instability, sociocultural modeling, modifying scientific data (Hucklenbroich 2014), but cannot be dismissed nor theorized, for it must remain "practical in the sense of viability to sustain the good of patient-centered clinical care" (Patil & Gordiano 2010).

Defining is also distinguishing, and there are many good reasons to make a distinction between illness and disease. A malformed fetus is diseased, but cannot be described as ill for, as far as anyone can tell, it has no lived experiences, whereas the pregnant woman is not diseased but may be deeply disjointed, and experience the illness of carrying an abnormal fetus, an observation germane to debates about abortion, the burgeoning field of perinatal bioethics, as well as empirical phenomenology applied to the experience of techniques such as ultrasound in pregnancy (Verbeek 2008).

## The clinical encounter

The communication involved in the clinical encounter—language, gestures, postures—has been analyzed in its complexity applying Bakhtinian semiotics to the "doctor-patient interaction" (DPI), refines the traditional view that symptoms are subjective and presented to the doctor who focuses on "*objective* and verifiable marks of disease and represents *solid, indisputable facts*". The physician reduces the polyphonic illness narrative into the medical language of "diagnostic classification" (Puustinen 1999, pp. 276, 279). Medical semiology differentiates between first-person rendering of illness symptoms, and the objective recording of disease signs. There is no denying the cognitive and diagnostic value of first-person anamnesis, as well as the humane importance of an empathic encounter, and yet patient narrative has been increasingly neglected, therefore deepening the epistemic rift between first-person experience and objective medical actions: "given the estimated average contact time between GP and patient of between 5 and 6 minutes, the possibilities for treating the person are slim" (Kennedy 1983, p. 21) The living body's narrative is often ignored and bypassed in favor of disease-oriented objective exploration. Also to be considered is the common clinical experience that first-person narrative contains inaccuracies, patients often suggesting misleading causal assignations and diagnoses (Cassell 1979). The clinical encounter is subject to a widening gap between phenomenology of illness and medical effort at disease diagnosis.

## Discussion

Medicine as a caring profession is turning into a biomedical endeavor where research and therapy are intertwined, a process described as a crisis, a nemesis, or an alarming sign of the dehumanization of traditional medical practice. The hope of uncovering the "deeper roots of medical "dehumanization"", leading to a "phenomenological sense of embodiment…with the potential to help "re-humanize" medicine" remains stagnant (Leder 1992, pp 3, 5). Healthcare increasingly becomes a contended issue, and patient dissatisfaction is on the rise suggesting that thinking about medicine may benefit from more stringency of the language game employed in debating these issues. Conceptual clarity should help reassess some unwanted developments of medical practices.

Seeking medical care for transient sickness has untoward consequences for overburdened, understaffed and insufficiently funded healthcare services, spurning medicalization, overdiagnosis, pharmaceuticalization and prescriptive excesses. Encouraging the medicalization of the transient discomforts of sickness results in excessive consumption and loss of efficacy of such essential drugs as antibiotics, psychopharmaca and anti-inflammatory agents, contributing to a worldwide overuse of medicines and medical services (Brownlee et al. 2017).

It has been traditionally agreed that health is felt by the lived body as a state of silent and adequate adaptation to a person's usual existential challenges, undisturbed by persistent discomfort or malfunction. Medicine and the so-called New Public Health (Petersen & Lupton 2000), no longer define health as a first-person experience, preferring to display what Armstrong has called the "rise of surveillance medicine" and the "problematization of the normal" (1995, p. 395). Screening programs, demands for self-responsibility in caring for one's health as defined by biomedicine, as well as prescribing certain life-styles, scheduling regular and frequent medical checkups, and resorting to molecular diagnostic probing, have led the medical world to replace traditional subjective health assignations with more or less vexing labels like predisposition, pre-clinical condition, risk-proneness. As a result, processes such as pharmaceuticalization, preventive breast amputations, culpability for overweight and obesity, create the figure of the "healthy patient" in need of permanent medical surveillance. Overweight and obesity are current examples of conditions declared by clinical medicine and public health to be unhealthy states of the body, whereas fat people proclaim to be happily obese, actively militating in the ranks of fat acceptance activists and researchers, and disinclined to follow medical suggestions for life-style changes (Saguy and Riley 2005).

Illness remains a lived experience that prompts medical diagnosis, evaluation and prognosis. Phenomenology has been invaluable in calling physicians' attention to the richness and informative value of first-person narrative of the ill, enhancing its cognitive value for medical diagnosis, helping rescue the clinical encounter's humane value and enriching interpersonal connection (Carel and Kidd 2014). Illness narrative centers around bodily discomfort, anxiety and helplessness, presented as a first-person narrative in need of assistance; it is the prescientific, distressed call for help, becoming a dramatic experience if and when severe disease and functional breakdown are diagnosed.

Disease-entities continue to be medicine's basic tool for nosological ordering of the human body's derangements. Of course, nosology is a cultural product subject to historical and social influences, but at a given time it is the accepted instrument for diagnostic specificity, prognostic evaluation, and therapeutically valid approaches. Evidence based medicine has given priority to research data and instrumental exploration of the body, to the detriment of the patient's personal need to present a coherent narrative of the lived experience of feeling ill and requiring medical assistance.

When severe disease is diagnosed, the experience of illness turns into a tragic and deeply unsettling condition. The original narrative depiction of ill-feeling is profoundly modified in the wake of new experiences of coping, readapting to and existence with disease: "When I was diagnosed with a lung condition in 2006, my personal life and my life as a philosopher were split apart. The effect of the diagnosis on my personal life was enormous" (Carel 2013, p. xiii). The meaning of illness is fractured and recomposed as the meaning of illness-in-disease as lived in severe bodily suffering and dysfunction. Once a severe disease is identified, the first-person narrative is reconstructed to include coping with poor function, despondency, adaptation to altered time/space experiences, to transformed relationships, social roles, existential questions and life expectancies (William 2004. Meaning and narrative of illness are now signified as living with disease. The interaction between chronically diseased patients and medical care are altered, often to the dismay of the patient who feel neglected and cursorily treated when experiencing how physicians tend to distance themselves from disease conditions they cannot therapeutically control.

According to phenomenology “*every person is diseased in her or his own way”* (Kirkengen and Thornquist 2012, p. 1098), whereas medicine is intent on tipifying the case as disease entity. If, in fact, every person were diseased in a singular way, medicine would fail to develop clinical generalities needed to undestand disease and program its treatment. More exactly, phenomenology might claim that every person lives disease in her or his own way. Multiple sclerosis is a disease entity that is lived by every patient in his/her own personal way, and the core of first-person disease narrative is meant to display this singularity in all its facets. The suggestion of a “phenomenological approach… to give a *general characteristic* of health and illness” that may help understand “why and how *this* person is ill” (Svenaeus 2001, p. 101), merits additional reflection.

Critics of phenomenology have suggested that the meaning of disease is a domain phenomenology shares with anthropological medicine, psychosomatics, narrative bioethics and non-allopathic approaches (Gergel 2012; Sholl 2015). First-person renderings of illness are singular narratives that ought to assist in a better understanding of individual cases, but will be less useful in developing generalized phenomenological descriptions of illness and disease (Sholl 2015).

An empirical turn, proposed as a phenomenology of practice “characterized by priorities that arise from everyday concerns and practices, not necessarily from scholarly questions”, has produced many thoughtful essays on specific medical situations such as intensive care units, visual impairment in the elderly, oncology, palliative medicine, national health policies, following a line of research focused on the “domain of public and professional practice”, (Van Manen 2001, p. 457). These efforts should help bridge the gap, but without disturbing the essential distinction, between the prescientific lived experience of illness, and medical focus on diagnosing disease entities and securing a scientifically based therapeutic approach. The reconstructed narrative of illness in disease is best captured by the empirical turn phenomenology has taken, described as a postphenomenological approach (Verbeek 2008). Thus refocusing its perspective, phenomenology ought to gain a welcome impact on the lived experiences of patients facing an ever-changing technical and ethical medical environment.

The clinical encounter is no longer the presentation of an illness narrative to a perceptive physician focused on understanding the personal plight of a patient. This traditionally personal moment of mutual interaction, has moved into an abridged anamnesis that triggers a multidisciplinary intervention of highly trained specialists commanding sophisticated and invasive diagnostic instrumentation. All these issues provide new research scenarios for scientists, phenomenologists, postphenomenologists (Ihde 2008), humanists and bioethicists, exploring the reconstructed experience of an ill patient living with disease. The empirical turn of phenomenology should help understand the meaning of disease-as-lived, with all its existential alienation, and help medical practitioners regain a certain complicity with the chronically suffering patient, in order to elicit and secure the experience of wellbeing in disease .

## Conclusion

After briefly reviewing the variety of descriptions and definitions that apply to core concepts of the human body in health and disease, it becomes noticeable that polysemy leads to medical practices that too often loose the focus of patients’ needs as an existentially wounded human being. “Understanding suffering requires an appreciation of the whole patient, while the remainder of medicine is atomistic and reductive” (Cassell 2001).

The physician as stranger (Veatch 1983) becomes ever more so as imagery, genetic exploration, robotic interventions and other sophisticated techniques erect artificial interfaces between patients and doctors. Dehumanized medicine has become an overexposed catchword, preferentially employed by the media and directed at medical practice that, of course, always is a human endeavor, though less humane than is desirable. Dehumanization in medicine has also been denounced as being endemic, stimulated by inherent features of medical settings (Haque and Waytz 2012).

Exploring concepts of health and non-health shows that first-person experiences are essential components of more efficient and humane medical services and public health programs. Nevertheless, the gap between phenomenology´s lived body findings and medicine’s positivistic approach to the organic living body has not been bridged and remains resistant to further philosophical probing. The “separate worlds of physician and patient”, vividly depicted 25 years ago by Kate Toombs, are more evident than ever. Misunderstandings may be increasing between lived experience of illness and medical pursuance of disease labels amenable to more precise diagnostic, prognostic and therapeutic indications. Whereas everyday parlance freely intermingles the meanings of health, sickness, illness and disease, phenomenology in medicine ought to insist on semantic clarification in an effort to avoid social practices like excessive medicalization and the undue preoccupations of “healthism” (Metcalfe 1993). The unconscionable dismissal by evidence based medical positivism of first-person narratives of illness and the experiences of living with disease, call for a reconceptualization of medical phenomenology with increased emphasis on phenomenology of practice and postphenomenological approaches .

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