SDU
Syddansk Universitet

Department of Media, Design, Education and Cognition
Human Health
Center for Philosophy of Health
Values, Welfare and Health

PhD Thesis

Thor Hennelund Nielsen

Philosophical Foundations of Health Assessment

Towards a Dynamic and Integrative Conception of Health

January 2023

Preface, abstracts, and acknowledgments

Preface

Carrying out this project during a time when the world underwent a pandemic was a curious experience. Suddenly, philosophical questions that ordinarily are considered remote from ordinary life, such as whether asymptomatic patients are ill or how to prioritize treatments and human lives, became heated discussions with serious societal and individual repercussions. It lent an air of legitimacy to the present project, for it investigates what health and disease are, and how these phenomena are measured through generic health assessment instruments, which forms the backbone of, for example, prioritization in health care. Indeed, events like the pandemic attest to the eternal topicality of such questions. When these fall out of vogue or seem too abstract to concern us, it does not owe to their irrelevance but perhaps rather to the human ability to repress essential parts of life, for "Illness", as Susan Sontag once wrote:

> "is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place" (Sontag, 1991).

sdu.dk

#sdudk

This dissertation differs somewhat in structure from other anthological or article-based PhD theses. Usually, these begin with the summary containing introduction, methodical reflections, results of the thesis and so on. I have chosen to structure the thesis much more like a monograph. This means that the articles are part of chapters, which are linked together through (sub)sections. The intention behind this was to ease the reading experience but also to emphasize that, despite the sometimes kaleidoscopic nature of the present collection of articles, there is a grander context for the different themes investigated.

Here, I will only very briefly introduce where the different articles appear since the introduction contains a much more detailed summation of the overall structure of the thesis. After the introduction and methodical considerations, the first article "The Normativist-Naturalist Puzzle: Functions and Assumptions of Health Assessment Tools" appears in chapter 3. After a chapter that bridges the empirical and theoretical studies, the article "The Dynamics of Disease – Towards a Processual Theory of Health" appears in chapter 5. Chapter 6 contains the article "Issues for a Phenomenology of Illness – Transgressing Psychologizations", while chapter 7 brings the fourth and final article of the project "Medical Individualism – What makes an Individual Individual?".

Abstract

Contemporary trends push health care towards gaining evidence-based knowledge of the severity of health conditions and the efficacy of health interventions. To this end, generic health assessment instruments are developed, which are questionnaires designed for (self)evaluation of health on broader dimensions like physical, mental, and social health. The aggregated scores of the instruments represent a quantified assessment of the overall degree of health and well-being attached to certain health conditions.

However, when operationalizing the overall state of health and well-being into quantified and measurable items on a questionnaire, the instruments implicitly rely on substantial philosophical assumptions about the nature of these phenomena. In the first article of this project, the philosophical workings and assumptions of these instruments are elucidated through a qualitative study of health professionals' thoughts on the practice. To really gauge what conceptions of health and disease are at play in the instruments, the dichotomy of normativism and naturalism within philosophy of health is used as an interpretive key. I strive to let the empirical investigations inform the theoretical and vice versa to avoid both a strictly bottom-up and top-down approach.

The juxtaposition of philosophical theories with qualitative analysis exposes weaknesses in established positions, which the remaining articles seek to revise. The second article argues that the discussion between normativism and naturalism founded on conceptual analysis is caught in a deadlock and suggests an ontological approach instead, which construes health and disease as a relation between capacities to adapt and demands imposed upon the organism if it is to thrive. The third article criticizes the cur-

sdu.dk

#sdudk

rent trend of phenomenology of illness for being too one-sided and psychologizing, instead proposing that health and illness manifest themselves phenomenologically as the preservation of or fundamental broaches upon conative activities. In recent times, certain movements within medicine like personalized medicine claim that health conditions are fundamentally individual and variable. The fourth article asks what this entails, and what model of medical anthropology is needed to accommodate such a perspective. As a whole, the project works towards providing the groundwork for a more dynamic and integrative conception of health and disease. Whether a maximalistic theory of health and disease is amenable with the measurement of generic health is, however, an open question, and the project is concluded by a discussion thereof.

Resumé

Nutidige tendenser nødvendiggør, at sundhedsvæsnet skaber sig et evidensbaseret overblik over alvorsgraden af helbredstilstande og sundhedsinterventioners effektivitet. Med dette formål in mente udvikles generiske helbredsvurderingsinstrumenter, som er spørgeskemaer, der måler selvvurderet helbred på bredere dimensioner såsom fysisk, mental og social sundhed. Instrumenternes aggregerede værdier repræsenterer en kvantificeret vurdering af den overordnede grad af sundhed og velbefindende knyttet til bestemte helbredstilstande.

I kraft af den proces, hvorved sundhed og velbefindende operationaliseres til målbare og kvantificerede størrelser, forlader instrumenterne sig imidlertid på substantielle filosofiske antagelser om sundhedens og sygdommens natur. I projektets første artikel bliver instrumenternes funktioner og filosofiske antagelser belyst gennem et kvalitativt studie af sundhedsprofessionelles holdninger til denne praksis. For at undersøge hvilke opfattelser af sundhed og sygdom, som råder i disse instrumenter, bliver dikotomien mellem normativisme og naturalisme i sundhedsfilosofien anvendt som en fortolkningsnøgle. Jeg efterstræber en ligevægt mellem de empiriske og teoretiske undersøgelser, der både undgår en rendyrket bottom-up og top-down tilgang.

Sammenstillingen af de filosofiske teorier med den kvalitative analyse afslører imidlertid svagheder i de etablerede positioner, som de resterende artikler forsøger at revidere. Den anden artikel hævder, at diskussionen mellem normativisme og naturalisme er funderet på begrebsanalysen, der er fanget i et dødvande. I stedet foreslås en ontologisk tilgang, som forstår sundhed og sygdom som en relation mellem evner til tilpasning kontra de krav om tilpasning, som organismen udsættes for, for så vidt den skal trives. Den tredje artikel kritiserer sygdomsfænomenologien, som den aktuelt praktiseres, for både at være for ensidig og psykologiserende. Artiklen foreslår i stedet, at sundhed og sygdom manifesterer sig fænomenologisk som opretholdelse af og fundamentale brud på livsaktivitet. Visse bevægelser indenfor sundhedsvidenskaberne såsom personlig medicin hævder, at helbredstilstande er fundamentalt variable og individuelle. Den fjerde artikel spørger, hvad der skal forstås derved, og hvilken medicinsk antropologisk teori kan imødekomme dette synspunkt. Som helhed stræber jeg i projektet mod at støbe fundamentet for en mere

sdu.dk

#sdudk

dynamisk og integrativ forståelse af sundhed og sygdom. Spørgsmålet er imidlertid, om en sådan maximalistisk teori om sundhed og sygdom er forenelig med generisk helbredsvurdering, og afhandlingen afsluttes med en diskussion af dette.

Acknowledgments

I am greatly indebted to a lot of people who have helped me throughout the course of this PhD. First and foremost, my supervisor, Lasse Nielsen, who has been a tremendous aid through the whole process and who has borne with a lot of overly ambitious ideas and unfinished drafts. Similarly, I am very grateful to Søren Harnow Klausen, who has been a great source of inspiration since my first days of studying philosophy at the University of Southern Denmark and has helped me with advice and feedback throughout the PhD. I am indebted to Anna Paldam Folker who graciously took the time to be the opponent at my pre-defence, which gave me a lot of valuable feedback. I also thank Jørgen Hass whose routine visits during the later parts of the afternoon for discussions about the history of philosophy were very inspiring as always. In general, I thank the research groups *Values, Welfare and Health* along with *Human Health* and the philosophy department at SDU for all the exciting and fruitful discussions.

I am grateful to all my PhD colleagues at the Humanities of University of Southern Denmark for the warm, inspiring, and intellectually stimulating work environment that has gradually been

established – “ingen nævnt, ingen glemt”. Special thanks are owed, however, to Anders Hee Nørbjerg Poulsen, who started his PhD at the same time as me and has been a trusty companion, with whom I have shared a lot of the ups and downs that the PhD process entails.

I could not have completed my project without my family and partner. I owe my mother, father, and brother, Ragna, Torben, and Aske, a huge thanks for their never-failing patience and genuine interest as well as their readthrough of my dissertation to check for grammatical errors and typos. Last but not least, my partner, Rikke, who has stood by me without fail – even when I have been less than reasonable due to stress. Thank you for always understanding and aiding me. I look forward to repaying the favour.

Any shortcomings are the author’s alone.

sdu.dk

#sdudk

Contents

sdu.dk

#sdudk

1. Introduction

> "To believe in medicine would be the height of folly. Not to believe in it would be greater folly still" (Proust, 1932, p. 929).

1.1 What is health assessment?

Health care in contemporary societies finds itself at a crossroad. The strides made in the advancement of health and prevention of disease at the turn of the 19th century and throughout the 20th – the democratization of health care, the virtual extermination of epidemic diseases like polio, measles, smallpox and so forth – have not continued. Though more resources than ever are channeled into the promotion of health and the prevention of disease, the prevalence of more complex clinical profiles along with health care expenses only grow. Faced with this paradox, it seems that the answer is not simply to channel further resources into health care but to put the resources to *better use*. Contemporary trends such as *evidence-based medicine* (Guyatt et al., 1992) and *value-based health care* (Miller, 2009) reflect this need. Health care, it is argued, needs a clearer picture of what works and what does not work and especially to what *degree* it works (Sackett et al., 1996). Only thereby can *resource allocation* and *prioritization* take place on rational grounds instead of through conjecture.

This also constitutes the rationale behind the practice of *generic assessment of health, disease, and well-being*. To gain evidence-based knowledge of the efficacy and utility of health

interventions as well as the severity of health conditions in terms of *health-related quality of life* ("HRQoL"), *health assessment instruments* – also known as patient-reported outcome measure ("PROMs") – are increasingly employed to evaluate *cost effectiveness*. In essence, the instruments are questionnaires designed to evaluate the self-reported health of a person on broader dimensions like physical, mental, and social health, which are aggregated to combined scores. These scores represent an assessment of the global level of well-being connected to a state of health, i.e., "how one is doing" overall. This, sometimes in conjunction with preference elicitation, is then used to measure quality-adjusted life years, QALYs (Nord, 1999), disability-adjusted life years, DALYs (Murray, 1994), etc. Through comparative, longitudinal, and demographical studies, the instruments can assess the ways that health conditions in average affect HRQoL along with the net bonuses of carrying out certain interventions over others in a non-arbitrary and standardized fashion, so the reasoning goes.

Originally, the instruments hail from the field of health economy where they were developed to inform political decision making regarding resource allocation, ultimately with the aim of levelling out health injustices and making fair priorities (Pedersen & Wittrup-Jensen, 2002, p. 26). Since then, however, they have found much broader application in clinical and welfare practices along with the study of population health. Developers have refined the instruments for decades, primarily working on *psycho-*

metric aspects and issues. Less attention, however, has been dedicated to elucidating the strong *philosophical* assumptions and implications that the instruments are founded upon.

To measure health, disease, and well-being, one must first have an idea of what they are, but the nature of these phenomena is both contested and unclear. When a medical professional wishes to measure, e.g., the pulse, insulin levels, or bodyfat percentage of a patient, certain biomarkers can be assessed through standardized medical tools, but how does one measure the overall state of health, disease, and well-being? Health and disease are phenomena more abstract and elusive than blood pressure and are typically assumed to include both functional, emotional, cognitive, and social dimensions. In lieu of biomarkers, the practice relies on self-reported evaluations on a standardized basis. In conceptualizing and operationalizing understandings of health or disease to make them available for measurement, however, the instruments invariably make substantial assumptions about the nature of these.

1.2 Research questions and aims of the thesis

In this project I investigate *which conceptions and assumptions about health and disease the practice of generic health assessment relies upon*. The problem is at one and the same time both deeply practical and deeply philosophical. Practical, since the assessment of the overall state of health utilizes and applies concepts to collect and interpret data with the ethical aim of guiding action; theoretical, since assessment relies upon fundamentally philosophical notions about *what* health and disease as phenomena *are*. Qua practical and theoretical, it calls for both empirical and philosophical methods. Rather than a purely bottom-up or top-down approach, however, I attempt to strike a balance be-

tween both approaches by letting the empirical study inform the philosophical and vice versa. In practice, this means that the project includes a qualitative study of the applications of and thoughts on health assessment by practitioners, researchers, and developers of the instruments to gauge the underlying philosophical assumptions. The data from this study is interpreted via the distinction between naturalism and normativism within philosophy of health to investigate which conceptions of health and disease are at play. Briefly put, naturalism as a theory understands health and disease as biological and functional phenomena, whereas normativism understands them as value-laden and tied to well-being and suffering.

To claim that health and disease – and the measurement thereof – are complex phenomena is almost a truism. Nevertheless, this was exactly what the empirical study confirmed: according to the responders, the instruments primarily assess functional indicators, but health and disease, though tied to functional properties, are more akin to a subjective state of overall bodily and mental well-being. The viewpoints that emerged corresponded neither with naturalism nor normativism strictly understood. Rather than concluding that these perspectives are the result of inconsequent theorizing, however, these become the impetus for the theory-driven work of the project that critically engages with established positions within philosophy of health.

The nature of health and disease is, at heart, an *ontological* question, I claim. They concern fundamental questions about what it is for an individual to be healthy or sick. In this thesis, I strive to stake out a different method of approach than the traditional methods of conceptual analysis or a psychologizing phenomenology, namely by drawing on ontology, biophilosophy, and philosophical anthropology. A rich tradition of philosophizing on the nature of health and disease precedes the current established positions within philosophy of health, and in taking inspiration from this, I attempt to pave the way for a more dynamic and integrative account of health and disease.

1.3 Structure and resumé of the thesis

Chapters 1 and 2 introduce the topic and methods of the thesis, respectively, while chapters 3 to 7 constitute the main part of the analysis that contain the articles written during this project. The 8th chapter concludes the dissertation by relating the theoretical investigations to the practice of health assessment again. In the following, I unfold the general argument of the thesis.

Chapter 3 is the point of departure of the analysis and concerns the practice of health assessment and the philosophical presuppositions thereof, including questions about what it is, how it is possible, and how it takes place in practice. The chapter contains the article "The Normativist-Naturalist Puzzle: Functions and Assumptions of Health Assessment Tools" (in review at the journal *International Journal of Qualitative Studies on Health and Well-being*, co-authored with Lasse Nielsen and Søren Harnow Klausen), which delivers a qualitative study of the applications of and thoughts on health assessment by practitioners, researchers, and developers of the instruments. Unlike in the field

sdu.dk

#sdudk

of health economy, the clinical application of the instruments is less well-documented, and the study was therefore in part explorative. In contrast to specific health assessment, which often measures more tangible and well-defined phenomena such as ability to stand up and sit down a certain number of times, pulse etc., which conceptions of health and disease that underlie the generic assessment practice is more diffuse. Therefore, naturalism and normativism as theories are included to interpret what is truly being measured.

Unsurprisingly, the study found that the conceptions of health and disease of the practitioners rarely corresponded exactly with philosophical positions, despite this fact, naturalistic and normativistic reflections played a part in the practice of generic health assessment. There was a tendency to understand health as a form of subjective well-being, i.e., as self-reported experience of health and well-being, the distinction between these being somewhat fuzzy. Simultaneously, it was widely recognized that there was a need for tangible, naturalistic parameters to assess this subjective state, but that the tools had clear limitations in this regard, seeing as the measurements were insufficient in themselves. There was, therefore, a two-sided issue: in practice, the instruments do not measure health, disease, and well-being the way that the practitioners understood these, at the same time, the theories were too one-sided to capture the nuances of these phenomena. This was the impetus behind moving beyond a strictly top-down

or bottom-up approach and instead attempt to strike a balance between the empirical and philosophical studies.

The 4th chapter contains the transition from the empirical work to the theoretical by treating four philosophical assumptions that underlie the operationalization of health and disease into measurable phenomena. The instruments:

1. Quantify qualitative conditions.
2. Objectivize subjective evaluations.
3. Fixate dynamic health conditions in static measurements.
4. Standardize conditions of great individual variability.

From the understandings that emerged in the qualitative studies, I choose to further explore the following three: 1) the dynamicity and processuality of health and disease 2) the subjectivity of health and disease, and 3) the individuality and contextuality of health and disease.

Chapter 5 revolves around the shortcomings of naturalism and normativism and the attempt to pave the way for a dynamic and processual theory of health and disease. Pure conceptual analysis often ends in a conflict over examples and counterexamples since the definitions prove either too narrow or broad. However, rather than claiming that the discussion is meaningless as the eliminativists do, I attempt to anchor the analysis in an ontological approach in the article "The Dynamics of Disease – Towards a Processual Theory of Health" (in press at *Journal of Medicine and Philosophy*). The article argues that health and disease is not constituted by the ability to live up to a certain abstract level of biological functionality or ability to realize well-being but instead suggests that health consists in the capacity to meet demands for

sdu.dk

#sdudk

adaptation if the organism is to thrive. The article, therefore, explicates a more responsive and dynamic understanding. It includes elements from naturalism, in so far as health and disease consist in capacities for adequate responses or lack thereof, and normativism, since adequate or inadequate responses rely on the relevant norms of the individual's life, which the individual itself and its environment poses.

The 6th chapter continues the dynamic approach but in a different arena. The article "Issues for a Phenomenology of Illness – Transgressing Psychologizations" (published in *Medicine, Health Care and Philosophy*) analyses phenomenology of illness, which investigates what it is like to be ill from a first-person perspective. The article critiques the movement for mistaking the original phenomenological project, which did not consist in the exposition of private experiences but of phenomena and their essences. Furthermore, that phenomenology of illness has a too psychologizing understanding of illness as experiences of alienation, bodily uncertainty, suffering etc. These undeniably play a role but makes it difficult to distinguish between problematic embodiment and illness. To supplement a too one-sided focus on experiences, an understanding of phenomenological illness as broaches upon conative activity is proposed. This conative activity designates the normative, temporal self-unfolding of existence, which avoids a too narrow focus on either the bodily or experiential. In develop-

ing this, I take inspiration from the phenomenology of Heidegger and Waldenfels.

Chapter 7 revolves around what role individuality plays in health and disease. The article "Medical Individualism – What makes an Individual Individual?" (submitted to the journal *History and Philosophy of the Life Sciences*) concerns the theory of medical individualism, i.e., whether individuals and their pathologies and physiologies are to be considered fundamentally unique and variable. This is done with a critical view to the movement of personalized medicine, which has an inadequate conceptualization of individuality as founded in a summative and material holism. It posits that due to the interplay of highly complex networks that the patient is composed of, any individual is bound to vary in some respect from another. What it lacks is both an adequate conceptualization of how different elements and dimensions of the individual add up to a unique whole and a sufficient understanding of the individual as not just a biological object of great complexity but a self with agency and values. In the article, I draw on philosophical anthropology, especially Plessner, to elucidate this integrative model of the individual.

The 8th chapter concludes the dissertation by weaving the empirical and philosophical threads together. What consequences does it have for the practice of health assessment if health and disease are dynamic and individual, and if more psychologizing approaches contain strong limitations? Can the generic and generalizing practice then still be maintained? Or is health assessment perhaps the best among sub-optimal ways in which health, disease, and well-being can be measured on a standardized basis?

sdu.dk

#sdudk

2. Methodical reflections

2.1 The general line of approach

Before describing in greater detail how the qualitative and ontological study were conducted, and how these approaches can shed light on the subject matter, I will briefly comment upon the general line of approach throughout the project. At first glance, the plurality of methods employed and topics treated might seem kaleidoscopic. From qualitative studies in the beginning to (a sort of) conceptual analysis to phenomenology and philosophical anthropology in the end. What at face value seems to be a multitude of approaches is, however, the expression and application of the principle that *the matter at hand determines the method*, as Aristotle says (1995, 1094b). Since the subject matter contains both practical and theoretical dimensions, the problematic calls for both a *qualitative* and *ontological* study.

Health assessment is to a certain extent ontologically committed regarding the nature of health, disease, and well-being. Even if granted that the readings are approximative and indicative rather than exact measurements of health conditions, they must operationalize certain assumptions about these phenomena to get measurable results. The qualitative study is a way to gauge these ontological assumptions that the practice implicitly or explicitly relies on. However, the mettle of these conceptions can only be tested or further developed upon through additional ontological

investigations, which gives occasion to the theoretical studies. Since the essence of health and disease manifests itself in various ways, the dissertation calls for a *multifaceted* investigation. There is, therefore, a guiding thread throughout the diverse topics investigated in this dissertation, namely that of an ontological investigation, which is carried out in various ways since health and disease are complex phenomena.

2.2 Doing qualitative studies

The philosophical assumptions underlying the health assessment practice are less documented, and the study therefore called for a more explorative approach. Since the instruments to a large degree are *practical*, and the application influence their philosophical workings and assumptions, the purely theoretical approach had to be supplemented by empirical data. Quantitative analysis was considered but decided against since the priority was to glean insight into the rationales behind the practice rather than gain a broader but more superficial overview. Semi-structured, qualitative interviews were therefore judged to be a better fit for the analysis, which required a certain amount of direction and flexibility (Poulsen, 2019, p. 98).

The different applications of the instruments, the varied terminologies in circulation, the fact that philosophical assumptions behind the practice were to a certain degree uncharted territory etc. – these facts called for an open but somewhat directed conversation in the form of semi-structured interviews. Although some of the responders had strong theoretical leanings and in general were very reflected regarding the practice, they were primarily practitioners, and a strictly philosophical mode of reasoning through abstract concepts might seem unfamiliar to them.

Formulating, for example, what the instruments "truly measure" can be tricky in and of itself, and the author group furthermore wanted to avoid eliciting automated responses or responses, which the interviewees felt obliged to give. From the provisional desktop study conducted before the interviews, which detailed some of the uses and purposes of instruments in circulation, it was difficult to gauge who were important actors within the field of health assessment in a Danish context, which was the area of study of this project. Qualitative interviews therefore allowed for snowball sampling by relying on the insider knowledge of the interviewees to find qualified – so-called "elite" – responders.

The interviews were conducted at the start of the first round of lockdowns in Europe due to the Covid19 pandemic in March 2020. While many struggled to carry out empirical work during these months, this project was perhaps aided by the lockdown since the responders were at home and reachable by digital means. The 13 interviews in total were carried out over a period of 1-2 months and recorded via Zoom, afterwards uploaded to an encrypted server, and then transcribed by the three student assistants affiliated with the project. The assistants also contributed to the collection of the interviews. Before being interviewed, each participant signed a declaration of consent and were informed of the purpose of the interviews. Afterwards, all personal information was anonymized except the employment status and educational background of the responders since it was deemed im-

portant to the results of the study. Because the data was less sensitive as it rarely contained personal information, this was not judged to be an issue.

The interview guide (see the appendix), contained four blocks of questions including intro and outro (Poulsen, 2019, p. 104). The starting question was deliberately very open-ended to gauge what the responders associated with the term "health assessment instruments" ("sundhedsevalueringsredskaber"). This was followed by a host of quite concrete questions to hone in on the theme, which progressively led into the more abstract and evaluative questions on the practice and rationale of health assessment. The questions were left as open as possible, while still providing some structure and direction to the conversation, to elicit the off-the-cuff responses, associations, and opinions of the responders. Though analysis of the data through coding is often suggested (Brinkmann & Kvale, 2018), we opted for a less rigid approach. The interviews were divided into two groups and through careful reading and rereading, salient points were drawn out and afterwards discussed and rechecked between the three members of the author group.

The qualitative study is driven by a more classical explorative approach, which collects its data inductively and then interprets these via theory. But in the broader project, I strive for an approach that rather resembles *grounded theory*. That is, a theory which develops and refines its concepts inductively from the data collected (Glaser & Strauss, 1967) in contrast to a hypothetico-deductive model, which draws its results from preconceived hypotheses that are put to empirical test. Although grounded theory is more nuanced than simply drawing inductive conclusions from data since it also involves the intricate process of comparing the

theoretical results to the data in feedback loops until "saturation" has been reached (Charmaz & Belgrave, 2012; David & Sutton, 2011, p. 110), it does not capture all that I attempt to elucidate. It is a crucial hypothesis of this project that the practice of health assessment and our conceptions of health and disease are to varying degrees mired in tacit theoretical assumptions even before they are operationalized into measurable properties or formulated into philosophical theories. Philosophical assumptions must be met by philosophical reasoning. Though grounded theory can shed light on assumptions, it falls short in substantial theory development and is therefore supplemented by an ontological approach.

2.3 Doing ontology

Ontology is the *study of being*. And though the term as such "only" dates to 1613, where the German philosopher Rudolf Glocenius invented it to refer to that subfield of philosophy, which investigates being *qua* being and therefore not the being of any particular entity as such, it is the oldest discipline of philosophy (Holm, 1964). It is the aims of ontology that Aristotle describes in book epsilon (E) of *Metaphysics* when he writes:

> "We are seeking the principles and the causes of the things that are, and obviously of things *qua* being. For there is a cause of health and of good condition, and the objects of

> mathematics have principles and elements and causes (…) but all these sciences mark off some particular being – some genus, and inquire into this, but not into being simply nor *qua* being, nor do they offer any discussion of the essences of the things of which they treat" (Aristotle, 1995, 1025a).

Ontology, in other words, enquires into the *essence* or *meaning* of being. What falls outside its domain, according to Aristotle, is the study of *particular* or *singular* beings such as singular biological, geological, or sociological entities etc., which constitute the objects of study for the specific sciences that stake out a certain domain of beings and declares the full analysis thereof its desiderata. To practice ontology therefore requires a certain level of abstraction in the method of analysis.

There are, however, manifold ways to be, as Aristotle remarks (Aristotle, 1995, 992b), whereby the door is left open for what can be termed *regional* ontologies that studies different *types* of being (Husserl, 2009a, p. 23). This transition is also reflected in the way that ontology is mostly done in modern philosophy: it has throughout history shifted from the attempt to elucidate what is common to all beings as beings into the study of what makes different types of being what they fundamentally are. Doing ontology, in this sense, is therefore a matter of tracing the *modalities* of certain types of phenomena.

How one exactly does this is another question. Heidegger writes in *Sein und Zeit* that "Ontologie ist nur als Phänomenologie

sdu.dk

#sdudk

möglich"[1] (2006, p. 35). By *phenomenology*, what is meant is not descriptions of psychological states of mind, which is often associated with it, but rather a *method* that is best summarized in Husserl's motto: "Zu den Sachen selbst!".[2] In short, the phenomenological investigation explicates the way that the object of study *appears* in its many forms. Through the careful analysis and comparison of these appearances, the gradual crystallization of what constitutes the core or essence of the thing, its invariant properties in contrast to its contingent, expose themselves, which is a method known as the *eidetic variation* (Husserl, 2009a). Through the eidetic variation, the conditions of possibility for the object as such is brough to light, whereby it, to illustrate it simply, shows itself as necessary that a triangle needs to have exactly three angles to be a triangle, but whether it is blue or red is accidental. Additionally, as phenomenologists continually point out, the thing or matter at hand always presents itself *to* a subject, from which its mode of appearance cannot be completely distinguished. Therefore, the adequate analysis of the ontology of a thing or type of being must delineate *how, why, and to whom* it manifests itself the way it does and therethrough discover what makes the type of object what it fundamentally *is*.

[1] "Ontology is only possible as phenomenology", my translation.

[2] "To the things themselves", as it is commonly translated.

The investigation of this dissertation into the nature of health and disease and how it is measured can therefore be summarized as a *regional ontological analysis* by means of a *phenomenological approach*. That is, an investigation that traces the meaning and being of health and disease through the explication of the ways that these phenomena essentially appear. What the essential features of health and disease are, is a contentious issue, though they are commonly assumed to have physical, mental, and social dimensions since they can refer to bodily functions or dysfunctions, to experiences of being healthy or ill, to the sick person as a societal role (Hofmann, 2002) etc. These distinctions are fruitful, I claim, though I prefer the nomenclature of biological, phenomenological, and social. These dimensions are manifestations of one and the same phenomenon that has an invariable core, it is argued. Therefore, the ontological study conducted in this dissertation is also an integrative account that seeks to synthesize these different aspects of health and disease.

To flesh out how the ontological approach specifically proceeded, the analysis took the theories of normativism and naturalism as a starting point into the investigation of the assumptions about health and disease that the generic assessment practice is governed by. Using traditional theories as a point of entry is common to many ontological analyses to both draw on the fruitful findings of former philosophers and to explicate "what remains unthought" in these theories, to use a Heideggerian turn of phrase (Heidegger, 1997). The comparative analysis between naturalism and normativism and the points that came to light during the qualitative work suggested that there were aspects of health and disease that the theories did not explicitly take account of.

sdu.dk

#sdudk

This sparked the theoretical articles of the dissertation, which all share a structural likeliness: they begin by examining established positions and notable proponents of archetypical theories within the philosophy of health. From these, certain weaknesses or blind spots are drawn out by explicating aspects of the phenomena that they are less capable of accounting for. This gives rise to the theory development, which serves the purpose of revising and supplementing conceptions of health and disease, ultimately, with the goal of explicating the conditions of possibility for and essence of health and disease.

2.4 Beyond bottom-up and top-down

The qualitative and ontological study work in conjunction by playing off the strengths and ameliorating the blind spots of each other. The qualitative approach enables insights into practice that philosophical theorizing alone cannot access, but whether the points that it derives are of a sufficient theoretical level can be difficult to tell. While the ontological approach can qualify imprecise theorizing, it cannot *a priori* glean insights into the practice. There is, therefore, a synergy between these approaches. The ambition is to reach a method beyond an inductive, bottom-up approach, where the data drove the formation of concepts a la grounded theory, and a deductive, top-down that interprets the data through a pre-conceived theoretical lens.

There is something artificial about the application of theory to practice; it introduces an approach that to a certain degree is external to the matter. Naturally, there is always an element of arbitrariness in selecting a research approach since this choice relies upon the personal sympathies or antipathies of the researcher. Whether the researcher can act as a neutral conduit or medium for the matter in investigation is a contentious issue, nevertheless, I strive to follow the principle that there is no method independent of the matter. In other words, that the matter at hand dictates the method instead of the reverse. This leads, as stated above, to the ontological approach aided by qualitative studies. Instead of two distinct methods working in isolation, however, I aim towards *striking a balance* between these. That is, to let the ontological analysis be driven by the topics that come to light through the qualitative study and to refine the qualitative studies through ontological theorizing, namely because the subject matter, generic measurement of health, calls for both approaches.

sdu.dk

#sdudk

3. Assessing health and well-being

3.1 What is generic assessment? Initial clarifications

First and foremost, some clarifications are in order since what counts as a generic, self-reported health assessment instrument, and what exact type of considerations they elicit, is debatable. Here, four main themes will be highlighted, namely: 1) generic assessment is to be understood in contrast to *specific*, 2) objective parameters of measurement in contrast to *subjective*, 3) philosophical issues in contrast to *psychometric*, and finally, 4) some clarifications regarding the terminology must be made.

1) Since medical practice utilizes a host of different ways to assess health or disease and their effects on well-being, delimiting exactly what constitutes a generic instrument can be rather difficult, and the lines are often blurry between specific and generic instruments. What is here understood as a specific health assessment instrument, however, is a type of standardized measure, which contains well-defined, concrete items that relate to a single dimension of health or a specific state of being, whereas a generic instrument contains *multiple* dimensions and assesses the total state of health, disease, and well-being. A specific instrument could, for example, be the *Hospital Anxiety and Depression Scale*, "HADS", (Zigmond & Snaith, 1983) that gauges the emotional life of a patient in clinical contexts – how well they are or are not doing. The instrument consists of 14 questions, 7 relating

to depression, 7 to anxiety, which, when aggregated, deliver an indication of whether and to what degree the patient suffers from these conditions. Though the HADS shares similarities with generic instruments by measuring mental health and well-being, it fundamentally operationalizes clinical symptoms of specific conditions, anxiety and depression, and does not purport to measure either social, physical, or the total state of health.

Generic assessment instruments can have well-defined, concrete items as well but draw conclusions about the overall state of health and well-being on several dimensions instead. The EQ-5D (Rabin & Charro, 2001), for example, is one of the most popular generic instruments that measures health-related well-being on five dimensions, namely mobility, self-care, usual activities, pain and discomfort, and anxiety and depression. Though the instrument leaves out social health, which was originally included but left out for the sake of simplicity and brevity (EuroQol, 1990), it still comprises both physical and mental health and additionally asks the responder to assess their own health as a totality from 0 to 100, 100 being perfect health, 0 being the worst imaginable. Since it consists of several dimensions and assesses the total state of health, it counts as a generic instrument.

Generic instruments, additionally, sometimes contain an element of preference elicitation, where the responders are asked to rank several hypothetical health conditions from best to worst, which are similarly utilized to compare the severity of health states. Although why the ‘gut feelings’ of responders about the severity of a hypothetical condition are adequate indicators of the actual severity of said condition remains an open question (Hausman, 2006). Whereas HADS operationalizes clinical symptoms or consequences of anxiety disorders and depression, EQ-5D

sdu.dk

#sdudk

operationalizes a more abstract understanding of what constitutes the salient elements in a state of good or bad health.

2) To avoid confusion, there is moreover a distinction to be drawn between the assessment of health care and assessment of health. Formerly, the quality of a health care system was primarily measured by statistical parameters such as number of incidents of certain diseases among populations, of hospital admissions, of deaths following admissions, and so forth. The issue with these parameters is that they only indirectly and with great uncertainty inform us about the quality of the health services provided or the state of the patient under or after treatments. Recent years have therefore seen a movement from volume-driven to value-driven health care (Miller, 2009), which to a higher degree measures the quality of health care systems through the generic assessment of the health status and quality of life of patients. When discussing health assessment in this context, it is the generic and self-reported health assessment of individuals as such rather than health care systems and objective parameters described above that is meant.

3) Though psychometric issues of health assessment are important, they are not the topic of investigation in this project. Health economists' concerns primarily lie with the reliability and validity of the instruments. That is, with questions regarding how well the instruments measure what they purport to measure, how to avoid 'noise' in the measurements that distort objective read-

ings, how exactly to formulate the items of the questionnaire since different people might attach different meanings to a term such as "strong pain" etc. This is not to say that there are not genuinely philosophical questions within psychometry such as how intercultural differences are levelled out. For instance, personal freedom is of large importance to western populations, whereas community is of bigger concern to other cultures. The dimension of social health might therefore affect the overall well-being of an individual in different ways according to culture, and this needs to be reflected in the weightings of the different items. Similarly, very comprehensive instruments would perhaps deliver more precise readings, but it is unfeasible in practice to have responders spend hours filling out questionnaires. Therefore, a trade-off between simplicity and comprehensiveness is needed, and this requires reflections on the most salient aspects of the different dimensions of health, which itself is a highly philosophical question. Psychometrical issues have, however, been subjected to philosophical critique by others such as Hausman (2006, 2015), Stegenga (2015) etc., and will therefore only be treated in this context when relevant.

Rather, this dissertation investigates the philosophical assumptions and workings of generic health assessment instruments more generally. Similar analyses have been carried out of specific instruments (Kusier & Folker, 2020, 2021) or of the practice of happiness measurement (Kusier & Folker, 2022; Landes, 2015), but to a lesser extent of the conceptions of health and disease that health assessment relies upon. Here, I will give two examples of what constitutes a philosophical issue, which will be fleshed out later.

sdu.dk

#sdudk

Firstly, in so far as the instruments are generic and thereby purport to measure the overall state of health in some way, they must make principial and methodical choices about what physical, mental, or social health are and what are salient indicators thereof. For example, most instruments assume that physical health is fundamentally linked to mobility, and some instruments, such as the EQ-5D, weight the physical dimensions higher than the psychological by having three items concern the former and two the latter. Even the fact that health is assumed to contain three isolable dimensions, namely physical, mental, and social, is a fundamentally philosophical assumption. These methodical choices fundamentally impact the readings (Pedersen & Wittrup-Jensen, 2002, p. 26), therefore, the construction of a philosophically sound conception of health is crucial to gaining adequate readings.

A second philosophical issue concerns the connection between well-being and health. Measuring qualitatively different states of health in and of themselves is tricky. How is a broken leg, for example, comparable to severe clinical depression? Both conditions have radically different natures, causes, and impacts. In lieu thereof, most opt for the heuristic measure of comparing conditions according to their evaluated effects on well-being or the state of overall health. This procedure, however, also harbors philosophical assumption, e.g., that there is a close enough connection that the measurement of well-being is also indicative of

the severity of the state of health; or that what matters about health is its impact on well-being. It is these sorts of issues, which give rise to fundamentally philosophical questions about the nature of health and disease, that are investigated in this thesis.

4) Lastly, when conducting the interviews, some responders were puzzled by the choice of words. Though all responders were familiar with the practice, they wondered why we opted for the terminology "health assessment instruments" rather than "(health-related) well-being assessment instruments". While true that many of the instruments, such as the EQ-5D, measure well-being or rather health-related quality of life – which I return to later – well-being is also a heuristic measure to create tangible evidence regarding the differences between conditions, which are tricky to evaluate in themselves. Without measuring the conditions in terms of an effect, it is unclear how to assess the severity of the conditions or the effects of a medical intervention. Therefore, the instruments often assess well-being but thereby *also* measure health conditions. Whether health or well-being is emphasized as the object of study partly depends on the applications of the instruments. Other generic instruments, such as the SF-36 and SF-12, seem more directly to measure health in terms of physical and mental functionality (Pedersen & Wittrup-Jensen, 2002, pp. 17-18). The terminological confusion could however indicate that there is a need for closer analysis of the practice.

3.2 Normativism and naturalism in theory and in practice

What health and disease are and what philosophical assumptions about these that the practice relies upon is another and difficult question – both because there is no consensus concerning the na-

sdu.dk

#sdudk

ture of these notions and because the practice is complex and driven by several concerns simultaneously. Health professionals, when asked about the nature of health and disease, often refer to WHO's definition (Pedersen & Wittrup-Jensen, 2002): "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 2020). This definition, if taken at face value, is extremely demanding. Anything short of complete well-being on all parameters of health is considered pathological, the conclusion seemingly being that there are no healthy people. Moreover, the definition seems to conflate well-being and happiness with health, but it is entirely possible to be healthy without being happy and happy without being healthy. However, despite the philosophical inadequacies of the definition, I would argue that it is misunderstood. From a philosophical perspective, the definition does not measure up, from a practical, it constitutes an action-guiding ideal (Callahan, 1973) – the aim of health care, ultimately, is the complete well-being of humankind, although this is an utopian ideal. Several assumptions about health and disease in the practice seemingly stem from this definition, namely that health has three dimensions and that it is fundamentally related to well-being. But it seems implausible that it is the sole driving philosophical assumption behind health assessment, for the definition makes no claims about what physical, mental, social health, and well-being are and therefore offers no concrete examples of what to measure. The

theories of naturalism and normativism, however, are more specific as to the nature of health and disease, and for this reason, they are used as the interpretive key in the study.

Together, naturalism and normativism constitute the archetypical theories of health and disease. Here, I will only briefly describe the theories as they are treated in greater detail in the first and second article. Naturalism is an umbrella term for theories, which share the assumption that health and disease essentially are value-free, naturally occurring phenomena. The most influential proponent of naturalism is Boorse, who in a host of articles from the 1970's and to this day has defended his *biostatistical theory* (Boorse, 1975, 1976a, 1976b, 1977, 2014). It is telling of the qualities of Boorse's theory that most philosophers of health since then have attempted to rebuke or substantially revise it. Despite this, the theory endures and has been defended and augmented by several philosophers such as Hausman (2012), Schramme (2007), Schwartz (2007), and others.

The biostatistical theory defines health as the *statistically normal ability of biological (sub)systems to contribute to the survival and reproduction of the organism* whereas disease is *subpar deviation therefrom* (Boorse, 1977). For example, diabetes is a disease since elevated levels of blood sugar usually cause conditions, which hinder the survival and reproduction of the organism, whereas statistically normal levels of blood sugar on average promote these organismic goals. It is important to notice that only subpar abilities are considered pathological because statistically abnormal conditions can be beneficial for the organism, such as abnormal intelligence, being abnormally fast etc. What is or is not a statistically normal function can, in principle, be determined wholly without reference to values and is therefore a descriptive

sdu.dk

#sdudk

and objective property. Few naturalists would, however, be radical enough to claim that normative concerns play no part in matters of health and disease. In certain cases, diseases can even be desirable. Sterility, for example, is the failure of a bodily subsystem to carry out a statistically typical function yet can be wanted if the person wishes to remain childless. In other cases, sterility can be the source of great suffering and would therefore be labelled an illness on the biostatistical account since it constitutes a disease that is bothersome or painful, medically relevant, and exempts the person from certain societal norms (Boorse, 1975).

Normativism, on the other hand, is a fuzzier term. It comprises a host of different theories, which all in some way agree that health and disease are value-laden concepts – sometimes, all that seemingly unites them is their staunch opposition to naturalism (Kingma, 2019). Some normativists such as Engelhardt (1974, 1976, 1986), Sedgwick (1973) and others emphasize the critical dimensions of normativism. They argue that diseases are social constructions, often made with the aim of discouraging deviant or socially undesirable and unacceptable behaviour, evident in cases such as the pathologization of masturbation, hysteria etc. Others such as Agich (1983), Clouser et al. (1981), Cooper (2002), and Nordenfelt (1995) have more positive conceptions of normativism. They understand disease as unwanted conditions that cause the afflicted person pain or distress and hinder well-being, while health conversely consists in conditions that are

wanted and promote well-being, though it is variable what they understand by the latter.

On Nordenfelt's account, for example, a person: "(…) is completely healthy if, and only if, A [he or she] has the ability, given standard circumstances, to reach all his or her vital goals" (Nordenfelt, 2007, p. 7), where vital goals constitute the "essential goals" for the person that promote their happiness or well-being. Therefore, a case of sterility can be both healthy or pathological depending on the context and the afflicted person. If the sufferer does not want children, a case of sterility can benefit the person in reaching their vital goals, for others, it can severely hinder the realization thereof. Health is therefore tied to the ability to realize one's happiness and therefore resembles capability approaches to well-being (Nussbaum, 1993; Venkatapuram, 2011, 2013) in contrast to more subjectivist understandings of well-being as the psychological feeling of or self-evaluation of having well-being (Kahneman, 1999).

Both types of theories are included in the interpretation of the study because medical practice often is driven by both naturalistic and normative concerns. Functional indicators are rarely the only measure or aim of health, for physiologically abnormal conditions can be desirable, and health care does not solely cure diseases and restore health but also treat non-pathological states like cosmetic or reproductive issues etc. That is, health care is also driven by more normative concerns such as the attempt to promote well-being, as this is seen as the true value of and closely tied to health. However, doing well is not the only concern of medical practice, for the aim of health care is not to promote every type of well-being but only that form of well-being, which is medically relevant. Health care therefore requires a notion of

health and disease understood as functional capacities if it is to treat only medically relevant cases. The generic health assessment practice is a marriage of convenience between normativistic and naturalistic concerns, between concerns for functional indicators and well-being. Therefore, both theories are included in the study.

3.3 Article 1: The Normativist-Naturalist Puzzle: Functions and Assumptions of Health Assessment Tools

Authors: Thor Hennelund Nielsen, Lasse Nielsen, Søren Harnow Klausen. In review at *International Journal of Qualitative Studies on Health and Well-being*.

The Normativist-Naturalist Puzzle: Functions and Assumptions of Health Assessment Tools

Abstract

Background: While there is no shortage in discussions of health assessment tools, little is known about health professionals' experience of their practical uses. However, these tools rely on assumptions that have significant impacts on the practice of health assessment.

Aim: In this study, we explore the relationship between background assumptions and health assessment practice.

Method: We combine a qualitative, interview-based study of the uses and understandings of health assessment tools among Danish health professionals with a philosophical analysis of these applications and perceptions.

Findings: Our study shows that contrary assumptions are involved in the use of the tools, to the extent that one can speak of a *normativist-naturalist puzzle*: health professionals generally apply a normativist conception of health, find health assessment useful and valuable for their clinical practice, but believe that what the tools measure is basically not health proper but some proximal entity of a more naturalist kind.

Conclusion: This result demonstrates the complexity of the nature of health assessment tools and suggests that they are used with care to ensure both that particular tools are used for the kinds of tasks they are most apt for, and that they are put to use in awareness of their limitations.

Keywords: Health assessment tools; Naturalism; Normativism; Philosophical assumptions; Qualitative research

Background

Several strong trends in current health care support the development and use of tools for more nuanced and accurate assessments of health and health-related conditions like wellbeing, thriving, or vulnerability. The constant drive to increase health care efficiency has led to a quest for more precise, valid, and reliable measures. In recent years, there has been a shift from measuring productivity

in the health sector in terms of sheer output (like the number of treatments performed) to focusing on the actual effects of interventions in terms of health, wellbeing, and personal satisfaction. This has come to be known as "value-based health care" (Miller, 2009) and is currently informing policy and practice on many different levels (With & Jensen, 2018; EU Commission, 2019).

The tendency to focus more strongly on the judgments and self-perceived needs of patients is connected to an equally widespread attempt to increase patient participation in health care. Patient participation has been motivated mostly by concerns for patient "empowerment" and justice (Castro et al., 2016) or patient's rights (Cavel, 2016, 180ff.), but is also considered a means to improve health care efficiency, in particular when this is understood as comprising more than just economic efficiency, e.g., patient safety or clinical effectiveness (Groene et al., 2010).

A further driver behind the search for more sensitive and comprehensive health assessment tools is a recognition of the complexity of most health conditions, that is, the extent to which patients' health is determined by a multitude of interrelated factors. Growing evidence that mental health and wellbeing are reliable predictors of physical health (Ohrberger et al., 2017; Hernandez et al., 2018) has led to a revival and mainstreaming of "holistic" or "inclusive" approaches, like the bio-psycho-social model (Engel, 1977; for more recent developments and reassessments, see Borrell-Carió et al., 2004; Smith et al., 2013; Solomon,

2015). This goes hand-in-hand with the trend towards increasingly individualized treatment, which includes more than just genetics-based "personalized medicine". Striving for the overall best treatment for the individual patient (or "pre-patient") engenders a need for more comprehensive and nuanced information about her condition.

Already a considerable number of different tools for assessing and measuring the health and wellbeing of patients (and other relevant groups) are in use. Some, like the SF-36 Health Survey or the EQ-5D instruments, have been used for decades, and evaluated and validated extensively. But they are currently being applied and adapted to new tasks and problems, especially the attempt to make treatments more sensitive to individual needs and circumstances. And the tools still give rise to methodological and philosophical questions about their underlying assumptions concerning the nature of health and wellbeing that go well beyond narrow concerns for validity, reliability, and psychometrics. Health assessment tools particularly build on assumptions about what defines health, on what basis health is to be evaluated, and how the relevant value of health can be measured. Though the uses of health assessment tools within health economy is widely discussed and documented, little is known about health professionals' perceptions of and experiences with these tools. This is a key omission in the literature. To firmly understand central assumptions underlying the practical use of health assessment tools, we need to study how these tools are defined and understood by all of their users.

In this study, we explore health professionals' experiences with health assessment tools. We investigate how they define and understand health assessment tools, how they use them in differ-

sdu.dk

#sdudk

ent parts of their work, and how they take these tools to contribute to the measurement of health and wellbeing. To gain insight into the complex but consequential relationship between assumptions and the actual function and use of the tools, we combine a qualitative, interview-based study of the uses and understandings of health assessment tools among Danish health professionals with a philosophical analysis of the underlying assumptions. Upon this study, we conclude that health professionals generally find health assessment tools useful in their clinical practice when used to gauge more normativist conceptions of health understood as subjective wellbeing, but that what the tools measure is basically not health proper but some proximal entity of a more naturalist kind. We call this the *normativist-naturalist puzzle* of health assessment practice.

The article is structured as follows. In the next section, we briefly touch upon the question of what a health assessment tool is. Without providing any complete definition, we shall make some qualifications and invite a generally broad understanding of health assessment. In the third section, we introduce some general philosophical issues around the assumptions underlying health assessment tools. Section four accounts for our methods, and section five presents the findings of the qualitative study. Section six discusses the findings and subject them to a philosophical analysis. The final section sums up the findings and discussions and

deliberates upon further perspectives concerning health assessment.

What is a health assessment tool?

Our study proceeds from the observation that a bewildering variety of health assessment tools are in use, or being considered for future use, with little systematic knowledge of, or consensus about, their precise significance, scope, or potential. This calls for an initially explorative approach. However, some preliminary clarification is needed to know what to look for in the first place.

First, by a health assessment tool, we understand a tool for assessing generic health; that is, the *overall* state of a person (this we call the *comprehensiveness requirement*). The process of assessing generic health differs in several important respects from disease-specific assessment. There are myriads of tools for assessing health conditions in some more specific, usually pathological, respect – e.g., radiology, blood tests, reflex tests etc. These do not qualify as health assessment tools in our sense. It is not a tool merely for the detection of specific diseases. Generic assessment is not *just* to evaluate the workings of a specific physiological process but to assess the health status of the whole person more generically. Often this requires relying upon judgements and evaluations in the form of stated values and self-assessments, the relation of which to health "as such" is complex and contested. Of course, a generic assessment tool might not purport to measure *all* relevant factors. It can have a somewhat restricted scope, for example by aiming at measuring *mental* health, but it has to be fairly comprehensive.

Generic health assessment may, unlike most specific measures, include both *emotional* and *cognitive* as well as *func-*

sdu.dk

#sdudk

tional indicators. *Emotional indicators* delineate what a state of health "feels like", i.e., the mood and emotional life that a state of health "causes" to the person in question internally or subjectively. *Cognitive indicators* delineate how a health state is judged to be, e.g., how satisfied a person is with her health state. *Functional indicators* delineate how the state of health affects the person's ability to interact with her environment broadly understood, i.e., externally or objectively.

A health assessment tool often will but need not have a person as its direct object, that is, the primary object of assessment. Often the primary object of assessment is an *intervention* or *treatment* (this holds for QALY and DALY, and much use of the EQ-5D as well) measured through the elicitation of self-reported health and wellbeing or preferences. This still satisfies the comprehensiveness requirement, as long as the assessment is made in terms of effects that amount to an overall state, like general health, functionality or quality of life (and not just, say, inflammation reduction or headache relief). The object can even be something like a physical or cultural, e.g., urban, environment or a personal character trait like neuroticism, attitude or belief system, like spirituality or religion. What matters is that the assessment is done in terms of overall impact on health or wellbeing.

Without committing to any precise and exhaustive definition, we shall understand health assessment tools as *a generic measurement of the effect of health on assessments of health-*

related needs in individuals or groups, comparison of treatments and other health initiatives. In order to illustrate this admittedly quite abstract and broad definition, we can point to the following tools which are more or less commonly referred to in presentations of health initiatives and strategies: SF-12, SF-36, EQ-5D, WHO-5, NHP, QALY, DALY etc.

Philosophical Issues and Assumptions

Health assessment tools rely on assumptions about the definition and value of health as well as the validity of its measures. These assumptions are in most cases merely implicitly acknowledged and sometimes completely ignored. This is unfortunate since they can have significant impact on the practice and function of health assessment. In this section, we bring some of the most central assumptions out in the open.

Multidimensionality

Health assessment tools raise philosophical questions in part because they are necessarily *multidimensional*. Because they directly or indirectly target comprehensive and complex states of persons, they must cover several factors. This means that the factors must be weighted and taken together (though not necessarily "aggregated" in any technical sense; "taking them together" can consist simply in a patient making an intuitive, global judgment). Indeed, several of the best-known tools are systematically interconnected. EQ-5D, for example, is used to estimate QALYs, and patient-reported outcomes are assessed with a ready-made "package" of measures (PROMIS – Patient-Reported Outcomes Measurement Information System). Since it is an open question to what extent the factors contributing to a state of health can be judged

independently, health assessment tools raise questions about the extent to which 'reductionistic' or more 'holistic' views of health states are the most appropriate, as well as about principles for weighting and combining factors.

Naturalism and normativism about health

It is an open question to what extent the tools are used for *normative* assessment. This is not just because they appear to be used for a large variety of purposes, but also because there has been a long and inconclusive discussion about whether health and disease are themselves normative concepts. This discussion involves a general divide between naturalists and normativists about health. On a naturalist account, health is defined in reference to functionality and thereby conceptually tied to the absence of pathology. The general gist of the naturalist view is that pathology, as the relevant counterpart to health, is seen as a failure of a part of an organism to make its normal and intended contribution to the species-typical functioning of the organism as a whole (Boorse, 1997). Consequently, this early instantiation of naturalism is sometimes referred to as the bio-statistical account of health. And while more recent developments within naturalism about health resists relying too heavily on statistical normality (Hausman, 2012), they still define health in reference to functional efficiency. Naturalism about health is conceptually narrow and value-neutral in the sense that it only takes on information about capacities of the organism

in question and thus leaves out broader issues of personal wellbeing. The ambition is to separate, at least conceptually, the assessment of health from broader normative issues relating to overall well-being, quality of life, or benefit (Hausman, 2012). Naturalism is roughly associated with a biomedical view of health, though it does not rule out a concern for psychological, environmental, or social influences as such.

Normativists about health, on the other hand, understand health precisely in terms of such normative ends. On the normativist account, health is defined in reference to wellbeing – how good a person's life is going – or the effective opportunity to achieve important goals in life (Engelhardt, 1974; Nordenfeldt, 1987). It follows that absence of health, according to normativists, is necessarily *bad* and that health assessments must be open to various sources of quality-of-life-related information. Normativists vary on how to determine, more particularly, the relevant goals. Some tie health to the realisation of objective human goals or functioning (Nordenfeldt, 1987; Venkatapuram, 2011), while others suggest a more subjectivist account of well-being. But health assessment, on all normativist accounts, must be sensitive to a broad spectrum of normative information regarding relevant life goals, subjective obstacles, and social conditions for any given person.

The evaluative basis of health

The assumptions on how to define health will have influence on health assessments. Regardless of what theoretical position one takes in this discussion, however, health assessment is almost always done with *regard* to the normative significance of the target state, i.e., its impact on wellbeing, prioritization concerns,

sdu.dk

#sdudk

rights and obligations etc. It is not least because health assessment tools operate at the interface between biomedical and other factual circumstances and norms and values that their uses raise philosophical questions. This points to the next area of assumptions underlying health assessment tools: what the evaluative basis of health is – or in other words, *what determines the value of health*. Most often, the value of health is simply generically and implicitly assumed in health assessment practice, but this is too hasty since questions concerning *how* and *why* health is valuable in part determines how it should be assessed.

The question of the value of health divides philosophers. Many believe that the value of health is tied to its impact on personal well-being (Broome et al., 2002; Brock, 2002). For them, health is valuable because it is *good* for people, and being unhealthy is *bad* because it makes people's life go worse. However, this is not the end of the discussion since philosophers are also divided on theories of well-being. Subjectivists about well-being believe subjective measures (e.g., positive affect and experiences, satisfaction of personal desires, preferences, or life projects) are what makes lives go well, whereas objectivists about well-being think that there are certain values that any human life must achieve. But others are dissatisfied with the well-being explanation and believe that the relevant value of health is its central role for opportunity or capability (Sen, 1992; Ram Tiktin, 2011; Daniels, 2008; Hausman, 2015). Where well-being seems in many

cases the intuitive explanation for why we value health, it could be argued that evaluating health in terms of opportunity or capability better captures the problems involved in many disabilities and mental disorders. For example, being born with impaired vision may not necessarily cause a significant decrease in life-satisfaction under the right social circumstances, but it will inevitably limit a person's social opportunities.

The issue of the value of health thus raises important philosophical questions about value-theory and wellbeing. But another, more particular, reason to be explicit about such assumptions for health assessments is that since different health states are difficult to compare directly, health professionals will often measure the *effects* of states of health rather than their states themselves. By what scale would one measure whether it is worse to suffer from an auto-immune disorder or a severe depression? Each of these states are invalidating and cause harm, but in different ways, and a ranking of which is worse seems implausible since they differ in essential respects from each other (this also relates to the issue of multidimensionality). In other words, there is no common scale on which to measure them. This is a well-known issue in the research (see Hausman, 2006; 2015), and it is a main reason why experts opt to measure the state of health through its effect on well-being or opportunity.

Measurement

This leads to the last area of assumptions, namely, how to measure the value of health *in terms of its effect on wellbeing or opportunity*. Surely, the assumptions made in this area often relate directly to assumptions about the definition and value of health – e.g., a health assessment tool measuring health by self-reported

life satisfaction would hardly make sense without the assumption that the value of health is its effect on subjective wellbeing – but it moreover drags along a number of assumptions on its own about how to appropriately measure the value of health. For example, there is a widespread assumption that the measure should be universal, so as to be applicable for inter-health-state comparisons. How realistic this is, depends on the degree to which the effect or health on wellbeing or opportunity is mediated by contextual factors. An equally widespread, and no less controversial, assumption is that subjective preferences can be trusted as valid indicators for evaluations of health states. This assumption is found not just in practices that directly target patients' perceptions but also underlying standard health economic measures like QALY and DALY, which, in spite of their quantitative more "objective" appearance, rely essentially on eliciting people's preference (for critical discussion of this, see Hausman, 2015).

Methods

Study design

The study design is a combination of qualitative, interview-based research with philosophical analysis. The interview data provides insights into the health professionals' perceptions of health assessment tools and their experiences using them in their own wordings. Subjecting the data to philosophical analysis enables us

to elaborately interpret the assumptions underlying the practical use of health assessment tools.

Recruitment

The qualitative study involved thirteen interviews, approximately twice as many were asked. The aim was not to gain an exhaustive overview but rather to glean insight into how professionals in the health assessment practice made use of the tools, and what theoretical conceptions laid behind this. The interviews can therefore be designated "elite" interviews. They were conducted in several rounds using snowball-sampling. The participants in the first round consisted of persons with a clear affiliation to the practice of health assessment. Throughout the following rounds, we asked the participants who might be relevant interview candidates, thereby making use of their inside knowledge of the practice. In selecting the participants, we explicitly chose not to target health economists but rather health professionals such as doctors, psychiatrists, and municipal workers, whose thoughts on the subject are much less documented.

Data collection

The interviews were semi-structured and conducted using an interview guide that allowed for improvisations. The guide was refined upon after an initial probing interview. In order not to prompt automatic responses, which the interviewees felt compelled to say but did not share, the questions were formulated in an indirect manner. The interviews were accompanied by an exploratory desktop study analysing the different ways in which assessment tools are integrated in health practices. This study was conducted using Google as the primary search engine because we

did not want to preclude any utilization of the instruments at the outset. A list of prominent generic tools, such as SF-36, SF-12, EQ-5D, Nottingham Health Profile etc., was compiled initially. Afterwards, searches were carried out using search queries that included both the full name and abbreviated names of tools followed by a specification of the region, e.g., "SF-36 Region Syddanmark". Using chain search, it was then decided whether the hits were to be included. The desktop study showed that health assessment tools are used in many different areas like diagnostic practices, improvement of health services, population studies etc. The study furthermore included a search of the University of Southern Denmark's research database and found that health assessment tools, especially SF-12 & SF-36, were widely used by researchers. The desktop study provided the impetus to further research the attitudes towards and applications of health assessment tools among health professionals since this topic has been far less documented than those of health economists.

Data analysis

While the data collection process was mainly bottom-up, the subsequent analysis and (especially) the interpretation was informed by concepts and distinctions from the philosophy of health, which helped us to identify and systematize points of particular relevance to our topic and research interest. We did neither expect, nor did we find the concepts to perfectly match the understand-

ings revealed by participants. On the contrary, hardly any of the participants expressed views that fitted neatly into any one category, and the study also gave reason to question the adequacy of some standard ways of framing discussions in philosophy of health. Still, the concepts did prove helpful in identifying different elements in the participants' complex understandings of health assessment.

Findings and analysis

Most participants were not familiar with the notion of health assessment tools as such but quite familiar with specific tools. One participant objected to calling them assessment tools at all, apparently because of their association with concerns for economic utility and use in cost-benefit-analyses. Some participants preferred to speak instead of "health-based well-being measurement", "patient-reported outcome measures" or something to that effect. This already indicated an understanding of health assessment as something essentially qualitative, value-oriented and subjectivity-involving. It also pointed to a strong interpretation of the comprehensiveness requirement (see Section 3), viz. an assumption that a genuine health assessment tool should measure the overall state of a person, including the impact of physiological health on subjective experience. This was confirmed by one of the most pervasive and striking of our findings: There seems to be a widespread commitment to a normativist conception of health, as health is seen as closely connected to and intertwined with well-being. Subjective wellbeing, i.e., "how one is doing" or "how one is feeling", is assumed to function as the measure of health, the aim that health care services seek to promote, and the criterion by which the effectiveness of interventions can be measured. A gen-

eral practitioner stated that: *The older you become in the medical profession, the better you understand the factors that ... have to do with the holistic rather than the mechanical problem. ... [W]hen you are inexperienced, you will simply think "this patient has pneumonia, which I must treat" and forget whether the patient is able to stand on her own two feet and take care of herself and what her quality of life is like.*

At medical school students are taught to examine and treat the body, but experience teaches that, when it comes to patients' health and well-being, the whole is greater than the sum of its parts. A researcher in the field of mental health promotion saw both health assessment and at least some of the tools as being predominantly about wellbeing: *We do not simply wish to measure the absence of symptoms but also to measure good mental health and wellbeing. ... I think that [WHO-5] mainly measures how well one is doing, the emotional dimension of mental health*. And a doctor at an emergency department spoke interchangeably about "health condition" and "quality of life": *[We assess] their health condition ... after a month, after six months, and if it develops. It's a study of older adults. Of whether they get a better or worse quality of life.* Still more bluntly, an associate professor of medicine who has worked with the development of EQ-5D said that: *Health in a narrow sense, that's whether you are sick or not, whether you have symptoms or there are signs of disease, but I*

take it more broadly. Health is positive and negative health, so it is physical and mental, and especially also wellbeing.

Despite these indications of normativism, it is unclear to what degree the practitioners' implicit and practically motivated conceptions of health match theoretical positions. It could also be argued that measuring conditions in terms of subjective quality of life is more of a pragmatic principle. Wellbeing can be used as a heuristic parameter that allows for comparability of qualitatively distinct phenomena. And while most of the participants seem to hold a more normative conception, a general practitioner also stated that: *Predominantly, our focus is whether there is something physically wrong ... which is what I am looking for. Once every other month ... I get the feeling that there's something which does not have to do with the patient's body. It has to do with something entirely different. It is not something that is important to us as such ... But I want to maintain that we need to know a lot more about a human being, about the whole, compared to today, because it tells us a lot more about what we have to do to help. It is rare for us in the emergency room to actively ask the patient: "what is your quality of life like right now?" I might ask them: "how is your quality of life? How are you really? What is your ordinary day like?", but I only do that when I am sure that something does not add up. You can't formalize that, you can't use that in a questionnaire, at least we can't since then it would become too fluffy and extremely hard to compare*.

Statements like this indicate that the biomedical notion of health remains the standard, and that the normativist perspective is an – albeit important – exception. Likewise, the participant who insisted on speaking of "health-based wellbeing measurement" seemed to implicitly acknowledge the distinction between health

sdu.dk

#sdudk

and wellbeing, and to conceive of the former in biomedical or functional terms, even though they insisted on their close relationship and the importance of measuring wellbeing.

This points to a view which can be more safely, and even more widely, attributed to the participants: They all seemed to endorse some kind of *contextualism* about health. They are contextualist in the *semantic* sense (Preyer & Peter, 2005) since they tend to attach different meanings to "health" depending on the context, sometimes using the term in a biomedical, sometimes in a more normativist sense. This reflects the fact that health professionals need the ability to shift between the somatic, mental, or holistic perspective according to the particular requirements of the patient and the situation. But the semantic contextualism often went hand in hand with an *ontological* contextualism, according to which health itself is a context-dependent state, and that it can only be adequately understood by taking the wider context of an apparent disorder into account. A doctor of psychiatry continually expressed both his commitment to contextualism and some reservations about the word "context" and the associations it may give rise to: *You always have to see these scores [the aggregated scores yielded by the use of health assessment tools] in a context … these scales and assessment tools, you can't take them out of their context. Although I don't like the word, it has to be seen in a context. You mustn't interpret such a number without taking into account the wider context.*

This again seems to point back to normativism, as the "wider context" is generally assumed to comprise more than the patient's physical condition. By assuming in this way that health should be assessed in a more comprehensive manner, the participants also seemed to accept some form of holism about health. They were not prepared to simply identify illnesses with organic lesions or biochemical processes, which has been seen as typical of modern hospital and laboratory medicine (Jewson, 2009), though they were used to take such a narrower view in practice and believed it to be the standard or professionally prescribed view.

The trend towards holism and contextualism can also be seen from the fact that the participants express reservations towards quantitative approaches of the kinds that health assessment tools exemplify. They repeatedly emphasize that the assessments must be supplemented by, e.g., disease-specific tools, consultations, individual screenings, or even self-made PROMs. The rationale seems to be that some facets of wellbeing and health are too complex to be captured solely through generic assessment. One participant remarked that: *You have to assess the whole, the entire human being (...) if you only consider the test in isolation, without placing it in its right context, then it has no value.*

Generic assessment, at its core, implies that there are certain universal – or at least regionally universal – traits to health and wellbeing that the instruments can systematize and extract readings of. As a project leader at a large Danish hospital remarked: *The more prominent [generic assessment] becomes, the clearer it also becomes that each individual is individual, and even though you have the same disease, you don't have the same symptoms or same perceptions, and you are not at the same point in life.* The

sdu.dk

#sdudk

assumption is that persons are affected functionally, cognitively, and emotionally in various ways and have diverse propensities for coping with certain physiological states. A person might be very susceptible to a condition and as a result experience a marked decrease in quality of life, while others will be less bothered by the same state. States of health, which might be very similar in terms of physical effects, affect everyone differently, which is bound to manifest itself in the readings of the tools. A professor at a health research department even said: *Well, I think that if you want to measure the same thing, then different tools might be exactly what you need in different cultures* ('cultures' here referring to different groups of patients and different contexts). To truly measure health and well-being, one would need different tools that are sensitive to the different ways that health and health-related conditions manifest themselves. The professor also found generic assessment to be too fixated on smaller details that might have no bearing on the individual's well-being. To assess whether these details are relevant or not, they thought it necessary to conduct qualitative, conversation-based studies.

The holistic and contextual views of health and well-being are accompanied by a belief that the health professional's attitude must likewise be holistic, and that the use of assessment tools should be qualified by a still more comprehensive and intuitive judgment. Several participants stressed that knowing how and when to apply generic assessment is an art in itself. A general

practitioner stressed the ability to take the entire individual into account and thought that this depended on: (…) *learning, knowledge, and insight. Experience. Those are the things we need to work on.*

Yet when it comes to the question of whom or what is ultimately best able to gauge the health and wellbeing of the patient, the participants almost overwhelmingly agreed that it must be the patient herself. As one researcher put it: *In principle, it is the patient that knows best about her quality of life.* There seems to be a strong tendency towards a more subjectivist understanding of health and wellbeing. It is also possible, however, to interpret the emphasis on the patient's knowledge and experience as more of an epistemic point – that is, the patient *knows* best, regardless of whether her health and wellbeing *are* themselves subjectively constituted states. In any case, the patient is considered the arbiter of her health and determining the patient's health profile is seen as matter of eliciting self-evaluations. The subjectivist tendency is not contradicted by the fact that, in the case of citizens suffering from dementia, it is suggested that PROMs should be administered to relatives. This reflects an assumption that if not the patient herself, then someone close to the patient and well acquainted with her personality and inner life should make the assessment.

However, this is not to say that the professionals perceive self-evaluation as unproblematic. A researcher found, for example, that in cases of self-assessment of physical activity, people over- or underestimate their level of activity significantly, making self-perceived evaluations of physical health quite unreliable in their experience (and so they seemed to implicitly acknowledge a difference between "real" (physical) and self-perceived health). Likewise, a project leader at a Danish hospital stated that: *What*

makes [the tools] work less well is that the patients can figure out what they are responding to, which means that they can change their answers in such a way that they don't have to talk about what is nagging them. So, there is a sort of schism in that it is up to the patient to fill out the form truthfully. I'm not saying that the patients are not truthful, but I also believe – or know, because I've interviewed many of them – that a lot of them actually avoid it. The project leader also noticed that it is the most resourceful patients who have the means to complete self-administered questionnaires, and that it creates a bias in the overall assessments.

These worries are connected to another significant trend. There is a strong awareness of the methodological limitations of the tools concerning reliability, validity, and applicability but much less awareness of questions of ontology and values. The health professionals do have views on this as well but tend to couch them in methodological language and to revert primarily to questions of psychometric reliability and validity. However, as pointed out in Section 4, views about the nature and value of health matter crucially to the choice and use of assessment practices. An example of this tendency to ignore ontology and focus on methodology is a doctor and professor, who at first dismissively remarked: *Well, first of all I can't define the word health. And I haven't read any particularly good definitions of it*. But then quickly went on to emphasize: *that content validity is crucial (...) and secondly, what one terms the psychometric measurement*

properties: how good or reliable are the measurements of this tool?

While this focus on practical methodology is understandable, given the health professionals' educational background and working conditions, the tendency to ignore or bracket ontology might seem problematic, in the light of recent studies suggesting that operationalizations of certain conceptions affect the resulting assessments fundamentally. For example, the EQ-5D has no social component and three out of its five dimensions concern physical health. The newly developed WALY, which grants social and mental wellbeing a much larger role, yields markedly different readings of well-being compared to the EQ-5D (Johnson et al., 2016). Neither the tools themselves nor their operationalizations are neutral regarding prioritization of values. Furthermore, it is an open question how far the state of health can be measured, if it is as contextual and subjectivity-involving as seems to be assumed by most practitioners. These sorts of questions fall by the wayside in favour of more practical concerns.

Despite their many reservations, the professionals generally find the tools to be valuable additions to their practice, though the understanding of their specific function and purpose varies according to professions and specializations. They are thought to be least reliable when applied singularly to individuals. A professor and doctor said very categorically: *You can make [generic health assessments] on a group level but never on an individual level.* Yet the tools are considered more valuable if the same patient can be assessed at different times, as this allows for intra-personal comparison and so can help register improvements or reductions in health. As a health service manager said: *Well, I use the tools on two levels. One concerns the citizen herself, for example, when*

sdu.dk

#sdudk

making preventive home visits, i.e., to measure changes in scores over time. (...) and if there is a change [in scores], you can address it. The tools are widely believed to be sufficiently reliable when applied to larger groups since the contextual and idiosyncratic differences that spell trouble in individual cases are then believed to be leveled out. A doctor and professor added that apart from being applied to patients and groups of patients, the tools are also used to assess treatments as well as to evaluate the work of health professionals and organizational units: *On the individual patient's level, the assessments can be used to motivate the patient to do something or assess if the treatment needs to be adjusted. They can also be used on a departmental level for assessing individual doctors. How does the doctor place in comparison to others, is there something they could do better? It can also concern the hospital as a whole, and, finally, societal levels, i.e. to assess what can be done on a broader scale.*

Somewhat paradoxically, however, it emerges that the tools are most often used for assessment of individual patients. This may not be all that surprising, given both the strong trend toward patient-centered health care mentioned at the outset and the particular roles of the health professionals interviewed. And the participants' skepticism towards using the tools for individual assessment was mitigated somewhat by their description of how they themselves tried to integrate them in a more comprehensive process also involving considered judgment, professional and

personal experience etc. However, the skepticism prevails, as there is little trust among the participants that sufficient care and caution is *generally* taken. One participant, a researcher, outrightly stated that: *Most of my colleagues probably don't use it [health assessment] as much, and if they do, they probably use it more uncritically*, and then went on to discuss situations where they personally had experienced misapplications of instruments among health professionals. One of the most pervasive and striking findings is that almost all participants seem to think that 'others', i.e., other professionals who use of the tools, tend to use them too uncritically. That is, they assume a 'naïve' understanding of the instruments as 'really measuring health', or of 'health being what the instruments measure', to be the norm in the medical profession.

This might seem paradoxical or simply as an expression of the typical self-confidence or superiority bias. It should be noted, however, that the participants pointed to different shortcomings and potentials of the tools and framed and characterized them quite differently. Hence it is not unlikely that most of them do have an experience of being fairly alone with their critical views, though our study indicates that this may be a superficial impression, and that many of the same insights and worries can be found even among different groups of health professionals. Moreover, because all the participants have, in virtue of our selection criteria, special knowledge, experience and interests related to generic health measurement, it is likely that they tend towards a more context-sensitive and holistic view of health, and are more reflective users of the tools, than their average colleagues who use the tools more occasionally and might take the results more at face value.

sdu.dk

#sdudk

Discussion

Our findings reveal wide agreement among health professionals on the following general points, (i) general optimism about the use and practical value of health assessment tools, (ii) a contexts-specific understanding of the definition of relevant health-assessment tools, (iii) strong commitment to some form of normativism about health, and (iv) that health assessment tools are inadequate to measure "health" as defined by this normativist conception. Together these points paint an intriguing picture of what we call *the normativist-naturalist puzzle* of health assessment practice. The puzzle covers the somewhat trilemmatic phenomenon that health professionals generally apply a normativist conception of health, find health assessment tools useful and valuable for their clinical practice, but believe that what the tools measure is basically not health proper but some proximal entity of a more naturalist kind. Below we elaborate the four points in turn.

Optimism about the usefulness and value of health assessment tools

It is a general trend in our findings that the participants' express optimism about the usefulness and value of health assessment tools. Although many also emphasize that health assessment tools should be used with care and only when well informed about their limitations, almost all respondents find their measures of practical

value and generally reliable. The participants accept that health assessment is a complex endeavour and that any standardised measure for that purpose will inevitably be vastly simplistic, and for that reason many admit that the health assessment tools they are familiar with have some problems with precision and validity, but our findings show that most find the common health assessment tools to be a useful if not necessary tool for clinical practice and research. For that reason, we conclude that health professionals are generally optimistic about the usefulness and practical value of health assessment tools. It is important to note, however, that while this optimism about the (ideal) use of the tools is widely accepted, participants are less optimistic about their actual use – that is, how far they are in fact used with sufficient care, how well standard medical training and thinking supports an optimal use of them etc.

Context-specific understanding and use of health-assessment tools

Most participants, when asked about their use of health assessment tools, express some uncertainty about the definition of health assessment tools and move on to give some more specific examples of some particular tools they are themselves familiar with. Many, moreover, note either explicitly or implicitly that what a health assessment tool *is* must depend on the context in which it is used. It is thus a general trend among the health professionals that they perceive of health assessment tools as a very broad and vaguely defined category. Our findings thus document a tendency to assume context-dependence on several different levels, ranging from the very understanding of health and wellbe-

sdu.dk

#sdudk

ing to the identification, definition and practical use of a specific health assessment tool.

One interesting observation in reference to this is that the subgroup of our participants engaged in both clinical practice and research draw a stark general distinction between the definition of health assessment tools for those different enterprises. The purpose, they believe, of health assessment tools for research is to provide generic measures of health to be used for comparative analysis in experimental trials and surveys, whereas in clinical practice the health assessment tools should serve as a proxy for measuring the patients' health and wellbeing, and these purposes to a large extent require quite different tools or at least a different use of the same tools.

Normativism about health

Our findings report a general commitment among participants to some form of normativism about health. Normativism understands health in reference to value and personal wellbeing and stands in contrast to naturalism about health, where health is defined value-neutrally in reference to functional capacities and absence of pathological abnormality (see section 4 above). The trend in our findings is that the participants invoke – often implicitly but occasionally even explicitly – a normativist conception of health tying health to expressions of the patients' general quality of life or how well the patients are doing rather than physiological

and functional performance. This normativist conception of health serves for many as a background assumption of health as a distinct entity or phenomenon with its own ontological status, which is what they believe health professionals should in principle be most concerned with and thus what health assessment tools ought, ideally, to capture.

While the assumption of a strong tie between health and wellbeing is quite pervasive, our data are inconclusive as to whether this expresses a commitment to full-scale normativism in the philosophical sense or merely a strong belief that the purpose of health assessment and interventions is to support wellbeing, and that they should be understood and used with this in mind. However, and to anticipate the coming point, the participants are well aware that health on this normativist account is not easily measured by existing health assessment tools (and might never be). In certain cases, some participants recall experiences where they get closest to actually examining patients' health in the sense of how they are actually doing, but interestingly, these experiences are reported to occur when leaving standardized tools aside and dedicating time and focus to dialogue and comprehensive conversation with and about the individual patient (see section 5 for specific examples).

Health assessment tools are inadequate measures of health

While there is wide-shared agreement on the general value and usefulness of health assessment tools, it is also an emergent trend in our analysis that the interviewed health professionals do not consider them adequate measures of health. Put differently, although health assessment tools measure something (of good use to clinicians and researchers), they do in fact not measure health, at

least according to the normativist conception applied by the participants themselves. What the participants believe that the health assessment tools do measure is unclear from our analysis, but the answer to this would likely be ambiguous given the trend to consider the definition of health assessment tools context specific. One apparent and plausible interpretation is that whereas health generally is understood as a normativist conception, the participants believe that health assessment tools are better equipped to capture naturalist properties in reference to functional capacities. Thus, however useful and valuable they are, they will inevitably serve as simplistic, and somewhat naturalist, proxies for health understood in a more holistic and normative sense.

Conclusion

Together, the above points ground the *normativist-naturalist puzzle* of health assessment practices. The puzzle helps explain the expansive development of different health assessment tools and the prevalence of their use in clinical practice. It also contributes to our understanding of why health professionals have ambivalent feelings towards these tools. On the one hand, the health assessment tools are considered generally useful as measures of particular expressions of functional capacity or the lack thereof, but on the other hand they do not in fact measure health in accordance with the conception of health widely applied by the health professionals themselves. This furthermore fits the general opinion that

health assessment tools cannot stand alone and ought in most cases to be supplemented by comprehensive qualitative assessments of patients' health and wellbeing well.

In order to examine more closely the extent and ramifications of the normativist-naturalist puzzle, a more focused and perhaps more theory-driven interview study might be needed. On the other hand, a possible advantage of the more explorative approach of our study is that the participants brought up the issues spontaneously, and so are more likely to have revealed the assumptions that are implicit in their use and understanding of health assessment tools, and which might differ from the outcome of more abstract and detached thinking about the nature of health.

Our findings point to both theoretical and practical implications. On the theoretical part, the normativist-naturalist puzzle should not just be taken to show that health professionals are confused or apply different understandings in different contexts. It also demonstrates the complexity of the issue, and the possibility to simultaneously entertain – and act on – views that otherwise might seem difficult to reconcile. For example, the observation that the same health state (narrowly conceived) may influence a patients' wellbeing very differently, depending on the context, may seem to express a normativist commitment; this did indeed seem to be how the participants intended it. But it is no less compatible with naturalism, inasmuch as it posits a contingent link between health (narrowly conceived) and wellbeing.

In terms of more practical implications, our findings suggest, firstly, that health professionals view health assessment tools not as independent of other sources of information about a patients' health, but rather as an integral part of a more comprehensive assessment practice. Second, that health assessments tools

are used carefully to ensure both that particular tools are used for the kinds of tasks they are most apt for, and that they are put to use in awareness of their limitations. Finally, while admitting that the vast variety of different tools is in itself not unproblematic, our findings may be taken to imply that there is a need to further develop tools that (like WALY) take non-physical factors sufficiently into account, provided that health professionals really want tools that measure health in a more comprehensive and wellbeing-involving sense. The alternative might be to keep the tools fairly simple and focused on physical and functional factors, but instead ensure that the readings are balanced against results obtained by other means, for example clinical judgment or doctor-patient dialogue.

References

Boorse, C. (1997). A Rebuttal on Health. In Humber, J. M. & Almeder, R. F. (eds.), *What is Disease? Biomedical Ethics Review*, Totowa, NJ: Humana Press: 3-134.

Borrell-Carrió, F., Suchman, A. L., & Epstein, R. M. (2004). The biopsychosocial model 25 years later: principles, practice, and scientific inquiry. *Annals of family medicine*, 2(6), 576–582. https://doi.org/10.1370/afm.245

Brock, D. (2002). The Separability of Health and Well-Being. *Summary measures of population health: concepts, ethics, measurement and applications*, 115.

Broome, J., Murray, C., Salomon, J., Mathers, C., & Lopez, A. (2002). Measuring the burden of disease by aggregating well-being. *Summary measures of population health: concepts, ethics, measurement and applications*. Geneva: World Health Organization: 91-113.

Castro, E. M., Regenmortel, T.v., Vanhaecht, K., Sermeus, W., Hecke, A.v. (2016). Patient empowerment, patient participation and patient-centeredness in hospital care: A concept analysis based on a literature review. *Patient Education and Counseling*, 99(12) 1923-1939.

Cavel, H. (2016). *Phenomenology of Illness*. Oxford: Oxford University Press.

Daniels, N. (2008). *Just Health: Meeting Health Needs Fairly*. Cambridge, UK: Cambridge University Press.

Engel, G. L. (1977). The Need for a New Medical Model. *Science* 196 (4286), 129-136.

Engelhardt, H. T. Jr. (1974). The Disease of Masturbation: Values and The Concept of Disease. *Bulletin of the History of Medicine* 48(2): 234-248.

EU Commission. (2019). *Defining Value in "Value-Based Health Care". Report of the Expert Panel on Effective Ways on Investing in Health*. European Union: Luxembourg.

Griffin, J. (1986). *Well-Being: Its Meaning, Measurement and Moral Importance*. Oxford: Oxford University Press.

Hausman, D. (2006). Valuing Health. *Philosophy and Public Affairs* 34(3): 246-274.

Hausman, D. (2012). Health, Naturalism, and Functional Efficiency. *Philosophy of Science* 79(4): 519-541.

Hausman, D. (2015). *Valuing Health: Well-Being, Freedom, and Suffering*. Oxford: Oxford University Press.

Hernandez, R., Bassett, S. M., Boughton, S. W., Schuette, S. A., Shiu, E. W., & Moskowitz, J. T. (2018). Psychological Well-Being and Physical Health: Associations, Mechanisms, and Future Directions. *Emotion Review* 10(1), 18-29. https://doi.org/10.1177/1754073917697824

Jewson N.D. (2009). The disappearance of the sick-man from medical cosmology, 1770-1870. *International Journal of Epidemiology*. 2009 Jun;38(3):622-33. doi: 10.1093/ije/dyp180.

Johnson, R., Jenkinson, D., Stinton, C., Taylor-Phillips, S., Madan, J., Stewart-Brown, S., & Clarke, A. (2016). Where's WALY? A proof of concept study of the 'wellbeing adjusted life year' using secondary analysis of cross-sectional survey data. *Health and Quality of Life Outcomes*, 14, Article 126.

Miller, H. D. (2009). From Volume to Value: Better Ways to Pay for Health Care. *Health Affairs* 28:5, 1418-1428.

Nordenfeldt, L. (1987). *On the Nature of Health: An Action-Theoretic Approach*. Dordrecth: Holland.

Ohrnberger, J., Fichera, E, & Sutton, M. (2017). The relationship between physical and mental health: A mediation analysis. *Social Science & Medicine* 195, 42-49.

Parfit, D. (1984). *Reasons and Persons*. Oxford: Oxford University Press.

Preyer, G. & Peter, G. (eds.). (2005). *Contextualism in Philosophy*. Oxford: Clarendon.

Ram-Tiktin, E. (2011). A Decent Minimum for Everyone as a Sufficiency of Basic Human Functional Capabilities. *American Journal of Bioethics* 11(7): 24-25.

Sen, A. (1992). *Inequality Re-examined*. Oxford: Oxford University Press.

Smith, R.C., Fortin, A.H., Dwamena, F. & Frankel, R.M. (2013). An evidence-based patient-centered method makes the biopsychosocial model scientific. *Patient Education and Counseling* 91(3), 265-270.

Solomon, M. (2015). *Making Medical Knowledge*. Oxford: Oxford University Press.

Sumner, L. W. (1996). *Welfare, Happiness, and Ethics*. Oxford: Clarendon Press.

Venkatapuram, S. (2011). *Health Justice: An Argument from The Capabilities Approach*. Cambridge: Polity Press.

With, J. M. & Jensen, S. N. (2018). Værdibaseret sundhed i Danmark. Anbefalinger for vejen frem. *Danske Regioner*, https://www.regioner.dk/media/11353/anbefalinger-for-det-fremtidige-arbejde-med-vaerdibaseret-sundhed.pdf.

3.4 Challenges of and further reflections on the study

The time since submission has given rise to some reflections on certain issues of the article, which I briefly address in this subsection before treating the philosophical aspects of the operationalization of health and disease in the following chapter.

Firstly, a concession. In the effort to encapsulate as multi-faceted a trend as health assessment, the definition winds up somewhat unclear. The article reads: "Without committing to any precise and exhaustive definition, we shall understand health assessment tools as *a generic measurement of the effect of health on assessments of health-related needs in individuals or groups, comparison of treatments and other health initiatives"* (p. 37). A clearer definition might read: "A health assessment tool is an instrument for generic measurement of the health status of an individual. It can be used to monitor health status over time, to compare health status within and between groups, and to measure the effect and quality of treatment and healthcare intervention", which encapsulates in a more lucid way the object of study.[3]

Secondly, it might be objected that the latent tension in the instruments between the measurement of functional indicators and the much more elusive and subjective experience of well-being does not hold for all instruments. Some instruments are seemingly more pure measures of well-being like the WHO-5; accordingly, the analysis misses the mark. However, in these cases it becomes an open question to what degree measures of well-being are generic rather than specific instruments. They are rarely multi-dimensional as generic instruments are and do not purport to measure the overall state of health but more specifically well-being. For this reason, they do not seem to be a relevant counter-example to the tendency described above.

---

[3] I owe this clarification to Anna Paldam Folker, who very generously acted as opponent at the pre-defence of this project.

Thirdly and lastly, due to the conflicting aims declared in the article, which in turn is described as a study of the philosophical assumptions of health assessment instruments *per se* and the assumptions underlying the application of the tools among health professionals, the purpose might seem unclear.[4] To put it explicitly, the purpose of the article – and the project – is to investigate philosophical assumptions about health and disease behind generic assessment *as such*. Seeing as this, to a certain extent, is influenced by the applications of the instruments, the article also analyses these utilizations. This raises other questions, however, such as to what extent the results can be generalized across several professions, whether all responders make the same philosophical assumptions etc. These are valid concerns, but the purpose of the article was not an exhaustive overview of the entire practice but rather to distil substantial assumptions underlying the practice, which glean insight into the implicit philosophical rationale. Moreover, among the responders were also developers of the instruments who must be assumed to have special insight into their intended workings.

[4] Anna Paldam Folker also called attention to this unclarity in the article.

4. Operationalizing health and disease

4.1 Instruments and "Denkstile" – Koyré & Fleck

Throughout the first chapters of the dissertations, I have maintained that the methods and ways of operationalizing health and disease within the generic health assessment practice are neither epistemologically nor ontologically neutral. On the contrary, they affect both conceptions of health and disease and the readings that the instruments deliver in fundamental ways. To reiterate, the instrument EQ-5D has three items pertaining to physical health and two mental health. This weighting presupposes a certain understanding of health and disease that favours physical dimensions and downplays social aspects and in virtue thereof delivers certain readings, which show physical conditions to have a larger effect on well-being. This is in contrast to other types of measurements like the WALY, which show social dimensions to have a larger effect on well-being than physical (Birkjær et al., 2020). It would, however, be erroneous to assume that disputes between ways of measurement can be adjudicated and the "true" measure that delivers the most objective readings be found. Rather, all *operationalizations* harbour substantial assumptions that influence the evidence produced.

In stating this, I am emphasizing a point from the French epistemologist Koyré that the practice of science ultimately grounds upon certain foundational theoretical assumptions and epistemological attitudes. Koyré treats this issue in the exposition of the transition from *the world of more-or-less to the universe of precision* ("du monde de à-peu-près à l'univers de la precision"),

sdu.dk

#sdudk

as he coins it, during the scientific revolution of the 16th and 17th century (Koyré, 1953, 1971). Why is it, Koyré asks, that it took approximately 400 years from the invention of the first spectacles to the development of the telescope and microscope (Koyré, 1998, p. 139)? Though the material conditions were not great, the technological presuppositions were present. A rudimentary telescope or pair of binoculars can be achieved merely by placing one lens in front of another, and it therefore seems unlikely that the reason was a lack of technological competency.

This did not happen, however, because people of the late Middle Ages and the Renaissance lacked the *idea*, according to Koyré. For them, the pair of glasses had a clear and practical purpose: to enhance poor eyesight and aid in viewing objects which, all other things being equal, would be viewable upon closer inspection. The pair of glasses were, differently put, an *extension* of the senses. The telescope, on the other hand, served the different purpose of viewing objects, which lie *beyond* human faculties. The idea needed to be present for Galilei to turn the first rudimentary telescope, which contained more finely honed lenses and adequately calculated angles of refractions, towards the skies to see things that otherwise could not be seen. For Koyré, this gives rise to the distinction between a *tool* and an *instrument*. A tool, as stated above, serves a practical purpose, it enhances "the human limbs and senses", whereas the instrument is "a materialization of

thought" (Koyré, 1998, p. 141), it is manufactured because of and via theory, though it afterwards may serve practical purposes.

The distinction can be exemplified further through the popularization and refinement of "chronometers", Koyré argues, which also roughly took place during the 15th and 16th centuries. Beforehand, watches were rare and only gave imprecise readings of time, which reflected a view of life that was less preoccupied with the exact pinpointing of time. Time and the experience thereof were regulated by the seasons, the break of day and dawn, and the occasional chime of the church bells. It was the world of more-and-less, as Koyré terms it. During this time, pocket watches gradually became more popular, but the definitive change happened with the scientific chronometers, the pendulum and spiral watches, respectively, that delivered exact readings of time. These instruments themselves were predicated on the theoretical tendency towards the *mathematization of time,* the universe of precision:

> " (…) 'the book of nature is written in geometrical character' declared Galileo; this implies that in order to reach its goal modern science is bound to replace the system of flexible and semi-qualitative concepts of the Aristotelian science by a system of rigid and strictly quantitative ones. Which means that modern science constitutes itself in substituting for the qualitative or, more exactly, for the *mixed* world of common-sense (and Aristotelian science) an Archimedian world of geometry made real; or – which is exactly the same thing – in substituting for the world of the more-or-less of our daily life a universe of measurement and precision. Indeed this substitution implies automatically the exclusion from – or the relativation in – this universe of every-

sdu.dk

#sdudk

> thing that cannot be subjected to exact measurement (…) Quality, indeed, is repugnant to the precision of measure" (Koyré, 1953, p. 223).

This quantification diffused into the rest of society and imposed a different regime of ordering life, for soon enough the scientific watches also became the watches of everyday life.

In the case of health assessment, there is no need to be as hyperbolic, for the empirical study of the first article demonstrates that quantitative measurements do not rule out qualitative. Yet, it is tempting to interpret the "paradigm shift" announced with the shift from the medicine of yesterday to evidence-based medicine (Guyatt et al., 1992), which generic health assessment is spiritually related to, in the same vein. That is, as a transition of medical theory and practice from an imprecise *conjectural art* (Ginzburg, 1999, p. 88), which functioned through abductive reasonings on idiographic grounds, to a *calculable science*, which strives towards precise, nomothetic knowledge of mechanisms and effects – towards precise quantifications of qualitative phenomena.

It is through technological tools and instruments that medicine achieves this purpose. The stethoscope, for example, allows the health professional to listen to internal sounds of the body and thereby enhances the natural senses, who, before the invention of this tool, had to put their ear to the patient's body to assess the beatings of the heart. An IQ-test, on the other hand, embodies a

host of theoretical and normative assumptions. Not only is the IQ-test predicated on an understanding of intelligence as abstract pattern recognition and problem solving measured on a quantitative scale, but it even posits standards about normal and abnormal values. The facts and evidence that the IQ-test elicits is predicated on strong theoretical assumptions, which the legitimacy of its results is contingent upon.

Though it might be to state the obvious, the facts that these instruments produce are not simply facts. Poincaré once stated that: "if a research worker had infinite time at his disposal, it would suffice to tell him: Look, but look well!", but there is, as Fleck holds, no neutral observation (Fleck, 1986b, p. 59). Behind the observation lies a host of presuppositions, a tradition, a theoretical outlook, a scientific culture, the worldview and experiences of the researcher etc. There is a whole sociology of knowledge production that cultivate certain cultures of thinking (Fleck, 1980, 1986a), which Fleck coins "Denkstile", *styles of thought*, that are always implicated in the practice of science.

4.2 Four tendencies

If generic health measurements are instruments that embody certain ideas and theoretical presuppositions, and if the generic health assessment practice is contingent upon a certain style of thought, which theoretical assumptions and styles of thought are then operationalized to measure health and disease? What is meant by *operationalization* in this context is essentially the process whereby theoretical or abstract assumptions and concepts are converted to measurable properties on a questionnaire. Below, four important features of this operationalization are thematized,

sdu.dk

#sdudk

and to a certain extent also problematized, although the purpose here is not to deliver an extensive critique.

4.2.1 Quantifying qualitative conditions

A measurement makes a host of related phenomena conform to a standard, which structures and shapes the measured phenomena on the same scale to enable gradations and comparisons between them. Unlike measuring the magnitude of alike phenomena such as temperature in terms of Celsius or sound volume in terms of decibel, this is not immediately possible with different states of health. There is not necessarily a natural basis of comparison between a broken leg and an anxiety disorder because they are fundamentally different conditions, which affect the afflicted in various ways. One of the most common denominators would perhaps be the pain that the conditions inflict, but there is a difference between mental and physical anguish, and not all conditions cause pain. Therefore, states of health are measured in terms of their effects on well-being, which is posited as the common denominator for two reasons. Firstly, because it is important to promote well-being since it – allegedly – constitutes the value of health, and secondly, in measuring well-being an insight can be gleaned into the severity of health conditions, which on their own terms are hard to compare.

It is difficult to conceive of a person with a high degree of well-being without also assuming that she possesses a certain de-

gree of health. To imagine a clinically depressed person with a deeply satisfying and fulfilling life seems counterintuitive. Aristotle formulates this well in the thought that there are "no happy people on the rack" (Aristotle, 1995, 1153b), and furthermore, that health is a prerequisite for the good life. Evidently, there is a certain connection between these phenomena, which speaks to the fact that the severity health conditions is measurable through well-being – especially in matters of mental health. However, depending on the definition, health without well-being is possible. Though these cases might be rare, it is not impossible for a person to be physically, mentally, and socially well-functioning and still fundamentally unhappy, which indicates that it is not unproblematic to infer well-being from the often quite functionally founded items on the questionnaires. Indeed, readings offer no insight into the etiology of the measured levels of health and well-being of conditions, and what the evaluation is influenced by. There is an epistemological challenge here in that individual items on the questionnaires often concern functional indicators – here understood broadly as measurements of levels of performance, which need not solely concern physical aspects but also can refer to mental and social – while the aggregated scores amount to the overall state of health and well-being.

Though identical terms are used, several understandings of well-being are actually at play in generic assessment. The terms (good) health, well-being, and health-related quality of life are often used interchangeably, but there is, as previously stated, no theoretical consensus about the nature of these phenomena. The overall state of physical, mental, and social well-being that the instruments measure seems at first glance to invoke a more objectivist understanding of well-being as a sort of well-functioning.

sdu.dk

#sdudk

The Nottingham Health Profile (NHP), for example, has dimensions concerning energy levels, pain, emotional reactions, sleep, social isolation, and physical abilities, which together amount to the overall state of well-being (Hunt et al., 1981). In these cases, the instruments seem to echo an understanding of health that already Canguilhem described: "Health, taken absolutely, is a normative concept defining an ideal type of organic structure and behavior; in this sense it is a pleonasm to speak of good health because health is organic well-being" (Canguilhem, 1991, p. 137).

However, one should be cautious to draw this conclusion, for it is *self-assessed* and *self-reported* HRQoL, which seemingly drive the instruments toward more subjectivist understandings. At times, the instruments contain questions that specifically address the evaluated well-being of the responders, i.e., how well they judge themselves to be doing, and this echoes understandings of well-being as satisfaction of subjective preferences (Griffin, 1988). The instruments, therefore, harbor substantial, conflicting assumptions about what health and HRQoL are.

Several assumptions influence the quantification of the qualitative phenomena of health and well-being. A strong enough connection is assumed to dictate the relation between self-reported, health-related quality of life and the nature and severity of "actual" conditions of health that the latter can be inferred from a measurement of the former. It is assumed that an assessment of the overall state of health and well-being can be inferred from the

specific items of the questionnaires, which often focus on functional dimensions. Finally, the instruments are predicated on a sufficient level of theorization of important aspects of health and the assumption that these are adequately defined in the items of the questionnaires.

4.2.2 Objectivizing subjective evaluations

At first glance, the instruments appear to be multidimensional. However, an equally strong case could be made for the fact that they are *unidimensional* since they solely measure the judgments of the responders. The readings hinge entirely on the (self)evaluations and elicited preferences pertaining to health conditions of the responders. From this, an inference to states of health in themselves is made – so it seems when readings are used in the context of research on, e.g., intervention effectiveness. The empirical study also confirmed a tendency among the health professionals to assume that, in principle, the patient could make the most adequate judgments about their own conditions of health, and that health generally consisted in a form of subjective well-being. Although it is an open question, if health is of a more subjective character, whether and to what degree objective measurements of health conditions "in themselves" can be made.

There are several unresolved questions concerning the objectivization of subjective evaluations. Certain philosophers like Gadamer hold that the thematization and measurement of health runs counter to health as such:

> "Messungen, ihre Maßstäbe und die Maßverfahren bedienen sich einer Konvention, in deren Gefolge wir an die Dinge herantreten und sie der Messung unterwerfen. Aber es gibt

sdu.dk

#sdudk

> auch ein natürliches Maß, das die Dinge in sich selbst haben. Wenn man Gesundheit in Wahrheit nicht messen kann, so eben deswegen, weil sie ein Zustand der inneren Angemessenheit und der Übereinstimmung mit sich selbst ist, die man nicht durch eine andere Kontrolle überbieten kann. Deshalb bleibt die Frage an den Patienten sinnvoll, ob er sich krank fühlt", later adding, "Aber es wäre fast lächerlich, wenn einer einen fragte: 'Fühlen Sie sich gesund?' Gesundheit ist eben überhaupt nicht ein Sich-Fühlen, sondern ist Da-sein, In-der-Welt-Sein, Mit-den-Menschen-Sein, von den eigenen Aufgaben des Lebens tätig oder freudig erfüllt sein" (Gadamer, 1994, pp. 138-139 & 144).[5]

For Gadamer, health is interpreted as a phenomenological *state of flow*, which, because it is inherently subjective, is unmeasurable

[5] "Measurements and the criteria and procedures by which we arrive at them depend on conventions. It is in light of these that we approach the object of enquiry and subject it to measurement. But there is also a natural form of 'measure' which things bear within themselves. If health really cannot be measured, it is because it is a condition of inner accord, of harmony with oneself that cannot be overridden by other, external forms of control. It is for this reason that it still remains meaningful to ask the patient whether he or she *feels* ill (…) but that it would be border on the absurd to ask someone 'do you feel healthy?' Health is not a condition that one introspectively feels in oneself. Rather, it is a condition of being involved, of being in the world, of being together with one's fellow human beings, of active and rewarding engagement in one's everyday tasks" (Gadamer, 1996, pp. 107-108 & 113).

and runs the danger of being broken when it is constantly evaluated. Although there is a case to be made that the preoccupation with health and the measurement thereof in itself can become unhealthy, as problems such as overdiagnosis (Brodersen et al., 2018; Green et al., 2020), medicalization (Conrad, 2007) etc. demonstrate, Gadamer overstates his case since it becomes the expression of a too one-sided subjectivism.

The relation of the self to the self and its body is an ambiguous matter. On the one hand, it is a privileged view. No one can know exactly how I experience myself and the world, therefore, the self-relation contains a unique perspective of one's bodily and mental workings and whether these accord with the goals of the person's life. On the other hand, self-knowledge is the hardest form of knowledge, as the Socratic dictum goes. Individuals in general are not infallible epistemological subjects, and objective evaluations of conditions require demanding insights. In the evaluations, the instruments also objectivize the idiosyncratic judgments of the responders. The problems with this extend beyond psychometrical issues, and often issues of adaptation, "false consciousness", biases, and so on muddy the picture (Guillemin et al., 2019). For example, empirical studies show that people are notoriously bad at judging what it is like to have a physical disability, which is consistently judged to have an extreme impact on well-being although persons with these forms of disabilities adapt to their circumstances and have normal degrees of well-being (Albrecht & Devlieger, 1999). The instruments here risk assessing the cultural and aesthetic prejudices rather than the conditions themselves. To what extent instruments assess conditions of health and well-being or rather subjective perceptions reached by questionable lines of thought is therefore debatable.

sdu.dk

#sdudk

A further trend is the implicit tendency towards *psychologizations*, which in this context means to posit and focus on experience as a crucial measure and aspect of health, i.e., the experience of functional disturbances, of lacking mobility, of feeling down etc. If and to what degree psychologizations are an issue depend naturally on the object and purpose of measurements. If the purpose is to measure the experience of subjective HRQoL, applying the instruments, although still vulnerable to the epistemological issues mentioned above, is more unproblematic. Often, however, the purpose is to measure the conditions in themselves, and this inference entails substantial assumptions.

A distinction is often drawn between illness and disease (Carel, 2016), i.e., the experience of illness and the bodily state of disease. It is entirely possible to feel sick and be healthy, as in cases of hypochondria, or to feel healthy and be sick, as in asymptomatic diseases such as cancer in the early stages. This puts the relation between experiences of health and disease and the conditions as such into question – even the nature of and relation between embodiment and cognition. Indeed, whether the patient knows best seemingly depends on whether their own body and state of being are transparent to them. I return to this problem in chapter 6, but cite Kierkegaard here who problematizes namely this assumption:

”I Almindelighed antager man, at et Menneske, naar han ikke selv siger, at han er syg, er rask, end sige, naar han selv siger, at han er rask. Lægen derimod betragter Sygdommen anderledes. Og hvorfor? Fordi Lægen har en bestemt og udviklet Forestilling om, hvad det er at være sund, og efter denne prøver han et Menneskes Tilstand. Lægen veed, at som der er en Sygdom, der kun er Indbildning, saaledes ogsaa en Sundhed; han anvender derfor i sidste Tilfælde først Midler, for at faae Sygdommen til at blive aabenbar. Overhovedet har Lægen, just fordi han er Lægen (den Indsigtsfulde) ikke ubetinget Tiltro til Menneskets eget Udsagn om sit Befindende. Hvis det var Tilfældet, at hvad ethvert Menneske sagde om sit Befindende, om han er sund eller syg, om hvor han lider o. s. v., var ubetinget til at stole paa, saa var det at være Læge en indbildning”[6] (Kierkegaard, 2006, p. 139).

4.2.3 Static assessments contra dynamic states

The readings of the instruments are snapshots. They reflect the respondents’ momentary evaluations of their state of health and well-being. Isolated readings can be fallacious and misleading,

[6] “As a rule, a person is considered to be healthy when he himself does not say that he is sick, not to mention when he himself says that he is well. But the physician has a different view of sickness. Why? Because the physician has a defined and developed conception of what it is to be healthy and ascertains a man's condition accordingly. The physician knows that just as there is merely imaginary sickness there is also merely imaginary health, and in the latter case he first takes measures to disclose the sickness. Generally speaking, the physician, precisely because he is a physician (well informed), does not have complete confidence in what a person says about his condition. If everyone's statement about his condition, that he is healthy or sick, were completely reliable, to be a physician would be a delusion” (Kierkegaard, 1980, p. 23).

sdu.dk

#sdudk

the same way that a single blood test may be, but this can to a certain extent be mitigated through comparative, longitudinal studies. That is, a series of snapshots where the relative gain or loss in self-evaluated health between readings is most important; whether improvements or deteriorations have taken place. Despite these measures, however, it could be argued that the momentary and static evaluations conflict with the way that health and disease unfold in reality. Health and disease are not fixed states but fundamentally *temporal processes*.

This holds both for the physiological disease and experienced illness. Pathological bodily processes have their courses from a point of onset to early symptoms, peak of the disease and either to remission, stabilization, or death. Experienced illness has its own peculiar phenomenological structure. It unfolds both as a "stream of ebbs and flows", that is, as constantly shifting states of suffering, relief, hope, despair etc. (Toombs, 1990). As such, it does not consist in a series of points but in a continuum of retained memories, experiences of the present, and future expectations, known as the difference between retention, the immediate present, and protention in Husserl's analysis of time (Husserl, 2013). The bodily and experienced dimensions do not work in isolation but as temporally interwoven. This is the case for simple as well as more complex cases like chronic illnesses that can have extended periods or short bursts of being asymptomatic or experiencing suffering and uncertainty etc.

It therefore seems, despite the attempt to mitigate the issues, that there is a structural asymmetry between the static readings and the dynamic processes of health. Can a reading pre-surgery, immediately post-surgery and after convalescence, for example, capture the way that the health condition unfolds temporally or "merely" the momentary snap judgment of the responder? Intuitively, it seems that something is lost in translation when the reading is abstracted from the lived experience.

4.2.4 Standardization contra individual variability

Generic instruments must contain a host of invariant factors common to all conditions to measure the overall state of health on a standardized basis. It is predicated on the assumption that, although individual variation exists, health conditions share certain common features. It is in virtue thereof that the instruments rely on substantial assumptions about the nature of health. The requirement for comprehension naturally steers the instruments towards more holistic models, and the influence from WHO's definition delivers the understanding of health as having three dimensions, namely physical, mental, and social. Moreover, it implies certain choices regarding the importance of the different dimensions including the weighting of the items, i.e., how much they count in the aggregated score. Lastly, it must determine which factors offer insights into these more general dimensions, e.g., that the ability to climb stairs is a reliable indication of physical health.

A sort of essentialism is at play when health through its countless instantiations is assumed to have invariant features consisting of, for example, the absence of negative emotions, ability to climb stairs and so on. The instruments are to a certain extent

normative – although not in the technical sense described above – in that they operationalize an ideal understanding of health that consists in fixed levels of performance of various bodily and mental functions. But, to reiterate, there is no consensus regarding notions of health or disease. To cite Canguilhem, it could be argued that:

> "What characterizes health is a capacity to tolerate variations in norms on which only the stability of situations and milieus – seemingly guaranteed yet in fact always necessarily precarious – confers a deceptive value of definitive normalcy. Man is truly healthy only when he is capable of several norms, when he is more than normal. The measure of health is a certain capacity to overcome organic crises and to establish a new physiological order, different from the old" (Canguilhem, 2008b, p. 132).

In other words, health consists in the individual's ability to establish new ways of life when others become unviable. Therefore, health cannot be fixated in certain performance levels of certain capacities but is dependent on the individual's adaptability to certain conditions. Such a conception would be decidedly more difficult to operationalize.

The practice is predicated on somewhat of a paradox. On the one hand, there is an explicit recognition of individual varia-

bility as the empirical study indicated – that conditions vary between people and affect their overall HRQoL in different ways – and, on the other, there is a need for standardization that allows for comparisons between conditions, demographics etc. If individuals and their conditions are complex and variable, and the instruments are static and fixed, then it is a matter of debate whether generic assessment is able to capture all or even the most relevant aspects of the individual's health. The answer, most likely, would be *no* since even generic instruments are not validated for all demographics, and when to apply which instrument is up to the expertise of practitioners and researchers. This concession, however, seemingly restricts the scope of generic assessment that strives to universalize standardized measures. This points to a paradox that characterizes the practice: to gain inter-comparable readings, individual factors must be levelled out, yet the individual's state of being is precisely what is elicited.

4.3 Can generic instruments measure health?

If the above analysis stands to reason, can generic instruments then measure health? Perhaps this is the wrong way to frame the question. Instead of asking about the measurability of health – a specific conceptualization of health and well-being *can* be measured as the instruments indicate – perhaps the question is rather what the measurements tell us about which type of phenomena and with what level of certainty. On the one hand, if the purpose of the instruments is restricted to the measurement of subjective evaluations, which are combined with other forms of investigation, the greater the reliability of the measurements becomes, although these assessments still have their issues. If, on the other hand, the instruments are thought to deliver objective readings of

sdu.dk

#sdudk

health conditions in themselves, the readings become more imprecise and uncertain, and it is questionable whether they actually capture the desideratum. Whether and to what degree this is an issue depends on the purpose and utilization of the results.

Specific instruments deliver specific results, however, the larger the scope of the instruments, the fuzzier the results become. Health as such is something more elusive than mobility or mood, and this is most likely the reason why the rationale of the instruments exhibits somewhat contradictory tendencies. The instruments are torn between measuring functional indicators or subjective well-being, between the multi- and unidimensional, between objectivizing and subjectivizing or individualizing and universalizing approaches, between static readings and dynamic conditions. However, when the instruments contain unclear conceptualizations that make the assessment criteria more abstract, it also reflects inherent conflicts or latent issues within philosophy of health, I would argue. And, it therefore seems, a clearer picture of the nature of health and diseases is needed to provide a more adequate way to measure and assess health.

4.4 Three themes for further investigation

Like the generic assessment practice, philosophy of health is also torn but in a deadlock between normativism and naturalism. Certain themes that came to light during the empirical study and interpretations thereof, e.g., the dynamicity and individuality of

health conditions, do not figure to a significant extent in the state of the art. Instead of arguing that this is caused by lack of coherence between practice and theory or insufficient theorizing, I take inspiration from these findings. In the theoretical work that follows, I draw out and explore three themes that have emerged during the preceding analysis and let them square off with established branches of philosophy of health. Listed in the order they appear, these are:

1. An understanding of health and disease as dynamic and processual states that blend naturalistic elements of functionality with normativistic of organismic norms. This is brought to bear on the traditional discussion of concepts of health and disease in chapter 5.
2. A phenomenological understanding of health and illness that is less psychologizing and more dynamic than the current notable theories of the phenomenology of illness. This is carried out in the 6th chapter.
3. Finally, an attempt to define and stake out what it means for health and disease to be phenomena of great individual variability and to pave the way for an integrative conception of health and disease. In chapter 7, this is related to current trends within medicine towards personalized and individualized medicine, which insufficiently conceptualize what "medical individualism", as I term it, entails.

sdu.dk

#sdudk

5. A dynamic and processual theory

5.1 The deadlock of conceptual analysis

Since the 1960's, a lively and still ongoing discussion has taken place about the correct definition of health and disease that gradually crystallized into two archetypical theories, namely normativism and naturalism, which occasionally are combined to form hybrid theories (Hofmann, 2002; Wakefield, 1992). The reason why this discussion stays relevant is the fact that several fields rely upon definitions of health and disease. How medicine is practised, i.e., what is construed as a pathological or normal state that calls for treatment, is an example of this, but definitions also play a role in other fields such as health justice (Daniels, 2008; Nielsen, 2015; Venkatapuram, 2011, 2013). How to make fair prioritizations, what societal consequences ill or good health have etc. are questions that hinge upon the correct understanding of health and disease. The discussion of these concepts therefore has far-reaching implications.

Despite the differences between normativism, naturalism, and hybrid theories, they (roughly) share the same method of approach towards defining health and disease. Firstly, the theory of the opponent is rebuked through copious counterexamples, secondly, a seemingly more fitting definition is posited, thirdly, this definition is shown to cover much of what is ordinarily understood or classified as a disease – more than the opposing theory –

following which either normativism or naturalism is rejected. Though this is partly a caricature, the discussion seemingly is stricken by a stalemate, revolving around examples and counter-examples that never quite fit the bill.

There are several reasons for this – barring the fact that the concepts are complex and/or vague and therefore hard to pin down in exact and concise definitions. One important reason is the method of approach, which is rooted in conceptual analysis that seeks to harmonize philosophical definitions with everyday understandings of health and disease (Murphy, 2012). However, whether scientific and philosophical understandings are congruent with common sense or folk psychology regarding these notions is highly contestable. Both because everyday understandings are vague, and the terms have several meanings, but also because the phenomena that are to be defined are complex and multifaceted.

Given this disagreement, it might seem obvious that philosophy should side with natural science (Lemoine, 2013, 2014), but there are noteworthy cases where folk intuitions seemed more adequate than scientific, e.g., in the declassification of homosexuality as a disease, which was achieved by the peoples' rights movement. Indeed, it might be argued that medicine for a very long time had very questionable intuitions about what constituted diseases such as masturbation (Engelhardt, 1974) including a number of different classifications that have since been rejected or revised. Normativists take this to entail that concepts of health and disease are deeply political and normative, and that there are no unbiased judgments. To this critique, the naturalist could object that the failure of previous times to define and correctly apply concepts of health and disease does not preclude the existence of an adequate notion, and that medical science, though fallible, still

sdu.dk

#sdudk

is better than the alternative. Or, it might be argued, that attempting to define health and disease *as such* is problematic.

5.2 Is eliminativism the answer?

Since the 1990's and in recent years, this stalemate has elicited critical responses from *eliminativists* like Hesslow (1993) and Worrall & Worrall (2001), who question both the feasibility and usefulness of constructing a concept of health and disease. Hesslow's and the Worralls' critique can be summarized as follows: if 1) there seemingly is no adequate concept of health and disease, and 2) practitioners have no issue recognizing what requires treatment and what does not, why bother defining these terms? This leads Hesslow to conclude "(…) that the concepts 'disease', 'health', and 'illness' do not play any significant role in medical science" and "(…) that the concept of disease is superfluous" (Hesslow, 1993, p. 3), while Worrall and Worrall draw the even more radical conclusion: "(…) that there is no such thing as disease [in general]", only disease*s* (Worrall & Worrall, 2001, p. 54).

According to the eliminativists, defining something as a disease is extraneous to the medical assessment; a second-order or meta-level judgement, or, to put it more pejoratively, a purely academic exercise. Removing the disease label will therefore have no appreciable impact on medical practice because medicine does not solely treat diseases, and because doctors can assess symptoms without these concepts. While the critics undoubtedly are

right in stating that a doctor does not strictly *need* a concept of disease to prescribe antibiotics against infections, I am not convinced that the notion is as easily disentangled or as divorced from practice as they claim. In fact, notions of health and disease play a more insidious role in medical practice by shaping inclinations and perceptions of both health professionals and patients.

For example, the status of whiplash as a disease is disputed within the medical community. It is recognized by some to be a disorder, while others claim that it is fabricated (Malleson, 2002). Taken in conjunction, some of the evidence paints quite a dubious picture of the disorder: despite attempts, researchers have yet to locate the structural damage caused by whiplash to either muscular, bony, or connective tissue (Ferrari et al., 1999). In countries where the syndrome is not commonly known or treated, the cases of late whiplash syndrome dwindle drastically. A study conducted in the mid-nineties by Schrader et al. (1996) in Lithuania, found that most of those who experienced neck pain and headaches after an injury were already afflicted by chronic neck pain and headaches pre accident. There was a marginal increase in numbers of persons who experienced pain in the upper extremities following an accident, but it was not statistically significant, and none of the persons in question reported feeling impaired because of the accident. Another study suggests that treating whiplash as a fully-fledged disorder seems to exacerbate and prolong the symptoms. When removing economic compensation from insurance in Saskatchewan, Canada (Cassidy et al., 2000), the incidence of claims greatly decreased along with the intensity of the symptoms, while recovery rates increased.

Whether whiplash is a constructed or genuine disorder is in this context a moot point since the classification of whiplash as a

sdu.dk

#sdudk

disease – and the knowledge of this fact – has medically significant implications. Hypostasizing symptoms, such as a bruised and sore neck, psychological trauma etc., as a syndrome, demonstrably affects not only the judgement of the medical practitioners, e.g., a greater increase in diagnoses, but also the self-conceptions of the afflicted persons, exacerbating the symptoms, thereby requiring stronger measures to alleviate the impairment, ultimately creating looping effects (Hacking, 1996). However, since the eliminativists never claimed that medical practice was infallible, it might be objected that whiplash is merely an exception to the rule that the classification of conditions as healthy or sick is in general irrelevant to medical practice.

This seems to be a dubious claim. Another significant example to the contrary is the host of disorders known as *functional disorders*, which seems to embody the inverse relationship to that of whiplash. The disorders are grouped under the umbrella term "functional disorders" because the aetiologies of the diseases are unclear, and the symptoms seemingly remain purely functional. Especially those afflicted by chronic fatigue syndrome have been marred by the fact that functional disorders did not fit into the mould of a traditional conception of disease, which raised doubts among medical professionals whether the disorders could even be characterized as such, directly affecting the treatment – or lack thereof – that sufferers have received. Once again, it is the status as a disease that directly affects the treatment and understanding

of the conditions. These are not negligible so-called "grey-zone" cases like wrinkles (Worrall & Worrall, 2001, p. 35) but serious maladies that severely disable the afflicted persons.

A diagnosis is, at its core, the positing of certain symptoms as a disease, which is a prerequisite for treatment in modern welfare states (Schramme, 2019). This classification is, however, predicated on what we understand by the terms "health and disease" and the concepts therefore do have consequences for practice. With the tendencies towards pathologization (Conrad, 2007), medicalization (Fitzpatrick, 2001), healthization (Rose, 2007) etc. that many western countries are undergoing, the discussion is as relevant as ever. Rather than continuing in the track of conceptual analysis, however, another approach could be attempted, namely an *ontological* approach.

5.3 Article 2: The Dynamics of Disease – Towards a Processual Theory of Health

Author: Thor Hennelund Nielsen. In press at *Journal of Medicine and Philosophy*.

The Dynamics of Disease: Towards a Processual Theory of Health

The following article presents preliminary reflections on a processual theory of health and disease. It does this by steering the discussion more towards an ontology of organisms rather than conceptual analysis of the semantic content of the terms 'health' and 'disease'. In the first section, four meta-theoretical assumptions of the traditional debate are identified and alternative approaches to the problems are presented. Afterwards, the view that

sdu.dk

#sdudk

health and disease are constituted by a dynamic relation between demands imposed upon an organism and individual presuppositions for adequate response is developed. In the last section, the paper takes stock of three possible objections to and clarifies some implications of this approach to the notions of health and disease.

Keywords: *health and disease, processualism, contextualism, naturalism, normativism*

I. INTRODUCTION

Throughout the history of medicine, two understandings of the nature of health and disease gradually emerged (Temkin, 1977, 441; Canguilhem, 1991, 41): is disease constituted by lesions, aberrations, invasions by foreign pathogens, and dysfunctions which can befall the body? Or does disease consist in the different harms that 'the whole person' as a feeling and thinking being can suffer and the consequent impairments in leading a successful life? The two current dominating strands of theories within philosophy of health, namely naturalism and normativism,[1] can to a

[1] This terminology is, as both Simon (2007) and Kingma (2014) point out, a simplification of several quite diverse positions, nonetheless, I maintain the terminology's use-

large extent be interpreted as derived from these. Naturalists claim that disease consists in physiological dysfunctions, defects, and abnormalities, while normativists maintain that disease is constituted by disvalued or unwanted states of being, which entail suffering or limit the person's ability to lead a fulfilling life.

Since the 1960s, where the debate concerning the nature of health and disease gained traction in mainstream philosophy (Kingma, 2019, 289), the discussion has revolved around deriving the correct definition, which would provide the necessary and sufficient conditions for sorting health from disease. However, all naturalist or normativist definitions seem to be met either with weighty counterexamples or with problems of being either too comprehensive or too narrow and thereby either including 'normal' conditions or excluding pathological states of being in its definition of pathology. In light of this, several philosophers within the field have begun exploring alternative approaches. These include Erehefsky (2009), Kingma (2010), Schwartz (2014), and Sholl (2016B), to name a few, while eliminativists such as Hesslow (1993) and Worrall & Worrall (2001) dismiss the attempt to find a definition of health and disease *in toto*. Other philosophers like Lemoine (2013, 2015) seek a way out of the conundrum by attempting to derive the meaning of the concepts by drawing on

---

fulness as denominations of ideal types of theories and will utilize it throughout this paper. Proponents of the naturalist theory of health include, e.g., Boorse (1975, 1977), Schramme (2007), Hausmann (2012), Schwartz (2014), and Thorell (2021) while the normativist position includes philosophers like Engelhardt (1974, 1976, 1986), Nordenfelt (1995, 2007), Cooper (2002) among others. Attempts have also been made to combine both strands in a hybrid theory, e.g., by Wakefield (1992) and Hofmann (2002).

sdu.dk

#sdudk

medical scientists' understandings thereof, i.e., a bottom-up approach. However, it is a questionable assumption that the expertise of medical researchers, who undoubtedly possess a much deeper understanding of pathological mechanisms, carries over to notions of health and disease *in abstracto*.

Theoretical attempts to clarify the meaning of health and disease should not be ruled out yet. Firstly, because the theory-practice distinction is far from clear in the world of medicine, where practice is regularly influenced by theoretical assumptions, and secondly, because there are still alternatives to the traditional naturalism-normativism debate to be explored. Such an alternative is what I investigate in this paper. More specifically, I suggest a shift of emphasis from conceptual analysis towards an ontological approach that understands health and disease as a processual and relational dynamic between organismic demands and organismic presuppositions for response. It is thereby my ambition to analyze an alternative approach that can aid and/or revise some problems of the current discussion and hopefully provide the provisional building blocks for the development of a fully-fledged processual theory of health.

In the first section of the paper, I identify four meta-theoretical assumptions of the current conceptual approach and suggest alternative ways of perceiving these issues. Based on this, the defining notions of a processual approach to the nature of health and disease are explicated, namely *demands and capaci-*

ties. In the final part of the paper, I reflect upon three possible objections and use this as an opportunity to clarify some implications of the processual understanding.

II. META-THEORETICAL ASSUMPTIONS AND QUESTIONS OF THE DISCUSSION

The traditional approach to elucidating the meaning of the concept of health and disease has been conceptual analysis (Lemoine, 2013). However, I will argue that conceptual analysis as a method of investigation is far from neutral, but rather carries some implicit assumptions and questions that shape the discussion in fundamental ways. I regard the following four issues as the most significant examples of this tendency:

1. Where is the line of demarcation between health and disease?
2. Does health imply the ability to perform at a certain level of functionality, and is disease privation thereof?
3. Are health and disease founded in the internal milieu of the organism, i.e., 'within' the body, or the person's relation to their environment, i.e., in the interaction with the surroundings?
4. What role – if any – does normativitiy play in health and disease?

As suggested, I believe conceptual analysis to be an erroneous *modus operandi* because language as a guiding thread for determining the nature of health and disease is flawed for at least two reasons. Firstly, it is a questionable assumption whether theoreti-

sdu.dk

#sdudk

cal concepts should correspond to or clarify ordinary language and common sense – there might be an extensive disconnection between ordinary perceptions of the phenomena and the phenomena 'in themselves', but theoretical endeavours should, at least in this case, strive to elucidate the latter. Secondly, the sharp but semantically vague distinctions contained within language lead us to draw similarly sharp distinctions within theory. Instead, we might pursue an ontological investigation that seeks to derive the meaning of the terms from a plausible ontology of the organism and human being.

Regarding the first point, demarcating the line between health and disease – between normality and pathology (cf. Canguilhem, 1991; Schwartz, 2007; Hausman, 2012) – lies at the heart of many issues in philosophy of medicine for both naturalism and normativism.[2] Why is frailty and diminished mobility 'normal', i.e., non-pathological, for a senior citizen but pathological for a person in their biological prime, though the impairments are identical? Is sterility pathological when unwanted but healthy when wanted? These and other such cases have been discussed extensively, trying to extract the principle that allows for a neat division between the healthy and pathological as mutually exclu-

[2] Cf. Kingma (2019) for more on the 'circumscription problem'.

sive and discrete phenomena. Engaging the problem as a dilemma or a question of finding the so-called *differentia specifica*, is, however, not a neutral approach: it presupposes that health and disease are binary and antagonistic, which has given rise to the constant discussion over examples and counterexamples. A way to circumvent this problem is to not assume a clearly definable line between health and disease, but instead to maintain that they are polyvalent and qualitatively complex. I suggest that health and disease are constituted by the *dynamic and polyvalent functional relation* between the capacities of organisms and demands imposed upon them. That is, the healthiness or pathology depends upon the capacity of the organism to adapt and respond in sound ways to influxes, which carries the implication that no condition is in and of itself healthy or unhealthy. By grounding health in a dynamic relation, one avoids drawing rigid lines of demarcation because the morbidity or non-morbidity of a state of health depends upon the qualitative state of the organism, not preconceived statuses of certain states of being.

The thought expressed in the second point, namely that health consists in performing to a certain level of functioning, is commonplace in the discussion. Naturalists such as Boorse claim that health is performance within a statistically normal range of biological functioning (1977, 562), while normativists such as Nordenfelt maintain that health is constituted by a certain level of ability to achieve 'minimal happiness' (2007, 7). I concur with both parties in interpreting health as a question of functioning but disagree on the interpretation of what this entails: the *raison d'être* of a function is to *fulfill the organismic tasks at hand* rather than performing to a certain abstract level. One poignant example of this is the phenomenon of neuroplasticity. In cases of brain

sdu.dk

#sdudk

damage, brain centers, that hitherto primarily served other functions and purposes, can replace and fulfill the function of the deficient part. That is, though bodily parts and subsystems perform below a 'normal' level or diverge from 'natural' functions, the organism is able to compensate and perform at full capacity. There are three general inferences to draw from such cases, I suggest: 1) The performative dimension must be determined with a view to the organism as a whole rather than more or less insolated subsystems. 2) Proper functioning lies in adapting to the task, which can be accomplished in several ways because functions are plastic rather than static. 3) The whole has ontological primacy in so far as it constitutes the nexus that governs, regulates and gives direction to the different parts via principles of self-regulation and -organization (Plessner, 2016, 246).[3] The organism is not merely an aggregate of functioning-performing parts, but is similarly constituted by the mutual relation between such parts. There is therefore a shift of emphasis towards the holistic dimension in contrast to more partitive conceptions of the organism: functions do not first exist to then contribute to a goal, rather, functions

[3] This is more than simply a speculative hypothesis. Empirical investigations have increasingly adopted more holistic views of the organism such as network analysis and systems theory, in order to explain the functioning of disease mechanisms, e.g., Barabási, Gulbache, & Loscalzo (2011), and Borsboom & Cramer (2013).

become functions in virtue of the goal they must perform. When the goal is unable to be fulfilled, organismic dysfunction is present.

As expressed in point three, the internal in contrast to the ecological perspective of organisms (Etxebarria, 2016, 128) play a large role in the traditional discussion. Naturalists identify disease as dysfunctions and abnormalities within the body, while normativists identify disease as the individual's diminished ability to successfully engage with their life and surroundings. It has been questioned whether this distinction is viable and whether health and disease truly can be separated from contextual conditions (Ryle, 1947; Kingma, 2010; Sholl, 2016A). I suggest that 1) organismic functioning cannot be determined apart from environmental factors, 2) the environment shapes the internal functioning of the organism in fundamental ways. Regarding the first point, there is a case to be made for the fact that normal and abnormal functioning is relative to circumstance and surroundings. Boorse explicitly opposes the concept (1977, 548) and delivers quite an uncharitable interpretation of Ryle's theory (cf. also Sholl, 2016A, 83). Ryle's point is, however, not to normalize any deviancy provided they somehow benefit the individual, but rather to emphasize that 'normal' functioning is variable and context dependent. Ryle delivers a striking example of this phenomenon: the enlargement of the thyroid gland seen in people located in rural, inland England, where access to iodine needed for the functioning of the thyroid gland is limited, could under 'normal' circumstances be interpreted as the warning sign of goiter. However, though there was an enlargement of the thyroid gland, it was in most cases not accompanied by goiter. What appeared to be a precursor for pathology was in fact an adaptive reaction to envi-

sdu.dk

#sdudk

ronmental deficiencies. In this case, any narrow reduction would have missed the point, namely that normal and abnormal internal functioning could not be construed apart from context and circumstance: "Organism and environment are indivisible" (Ryle, 1947, 3). Regarding the second point, an instructive example of the way that environments influence internal functioning is Tourette's syndrome, which defies any easy classification. Tourette's syndrome seems dependent on the prevalence of certain genes, but how and to what degree it manifests itself is highly conditioned by social factors and personality (Murphy, 2012, 3), in other words, the internal organismic functioning is highly dependent on the environment. I suggest, therefore, that the discussion would be better off trying to transgress any reductive attempts to internal functioning or environmental relations.

Fourth and final point: one of the main controversies in trying to define health and disease have been what role normativity plays.[4] Sedgwick, for example, defends a very strong normativist position:

> "The fracture of a septuagenarian's femur has, within the world of nature, no more significance than the snapping of

[4] Cf. Boorse, 1977; Agich, 1983; Etxebarria, 2016; Kingma, 2019, 298; Lennox, 1995.

> an autumn leaf from its twig: and the invasion of a human organism by cholera-germ carries with it no more the stamp of 'illness' than does the souring of milk by other forms of bacteria" (1981, 121).

Adding furthermore that "all sickness is essentially deviancy" from social norms. A more moderate normativist, such as Agich, would concede that norms and values play major roles in disease but deny that they play the only role: "To call a state of affairs a disease, then, is not simply to describe it in species typical or biological terms, but to characterize it as somehow bad or undesirable relative to human freedom in general and various particular values" (1983, 36). I.e., disease is a state of being, which is disvalued because it inhibits the person's freedom or well-being, causes suffering, and generally is at odds with human values, thereby fusing a descriptive and normative component together. The textbook example of a purely descriptive theory of disease is Boorse's biostatistical theory, which, to reiterate, states that disease is subpar functioning of a bodily (sub)system in comparison to the average level within the relevant reference class (1977, 555). This can be determined on purely descriptive grounds; therefore, values never enter the equation. However, some sort of normativity is at hand:

> "Organisms are vast assemblages of systems and subsystems which, in most members of a species, work together harmoniously in such a way as to achieve a hierarchy of goals. Cells are goal-directed toward metabolism, elimination, and mitosis; the heart is goal-directed toward supplying the rest of the body with blood; and the whole organism

sdu.dk

#sdudk

> is goal-directed both to particular activities like eating and moving around and to higher-level goals such as survival and reproduction. The specifically physiological functions of any component are, I think, its species-typical contributions to the apical goals of survival and reproduction" (Boorse, 1975, 57).

The functions of an organism *should,* therefore, adhere to the species design and promote survival and reproduction, if not, disease is present. As Boorse himself remarks, this conception is essentially Aristotelean (1977, 554), in so far as it assumes a universal form – of reference classes – of organisms, though it leaves out the thought of inherent teloses of different species of organisms (Agich, 1983, 30).

These positions give strikingly different answers to the questions: what role does normativity play in health and disease? Is disease constituted by social values, norms of what constitute a good life, or rather species-dependent norms of organismic constitutions? All three proposals have their issues. If we consider the cases that Sedgwick mentions, they seem to be false analogies. Breaking a leaf from a twig and fracturing a femur are disanalogous because the broken femur is still part of the organism. The analogy could be amended by comparing it to the amputation of the outer joint of a finger instead, even so, the tree habitually sheds its leaves, but for the human being the lack of a finger joint

(mostly) presents itself *as a* lack, which is different than a mere breach of social convention. Given this, individual norms of what constitutes a good life or similar values might seem more promising, but this viewpoint suffers from being too broad as well as too demanding. Kingma terms it 'the circumscription problem', which is "(…) the problem of giving good criteria that delineates, amongst *all* bad conditions (…) only those bad conditions that are also *diseases*" (2019, 301). Roughly stated, that there is no ground on which to distinguish between, e.g., a streak of bad days and a depressive episode, when both inflict the same degree of suffering. Species-typical biological norms, in this context, is not more appealing, since it is unclear why natural functions should aim at exactly survival and reproduction (Agich, 1983, 31). Similarly, Boorse's analysis of health as adherence to a biological norm – the same way that an artifact conforms to the design of a creator – falls short in one crucial aspect.

According to Boorse (1975, 59), organisms liken machines except for the underlying intent of a creator. Sub-systems such as hearts and kidneys can be replaced, performance capacities can be improved, the system is 'fueled' by the 'combustion' of foreign matter etc. Yet certain features of the organism are harder to explain without taking recourse to the inherent normativity of life. Metabolism, for example, is not exclusively the process of replenishing empty energy reserves, but a process of transformation of foreign matter *into* the organism itself (Jonas, 2001, 76). This points to a structural difference between the artifact and living being that can best be explained in terms of the self-organizing and self-constituting qualities of organisms. The actions of the organism have an 'inward' as well as an 'outward' orientation (Plessner, 2016, 247): the 'machine-like' functions – the pumping

sdu.dk

#sdudk

of blood, the filtration of toxins, the digestion of food etc. – are performed with the goal of promoting the thriving of the organism. That is, functions are imbued with a purposive quality.[5] Boorse's Aristotelianism is therefore in many ways theoretically well-founded but mistaken in assuming that health consists in conforming to a fixed species design rather than individual norms. That is, life posits its own norms of what constitutes proper functioning, what is tolerable and intolerable, which can range from a quite rudimentary biological perspective to experientially founded phenomena, dependent on the life (form) afflicted. This, I suggest, is a necessary presupposition to establish the 'wrong-going'-quality to organismic process, which otherwise would be mere physicalistic processes.[6] This 'naturalizing of normativity' moves beyond the simple fact-value distinction and understands normativity as founded in the phenomenon of life itself. The implications of this will be made clearer later.

---

[5] One might also recall Kant's heuristic principle in the *Critique of Judgment*, which states that the organism is that "(…) *in which everything is a purpose and reciprocally also a means*" (1987, §66), which laid the foundation for theories of the organism as a self-organizing, systemic unity.

[6] This demanding understanding of normativity has important historical precursors such as Grote (1921), Goldstein (1995), and Canguilhem (1991), who have been instrumental in formulating a normative account of disease on naturalistic grounds. Recently, this theory has gained traction and been taken up by Sholl (2016A, 2016B), Etxebarria (2016), Saborido et. al. (2016) among others.

To sum up, the distinction between health and disease is not absolute, but qualitatively complex. Rather than performance to pre-determined abstract levels of functioning, 'proper' functioning lies in adapting to the influxes of assertive tasks, which eschew a narrow inside-outside perspective. Finally, life posits its own norms of functioning, which is the reason that compulsions to change can arise. These elements become crucial in a processual approach.

III. ELEMENTS OF A PROCESSUAL APPROACH TO HEALTH AND DISEASE

Contentions put aside, there seems to be unanimity – to a certain extent – in contemporary philosophy of medicine: health and disease have to do with *functionality*.[7] Differences ensue when this concept is fleshed out. For example, Boorse states that: "Health (…) is *normal functional ability*: the readiness of each internal part to perform all its normal functions on typical occasions with at least typical efficiency" (1977, 562), while Nordenfelt contends that: "A is completely healthy if, and only if, A has the ability, given standard circumstances, to reach all his or her vital goals" (2007, 7). That is, both conceive of health in terms of ability; either of organismic (sub)systems to perform within a normal range of functionality *or* to realize vital goals. Disease ensues when the

[7] Except, to a certain extent, phenomenological theories of health such as Carel's (2018), Svenaeus' (2018), and Gadamer's (1994), whose theories cannot be dealt with here for the sake of brevity.

sdu.dk

#sdudk

person is deprived of this ability. Disease is therefore a principally privative phenomenon for Boorse and Nordenfelt.

This conception of functionality is rather impoverished, I claim, because it only to a limited extent factor in central workings of organisms, for example, that functions are never isolated but unfold under certain circumstances, for different reasons and with different aims – as responses, as serving several purposes, as being potentially harmful instead of beneficial and so on. In other words, what I am suggesting is a concept that emphasizes processuality, contextuality and potentiality to a higher degree. To differentiate this from the traditional discussion of abilities, we might more fittingly term this a *capacity*, which implies both activity and potentiality. I suggest that health and disease is constituted by powers and constraints upon powers in the organism's living engagement between itself and its surroundings. The rest of the paper is an attempt to unfold what this entails.

In the original rendition of Boorse's biostatistical theory, an organism, whose subsystems did not constantly perform at a statistically normal level or above, would be considered diseased. The deficiency of such a view is however quickly made clear because organisms only need to perform functions when it is relevant to do so. Boorse modified the biostatistical theory on account of this fact to include the *readiness* of organismic parts to perform in his definition of health (1977, 562). I suggest that rather than being marginal concepts, dispositionality and receptivity are es-

sential to understanding health and disease.[8] When the organism falls ill, when it is affected by obstructions and intrusions of different sorts, the pre-morbid regime of functioning becomes invalid in the sense that it cannot be maintained vis-à-vis a new, potentially destructive state of affairs, which entails that the organism can only keep itself in and through change. Some organisms will possess the necessary capacity to adapt while other organisms' attempts at response will prove insufficient. It is in this functional dynamic that healthy and diseased organisms differentiate themselves.

Thus interpreted, health and disease are constituted by the relation between organismic capacities and demands[9] or, in other words, the tension between adaptability and affectability. A common example may illustrate this point: when an organism accrues a pathogen such as the influenza virus, the infection alters the organismic regime of functioning on a cellular level, compelling the organism to adapt in so far as 'normal' functioning is to be maintained. Whereas disease implies a perturbance of a former state of being that has, temporarily or permanently, become unviable, health is the capacity to adapt to demands in a sound way. A specification of what a proper response entails is hard to deter-

[8] Cf. Kingma (2010) for an extensive explication of this shortcoming in Boorse's theory. Hausman (2011) has defended the biostatistical theory against this critique, to which Kingma (2016) has responded.

[9] There is a surface-level affinity between the terminology here employed and that of some normativists, e.g., Venkatapuram (2011, 2013) and Bircher (2005), the former making *capability* the primary notion of health, the latter employing concepts such as *potentiality* and *demand*. The similarity is mostly superficial – both theories carry the traits of a normative theory in positing health as the ability to realize one's well-being.

sdu.dk

#sdudk

mine in theory, since what constitutes a demand, and how the organism responds, depends upon a plethora of contextually conditioned factors. A viral infection of a senescent or aged organism might radically differ from that of an organism in its biological prime. By including contextuality, a processual approach can more plausibly account for the extreme individual variance that the world of medicine and biology exhibits. Disease is constituted by relational maladaptivity rather than dysfunction or privation of abstract levels of ability.

There is, naturally, a great difference between the ways that a viral infection and schizophrenia affect the organism, but both exhibit the same organismic dynamic despite their considerable differences: they entail new regimes of functioning that disrupt the status quo and is at odds with the goals of the organism. This means that if the organism is to maintain functioning and further its goals, it must adapt. Where they differ is in type and magnitude, i.e., in the force and type of the compulsion and the individual presuppositions for response. The demand of the common cold on an otherwise healthy organism to adapt is in most cases moderate, implying that most organisms possess the means to gradually activate the immune system and develop antibodies, whereas schizophrenia, *ceteris paribus*, is more complex and the playing field of adaptability severely restricted.

An instructive example of the qualitative ambiguity of organismic responses is the fever response (Hucklenbroich, 2014,

622; Nervi, 2010, 221). Fever responses are not symptoms of disease but are rather attempts to stave off infections by creating an inhospitable environment for the pathogen. That is, the fever is a defense mechanism that aims to liberate the organism from a potentially even greater evil. What for the person is experienced as harmful is in this case an adequate adaptive reaction. Yet, there are situations in which the fever can put the organism at even higher risk, namely when the body temperature exceeds 42 degrees Celsius.[10] Ascribing the status of disease to the fever response because it inhibits functioning or reduces well-being misjudges its character of sound response that seeks to reinstate a tenable equilibrium, simultaneously, the fever can hardly be categorized as healthy *per se* since it inhibits the organism to a great degree. Rather, we must construe the reaction in terms of aptness and adeptness at responding to compulsions that threaten the organism. Since health and pathology is constituted by this dynamic exchange between capacities and demands, the theory does not easily lend itself to dualistic ascriptions of healthy or sick. It requires instead that we perceive disease and health not as binary, antagonistic terms, but as qualitatively complex and polyvalent. The health or illness of the individual must be viewed through a broader lens that traces the different exchanges and developments in the organism as a whole, whether it possess the adequate means of response or not.

[10] Although it might well be objected that the representativeness of this case is dubious. Hopefully, the reader gauges the point that on this account, health and disease cannot be ascribed to isolated functions, conditions, and symptoms but are constituted by the organism's entire regime of functioning.

sdu.dk

#sdudk

To divide the responsive patterns of the organism into successful or unsuccessful is therefore an abstraction for two reasons. Firstly, since capacities and demands are contextual, so, too, must the response be – consequently, adaptation or the lack thereof can be realized in multitude ways. Secondly, successful or unsuccessful adaptation must be understood as a temporally unfolding process, where the organism gradually grows to counteract or succumbs to the demands placed upon it. This stands in contrast to a dichotomous perception as either complete success in or failure to adapt. It is possible for the organism to be somewhat adapted or maladapted to a demand, or to possess adaptive capacity in certain areas while lacking them in others.

The different ways in which adaptation is carried out would be too complex to enumerate, but certain archetypical responses can be differentiated. The most common responsive pattern would be restitution or recuperation, i.e., a reestablishment of a status quo that has been disrupted, regaining functionality from a disease by developing antibodies for instance. Another archetype is the organismic capacity to establish a new status quo rather than regaining the former, evident, for example, in cases of pneumonectomy wherein the organism gradually attains 'normal' respiratory capacity with a single lung. Furthermore, since the organism acts as a whole, it has the ability to pursue systemic compensatory strategies and regulate the different parts in relation to each other (Etxebarria, 2016, 130); a capacity, viewed in isolation, might be

entirely unfit to perform a certain function, but macro-level regulations can replace the inhibited capacity, which is evident in the aforementioned example of neuroplasticity. Finally, a common adaptive pattern is symptom treatment or management, where the underlying demand is still present, but momentarily subdued, such as the administration of insulin against diabetes (Marcum, 2011).

The pattern of reaction is not always transformative but may only entail further suffering. For example, when the organism has incurred overwhelming trauma, or when it does not possess the adequate means of response – the proliferation of cancerous cells being an example of a demand the organism seems particularly vulnerable to since this growth mimics 'normal' cell growth without the cell inhibitors being able to subdue the proliferation. In other words, when the new state of being outmatches the restorative powers of the organism. Finally, since responses are answers to compulsions to change (Goldstein, 1995, 35), some responses will be unsuccessful, others might contribute to the predicament. 'Catastrophic reactions', as Goldstein (ibid, 48) terms them, do not only not address the compulsion but further the suffering, an example thereof being allergic reactions or anaphylactic shock to what otherwise might be trivial demands. To reiterate, these are merely sketches of archetypical responses that are too complex in practice to boil down to a single pattern.

How do demands – understood as compulsions to change – arise? On purely mechanistic terms, there is no structural difference between what is ordinarily termed a pathological and 'normal' process, the difference between these arises in virtue of the inner purposiveness of organisms. I.e., only in so far as life posits its own norms of goals, functioning, and tolerance levels, do cer-

sdu.dk

#sdudk

tain states of being mark themselves as obstructions and inhibitions of the organism's functioning. A demand therefore arises when an organism does not have the immediate means to adapt to a compulsion that is at odds with organismic norms. When compulsions to change are posited, so are the impulses to overcome them. Whereas in health, the capacity to carry out vital norms is to differing degrees intact or effortless.

A processual approach therefore understands disease as a matter of *doing* rather than *being*. This entails that health and disease are not entities or qualities as such but *activitie*s that are contextually conditioned and constantly in flux. More specifically, health and disease are constituted by the exchange between capacities and *demands* in the organism, which is perpetually given to change in that the relata are altered in accordance with the adaptive process and the force of the demand. Disease arises when the organism is compelled to adapt because a demand makes a former regime of functioning unviable, i.e., when it can only keep or maintain itself in and through change. A theory of this sort is more adept at explaining traits of disease that traditional theories have devoted less attention to, namely individual variance, temporal alterations, generative factors, capacities for adaption etc.

IV. IMPLICATIONS AND ISSUES

Throughout the remainder of the paper, I will consider some issues and implications that arise from the approach outlined above and offer up some tentative perspectives. Firstly, if not suffering or experienced harm, then what differentiates pathology from normality, improper from proper responses? Secondly, by not positing a natural type of disease, a dynamic account makes itself vulnerable to the objection that *nothing* is a disease, even states that ordinarily would be considered quite grave, or inversely, that *everything* is a disease, even conditions that under normal circumstances would be considered menial. Thirdly, which status do dispositional and asymptomatic states of being, respectively, have in a processual approach?

Differences Between Suffering and Pathology

There can be no doubt that experienced harm and pathology in most cases supervene,[11] yet there are good reasons for wanting to maintain a distinction. Here, I will outline what I take to be two fundamental differences between suffering and pathology: one morphological, one ontological.

There is a morphological difference between disease and suffering in so far as disease is constituted by a *reification* or *objectivization* of organismic processes. That is to say, the processes in which elements of the organism become autonomous (Engel, 1977, 133), outside the organism's control, and at odds with the rest of the organism's functioning and aims *while still being part of the organism*. Reification here refers to the 'thing-character' of

[11] Several philosophers of health argue that suffering is constitutive of disease, e.g. Clouser, Culver, & Gert (1981), and Cooper (2002).

sdu.dk

#sdudk

disease, i.e., that disease consists in a self-subsisting process incommensurate with the life of the afflicted. The autonomy of disease is therefore to be taken quite literally – the pathology operates according to its own 'laws' (Nervi, 2010), which do not cohere with the laws of the rest of the organism, and it is by virtue of this severance from the rest of the organism that it achieves a thing-character, which is simultaneously a part of the system and cannot simply be done away with.

For example, though it is a highly contested and controversial case,[12] the difference between complex, i.e., pathological, and 'normal' grief, is an illustrative example of this distinction. As expression of universal human behavior, or "personal, social, and ethical problems in living" as Szasz puts it (2010, 262), diagnosing grief as a disorder has seemed to some an unduly pathologization of normal behavior, yet still, there seems to be cases where grief borders on pathological behavior, namely when the processing of the loss is severely arrested.[13] Wherein lies the differ-

[12] For a historical account of the shifting status of grief as a pathological or non-pathological state, see Granek (2010).

[13] Fuchs narrates a striking example of such a case from his own practice: "A 55-year-old married woman was admitted to the psychiatric department with a severe depressive episode. For more than two years, she had been taking care of her beloved mother who suffered from cancer. After she had eventually died, it turned out that she had left her corpse to the medical department for scientific purposes, meaning that since then

ence, if ordinary grief and the persistent complex bereavement disorder both contain great suffering? 'Normal' grief is inherently painful but simultaneously meaningful in so far as it is a process of coming to terms with a suddenly displaced affection, but this process "cannot be successful", as Thomas Fuchs emphasizes, "without ultimately acknowledging a fundamentally changed reality" (2018, 56). Complex grief can be interpreted as lacking the capacity to carry out this acknowledgment. In cases of pathological grief, the grief attains a self-subsisting and autonomous character, it ceases to be a meaningful processing. The grief therefore transitions from an adaptive response to a pathological manifestation when the integrative process is completely arrested, though both phenomena entail great suffering.

This distinction is generalizable, I suggest. The proliferation of cancer cells, compulsory thoughts, organic failure like appendicitis, viral infections are autonomous processes that run counter to the functioning of the organism. They are not states of privation but rather excesses of function that cannot immediately be subsumed under the organism's regime of functioning. They thereby instate a schism between the current functioning and the natural teleology of the organism. This distinction makes it possi-

---

there had been no funeral, no burial, nor a grave. One year later, the patient still felt the bodily proximity of her mother, often in a frightening way. When falling asleep, she frequently heard her voice asking where she was and why she left her alone for so long. On a holiday by the sea, she heard her mother calling again and started to drown herself, but was eventually rescued by her husband. From then on, she no longer dared to enter the balcony of her flat in the 6th floor for fear of jumping down in a suicidal impulse. She could no longer take part in social life, kept musing about the past and possible faults she had committed, and felt more and more desperate" (2018, 56-57).

sdu.dk

#sdudk

ble to distinguish between healthy and pathological adaptive responses, where the former often might entail suffering for the afflicted person *without* being pathological. To reiterate, this presupposes an ontology of the organism as a hierarchy of systemic macro functions and aims in contrast to nested micro functions. Conflicts can arise in the interaction between these levels.

The ontological distinction between experienced harm and pathology follows from the determinations of capacities made above. There are limits to capacities, which implies that beyond a certain point, the organism's adaptive potential is either exhausted or becomes insufficient. These border cases can occur 'naturally' – menopause, for instance, entails the incapacity to become pregnant, though by no means being pathological in virtue thereof. Or they can occur by external means, for example, when the organism is exposed to acute trauma or reaches a breaking point in connection with injuries, lesions, or stress – losing a limb, breaking a bone, psychological trauma etc. These are not to be considered pathological because they far exceed an organism's capacity for adaptation, while still entailing severe suffering for the afflicted person. Often, these traumatic reactions have readily apparent etiologies. Some argue that grief, for example, must be construed along the same lines. Engel likens grief to a wound (1977, 133), and Fuchs states that bereavement is like an amputation and the lost person similar to a phantom limb (2018, 54). Though grief implies a great deal of suffering and shares several effects with

disease like clinical depression, it is not to be considered pathological, namely because it far exceeds adaptive potential.

Why should a certain process be any less pathological merely because it far exceeds the individual's capacity for adaptation? After all, traumatic reactions often give rise to pathologies of different sorts. Here, a distinction must be made between the *causes* of pathology and pathology *in itself*. Traumatic reactions heighten the likeliness of incurring pathologies, though not in and of themselves being pathological, the same way a disease-bearing gene might heighten the risk of developing a certain disease, senescence heightens the risk of dementia etc., while still being distinct from disease. But the distinction is, admittedly, fuzzy. In practice it would require precise determinations of etiological factors, disease courses, the medical history of the individual etc. to distinguish between causes of disease and disease in itself. It is, however, a major philosophical question when exactly limits cease to be limits and become limitations, but this is a distinction that must be made on a case-to-case basis.

Everything or Nothing is a Disease

It might be objected that a theory of this sort has the unfortunate consequence that there is no a priori disease. Differently stated, that everything can be a disease, even things that could be considered menial or non-pathological by most standards, or that nothing is disease, even cases that would be considered very severe. By removing a fixed demarcation line, is an unwarranted pathologization and medicalization in effect not extended to all aspects of life?

Though it might from a commonsense perspective seem counterintuitive, it is a consequence of understanding disease as a

sdu.dk

#sdudk

functional relation that there is no prima facie pathology or natural kinds of diseases. A state of being *becomes* pathological when it constitutes a compulsion to change that the organism does not have the capacity to meet. This does not entail a subversion of general classifications and nosology but is rather an emphasis on the contextuality and individuality of disease. Philosophy of health has traditionally paid less attention to the uniqueness and variability of disease manifestations. But this, I claim, is necessary to truly grasp the phenomenon. It is not the presence of a pathogen, a structural abnormality, or a disease-bearing gene that constitute disease but the consequent functional impairment and alteration in conjunction with individual presuppositions for response. A processual approach allows for a more finely grained differentiation between, for example, a bout of asymptomatic influenza for the young adult and a bout of influenza for the elderly adult with a weakened immune system. While it therefore might seem counterintuitive, it is of no theoretical or practical concern that certain states of being are not labelled pathological *ex ante*. A processual approach essentially emphasizes what recent trends such as precision and personalized medicine also do: that pathological states of being are unique expressions of a total sum of conditions that concern the circumstances, environment, genetic makeup, susceptibilities etc. of the afflicted person.

Are Dispositional or Asymptomatic States Diseases?

A fair objection would be that when disease is constituted by the forceful opposition between demands upon and the capacities of an organism, what status do dispositional or asymptomatic states then have? That is, states of being that have yet to develop into disease, though they are likely to, e.g., having a disease-carrying gene, or states that have no experiential correlate though they entail pathological biological processes, e.g., some forms of cancer in the early stages.

Regarding pre-morbid, dispositional states, the distinction between causes of disease and diseases in themselves still must be maintained. A dispositional state does not constitute disease, but this does not entail that they are not worthy of treatment, namely because they are likely to develop into disease. Asymptomatic states, on the contrary, would constitute disease. The processual approach developed above does not preclude the possibility that the forceful opposition cannot play out below the threshold of consciousness. Indeed, the clash between compulsions to change and capacities to accommodate demands can play out at different micro and macro levels of the organism. In the case of asymptomatic cancer, the dynamic occurs at a cellular level, in the case of liver failure, at the level of bodily subsystems etc.

V. CONCLUSION

In this paper, I have attempted to develop a processual approach to the question of the nature of health and disease that is able to circumvent the contentious issues that cause a deadlock in the traditional debate between naturalism and normativism. In the processual approach, health and disease is constituted by the dynamic relation between demands placed upon an organism to

sdu.dk

#sdudk

adapt and its capacities to redeem these demands. By replacing conceptual analysis with an ontological approach, several questions of a grander nature about organisms and the phenomenon of life open themselves up for investigation. Nonetheless, finding the necessary and sufficient conditions to sort the pathological from the normal through linguistic analysis looks increasingly less promising. By opening the processual perspective up for investigation, I hope to have shown that ontological theories of health and disease have not overstayed their welcome.

ACKNOWLEDGMENTS

I wish to thank the two anonymous reviewers for their very helpful comments. I am also indebted to Lasse Nielsen, Søren Harnow Klausen and the research group *Values, welfare and health* at the University of Southern Denmark for their constructive criticisms of earlier drafts of this paper including all others who have aided me in the process.

REFERENCES

Agich, G. J. 1983. Disease and Value: A Rejection of the Value-Neutrality Thesis. *Theoretical Medicine* 4(1): 27-41.

Barabási, A., Gulbache, N., Loscalzo, J. 2011. Network Medicine: a network-based approach to human disease. *Nature* 12(1): 56-68.

Bircher, J. 2005. Towards a dynamic definition of health and disease. *Medicine, Health Care and Philosophy* 8(3): 335-41.

Boorse, C. 1977. Health as a Theoretical Concept. *Philosophy of Science* 44(4): 542-73.

———. 1975. On the Distinction between Disease and Illness. *Philosophy & Public Affairs* 5(1): 49-68.

Borsboom, D., Cramer, A. O.J. 2013. Network Analysis: An Integrative Approach to the Structure of Psychopathology. *Annual Review of Clinical Psychology* 9: 91-121.

Canguilhem, Georges. 1991. *The Normal and the Pathological*. 1st ed. New York: Zone Books.

Carel, Havi. 2018. *Phenomenology of Illness*. 1st ed. Oxford: Oxford University Press.

Clouser, D., Culver, C. M., Gert, B. 1981. Malady: A New Treatment of Disease. *The Hastings Center Report* 11(3): 29-37.

Cooper, R. 2002. Disease. *Studies in History and Philosophy of Biological and Biomedical Sciences* 33(2): 263-82.

sdu.dk

#sdudk

Engelhardt, T. H. 1974. The Disease of Masturbation: Values and the Concept of Disease. *Bulletin of the History of Medicine* 48(2): 234-48.

———. 1976. Ideology and Etiology. *The Journal of Medicine and Philosophy* 1(3): 256-68.

———. 1986. Clinical Complaints and the Ens Morbi. *The Journal of Medicine and Philosophy* 11(3): 207-14.

Erehefsky, M. 2009. Defining 'Health' and 'Disease'. *Studies in History and Philosophy of Biological and Biomedical Sciences* 40(3): 221-7.

Etxebarria, A. 2016. Biological Organization and Pathology: Three Views on the Normativity of Medicine. In *Naturalism in the Philosophy of Health*, ed. E. Giroux, 121-41. London: Springer.

Fuchs, T. 2018. Presence in absence. The ambiguous phenomenology of grief. *Phenomenology and the Cognitive Sciences* 17: 43-63.

Gadamer, Hans-Georg. 1994. *Über die Verborgenheit der Gesundheit*. 1st ed. Berlin: Suhrkamp.

Goldstein, Kurt. 1995. *The Organism: A Holistic Approach to Biology Derived from Pathological Data in Man.* 1st ed. New York: Zone Books.

Granek, L. 2010. GRIEF AS PATHOLOGY: The Evolution of Grief Theory in Psychology From Freud to the Present. *History of Psychology* 13(1): 46-73.

Hausman, D. 2012. Health, Naturalism, and Functional Efficiency. *Philosophy of Science* 79(4): 519-41.

———. 2011. Is an Overdose of Paracetamol Bad for One's Health?. *The British Journal for the Philosophy of Science* 62(3): 657-68.

Hesslow, G. 1993. Do We Need a Concept of Disease?. *Theoretical Medicine* 14(1): 1-14.

Hofmann, B. 2002. On the Triad Disease, Illness and Sickness. *Journal of Medicine and Philosophy* 27(6): 651-73.

Hucklenbroich, P. 2014. "Disease Entity" as the Key Theoretical Concept of Medicine. *Journal of Medicine and Philosophy* 39(6): 609-33.

Jonas, Hans. 2001. *The Phenomenon of Life: Towards a Philosophical Biology*. 1st ed. Evanston: Northwestern University Press.

sdu.dk

#sdudk

Kant, Immanuel. 1987. *Critique of Judgment*. 1st ed. Indianapolis & Cambridge: Hackett Publishing Company.

Kingma, E. 2010. Paracetamol, Poison, and Polio: Why Boorse's Account of Function Fails to Distinguish Health and Disease. *The British Journal for the Philosophy of Science* 61(2): 241-64.

———. 2014. Naturalism about Health and Disease: Adding Nuance for Progress. *The Journal of Medicine and Philosophy* 39(6): 590-608.

———. 2016. Situation-Specific Disease and Dispositional Function. *The British Journal for the Philosophy of Science* 67(2): 391-404.

———. 2019. Contemporary Accounts of Health. In *Oxford Philosophical Concepts: A History*, ed. P. Adamson, 289-318. Oxford: Oxford University Press.

Lemoine, M. 2013. Defining disease beyond conceptual analysis: an analysis of conceptual analysis in philosophy of medicine. *Theoretical Medicine and Bioethics* 34(4): 309-25.

———. 2015. The Naturalization of the Concept of Disease. In *Classification, Disease and Evidence – New Essays in the Philos-*

ophy of Medicine, ed. P. Huneman, G. Lambert, M. Silberstein, 19-41. Paris: Springer.

Lennox, J. G. 1995. Health as an Objective Value. *The Journal of Medicine and Philosophy* 20(5): 499-511.

Marcum, J. A. 2011. Medical Cure and Progress: The Case of Type 1 Diabetes. *Perspectives in Biology and Medicine* 54(2): 176-88.

Murphy, Dominic. 2012. *Psychiatry in the Scientific Image*. 1st ed. Cambridge & London: The MIT Press.

Nervi, M. 2010. Mechanisms, malfunctions and explanation in medicine. *Biology and Philosophy* 25(2): 215-28.

Nordenfelt, Lennart. 1995. *On the Nature of Health – An Action-Theoretic Approach*. 2nd ed. Dordrecht: Springer.

———. 2007. The concepts of health and illness revisited. *Medicine, Health Care and Philosophy* 10(1): 5-10.

Plessner, Helmuth. 2016. *Die Stufen des Organischen und der Mensch: Einleitung in die philosophische Anthropologie*. 1st ed. Frankfurt am Main: Suhrkamp.

Ryle, J. A. 1947. The Meaning of Normal. *The Lancet* 249(6436): 1-5.

sdu.dk

#sdudk

Saborido, C. 2016. Organizational Malfunctions and the Notions of Health and Disease. In *Naturalism in the Philosophy of Health*, ed. E. Giroux, 101-20. London: Springer.

Schramme, T. 2007. A qualified defence of a naturalist theory of health. *Medicine, Health Care and Philosophy* 10(1): 11-7.

Schwartz, P. H. 2007. Defining Dysfunction: Natural Selection, Design, and Drawing a Line. *Philosophy of Science* 74(3): 364-85.

———. 2014. Reframing the Disease Debate and Defending the Biostatistical Theory. *Journal of Medicine and Philosophy* 39(6): 572-89.

Sedgwick, P. 1981. Illness – Mental and Otherwise. In *Concepts of Health and Disease. Interdisciplinary Perspectives*, ed. A. L. Caplan, H. T. Engelhardt, J. J. McCartney, 119-29. Reading: Addison-Wesley Publishing Company.

Sholl, J. 2016A. Contextualizing Medical Norms. In *Naturalism in the Philosophy of Health*, ed. E. Giroux, 81-100. London: Springer.

———. 2016B. Escaping the Conceptual Analysis Straitjacket – pathological mechanisms and Canguilhem's biological philosophy. *Perspectives in Biology and Medicine* 58(4): 395-418.

Simon, J. 2007. Beyond Naturalism and Normativism: Reconceiving the 'Disease' Debate. *Philosophical Papers* 36(3): 343-70.

Svenaeus, Fredrik. 2018. *Phenomenological Bioethics: Medical Technologies, Human Suffering and the Meaning of Being Alive*. 1st ed. London and New York: Routledge.

Szasz, Thomas S. 2010. *The Myth of Mental Illness – Foundations of a Theory of Personal Conduct*. 2nd edition. New York: Harper Perennial.

Temkin, Owsei. 1977. *The Double Face of Janus and Other Essays in the History of Medicine*. 1st ed. Baltimore and London: The Johns Hopkins University Press.

Thorell, A. 2021. Distinguishing Health from Pathology. *The Journal of Medicine and Philosophy* 46(5): 561-85.

Venkatapuram, Sridhar. 2011. *Health Justice: An Argument from the Capabilities Approach*. 1st ed. Cambridge: Polity Press.

———. 2013. Health, Vital Goals, and Central Human Capabilites. *Bioethics* 27(5): 271-9.

sdu.dk

#sdudk

Wakefield, J. C. 1992. The Concept of Mental Disorder – On the Boundary Between Biological Facts and Social Values. *American Psychologist* 47(3): 373-88.

Worrall, J., Worrall, J. 2001. Defining Disease: Much Ado about Nothing?. *Analecta Husserliana* 72: 33-55.

5.4 A positive notion of health?

To conclude this chapter, some reflections on a notion, which was not treated in the article, is warranted, namely *positive health*. Boorse explicitly rejects the thought of positive health on several grounds (Boorse, 1977). Firstly, since health is normal functioning according to the statistically average species design, positive health must be a sort of excellence in natural capacities, but how does excellence in one ability, which often precludes excellence in other abilities, translate to greater health in total? Is the person with a natural propensity for mathematics, for example, healthier than the talented marathon runner? This seems to involve questions about what is most valuable to us, Boorse argues, and the argument has therefore moved beyond health and disease – as these are value-free and naturalistic phenomena – into the domain of ethics. Normative theories would welcome this development since positive health could be construed as a higher-than-normal degree of well-being, but this view still faces the circumscription problem.

Intuitively, however, there seems to be a case for the distinction between being healthy and being in good health even on naturalistic grounds. For example, newer theories within medical research are increasingly discovering the *robustness* of living systems, i.e., the "property that allows a system to maintain its functions against internal and external perturbations" (Kitano, 2007), which does not consist in excellence within specific abilities but refers to the overall ability of the organism to preserve and further itself. Canguilhem describes this characteristic of life and health in the passage, which was partially quoted above but here is rendered in full:

> "Now, to live, already for animals and even more so for man, is not merely to vegetate and conserve oneself. It is to confront risks and to triumph over them. Especially in man, health is precisely a certain latitude, a certain play in the norms of life and behavior. What characterizes health is a capacity to tolerate variations in norms on which only the stability of situations and milieus – seemingly guaranteed yet in fact always necessarily precarious – confers a deceptive value of definitive normalcy. Man is truly healthy only when he is capable of several norms, when he is more than normal. The measure of health is a certain capacity to overcome organic crises and to establish a new physiological order, different from the old. Health is the luxury of being able to fall ill and recover. Every disease is, by contrast, a reduction of the power to overcome others" (2008b, p. 132).

No organism goes through life without suffering disease. From a statistical vantage point, disease is normal, and absence of disease

sdu.dk

#sdudk

is abnormal. What marks positive or good health of an organism is its capacity to endure, to excel in terms of robustness, resilience, and adaptability, and to establish new organismic norms – especially when these are put to the test. Though it remains provisional, this is a promising avenue for the processual theory of health to explore.

5.5 Concluding thoughts on chapter 5

This chapter sought to explicate and unfold what it means for health and disease to be dynamic, processual, and temporal phenomena, which the analysis of health assessment hinted at. By taking an ontological approach that explicates what it is for an organism to be healthy or sick, one can circumvent the snares of conceptual analysis that seeks to harmonize folk psychology with philosophical conceptions. Inversing the relation, namely that in an organismic sense what is important is not to live up to a predetermined and abstract standard but to the demands for adaptation that the organism is exposed to given its inherent normativity, puts matters in a new light. Then it becomes a matter of doing rather than being, as the article in this chapter argued. Still, there was a distinct element that the analysis only partially unfolded, namely the givenness of the disease to the afflicted person, and what adaptation entails on a phenomenological level. The next chapter delves into the phenomenological dimensions of the ontological analysis.

6. The phenomenology of health

> ”It is in moments of illness that we are compelled to recognize that we live not alone but chained to a creature of a different kingdom, whole worlds apart, who has no knowledge of us and by whom it is impossible to make ourselves understood: our body. Say that we met a brigand by the way; we might yet convince him by an appeal to his personal interest, if not to our own plight. But to ask pity of our body is like discoursing before an octopus, for which our words can have no more meaning than the sound of the tides, and with which we should be appalled to find ourselves condemned to live”
> (Proust, 1932, p. 928).

6.1 Phenomenology and its importance for philosophy of health

Phenomenology hails from the early beginning of the 20th century, where Husserl, inspired by Brentano’s *descriptive psychology*, conceived it as an independent and foundational method of philosophy in *Logische Untersuchungen* (Husserl, 1968; Zahavi, 2011). At the time, philosophy had devolved into unsystematic life philosophies and positivism, and Husserl wished to restore philosophy to the status of a “rigorous science” (Husserl, 1987). A purely naturalistic oriented philosophy, Husserl argues, is based on an abstraction of the things as they first and foremost and primarily are, namely as *given*. Phenomenology is, briefly put, the study of *appearances* or *phenomena* (Sokolowski, 2000). However, phenomena have distinct aspects – they contain a *what*, the phenomenal content and qualities, a *how*, the mode of appearance,

sdu.dk

#sdudk

and a *to*, the subject to whom they appear. These different dimensions of the phenomena are what phenomenology analyses.

Phenomenology is, however, more than a description of the contents of mind for it does not strive to elucidate my private experiences or my private outlook of the world but rather *essences*. As such, it strives to explicate invariant structures and truths of the subject and the world and becomes a science in virtue thereof. Since the time of Husserl, phenomenology has undergone many instantiations and have expanded its repertoire of themes, for example, with Heidegger's *fundamental ontology* and its emphasis on the temporal embeddedness of existence or Merleau-Ponty's explication of the corporeal nature of the subject etc.

Phenomenology is important to philosophy of health because it provides both a method and a theme of analysis, which is unavailable to a strictly naturalistic approach. This is connected to one of the most – if not the most – crucial insights of phenomenology, namely the *non-objective nature of the subject*. The human being has a corporeal and mental nature, and it can *reify* its own existence or be *reified* by others. This happens, for example, when the human being is reduced to a diagnosis or to its body, but neither the diagnosis nor the corporeal properties adequately capture the being of the subject. Only because there is such a "thing" as a subject to which the world appears, can the world become objectivized. That is to say, there is an ontological primordiality to human existence that cannot be bracketed or "preceded". For

all understandings of being, be they scientific, aesthetic, or even medical, are contingent upon an active subject, to which the world appears, and who carries out certain interpretations of its world (Husserl, 2012). It is because health and disease appear to the subject as existential experiences of utmost significance that either promote or restrict its being – and not simply as mechanisms within the physical organism – that phenomenology becomes crucial for the full and adequate analysis of these phenomena.

There is a rich tradition for the utilization of phenomenology within *psychopathology*. Already Jaspers in his *Allgemeine Psychopathologie* sought to describe and understand the phenomenal dimensions of mental illnesses. Unlike neurology, the ambition is not to *explain* the phenomenon through a reduction to more fundamental naturalistic properties, but to *understand* it. Jaspers writes:

> "Der *Gegenstand* der Psychopathologie ist das wirklich bewußte psychische Geschehen. Wir wollen wissen, was und wie Menschen erleben, wir wollen die Spannweite der seelischen Wirklichkeiten kennenlernen. Und nicht nur das Erleben der Menschen, sondern auch die Bedingungen und Ursachen, von denen es abhängt, die Beziehungen, in denen es steht, und die Weisen, wie es sich irgendwie objektiv äußert, wollen wir untersuchen"[7] (Jaspers, 1965, p. 2).

[7] "Psychopathology has, *as its subject-matter*, actual conscious psychic events. Although the main concern is with pathological phenomena, it is also necessary to know what people experience in general and how they experience it; in short, to take the full range of psychic reality. It is necessary not only to examine the actual experience but also the causes and conditions at work, as well

sdu.dk

#sdudk

The distinction between understanding and explanation stretches back to Dilthey (1968) and has formed the basis for subsequent phenomenological analyses of psychopathology. Like the mother science, this branch of phenomenology has also undergone many iterations, for example, through Binswanger's (1922) and Boss' (1975) combination of Heidegger's analysis of *Dasein* with psychotherapy, and it is still a fruitful and active field of research represented by, e.g., Fuchs (2010), Ratcliffe (2012b), and others. The newer tradition of phenomenology of illness shares the wish to elucidate and understand the lifeworld of the ill person, "what it is like" to be ill, but broadens this from the study of psychopathology to the common and invariant core of illness as such. The following article presents a critique of this tradition and an attempt to present a revised understanding of the phenomenology of illness.

6.2 Article 3: Issues for a Phenomenology of Illness – Transgressing Psychologizations

---

as the relationships and the modes in which the experience comes to expression" (Jaspers, 1972, p. 2).

Author: Thor Hennelund Nielsen. Published in *Medicine, Health Care and Philosophy*.

Issues for a Phenomenology of Illness
Transgressing Psychologizations

ABSTRACT: Phenomenology of illness has grown increasingly popular in recent times. However, the most prominent phenomenologists of illness defend a psychologizing notion of phenomenology, which argues that illness is primarily constituted by embodied experiences, feelings, and emotions of suffering, alienation etc. The article argues that this gives rise to three issues that need to be addressed. 1) How is the theory of embodiment compatible with the strong distinction between disease and illness? 2) What is the difference between problematic embodiment and illness? 3) How is existential edification, that illness can give rise to according to the phenomenologists, to be understood? The article then engages in an analysis of Heidegger's and Waldenfels' phenomenology with the ambition of developing a notion of existence, which can transgress the psychologization of illness. Rather than arguing that illness is constituted by experiences of suffering and alienation, it emphasizes that broaches upon conatively guided activities constitute illness.

Keywords: Phenomenology, illness, transcendental phenomenology, phenomenological psychology, psychologization, Heidegger

Introduction

Recent years have seen a blossoming of phenomenological perspectives on health and disease. Through insights drawn from

sdu.dk

#sdudk

traditional phenomenology, several distinct but closely related theories of the *phenomenology of illness* (*PHI*)[8] have been formulated by philosophers such as Carel, Svenaeus, and Toombs with Leder and Zaner as important precursors. Briefly put, phenomenologists of illness emphasize the *first-person* rather than the *third-person* perspective. They explicate 'what it is like' to have an illness, and how it affects the sick person's relation to their body, ability to interact with others and surroundings, self-conceptions and so on. Rather than conceiving the body as primarily a conglomerate of biological parts and processes, phenomenologists of illness maintain that there is an intimate – albeit not always harmonic – unity between body and mind. I do not merely *have* a body; I *am* my body. Consequently, consciousness is *embodied* and pathology affects the entire being of the sick person. This conception does not negate but complements a biomedical perspective on pathology. Indeed, phenomenologists maintain the Boorsean distinction between disease and illness (Boorse 1975)

[8] In this context, *phenomenology of illness* specifically refers to the theories of Carel, Svenaeus, and Toombs. The use of the term 'PHI' is therefore a generalization of several quite diverse positions and might seem to be an oversimplified and artificial construct of a theory. What the theories do share, however, is a certain psychologizing approach to phenomenology, and I therefore elect to use the term "PHI" throughout, although the reader should be aware that the philosophies of Carel, Svenaeus, and Toombs are quite nuanced and internally varied.

but argue that a narrow focus on physiological dysfunction relativizes the existential gravity of illness. For this reason, biomedical accounts of disease must be supplemented by an account of what it is like to live with the illness. With Zaner, a distinction can therefore be drawn between two perspectives, namely disease-as-scientifically-constructed and illness-as-lived (Zaner 1981). The former refers to disease as a series of pathological causal processes within the organism and the latter to the lived reality of the sick person, which involves suffering, changes to the body, existential uncertainty etc. For the sick person, it is the suffering that matters. It is the latter perspective that PHI sets itself to disclosing.

There is no doubt that phenomenology of illness has enriched philosophy of health and health research in general through a systematic and methodical focus on the experiential dimensions of health and disease along with illuminating personal accounts of what it is like to live with disease. It uncovers dimensions of illness, which have traditionally been neglected and are fundamentally inaccessible to purely biomedical perspectives. However, there are problematic elements in the way that phenomenology of illness is currently practiced and conceived. One of these issues is that phenomenology of illness has a *psychologizing* understanding of phenomenology. The focus primarily lies on the pathic dimensions of illness, i.e., moods, emotions, feelings of alienation, of suffering, bodily doubt and so on. While the experiential dimension is essential to phenomenology since the phenomena must appear *to* someone, the strong focus on experiences, though bodily-situated and embodied, generates some issues with regards to the strong thesis of embodiment that phenomenologists of illness wish to maintain. To accommodate these issues, a notion of em-

sdu.dk

#sdudk

bodiment, which transgresses a more psychologizing understanding of illness, must be developed. I attempt to do this in this paper by steering the discussion towards the performative and practical dimensions of existence by drawing on the Heideggerian phenomenology. Heidegger's philosophy is particularly suited to this purpose because it eschews strong distinctions between mind-body and subject-object by focusing on the way that existence unfolds as a holistic, temporal, and conative activity. The aim of this article is therefore not to show the irrelevance of the phenomenological perspective but to point out and hopefully revise some problematic features of the way that phenomenology is currently conceived within this promising field.

In this article, I firstly offer a brief recap of the defining features of PHI with the aim of drawing out some problematic features thereof, which I elaborate on in the second section. Three specific issues are opened for discussion: 1) the relation between the strong hypothesis of embodiment and the strong distinction between disease and illness, 2) the difference between problematic embodiment and illness, and 3) how existential edification is to be interpreted. I offer tentative answers to these questions by engaging in an analysis of selected passages from the works of Heidegger and Waldenfels.

Setting the stage

The defining feature of phenomenology of illness is its emphasis on the first person rather than third person perspective. It attempts to lay bare the meaning structures of experience, *in casu*, the meaning structures of the sick or healthy person's embodiment (Svenaeus 1999, 134-135; Toombs 1992, XIV; Carel 2018, 17). Here, the phenomenologists distinguish sharply between the healthy and sick person's embodiment. Health, it is claimed, is a state of transparency that withdraws from explicit attention (Gadamer 1994, 144; Leder 1990), allowing for uninhibited engagement with the world (Toombs 1992, 34). In health, the body therefore serves the person's different projects and tasks, which the phenomenologists refer to as the *lifeworld*, and which is mostly pre-reflective and non-thematized. This unimpeded engagement with the world becomes problematic in illness. When I find myself unable to complete my daily tasks, when all my activities and interests are accompanied by insistent headaches, nausea, exhaustion etc., the body stops being a tool of my living engagement and becomes a hindrance. The self-sufficiency and self-assuredness that characterizes the state of health dissipates in illness and is replaced by experiences of suffering and anxiety, of lost opportunities, of lack of ability to connect with others and so on.

If the body is not something we have, but something we are, as phenomenologists of illness claim with reference to Merleau-Ponty (Merleau-Ponty 2012, 213; Zaner 1981, 47) and if illness effectuates a schism between the lived and physical body, then illness produces a schism in the sick person's being. This schism appears when the body no longer acts as a conduit of the person's will but appears in its physicality, as a dysfunctional object among objects. As an object, the body can malfunction, be objec-

sdu.dk

#sdudk

tivized, stigmatized etc. Yet, the body is not accidental to but an inherent part of the living unity that cannot be bracketed. This conflict between both perspectives, the body as dysfunctional object versus living unity respectively, engender the experience of alienation and uncanniness, which Svenaeus (1999, 186) and Toombs (1992, 75) among others emphasize as a core element in the experience of illness. For Svenaeus, 'unhomelikeness' or alienation (a literal translation of Heidegger's term *Unheimlichkeit*, cf. Heidegger 2006, §40) is constitutive for illness.

Here, two different perspectives are at play: the body in its primordial givenness to consciousness, and the body as physical organism (Carel 2018, 26). Consequently, there are two fundamental perspectives on pathology, namely disease and illness, which is a distinction that phenomenology of illness adopts from Boorse (1975). 'Disease' designates the failure of a biological part or bodily system to perform within a certain range of normality. Such dysfunction (disease) can occur without crossing the threshold of consciousness, e.g., in asymptomatic diseases like cancer in the early stages or comatose states. Conversely, the experience of being sick (illness) may be given to consciousness without having a (purely) physiological basis, e.g., hypochondria. Embodiment always entails a dual perspective between the body as object, i.e., as affective and passive, and subject, i.e., as engaged and active – the body as *Leib* and *Körper* in Husserl's nomenclature or *corps-propre* and *corps-sujet* in Merleau-Ponty's.

By stressing the primordial unity of these, the phenomenologists of illness hope to bridge the mind-body dichotomy.

Pathology is therefore not only something that attacks the body, but the entire being of the sick person and has existential implications in virtue thereof. These are often of a detrimental character – life plans are frustrated, well-being is diminished, the body is weakened and hurting etc. – yet the phenomenologists leave room for the possibility of existentially transformative and edificatory experiences in the wake of illness (e.g., Carel 2018, 214-218; Svenaeus 2018, 26-29). Since the lifeworld is pre-reflexive and characterized by an experience of flow, the relation to one's mortality and deeper values in life are seldom thematized. Illness disrupts this natural state, forcing one to reflect upon these questions. In a certain sense, illness enforces an *epoché* (Husserl 1983, §32) that enables a more conscious engagement with one's life. This, Carel maintains (2018, 130), supported by empirical science (Albrecht and Devlieger 1999; Birkenbach, Felder and Schmitz 2013), need not be detrimental. Instead, well-being can thrive despite – perhaps even because of – illness.

Issues

Husserl distinguishes between *phenomenological psychology* and *transcendental phenomenology*, which are two methods of phenomenological analysis with different goals (cf. Husserl 1968, 343; Zahavi 2013, 38).[9] The former is primarily a descriptive regional analysis of the phenomenal qualities of different acts and

[9] Here I am not suggesting a theory of the transcendental Ego but rather the utilization of transcendental phenomenology as a method of investigation.

sdu.dk

#sdudk

states of consciousness, whereas the latter seeks to extricate the conditions of possibility of phenomena. Phenomenologists of illness lean decidedly more towards phenomenological psychology; it is the description of the *experience* of illness, 'what it is like' to be sick, which is the object of study (Carel 2018, 1; Svenaeus 1999, 129), more so than investigations into the constitutive basis of such experiences. Phenomenologists of illness rarely ask what the constitutive basis of illness is because it tries to *understand* rather than *explain* illness. Svenaeus (2019, 467), for example, subscribes to the famous dictum of Karl Jaspers (cf. 1965),[10] which distinguishes between explaining the causal mechanisms that lead to pathology and understanding what it is like to live with an illness. The distinction is appealing because it wards off potential attempts at reducing the lifeworld to naturalistic properties, the tacit assumption being that such a reduction would relativize the experiences of the ill person. Yet a narrower focus on a more psychologizing phenomenology has other unfortunate consequences that I explicate below.

[10] In the article *Die phänomenologische Forschungsrichtung in der Psychopathologie*, Jaspers writes: "Die psychopathologischen Phänomene legen eine solche isolierende, von Zusammenhängen abstrahierende, phänomenologische Betrachtung, die nur sehen, nicht erklären will, sehr nahe" (1912, 399).

The personal impetus for several phenomenologists of illness, e.g., Carel (2019) and Toombs (1992), have been personal cases of illness, which are often utilized in phenomenology of illness to exemplify and draw out salient features of the illness experience. These narratives have yielded very fruitful descriptions of what it is like to live with disease and have enriched what would otherwise be a schematic top-down approach to the study of the phenomenon. However, first-person accounts have an ambivalent status in phenomenology. Explications of personal experiences can naturally inform phenomenological investigations, but what sets phenomenology apart as a science is that it is not a private endeavor but an investigation of conditions of possibility for experience as such. By relying too heavily on personal accounts, one simultaneously risks making the phenomenological analysis unassailable for others as well as making accidental features of illness essential. In this case, the radical doubt, the upheaval of one's lifeworld, that Carel and Toombs draw out as a salient feature of illness (Carel 2018, 42; Toombs 1992, 80), are not essential to all illness experiences, it seems. McConville (2021) argues that congenital illness has a different character.[11] Since there is no life prior to or after illness, there is no radical upheaval of the familiar, loss of prior ability etc. Instead, the lifeworld is from the very outset shaped by illness.

Husserl reflected on this methodological issue. In order to draw out the salient features of a phenomenon, the phenomenologist must sort the accidental features from the essential. At the

[11] A similar critique could be made regarding chronic illness.

sdu.dk

#sdudk

beginning of the inquiry, an example is therefore posited that serves as a point of reference, which is then compared to other examples of the same phenomenon whereby common features are drawn out via the eidetic variation (Husserl 1973, §87). When faced with two internally contradictory descriptions of the same phenomenon, the phenomenologist is forced to concede that the common features of the phenomenon were not essential but accidental, and that the phenomenological analysis was not radical enough. McConville's critique demonstrates that loss, though undoubtedly an important element in most illnesses with great repercussions for the life of the afflicted, is not a constitutive feature thereof. In general, phenomenology of illness seems to occupy an awkward place between a more transcendental and naturalized phenomenology, i.e., between a phenomenology that seeks to extricate essential features of a phenomenon, *in casu* illness, or a phenomenology that is more oriented towards systematically describing private experiences and the inner world of the ill person. Regardless of which conception one subscribes to, there is an issue here that the phenomenologists of illness need to more explicitly address.[12]

[12] This is an issue because, according to Husserl, phenomenology as a rigorous science is predicated on not being a method of individual introspection but a systematic analysis of structures of appearances (Husserl 2009), i.e., in not being de-

Traditionally, phenomenology was not concerned with the investigation of experiences but of *appearances*, though these concepts are often conflated. This distinction might seem inconsequential, but phenomenologists emphasize it in order not to fall victim to that which phenomenologists of illness also seek to avoid, namely, a theory of a disembodied spectator for whom the world is merely given as representations ('Vorstellungen'). That is, a theory where the body acts as a mere appendix to or ontologically distinct from the reflective self, which is often referred to as a sort of Cartesianism in the literature.[13] However, a strong emphasis on experience obscures what must be explained if we operate with a strong notion of embodiment, i.e., how bodily functionality and conscious experience condition one another. Here, I will analyze three specific issues that arise from this: 1) how is the theory of embodiment compatible with the strong distinction be-

---

scriptions of 'my' private experiences but of phenomena 'as such'. In principle, phenomenology is an intersubjective enterprise that seeks to investigate essences of appearances. Heidegger strongly underscores the ontological level, i.e., structural or essential features, instead of the ontic or empirical as the main focus of the phenomenological analysis as well (2006, §3-4).This elaborate discussion between naturalized and transcendental phenomenology is, however, far too extensive to be done justice in this context (cf. for example Zahavi 2013, 2019). Both approaches naturally have their merit, here, I simply wish to make the point that an analysis, which draws less on private experiences and more on the analysis of transcendental conditions, might alleviate some of the issues that PHI faces.

[13] Which is almost a pejorative term in this context even though Descartes is much more nuanced than he is given credit for. In Descartes' view, the soul does not relate to the body like a sailor on her ship who can jump overboard when danger looms (Descartes 2013: 113). The union between body and soul is much more intimate, it forms a unity, and the soul is "truly joined to the whole body" (1989: §30) though this connection is difficult to (satisfyingly) explain on dualistic terms.

sdu.dk

#sdudk

tween disease and illness? 2) What distinguishes experiences of problematic embodiment from experiences of illness? 3) How should existential edification and transformative experiences in illness be understood? It is my assumption that an investigation of the transcendental properties and genetic conditions for illness can alleviate these issues.

Regarding the first issue, the strong focus on psychological phenomenology leads the phenomenologists of illness to strongly differentiate the experiential from the functional dimensions in pathology. To pick two examples, Carel (Carel 2018, 17) and Svenaeus (2018, 42) adopt the Boorsean distinction between *disease* and *illness* and consequently severs the tie between organismic dysfunctions and 'feeling sick'. It is essential for PHI that "human experience is incarnated" (Leder 1990, 1) and that the body is an *existential*, i.e., a fundamental structure of existence according to Heidegger's terminology (Svenaeus 1999, 183). Consequently, they understand subjectivity not as a body-independent substance of pure cogitations and affections but as an embodied subjectivity. The mind is not independent from but closely tied to and interconnected with the body. Simultaneously, points such as "Illness is, first and foremost, a subjective experience. As such, it is an inner - rather than an outer – event (…)" (Toombs 1992, 23) are commonplace in the literature, which seems to emphasize the ill body *as given to* consciousness. There is here a risk of exchanging the emphasis on the objective body

with an emphasis of the lived body, which would be equally one-sided, as Leder warns (Leder 1990, 6; Zaner 1981, 89-90). Despite the proposed grounding of illness in an embodied subjectivity, there also seems to be an inconsistency between the theoretical aims of the phenomenologists and the phenomenological descriptions of illness that they provide, namely of illness as consisting of inner experiences of loss, feelings of *Unheimlichkeit* and so on. The phenomenologists of illness maintain the irreducibility of the experiential dimension but neglect the connection between biological functioning and experience, which cannot be conceived as downward or upward causation, as Svenaeus at times explicitly does (1999, 170), if a strong thesis of embodiment is upheld. In essence, a unified theory of mind and body as embodied subjectivity similarly requires a unified theory of disease and illness, but it is difficult to see how these aspects of the same phenomenon form a coherent whole. The ontological status and interrelation of these perspectives on pathology therefore remain unclear.

The second issue is that the clash between the lived and physical body, i.e., a negative awareness or consciousness of one's body, does not in and of itself deliver the means of distinguishing illness from obstructions in embodiment.[14] On the one hand, this is explicitly recognized by the phenomenologists (e.g., Toombs 1992, 62), on the other, "illness manifests itself essential-

[14] By aligning itself with normative theories, phenomenologists like Svenaeus (1999, 193) also incur the problem of making plausible demarcations between pathological and "normal" states of being (cf. Kingma 2019 for more on the circumscription problem).

sdu.dk

#sdudk

ly as a disruption of lived body" (ibid.)[15] Disturbances "… in the various and varying interactions between embodied consciousness and the world" occur on many levels and with high regularity. The transparency of the lived body is quite fragile, and the biological organism perpetually intrudes upon and limits it in uncountable ways. Most intrusions are mild, e.g., when I cannot help but to blush, or laugh and burst into tears at inappropriate moments,[16] when I receive an odd look from a stranger and become aware of my own body, when one coughs, sneezes, regurgitates, gets erections, periods, hot flashes, becomes hungry, thirsty, out of breath, shocked, urgently needs to visit the bathroom, along with the myriad of lesser aches, pains, itches, and indefinable sensations. Core elements of human existence are unintelligible without thematized or challenged embodiment like sexuality, where being 'turned on' or 'turned off' are notoriously independent of conscious choice, or tough physical exertion, which entails a complex interplay between the lived body and the physical limitations of the organism. These disturbances usually do not pose serious challenges to the lived embodiment in the sense that they alienate

[15] Cf. Svenaeus (1999, 138) for a similar point.

[16] Cf. Plessner's work *Lachen und Weinen. Eine Untersuchung der Grenzen menschlichen Verhaltens* (1982), wherein Plessner argues that laughing and crying as liminal phenomena expose the dual aspect of human nature.

the afflicted person from the familiar meaning structures of existence. Not even more serious albeit temporary intrusions, such as the common cold, need fundamentally shake this trust. Not every bodily intrusion therefore causes alienation, but this begs the question: if problematic embodiment, understood as the disruption between the objective and lived body with a certain negative awareness and consciousness of one's body as a result, does not constitute illness, what then?

Toombs (1992, 100) and Svenaeus (1999, 164-167) suggest that the difference lies in extent and duration. Carel ruminates on this issue as well and concedes that the model of the transparent body is idealized but maintains that it is a matter of degree whether problematic embodiment constitutes illness (2018, 57-59). This seems implausible for several reasons. To give two examples, the chronically lazy person who wishes to be active but for whom the sluggishness of the body is a constant obstacle, or the aging person who perpetually find themselves less and less able-bodied and are fundamentally bothered thereby, are both cases of durative bodily intrusions that are negatively thematized. Mostly, such types of embodiment are not tinted with the same experiential hue as illness, though they might occasionally be. Moreover, even if granted that duration distinguishes illness from problematic embodiment, this would also include more permanent and fundamental bodily disruptions, such as disability, or changes in life stages like puberty, pregnancy, menopause etc. While there plainly are some common characteristics between these types of existential events, such as bodily uncertainty or loss of familiarity, we commonly associate illness with a degree of suffering or alienation, which these cases only potentially involve.

sdu.dk

#sdudk

Regarding the third issue, according to the phenomenologists of health, illness harbors an existentially edifying and transformative potential. Illness brackets the everyday and thereby brings the sick person face to face with their mortality, which occasions a deeper connection with, reflection upon, and appreciation of one's life and values that for the most part lay hidden in 'ordinary' life. Phenomenologists of illness here seem to implicitly rely on the thought figure of *authenticity* especially prevalent within existential philosophy.[17] The general gist being that illness is not necessarily existentially detrimental but enables the sick person to live more purposefully, intensely and genuinely. One of the most striking literary depictions of this comes from Tolstoy's *The Death of Ivan Ilyich*, a very common point of reference in the literature, wherein the protagonist, in all ways an ordinary man who leads a shallow life despite his prominent position as a judge in the supreme court, receives a revelation on his deathbed. Ilyich realizes that his entire life until that point has been a life of 'falsity', of having and acting out the wrong values, but the illness lifts

[17] Both Carel and Svenaeus operate within this Heideggerian distinction between "Eigentlichkeit" and "Uneigentlichkeit", i.e., authenticity and inauthenticity (Heidegger 2006, §27), when they relate illness to "being-towards-death" (Carel 2018, 150) or "Unheimlichkeit" (Svenaeus 1999).

the veil and enables him to realize the 'true' meaning of life in the nick of time.[18]

The thought is compelling, and the psychological edge that it could give the sick person to inscribe their illness in a narrative, which gives it meaning and purpose, should not be underestimated. Nevertheless, the question still lingers whether it is a fallacy, albeit a very human one, or a useful form of self-deceit to expect compensation for the suffering that one needlessly endures. Two immediate concerns raise themselves: is this viewpoint an expression of a survivor bias, which only relays the positive accounts of life overcoming disease? And is it an unduly romanticization of illness and suffering? In *The Jargon of Authenticity*, Adorno remarks upon the implicitly moralizing nature of the notion of authenticity as a romanticizing of the 'true' existence that undergirds the present life of inauthenticity.[19] Adorno writes:

> "[In the feeling of meaninglessness] what this consciousness dreads it turns in such a way that the threat seems to be an innate part of it, and thus it weakens that element of the threat which can no longer be grasped in human terms. The fact that on all sides meaning of every kind seems to be im-

[18] Heidegger explicitly refers to *The Death of Ivan Ilyich* in *Being and Time* as an example of a person who does not shy away from their death as 'One' does but gains an authentic relation to it (2006, §51).

[19] It has been suggested that Heidegger's reassurance that the inauthenticity of "das Man" is not a negative valuation (2006, §38) nears that of a performative contradiction, given that there is an unmistakable air of negative judgment both in the terminology and the descriptions of the inauthentic life, to which labels such as *alienation* ('Entfremdung'), *being lost* ('Verlorenseins') are attached.

sdu.dk

#sdudk

> potent against evil [Unheil],[20] that the latter yields no meaning at all, and that the assertion of meaning may even promote evil, is registered as a lack of metaphysical content (…)" (Adorno 2003, 28).

To Adorno, the compulsive need to extract positivity from negativity and meaning from meaninglessness is itself an ideology, which divulges the inability to confront the catastrophe as such. To say that the phenomenologists of illness revert to as crude a theory would be an exaggeration, yet the same distinction between the authentic and inauthentic life seems to pervade the phenomenologists' writing. I will leave this topic as an open question but argue that the transformative and edifying potential of illness can be given another interpretation that is less normatively laden, namely as an *adaptation* of the alien into the lifeworld.

In the following, I suggest that a Heideggerian understanding of existence as a temporal, conatively guided activity might alleviate some of the problematic aspects of a psychologizing understanding of illness. Since Svenaeus has worked extensively with Heidegger's philosophy as well, a short declaration of the differences between our interpretations is warranted. Svenaeus

[20] 'Evil' is a quite normative translation of 'Unheil', which can also mean 'misfortune' or 'catastrophe'.

primarily interprets illness as a *Stimmung* (Heidegger 2006, §29) of uncanniness and "unhomelikeness", i.e., a mood or 'existential feeling', as conceptualized by Ratcliffe (2012), which causes feelings of suffering and alienation and inhibits the sick person's embodiment, comportment into the world etc. (Svenaeus 2021). Moods differ from emotions in not being object-oriented but rather fundamental affective states that color the entire experiential field. For example, a feeling such as anger is directed at a person, thing, or event that aroused it, whereas depression is a mood that makes the world in its totality appear fundamentally irrelevant, sad, hopeless etc. Svenaeus and I agree that alienation as a mood is undoubtedly an important element in illness, but in the interpretation below it is a consequence rather than primary characteristic of illness. My interpretation of Heidegger emphasizes the dynamic elements of the analysis of *Dasein* to a higher degree, i.e., that existence is a conatively guided, temporal activity and that fundamental broaches upon this activity generate illness. By underscoring illness as an activity rather than a mood, a more psychologizing phenomenological approach can possibly be transgressed and supplemented.

Functionality and experience

Though having a limited regard for the body, Heidegger has been a large inspiration to phenomenology of health. Yet many phenomenologists bypass a crucial determination of *Dasein*, which could shed some light on the above-enumerated difficulties, namely that "Dasein is the being [Seiende], which revolves

sdu.dk

#sdudk

around its own Being [Sein]".[21] In Heidegger's nomenclature, existence has the character of *sorge*, i.e., *care* (Heidegger 2006, §41). Perhaps it is tempting to read a quasi-Darwinian animalistic striving towards self-preservation, the Freudian pleasure principle, an essentialist teleology etc. into this statement, but this would be a mistake. *Sorge* does not refer to any empirical drive per se, but the structure of striving inherent to existence that founds or shapes all particular drives and projects as such. *Sorge* is not a contingent, empirical property (an 'ontic' trait), but an *ontological* determination (a so-called *Existentiale*). What it means to exist is to be in a constant process of 'caring for' one's existence. The ontological structure of Sorge is what constitutes the meaningfulness of structures of meaning in contrast to the meaninglessness of others.

This can be illustrated in the following way: one always finds oneself amidst the furthering of certain goals and projects. Even when one decides to have no such goals, one is still 'doing something', namely actively trying to be devoid of goals, thereby proving the point negatively. But not all goals can be pursued simultaneously, some opportunities must be realized at the behest of other. Say, if one's purpose in life was to become a great phi-

[21] "Das Seiende, dem es in seinem Sein um dieses selbst geht" (Heidegger 2006, §9).

losopher, this ambition would be difficult to reconcile with a life of intellectual inactivity. This grander meaning trickles down through the entirety of the Dasein's actions and values. I read the book to write the paper, I write the paper to receive recognition from my peers, I receive recognition from my peers to gain traction within the philosophical milieu and so on. All these actions carry an implicit meaning, which ultimately aim at my goal of becoming a great philosopher. Life consists of such intricate structures of cross-connected meanings, which as a totality point towards a given project, according to Heidegger (ibid, §15). This totality can be called the *lifeworld*,[22] which denotes the whole of familiar structures, habits, meanings, and actions that undergird life in its '*Alltäglichkeit'*, its 'everydayness'. Note, these structures of meaning are not projections of deliberate preferences – the phenomena themselves *appear* to Dasein as more or less meaningful.[23] The book has an allure, exerts a certain pull, as a possibility of realizing a project, while other things leave one indifferent. The world appears to Dasein as normatively structured. These projects are mostly adopted from what 'one' does, i.e., *das Man* (ibid, §27), according to Heidegger. Hence the emphasis on the expression that Dasein finds itself in an *understanding* (*Verstehen*) of its world (ibid, §31). The essence (*Wesen*) of Dasein

[22] Though this is a Husserlian term (Husserl 2012), I use it to stay within the conceptual framework of PHI.

[23] In *Experience and Judgment*, Husserl emphasizes a similar point, although he distinctly relates it to perception (1973, §21). Other phenomenologists of health such as Ratcliffe (2012) and Fuchs (2013) have also explored this topic in relation to mental illness where the conative drive is suspended.

sdu.dk

#sdudk

does therefore not consist in a certain inner feeling or immediate self-presence, a primary experiential field, or a series of actions contained within the mind carried to fruition in the external world etc. Dasein's being unfolds as an immediate *praxis*, i.e., as active striving and a striving activity.

Heidegger's understanding of existence is therefore less psychologizing. Instead of stressing the qualia of experience, he emphasizes the dynamic nature of existence. Subjectivity is on this account therefore understood as a praxis, i.e., a directed, temporally structured activity laden with structures of meaning. The phenomenologists of illness naturally recognize the dynamical nature of subjectivity and its relation to the body, but the distinguishing property of illness in their account still seems to be encroachments upon embodied consciousness by the physical body with experiences of suffering and alienation as result. We must, however, distinguish between problematic embodiment where the sense of self is intact though the body asserts itself in a troubling way such as aging and pregnancy, and embodiment, which engenders experiences of radical alienation on a fundamental bodily and existential level.

To reiterate, illness is not necessarily engendered by negative disruptions between the lived and physical body, the 1. and 3. person perspective. The body as object may interrupt, impose itself, or change in significant ways without necessarily causing breakdowns in conations. Instead, we might introduce the concept

of a *vital break*, which denotes that which fundamentally cannot be integrated into the lifeworld understood as the orders of conations, of sought-after possibilities, preconceived understandings, and habits of actions that is integral to existence. This gives us some distinct advantages in understanding and explaining the embodiment of, e.g., a disabled person in contrast to a sufferer of sclerosis, where the former's mode of embodiment might be entirely integrated into their lifeworld though being limited or thematized and the latter most likely not.

Furthermore, this hints at another way of conceiving the relation between physiological functionality and conscious experience. As stated, the strong thesis of embodiment necessitates that the identification between body and mind goes both ways, though phenomenologists of health have mostly focused their attention on describing the subjective aspects of embodied consciousness. We must, however, assume that a certain objectiveness, physicality and alienness adheres to the body even in the mode of being most familiar to the subject, which phenomenologists such as Svenaeus admit (1999, 157), but which is difficult to reconcile with the paradigm of the withdrawing and transparent body that absorbs its milieu into its mode of being. Hans Jonas proposes the alternative that embodiment is not constituted by smooth and effortless comportment into the world, but that:

> "Experience has its seat in the *effort* I must make to overcome the resistance of worldly matter in my acting and to resist the impact of worldly matter upon myself. This happens through and with my body, with its extensive outwardness and its intensive inwardness at once, which both are genuine aspects of myself" (Jonas 2001, 23).

sdu.dk

#sdudk

That is to say, subjectivity is constituted not by 'effacing' objectivity but by the subject discovering its limits through *effortful* interaction with its surroundings. In and through resistance, bodily or otherwise, a sense of self is cultivated in direct correlation with the objectivization of the world, which are two aspects of the same process. Exploring this hypothesis further is unfortunately outside the scope of this article, but there are alternatives to the model of the transparent and withdrawing body, which are worth investigating.

Problematic embodiment and illness

The practical engagement, which characterizes existence, is conditioned by, firstly, a temporal structure, and, secondly, a primordial openness to the world, which enables *self-transcendence* but simultaneously opens Dasein to negative experiences. The temporal structure of life discloses itself in the fact that the conations of Dasein are principally without end; it finds itself in the constant process of realizing a not-yet-actual state of affairs. For Dasein, the potential of becoming is just as, if not more, present than the immediate reality, the actual. But these acts are themselves founded in already-established conceptions of the self and world, which lie in the past, and through which Dasein continually draws meaning and purpose. In its engagement with the world, Dasein therefore 'draws in' the three modalities of being, i.e., necessity,

reality, and potentiality, and the temporal *exstases*, i.e., past, present, and future, which together form a functional whole. When Dasein acts, it seeks to actualize in the present a future, potential state of affairs based upon a past, and in this sense necessary, understanding of its world. Dasein is never just an object at hand, but a process that is constantly realized but never completed.

This would, however, be unthinkable without a principal *openness* – a term with several extensions in Heidegger's 'fundamental ontology'. It denotes a property of Dasein's own nature (*Wesen*): what project Dasein pursues, what understanding of the world it finds itself in, is contingent. When Dasein acts, it acts not out of biological or ontological necessity but because one out of countless possibilities has been – implicitly or explicitly – chosen. However, it simultaneously denotes that Dasein is open to the world, that it is responsive. Indeed, that it is in virtue of Dasein's ontological responsiveness that phenomena such as anxiety and awareness of death can even present themselves. These phenomena cannot simply be ignored; they present themselves with a certain compulsion and forcefulness because we are delivered to the world. In other words, we cannot not care or not respond to what imposes itself because existence is fundamentally affective and receptive. According to Waldenfels' responsive phenomenology, responses are not first and foremost conscious, deliberate answers; we have always already responded before being aware of doing so (Waldenfels 2011, 37). If someone calls out our name on the street, we turn our head and listen intently before deliberating how to react. In so far as we register ourselves as the recipient of the call, our response precedes the deliberate answer, and the response eschews a compartmentation into a physiological or psy-

sdu.dk

#sdudk

chological reaction: it manifests itself throughout the entire embodiment of the person.

What is of special interest here is why certain responses are elicited and others not. If someone mistook us for another person and called us by a wrong name, we might not react in the slightest though being explicitly addressed. What this simple example demonstrates is that our experience is structured through certain orders, Waldenfels argues, which separates the comprehensible from the incomprehensible, identity from non-identity, the familiar from the alien. As simple a case as hearing an unknown language in contrast to hearing one's mother tongue demonstrates this point. There is nothing alien about the foreign language in and of itself, but it receives the branding of 'foreign' in virtue of not being my mother tongue. Orders are therefore orders in virtue of what they exclude. These "boundaries emerge from ordering processes" (Waldenfels 2011, 8). At the point of confrontation with the phenomenon, certain 'breaking points' (*Bruchlinien*) appear (Waldenfels 2002), through which the intake is 'sorted' into the ordinary or extraordinary. This holds none the less so for

pathology, which is one of the experiences of alienation *par excellence.*[24]

The radically alien is that which cannot be assimilated in or fundamentally breaks a given order, a principally non-indifferent experience which one cannot help but pay heed to (Waldenfels, 35-37). According to Heidegger, the absolutely alien is death (Heidegger 2016, §47), not because it invalidates any particular possibility but *possibilities as such*. Illness can be interpreted in much the same way. If we return to our ambitious philosopher, she might experience an interruption of the ability to carry on with her projects because she is too tired to think, without the meaning structures of her life suffering for this reason. But if she lost cognitive ability, e.g., due to early onset of Alzheimer's, it would in all likeliness be irreconcilable with the conations of her life. Here, the issue is not simply that the experience cannot immediately be assimilated into the lifeworld, but that it fundamentally invalidates it. Not only is she unable to do the intellectual work that the life as a philosopher requires, but the Alzheimer's instates a new order of embodiment incompatible with her projects. The illness does not simply produce inability but changes the meaning structures of life in a fundamental way. The radically alien therefore distinguishes itself from problematic embodiment by having a lifeworld-shattering character. In other words, some affections can be integrated into the lifeworld while others fundamentally cannot, giving rise to alienation. Alienation is there-

[24] Cf. the essay *Der Kranke als Fremder* (Waldenfels 2016). Here, alienation is to be understood in a different way to Svenaeus' understanding thereof and I will get to the difference shortly.

sdu.dk

#sdudk

fore not to be construed as a mood or an emotion but as the conflict between the praxis of the individual's life and the new, irreconcilable state of being.

Life essentially unfolds as a temporally projected activity because existence is always directed towards the future where certain possibilities are sought realized based on pre-conceived understandings and given conditions of life. The affections that force themselves upon the person must be integrated into this activity. For the large part, these affections, from trivial bodily intrusions such as temporary shortness of breath to significant ones such as aging, are to varying degrees unproblematic. Embodiment can be both thematized and/or problematic and still be integrated in the lifeworld, meaning that understandings and abilities to project one's conatively guided activities into the future do not suffer. Other cases, such as a promising track star falling ill with osteoporosis, is of a more severe character. At first, the onset of physical disability might be slow, gradually growing more and more severe until the point of extensive bodily disability. The issue here lies not in physical disability, which cases such as well-adjusted persons with disabilities attest, but that the care for oneself is obstructed. The order of meanings that governed life for the former track star quite literally has no future, along with the pre-conceived meaning structures of life from which these ambitions drew their meaning and relevance. The possibilities of rising to

prominence in the world of athletics are made null. In other words, the care for the self is rendered inviable.[25]

Sorge is however not only an activity, but simultaneously a process of identification, of creating identity. Life is not a thing at hand with a certain essence; life *comes into being through action*, and through acting, Dasein constitutes its identity and implicitly posits the value of the pursued goal because of the contingency of the choice. When an affection brings this dynamic out of play, Dasein undergoes both a crisis of identity as well as meaning. Orders of meaning are constituted by what they exclude, when the meaningless therefore relentlessly imposes itself, it produces a schism in the person's being. As several phenomenologists and medical professionals have noted, patients often refer to their illness as an 'it' (Leder 1990, 76; Toombs 1992, 73), even though this 'it' is part of 'me'. Phenomenologically, this implies a lack of identification: There is a split between the endured affection and the self, between the 'I' and the 'it'.[26] Empirical accounts of the biographical disruption that patients face in the wake of severe illnesses also lend some credence to this theory (Bury 1982). Due to the pathic character of existence, this 'non-I' imposes itself, is autonomous and not under the spell of my will. I am unable to

[25] Cases of permanent, progressive pathology lend themselves well to illustrating this, but an example of a person who suffers an unexpected heart attack could be equally relevant. Though a single event, the heart attack might threaten and invalidate the orders of meanings and ability for temporal projection in much the same way as sclerosis.

[26] Toombs (1992, 75) and Svenaeus (1999, 186) have very similar sounding phrasings of this phenomenon, but the phenomenon is given another interpretation in this context.

sdu.dk

#sdudk

will a pain away, though I can attempt to willfully ignore it, the same way that I am unable to will cancer cells to stop procreating. Consequently, my ability to extend myself in the dynamic activity of creating meaning and identity becomes fundamentally obstructed. This irresolvable conflict between the praxis of the individual's life and a new state of being then begets feelings of loss, suffering, and other core features in the experience of illness, which phenomenologists have explored in great detail.

The difference between thematized, problematic embodiment and illness is therefore that the latter not only puts the praxis of life, the care for oneself, to a halt but fundamentally invalidates it temporarily or permanently. That is, rather than as a disruption of the lived body or experiences of alienation, here, illness is understood as a *vital break*, a break in the dynamic, conative activity of life. In the case of Dasein, its freedom to shape life along with its receptiveness and responsiveness towards the world makes it vulnerable to countless ways in which this dynamic activity can be perturbed. This, I claim, is the *differentia specifica* between thematized, problematic embodiment and illness: illness involves a fundamental break with conative activity.

Edification as adaptation

Though a complete revolution of the way that life is conducted is unlikely, the functional openness in Dasein's existence points to the possibility of a new lifeworld, in which the vital break is

coped with, i.e., adapted to or integrated into the lifeworld of the person. To reiterate, this is not a matter of conscious, deliberate effort. Dasein cannot help but habituate the circumstances, in which it finds itself, to revert (*zu verfallen*) to a certain everydayness (Heidegger 2006, §38). Ordinary life, which is sometimes negatively appraised as the 'inauthentic' and 'average', is the saving grace of the ill person, for it is the ability to cope with one's circumstances that makes it possible for the extraordinary to become ordinary and for the alienating to become familiar. And though there is no question that a certain lack of reflectiveness often characterizes everyday life, it seems questionable whether illness actually prompts existential growth, when more often it seems that for the person who suffers, the world shrinks and their entire being is consumed by the affliction. Moreover, demanding a meaning from the inherently meaningless might only serve to further the feeling of alienation and suffering.

There is, however, another sense in which illness can be understood as a catalyst for a recalibration of life, namely as *adaptation*. Illness is the disturbance of the person's lived praxis, their striving for self-unfolding. As such, it carries an implicit impetus; the illness is something to be rid of ("mit dem es fertigzuwerden gilt"), as Gadamer remarks (1993, 135). The contingency of specific existential modes of being and the tendency to habituate the unfamiliar allows the person to integrate the alienating circumstances into their lifeworld. I will not go into detail with the countless ways in which such an adaptation can take place since empirical science can give a much more nuanced picture thereof. Priorities in life shift, expectations are modified, the everyday is restructured, social interactions are more cherished, one's energy is more carefully used and so on. Each of these smaller activities

sdu.dk

#sdudk

can be interpreted in the same way: as a way of accommodating to or integrating the alien in the lifeworld, whereby it ceases to be alien. Naturally, this process is seldom exhaustive, and a total accommodation is unlikely, but the 'inauthentic' everydayness of existence allows Dasein a way to make illness less cumbersome.

Conclusion

Phenomenology of illness is a field in development and therefore has some way to go before it is not merely considered an additional perspective, but an integrated part of the understanding of health (cf. Klausen 2021, 12). Though it is most likely true that the phenomenological perspective still encounters resistance from purely biomedical understandings, the phenomenologists of health have themselves played a part in perpetuating a psychologizing understanding of phenomenology, which is hard to integrate in a holistic conception of disease and health. I have tried to argue that the Heideggerian framework could provide a way out of this issue. By interpreting existence as a temporal, conatively driven activity, it transgresses sharp distinctions between disease and illness, physical and lived body. In doing so, it is more adept at maintaining a strong theory of embodiment.

Author contributions: This is a sole authored paper.

Declarations: There are no conflicts of interests to declare.

Cited literature

Adorno, Theodor W. 2003. *The Jargon of Authenticity*. London: Routledge.

Albrecht, Gary L., Devlieger, Patrick J. 1999. The Disability Paradox. High Quality of Life Against All Odds. *Social Science & Medicine* 48: 977-988. https://doi.org/10.1016/S0277-9536(98)00411-0

Birkenbach, Jerome E., Felder, Franziska, Schmitz, Barbara. (ed). 2013. *Disability and the Good Human Life*. Cambridge: Cambridge University Press.

Boorse, Christopher. 1975. On the Distinction between Disease and Illness. *Philosophy & Public Affairs* 5: 49-68.

Bury, Michael. 1982. Chronic illness as biographical disruption. *Sociology of Health and Illness* 4: 167-182. https://doi.org/10.1111/1467-9566.ep11339939

Carel, Havi. 2019. *Illness – The Cry of the Flesh*. London and New York: Routledge.

Carel, Havi. 2018. *Phenomenology of Illness*. Oxford: Oxford University Press.

Descartes, René. 2013. *Meditations on First Philosophy: With Selections from the Objections and Replies*. Cambridge: Cambridge University Press.

sdu.dk

#sdudk

Descartes, René. 1989. *The Passions of the Soul*. Indianapolis/Cambridge: Hackett Publishing Company.

Fuchs, Thomas. 2013. Temporality and psychopathology. *Phenomenology and the Cognitive Sciences* 12: 75-104. https://doi.org/10.1007/s11097-010-9189-4

Gadamer, Hans-Georg. 1993. *Über die Verborgenheit der Gesundheit. Aufsätze und Vorträge*. Frankfurt am Main: Suhrkamp.

Heidegger, Martin. 2006. *Sein und Zeit*. Tübingen: Max Niemeyer Verlag.

Husserl, Edmund. 2012. *Die Krisis der europäischen Wissenschaften und die transzendentale Phänomenologie*. Hamburg: Felix Meiner Verlag.

Husserl, Edmund. 1973. *Experience and Judgment. Investigations in a Genealogy of Logic*. Evanston: Northwestern University Press.

Husserl, Edmund. 1968. *Husserliana Band IX: Phänomenologische Psychologie*. Den Haag: Martinus Nijhoff.

Husserl, Edmund. 1983. *Ideas pertaining to a pure phenomenology and to a phenomenological philosophy*. The Hague: Martinus Nijhoff Publishers.

Husserl, Edmund. 2009. *Philosophie als strenge Wissenschaft*. Hamburg: Felix Meiner Verlag.

Jaspers, Karl. 1965. *Allgemeine Psychopathologie*. Berlin: Springer Verlag.

Jaspers, Karl. 1912. Die phänomenologishce Forschungsrichtung in der Psychopathologie. *Zeitschrift für die gesamte Neurologie und Psychiatrie* 9: 391-408. https://doi.org/10.1007/BF02911781

Jonas, Hans. 2001. *The Phenomenon of Life: Towards a Philosophical Biology*. Evanston: Northwestern University Press.

Kingma, Elsejin. 2019. Contemporary Accounts of Health. In *Oxford Philosophical Concepts: A History*, ed. Peter Adamson, 289-318. Oxford: Oxford University Press. https://doi.org/10.1093/oso/9780199916429.001.0001

Klausen, Søren Harnow. 2021. Phenomenology of Illness and the Need for a More Comprehensive Approach: Lessons from a Discussion of Plato's *Charmides*. *The Journal of Medicine and Philosophy* 46: 630-643. https://doi.org/10.1093/jmp/jhab019

Leder, Drew. 1990. *The Absent Body*. Chicago and London: The University of Chicago Press.

McConville, Pat. 2021. Toward a phenomenology of congenital illness: a case of single-ventricle heart disease. *Medicine, Health Care and Philosophy* 24: 587-595. https://doi.org/10.1007/s11019-021-10026-3

Plessner, Helmuth. 1982. *Gesammelte Schriften VII, Ausdruck und menschliche Natur*. Frankfurt am Main: Suhrkamp.

Ratcliffe, Matthew. 2012. The Phenomenology of Existential Feeling. In *Feelings of Being Alive*, ed. Joerg Fingerhut, Sabine Marienberg, 23-54. Berlin: De Gruyter. https://doi.org/10.1515/9783110246599.23

Ratcliffe, Matthew. 2012. Varieties of Temporal Experience in Depression. *Journal of Medicine and Philosophy* 37: 114-138. https://doi.org/10.1093/jmp/jhs010

Svenaeus, Fredrik. 2019. A Defense of the Phenomenological Account of Health and Illness. *Journal of Medicine and Philosophy* 44: 459-478. https://doi.org/10.1093/jmp/jhz013

Svenaeus, Fredrik. 2021. Health and Illness as Enacted Phenomena. *Topoi* 41: 373-382. https://doi.org/10.1007/s11245-021-09747-0

Svenaeus, Fredrik. 2018. *Phenomenological Bioethics: Medical Technologies, Human Suffering and the Meaning of Being Alive*. London and New York: Routledge.

Svenaeus, Fredrik. 1999. *The Hermeneutics of Medicine and the Phenomenology of Health: Steps towards a Philosophy of Medical Practice*. Linköping: Linköping University.

Toombs, S. Kay. 1992. *The Meaning of Illness – A Phenomenological Account of the Different Perspectives of Physician and Patient*. Dordrecht: Springer.

Waldenfels, Bernhard. 2002. *Bruchlinien der Erfahrung*. Frankfurt am Main: Suhrkamp.

Waldenfels, Bernhard. 2016. *Grenzen der Normalisierung*. Frankfurt am Main: Suhrkamp.

Waldenfels, Bernhard. 2011. *Phenomenology of the Alien: Basic Concepts*. Evanston: Northwestern University Press.

Zahavi, Dan. 2019. Applied phenomenology: why it is safe to ignore the epoché. *Continental Philosophy Review* 54: 259-273. https://doi.org/10.1007/s11007-019-09463-y

Zahavi, Dan. 2013. Naturalized Phenomenology: A Desideratum or a Category Mistake?. *Royal Institute of Philosophy Supplements* 72: 23-42. https://doi.org/10.1017/S1358246113000039

sdu.dk

#sdudk

Zaner, Richard M. 1981. *The Context of Self: A Phenomenological Inquiry Using Medicine as a Clue*. Athens: Ohio University Press.

6.3 A critique of the critique

The newer tradition of phenomenology of illness perceives itself as combating a one-sided reductionism but thereby ends up perpetuating an equally one-sided conception itself. Nowhere is this more evident than in the critique of biomedicine and its descendance from the philosophy of Descartes. This critique dates to Engel's article, in which the biopsychosocial model is proposed, motivated by the insufficiencies of biomedicine (Engel, 1977). In this article, it is argued that the Cartesian distinction between *res cogitans* and *res extensa*, which entailed a view of mind and body as fundamentally distinct, is the direct cause of biomedicine. Whereas mind was conceived as an independent realm of immaterial thoughts, emotions, and experience, body was interpreted as a complex physical mechanism, likened to an intricate, self-winding clockwork. This resulted in a view of the diseased body as a malfunctioning machine and entailed both a systematic downplaying of social, environmental, and experiential dimensions along with the attempt to reduce consciousness to physical processes; poignantly expressed by the 18th century French physician Cabanis: "the brain secretes thought as the liver secretes bile" (Canguilhem, 2008a, p. 7). Through this framework, the path was

paved towards a view and practice of medicine that focused on understanding and correcting bodily mechanisms while simultaneously disregarding the patient perspective.

This standard view has several issues. The glaring contradiction between the ascription of reductionism and Cartesian dualism to biomedicine has, to my knowledge, not been explicated, though it makes little sense philosophically. Dualism entails that mind and body are two fundamentally distinct and irreducible ontological spheres, while reductionism – mostly but not necessarily – is a materialistic or physicalist theory, often of a scientistic sort, that views consciousness as an epiphenomenon to material properties. Not only does Descartes explicitly reject a reductionistic conception of mind, but he also devotes long passages of several works to elucidating the interaction between mind and body. Indeed, the doctrine of the pineal gland as the epicenter of interaction between mind and body directly contradicts the crude picture of the complete separation between mind and body and consequent devaluation of the experiential dimension.

In fact, Descartes has a remarkably holistic picture of man:

> "(…) the soul is truly joined to the whole body, and that one cannot properly say that it is in any one of its parts to the exclusion of the others, because [the body] is one, and in a way indivisible, in proportion to the disposition of its organs, which are all so related to one another that when any of them is removed this renders the whole body defective; and because [the soul] is of a nature which has no relation to extension, or to the dimensions or other properties of the stuff the body is composed of, but only to the whole collection of its organs – as becomes apparent from the fact that

sdu.dk

#sdudk

> one cannot in any way conceive of a half or a third of a soul, or of what extension it occupies, and from the fact that [the soul] does not become smaller from some part of the body being cut off, but separates from it entirely when the collection of its organs is dissolved" (Descartes, 1989, p. 35).

That is, Descartes assumes a theory of embodiment. This is especially evident in his conception of *passions* or *emotions*. If a person perceives someone being wronged, the sense perception is first carried to the brain through a series of intricate mechanisms, the impression is relayed to the soul, the soul interprets and reacts to the picture, which is then relayed through the body again and manifested into action. Descartes operates with a fully and holistic picture of man, and his conception of medicine, which was a significant concern of his (Shapin, 2000), was neither reductionistic nor biomedical but *psychosomatic* (Brown, 1989). When Descartes compares the human organism to a machine, this must also be interpreted in its historical context, for medicine up to this time was influenced by Aristotelianism and humoralism (Manning, 2019, p. 9) and the unclear conceptualizations of bodily processes contained therein. On this background, the emphasis of bodily mechanisms and organic processes – which do have machine-like properties, the heart, e.g., functions like a pump – was a valuable contribution to the scientific progress of medical

science. The human being is simply much more than a machine – which Descartes would agree with.

To put it bluntly, it is not Descartes that has a reductionistic view of mind, body, and medicine; it is phenomenology of illness as it is currently practiced since it solely treats health and disease from the perspective of experience, thereby forgoing how the physical and lived body, disease and illness interact despite ambitions towards a theory of embodiment. There is both identity and difference between mind and body, and phenomenology undoubtedly constitutes a fundamental and irreducible element in this equation, but it is one side of the coin, which needs to be supplemented by a more integrative and comprehensive approach if one wishes to construct a holistic picture of the individual as well as health and disease. This is what I attempt to do in the next chapter.

6.4 Concluding thoughts on chapter 6

This chapter argued that, despite the importance of phenomenology for philosophy of health, illness cannot be narrowed down to experiences of bodily uncertainty, suffering etc., as the current tradition seemingly posits, but is constituted through fundamental broaches upon the dynamic activity that life constitutes. In this way, it harmonizes with the picture of health and disease as dynamic and processual phenomena, which was proposed in the above chapter. The article argues against a tendency to psychologize health and illness, which also has implications for the generic health assessment practice. However, the organismic and phenomenological dimensions of health are not just two isolated perspectives but truly united. What is missing within philosophy of health is a theory that truly combines these. Similarly, the ques-

sdu.dk

#sdudk

tion why individuals, as the empirical study suggested, differ in matters of health and disease must be addressed. These themes are what the next chapter investigates.

7. Medical individualism

7.1 Do individuals differ from one another?

The relation between the universal and the particular or individual is one of the oldest and most fundamental problems of metaphysics (Gracia, 1988). That is, the question how an individual can be a particular thing while simultaneously being universal, and why particulars, though instantiations of the same pattern or idea, differ from one another. Though this problematic may seem remote and abstract, medicine echoes this discussion, for it similarly contains the tension between the particular and universal, between its status as an *idiographic* and *nomothetic* science, i.e., as striving towards greater specifications and greater generalizations, respectively. Medicine exhibits two distinct albeit related trends: as a natural science, it delineates nomological patterns of pathological conditions, typologies, stochastic mechanisms etc.; as a therapeutic art, its *raison d'être* consists in aiding the individual patient, in relieving them of suffering and illness, and helping them to lead a fulfilling life. Medicine needs both approaches. Yet, movements such as personalized medicine argue that these approaches on closer inspection *converge* because all individuals differ in significant or miniscule ways from one another. To help the patient, medicine needs a clearer picture of what makes them unique.

Whether and in what sense individuals fundamentally vary naturally depends on what is understood thereby. Traditionally, the body was conceived as *objective*. Qua corporeal object, it remains in the common sphere that in principle is accessible to everyone. As such, it can be made the object of scientific investiga-

sdu.dk

#sdudk

tion and thereby the general traits that seemingly hold for everyone can be established. The mind, conversely, was thought of as subjective in so far as it is *private*. Despite the best attempts at empathizing, no one can experience the world from exactly my perspective, while I, though I can attempt to imagine what it must be like, cannot fully know the fellow human being's perspective. The unity and continuity of my consciousness and experiential sphere furthermore provide the impression of being a distinct person. Jaspers echoes these lines of thought when he, in discussing the limits of psychopathology, remarks:

> "(…) daß er den einzelnen Menschen niemals ganz in psychologische Begriffe auflösen kann. Je mehr er auf Begriffe bringt, als typisch, als regelmäßig erkennt und charakterisiert, desto mehr erkennt er, daß in jedem einzelnen Menschen sich ihm etwas Unerkennbares verbirgt"[27] (Jaspers, 1965, p. 1).

Therefore, the corporeal nature, our matter, constitutes what is common to human beings, while mind, given its inaccessibility,

[27] "(…) there can be no final analysis of human beings as such, since the more we reduce them to what is typical and normative the more we realize there is something hidden in every human individual which defies recognition" (Jaspers, 1972, p. 1)

constitutes the seat of personality and therefore of what makes us individual and unique. And these views perhaps also play a part in the way that biomedicine is practised: as establishing typologies and lawlike features of the body, while relegating the experiential perspective of the patient or consciousness to an unknown X that principally cannot be the object of science.

Modern medicine does not abide by this picture of individuality. For movements like personalized medicine, the uniqueness of individuals arises in the conflux of factors from the molecular level to the conscious and social that make up an individual. Each human being varies in small or significant ways in terms of genetic makeup, personality, social circumstance etc., and when this untold number of elements in interaction are combined, a unique composite arises. For this reason, conditions of health and disease invariably differ fundamentally from each other. A sort of holism is thereby assumed as the cause of individuality. In this claim, they have some support from the history of philosophy, for Leibniz, for example, also stated that individuality arises through "the entire being of an individual" ("Omne individuum sua tota Entitate individuatur") (Borsche, 1976, p. 311). This, however, only shifts the discussion to the question about the nature of holism.

By relating this timely question within medical anthropology to an ontological tradition, *in casu* philosophical anthropology and biophilosophy, new insights can be garnered, I claim. What I suggest as a framework through which to unite what appears to be distinct aspects and perspectives of the person, namely the organismic and phenomenological dimensions, is essentially already expressed in a principle of Heraclitus': "ἓν διαφέρειν ἑαυτώ" (Diels & Kranz, 1972, p. 162), a "unity in difference" (Borsche, 1976, p. 315). The article attempts to unfold what this principle

sdu.dk

#sdudk

entails for a medical anthropology; whether it allows for an integrative account that combines seemingly distinct dimensions of health and illness, and what consequences it has for the individuality of these phenomena.

7.2 Article 4: Medical individualism – what makes an individual individual?

Author: Thor Hennelund Nielsen. Submitted to the journal *History and Philosophy of the Life Sciences*.

Medical Individualism – What Makes an Individual Individual?

Abstract: Recent times have seen a turn towards what can be termed *medical individualism*, that is, the theory that individual human beings, their pathologies and physiologies, are fundamentally unique and variable. This is especially evident in movements such as *P4* and *Personalized medicine* that promise a science of the individual variability within health and disease. Despite these promising ambitions, however, it remains mostly an unfulfilled ideal, in part because these movements construe individuality through the lens of a summative and material holism that interprets individuality as a complex confluence of biological, psychological, and environmental factors. This article argues that if medical individualism is to be successful, it requires a solid philo-

sophical foundation. By drawing on classical biophilosophy and philosophical anthropology, a theory of the individual as a "differentiated whole" is developed, which highlights individuality as constituted through both the totality of interdependent factors of a biological, phenomenological, and social kind and as a self with agency that relates to its own body and psyche. This alternative to a summative and material holism has three implications for the individual variability of health and disease, namely their nature as totalities, as conditioned by the norms of the individual, and as context-sensitive phenomena.

Key words: Reductionism, personalized medicine, medical individualism, philosophical anthropology, contextualism, health and disease

> "…for the physician does not cure man, except in an incidental way, but Callias or Socrates or some other called by some such individual name, who happens to be a man. If, then, a man has the theory without the experience, and knows the universal but does not know the individual included in this, he will often fail to cure; for it is the individual that is to be cured"
> (Aristotle, 1995, 981a).

sdu.dk

#sdudk

Introduction

According to Galenic tradition, there is no such thing as a "science of the individual" (Temkin, 1977, pp. 445-446). Every individual will inevitably vary in fundamental respects from idealized abstractions. When the doctor sets herself to treating the ailments of the patient, she therefore cannot simply rely on theory but must carry out the examination with a view to the unique physiological constitution of the patient, the norms of the individual's life, the society that surrounds them, their lifestyle as well as environmental circumstances. According to the Galenic rationale, the health or disease of an individual depends upon a plethora of different factors, which combined constitute an individual's life. Whether the Galenics held that there currently is or principally cannot be a science of the individual is not immediately clear. However, if there was no comparative basis between individuals at all, it would be impossible to establish general features, types, or causal processes. Throughout most of the modern history of medicine, its aim has namely been to establish general types of physiologies, to explicate causes and courses of disease, and to distinguish between normal contra abnormal functioning (Jewson, 2009). In other words, to investigate and determine the *nomological* features of disease and health – an endeavor, in which the individual *per se* played no great part.

New movements within medicine such as *P4 medicine* (predictive, preventive, personalized, and participatory), *individual-*

ized medicine, *precision medicine*, *systems medicine*, *stratified medicine* among other labels (De Grandis & Halgunset, 2016), which here will simply be referred to under the umbrella term *personalized medicine* ('PM' for short), once more emphasize the individuality of health and disease but, unlike its spiritual predecessor, additionally holds the promise of a science of the individual that can unite the study of nomological features with an *individualized* approach. In the words of Childs, Wiener, and Valle:

> "It is not clear what they [the Galenics] thought that science of the individual was, but we know what it is today. It is the uniqueness of the individual—genetic, developmental, and experiential—that accounts for human variation, whether in health or disease" (2005, p. 313)

Proponents of PM argue that modern medicine has the technical competency to explicate what constitutes the individuality of individuals. Genome sequencing, mass-collection of biometric data, access to the molecular levels of organisms etc. all contribute towards an unprecedented understanding of individual variation within health and disease.

Medicine, it therefore seems, has taken a turn once more towards what I elect to term *medical individualism*, i.e., the theory or theoretical assumption that *human beings, their pathologies and physiologies, are fundamentally unique and variable*. The transition into an individually oriented medicine is a consequence of the shift from a reductive paradigm that understands health and disease as narrowly delimited endogenous functions into a systemic paradigm that construes health and disease as a complex confluence of physiological, psychological, and environmental

sdu.dk

#sdudk

factors. It is the whole of this complex of factors, which makes the individual unique. Hood & Flores write:

> "Systems medicine, by contrast, is holistic and utilizes all types of biological information – DNA, RNA, protein, metabolites, small molecules, interactions, cells, organs, individuals, social networks and external environmental signals – integrating them so as to lead to predictive and actionable models for health and disease" furthermore adding, "We must understand the individual in the context of all of these integrated networks" (2012, p. 614 & 621).

Despite the promising ambitions of PM towards holism and individuality, this ideal remains mostly unfulfilled. PM still primarily consists of detail studies that focus on particular (macro)molecular levels (Loscalzo & Barabasi, 2011), facilitated through the analysis of averages and correlations (Voit & Brigham, 2008) rather than 'the grand context' of the individual. This is perhaps in part due to its inadequate conceptualization of individuality as constituted by interactions between large host of factors that together yield a unique composite, thereby making the notion of individuality hinge on the notion of holism. In this article, I argue that PM falls short in accounting for both individuality and holism. PM fundamentally lacks an adequate integrative model of the organism (Vogt et al., 2016; Vogt et al., 2014;

Wolkenhauer & Green, 2013) and thereby fails to draw out what exactly makes the individual individual. In order to arrive at a science of the individual, we must first know what it means to be individual – providing the philosophical cornerstones of a theory of medical individualism is what this article attempts.

The first section briefly details how the reductionistic paradigm gradually has given way to more holistic, systemic, and individualized approaches emblematic in personalized medicine, which implicitly or explicitly espouses an understanding of the individual that relies on a summative and material understanding of holism. Afterwards, I analyze both the nature and deficiencies of this understanding. The second part of the article suggests an alternative model of holism that understands the individual as a "differentiated whole", which is developed through insights from biophilosophy and philosophical anthropology. The third and concluding section draws out what this model entails for medical individualism and the following three determinations of the individual variability of health and disease are further investigated, namely their nature as totalities, as conditioned by the norms of the individual, and as context-sensitive phenomena.

From general types to individual complexity

When discussing reductionism in medicine, what is often meant is *ontological reductionism*, i.e., the view that the nature and behavior of a thing is determined by its most fundamental constituent features (Nagel, 1935). This should not be conflated with *methodological reductionism*, which is a mode of analysis whereby a phenomenon is broken down into its most fundamental constituents and studied without making any grand ontological commitments as to the nature of the thing under investigation. Within this

sdu.dk

#sdudk

context, reductionism is to be understood *ontologically*, namely as the framework that understands health and disease as fundamentally reducible to more basic entities or processes (Ahn et al., 2006a, 2006b), often of a biochemical nature. To illustrate, a depression might on an experiential and social level manifest itself as diminished mood, lack of energy and ability to connect with others, while ultimately being reducible to and caused by an abnormal neurochemical process. Naturally, one case of depression might differ in some respect from another, but both cases constitute divergent manifestations of the same types of causes. *If* the disease can be exhaustively reduced to general types of physiological processes that causally produce certain outcomes, an individualizing approach becomes superfluous since treatments can be directed towards causes without paying much regard to individual variations.

Due to this understanding of pathological mechanisms, reductionism is often closely associated with the *biomedical paradigm* that has allegedly influenced modern medicine (Engel, 1977). Biomedicine is often less of a theory and more of a set of tacit practical and theoretical assumptions or a tendency within medicine (Valles, 2020) to reduce health and disease to physiological processes. This emphasis does not preclude a more individualized practice of medicine *per se*, but two tendencies make it difficult to conceptualize medical individualism within this framework. Firstly, reductionism primarily understands functions

as monocausal and linear and thereby *a priori* preclude modes of functioning such as emergentism and top-down causation, which greatly increase the complexity of physiological functions, making the comparative basis between individuals smaller. Secondly, by construing manifest symptoms as secondary to more basic processes, reductionism simultaneously marginalizes factors such as the experiential dimension, lifestyle, social circumstances etc., which are not merely epiphenomena but exert influence on the physiological level. These issues coupled with a strong preoccupation with typologies have made reductionism emblematic of a depersonalized, non-individualizing approach to health and disease. Although biomedicine often is caricatured, and there plainly are medical cases where a reductive view is appropriate like appendicitis (Ahn et al., 2006a, p. 0957), it nonetheless seems to rely on models which are too simplistic to capture the complexities of living systems (Wolkenhauer & Green, 2013).

The critique of reductionism in medicine does not come from a single but a host of diverse movements, which all share the theoretical assumption that "…the forest cannot be explained by studying the trees individually" (Ahn et al., 2006b, p. 0709). Health and disease are rarely reducible to single factors but instead have complex, dynamic, and systemic characters that are highly subject to individual variation. This constitutes the core assumption of personalized medicine across its variable iterations, which draws inspiration from systems biology that investigates the organism and subsystems thereof as complex wholes rather than isolated components and linear functions (Green, 2016), often by means of computational modeling, big data, algorithms etc. (Kitano, 2002). PM similarly conceives physiological processes as multileveled and non-modular. Diseases cannot simply be re-

sdu.dk

#sdudk

duced to abnormal physicochemical processes since the different levels of the organism, the molecular, tissue, organic etc., are fundamentally connected, even possessing emergent qualities. In light thereof, pathologies are rather being researched as systems or networks (Barabási et al., 2011; Borsboom & Cramer, 2013). Given the enormous complexity of these processes and fundamental variations within biological constitutions across individuals, which the medical sciences have only begun to scratch at, the typologies of more reductionistic approaches to medicine seem to be overgeneralizations. Diseases with similar pathophenotypical profiles, for example, can be the result of diverse biological states as in the case of sickle cell disease (Loscalzo & Barabasi, 2011), and treatments and pharmacological interventions affect patients differently, engendering the need for individually targeted treatments. Personalized medicine, as the name indicates, therefore directs its efforts towards investigating and treating individuals or at least types that are much more fine-grained than Boorse's traditional division of functional types according to gender, age, and species (Boorse, 1977), namely as functional wholes consisting of an untold number of complex interactions between physiological, psychological, and environmental factors:

> "Systems (P4) medicine is now pioneering something that never existed before – actionable understandings of disease and wellness as a continuum of network states unique in

> time and space to each individual human being" (Hood & Flores, 2012, p. 166).

Where reductionism strives to reduce the totality to its constituent parts, PM holds that the individual as a whole possesses irreducible, emergent qualities. However, PM has been criticized for (still) being too specialized and lacking adequate conceptions of organizing principles (Wolkenhauer & Green, 2013) and for having an overly restrictive understanding of holism (Vogt et al., 2016; Vogt et al., 2014) that only nominally investigates the person as a whole (Giroux, 2020a; Greene & Loscalzo, 2017). Due to the interpretation of the organism as a non-modular, multileveled totality, whose complexity makes it fundamentally distinct, PM grounds individuality in a *summative* and *inductive, material holism* (Bertalanffy, 1960, p. 10). Summative and inductive, because it construes the wholeness of the individual as a conflux of diverse factors; material, because it conceives these factors as – primarily although not exclusively – material properties. It is the so-called "quantified self" (Hood & Flores, 2012, p. 166), the biometrics of the individual, that PM often strives to elucidate. Difficulties arise, however, when the pieces of the puzzle that constitute the individual are to be assembled:

> "As biomedical research and clinical practice try to assemble these atomized pieces into meaningful wholes, the process of putting the patient back together again has proven to be highly complex" (Greene & Loscalzo, 2017, p. 2493).

Indeed, it is a fundamental problem of all atomistic or partitive theories of the organism how the qualitative leap from a mere

sdu.dk

#sdudk

aggregation of parts to the whole as a non-reducible and integrative totality is possible.

PM follows the cue of by now firmly established trends towards viewing health and disease as phenomena of a biological, psychological, and social kind, originally posited by Engel (1977) in the *biopsychosocial* model as a corrective to biomedical reductionism. PM takes a similarly inclusive approach but, like the biopsychosocial model, has difficulty in describing the whole that the patient and the patient's afflictions constitute as anything but an aggregation of different factors. This is also reflected in the terminology that PM uses to describe the organism; 'upward and downward' causation, stratifications, levels of organization etc. that all rely on spatial metaphors, which encourage thinking in terms of layers. This is innocuous when used regulatively as a method of illustration or analysis since ontological irreducibility does not preclude methodological reductionism, but it is misguided when these metaphors are thought to have an ontologically constitutive function. There are no actual layers 'within' the organism (Dupré, 2021, p. 6). Conceptualizing the whole as a composite turns the matter on its head. Aspects like the biopsychosocial dimensions are constituted as aspects *in virtue of* a whole. What furthermore often seems to be meant by individuality is rather *biological variation*, i.e., the inherent variability within genetic makeup, life circumstances etc. that is to be found be-

tween individuals. Though this is undoubtedly important, it is only one part of the equation that constitutes individuality.

Piecing the puzzle of the individual together is therefore not purely an empirical question. The turn from reductionism to medical individualism in the form of personalized medicine is not simply a result of new empirical discoveries; the object of study, the human being and its body, never changed, but the perceptions thereof did. An important driver behind the process was rather different interpretations of fundamental questions about the nature of organisms, individuality, and life itself. It therefore seems questionable whether another empirical discovery or more finely tuned understanding of molecular processes would deliver the last piece of the jigsaw to "put the patient back together", as Greene & Loscalzo put it. The individual *per se* cannot be arrived at through *induction*. What an adequate theory of medical individualism lacks is an extensive study of organizing principles and the construction of an epistemic framework (Wolkenhauer & Green, 2013) that adequately conceptualizes holism and individuality.

Building blocks for a theory of the individual

What makes an individual individual has puzzled metaphysicians for centuries and any exposition thereof is bound to be selective (Borsche, 1976; Pieper, 1973). In this context, the concept more narrowly refers to *biological individuals* or *organisms*, or, more specifically, to what makes *human beings* individual. In the following, I outline three important issues of holism and individuality, which call for investigation: I) The peculiar dialectic between a whole that conditions and constrains the parts, while simultaneously only existing in and through the differentiated and relatively autonomous parts. II) How ontologically distinct elements such as

sdu.dk

#sdudk

the physiological, environmental, and psychological dimensions can be integrated within a comprehensive understanding of the organism without reducing or neglecting the undeniable differences between these. III) How the individual is not simply an object of great complexity or variability but a subject with agency that acts and posits norms. Together, these issues constitute important conditions of possibility for what makes an individual individual, which are here provisionally sketched perspectives for further explication, and contain three immediate implications for a medical individualism, which are treated in the next section.

I) The whole-part dialectic

A summative understanding of the individual is both biologically and philosophically ill-equipped at conceptualizing holism. Conceptually, parts or modules of an organism presuppose a whole to which they belong. Only in so far as they are subunits within a superordinate context can they be isolated as aspects. This implies that the whole cannot be the result of an addition of its constitutive parts since it logically precedes the parts. Neither can it be an element – albeit a particularly important one – among other elements since this would imply a self-referential paradox. Jonas points out that materially, a biological individual is perpetually changing. Its survival and thriving are dependent upon exchange of matter with its surroundings and constantly revitalizes itself. What survives and conditions the constant metabolic process is

not the individual parts of the organism, the cells and other material constituents, which are gradually replaced, but the *form* of the organism (Jonas, 2001), here understood as the self, life, or living form that is the subject of this incessant flux. Yet, the form can only find expression in and through the individual parts; the individual parts *are* the manifestations of the form. Without cells, tissues, organs etc., there would be nothing to form into a coherent, dynamic whole. Both parts of the equation, the whole and its parts, are necessary and one cannot be accorded ontological primacy over the other.

This peculiar duplicity makes it difficult to understand the whole-part relation inherent to individuality as either constituted bottom-up, through the interplay of different, relatively autonomous elements, or top-down, as the imposition of the whole upon the parts that it comprises. Both aspects are essential, therefore, the holism of the individual is more adequately conceptualized as *dialectical*. Dialectical, in this context, means that the unity of the organism arises in virtue of two opposing but mutually conditioning and distinct moments. It furthermore emphasizes that this unity is not primordially given but is a process, which must be enforced and is open to modifications and disruptions. This type of organization can more fittingly be designated a *differentiated whole* (Plessner, 2016, p. 227), i.e., a unity of distinct elements. This would bypass the issue of assembling the individual from components, i.e., making the qualitative leap from parts to wholes, since there would be no parts without the whole and vice versa.

This dialectical holism entails a circular dynamic of two fundamental kinds between the parts and the whole, which do not constitute different phases in a succession of events but rather two

sdu.dk

#sdudk

moments within a complex. The first moment concerns how the whole constrains and guides its parts by staking out and delimiting functions of individual components with a view to overall organismic objectives and environmental demands. This is a core tenet in holism, which stretches back to Aristotle: "For animals do not see in order that they may have sight, but they have sight [in order] that they might see" (1995, 1050a). The organism makes *organs*, i.e., *instruments* or *tools* purposed to fill out vital functions or fundamental organismic capacities, out of its parts (Heidegger, 1983, p. 312). E.g., the capacity for sight, which the eyes in conjunction with the central and peripheral nervous system realize. In this sense, the vital capacities of the whole constitute the *sine qua none* for the functioning of the parts. The second dynamic consists in the differentiation of the whole into autonomous parts that fulfill certain roles. The cell, for example, is structurally ambiguous since it functions independently as a whole in and of itself while at the same time being integrated within and dependent on a grander whole, thereby constituting what Koestler coined a *holon* (Koestler, 1967). These parts work together in complexes of functions. The eyes receive impression, the peripheral nervous system carries sense data to the brain, the brain interprets the data, which produces a conscious perception etc. Though the whole constrains and binds these together, it is not something apart from but exists in and through these parts and their functions. From this fact the systemic nature of the whole-

part relation can be deduced, since changes to or influences upon parts also entail changes to the whole, while changes to the whole entail further changes to the parts. This dynamic does not constitute a homogenous order, but a multitude of integrated suborders some of which are functionally more closely interwoven, while others are more autonomous.

The differentiation of functioning allows for a more complex playing field of actions and reactions but simultaneously necessitates a stronger centralization, which binds the parts together into a functional whole (Bertalanffy, 1960, pp. 45-47). The stronger the need for a differentiation of functions, the stronger the need for a core of a more complex character. Plessner terms this a *centralized organization* (2016), i.e., an organization in which differentiated parts function by way of a core, which binds their performance together. The nervous system naturally facilitates and coordinates actions and reactions in accordance with external and internal impulses, and so could be perceived as the core around which the parts are oriented. A distinction, however, must be drawn between the whole as the functional unity of the physiological and psychological parts and functions and the core as the *carrier* or *subject* of the functional unity and parts. When all material constituents are accounted for, what remains is this subject, which is not strictly identical to nor different from consciousness and the biological organism. The core is both and none of these at the same time. That is, though the body facilitates the engagement with the world and incarnates consciousness, and though consciousness through volitions, thoughts and feelings directs the body while being fundamentally conditioned thereby, the self can still thematize, reflect upon and distance itself from both its body and the contents of its consciousness (Plessner,

sdu.dk

#sdudk

2016, p. 365). The body and psyche is, in other words, given to the *self* as something to which it explicitly relates and with which it never fully overlaps. The individual, therefore, constitutes both a psychophysical unity as well as a self, which stands in a *mediated* relation to itself and possesses *self-givenness* in a phenomenological sense, according to Plessner. Both aspects are invariant features of its nature. From this framework of the differentiated whole, a more nuanced model of the physiological, psychological, and environmental dimensions as ontologically distinct albeit interconnected can be worked out.

II) The identity and difference of ontologically distinct aspects

The medical mind-body problem differs from the philosophical in that the nature and unity of mind and body is not contested but given as a fundamental condition to be explained (Tsouyopoulos, 1988). And the problem remains especially relevant within medical contexts due to the difference between biological dysfunctions and experienced illness, traditionally known as the distinction between disease and illness (Boorse, 1975; Carel, 2016). There is both a fundamental unity as well as disparity between mind and body. The experience of pain, for example, and the biological processes through which the sensation of pain arises are two distinct phenomena. Alterations to the physical organism can naturally cause or modify states of mind, while states of mind alter the physical organism, but neither dimension exerts complete control

over the other nor is directly causally related. Visceral processes, e.g., occur automatically and through no effort of the will and are often hidden from experience, yet can be experientially thematized, especially when going awry, and are generally correlated except in liminal situations like comatose conditions. Conversely, in cases of placebo and nocebo, conscious states of belief can alter both the experience of one's body and the state of the body in itself, though only to a certain point. Consciousness both *is*, *has*, and *is being had* by the body at the same time (Blankenburg, 1989).

Given the model sketched above, the difference between mind and body and the relation between these can be interpreted as a differentiation of the whole into different functional "spheres". This differentiation allows for distinct biological advantages since it frees the individual up to shape and respond to its surroundings without needing to deliberately initiate and direct visceral processes, but it simultaneously carries the disadvantage that pathological processes may develop below the threshold and outside the control of consciousness (Leder, 1990). This enables the seemingly paradoxical phenomenon that a person can feel healthy and still be sick or feel sick and still be healthy. Though semi-autonomous, however, both dimensions function by way of a core, changes to which diffuse into other parts of the organism, and it is in virtue thereof that mind and body are generally correlated. This complex identity and difference between mind and body cause a wide array of expressions within physiological, psychological, and psychosomatic symptoms, which only grow more complex since the individual is not directly determined by but able to thematize and evaluate features of its own corporeality and sentience.

sdu.dk

#sdudk

Regarding the dynamics between the individual and environment, an apparent contradiction appears between the organism as a self-contained system and as fundamentally dependent upon exchanges with its surroundings. Where to draw the distinction between individuals and environments has long been a matter of discussion within biology (Bertalanffy, 1960; Wilson, 1999), with some arguing that there is no clear demarcation between individuals since they are fundamentally dependent upon symbiosis with other organisms (Gilbert et al., 2012). This discussion has extended to medicine where it also is a matter of contention if individual health can be neatly demarcated from population health (Giroux, 2020b). Although proponents of ecological in contrast to individual interpretations of life neglect important elements of individuality such as the phenomenological self-givenness of the body and psyche in contrast to the non-givenness of others, it must be conceded that the distinction in practice is fuzzy. Here, however, I argue that the distinction between individuals and environment is not dichotomic but dialectic, and that the individual can only emerge via engagements with an environment.

One of the most fundamental characteristics of life, according to Plessner, is that it has *boundaries* (2016). Inanimate bodies have spatial confines, but these only mark the line between the body and the surrounding medium. For the living, the boundary is fundamentally *part* of the organism. This is not solely understood as the outermost periphery of the organism, i.e. the skin, although

the skin is a membrane (Plessner, 1969) that acts as both a filter and a barrier, which enables beneficial exchanges with the environment and filters out or wards off detrimental influences. This "dynamic polarity" (Canguilhem, 1991, p. 136) constitutes two distinct but mutually conditioning moments that enable exchanges between individual and environment, which are variously manifested as ingestions and excretions, preferences and exclusions, propulsions and repulsions facilitated through the organs. Here, boundary is rather interpreted as the *body*, which mediates between the self and the surrounding medium (Plessner, 2016, p. 297) and opens the world to the individual but simultaneously to external influences. The environment imposes norms, i.e., conditions of life, that the individual must meet, but the individual similarly posits and enforces norms upon its environment. In other words, the environment is the medium through which the organism sustains itself and enforces its own norms. It does not stand in opposition to but is the necessary condition for the individual to emerge as a self-contained system.

The boundary being part of the organism similarly entails that it has *positionality*. It does not simply have a spatial and temporal location but a *place*, which has normative connotations. The place constitutes the way that the environment is given to the organism as points of significance that excite actions. This holds equally for organisms of lesser or greater complexity. But man has no straightforward natural habitat. The places that humans inhabit, though inextricably tied to natural surroundings, are to a very large extent *cultural* (Gehlen, 2016). The same dynamic that characterizes natural habitats, however, applies to cultural milieus – the sociocultural milieu imposes norms upon the individual, while the individual conversely constructs and modifies the norms

sdu.dk

#sdudk

of its culture and society. These norms constitute rules of behavior, values, and certain social structures that shape how the individual can and should express itself. Although social norms prescribe conducts of behavior for the individual, the individual is never fully determined by but can critically engage with these norms. This gap between sociocultural and individual norms is a necessary presupposition for the self-understanding and identity of the individual. The same way that the organism emerges as an individual being through engagement with its environment, the *person*, i.e., the narrative, reflexive self with a *social role* and *personal identity*, arises through exchanges with the cultural. Individuals and environments do not oppose but presuppose each other.

III) The agency of the individual

That the dialectical relation between the parts and the whole is not static but in process is especially evident from considering the countless ways in which this dynamic may go wrong. An organ might fall short in fulfilling its function, cancerous cells may propagate and become self-maintaining sub-systems incompatible with the remaining organism, external influences can prove overwhelming and therefore harmful etc. Through perturbations, the organism is not merely a receptacle of influences but actively strives to (re)impose order upon the parts. Moreover, phenomena like metabolism, development and deterioration, adaptions all

attest to the fundamental processualism of the organism (Dupré, 2021). What a medical anthropology therefore must account for is that the organism is as much active as reactive. In former medical theories, this was known as the distinction between excitability and irritability, which designated the capacity to receive input and carry out actions, facilitated through the sensorimotor apparatus. The individual is, in other words, *subject* in both meanings of the term, namely as that which underlies and is the object of influences, and that which is the carrier and enactor of actions and therefore possesses *agency*.

Part of what it entails to be a biological individual whose actions stem from inner processes rather than external circumstance is the capacity to realize certain states of affairs over others in a non-predetermined way. It might be objected that any talk of "choice" among organizationally simpler individuals is anthropomorphism, but it is important to note that the capacity to act does not entail a radical conception of freedom. To act simply means to choose in some fashion the action perceived as most favorable among a host of possible actions rather than by complete determination through outer events. The capacity for volitional and deliberate contra biologically automated action grows with increasingly complex life forms and takes on two fundamental forms: either as freely or spontaneously acting or as acting when external demands require it, i.e., as reacting. Even while receiving impressions and influxes, the organism actively shapes and acts upon the intakes. Consequently, acting and reacting do not work in isolation but on the basis of each other, forming a *Gestaltkreis* (Weizsäcker, 1968) or feedback loop. This is part of the underlying rationale behind viewing pathology not merely as symptoms inflicted upon organisms but similarly as the organ-

sdu.dk

#sdudk

ism's attempt to actively restore order (Goldstein, 1995). Indeed, the reactions of the organism to stimuli or changes are not simply automated reactions, but *responses* with a unique rationale (Plessner, 2016, pp. 262-263).

To sum up, materially, the individual is nothing more than its physiological constituents; organizationally, however, the self is never identical to the biological constitution (Plessner, 2016, p. 373). The self is both given *from* its constitutive parts, i.e., body and psyche, but its constituent parts are also given *to* it. This duplicity makes the individual more than its biological, psychological, and environmental dimensions, hence why it cannot be exhausted through a comprehensive summation of its constitutive elements, as proponents of personalized medicine claim. The biological individual is both a biological and conscious entity situated in an environment as well as an acting and evaluating self. Though it is only a sketch, the model of the differentiated whole holds greater promise of explaining the organizing and integrative principles of the individual since it strives to elucidate the immanent cohesion between differentiated elements. What implications this model carries for medical individualism as a theory will be explicated in the concluding section.

Medical individualism explicated

The question raised concerns why individuals, their pathologies and physiologies, are fundamentally unique and variable – or,

differently put, through which factors individuals differ from each other within matters of health and pathology. The answer given by PM is that individuality – here implicitly understood as variability – arises due to the totality of interacting networks of the organism, which is of such complexity that individuals ultimately diverge in some form or degree from one another. Though it fails to adequately conceptualize the qualitative leap from an aggregation of different components to the patient as a whole, the understanding of the individual as a unique singularity due to its compositeness of variable factors has a kernel of truth to it, which, however, must be revised and supplemented. Here, three general features will be outlined, namely 1) states of pathology and health as unique totalities of biological, phenomenological, and social dimensions, 2) the individual as a norm-positing agent, 3) the individual as context-sensitive and contextually situated.

1. Individual health and disease as totalities of biological, phenomenological, and social dimensions

Insisting upon understanding states of health and disease as totalities of biological, phenomenological, and social dimensions might at first glance seem to rehash central points from the biopsychosocial model and PM, however, both operate with a quite *positivistic* understanding of the psychological and social. The psychological is equated with measurable psychological traits and factors while the social is understood as demographic tendencies and environmental factors. Both understandings are restrictive, qua the model outlined above, and fail to demonstrate the immanent cohesion and disparity between these dimensions. The psychological is here more broadly interpreted as the *phenomenological*, i.e., as the unity and continuity of experience, the givenness of

sdu.dk

#sdudk

myself to myself in contrast to the non-givenness of others, the self's intimate identity with and distinctness from the body and psyche – in other words, the structural facets that shape the givenness and contents of consciousness and ultimately the experience of oneself as an individual. The social, similarly, is understood more broadly as the norms that the cultural or natural environment imposes on the individual and vice versa, through which the sense of selfhood and personal identity emerges.

It follows from the model of the differentiated whole that these dimensions are fundamentally linked. The various biological and psychological constitutions is the precondition for the self, but the body and psyche are similarly given to the self, which relates to and shapes them in divergent fashions, while situated in certain environments that contain unique challenges to be met. Through the totality of these factors, the individual distinguishes itself as unique. It is this picture of individuality, which can be transferred to medicine to unfold a medical individualism, where the causes, states, and effects of health and disease are interpreted as unique totalities. That is, since changes to parts diffuse into and influence the entire system, health and disease do not simply consist in genotypes and phenotypes of biological and psychological conditions but extends to the phenomenological givenness of the conditions, how the self relates to them, what sort of challenges they generate in relation to environmental and personal norms, and what capacities for action that the individual possesses. This

is something broader than a conglomeration of factors because states of health and disease truly constitute unities of disparate aspects and elements that hold for the entire organization of the organism rather than isolated aspects of it.

2. The individual as a norm-positing agent

The self relates to itself including its body and environment. As such, it is not completely determined through its biological and psychological constitution – unless a radical behaviorism or stimulus-response theory is adopted, which contain other problematic aspects – but is able to freely act and evaluate its own state of being. As such, it possesses agency. The individual is unique not simply due to the inherent variation within its biological constitution but similarly to the variability within its actions and capacities therefor.

According to Canguilhem, it is the mark of all life that it is principally *non-indifferent* (Canguilhem, 1991, p. 126). Life always *posits norms*, i.e., attaches values to states of affairs, seeking to promote conditions favorable to its thriving and survival while conversely depreciating states that inhibit this drive. Though these norms seem quite universal:

> ”Life, a long life, the capacity for reproduction and physical work, strength, resistance to fatigue, the absence of pain, a state in which one notices the body as little as possible outside of the joyous sense of existence” (Canguilhem, 1991, p. 122),

Canguilhem still maintains: “…that the norm in pathology is above all an individual norm” (1991, pp. 118-119). This is not a

sdu.dk

#sdudk

contradiction in terms. The valuation, which is the basis of pathology as "the direct and concrete feeling of suffering and impotence, the feeling of life gone wrong" (1991, p. 137) and therefore of what is and is not in need of treatment, ultimately rests upon the individual. Though organisms mostly strive for alike values, they reach these by different means, and what is conducive for the thriving of one person might not be for another. Norms are not conjured out of thin air but arise due to variations in biological and psychological constitutions, the habitat and cultural environment, which constantly counterpose conditions that the individual must adapt to, etc. Because individuals are equipped with different constitutions, norms, and capacities for action, what is appraised as healthy and pathological, what responses and actions they give occasion to, takes on an individual form.

3. The individual as contextually situated

What context sensitivity typically entails is that the circumstances, which *cause* and *influence* a given situation, fundamentally forms and conditions the nature of this situation. This has both a causal and situative meaning. Beginning with the causal sense, if a state of pathology or health is conceived processually as a chain of events that build upon one another, each link of the chain being a consequence of the former highly particularized set of conditions, then these states must be considered contextual. Even identical disease entities (Hucklenbroich, 2014) impact variable bodi-

ly and psychological constitutions in different ways, eliciting different responses from the individual that in turn further impact the disease entity, which develop in complex feedback mechanisms. This ultimately gives states of health or disease highly variable expressions. This does not preclude that nomological features can be approximated through stochastic explanations, but pathological and healthy states of the individual ultimately vary according to the context in which they take part, be the differences significant or miniscule.

Regarding the situative meaning of contextualism, qua incarnated, what counts as a significant or insurmountable challenge to an individual in one environment or situation might be of no consequence in another. Consider a pianist who loses the use of his index finger due to a motor disorder compared to an academic, who suffers the same condition. Not only is the way that the condition affects the lives of the individuals different, but their capacities for physiological or mental adaptation, their comportment into the environment, their way back to health are as well. The situation carries great significance for the way that the variable state of health or pathology manifests itself and how the individual responds to it. Therefore, the conflict between capacities to meet challenges and demands forced upon an individual contribute to the incomparability between these.

Conclusion

To what extent a science of the individual in the above sense is feasible is open to debate. The Galenics thought it impossible since they held the individual to be ineffable according to the dictum of philosophy in Antiquity: “individuum est ineffabile” (Borsche 1976). Because the individual is particular and reason

sdu.dk

#sdudk

only grasps universal, the individual is inexplicable except as an instantiation of a general type. This implied that every treatment and understanding of the pathology or health of an individual must be carried out on a case-to-case basis. PM, however, promises a veritable science of the individual. Leaving aside questions of the extremely comprehensive tools and methods of investigations required to sequence all relevant networks of the individual, there is a principial problem in the way that it investigates and conceives of the individual. Qua analytical, PM breaks the individual into smaller units and networks to investigate its nature, thereby missing exactly what makes it individual, namely as a whole, which cannot be reduced to its constituent parts, i.e., its organizational character as a self. The individual is an environmentally situated being, which consists of both biological and psychological dimensions that are differentiated functions of the same whole. This whole constitutes the individual's core or self, identical with yet distinct from its constitution, thereby actively relating to and acting on the basis of it. A science of the individual would to a certain extent presuppose that the active dimensions of the individual were completely determinable and describable, which would require demanding ontological commitments.

This model can shed light on how and why states of health and disease in individuals fundamentally vary, which is a theoretical assumption that runs as a not fully developed undercurrent in several movements and theories of health and disease. What dis-

tinguishes an individual as individual is its holism. Viewing health and disease through the same lens yields some insights into the theory of medical individualism. Firstly, health and disease vary through being totalities of biological, phenomenological, and social dimensions, complex to such a degree that they are different from individual to individual. To be an individual, however, also implies agency, and the individual evaluates and acts upon these complexes of health and pathology in various ways. Both the constitution and actions of the individual are context sensitive, meaning that they build upon each other in chains of events and are conditioned by the situations in which they play out. Taken together, these provide tentative determinations of a theory of medical individualism, which is a promising avenue for further investigation.

References

Ahn, A. C., Tewari, M., Poon, C.-S., & Phillips, R. S. (2006a). The Clinical Applications of a Systems Approach. *PLoS medicine*, *3*(7), 0956-0960. https://doi.org/10.1371/journal.pmed.0030209

Ahn, A. C., Tewari, M., Poon, C.-S., & Phillips, R. S. (2006b). The Limits of Reductionism in Medicine: Could Systems Biology offer an Alternative? *PLoS medicine*, *3*(6), 0709-0713. https://doi.org/10.1371/journal.pmed.0030208

Aristotle. (1995). *The Complete Works of Aristotle: volume two*. Princeton University Press.

Barabási, A.-L., Gulbahce, N., & Loscalzo, J. (2011). Network medicine: a network-based approach to human disease. *Nature Reviews Genetics*, *12*(1), 56-68. https://doi.org/10.1038/nrg2918

Bertalanffy, L. v. (1960). *Problems of Life: An Evaluation of Modern Biological and Scientific Thought*. Harper & Brothers.

Blankenburg, W. (1989). Phänomenologie der Leiblichkeit als Grundlage für ein Verständnis der Leiberfahrung psychisch Kranker. *Daseinsanalyse*, *6*, 161-193.

Boorse, C. (1975). On the Distinction between Disease and Illness. *Philosophy & public affairs*, *5*(1), 49-68. https://doi.org/10.1515/9781400853564.3

Boorse, C. (1977). Health as a Theoretical Concept. *Philosophy of science*, *44*(4), 542-573. https://doi.org/10.1086/288768

Borsboom, D., & Cramer, A. O. J. (2013). Network Analysis: An Integrative Approach to the Structure of Psychopathology. *Annual review of clinical psychology*, *9*(1), 91-121. https://doi.org/10.1146/annurev-clinpsy-050212-185608

Borsche, T. (1976). Individuum, Individualität. In J. Ritter & K. Gründer (Eds.), *Historisches Wörterbuch der Philosophie* (Vol. 4: I-K). Basel: Schwabe & Co.

Canguilhem, G. (1991). *The Normal and the Pathological*. Zone Books.

Carel, H. (2016). *Phenomenology of Illness*. Oxford University Press. https://doi.org/10.1093/acprof:oso/9780199669653.001.0001

Childs, B., Wiener, C., & Valle, D. (2005). A Science of the Individual: Implications for a Medical School Curriculum. *Annual review of genomics and human genetics*, *6*(1), 313-330. https://doi.org/10.1146/annurev.genom.6.080604.162345

De Grandis, G., & Halgunset, V. (2016). Conceptual and terminological confusion around personalised medicine: a coping strategy. *BMC medical ethics*, *17*(1), 43-43. https://doi.org/10.1186/s12910-016-0122-4

Dupré, J. (2021). *The Metaphysics of Biology*. Cambridge University Press.

Engel, G. L. (1977). The Need for a New Medical Model: A Challenge for Biomedicine. *Science*, *196*(4286), 129-136. https://doi.org/10.1126/science.847460

Gehlen, A. (2016). *Der Mensch: Seine Natur und seine Stellung in der Welt*. Vittorio Klostermann.

Gilbert, S. F., Sapp, J., & Tauber, A. I. (2012). A Symbiotic View of Life: We Have Never Been Individuals. *The Quarterly review of biology*, *87*(4), 325-341. https://doi.org/10.1086/668166

Giroux, É. (2020a). The individual relativity of health and disease: Personalized medicine in the light of Canguilhem's philosophy of medicine. In P.-O. Méthot & J. Sholl (Eds.), *Vital Norms: Canguilhem's The Normal and the Pathological in the Twenty-First Century*. Hermann.

Giroux, É. (2020b). Is personalized medicine humanist? *Archives de Philosophie*, *83*(4), 59-82. https://doi.org/10.3917/aphi.834.0059

Goldstein, K. (1995). *The Organism: A Holistic Approach to Biology Derived from Pathological Data in Man* (1. ed.). Zone Books.

Green, S. (2016). Introduction to Philosophy of Systems Biology. In S. Green (Ed.), *Philosophy of Systems Biology* (Vol. 20, pp. 1-23). Springer International Publishing. https://doi.org/10.1007/978-3-319-47000-9_1

Greene, J. A., & Loscalzo, J. (2017). Putting the Patient Back Together — Social Medicine, Network Medicine, and the Limits of Reductionism. *The New England journal of medicine*, *377*(25), 2493-2499. https://doi.org/10.1056/NEJMms1706744

Heidegger, M. (1983). *Gesamtausgabe Band 29/30: Die Grundbegriffe der Metaphysik. Welt - Endlichkeit - Einsamkeit*. Vittorio Klostermann.

Hood, L., & Flores, M. (2012). A personal view on systems medicine and the emergence of proactive P4 medicine: predictive, preventive, personalized and participatory. *New biotechnology*, *29*(6), 613-624. https://doi.org/10.1016/j.nbt.2012.03.004

Hucklenbroich, P. (2014). "Disease Entity" as the Key Theoretical Concept of Medicine. *The Journal of medicine and philosophy*, *39*(6), 609-633. https://doi.org/10.1093/jmp/jhu040

Jewson, N. D. (2009). The disappearance of the sick-man from medical cosmology, 1770–1870. *International journal of epidemiology*, *38*(3), 622-633. https://doi.org/10.1093/ije/dyp180

Jonas, H. (2001). *The Phenomenon of Life – Towards a Philosophical Biology*. Northwestern University Press.

Kitano, H. (2002). Systems Biology: A Brief Overview. *Science (American Association for the Advancement of Science)*, *295*(5560), 1662-1664. https://doi.org/10.1126/science.1069492

Koestler, A. (1967). *The ghost in the machine*. Hutchinson.

sdu.dk

#sdudk

Leder, D. (1990). *The absent body*. University of Chicago Press.

Loscalzo, J., & Barabasi, A.-L. (2011). Systems biology and the future of medicine. *WIREs Systems Biology and Medicine*, *3*(6), 619-627. https://doi.org/10.1002/wsbm.144

Nagel, E. (1935). The Logic of Reduction in the Sciences. *Erkenntnis*, *5*, 46-52.

Pieper, A. (1973). Individuum. In Hermann Krings, H. M. Baumgartner, & C. Wild (Eds.), *Handbuch philosophischer Grundbegriffe* (Vol. II: Gesetz-Relation, pp. 728-737). München: Kösel-Verlag.

Plessner, H. (1969). "A Newton of a blade of grass"? *Psychological Issues*, *6*(2), 135-176.

Plessner, H. (2016). *Die Stufen des Organischen und der Mensch: Einleitung in die philosophische Anthropologie*. Suhrkamp.

Temkin, O. (1977). *The Double Face of Janus and Other Essays in the History of Medicine*. The Johns Hopkins University Press.

Tsouyopoulos, N. (1988). The Mind-Body Problem in Medicine (The Crisis of Medical Anthropology and its Historical Preconditions). *History and Philosophy of the Life Sciences*, *10*, 55-74.

Valles, S. (2020). Philosophy of Biomedicine. In E. N. Zalta (Ed.), *Stanford Encyclopedia of Philosophy*.

Vogt, H., Hofmann, B., & Getz, L. (2016). The new holism: P4 systems medicine and the medicalization of health and life itself. *Medicine, health care, and philosophy*, *19*(2), 307-323. https://doi.org/10.1007/s11019-016-9683-8

Vogt, H., Ulvestad, E., Eriksen, T. E., & Getz, L. (2014). Getting personal: can systems medicine integrate scientific and humanistic conceptions of the patient? *Journal of evaluation in clinical practice*, *20*(6), 942-952. https://doi.org/10.1111/jep.12251

Voit, E. O., & Brigham, K. L. (2008). The Role of Systems Biology in Predictive Health and Personalized Medicine. *The open pathology journal*, *2*(1), 68-70. https://doi.org/10.2174/1874375700802010068

Weizsäcker, V. v. (1968). *Der Gestaltkreis: Theorie der Einheit von Wahrnehmen und Bewegen* (1. ed.). Georg Thieme Verlag.

Wilson, J. (1999). *Biological Individuality: The Identity and Persistence of Living Entities*. Cambridge University Press. https://doi.org/10.1017/CBO9781139137140

sdu.dk

#sdudk

Wolkenhauer, O., & Green, S. (2013). The search for organizing principles as a cure against reductionism in systems medicine. *The FEBS journal*, *280*(23), 5938-5948. https://doi.org/10.1111/febs.12311

7.3 An integrative account of health and disease

So far, several far-reaching philosophical critiques and theories have been posited. This subsection will attempt to weave the threads together and show how they point to an integrative conception of health and disease. The state of the art regarding the nature of health and disease is governed by a host of – often mutually exclusive – perspectives. Health and disease are in turn interpreted as normative, naturalistic, or hybrid phenomena, as phenomenological, as holistic etc. Even within theoretical positions that argue for holistic conceptions, however, it is seldom explicated how these different dimensions of health interact. Take, for example, the biopsychosocial model that posits three dimensions of health without showing how these add up to a unique whole, though this is exactly what holism conceptually entails. The field as it stands is caught in a deadlock, I argue, and this motivates a different manner of approach.

Rather than beginning with conceptual analysis, this project takes its point of departure with an ontological analysis, which is based on the clues yielded by investigating the generic health assessment practice. That is, through explicating fundamental

modes of being for the human being, the project seeks to delineate the essence of health and disease. As a creature endowed with certain capacities and a fundamental care for itself, certain states of being run counter to its vital goals since it is incarnated and embedded in certain contexts. Consequently, there are different modes of manifestation for health and disease. These manifest themselves biologically as the capacity or failure to adapt to conditions that go against organismic norms, and phenomenologically, as the maintaining of or broaches upon life activity. Though consisting of distinct aspects, conditions of health and disease constitute totalities because they consist of differentiated functions within a complex whole. This whole, the human being, has different biological presuppositions, different norms and agentialities, take part in different contexts and exhibit highly individualized conditions in virtue thereof. Though this conception is provisional, the theories developed in each article lend themselves to a more integrative theory that views health and disease as multidimensional, dynamic, systemic, and individualized phenomena.

The ontological study therefore leads to a maximalistic theory in contrast to minimalistic (Klausen, 2021a). That is, rather than health and disease consisting in isolated aspects such as levels of performance within biological functions, the notions are multidimensional because the individual is a biological, existential, and social being. Whereas minimalistic theories run the danger of being too restrictive and failing to take account of all relevant aspects, maximalistic theories carry the opposite risk. The greater the scope of a theory, the more intricate and potentially vague it also becomes. Quite concretely, it becomes difficult to tell cause, symptom, and effect of health and disease from each other. Nevertheless, health and disease harbour distinct aspects

sdu.dk

#sdudk

that are not easily reducible to each other. Faced with this conundrum, the ontologist's only option is to show attentiveness and diligence to the phenomenon at hand, to trace its different manifestations and show how they relate to a common core. Though a truly well-defined and worked-through integrative account still lacks, I have attempted to develop some important elements thereof through the theoretical parts of this project.

7.4 Concluding thoughts on chapter 7

The present chapter sought to analyze what it means for health and disease to be individualized and context-sensitive phenomena. This is not solely a view that circulates in practice, as the empirical study discovered, but also within current movements of medical theory. However, when pushed, the conceptions of individuality espoused within these movements builds on a philosophically ill-founded theory of holism. The theory of medical individualism therefore gives rise to fundamental philosophical reflections about the nature of the individual, which this chapter sought to investigate. This also concludes the three themes for investigations that came to light during the empirical work. What is left to discuss is which implications this maximalistic conception of health and disease has for the generic health assessment practice.

8. Health assessment in light of theory

8.1 The best among non-optimal methods?

To return to the generic health assessment practice, which was the initial object of examination and spurred on the preceding theoretical deliberations, it was argued that this practice is founded upon strong theoretical assumptions about health, disease, and well-being. Therefore, improving the latter would seemingly provide more adequate ways of measuring generic health. It is an open question, however, whether maximalistic conceptions of health and disease such as the one explicated above can even be measured. The answer, as far as I see it, is mostly negative for several reasons.

If health is interpreted as a meta-capacity to adapt, which includes both biological adjustments to demands and the maintenance of a phenomenological conative drive, then it seems difficult to operationalize this into common indicators on a questionnaire. For this capacity is of a second order, compared to, for example, different manifestations of functional mobility such as ability to climb stairs, since it concerns the subject's relation *to* its own capacities and the demands imposed upon it. This feeds into another issue: the instruments are typically perceived to be multidimensional, although they solely measure self-reported data and in virtue thereof just as well could be interpreted as unidimensional. Were the instruments to measure all elements within the above conception of health and disease, it is difficult to see how this could be done without two- or three-pronged instruments that in turn would compromise the practicality. Lastly, if conditions of

sdu.dk

#sdudk

health are strongly individual, then this raises doubts about the ability to capture all relevant aspects and dimensions on a generic instrument, which cannot differentiate between individuals qua generic.

If the points developed above stand to reason, it could even be argued that they put the *cardinal* assumption of health assessment concerning the *measurability* of health in itself into question. The behaviour of the patient could be observed, the vitals could be examined, and the testimonies of the patient could be elicited without any of these parameters covering health and disease as such. Because health is a temporal and dynamic activity rather than a state with clear-cut properties and biomarkers, it eludes direct measurement. At most, what measurements deliver could be *signs* or *indicators* of health or disease.

Many proponents of generic health assessment would argue, however, that this is exactly the point. It could always be contended that the instruments are not optimal, but neither are many other options such as costly, extensive individual screenings. Imperfectability is a fundamental condition of medical practice, but the answer is not to forgo the use of generic instruments or to adopt a position of *medical nihilism* (Stegenga, 2018b) that sows doubt about the validity and usefulness of health care in general, but rather a conscientious use of instruments that takes their limitations into account. That is, the generic health assessment practice, despite its weaknesses, is the best among non-optimal ap-

proaches to measuring overall states of health and well-being on a standardized basis. Namely because self-assessment – despite the epistemic fallibility of the responder – also constitutes a privileged insight into the health and well-being of the responder that cannot be reached without asking them. This assessment seemingly is the most comprehensive since it encompasses both functional workings, satisfaction with life etc. of the responder according to themselves and therefore is the best option when the purpose is to assess overall health in a convenient way.

Therefore, one thing is adequate philosophical theories; another thing is the generic health assessment practice, which relies on compromises, pragmatic decisions, and heuristic measures. While the former strives for conceptual precision, the latter is aimed at making actionable conceptualizations that can be implemented in practice, where precision sometimes must be sacrificed for pragmatism. Though there is a case to be made for these points, if the underlying theoretical assumptions are too unclear, it is debatable what the instruments measure at all. In other words, though the instruments are practical, they must to a certain extent build upon sound conceptualizations of health and disease – must strike a balance between pragmatism and precision – otherwise, the epistemological status of the measurements become too uncertain and unreliable.

Generic health assessment inscribes itself in a larger problematic regarding the nature of (good) medical evidence and the criteria therefor (Stegenga, 2018a). Throughout the ages, medicine has undergone a shift of identity from a *conjectural art* (Ginzburg, 1999, p. 88) to a *calculable science*. For the longest time, in lieu of methods or techniques of measuring vital parameters that were not rather drastic, the doctor mostly had to rely on

sdu.dk

#sdudk

their judgment in making diagnoses and prognoses. Medicine posed a certain hermeneutical challenge that consisted in interpreting surface-level symptoms without access to the visceral dimensions of the body and listening to the testimonies of the patient. Medicine, therefore, was an *art* with a certain degree of imprecision, which was predicated on the experience and resourcefulness of the medical professional to make adequate *conjectures* about what was or was not wrong.

As medicine transitioned from the bedside to the hospital to the laboratory (Jewson, 2009), it gradually attained a greater degree of scientific precision. It became a *science* rather than an art, which founded its expertise on intricate knowledge of molecular processes, clinical profiles, statistical data etc. Evidence-based medicine is the latest iteration of this trend. Given that the prescriptions and methods are followed, which usually means the randomized controlled trial ("RCT"), highly precise evidence can be achieved. But evidence-based medicine promises something more; a paradigm shift (Guyatt et al., 1992) where all medical expertise is to be based on tried-and-tested evidence instead of anecdotal evidence and intuitions (Sackett et al., 1996). Evidence-based medicine itself has, however, also been subjected to much critique (Stegenga, 2018b; Worrall, 2002, 2007).

Where does generic health assessment fit in this picture? On the one hand, it is an expression of the ambition towards securing precise and standardized evidence regarding (self-assessed) con-

ditions of health and well-being, on the other, evidence-based medicine is predicated on devaluing the intuitions that health assessment explicitly hinges on. How can the responder of the questionnaire intuit their condition of health well enough that they glean insight into the severity of conditions on health-related quality of life, but a health professional with expertise cannot? Perhaps, it could be argued, because responders possess special insight into their own conditions. But, to reiterate, human beings are not infallible epistemological subjects, and preferences regarding hypothetical conditions of health are routinely elicited as well. The fact that standardized data can be gathered through generic forms is indisputable. The question is what kind of evidence they elicit and what level of certainty this evidence possesses – even if granted that generic measurements are indicators rather than exact readings. In this context, the answer is not immediately clear. Despite its ambitions, it seems that the generic health assessment practice straddles a line between a conjectural art and a calculable science.

Although the theory of health sketched above does not immediately lend itself to generic assessment, and although it problematizes core assumptions of this practice, there is more cause for optimism concerning the implementation of certain theory points into the current practice. In this regard, the practice often relies upon conceptualizations that make it unclear exactly what they measure and with what degree of validity. For example, the conflicting views on well-being as both a more objective and subjective state, the conflict between standardization and individuality etc. There are several avenues for implementation that can refine the philosophical assumptions about health and disease that

sdu.dk

#sdudk

underlie the instruments, which, in turn, hopefully can further qualify the utilization of generic health assessment instruments.

8.2 Future avenues for research

A project with as broad a scope as the present one naturally raises as many questions as it answers. Although not exhaustive, in this subsection I will list four themes that warrant further research.

Firstly, this project has a more generalizing approach to the investigation of notions of health and disease and how these affect health assessment instruments, but it would be equally interesting with a more specified approach that investigates concrete instruments. Though the instruments share certain assumptions that have been outlined in this project, they also contain variations, e.g., in weightings, items, dimensions, extensiveness and so on. Therefore, it could be quite interesting with a more in-depth investigation of nuances within specific conceptions of health of concrete instruments.

Secondly, it emerged throughout the qualitative study that perceptions of health, disease, and well-being among health professionals are very nuanced and a far cry from the biomedical reductionism that they often are accused of being. This might reflect a sample bias, nevertheless, it warrants attention and could be a very interesting subject matter for further research, since health professionals' views on health and disease often differ

from theoretical positions since they are formed both through experience and with practical goals in mind.

Thirdly, the integrative conception of health and disease teased in the latter part of this project similarly calls for more in-depth analysis. Current holistic theories posit several aspects or perspectives of health and disease without showing how they add up to a unique whole, though this is what holism implies on a conceptual level. Researching an integrative conception further might lend more credence to holistic conceptions in general and more adequately reflect what medical research is increasingly investigating, namely states of health and disease as complex totalities.

Fourthly, the theory of medical individualism warrants a thorough examination. As suggested, it is a trend, which has cropped up throughout history at different times and has gained a lot of traction in contemporary medicine. What it means for health and disease to be individual, and what it means to be an individual are questions of central importance that, however, lack substantiation since much of current medicine relies on inadequate conceptualizations thereof, as argued in the fourth article.

8.3 Results and final thoughts

Throughout this project, I hope to have showed how the generic health assessment practice is founded upon strong philosophical assumptions about health, disease, and well-being, which shape what kind of evidence the instruments produce, and what degree of certainty they have. Through the qualitative study, the first steps towards elucidating the sprawling practice that is the utilization of generic assessment tools in a Danish context are taken. This explorative approach contributes to a greater overview of the

sdu.dk

#sdudk

practice since many ways of using these instruments are in circulation, although little is known about the overall landscape. The inherent operationalizations of the instruments are found to be conflicted between measuring functional indicators and subjective well-being, between the multi- and unidimensional, between objectivizing and subjectivizing, individualizing and universalizing approaches, and in wishing to make static readings of dynamic conditions. However, theoretical notions of health and disease cannot capture the practice either, which spurs on renewed engagement with traditional positions within philosophy of health.

In the theoretical parts of the project, the ambition was to demonstrate that classical philosophy has much to offer philosophy of health; in revising the deadlock of normativism and naturalism along with a one-sided and psychologizing understanding phenomenology of health and an inadequate conceptualization of individuality and holism in newer medical trends. The ontological approach instead uncovers how health and disease are dynamic and processual phenomena that consist in the capacities for adaptation in the face of demands imposed on the organism; how it from a phenomenological point of view manifests itself as maintenance of or broaches upon conative activities of existence; how a more adequate conceptualization of holism can accommodate an integrative account of these dimensions while simultaneously outlining why each individual differs in matters of health and disease. These insights in turn point towards future avenues

for research within both health assessment and medicine and the philosophy of health that are, as the project has demonstrated, inextricably linked.

9. Complete bibliography

Adorno, T. W. (2003). *The Jargon of Authenticity*. Routledge.

Agich, G. J. (1983). Disease and value: A rejection of the value-neutrality thesis. *Theoretical Medicine*, *4*(1), 27-41.

Ahn, A. C., Tewari, M., Poon, C.-S., & Phillips, R. S. (2006a). The Clinical Applications of a Systems Approach. *PLoS Medicine*, *3*(7), 0956-0960. https://doi.org/10.1371/journal.pmed.0030209

Ahn, A. C., Tewari, M., Poon, C.-S., & Phillips, R. S. (2006b). The Limits of Reductionism in Medicine: Could Systems Biology offer an Alternative? *PLoS Medicine*, *3*(6), 0709-0713. https://doi.org/10.1371/journal.pmed.0030208

Albrecht, G. L., & Devlieger, P. J. (1999). The disability paradox: high quality of life against all odds. *Social Science & Medicine*, *48*(8), 977-988. https://doi.org/10.1016/S0277-9536(98)00411-0

Aristotle. (1995). *The Complete Works of Aristotle: volume two*. Princeton University Press.

Barabási, A.-L., Gulbahce, N., & Loscalzo, J. (2011). Network medicine: a network-based approach to human disease. *Nature Reviews Genetics*, *12*(1), 56-68. https://doi.org/10.1038/nrg2918

Bertalanffy, L. v. (1960). *Problems of Life: An Evaluation of Modern Biological and Scientific Thought*. Harper & Brothers.

Bickenbach, J., Felder, F., & Schmitz, B. (Eds.). (2013). *Disability and the Good Human Life*. Cambridge University Press. https://doi.org/10.1017/CBO9781139225632.

Binswanger, L. (1922). *Einführung in die Probleme der Allgemeinen Psychologie*. Springer.

Bircher, J. (2005). Towards a Dynamic Definition of Health and Disease. *Medicine, Health Care and Philosophy*, *8*(3), 335-341. https://doi.org/10.1007/s11019-005-0538-y

Birkjær, M., Kaats, M., & Rubio, A. (2020). *Wellbeing Adjusted Life Years - A universal metric to quantify the happiness return on investment*. https://www.happinessresearchinstitute.com/_files/ugd/928487_4a99b6e23f014f85b38495b7ab1ac24b.pdf

Blankenburg, W. (1989). Phänomenologie der Leiblichkeit als Grundlage für ein Verständnis der Leiberfahrung psychisch Kranker. *Daseinsanalyse*, *6*, 161-193.

Boorse, C. (1975). On the Distinction between Disease and Illness. *Philosophy & Public Affairs*, *5*(1), 49-68. https://doi.org/10.1515/9781400853564.3

Boorse, C. (1976a). What a Theory of Mental Health should be. *Journal for the Theory of Social Behaviour*, *6*(1), 61-84. https://doi.org/10.1111/j.1468-5914.1976.tb00359.x

Boorse, C. (1976b). Wright on Functions. *The Philosophical Review*, *85*(1), 70-86. https://doi.org/10.2307/2184255

Boorse, C. (1977). Health as a Theoretical Concept. *Philosophy of Science*, *44*(4), 542-573. https://doi.org/10.1086/288768

Boorse, C. (1997). A Rebuttal on Health. In J. M. Humber & R. F. Almeder (Eds.), *What Is Disease?* (pp. 1-134). Humana Press. https://doi.org/10.1007/978-1-59259-451-1_1

Boorse, C. (2014). A Second Rebuttal on Health. *Journal of Medicine and Philosophy*, *39*(6), 683-724. https://doi.org/10.1093/jmp/jhu035

Borrell-Carrió, F., Suchman, A. L., & Epstein, R. M. (2004). The Biopsychosocial Model 25 Years Later: Principles, Practice, and Scientific Inquiry. *The Annals of Family Medicine*, *2*(6), 576-582. https://doi.org/10.1370/afm.245

Borsboom, D., & Cramer, A. O. J. (2013). Network Analysis: An Integrative Approach to the Structure of Psychopathology. *Annual Review of Clinical Psychology*, *9*(1), 91-121. https://doi.org/10.1146/annurev-clinpsy-050212-185608

Borsche, T. (1976). Individuum, Individualität. In J. Ritter & K. Gründer (Eds.), *Historisches Wörterbuch der Philosophie* (Vol. 4: I-K). Basel: Schwabe & Co.

Boss, M. (1975). *Grundriss der Medizin und der Psychologie* (2. ed.). Hans Huber.

Brinkmann, S., & Kvale, S. (2018). *Doing interviews* (2. ed., Vol. 2). SAGE. https://doi.org/10.4135/9781529716665

Brock, D. W. (2002). The Separability of Health and Well-Being. In C. J. L. Murray, J. A. Salomon, C. D. Mathers, & A. D. Lopez (Eds.), *Summary Measures of Population Health: Concepts, Ethics, Measurement and Applications* (pp. 115-120). World Health Organization.

Brodersen, J., Schwartz, L. M., Heneghan, C., O'Sullivan, J. W., Aronson, J. K., & Woloshin, S. (2018). Overdiagnosis: what it is and what it isn't. *BMJ Evidence-Based Medicine*, *23*(1), 1. https://doi.org/10.1136/ebmed-2017-110886

Broome, J. (2002). Measuring the Burden of Disease by Aggregating Well-Being. In C. J. L. Murray, J. A. Salomon, C. D. Mathers, & A. D. Lopez (Eds.), *Summary Measures of Population Health: Concepts, Ethics, Measurement and Applications* (pp. 91-113). World Health Organization.

Brown, T. M. (1989). Cartesian Dualism and Psychosomatics. *Psychosomatics: Journal of Consultation and Liaison Psychiatry*, *30*, 322-331. https://doi.org/10.1016/S0033-3182(89)72280-5

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness*, *4*(2), 167-182. https://doi.org/10.1111/1467-9566.ep11339939

Callahan, D. (1973). The WHO Definition of 'Health'. *The Hastings Center Studies*, *1*(3), 77-87. https://doi.org/10.2307/3527467

Canguilhem, G. (1991). *The Normal and the Pathological*. Zone Books.

Canguilhem, G. (2008a). The brain and thought. *Radical philosophy*(148), 7-18.

Canguilhem, G. (2008b). *Knowledge of Life*. Fordham University Press.

Carel, H. (2016). *Phenomenology of Illness*. Oxford University Press. https://doi.org/10.1093/acprof:oso/9780199669653.001.0001

Carel, H. (2019). *Illness – The Cry of the Flesh*. Routledge.

Cassidy, J. D., Carroll, L. J., Côté, P., Lemstra, M., Berglund, A., & Nygren, Å. (2000). Effect of Eliminating Compensation for Pain and Suffering on the Outcome of Insurance Claims for Whiplash Injury. *The New England Journal of Medicine*, *342*(16), 1179-1186. https://doi.org/10.1056/NEJM200004203421606

Castro, E. M., Van Regenmortel, T., Vanhaecht, K., Sermeus, W., & Van Hecke, A. (2016). Patient empowerment, patient participation and patient-centeredness in hospital care: A concept analysis based on a literature review. *Patient Education and Counseling*, *99*(12), 1923-1939. https://doi.org/10.1016/j.pec.2016.07.026

Charmaz, K., & Belgrave, L. L. (2012). The SAGE Handbook of Interview Research: The Complexity of the Craft. In (2 ed.). SAGE Publications, Inc. https://doi.org/10.4135/9781452218403

Childs, B., Wiener, C., & Valle, D. (2005). A Science of the Individual: Implications for a Medical School Curriculum. *Annual Review of Genomics and Human Genetics*, *6*(1), 313-330. https://doi.org/10.1146/annurev.genom.6.080604.162345

Clouser, K. D., Culver, C. M., & Gert, B. (1981). Malady: A New Treatment of Disease. *The Hastings Center Report*, *11*(3), 29-37. https://doi.org/10.2307/3561321

European Commission. (2019). *Defining Value in "Value-Based Health Care". Report of the Expert Panel on Effective Ways of Investing in Health*. https://health.ec.europa.eu/system/files/2019-11/024_defining-value-vbhc_en_0.pdf

Conrad, P. (2007). *The Medicalization of Society: on the Transformation of Human Conditions into Treatable Disorders*. Johns Hopkins University Press.

Cooper, R. (2002). Disease. *Studies in History and Philosophy of Science. Part C, Studies in History and Philosophy of Biological and Biomedical Sciences*, *33*(2), 263-282. https://doi.org/10.1016/S0039-3681(02)00018-3

Daniels, N. (2008). *Just Health: Meeting Health Needs Fairly* (First ed.). Cambridge University Press. https://doi.org/10.1017/CBO9780511809514
David, M., & Sutton, C. D. (2011). *Social Research: an Introduction* (2. ed.). SAGE.
De Grandis, G., & Halgunset, V. (2016). Conceptual and terminological confusion around personalised medicine: a coping strategy. *BMC Medical Ethics*, *17*(1), 43. https://doi.org/10.1186/s12910-016-0122-4
Descartes, R. (1989). *The Passions of the Soul* (S. Voss, Trans.; 1. ed.). Hackett Publishing Company.
Descartes, R. (2013). *Meditations on First Philosophy: With Selections from the Objections and Replies*. Cambridge University Press.
Diels, H., & Kranz, W. (1972). *Die Fragmente der Vorsokratiker, Erster Band* (6. ed.). Weidmann.
Dilthey, W. (1968). *Gesammelte Schriften V. Band: Die Geistige Welt - Einleitung in die Philosophie des Lebens* (1. ed.). Vandenhoeck & Ruprecht.
Dupré, J. (2021). *The Metaphysics of Biology*. Cambridge University Press.
Engel, G. L. (1977). The Need for a New Medical Model: A Challenge for Biomedicine. *Science*, *196*(4286), 129-136. https://doi.org/10.1126/science.847460
Engelhardt, H. T. (1974). The Disease of Masturbation: Values and the Concept of Disease. *Bulletin of the History of Medicine*, *48*(2), 234-248.
Engelhardt, H. T. (1976). Ideology and Etiology. *Journal of Medicine and Philosophy*, *1*(3), 256-268. https://doi.org/10.1093/jmp/1.3.256
Engelhardt, H. T. (1986). Clinical Complaints and the Ens Morbi. *Journal of Medicine and Philosophy*, *11*(3), 207-214. https://doi.org/10.1093/jmp/11.3.207
Ereshefsky, M. (2009). Defining 'health' and 'disease'. *Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences*, *40*(3), 221-227. https://doi.org/10.1016/j.shpsc.2009.06.005
Etxeberria, A. (2016). Biological Organization and Pathology: Three Views on the Normativity of Medicine. In E. Giroux (Ed.), *Naturalism in the Philosophy of Health* (Vol. 17, pp. 121-142). Springer International Publishing. https://doi.org/10.1007/978-3-319-29091-1_8
EuroQol. (1990). EuroQol - a new facility for the measurement of health-related quality of life. *Health Policy*, *16*(3), 199-208. https://doi.org/https://doi.org/10.1016/0168-8510(90)90421-9
Ferrari, R., Kwan, O., Russell, A. S., Pearce, J. M. S., & Schrader, H. (1999). The best approach to the problem of whiplash? One ticket to Lithuania, please. *Clinical and Experimental Rheumatology*, *17*(3), 321-326.
Fitzpatrick, M. (2001). *The Tyranny of Health: Doctors and the Regulation of Lifestyle*. Routledge.
Fleck, L. (1980). Entstehung und Entwicklung einer wissenschaftlichen Tatsache: Einführung in die Lehre vom Denkstil und Denkkollektiv. In L. Schäfer (Ed.), (1. ed.). Frankfurt am Main: Suhrkamp.

sdu.dk

#sdudk

Fleck, L. (1986a). The Problem of Epistemology. In R. S. Cohen & T. Schnelle (Eds.), *Cognition and Fact: Materials on Ludwik Fleck* (pp. 79-112). Reidel.

Fleck, L. (1986b). Scientific Observation and Perception in General. In R. S. Cohen & T. Schnelle (Eds.), *Cognition and Fact: Materials on Ludwik Fleck* (pp. 59-78). Reidel.

Fuchs, T. (2010). Temporality and psychopathology. *Phenomenology and the Cognitive Sciences*, *12*(1), 75-104. https://doi.org/10.1007/s11097-010-9189-4

Fuchs, T. (2018). Presence in absence. The ambiguous phenomenology of grief. *Phenomenology and the Cognitive Sciences*, *17*(1), 43-63. https://doi.org/10.1007/s11097-017-9506-2

Gadamer, H.-G. (1994). *Über die Verborgenheit der Gesundheit: Aufsätze und Vorträge* (3. ed.). Suhrkamp Verlag.

Gadamer, H.-G. (1996). *The Enigma of Health - The Art of Healing in a Scientific Age* (1. ed.). Polity Press.

Gehlen, A. (2016). *Der Mensch: Seine Natur und seine Stellung in der Welt*. Vittorio Klostermann.

Gilbert, S. F., Sapp, J., & Tauber, A. I. (2012). A Symbiotic View of Life: We Have Never Been Individuals. *The Quarterly Review of Biology*, *87*(4), 325-341. https://doi.org/10.1086/668166

Ginzburg, C. (1999). *Spor - Om historie og historisk metode* (1. ed.). Museum Tusculanums Forlag.

Giroux, É. (2020a). The individual relativity of health and disease: Personalized medicine in the light of Canguilhem's philosophy of medicine. In P.-O. Méthot & J. Sholl (Eds.), *Vital Norms: Canguilhem's The Normal and the Pathological in the Twenty-First Century*. Hermann.

Giroux, É. (2020b). Is personalized medicine humanist? *Archives de Philosophie*, *83*(4), 59-82. https://doi.org/10.3917/aphi.834.0059

Glaser, B. G., & Strauss, A. L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Aldine de Gruyter. https://doi.org/10.4324/9780203793206

Goldstein, K. (1995). *The Organism: A Holistic Approach to Biology Derived from Pathological Data in Man* (1. ed.). Zone Books.

Gracia, J. J. E. (1988). *Individuality: An Essay on the Foundations of Metaphysics*. State University of New York Press.

Granek, L. (2010). GRIEF AS PATHOLOGY: The Evolution of Grief Theory in Psychology From Freud to the Present. *History of Psychology*, *13*(1), 46-73. https://doi.org/10.1037/a0016991

Green, S. (2016). Introduction to Philosophy of Systems Biology. In S. Green (Ed.), *Philosophy of Systems Biology* (Vol. 20, pp. 1-23). Springer International Publishing. https://doi.org/10.1007/978-3-319-47000-9_1

Green, S., Vogt, H., & Brodersen, J. (2020). De raske patienter i personlig medicin: Sygdomsforebyggelse og overdiagnosticering. In S. H. Klausen & K. Christiansen (Eds.), *Personlig medicin - Filosofiske og tværvidenskabelige perspektiver* (1. ed.). Munksgaard.

Greene, J. A., & Loscalzo, J. (2017). Putting the Patient Back Together — Social Medicine, Network Medicine, and the Limits of Reductionism. *The New England Journal of Medicine*, *377*(25), 2493-2499. https://doi.org/10.1056/NEJMms1706744

Griffin, J. (1988). *Well-Being: Its Meaning, Measurement and Moral Importance*. Oxford University Press. https://doi.org/10.1093/0198248431.001.0001

Guillemin, F., Leplége, A., Briançon, S., Sptz, E., & Coste, J. (Eds.). (2019). *Perceived health and adaptation in chronic disease* (1. ed.). Routledge. https://doi.org/10.1201/9781315155074.

Guyatt, G., Cairns, J., Churchill, D., Cook, D., Haynes, B., Hirsh, J., Irvine, J., Levine, M., Levine, M., Nishikawa, J., Sackett, D., Brill-Edwards, P., Gerstein, H., Gibson, J., Jaeschke, R., Kerigan, A., Neville, A., Panju, A., Detsky, A., . . . Tugwell, P. (1992). Evidence-Based Medicine: A New Approach to Teaching the Practice of Medicine. *JAMA: the Journal of the American Medical Association*, *268*(17), 2420-2425. https://doi.org/10.1001/jama.1992.03490170092032

Hacking, I. (1996). The looping effects of human kinds. In D. Sperber, D. Premack, & A. J. Premack (Eds.), *Causal Cognition: A Multidisciplinary Debate* (pp. 351–394). Oxford University Press. https://doi.org/10.1093/acprof:oso/9780198524021.003.0012

Hausman, D. M. (2006). Valuing Health. *Philosophy & Public Affairs*, *34*(3), 246-274. https://doi.org/10.1111/j.1088-4963.2006.00067.x

Hausman, D. M. (2011). Is an Overdose of Paracetamol Bad for One's Health? *The British Journal for the Philosophy of Science*, *62*(3), 657-668. https://doi.org/10.1093/bjps/axr008

Hausman, D. M. (2012). Health, Naturalism, and Functional Efficiency. *Philosophy of Science*, *79*(4), 519-541. https://doi.org/10.1086/668005

Hausman, D. M. (2015). *Valuing Health: Well-Being, Freedom, and Suffering*. Oxford University Press. https://doi.org/10.1093/acprof:oso/9780190233181.001.0001

Heidegger, M. (1983). *Gesamtausgabe Band 29/30: Die Grundbegriffe der Metaphysik. Welt - Endlichkeit - Einsamkeit*. Vittorio Klostermann.

Heidegger, M. (1997). *Was heißt Denken?* (5. ed.). Max Niemeyer Verlag.

sdu.dk

#sdudk

Heidegger, M. (2006). *Sein und Zeit*. Max Niemeyer Verlag.

Hernandez, R., Bassett, S. M., Boughton, S. W., Schuette, S. A., Shiu, E. W., & Moskowitz, J. T. (2018). Psychological Well-Being and Physical Health: Associations, Mechanisms, and Future Directions. *Emotion Review*, *10*(1), 18-29. https://doi.org/10.1177/1754073917697824

Hesslow, G. (1993). Do We Need a Concept of Disease? *Theoretical Medicine*, *14*(1), 1-14.

Hofmann, B. (2002). On the Triad Disease, Illness and Sickness. *Journal of Medicine and Philosophy*, *27*(6), 651-673. https://doi.org/10.1076/jmep.27.6.651.13793

Holm, S. (1964). *Ontologi*. Bianco Lunos Bogtrykkeri.

Hood, L., & Flores, M. (2012). A personal view on systems medicine and the emergence of proactive P4 medicine: predictive, preventive, personalized and participatory. *New Biotechnology*, *29*(6), 613-624. https://doi.org/10.1016/j.nbt.2012.03.004

Hucklenbroich, P. (2014). "Disease Entity" as the Key Theoretical Concept of Medicine. *Journal of Medicine and Philosophy*, *39*(6), 609-633. https://doi.org/10.1093/jmp/jhu040

Hunt, S. M., McKenna, S. P., McEwen, J., Williams, J., & Papp, E. (1981). The Nottingham health profile: Subjective health status and medical consultations. *Social Science & Medicine. Part A: Medical Psychology & Medical Sociology*, *15*(3, Part 1), 221-229. https://doi.org/https://doi.org/10.1016/0271-7123(81)90005-5

Husserl, E. (1968). *Husserliana Band IX: Phänomenologische Psychologie*. Martinus Nijhoff.

Husserl, E. (1973). *Experience and Judgment. Investigations in a Genealogy of Logic*. Northwestern University Press.

Husserl, E. (1983). *Ideas pertaining to a pure phenomenology and to a phenomenological philosophy*. Martinus Nijhoff Publishers.

Husserl, E. (1987). *Husserliana Band XXV: Aufsätze und Vorträge (1911-1921)* (1. ed.). Martinus Nijhoff.

Husserl, E. (2009a). *Ideen zu einer reinen Phänomenologie und phänomenologischen Philosophie: Erstes Buch - Allgemeine Einführung in die Phänomenologie*. Felix Meiner Verlag.

Husserl, E. (2009b). *Philosophie als strenge Wissenschaft*. Felix Meiner Verlag.

Husserl, E. (2012). *Die Krisis der europäischen Wissenschaften und die transzendentale Phänomenologie*. Felix Meiner Verlag.

Husserl, E. (2013). *Zur Phänomenologie des inneren Zeitbewusstseins* (Vol. 649). Felix Meiner.
Jaspers, K. (1912). Die phänomenologische Forschungsrichtung in der Psychopathologie. *Zeitschrift für die gesamte Neurologie und Psychiatrie*, *9*(1), 391-408. https://doi.org/10.1007/BF02911781
Jaspers, K. (1965). *Allgemeine Psychopathologie* (8. ed.). Springer Verlag.
Jaspers, K. (1972). *General Psychopathology* (1. ed.). Manchester University Press.
Jewson, N. D. (2009). The disappearance of the sick-man from medical cosmology, 1770–1870. *International Journal of Epidemiology*, *38*(3), 622-633. https://doi.org/10.1093/ije/dyp180
Johnson, R., Jenkinson, D., Stinton, C., Taylor-Phillips, S., Madan, J., Stewart-Brown, S., & Clarke, A. (2016). Where's WALY? : A proof of concept study of the 'wellbeing adjusted life year' using secondary analysis of cross-sectional survey data. *Health and Quality of Life Outcomes*, *14*(1), 126. https://doi.org/10.1186/s12955-016-0532-5
Jonas, H. (2001). *The Phenomenon of Life – Towards a Philosophical Biology*. Northwestern University Press.
Kahneman, D. (1999). Objective Happiness. In D. Kahneman, E. Diener, & N. Schwarz (Eds.), *Well-Being: The Foundations of Hedonic Psychology*. Russell Sage Foundation.
Kant, I. (1987). *Critique of Judgment* (1. ed.). Hackett Publishing Company.
Kierkegaard, S. (1980). *The Sickness unto Death - A Christian Psychological Exposition for Upbuilding and Awakening* (H. V. Hong & E. H. Hong, Trans.; 1. ed.). Princeton University Press.
Kierkegaard, S. (2006). Sygdommen til Døden. In N. J. Cappelørn, J. Garff, J. Kondrup, A. McKinnon, & F. H. Mortensen (Eds.), *Søren Kierkegaards skrifter, bind 11* (1. ed.). Gads Forlag.
Kingma, E. (2010). Paracetamol, Poison, and Polio: Why Boorse's Account of Function Fails to Distinguish Health and Disease. *The British Journal for the Philosophy of Science*, *61*(2), 241-264. https://doi.org/10.1093/bjps/axp034
Kingma, E. (2014). Naturalism about health and disease: adding nuance for progress. *Journal of Medicine and Philosophy*, *39*(6), 590-608. https://doi.org/10.1093/jmp/jhu037
Kingma, E. (2016). Situation-Specific Disease and Dispositional Function. *The British Journal for the Philosophy of Science*, *67*(2), 391-404. https://doi.org/10.1093/bjps/axu041
Kingma, E. (2019). Contemporary Accounts of Health. In *Health: A History*. Oxford University Press. https://doi.org/10.1093/oso/9780199916429.003.0015
Kitano, H. (2002). Systems Biology: A Brief Overview. *Science*, *295*(5560), 1662-1664. https://doi.org/10.1126/science.1069492
Kitano, H. (2007). Towards a theory of biological robustness. *Molecular Systems Biology*, *3*(1), 1-7. https://doi.org/10.1038/msb4100179

Klausen, S. H. (2021a). Kropslig og sjælelig sundhed i antik og moderne filosofi. *AIGIS: Nordisk tidsskrift for klassiske studier*, *21*(1), 1-22.

Klausen, S. H. (2021b). Phenomenology of Illness and the Need for a More Comprehensive Approach: Lessons from a Discussion of Plato's Charmides. *Journal of Medicine and Philosophy*, *46*(5), 630-643. https://doi.org/10.1093/jmp/jhab019

Koestler, A. (1967). *The Ghost in the Machine*. Hutchinson.

Koyré, A. (1953). An Experiment in Measurement. *Proceedings of the American Philosophical Society*, *97*(2), 222-237.

Koyré, A. (1971). *Etudes d'histoire de la pensée philosophique*. Gallimard.

Koyré, A. (1998). *Tankens enhed: Essays om filosofi, videnskabshistorie og teknologi*. Hans Reitzels Forlag.

Kusier, A. O., & Folker, A. P. (2020). The Well-Being Index WHO-5: hedonistic foundation and practical limitations. *Medical Humanities*, *46*(3), 333-339. https://doi.org/10.1136/medhum-2018-011636

Kusier, A. O., & Folker, A. P. (2021). The Satisfaction with Life Scale: Philosophical Foundation and Practical Limitations. *Health Care Analysis*, *29*(1), 21-38. https://doi.org/10.1007/s10728-020-00420-y

Kusier, A. O., & Folker, A. P. (2022). Filosofi i folkesundhedsvidenskab: Hvad er det, vi måler, når vi måler livskvalitet? In A. N. Holm (Ed.), *Filosofi og empiri* (1. ed.). Aalborg Universitetsforlag.

Landes, X. (2015). Building Happiness Indicators Some Philosophical and Political Issues. *Les ateliers de l'éthique*, *10*(2), 4-37. https://doi.org/10.7202/1035325ar

Leder, D. (1990). *The Absent Body*. University of Chicago Press.

Lemoine, M. (2013). Defining disease beyond conceptual analysis: an analysis of conceptual analysis in philosophy of medicine. *Theoretical Medicine and Bioethics*, *34*(4), 309-325. https://doi.org/10.1007/s11017-013-9261-5

Lemoine, M. (2014). The Naturalization of the Concept of Disease. In P. Huneman, G. Lambert, & M. Silberstein (Eds.), *Classification, Disease and Evidence - New Essays in the Philosophy of Medicine* (pp. 19-41). Springer Netherlands. https://doi.org/10.1007/978-94-017-8887-8_2

Lennox, J. G. (1995). Health as an Objective Value. *Journal of Medicine and Philosophy*, *20*(5), 499-511. https://doi.org/10.1093/jmp/20.5.499

Loscalzo, J., & Barabasi, A.-L. (2011). Systems biology and the future of medicine. *WIREs Systems Biology and Medicine*, *3*(6), 619-627. https://doi.org/10.1002/wsbm.144

Malleson, A. (2002). *Whiplash and other useful illnesses*. McGill-Queen's University Press.

Manning, G. (2019). Descartes and Medicine. In T. M. Schmaltz, D. Antoine-Mahut, & S. Nadler (Eds.), *The Oxford Handbook of Descartes and Cartesianism*. Oxford University Press. https://doi.org/10.1093/oxfordhb/9780198796909.013.9

Marcum, J. A. (2011). Medical Cure and Progress: The Case of Type-1 Diabetes. *Perspectives in Biology and Medicine*, *54*(2), 176-188. https://doi.org/10.1353/pbm.2011.0026

McConville, P. (2021). Toward a phenomenology of congenital illness: a case of single-ventricle heart disease. *Medicine, Health Care and Philosophy*, *24*(4), 587-595. https://doi.org/10.1007/s11019-021-10026-3

Miller, H. D. (2009). From Volume To Value: Better Ways To Pay For Health Care. *Health Affairs*, *28*(5), 1418-1428. https://doi.org/10.1377/hlthaff.28.5.1418

Murphy, D. (2012). *Psychiatry in the Scientific Image* (1. ed.). The MIT Press.

Murray, C. J. L. (1994). Quantifying the burden of disease: The technical basis for disability-adjusted life years. *Bulletin of the World Health Organization*, *72*(3), 429-445.

Nagel, E. (1935). The Logic of Reduction in the Sciences. *Erkenntnis*, *5*, 46-52.

Nervi, M. (2009). Mechanisms, malfunctions and explanation in medicine. *Biology & Philosophy*, *25*(2), 215-228. https://doi.org/10.1007/s10539-009-9190-x

Nielsen, L. (2015). Why Health Matters to Justice: A Capability Theory Perspective. *Ethical Theory and Moral Practice*, *18*(2), 403-415. https://doi.org/10.1007/s10677-014-9526-8

Nord, E. (1999). *Cost-Value Analysis in Health Care: Making Sense out of QALYs*. Cambridge University Press. https://doi.org/10.1017/CBO9780511609145

Nordenfelt, L. (1995). *On the Nature of Health: An Action-Theoretic Approach* (Second ed., Vol. 26). Springer Netherlands. https://doi.org/10.1007/978-94-011-0241-4

Nordenfelt, L. (2007). The concepts of health and illness revisited. *Medicine, Health Care and Philosophy*, *10*(1), 5-10. https://doi.org/10.1007/s11019-006-9017-3

Nussbaum, M. (1993). Non-Relative Virtues: An Aristotelian Approach. In M. Nussbaum & A. Sen (Eds.), *The Quality of Life* (pp. 242–269). Oxford University Press. https://doi.org/10.1093/0198287976.003.0019

Ohrnberger, J., Fichera, E., & Sutton, M. (2017). The relationship between physical and mental health: A mediation analysis. *Social Science & Medicine*, *195*, 42-49. https://doi.org/10.1016/j.socscimed.2017.11.008

Parfit, D. (1984). *Reasons and Persons*. Oxford University Press.

Pedersen, K. M., & Wittrup-Jensen, K. (2002). *Værd(i)sætter danskerne deres helbred? - Et øjebliksbillede*. Syddansk Universitetsforlag.

sdu.dk

#sdudk

Pieper, A. (1973). Individuum. In Hermann Krings, H. M. Baumgartner, & C. Wild (Eds.), *Handbuch philosophischer Grundbegriffe* (Vol. II: Gesetz-Relation, pp. 728-737). München: Kösel-Verlag.

Plessner, H. (1969). "A Newton of a blade of grass"? *Psychological Issues*, *6*(2), 135-176.

Plessner, H. (1982). *Gesammelte Schriften VII, Ausdruck und menschliche Natur*. Suhrkamp.

Plessner, H. (2016). *Die Stufen des Organischen und der Mensch: Einleitung in die philosophische Anthropologie*. Suhrkamp.

Poulsen, B. (2019). Semistrukturerede interviews. In C. Juul Kristensen & M. A. Hussain (Eds.), *Metoder i samfundsvidenskaberne* (2. ed.). Samfundslitteratur.

Preyer, G., & Peter, G. (2005). *Contextualism in Philosophy: Knowledge, Meaning, and Truth*. Clarendon Press.

Proust, M. (1932). *Remembrance of things past*. Random House.

Rabin, R., & Charro, F. d. (2001). EQ-5D: a measure of health status from the EuroQol Group. *Annals of Medicine*, *33*(5), 337-343. https://doi.org/10.3109/07853890109002087

Ram-Tiktin, E. (2011). A Decent Minimum for Everyone as a Sufficiency of Basic Human Functional Capabilities. *The American Journal of Bioethics*, *11*(7), 24-25. https://doi.org/10.1080/15265161.2011.577512

Ratcliffe, M. (2012a). The Phenomenology of Existential Feeling. In J. Fingerhut & S. Marienberg (Eds.), *Feelings of Being Alive* (Vol. 8, pp. 23-54). DE GRUYTER. https://doi.org/10.1515/9783110246599.23

Ratcliffe, M. (2012b). Varieties of Temporal Experience in Depression. *Journal of Medicine and Philosophy*, *37*(2), 114-138. https://doi.org/10.1093/jmp/jhs010

Rose, N. (2007). *The Politics of Life Itself: Biomedicine, Power and Subjectivity in the Twenty-First Century*. Princeton University Press.

Ryle, J. A. (1947). The Meaning of Normal. *The Lancet*, *1*(6436), 1-5.

Saborido, C., Moreno, A., González-Moreno, M., & Hernández Clemente, J. C. (2016). Organizational Malfunctions and the Notions of Health and Disease. In E. Giroux (Ed.), *Naturalism in the Philosophy of Health* (Vol. 17, pp. 101-120). Springer International Publishing. https://doi.org/10.1007/978-3-319-29091-1_7

Sackett, D. L., Rosenberg, W. M. C., Gray, J. A. M., Haynes, R. B., & Richardson, W. S. (1996). Evidence Based Medicine: What It Is And What It Isn't: It's About

Integrating Individual Clinical Expertise And The Best External Evidence. *BMJ*, *312*(7023), 71-72. https://doi.org/10.1136/bmj.312.7023.71

Schrader, H., Bovim, G., Sand, T., Obelieniene, D., Siurkiene, D., Mickevičiene, D., & Misevičiene, I. (1996). Natural evolution of late whiplash syndrome outside the medicolegal context. *The Lancet*, *347*(9010), 1207-1211. https://doi.org/10.1016/S0140-6736(96)90733-3

Schramme, T. (2007). A qualified defence of a naturalist theory of health. *Medicine, Health Care and Philosophy*, *10*(1), 11-17. https://doi.org/10.1007/s11019-006-9020-8

Schramme, T. (2019). *Theories of Health Justice: Just Enough Health*. Rowman & Littlefield International.

Schwartz, P. H. (2007). Defining Dysfunction: Natural Selection, Design, and Drawing a Line. *Philosophy of science*, *74*(3), 364-385. https://doi.org/10.1086/521970

Schwartz, P. H. (2014). Reframing the Disease Debate and Defending the Biostatistical Theory. *Journal of Medicine and Philosophy*, *39*(6), 572-589. https://doi.org/10.1093/jmp/jhu039

Sedgwick, P. (1973). Illness: Mental and Otherwise. *Hastings Center Studies*, *1*(3), 19-40. https://doi.org/10.2307/3527464

Sen, A. (1995). *Inequality Reexamined*. Oxford University Press. https://doi.org/10.1093/0198289286.001.0001

Shapin, S. (2000). Descartes the doctor: rationalism and its therapies. *The British Journal for the History of Science*, *33*(2), 131-154. https://doi.org/10.1017/S000708749900391X

Sholl, J. (2015). Escaping the Conceptual Analysis Straitjacket: Pathological Mechanisms and Canguilhem's Biological Philosophy. *Perspectives in Biology and Medicine*, *58*(4), 395-418. https://doi.org/10.1353/pbm.2015.0032

Sholl, J. (2016). Contextualizing Medical Norms: Georges Canguilhem's Surnaturalism. In E. Giroux (Ed.), *Naturalism in the Philosophy of Health* (Vol. 17, pp. 81-100). Springer International Publishing. https://doi.org/10.1007/978-3-319-29091-1_6

Simon, J. (2007). Beyond Naturalism and Normativism: Reconceiving the 'Disease' Debate. *Philosophical Papers*, *36*(3), 343-370. https://doi.org/10.1080/05568640709485206

Smith, R. C., Fortin, A. H., Dwamena, F., & Frankel, R. M. (2013). An evidence-based patient-centered method makes the biopsychosocial model scientific. *Patient Education and Counseling*, *91*(3), 265-270. https://doi.org/https://doi.org/10.1016/j.pec.2012.12.010

Sokolowski, R. (2000). *Introduction to Phenomenology* (1. ed.). Cambridge University Press.

Solomon, M. (2015). *Making Medical Knowledge*. Oxford University Press. https://doi.org/10.1093/acprof:oso/9780198732617.001.0001

Sontag, S. (1991). *Illness as Metaphor and AIDS and Its Metaphors*. Penguin.

Stegenga, J. (2015). Measuring effectiveness. *Studies in History and Philosophy of Science. Part C, Studies in History and Philosophy of Biological and Biomedical Sciences*, *54*, 62-71. https://doi.org/10.1016/j.shpsc.2015.06.003

Stegenga, J. (2018a). *Care and Cure: An Introduction to Philosophy of Medicine*. The University of Chicago Press. https://doi.org/https://doi.org/10.1080/02698595.2020.1796038

Stegenga, J. (2018b). *Medical Nihilism* (1. ed.). Oxford University Press. https://doi.org/10.1093/oso/9780198747048.001.0001

Sumner, L. W. (1999). *Welfare, Happiness, and Ethics*. Oxford University Press. https://doi.org/10.1093/acprof:oso/9780198238782.001.0001

Svenaeus, F. (1999). *The Hermeneutics of Medicine and the Phenomenology of Health: Steps towards a Philosophy of Medical Practice*. Linköping University. Linköping.

Svenaeus, F. (2018). *Phenomenological Bioethics: Medical Technologies, Human Suffering and the Meaning of Being Alive* (1. ed.). Routledge.

Svenaeus, F. (2019). A Defense of the Phenomenological Account of Health and Illness. *Journal of Medicine and Philosophy*, *44*(4), 459-478. https://doi.org/10.1093/jmp/jhz013

Svenaeus, F. (2021). Health and Illness as Enacted Phenomena. *Topoi*, *41*(2), 373-382. https://doi.org/10.1007/s11245-021-09747-0

Szasz, T. S. (2010). *The Myth of Mental Illness – Foundations of a Theory of Personal Conduct* (Second ed.). Harper Perennial.

Temkin, O. (1977). *The Double Face of Janus and Other Essays in the History of Medicine*. The Johns Hopkins University Press.

Thorell, A. (2021). Distinguishing Health from Pathology. *Journal of Medicine and Philosophy*, *46*(5), 561-585. https://doi.org/10.1093/jmp/jhab022

Toombs, S. K. (1990). The Temporality of Illness: Four Levels of Experience. *Theoretical Medicine*, *11*(3), 227-241. https://doi.org/10.1007/bf00489832

Toombs, S. K. (1992). *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient* (Vol. 42). Springer Netherlands. https://doi.org/10.1007/978-94-011-2630-4

Tsouyopoulos, N. (1988). The Mind-Body Problem in Medicine (The Crisis of Medical Anthropology and its Historical Preconditions). *History and Philosophy of the Life Sciences*, *10*, 55-74.

Valles, S. (2020). Philosophy of Biomedicine. In E. N. Zalta (Ed.), *Stanford Encyclopedia of Philosophy*.

Venkatapuram, S. (2011). *Health Justice: An Argument from the Capabilities Approach* (1. ed.). Polity Press.
Venkatapuram, S. (2013). Health, Vital Goals, and Central Human Capabilities. *Bioethics*, *27*(5), 271-279.
Vogt, H., Hofmann, B., & Getz, L. (2016). The new holism: P4 systems medicine and the medicalization of health and life itself. *Medicine, Health Care and Philosophy*, *19*(2), 307-323. https://doi.org/10.1007/s11019-016-9683-8
Vogt, H., Ulvestad, E., Eriksen, T. E., & Getz, L. (2014). Getting personal: can systems medicine integrate scientific and humanistic conceptions of the patient? *Journal of Evaluation in Clinical Practice*, *20*(6), 942-952. https://doi.org/10.1111/jep.12251
Voit, E. O., & Brigham, K. L. (2008). The Role of Systems Biology in Predictive Health and Personalized Medicine. *The Open Pathology Journal*, *2*(1), 68-70. https://doi.org/10.2174/1874375700802010068
Wakefield, J. C. (1992). The Concept of Mental Disorder: On the Boundary Between Biological Facts and Social Values. *The American Psychologist*, *47*(3), 373-388. https://doi.org/10.1037/0003-066X.47.3.373
Waldenfels, B. (2002). *Bruchlinien der Erfahrung*. Suhrkamp.
Waldenfels, B. (2011). *Phenomenology of the Alien: Basic Concepts*. Northwestern University Press.
Waldenfels, B. (2016). *Grenzen der Normalisierung*. Suhrkamp.
Weizsäcker, V. v. (1968). *Der Gestaltkreis: Theorie der Einheit von Wahrnehmen und Bewegen* (1. ed.). Georg Thieme Verlag.
WHO. (2020). *Basic Documents: Forty-Ninth Edition 2020*. World Health Organization. Retrieved 22.09.2022 from https://apps.who.int/gb/bd/pdf_files/BD_49th-en.pdf
Wilson, J. (1999). *Biological Individuality: The Identity and Persistence of Living Entities*. Cambridge University Press. https://doi.org/10.1017/CBO9781139137140
With, J. M., & Jensen, S. N. (2018). *Værdibaseret sundhed i Danmark - Anbefalinger for vejen frem*. https://www.regioner.dk/media/11353/anbefalinger-for-det-fremtidige-arbejde-med-vaerdibaseret-sundhed.pdf
Wolkenhauer, O., & Green, S. (2013). The search for organizing principles as a cure against reductionism in systems medicine. *The FEBS Journal*, *280*(23), 5938-5948. https://doi.org/10.1111/febs.12311
Worrall, J. (2002). What evidence in Evidence-Based Medicine? *Philosophy of Science*, *69*(3), S316-S330. https://doi.org/10.1086/341855
Worrall, J. (2007). Evidence in Medicine and Evidence-Based Medicine. *Philosophy Compass*, *2*(6), 981-1022. https://doi.org/10.1111/j.1747-9991.2007.00106.x
Worrall, J., & Worrall, J. (2001). Defining disease: Much ado about nothing? In A.-T. Tymieniecka & E. Agazzi (Eds.), *Life Interpretation and the Sense of Illness Within the Human Condition* (pp. 33--55). Kluwer Academic Publishers.
Zahavi, D. (2011). *Husserls fænomenologi* (2. ed.). Samfundslitteratur.

sdu.dk

#sdudk

Zahavi, D. (2013). Naturalized Phenomenology: A Desideratum or a Category Mistake? *Royal Institute of Philosophy Supplements*, *72*, 23-42. https://doi.org/10.1017/S1358246113000039

Zahavi, D. (2019). Applied phenomenology: why it is safe to ignore the epoché. *Continental Philosophy Review*, *54*(2), 259-273. https://doi.org/10.1007/s11007-019-09463-y

Zaner, R. M. (1981). *The Context of Self: A Phenomenological Inquiry Using Medicine as a Clue*. Ohio University Press.

Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, *67*(6), 361-370. https://doi.org/https://doi.org/10.1111/j.1600-0447.1983.tb09716.x

10. Appendix

10.1 Interview guide in Danish

Herefter følger en interviewguide. Udgangspunktet er et semistruktureret interview af udvalgte sundhedsprofessionelle mhp. at afdække deres anvendelse af og holdning til sundhedsevalueringsredskaber. At det er semistruktureret vil i denne sammenhæng sige, at interviewguiden primært tjener som en tjekliste af spørgsmål, som intervieweren gerne vil afdække i løbet af interviewet, men at intervieweren forsøger, ikke at lade sig binde af interviewguiden og dens kronologi, og i øvrigt forholder sig åbent til interviewpersonens indvirken på interviewsituationen.

Det betyder, at intervieweren foruden interviewguidens spørgsmål bør være forberedt på at stille såkaldte ”probing”-spørgsmål, det vil sige, opfølgende uddybende spørgsmål såsom, ”hvordan det?”, ”kan du uddybe det?”, ”kan du give et eksempel?”, ”hvordan oplevede du det?”, ”hvad fik det dig til at tænke?” mv.

Forskningsspørgsmålet er, *hvad er sundhedsprofessionelles anvendelse af og holdning til sundhedsevalueringsredskaber?* Og det skal tjene et projekt om anvendelsen af sundhedsevalueringsredskaber i sundhedsvæsnet. Interviewets ses i den henseende at spille den rolle at afdække både den faktiske anvendelse samt sundhedsprofessionelles holdning. Det kan man ikke bare spørge alle mulige læger og sygeplejersker om, da sundhedsevalueringsredskabers anvendelse oftest foregår på et mere abstrakt niveau. Derfor er interviewpersonerne strategisk udvalgt ud fra kriterier om kendskab til sundhedsevalueringsmetoder. Interviewene er

sdu.dk

#sdudk

derfor en form for ”eliteinterview”, idet interviewpersonen er udvalgt ud fra deres profession, men er samtidig ”repræsentantinterview”, da de søger at afdække interviewpersonernes oplevelser af og holdning til anvendelsen af sundhedsevalueringsredskaber.

Den strategiske samplingsproces følges op af såkaldt snowball sampling, hvorved interviewpersonerne kan give inputs til, hvem der ellers skal samples til interviews. Det overvejes, om interviews skal følges op af spørgeskema survey.

Forskergruppen er Thor Hennelund Nielsen, Søren Harnow Klausen og Lasse Nielsen. Interviewene påtænkes gennemført af en forskningsassistent og evt. Thor Hennelund Nielsen.

- *Lasse Nielsen*

Interviewguiden er lavet på inspiration fra følgende kilder:

Bryman, A. (2004), *Social Research Methods* 2nd Ed., Ch. 15 “Interviewing in qualitative research”, Oxford: Oxford University Press.

Harrits, G. S., Pedersen, C. S. & Bente Halkier (2010), ”Indsamling af interviewdata”, kap. 6, i Andersen, L., Hansen, K. L. & Klemmensen, R. (red.), *Metoder i statskundskab*. København: Hans Reitzels Forlag.

Vromen, A. (2017), ”Qualitative Methods”, Ch. 14 in Lowndes, V., Marsh, D. & Stoker, G. (eds.), *Theory and Methods in Political Science*. Palgrave MacMillan.

Interviewguide

	Forskningsspørgsmål	***Interviewspørgsmål***
Tema	**Intro**	
	Hvem er interviewpersonen og hvad er vedkommendes stilling og arbejdsopgaver?	***Hej, og mange tak fordi, du vil stille op til interview. Jeg vil stille dig en række spørgsmål*** *- Hvad er dit navn?* *- Hvad er din stilling?* *- Hvad er din funktion?* *- Hvad er dine mest typiske arbejdsopgaver?*
Tema	**Anvendelse og udbredelse af sundhedsmål og evalueringsredskaber**	
	Hvad er de sundhedsprofessionelles **kendskab til** sundhedsmål og evaluering?	*- Hvad forstår du ved ”sundhedsevalueringsredskaber”?* *- Hvilke sundhedsevalueringsredskaber er du bekendt med?* *- Her er nogle forskellige sundhedsmål og evalueringsred-*

		*skaber (fx **Short form 36 (SF-36)**, **EQ-5D**, **WHO-5**, **QALY**). Hvilke af dem kender du?* *- Hvad siger evalueringsredskaberne og evt. hvordan er de forskellige?* *- Hvor udbredt er kendskabet til disse sundhedsmål, vil du vurdere?* *- Kender du til andre redskaber?*
	Hvad er de sundhedsprofessionelles **brug af** sundhedsmål og evalueringsredskaber?	*- Hvordan anvender du sundhedsevalueringsredskaber i dit arbejde?* *- Hvilke sundhedsevalueringsredskaber anvender du?* *- Kan du give eksempler, hvor du har anvendt sundhedsevalueringsredskaber?* *- Er anvendelsen af sundheds-*

		evalueringsredskaber særlig udtalt i dit arbejde? *- Hvordan er anvendelsen af sundhedsevalueringsredskaber i dit arbejde forskelligt fra anvendelsen i dine kollegers arbejde (fx indenfor givne specialer).*
Tema	**Opfattelse af og holdning til sundhedsmål og evalueringsredskaber**	
	Hvad er de sundhedsprofessionelles **holdning til sundhedsmål** og evalueringsredskaber?	*- Hvad mener du om brugen af sundhedsevalueringsredskaber?* *- Mener du, at sundhedsevalueringsredskaber er brugbare mål? Hvis ja, brugbare til hvad? Fx iht. at vurdere behandlinger og lave prioriteringer?* *- Hvad er succeskriterierne for et godt sundhedsevalueringsredskab? Og lever de, du er bekendt med, op til dem?* *- Hvad er problemerne med sundhedsevalueringsredskaberne og anvendelsen af dem?* *- Hvis du skulle bestemme, hvordan skulle man så evaluere?*

sdu.dk

#sdudk

		Og evt. hvordan skulle man så designe sundhedsevalueringsredskaber? *- Er det nødvendigt at bruge sundhedsevalueringsredskaber? Kunne man fx udføre din arbejdsfunktion lige så godt uden evalueringsredskaber?* *- Er der noget alternativ til at bruge sundhedsevalueringsredskaber, og hvis ja, hvad er alternativet så?* *- Hvis du skulle give en anbefaling til myndighederne om brugen af sundhedsevalueringsredskaber, hvad ville din anbefaling så være?*
Tema	**Afrunding**	
	Afslutning og snowball sampling	*Tusind tak for din tid og alle dine svar. Det har været en stor hjælp.*

		- Er du interesseret i at blive opdateret på, hvad vi finder ud af med studiet? *- Kender du til andre, som du mener, det kunne være relevant at interviewe?*

sdu.dk

#sdudk

SDU
Syddansk Universitet

University of Southern Denmark
Campusvej 55
DK-5230 Odense

Phone: +45 6550 1000
sdu@sdu.dk
www.sdu.dk