HEALTH AND RESILIENCE

HEALTH AND RESILIENCE

Edited by
TADEUSZ MARIAN OSTROWSKI
IWONA SIKORSKA

The monograph *Health and resilience* is a collection of papers providing the reader with an opportunity to look at the issue of mental health and resilience from various perspectives. It examines numerous concepts of resilience as related to patterns of adaptation in adverse contexts. Resilience accordingly can be conceived as good adaptation, effective coping or well-being attained despite of adversities. As referring to a class of complex phenomena, resilience is not only a basic category for developmental psychopathology and positive psychology, but also applies to developmental, educational, family and health psychology as well as to psychoneuroimmunology. The chapters of the book address the issue of resilience from either the nomothetic or the idiographic perspective. The monograph discusses theoretical models of resilience, investigates mechanisms and processes connected with health and resilience, scrutinizes various aspects of the latter (such as risk and protective factors or internal and external resources) and provides examples of support in difficult life circumstances.

“The monograph *Health and resilience* addresses a very important and still neglected in Poland, issue of the relationship between psychological resilience and health. This issue is the subject of interest to a variety of scientific disciplines, including psychology. The very concept of resilience, however, is still variously understood and there is no common position in this regard. It is also in the context of this fact that the present monograph seems to be important. (...) The monograph may be directed at a wide audience interested in health-related issues, primarily at psychologists, both researchers and practitioners. It can also provide a valuable source of information for pedagogues, sociologists, philosophers, physicians, and other medical professions’ representatives.”

From the review of Professor Nina Ogóńska-Bułak, Ph.D.,
Institute of Psychology, University of Łódź
HEALTH AND RESILIENCE

Edited by
TADEUSZ MARIAN OSTROWSKI
IWONA SIKORSKA

JAGIELLONIAN UNIVERSITY PRESS
The publication of this volume was supported by The Faculty of Applied Psychology of the Jagiellonian University.

REVIEWER
prof. dr hab. Nina Ogińska-Bulik

COVER DESIGN
Jadwiga Burek

© Copyright by Tadeusz Marian Ostrowski, Iwona Sikorska & Jagiellonian University Press
First edition, Kraków 2014
All rights reserved

No part of this book may be reproduced, translated, stored in a retrieval system, or transmitted, in any form or by any means, electronic, mechanical, photocopying, microfilming, recording, or otherwise, without written permission from the Author and the Publisher.


Jagiellonian University Press
Editorial Offices: Michałowskiego St. 9/2, 31-126 Kraków
Phone: 12-631-18-81, 12-631-18-82, fax 12-631-18-83
Sales: Phone 12-631-01-97, Phone/Fax 12-631-01-98
Mobile: 506-006-674, e-mail: sprzedaiz@wuj.pl
Bank account: PEKAO SA, no. 80 1240 4722 1111 0000 4856 3325
<table>
<thead>
<tr>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>7</td>
</tr>
<tr>
<td><strong>I. SOCIAL AND METHODOLOGICAL CONTEXTS OF RESILIENCE</strong></td>
<td></td>
</tr>
<tr>
<td>Tadeusz Marian Ostrowski</td>
<td>13</td>
</tr>
<tr>
<td>Resilience in the light of research and theoretical reflection</td>
<td></td>
</tr>
<tr>
<td>Konrad Banicki</td>
<td>25</td>
</tr>
<tr>
<td>Naturalism, normativism and Havi Carel’s phenomenological approach</td>
<td></td>
</tr>
<tr>
<td>to health and illness</td>
<td></td>
</tr>
<tr>
<td>Krzysztof Gerc</td>
<td>39</td>
</tr>
<tr>
<td>Testing the sense of identity in people with highly functioning autism</td>
<td></td>
</tr>
<tr>
<td>as theory-methodological problem</td>
<td></td>
</tr>
<tr>
<td>Urszula Tokarska</td>
<td>57</td>
</tr>
<tr>
<td>“The beneficial life stories.” Health and mental resilience from</td>
<td></td>
</tr>
<tr>
<td>the narrative perspective</td>
<td></td>
</tr>
<tr>
<td><strong>II. RESILIENCE IN DEVELOPMENT</strong></td>
<td></td>
</tr>
<tr>
<td>Iwona Sikorska</td>
<td>85</td>
</tr>
<tr>
<td>Theoretical models of resilience and resilience measurement tools</td>
<td></td>
</tr>
<tr>
<td>in children and young people</td>
<td></td>
</tr>
<tr>
<td>Bogusława Piasiecka, Krzysztof Gerc, Iwona Sikorska</td>
<td>101</td>
</tr>
<tr>
<td>Siblings – a retrospective analysis of deidentification processes</td>
<td></td>
</tr>
<tr>
<td>Klaus Fröhlich-Gildhoff, Maike Rönnau-Böse</td>
<td>117</td>
</tr>
<tr>
<td>Empower children! The promotion of resilience in early childhood</td>
<td></td>
</tr>
<tr>
<td>institutions (kindergarten) and primary schools</td>
<td></td>
</tr>
<tr>
<td><strong>III. RESILIENCE AND DISEASE</strong></td>
<td></td>
</tr>
<tr>
<td>Władysława Pilecka</td>
<td>141</td>
</tr>
<tr>
<td>Resilience as a chance of developmental success for a child</td>
<td></td>
</tr>
<tr>
<td>with a chronic illness</td>
<td></td>
</tr>
<tr>
<td>Wojciech Otrębski, Barbara Czuba</td>
<td>157</td>
</tr>
<tr>
<td>Coping with stress amongst families with children suffering from</td>
<td></td>
</tr>
<tr>
<td>chronic psychosomatic diseases – recommendations for psychoprophylactic actions</td>
<td></td>
</tr>
</tbody>
</table>
Izabella Januszewska, Stanisława Steuden
Styles of coping with negative emotions and stress in patients with hypertension ................................................................. 169

Krzysztof Gerc, Marta Jurek
Family life dimensions and self-assessment of adolescents and young adults using psychoactive substances – the comparative studies .................. 193

List of Authors ........................................................................................................................................................................ 211
“My body is me. This is an essential feature of our embodied existence that is brought out be illness. Illness is an abrupt, violent way of revealing the intimately bodily nature of our being.”

Carel, 2008, p. 27

Abstract

The notions of health, disease, and illness as essentially applicable in all medical contexts have been extensively discussed within contemporary philosophy of medicine. Among the variety of perspectives offered there are two which seem to be currently dominating: the naturalistic and the normativist ones. The former approach, as represented by Boorse’s biostatistical theory, tends to focus on the notion of disease, which is understood in terms of an impairment of statistically normal biological functioning. The latter one in turn, as developed for instance within the action-theoretical theory of Nordenfelt, denies the possibility of specifying health and illness in purely objective biological terms and provides an openly normative framework which is founded on the notions of human ability and vital goals. These two approaches, though obviously different in many non-negligible aspects, still share one crucial feature: they are formulated from a third-person perspective and use third-person language, accordingly. Having made this point, Carel intended to develop a perspective which would do justice to first-person experiences, especially to those of an ill person. The phenomenological framework offered by her as well as its philosophical sources are briefly scrutinised.

Key words: health, disease, illness, Boorse, Nordenfelt, Carel, biostatistical theory, action-theoretic approach, phenomenology
One of the central purposes of contemporary philosophy of medicine and bioethics is an attempt to delineate and discuss the notions of health, disease and illness (for general introduction see Murphy, 2008). The focus on these particular concepts, importantly, is motivated by their general character and breadth. They can be meaningfully referred, in particular, not only to all these medical contexts in which they explicitly appear but also to those in which they may initially seem to be absent. A particular philosophical position concerning health, diseases and illness; a position which can be implicit, unsystematic, and incoherent, but which still is as a philosophical position, for instance, seems to be inevitable within all discussions of such normatively-laden concepts as therapy, treatment, recovery, or development. Any serious investigation into the notion of resilience, furthermore, as the one obviously dependend on the concept of normal (healthy) functioning, can also greatly benefit from an explicit discussion of the problematic area of health, disease, and illness.

The attempt to reliably discuss the latter notions, what is more, is not only driven by purely theoretical considerations but also by those of more practical character. The notions in question, in particular, can be easily shown as having a far-reaching consequences for medical practice, a practice for which they determine its specific goal: the removal of disease (illness) and/or the achievement of health. As such they can have a considerable bearing on the whole medical world, not only on the very clinic but also on medical education and politics (including health insurance policy).  

One of recent attempts to offer a new approach to the issues of illness and health has been made by the British philosopher Havi Carel in her book titled Illness. The Cry of the Flesh (Carel, 2008; cf. Carel, 2011, 2012). The importance of this proposal results not only from its theoretical merits but also from the fact that it is based of the author’s own “experience of living with a degenerative and potentially fatal illness: an illness that has no treatment” (Carel, 2008, p. 7).  

This fact, as one will see in what follows, is especially important within the context of particular approach offered by Carel – the phenomenological one.

The experience of a very serious illness, as Carel (2008, p. 7) herself reports, has pushed her “to reflect abstractly on health and illness” and to ask “what these concepts mean and how best to understand them.” What she found out as a result, however, was that the routinely applied medical language is “inappropriate, incomplete and often misleading.” One of the direct consequences of this impoverishment of medical conceptual framework, as she believes, is “the inability to speak of important things” and, hence, the need for a new approach

\[1\] For the analysis of health concept’s consequences for health care see Nordenfelt (1993).

that would enable “us to express the experience of illness” (Carel, 2008, p. 6 and 10, respectively).

While speaking about the “inappropriate, incomplete and often misleading” medical language and concepts Carel refers especially to two particular perspectives that have dominated philosophy of medicine in recent decades: the naturalistic and normativist ones. The naturalistic approach to disease and health, to begin with, can be called an orthodox or mainstream one within the contemporary medical world. The naturalism of this approach refers to the fact that it conceives the human being as, entirely or at least primarily, “a complicated biological organism with a vast number of interacting parts” (Nordenfelt, 1986, p. 281). Human diseases, accordingly, are perceived as fully belonging to the natural world and, hence, as exhaustively describable and explainable in naturalistic terms, such as those of physics, biology, and chemistry.

Even thought medical naturalism is an umbrella term that covers a relatively broad spectrum of perspectives, it is the biostatistical theory developed by Christopher Boorse (1975, 1977, 1997; cf. Cooper, 2002) that seems to be dominating, both as a source of positive inspiration and as an aim of naturalism’s critics. A disease, according to this proposal, can be identified with “a type of internal state which is either an impairment of normal functional ability, i.e. a reduction of one or more functional abilities below typical efficiency, or a limitation on functional ability caused by environmental agents.” Health, in turn, is nothing more than “the absence of disease” (Boorse, 1977, p. 567). The theoretical cornerstone of this definition is the concept of functional ability, which, in turn, is based on the notions of survival and reproduction. A normal function of a bodily organ or system, more particularly, is its contribution to the individual’s survival and reproduction, which is statistically typical of a respective reference class, i.e., a class of organisms of the same species, sex, and age as the one in question.

A crucial feature of Boorse’s theory, as well as the one that makes it an instance of an objectivist approach (cf. Murphy, 2008), is that it conceives the notions of disease and health as essentially “value-free and descriptive in the same sense as the concepts of atom, metal and rain are value-free and descriptive” (Nordenfelt, 2007, p. 5). The diagnosis of an organism as diseased, accordingly, is a matter of discovering some biochemical facts. It can be objectively made by standard medical and scientific procedures, without the necessity of referring to any normative issues.

The fact that Boorse’s approach is currently dominant is not accidental. The biostatistical theory is certainly sophisticated, well-organised and quantitative. Also, as even its critics admit, it has many considerable advantages. Nordenfelt (2007, p. 6), for example, points to the fact that its reliance on the concepts of survival and reproduction makes it not only well-fitted into the evolutionary framework but also easily applicable to non-humans including animals from apes to “worms and amoebas” and plants “from orchids to mosses.” Even despite of these indisputable advantages, however, the biostatistical perspective,
or naturalistic approach to the phenomena of disease and health in general, has been subjected to substantial criticism (see especially Nordenfelt, 1995). It has been argued, for instance, that it underestimates the environmental and inter-individual variations of human functioning as well as the extent to which one subnormal function can be compensated by another supernormal one.

The most important doubt, however, concerns Boorse’s consistency in providing a value-free account. Or, more significantly, it is the very possibility of addressing the issues of health and disease without presuming any normative viewpoint that is put into question. The whole family of the approaches that deny such a possibility can be conveniently subsumed under the heading of normativism.

The most general tenet, common to all normativist approaches, is that the notions of health and disease are essentially value-laden. These notions, more particularly, are believed to be inevitably entangled with normative presumptions concerning human behaviour and/or well-being. To say that somebody suffers from a disease, in consequence, is something more than to objectively diagnose this person’s bodily functions. Contrary to the views of the naturalists, it is also non-accidentally to make a normative statement concerning the undesirability of these functions’ current state as well as its behavioural and experiential consequences.

Normativism, importantly, conceives the human as “fundamentally a social agent, a complete human being acting in society” (Nordenfelt, 1986, p. 281). As soon as one takes such a perspective, significantly, the notions of biochemical and physical kind turn out to be principally insufficient to describe and account for a human being, including an ill human being. These are the value-laden concepts derived from social sciences and the humanities, instead, that need to be applied.

One of the most often debated version of normativism has been proposed by Lennart Nordenfelt (1995, cf. 1986, 1993, 2007) as so called holistic or action-theoretical approach. Within a framework of theory of action and essentially social view of human being, in particular, health has been defined as “a person’s ability, in standard circumstances, to reach his vital goals” (Nordenfelt, 1995, p. 145). A disease, in turn, has been conceived as physical or mental process “which is such that it tends to reduce its bearer’s health” (Nordenfelt, 1993, p. 280).

The notion which is crucial to the above-given definitions is the one of vital goals as “those states of affairs the realization of which are necessary and jointly sufficient” (Nordenfelt, 1995, p. 145) for the minimal welfare of a person in question. Its importance lies in the fact that it is the seat of the health and disease notion’s normativity. The exact character of minimal welfare, in particular, is left undetermined. The question concerning the latter “is not a question of science” (Nordenfelt, 1995, p. 78). It has to “be decided upon, and cannot simply be the result of empirical investigation” (Nordenfelt, 1995, p. xvi). This necessity
of referring to so called primary evaluation (Nordenfelt, 1995, p. 78, italics added) while determining the particular content of the health concept is a feature that most directly reflects the essentially normative character of the latter.3

If one wanted to set the biostatistical and action-theoretical approaches together, one would obviously found a lot of non-trivial differences (Nordenfelt, 1986, 1993, 2007). The perspective offered by Boorse, to begin with, is founded on the notion of disease (the concept of health is defined in negative terms) and specified in terms which are derived from biology and statistics. The health-related goals of an organism, accordingly, are the ones of reproduction and survival. Both health and disease, furthermore, are believed to be purely objective matters to be determined by scientific methods. Nordenfelt’s approach, in turn, is built on the concept of health (the one of disease is derivative) and applies conceptual framework which is proper to social sciences including the terms such as those of goal or welfare. Human vital goals, importantly, are understood as significantly broader than pure survival, which they include as “a necessary condition for the accomplishment of all other goals” (Nordenfelt, 2007, p. 9). The phenomena of health and disease as viewed from this perspective, finally, are explicitly and consequently depicted as value-laden.

All these differences can be hardly overemphasised. Still, however, there is an important formal feature that these both approaches share and that has become the origin of Carel’s criticism directed at them. The characteristic in question is a third-person perspective and language employed by these two proposals. The first-person perspective, including the first-person experience of an ill person, accordingly, seems to be non-accidentally and seriously neglected.

It is exactly due to this neglect that the Illness’ author, even though having admitted that the accounts summarized above “both have merits and have spawned a large literature,” insists that there is “a different set of issues pertaining to illness that is not captured by either approach (Carel, 2008, p. 12). What is principally excluded by them, more particularly, is “the experience of being ill: illness as it is lived by the ill person.” Illness, as Carel argues, is not only a disease, i.e. an abnormal bodily state or process. It is also, or even primarily, a first-person physical, psychological and social experience including the experience of the life changes that disease may entail. Both naturalism and normativism, with all the non-trivial differences between these two models, are both substantially unable to address these kind of issues: “the world of the ill person,” in Carel’s (2008, p. 12) own words, “is not heard.”

It is with this critical diagnosis of currently dominating approaches to health and disease and their ability of doing justice to “the world of the ill person” in

---

3 Another case, in which this normativeness is visible, is the fact that the notion of standard circumstances used is the definition of health is different from the one of statistically normal environment (proper to Boorse’s approach). Standard circumstances, in particular, “are related to a cultural norm” (Nordenfelt, 2007, p. 7).
mind that Carel attempted at finding a language and conceptual framework that would be more appropriate to let the patient speak for him/herself. The place in which she found what she was looking for was *philosophical phenomenology*.

Having said this, there are at least two remarks that have to be necessarily made. Phenomenology, at first, is a very complex and internally heterogeneous philosophical movement, which used to to be associated with such diverse figures as Franz Brentano (cf. his idea of descriptive psychology), Edmund Husserl, or Martin Heidegger. Even Husserl, i.e. the very founder of the movement, cannot be simply connected with one particular idea of phenomenology, because his approach had substantially evolved. This considerable heterogeneity should be always kept in mind in the context of Carel’s presentation, which usually does not dwell much on technicalities. The second remark that could be made concerns the closer context of Carel’s project. The idea of applying phenomenology to the experience of illness and health, in particular, is shared by her with some other interesting thinkers such as Richard Zaner (1981, 2005), S. Kay Toombs (1987, 1993), or Fredrik Svenaeus (2000, 2001).

The phenomenological idea that has been of crucial appeal to Carel can be easily derived from the very name of the current: “the phenomenology.” Phenomenology as understood etymologically, in particular, is nothing less that the science (gr. *logos*) of what is in the most general sense experienced, i.e. of the *phenomena*. What is especially significant is the fact that phenomenology has explicitly first-person and descriptive character. It is “a descriptive philosophical method” (Carel, 2011, p. 34) that focuses on direct individual experiences without any ambitions to go beyond them. Not only are all possible philosophical and scientific explanations of what (and how) is experienced put into bracket, but also the very reality of experienced things is put aside. The phenomenologist, accordingly, is interested in “things (*phenomena*) as they appear to us,” not in the things themselves (Carel, 2008, p. 10).

When applied to illness, it would mean that it is the lived experience of a suffering person, his/her acts of consciousness, experiences, and perceptions, rather then scientifically, third-personally and objectively specified biochemical fact of disease, that will be put to the fore. In the cases of serious and/or chronic illnesses, what is more, *the phenomenology of illness* will focus on these experiences as more holistically and globally structured, i.e. on the “illness as a way of living, experiencing the world and interacting with other people” (Carel, 2008, p. 8).

---

4 Understandably, it is mostly the case of the book (Carel, 2008), which is aimed at general audience, rather than the texts written mostly for scholars (Carel, 2011, 2012). In her paper from 2011, for instance, Carel admits that within phenomenology “there are different views and emphases” and that phenomenology itself is “normally described as a transcendental mode of inquire” (p. 34 and 35, respectively). The latter remark is especially important, because the transcendental thread, crucial as it was for Husserl, is not usually regarded important by the author of *Illness* (cf. “For the purposes of describing the experience of illness, it is enough to consider the general features of illness without insisting on the transcendental nature of its features,” Carel, 2011, p. 35).
Phenomenology as it is conceived by Carel (2008, p. 71) is first of all “a view that enables a complete description of the ways in which the life and world of the ill person changes.” As such, importantly, it is not intended to “displace” the thirdperson perspectives such as naturalism and normativism. It is meant, rather, to “augment” them or, in the words of Svenaeus (2001, p. 87), to “enrich our understanding of health in adding to the disease-level analysis a level of analysis that addresses the question how the physiological states are lived as meaningful in an environment.”

Within the whole bunch of phenomenological approaches it was the French philosopher Maurice Merleau-Ponty that turned out to be the most helpful for the Carel’s attempt. The reason for which she found this philosopher “particularly compelling in relation to illness” (Carel, 2008, p. 20) was his view of human lived experience and existence as substantially embodied and founded on perception. The body and perception, as seen by Merleau-Ponty in particular, are “the seat of personhood, or subjectivity” (Carel, 2008, p. 20), the “sine qua non of human existence” (Carel, 2011, p. 37). Any change affecting the body and/or perception can and, in fact, must influence the very subjectivity itself. The human being, what is more, is always enworlded, i.e. substantially related to the meaningful world he/she perceives and in which he/she acts: “a perceiving and experiencing organism, intimately inhabiting and immediately responding to her environment” (Carel, 2008, p. 20).

This view of human subjectivity and personhood has many non-negligible consequences. The most general of them concerns epistemological issues. It turns out, in particular, that any theoretical attempt aiming at the understanding of the human has to be founded on thick enough account of body and perception as the foundations of the self or, in slightly more concise terms, on the idea of the human “both as having a body and as having a world” (Carel, 2008, p. 13). Any perspective that does not include these dimensions will be simply “a deficient account.”

The approach offered by Merleau-Ponty, significantly, is through and through anti-dualistic and, in a sense, anti-intellectual. As such it can be directly contrasted with the views of Descartes who famously conceived the human as essentially a mind or a soul (Latin res cogitas, or thinking substance) which is only contingently connected with a body (Latin res extensa, or extended substance). Descartes’ dualism, as one may remember, is one of the two founding principles of contemporary biomedical, or naturalistic, medical paradigm (see Engel, 1977; the second presumption is reductionism). Phenomenological approach, accordingly, will remain in essential tension with the latter. Anti-dualism of Merleau-Ponty, when stated in more positive terms, can be identified as a holistic position which emphasises “the inseparability of mind and body, of thinking and perceiving” (Carel, 2008, p. 21). Consciousness and mental activity, in short, even in their most subtle and abstract forms, are always both embodied and mediated by perception.
The rejection of dualism, interestingly, affects not only the view of the mind (soul) but also that of the body. The Cartesian body was significantly passive: a material being susceptible to the commands of active and intentional mind. By itself it was nothing more than a mechanism “that only comes to life when infused with a soul” (Carel, 2008, p. 21). Within Merleau-Ponty’s perspective, to compare with, the body is as ‘ensouled’ as the soul is embodied. The body, in particular, is not only active in a general sense of the term, but also “an intelligent, planning, and goal-oriented entity” (Carel, 2008, p. 38), an entity that is permanently engaged in meaningful relationships with the world it inhabits. This body, as a matter of fact, can be quite literally assigned the property of intentionality.

The body as seen by Merleau-Ponty, what is more, is unique in that aspect that it “can be experienced both from a third-person point of view... and from a first-person point of view” (Carel, 2008, p. 23). When the former perspective is taken, the body is simply a physical or material object: the biological body (ger. der Körper, franc. le corps objectif) that can be subjected to standard scientific procedures including weighing, measuring, and inspection. It can be described and accounted for, accordingly, in objective terms derived from natural sciences including biologically understood medicine. What is crucial, however, is the fact that it is always something more than this. When conceived from a subjective perspective, namely, the body becomes “the first-person experience of the biological body... the body as lived by the person” (Carel, 2008, p. 26).

The notion of the lived body (ger. Der Leib, franc. le corps propre) is of central importance here, because it represents the whole potential of phenomenological approach to illness. A healthy biological body, to begin with, is usually transparent: it is either not experienced at all or remains in the experiential background. As long as everything goes smoothly, this body is taken for granted in the very same sense in which an efficient instrument is taken for granted while utilizing it. The biological body and the body as lived “are aligned, in harmony.” (Carel, 2011, p. 39). When something adverse and/or surprising happens to the biological body, however, this harmony becomes disrupted. When a body part rejects to cooperate, for instance, our awareness is “drawn to the malfunctioning body part and suddenly it [this body part, KB] becomes the focus of our attention, rather than the invisible background for our activities... It ceases to be an invisible background enabling some projects and becomes a stubborn saboteur instead” (Carel, 2008, p. 26).

A crucial point to make is that illness is one of the most obvious examples of this kind of collision. Its crucial aspect is the fact that an ill person begins to feel

---

5 An exact way in which this relationship between two substantially different substances can be at all possible was obviously very mysterious. The vicissitudes of so called body-mind problem is the best evidence for that.
estranged from his/her own body\textsuperscript{6} and is, in a sense, removed “from the normal flux of life” (Carel, 2012, p. 104).\textsuperscript{7} The illness, in general, can be potentially full of very tremendous and far-reaching consequences to the person him/herself. As such, accordingly, it turns out to be nothing less than “a painful and violent way of revealing the intimately bodily nature of our being” (Carel, 2011, p. 40).

Necessarily concise remarks made above can be a good illustration of the way in which Merleau-Ponty’s idea of the lived body as something distinct from the biological one provides a conceptual tool, by which we can express an insight that illness in not only, or even not primarily, an isolated fact concerning human physiology, but a phenomenon that substantially affects the embodied person as a whole, including his/her relationships to the environment. Illness, as a result, turns out to be a situation in which “one’s entire way of being in the world is altered” (Carel, 2008, p. 73). And it is exactly the task of doing justice to the experience of this tremendous change that cannot be done by any third-person approach and that is the point at which phenomenology can reveal all its merits and potential. The shift in one’s existence imposed by illness, as Carel (2008, p. 29) emphasises, “is not local but global, not external but strikes at the heart of subjectivity.” This truth applies especially to severe and/or chronic diseases (as well as to disability). The conditions of this kind, accordingly, are hardly addressable by any approach that does not include a comprehensive and consistent account of the embodied self. It is only “through embodied phenomenology,” in brief, that “the tremendous impact of illness becomes visible” (Carel, 2011, p. 41).

The experience of illness, obviously, can take a great number of different shapes. Still, however, it seems to be possible to identify some features which are common to all, or at least to the majority of them. Before Carel, an attempt at identifying these features has been made by Toombs (1993, p. 90) who developed a list of the essential characteristics of the experience of illness including “a loss of wholeness, a loss of certainty, a loss of control, a loss of freedom to act, and a loss of the familiar world.” This list has been supplemented by the author of Illness with “three additional themes” (Carel, 2012, p. 103): (1) the changes in the way space and time is experienced, (2) lost abilities, and (3) adaptability. The distinctions between the characteristics and themes proper to illness, importantly, should not be interpreted as implying that this experience can be “compartmentalized into discrete areas” (Carel, 2012, p. 102). These features, quite oppositely, are only dimensions of ultimately unitary and global phenomenon. In serious and/or chronic conditions, even more, they can be conceived as aspects of an illness that has become “a complete form of life” (Carel, 2012, p. 97).

\textsuperscript{6} Cf. Svenaeus’ (2000, 2001) application of the notion of „Unheimlichkeit” as a state in which one is not at home in one’s own lived body.

\textsuperscript{7} This removal, as Carel (2012, p. 104) notices, is not only due to the confinements of bodily abilities connected with a disease, but also “because of social and psychological barriers to participation, for example, embarrassment or anxiety.”
(1) The modification concerning the experience of time and space, to begin with, can be understood as these two dimensions of the experienced physical world becoming “less welcoming, full of obstacles, difficult” (Carel, 2012, p. 103). When one is ill, distances which used to be short increase. Tasks which used to take a short time require a considerably longer one. These changes are especially vivid in the cases of disability, such as those requiring one to use a wheelchair. Even common headache or sore feet, however, can lead a person to the experience of time and distance to be walked as both painfully long.

Toombs (1993, p. 97) writes that illness “truncates experiencing” in its spatio-temporal dimension. The “unavoidable preoccupation with pain, sickness, or incapacity, grounds one in the present moment” and makes the future “suddenly disabled, rendered impotent and inaccessible.” The space, similarly, becomes considerably confined (“to the bed, to the house, to the hospital”) and restrictive (“a location may be ‘too far’ from the bed or chair, a step ‘too high’ to climb, a room ‘too crowded’ to navigate”). Diagnosis, especially a diagnosis of an illness with uncertain prognosis, as Carel adds, may confront one with limited time given to a fragile and mortal human being. As such, in turn, it may lead to the reconsideration of one’s values and commitments and give “an opportunity to consider how one has lived and how one would like to live” (Carel, 2012, p. 104).

(2) The second of the themes explored by Carel are lost abilities. A healthy body is, first of all, an able body, a body that remains transparent and taken for granted just because it is able to be engaged in the tasks that capture whole attention. An ill body, on the other hands, “thwarts plans, impedes choices, renders actions impossible” (Toombs, 1993, p. 90). The idea of embodied existence, as one may remember, posits that all goal-directed activity, including one directed at even the most abstract goals, is necessarily mediated by bodily action, including perception. Any weakness of the body or the restriction of physical and perceptual potential, respectively, is inevitably connected with the confinement of one’s ability to “assert oneself, perform actions and carry out activities that promote one’s goals” (Carel, 2008, p. 73). As such, it does transform the very heart of the self, the agent’s subjectivity and global existence.

(3) The illness as lived, importantly, although it may seem to be constituted by negative dimensions only (cf. the Toombs’ list of losses mentioned above), can also involve more positive aspects among which there are creative responses to all that have been lost. The process of adaptability, in general, is directed at the discovery of new ways to achieve old goals and, as such, can be very broad and global. In many cases, as a matter of fact, it can be understood as aiming at the discovery (or invention?) of a completely new way of being, a way in which a person can be happy and lead a worthwhile life despite the fact that he/she is seriously ill. Creative reactions to illness, importantly, apart from their intrinsic and direct value, can also lead to some further positive outcomes such as a sense of achievement while coping with obstacles, the feeling of joy about the present,
serene attitude towards one’s adverse circumstances, or a deeper insight into
the human condition with all its fragility and accidentality. These kind of out-
comes are often subsumed under the heading of “health within illness” (Lindsey,
1996).

The very possibility of health within illness revealed by phenomenological
analyses, as Carel argues, entails the necessity of making a considerable concep-
tual shift. Health and illness, to begin with, can no longer be conceived as mutually exclusive and opposite to each other. They should be rather conceived in
terms of “a continuum or a blend of the two, allowing for health within illness
in people who seem objectively ill” (Carel, 2008, p. 78). A business-as-usual
assessment focused on objectively measured deficits, what is more, should be supplemented by more first-person approach which would let the patients, who often report positive aspects even while suffering very serious diseases, to speak.
The most general insight gained by the application of phenomenological view-
point is that “illness is part and parcel of life, and on a continuum with health”
(Carel, 2008, p. 80). The traditional model of medical thinking and healthcare
practice built around the notions of disease and cure, as a result, should be at least complemented by more positive one emphasising health and well-being promotion as well as healing.

The necessary conceptual shift summarized above, as Carel argues, can and
should be followed by particular applications referring not only to medical train-
ing and practice, but also to the study of therapeutic outcomes, or methodologi-
cal issues (Carel, 2011).

Medical training, for instance, is currently founded on the biomedical model
with all its reductionism and mechanicism. As such it has certainly proved to be very efficient in many areas. Still, however, it is completely impotent as far as the global and subjective experience of illness is concerned, which makes the ill-
ness as lived “unacknowledged within clinical medicine” (Carel, 2012, p. 98).
Phenomenological perspective, on the other hand, if it was included into medi-
cal training could help such acknowledgement happen. It could, for example, be applied as a medium through which the clinicians could become aware of the common features of illness, such as those enumerated by Toombs and Carel.
New insights and sensibilities, accordingly, could be developed and the general ability to empathise increased.

The biomedical conceptual model, significantly, not only hinders health care
professionals in their attempts to understand patients, but also has a very seri-
ous impact on the latter. In fact, it could be hard to overemphasise “the extent
to which patients’ own understanding of their illness is influenced by medical
attitudes and their encounters with the health care system” (Carel, 2012, p. 98).
Medical staff is the primary source from which patients obtain the information
about their maladies. While receiving these information, importantly, patients
are not only provided with facts concerning their condition but also with a par-
ticular discourse, in which they learn, are taught, to think about themselves. This
biomedical discourse, importantly, can seriously confine the ability of addressing the subjective and existential dimension of an illness and, as such, “may lead to a sense of alienation and a lack of a first-person voice in patients’ discourse about their illness” (Carel, 2012, p. 98).

A remedy for this situation, according to Carel (2012, p. 99), can be provided by the phenomenological perspective with its avowedly descriptive, i.e. non-prescriptive and non-explanatory, and first-person approach which makes it “uniquely suited to the exploration of the experience of illness” with all its far-reaching consequences to the very subjectivity of a patient and his/her way of being. The author of Illness, as a matter of fact, has recently initiated the development of “a phenomenological toolkit that can be offered to patients as a workshop” (Carel, 2012, p. 97, italics added). This toolkit, more specifically, would provide patients with phenomenological language and viewpoint helping them to describe and order their experience of illness.8 A new perspective on illness gained by the application of this toolkit, furthermore, could be subsequently presented to health care professionals and “help construct a shared meaning of illness” (Carel, 2011, p. 42).

The development of a phenomenological toolkit, apart from its most straightforward character and merits, can be understood as a point at which Carel comes back to the most direct reality of illness. A considerable part of her work has been devoted to relatively distanced and abstracted investigations into the themes of illness and health. It is in this part that she introduced the phenomenological viewpoint and argued for its importance for the medical discourse and practice currently dominated by third-person approaches of naturalism and normativism. Still, however, the ultimate goal of her work was connected with real people, whose illnesses she hoped to make “a little less scary, less anonymous” (Carel, 2008, p. 18).

While concluding her book Havi Carel (2008, p. 134) wrote: “Illness can be a journey. Like some journeys, you do not always know where it will take you. This particular journey moved from personal experiences of illness to a philosophical exploration of their meaning.” One of the things that she wanted to convey was that her reflections on illness had been neither exclusively philosophical and, hence, mostly third-personal and objective, nor solely personal and subjective. Phenomenology as depicted by her, in other words, is “a theory that has become a lived experience and is then rethought in light of experience” (Carel, 2008, p. 117). This “sometimes difficult” (Carel, 2008, p. 13) attempt at remaining simultaneously committed to both first- and third-person approaches is certainly one of the features that makes her account that precious.

An important point to be made is that by the very same token the brief presentation of the phenomenological approach offered in this chapter, a presentation

8 The workshop, interestingly, is also intended to include “nonlinguistic means for self-description and self-reflection” (Carel, 2012, p. 109) such as collage or a song.
that has been made in an objective and third-person manner, is inevitably one-sided and limited. This kind of fundamental confinement can be remedied only within more personal perspective such as that proper to experience or genuine interpersonal dialogue.

References


