

Disease: An Ill-Founded Concept at Odds with the Principle of Patient-Centred Medicine

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Abstract

Background:

Despite the at least decades long record of philosophical recognition and interest, the intricacy of the deceptively familiar appearing concepts of ‘disease’, ‘disorder’, ‘disability’, etc., has only recently begun showing itself with clarity in the popular discourse wherein its newly emerging prominence stems from the liberties and restrictions contingent upon it. Whether a person is deemed to be afflicted by a disease or a disorder governs their ability to access health care, be it free at the point of use or provided by an insurer; it also influences the treatment of individuals by the judicial system and employers; it even affects one’s own perception of self.

Aims:

All existing philosophical definitions of disease struggle with coherency, causing much confusion and strife, and leading to inconsistencies in real-world practice. Hence, there is a real need for an alternative.

Materials & Methods:

In the present article I analyse the variety of contemporary views of disease, showing them all to be inadequate and lacking in firm philosophical foundations, and failing to meet the desideratum of patient-driven care.

Results:

Illuminated by the insights emanating from the said analysis, I introduce a novel approach with firm ethical foundations, which foun-

dations are rooted in sentience, that is the subjective experience of sentient beings.

Discussion:

I argue that the notion of disease is at best superfluous, and likely even harmful in the provision of compassionate and patient-centred care.

Conclusion:

Using a series of presently contentious cases illustrate the power of the proposed framework which is capable of providing actionable and humane solutions to problems that leave the current theories confounded.

Keywords: illness; sickness; disability; personalized; targeted.

1 Introduction

The concepts of disease, illness, disability, disorder, sickness, etc. — for the sake of brevity and the avoidance of awkward linguistic constructions, in the present article all henceforth referred to simply as ‘disease’ (this decision will be elaborated upon shortly), despite the subtle differences in the manner the aforementioned terms are used and understood — are only all too familiar ones. For the most part, they feature in everyday discourse without much doubt that their meaning is readily understood by all; indeed, a search on <https://www.newspapers.com/> constrained only to the first 10 months of 2022 retrieves 150,616 articles containing the term ‘disease’ alone. Yet, that what disease actually *is* may not be quite as clear cut as it seems at first becomes readily apparent when disagreement does emerge and when in an attempt to reach a consensus, major differences between different individuals’ views on the topic are brought to the fore. Oftentimes this happens when there is a change in what is and what is not classified as a disease. For example: is obesity a disease? Loos and Bouchard [1] take the positive answer for granted as do Marcus and Wildes [2], the difference between their views being only in the classification thereof (genetic vs mental, respectively). Yet, a large swathe of the public disagrees and even finds this suggestion offensive [3] (n.b. this does not mean that they do not recognize the broad spectrum of negative health consequences *consequent* on obesity). Is this because the latter are scientifically uneducated? Is the question a scientific

one at all? No lesser disagreement is found in the consideration of addiction, to give another prominent topical example. Lewis [4] explains at length why what is deemed addiction is actually a manifestation of a perfectly normally functioning brain. On the other hand, both Leshner [5] and Levy [6] disagree, arguing that addiction is a disease after all, though as before disagreeing on whether it is a disease of the brain or if the (claimed) disease is rooted elsewhere. Examples of similar disagreements are numerous, and include ADHD [7], ‘transsexualism’ [8], gambling [9], and many other traits and behaviours [10; 11; 12].

Far from being an intellectual exercise in semantics and pedantry, how (and indeed, *if*) we distinguish between disease and not-disease, and whether we attach the label ‘disease’ to a phenomenon has serious real-world consequences. For example, in jurisdictions that offer state provided health care, the aforementioned distinction shapes individuals’ access to various treatments [11]. In the judicial context, the presence of a recognized mental disorder can be a major factor in assessing and quantifying one’s culpability for their acts [13]; on the flip side, the ‘disease’ label has a profound impact on employers’ liability and potential claims of damages [14]. Interestingly though not at all surprisingly, the mere labelling itself affects people’s perception of their own selves, influencing both their mental well-being and behaviour [15]. The presence of disease also affects one’s access to health insurance and potential treatment [16].

To make my aims herein clear, right at the start I would like to preface

my argument by explaining what I am and what I am *not* trying to achieve in the present article. In particular, I am *not* arguing that the definition I put forward is *the correct one* and that those I challenge are in some sense *wrong* (that is, not those that are internally consistent). Indeed, this would be a meaningless claim, a *contradictio in adjecto*, as the central question is that of defining a notion, and a definition in this context cannot be ‘wrong’; it is what we agree it to be. Inverting our labels for what we usually refer to as ‘apples’ and ‘oranges’ would not result in any conflict *per se*. Rather, it would be a rather pointless exercise, for there would be no new insight or the potential of one, and nothing substantial would change. Hence, the question at the crux of the debate is what definition would be *instrumentally most useful* rather than ‘correct’. Ultimately, this means that we are after a definition which serves best to effect a reduction in people’s suffering and an increase in their ability to pursue pleasure, noting that I use these notions in what I would describe as neo-Epicurean sense [17; 18; 19], rather than in the more superficial, colloquial one. In particular, when speaking of pleasure, I subsume under the notion both the positive sentient experiences effected immediately, such as the consumption of tasty food [20], the feeling of the warmth of the sun’s rays on a clear day [21], or perhaps the touch of a loved person [22]; as well as those experienced mediately, whose pleasant effects emerge through the processes of apprehension and cognitive judgement, say the making of a charitable donation which resonates with one’s values [23], the process of imagination of future happy experiences [24], and even the

act of sacrifice for a subjectively hypostatized worthy cause [25]. The same applies to my use of the term ‘suffering’ [26], which also includes immediately felt unpleasantness, such as malodorous smells [27], loud noises [28], or a physical injury [29], as well as those experienced mediately, such as due to deprivation that is the denial of pleasure [17], through the expectation of fearful futures [30], or through reflection and the consequent sense of guilt and remorse [31].

It should be noted that while my focus on the alleviation of suffering is a widely supported one in the bioethics community [32; 33; 34], there have been attempts at challenging this view. However, I contend that most of these challenges are in appearance only, stemming from semantic rather than substantial differences and emerging from the understanding of the notion of suffering which is much narrower than that which I laid out *ut supra*, e.g. one which excludes mental or spiritual anguish in connection with treatment [33; 35]. In other cases the apparent difference in views is found in the seeming distinction between problem-oriented and goal-oriented approaches [34]. Yet, this is a sleight of proverbial hand, for how else is a problem to be defined if not with respect to a certain goal? The very notion of a problem implies the existence of a goal whose reach is troubled by an obstacle that the problem conceptualizes.

Lastly, before proceeding with an overview of the existing views of disease, I would like to return to what was stated right at the beginning of the present article, namely that for the sake of brevity and the avoidance of

verbal clumsiness, I ask the reader to understand that when I refer to ‘disease’ in the present paper the reference is made to a range of familiar notions such as disease, illness, sickness, disability, etc. By doing so I do not mean to suggest that these are identical, equivalent, or absolutely interchangeable notions; certainly not. There has been a considerable amount of work on the elaboration of the distinction between these as they are currently understood, e.g. by Boorse [36], Cassell [37], Eisenberg [38], Wikman et al. [39], Scully [40] and others [41; 42]. Rather, the rationale stems from the observation that they are all in some way undesirable to the individual, or in the words of Savulescu and Kahane [42] whose focus is on disability specifically:

“...the welfarist approach sees disability as a harmful state...”

and that they are all grounded in some objective, physical fact, subject to medical science, as explained with clarity by Glackin [43]. It is in that sense that they can be abstracted by a single label *for the purposes of the analysis herein*, the choice of the specific label ‘disease’ merely resting on its familiarity. The key contribution will lie in the answer to the central question of the evaluative authority pertaining to the judgement of harm; as asked by Glackin:

“But who is doing the evaluation here? ‘Regarded’ by whom?”

2 Contemporary views

In order to motivate the views which I advance in the present article, as well as to contextualize the contribution, I would like to begin with an overview of the existing thought on the distinction between disease and not-disease. I shall start with the lowest hanging fruit, so to speak, that is with the definitions of disease which have attracted a fair following despite being rather obviously flawed; rejecting these right away shall allow us to focus on the most interesting and widely adopted views which necessitate a more nuanced analysis and rebuttal.

Nominalist approach A nominalist view of disease [44; 45] can be succinctly summarized as follows:

“A disease is whatever physicians say is a disease.”

With reference to what I said in the previous section, this definition is not unreasonable, though I expect it to be met with immediate disapproval. Deconstructing and explicating the reasons why the nominalist definition indeed should be rejected, to wit, in what way it does not meet the desiderata that I explained a *useful* definition should possess, helps set up ground for understanding the alternatives and their advantages and disadvantages. Let us begin with the apparent appealing aspects of the nominalist approach: it seems simple and clear cut, and it places experts at centre stage. Nevertheless, despite this first impression, the definition in fact fails on both accounts.

Firstly, through the use of the word ‘physicians’, the definition conceals the plurality of opinion regarding the issue at hand that exists within the medical community. The very reason why this plurality exists is that physicians, to one degree or another, understand that how disease is defined has important real-world consequences, some of which I highlighted previously; and yet, physicians are *not* expert at understanding these, for they feature economic, social, psychological, and numerous other considerations outwith medicine. Thus, we can see how the nominalist definition also suffers from a false appeal to authority (*argumentum ad verecundiam*). Nominalism here gives us neither clarity nor a solid fundamental philosophical basis upon which a coherent framework for the understanding of, diagnosing, and treating disease could be erected.

Idealistic, functional approach Seeking to address one of the most glaring flaws of the nominalist approach, to wit, the lack of any philosophical insight which should serve as the guiding light in postulating a definition of disease, the idealistic view grounds itself with respect to *function*, that is, the deviation of the actual performance of a bodily system (large or small) from that which is optimal or desired [46]. This view is consonant with a teleological conceptualization of the physiology of a body: different processes are seen as serving a certain *purpose* and the degree to which this purpose is achieved is seen as crucial in the judgement of their ‘normality’ or, conversely, pathology (i.e. malfunction, abnormality, disease, disorder, etc.). While ad-

mittedly appealing — and indeed likely quite adequate and reasonable for everyday, informal discourse — it does not take much to see that attempts to define disease in this manner fail to provide a sufficiently rigorous and well-founded philosophical basis. Lacking a rooting in either the nominal or in the statistical (which I shall come to shortly), the reference functioning that the idealistic [47], functional approach has to be referred to is nothing short of a form of neo-Platonic ideal. Not only is this ideal philosophically unsound, a mere nebula existing nowhere and outwith the kin of mere mortals, it is also ignorant of the biological reality; humans (and indeed organisms of other species) exhibit variation in nearly if not literally every characteristic worthy of consideration as well as perhaps more pertinently, in the potential for the development of a particular characteristic, be it height [48], muscular strength [49], memory [50], sense of spatial orientation [51], general intelligence [52], or any one of a plethora of other possible traits [53]. This variation is not only evolutionarily expected but rather is necessary and desirable in the context of the species' ability to adapt to novel pathogens and other environmental change.

Though seemingly seeking to root itself in the objective and absolute, the idealistic, functional approach fails in achieving this also by virtue of failing to account for the contingency of what proper or ideal function means on *context*. Many physiological processes have evolved as adaptive and beneficial to the organism within the backdrop of the environment as it was during the greater part of our evolution. Yet, the processes are often undesirable in that

they cause suffering to individuals living in the present-day, modern world; examples include insulin resistance [54] and postnatal depression [55] (listed in DSM-5 as “a major depressive episode with an onset in pregnancy or within 4 weeks of delivery”). Various types of what DSM-5 calls the ‘antisocial personality disorder’ also have a rather straightforward adaptive explanation — e.g. those characterized by (quoting from DSM-5) ‘deceitfulness’, ‘lack of remorse after hurting or mistreating another person’, ‘reckless behaviors that disregard the safety of others’, ‘aggressiveness’, etc. [56; 57] — which explanation is ignored due to the absence of a coherent view of what disease is, and the fear of a social judgement emerging from the popular *argumentum ad naturam* [58].

Relativistic, socio-cultural approach Unlike the nominalist view (as well as the idealistic, functional one, albeit indirectly) which approaches the concept of disease as one bequeathed by the authority (albeit false authority, as I have shown) and having nothing to do with the opinions of the population at large, relativistic and socio-cultural views of disease see the notion as contingent on a specific context, thereby denying its absoluteness and instead allowing it to be malleable and, at least in principle, shaped by all: physicians, patients, and potential patients [43]. Notwithstanding the appeal of the aforementioned malleability in an abstract, qualitative sense, what should be readily apparent is that this flexibility comes at a cost, indeed an unacceptable cost, of having any basis upon which the concept of

disease rests removed. In other words, this definition tells nothing about what fundamental principles, which have to be shared for this kind of consensual decision-making process to make sense, should guide one's view of what ought to be deemed disease. Even a quick look at historical (or indeed, present-day) examples readily raises the colossal flaws of the socio-cultural approach to the surface where they are obvious to see. Consider male homosexuality, which the American Psychiatric Association (APA) included in the Diagnostic and Statistical Manual of Mental Disorders (DSM) in 1952 [59]. That the American Psychiatric Association has since declassified homosexuality as a mental disorder [60] does not change the fact that the acceptance of the relativistic, socio-cultural definition of disease would have it that homosexuality was not merely listed in the DSM for over 20 years, but rather that over that period in time *it actually was a disorder* for that was the socio-cultural view of the phenomenon at the time. Examples like this are not historical only; a proponent of the socio-cultural definition would have to concede that homosexuality *is* a 'damage in the mind' in the present-day Qatar, as stated by Khalid Salman, an ambassador for the 2022 FIFA World Cup [61].

The superficial attractiveness of the dispersal of authority, and indeed responsibility, at the heart of the relativistic, socio-cultural approach to disease can be seen to be little more than a deceptive wave of the hand, raising more questions than it answers and creating more problems than it solves. How are the views of the medical community, diverse as they themselves are bound to

be, to be traded off against the views of the general public? Are the former to be weighted more, or is the ‘one person, one vote’ to be applied? Surely, it is clear that neither can be accepted as principled and well-founded, necessitating a summary rejection of the overarching proposition. This specious ‘democratization of disease’ may very well resonate with the present-day zeitgeist wherein ‘democratization’ is seen as a panacea to most social ills [62], but it is in want of a morally grounding substance. What Glackin [43] describes as a ‘liberal’ approach, namely the call “not to impose one faction’s views on all parties, but to negotiate as wide as possible a *modus vivendi*, which will allow all parties to proceed on a basis of respectful disagreement, and tolerable compromise” is one that few would object to in general, but as even the handful of examples I described illustrate, this approach often does not result in a successful resolution [63]; therein is the very *terminus a quo* of the present discussion and the need thereof. Focusing instead on grounding conditions, Glackin does not venture to answer this question, describing it as “a debate primarily of interest to philosophers”, while recognizing that “it will have practical consequences”.

The intellectual gymnastics that has to be practised in trying to make the relativistic, socio-cultural approach ‘work’ is made apparent by Heshka and Allison [64], commenting on obesity:

“...it might nevertheless be possible to achieve a social consensus that it is a disease **despite** its failure to fit traditional models of disease...”

Finally, notwithstanding the aforementioned dispersal of authority which seemingly sets the relativistic, socio-cultural view of disease apart from the nominalist and idealistic, functional ones, a different conceptualization reveals an interesting similarity instead. In particular, with reference to any *specific* individual, that is a specific patient, the authority that decides on what is a disease and what not, is external to them. In the latter case — to wit, nominalism, and relativism & idealism — the power of authority is given explicitly to the medical experts; in the former case, the authority rests on the society as a whole, disempowering any *specific* individual, leaving their voice as but a faint whisper drowned out by the vocality of the many.

Statistical approach Owing to its seeming pragmatism and the rooting in “hard data” and empiricism, the statistical view of disease sees it as a deviation from a statistically (rather than normatively) derived reference [65; 66]. However, despite the superficial appearance of its basis being in evidence driven medicine, this approach instead introduces a degree of malleability, and practically arbitrary and potentially rapid change that render the concept all but meaningless. For example, it leads to the bizarre conclusion that it is impossible for an entire population to be diseased. A more practical example can be found in the so-called diseases of affluence which are constantly changing the statistical profile of conditions which are variously considered as disease, such as obesity. Put simply, if the population as a whole is getting progressively fatter, as it indeed is [67], does that mean that what was

yesterday considered clinically overweight and obese, can today become a disease-free state instead? I do not think that I need to say much to convince the reader that this position is untenable. Yet, this is precisely what has been happening. For children, a BMI that is lower than the fifth percentile is used to classify a child as underweight and above the 95th percentile as obese [67].

And how are the disease/not-disease cut-offs to be determined? Statistics offers no answers here: the answer has to come from philosophy. *Ad hoc, a priori* values are clearly unacceptable; at the very least there has to be some dependence of the thresholds, some reference thereof, to the condition itself and its specific, *sui generis* nature. If the solution is to be sought in the practical, e.g. based on the available resources to treat or the treatability of a condition, then we are again confronted with the absurd situation wherein a patient is told that they are not diseased simply because they cannot be treated, despite them experiencing suffering and their well-being being affected adversely. As an example, albeit in a different direction (which does not change the point being made), in 1998 the U.S. National Institutes of Health lowered their BMI cut-off for overweightedness from 27.8 for men and 27.3 for women, to 25, making in an instant approximately 25 million individuals previously deemed as having a healthy body mass, overweight; regional differences the aforementioned thresholds across the world still exist [68]. On the other hand, the thresholds cannot be deduced from the outcomes to patients, for then the definition of disease would cease to be

a statistical one in the first place: there would merely be statistics which *emerge* from disease/not-disease differentiation based on other criteria, as they would indeed emerge with any otherwise conceived differentiation (such as those discussed previously). To be clear, I do not mean to suggest that the answers to the aforementioned questions can emerge from a purely philosophical consideration. Rather, any statistical or other empirical determination of the threshold has to be preceded by the establishment of a philosophical, axiological principle. This principle also, it should be said, may draw from science (statistics included) but it is not fully determined by it — a philosophical basis, which is lacking at present, is needed as a key constituent of the framework.

Hybrid approaches The limitations of the definitions of these I criticized in the preceding sections have been recognized by others, e.g. Cooper [69], Wakefield [70], Hesslow [71], Ereshefsky [72], and Boorse [66]. In turn, this has given rise to alternatives which have been variously described as ‘hybrid’ or ‘biopsychosocial’. These attempt to combine different elements of the primitive definitions discussed previously with the goal of formulating a coherent framework in their stead. As I shall illustrate shortly, ultimately all of these fail because no matter what specific hybrid variant, any attempt to avoid a rooting in a *specific* patient’s values, values which cannot be known objectively or *a priori*, is ultimately reduced to at least one of primitive (I use this term value-free, referring to their *point d’appui*) views: the statisti-

cal, the normative, the social, or the functional. The apparent appeal of the seeming nuance and intricacy of hybrid approaches ends up being a superficially mesmerising Möbius strip which in the end offers no means of egress from the landscape of problems it is aiming to escape from.

Consider the cornerstone of Cooper's proposition:

“A condition can only be a disease if it is a bad thing for the potential patient. [...] Ginger-haired people are different from other people but having ginger hair is not a disease.”

In short, Cooper is trying to erect an objective definition of disease which I, as well as Wakefield [70], Hesslow [71], and Ereshefsky [72], rebutted at some length. The unacceptability of Cooper's argument is also readily apparent from the following:

“Someone who has a disease is unlucky. We only consider someone to be diseased if they could reasonably have hoped to have been otherwise.”

Herein we can see a thinly veiled, latent imposition of value judgement (c.f. socio-normativity). A consequence of Cooper's view is that it is not the purely objective physiological state of one's body (this, lest there be no mistake, includes psychological states which too are rooted in the physical) that makes something a disease. In this I agree. However, the value judgement imposed upon the patient is an external to the patient. As a corollary, an individual whose bodily condition causes them suffering can be either diseased

or not diseased depending on the individual's choices, such as whether they willingly engaged in risky behaviour, i.e. depending on whether their state is a result of 'bad luck' or not. For example, a promiscuous individual who engages in frequent acts of unprotected sex and hence contracts what is at present referred to as a venereal disease, should not be considered diseased. This is a rather extreme and bizarre position which finds Cooper at odds both with my view and all other accounts of disease, and I trust that I am on safe ground in claiming that virtually everybody would reject it.

On the other hand, Wakefield [70] attempts to create a hybrid of 'biological facts' and 'social values' (i.e. the 'bio' and 'social' in 'biopsychosocial'). Despite his criticisms of functional definitions, his hybrid approach ultimately relies upon their central tenant (a point also correctly observed by Ereshefsky [72]). Thus, Wakefield writes:

“Consequently, an evolutionary approach to personality and mental functioning is central to an understanding of psychopathology. Dysfunction is thus a purely factual scientific concept.”

As I have explained earlier, function and the adaptive (or maladaptive) nature of a certain function in evolutionary terms is a distracting irrelevance. Many evolutionarily adaptive traits no longer are such and the *value*, that is the meaningfulness in the context of patient-centred care, of any function can only be seen as relevant from the point of a patient's values and axiological views. Ultimately, Wakefield too falls into the trap of thinking that he can find grounding for the definition of the pathological which would make

it value-free, which is a mistake that has already been highlighted by others.

As Ereshefsky [72] put it:

“Another problem with the hybrid approach concerns its naturalist component. Wakefield’s hybrid account requires an evolutionary account of function. He tells us that the sort of evolutionary explanation he has in mind concerns an organ’s ability to perform ‘a naturally selected function’. In our discussion of Boorse on ‘normal function’ we saw that evolutionary biology does not tell us what the natural states of an organism are. One might then attempt to find an account of normal or natural functions in physiology. But functional ascription in physiology has little to do with adaptation and selection. Wakefield’s account requires an evolutionary account of normality, but there are no norms in evolutionary biology and the norms of physiology are not evolutionary.”

or, in summation:

“...biological theory does not distinguish natural states from unnatural states. Nor does biological theory distinguish theoretically normal from abnormal states.”

2.1 Reflecting remarks

As I have shown, all existing attempts to defining disease suffer from major shortcomings. My analysis highlights that these ultimately stem from the unfirm philosophical basis of the frameworks which the aforementioned definitions rest upon, often implicitly and without an express understanding and recognition thereof. Another important feature of the contemporary views of disease, which is shared by them all despite the great diversity of the philosophical underpinnings on display, is the lack of an individual patient's say in the matter. At the very 'best', a patient's voice is a faint contributor to the choir dominated by the society as a whole, which contribution can hardly pass off as salient in the context of much-lauded individualized medicine [73]. In short, as it stands, purely medical based views of disease are ironically at stark odds with, nothing short of an anathema to, patient-centred care. The definition and thus the presence of disease in an individual is treated as a judgement external to the patient, as an objective or inter-subjective fact, and any patient involvement is relegated to the consequent choices, e.g. that of treatment of a thus externally postulated medical condition. In summary, I agree with Engel [74] that:

“...all medicine is in crisis and, further, that medicine's crisis derives from...adherence to a model of disease no longer adequate for the scientific tasks and social responsibilities of...medicine...
The importance of how physicians conceptualize disease derives

from how such concepts determine what are considered the proper boundaries of professional responsibility and how they influence attitudes toward and behavior with patients.”

Engel’s writing offers an insightful analysis of the problems of the existing views, while failing to formulate fully an alternative, both as seen from the viewpoint of the theoretical, given the incompleteness of his biopsychosocial approach, as well as the practical, owing to a lack of clarity as to how the different elements of his model are to be integrated in the clinic. The same can be said of other accounts of disease with a subjectivist underpinning [75; 66; 76; 77]. As Nordenfelt said [77], there remains:

“...the need for a reconstruction of this network of concepts [ethical, social and economic]...”,

which is the purpose of the present work.

3 A coherent, sentientist view of disease, consonant with patient-centred care

What I trust emerges with clarity from the discussion I presented in the previous section, is the infirmity of the foundations upon which all of the existing views of disease are founded [71]. I consider this to be of paramount importance and hence it is with the establishment of the philosophical and ethical basis that I would like to begin my exposition.

My starting point draws from the traditions of Epicureans and Existentialists, amongst others [78; 18], and focuses on *sentience*, to wit, the ability of (in this case) humans¹ to experience pleasure on the one hand and suffering on the other. The overarching goal of medicine should thus be on alleviating this suffering, whatever its aetiology may be. This resonates with Cassell's observations [32]:

“The obligation of physicians to relieve human suffering stretches back into antiquity. Despite this fact, little attention is explicitly given to the problem of suffering in medical education, research, or practice... Even in the best settings and with the best physicians, it is not uncommon for suffering to occur not only during the course of a disease but also as a result of its treatment.”

To be clear, I contend that the entire notion of what is currently referred to as disease should be based on this, a person's subjectively experienced suffering, and indeed *on this alone*. In other words, the end focus of a medical professional, as a cognitive agent other than the patient whose understanding of patients' sentient experiences can only emerge mediately by means of cognitive apprehension, should be on what is experienced by the patients' sentient organ, that is, the brain. In this, note that the shift to the purely subjective fountainhead of the notion does not divorce it from the objective reality. Any suffering, though *experienced* only subjectively, is inherently

¹The same principle, without any change, can be adopted in the consideration of disease in animals.

contingent on the physical since, be it ‘mental’ or ‘physical’ as they would be termed presently, any suffering is tied to a physical manifestation in which we find its grounding, i.e. the underlying biological (including behavioural) state upon which the notion is metaphysically dependent. The need and the importance of such grounding has been eloquently explained by Glackin [43]. It is by means of this grounding that the link between the subjective experience and the medical practice is established — for the notion of disease to have the relevance in the real world that one would expect it to have, it needs to be treatable by the application of medical science (that is, in principle; there will be conditions for which effective treatment merely does not exist at present). This understanding thus readily permits treatments which address a patient’s perception, say, such as Cognitive Behaviour Therapy [79] which may be seen as being less direct in nature, as well those that may be seen as more direct and which involve a physical manipulation of the patient’s body, such as surgery, radiation therapy, amputation, and so on. Ultimately, the inability of a physician to share a patient’s subjective experience and thus to directly affirm it, presents no new practical challenge: we do not find it questionable when a medical professional deals with a patient presenting with pain or hunger management problems following extreme weight loss, despite them not being able to experience either — both are grounded in the physical. I shall elaborate on this further in Section 3.5 wherein I discuss the relevant praxis.

To facilitate the conceptual shift necessary to fully internalize the pro-

posed idea, I furthermore suggest that herein at least we abandon the use of the word or indeed the notion of ‘disease’ (and the related ones, as highlighted right at the start of the present article; I also note that I do not necessarily think that this level of rigour is required in everyday, colloquial communication), and instead think of ‘that which should be treated’ so that an improvement in patients’ well-being can be effected. Therein we see a marrying of the previously disconnected and artificially separated components of health care, to wit, of diagnosis and treatment. Here I note some overlap between my arguments and those of Canguilhem [80; 81], in that we both reject, in the words of Trnka [82]:

“...the falsehoods of (a) neutral, pure fact-based medical science, and (b) cultural, arbitrary notions of value.”

and thus the ideas espoused by [36]:

“According to this consensus view, a value-free science of health is impossible. This thesis I believe to be entirely mistaken.”

At the same time, there are major differences in my views and those of Canguilhem. For example, my conceptualization rejects his objectivist definition summarized by Horton [83]:

“He [Canguilhem] defines health as the ability of the organism to adapt to challenges posed by the environment, to create new norms for new settings.”,

and hence also:

“For him [Canguilhem], normality is measured by the adaptability of the individual; the physiological parallel is autoregulation. Disease is defined, not at an arbitrary point within the range of biological variation, but by the functional meaning of any disturbance for the whole organism. Health, for Canguilhem, ‘means being able to fall sick and recover’. By contrast, ‘to be sick is to be unable to tolerate change.’”,

which ignores the importance of subjective values in determining what changes and what adaptability are of importance to a specific individual, imposing instead these from outwith the patient.

Hesslow’s views [71] are much closer in spirit to those that I argue for in the present work. Hesslow focuses his attention on the criticism of the existing definitions of disease, pointing out similar deficiencies to those that I have laid out earlier, thus rejecting the need for the notion of ‘disease’ altogether. At the same time, Hesslow’s rejection is weaker than mine in the sense that he does little in the realm of the constructive, that is, he fails to elucidate a coherent framework which is free of the notion and yet able to withstand the challenges of the real-world clinical practice (this limitation of Hesslow’s contribution is recognized by Ereshefsky).

In the literature, Ereshefsky’s thought [72] is by far the closest to my own: he sharply criticises all of the views I do too, be they normative, social,

statistical, functional, or hybrid; acknowledges the value of Hesslow's contribution while also recognizing its limitations; and while seeking to abandon the reliance of dichotomization imposed by delineating diseased states in the clinic, does not object to a colloquial, everyday use of the word. There is very little that I would disagree about with him. As far as disagreement, or more appropriately, a divergence, in our thoughts is to be found, Ereshefsky fails to fully appreciate the need to and thus does not place the ultimate axiological power, that is the evaluative judgement of benefit and harm, in the hands of an individual patient. The following paragraph illustrates this:

“Many consider deafness a disease and believe that, if possible, deaf people should be given the ability to hear. This can be done for some deaf people with cochlea implants. However, some in the deaf community argue that deafness is not a disease. They argue that deafness has advantages over hearing. Being deaf heightens other senses, it reduces noise pollution, and it allows one to have the benefits of being part of the deaf community. The debate over deafness is framed in terms of ‘health’ and ‘disease’, but framing the debate in those terms masks points of agreement and disagreement between the two sides. Both parties agree that there is a physiological state involving hearing, but they disagree over whether such a state should be valued or disvalued. Using the distinction between state descriptions and normative claims makes clear where the disputants agree and where they disagree

rather than lumping two central aspects of the debate under the heading ‘disease’.

We can see that while correctly rejecting an objectivist stance, Ereshefsky cannot bring himself to avoid seeking some extra-personal reference, some authority other than the patient in the establishment of a value based judgment which concerns the patient, in particular by attempting to bring about an intra-subjective consensus. In contrast, within the framework I introduced, there can be no talk of disagreement in the scenario above since the two sides are talking about different things: each is talking about *their own* values and applies them to the conceptualization of *their own* good life and health.

Conterminous with this difference is a limitation of Ereshefsky’s work similar to that of Hesslow’s in that it fails to formulate and elucidate a concrete and practical framework; while Ereshefsky goes further in this than Hesslow, he fails to complete the task. Ereshefsky recognizes the need of the objective as a way of informing a patient, as well as the importance of values, but does not make a concrete proposal as to how the two should be integrated in clinical decision-making or health care provision.

As a way of concretizing my proposal and illustrating the real-world consequences that its adoption would result in, I would like to present a few examples before finalizing the discussion with a reflection on the practical consequences of my ideas.

3.1 Example 1: cosmetic surgery

Consider Mary, a hypothetical woman who as part of her cancer treatment has undergone mastectomy. In the United Kingdom, for example, Mary is entitled to free breast reconstruction through the National Health Service (NHS).

Maria, another hypothetical woman, on the other hand, is experiencing anguish and feelings of dissatisfaction with her body, these affecting her romantic and social relationships, by virtue of having breasts which she considers too small. Hence, she would like to undergo a breast enlargement surgery. In contrast to Mary, Maria's surgery would not be covered by the NHS, the said surgery being categorized as being for 'cosmetic' reasons. Maria would have to pay for it between £3,500 to £8,000, excluding the costs of consultations or any follow-up care.

Are the differential options available to Mary and Maria morally justifiable? As I am sure the reader can surmise, following the sentientist grounding I introduced in the previous section, my resounding answer would be in the negative. Maria's mental suffering is no different than the suffering of another woman, regardless of the fact that the *subjectively hypostatized* (n.b. there is no reason why all women who undergo mastectomy should desire reconstructive surgery thereafter) need for what is *also* a cosmetic intervention of the latter was consequent on mastectomy due to cancer. The present-day distinction drawn between the two has no principled moral or other philosophical basis, but is rather little more than a projection of social norms and

prejudice.

Maria has a genuine medical problem in so much that medical experts can help alleviate her suffering. Patient-centred care demands that this is recognized, that her suffering is put at the crux of any decision-making, and that the options for her treatment are not artificially narrowed. In other words, if the aforementioned suffering is kept as the focus, it can be seen that in general there are a multitude of ways in which it may be addressed. Breast enlargement surgery is one. A neuro-psychiatric approach is another. It may very well be that a therapy which proximally centres on Maria's perception of her own body could alleviate her suffering. It is quite possible that this route would carry lesser risk too. It is also likely that a psychiatric or psychological treatment would be able to address a more fundamental underlying problem, and thus have more extensive benefits to the patient. The ultimate point, however, is that patient-centred care demands that the choice is left to Maria, and that the different options, with their advantages and disadvantages, are discussed with her.

3.2 Example 2: homosexuality

In Western societies the prevailing attitude is that homosexuality is a variant of 'normal' (I would refer the reader to the preceding section wherein in the context of various views of disease I discuss the overloaded nature of this term which for that reason I enclose in inverted commas) sexuality, and it is certainly accepted as such by the medical authorities in the corresponding

countries. But let us consider how the following (not so) hypothetical scenario plays out in one of these ‘progressive’ societies.

Mario is a gay man who relates to his general practitioner (GP) the anguish he experiences with his sexuality and asks to be offered so-called ‘conversion therapy’ [84]. There is no doubt that Mario’s request would be summarily rejected: not only does the NHS not offer conversion therapy but has moreover gone out of its way to issue a memorandum condemning it and describing it as ‘unethical’ [85]. The doctor’s response would most likely be to attempt and explain that homosexuality is not a disease (as decreed by Authority the patient is forced to accept) and instead offer some form of psychological treatment or counselling, i.e. following Haldeman [86] to:

“...provide treatments to gay men and lesbians that are **consonant with psychology’s stance** on homosexuality. [all emphasis added]”

So as to direct my focus with precision, let us disentangle two cotermi-
nous issues here, namely (i) the idea of conversion therapy in principle and
(ii) the effectiveness of interventions currently presented under the umbrella
of conversion therapies [87]. As regards the latter, the issue is an objective,
scientific one, and there is ample data evidencing both harm and ineffec-
tiveness of claimed conversion therapies [88; 89]; on this basis they must be
rejected on moral grounds [87]. However, the former question, that of *per-*
missibility of conversion therapy *in principle*, is one where empiricism does
not help us, its crux being firmly outwith the scientific realm; the answer has

to be found in the philosophical. In other words, imagine that tomorrow a ‘treatment’ is discovered whereby an individual’s sexuality can be changed. Should Mario be offered this treatment?

With the Law increasingly being called upon to intervene [84], this question is a highly topical one with disagreement voiced both in the academic literature [90; 87] and in the popular culture (though both almost universally confounding the principle with the present-day options addressed earlier [86]). The moral framework I introduced helps answer this question in a manner coherent with the way other patient preferences and sources of suffering are treated. In particular, with reference to the sentientist grounding I advocate, the clear answer is that the principle of conversion therapy is permissible, and should an effective means of changing one’s sexuality be found, individuals like Mario should be offered it. As in the case of breast augmentation surgery, Mario should have the choice between the whole gamut of possible options aimed at relieving his suffering, the hypothetical, effective conversion therapy being one of them, psychiatric or psychological treatment another, etc., as always contextualized by their advantages and disadvantages, potential risks, etc. Rejection of the hypothesised conversion therapy can only be seen as yet another imposition of authority — in this instance in the form of social norms — a cultural diktat that imposes itself on the individual, prohibiting the pursuit of truly patient-centred health care.

3.3 Example 3: ‘transsexualism’

Transsexualism was included for the first time in the DSM-III in 1980, that is 6 years after homosexuality was removed from the list of disorders in DSM-II. It remains in DSM-5 under the name ‘gender dysphoria’, defined as:

“marked incongruence between their experienced or expressed gender and the one they were assigned at birth.”

It is insightful to contrast the accepted practices in treating individuals experiencing gender dysphoria with the treatment of individuals who may be unhappy with their sexuality, such as Mario in the hypothetical scenario I considered earlier. A gender dysphoric person would be offered hormonal therapy or surgical therapy, with psychiatric counselling *complementing and supporting* these [91; 92], but a purely psychiatric option aimed at possibly changing the person’s “experienced gender”, to use the wording from DSM-5, is widely rejected [93]. What we again see here in plain sight is the exclusion of viable treatment options, that is viable care routes for alleviating patient suffering, neither driven by the objective and scientific, not by principled philosophical reasons, but rather by socially agreeable norms. The sentimentist approach I advance in the present paper re-establishes the authority of the patient in their treatment, neither eliminating any course supported by evidence nor pressurizing the patient in their preferred choice driven by personal judgement, values, and self-reflection.

The phenomenon of ‘transsexualism’ offers yet further insight into the

weaknesses of the existing views of disease. In particular, a number of thinkers have argued that although individuals presenting with ‘transsexualism’ experience suffering, its aetiology is not medical but rather that the experienced distress is a response to social intolerance and prejudice [94]. In other words, the argument is that transsexualism is a normal expression of one’s identity (much like homosexuality is seen to be a form of normal expression of sexuality), pathologized and medicalized by the society which artificially dichotomizes gender [16]. We can see that this viewpoint is not normative, considering that it is stated in the language of the objective out-with the realm of human authority; nor is it statistical; it is also explicitly not socio cultural; rather, it is functional, the said function of relevance being that of ‘normal’ socialization. That social attitudes negatively affect transsexual individuals’ perception of their own identity and amplify the severity of a range of psychiatric comorbidities (such as depression, suicidal ideation, anxiety, and many others [95; 96]) is beyond any doubt. However, the thesis that these dysphoric feelings are caused purely by the social environment is rather fantastic; in fact, it is borderline inconsistent with the definition of the phenomenon of transsexualism which has at its core one’s feeling of *incongruence* (between their experienced or expressed gender and the one they were ‘assigned at birth’). The rejection of a medical explanation by the proponents of this view of transsexualism is additionally bizarre considering that the aforementioned incongruence can only be resolved by medical means. This alone firmly places the condition in the realm of medicine, contrasting

the claim that ‘medicalization’ is somehow being artificially imposed.

What we can see in transsexualism is an *objective* discrepancy, that between a person’s *experienced* gender identity and their *perception* of their bodily gender. Both the aforementioned experience and the perception are subjectively known to the transsexual individual in question (the former immediately, the latter mediately with the involvement of cognition), the discrepancy being raised to the level of the objective by others’ mediate apprehension thereof, that is, by having this subjective hypostatization of gender communicated to them. Therein lies the crux of the ongoing debate over the aetiology of the condition. Is the source of the discrepancy in one’s perception, which would place the aetiology in the realm of the mental (as I noted before, here speaking in the language of the current conceptions of disease), or is it in the bodily, which would make it a physical condition? Or, using Glackin’s framing [43], is the grounding to be found in one’s brain or body? A significant voice rejects that transsexualism is a mental disorder [94; 16; 97]. But how can one tell? The obvious answer that this is impossible shows with clarity the flaw of the existing definitions of disease which fail to establish an objective reference point, leaving questions like the present one floating in thin air, with nothing to ground them. In contrast, the view I introduced recognizes the impossibility of a principled way of establishing such grounding and shows it to be an unnecessary and unproductive framing of the problem. The proposed sentientist framework focuses on the patient’s experience of suffering and rather than seeking an arbitrary reference point which would

direct the subsequent treatment, considers all means — all evidence based and ethically permissible means, that is — of alleviating that suffering, ultimately as directed by the patient, appropriately informed as regards the objective.

3.4 Example 4: paranoia

The list of potential examples that the current definitions of disease struggle with, in that their internal inconsistency is readily exposed, and yet that the view I advance in the present article deals with effortlessly and in a principled manner, consonant with the basic tenet of ethics that is ‘*neminem laede; immo omnes, quantum potes, juva*’, is a long one and I am limited by space. Hence, in an effort to avoid unnecessarily prolixity, I shall conclude my exposition with one final example, trusting that the reader will find it a simple matter to adopt and apply the core principles laid out to other instances of interest.

The aspect of this example which sets it apart from those previously analysed is that the ‘disease’ at the crux of it affects directly the very cognitive processes of the patient, which processes are instrumental in the proposed sentientist, patient-driven framework herein. I am partly inspired by an actual case, that of the mathematical genius Kurt Gödel, who late in his life developed an obsessive fear of being poisoned and would eat only food prepared by his wife Adele. Following Adele’s hospitalization and thus her inability to cater for Kurt, he refused to eat, dying mere months later of

malnutrition and inanition, weighing 29 kilograms. Thus, I ask, what should the duties of a physician be in this instance?

Firstly, let us recognize that offering the patient psychiatric treatment or drugs (when possible) is an immediate option which in no way conflicts with the focus on patients' preferences, experiences, and ultimate power in steering their own health care. The person is clearly in distress; the question is merely whether they consider medical treatment to be a viable and otherwise acceptable means of alleviating the associated suffering. I contend that if the patient rejects this, then they *de facto* do not have a medical problem in that the claimed remedies would indeed *factually* not be best for them. This may seem like an odd claim, so let me elaborate. As an outside observer, the physician can most reasonably see that a pharmaceutical intervention, say, could resolve, or partially resolve, the patient's problem, allowing them to enjoy life thereafter. So, how can this not be best for them? With reference to the sentientist foundation of my proposal, the answer lies in the primality of the subjectively felt experiences of the patient. The hypothesised life of pleasure, void of the present suffering is predicated on the prior experience of the treatment, the conceptualization of which is *prima facie* a cause of so much pain to a patient rejecting it, that the suffering associated with the anticipation of living through it outweighs the subjectively hypostatized pleasure which would follow. Even if the patient's predictions of the strength of their experiences are erroneous, the experienced pain is such as it is — it is no less real than if it were consequent on correct predictions. The physician

would be perfectly within the bounds of ethics set by my proposal to discuss and question whether the patient's expectations are correct, but ultimately the patient's choice becomes *objectively* correct once it is hypostatized by the patient's subjective.

In conclusion, and to emphasise an important point that the present example illustrates, if a patient does not recognize their distress as being treatable (in principle, rather than merely due to practical reasons) by medical means, the situation should not be regarded as that of a morbid patient whose refusal of a treatment is respected by their physician (as the present-day view would have it); rather, the rejection of treatment, though subjectively hypostatized, thereafter becomes *de facto objectively* the correct patient choice. This is so even if the physician, apprehending the patient objectively, believes that the said choice will lead to suffering in future, as the intensity of the patient's prior suffering prohibits the alternative; what is impossible cannot be preferable.

3.5 Praxis

Echoing the view that “philosophy done well must have real-world consequences” [98; 99; 30], I started my exposition with a focus on seeking a definition of disease which is coherent, conceptually well-founded, and instrumentally useful. In that this task concerns not the introduction of a wholly new concept, but rather one which has been in use for a long period of time, the term ‘disease’ comes with a series of connotations and expect-

tations as regards its meaning [100] which would be imprudent to reject summarily. For example, ‘disease’ ought to describe a state of one’s being that is inherently undesirable. Hence, I sought to formulate a philosophical definition which also fits the aforementioned expectations to the extent to which that is possible, i.e. noting that I have already showed the present-day views often to be antinomic; it is in part by virtue of this congruence that a definition is capable of exercising its usefulness in practice.

I rooted my inquiry in the goal of patient-centred care which is increasingly seen as the primary aim of medicine [101; 102; 103; 104]. Hypostatizing this goal through the medium of a neo-Epicurean focus on the subjective experiences of pleasure and suffering (understood in their extended sense), I showed how this leads to a coherent framework which can answer real world challenges which at present lead to incongruent health care decisions and opinions available to patients. I illustrated this through a series of examples in Sections 3.1–3.4, in which the proposed ideas are shown to lead to radically different real-world treatment choices and outcomes from those based on the existing views of disease.

I would like to wrap up this discussion of practical consequents of the adoption of the proposed definition with the highly pertinent question of resource allocation. At first sight, this appears to pose an insurmountable problem in the context of a subjectively hypostatized notion of disease. However, the seeming unprecedentedness of this challenge is illusory; it is no different than those that physicians confront already on a daily basis in their

everyday practice; a similar point has previously been made by Hesslow [71] with whom I am in complete agreement on this issue. Consider two patients who present with pain, one with mild pain and one severe. Can a physician actually verify the subjectively experienced intensity of the patients' pains? Can a physician objectively compare them one with another [105]? Certainly not. Yet, the same physician would have no qualms about allocating more resource (most costly medication, more costly and time consuming therapy, etc.) to the more harshly affected patient. The manner in which such assessment is done relies on patient-clinician discourse and the understanding of objectively apprehensible effects that the pain has on a patient, just as I illustrated in the case of Maria in Section 3.1, i.e. by observing the effect that the pain has on the patient and their life experience, underlain by the context of the patient's values and desires. Thus, for example, a clinician would approach the treatment of a pianist presenting with a pain in their hand differently than another patient whose life may be differently affected by exactly the same physical symptoms, demonstrating the already present recognition that a person's mental suffering is no different than one originating in the purely physical. Ultimately, it is important to stress that while the aetiology of pain and suffering is important in informing the possible treatment options, the decision on whether to treat or how much resource should be allocated to treatment, should be indifferent to the said aetiology. As Misselbrook [106] put it:

“...clinicians need to understand the significance of Hume's fact/value

distinction in medicine, for medicine relies on both facts and values.”

4 Summary and conclusions

Both in academic literature [107; 108; 109] and the mainstream discourse [110; 111], patient involvement is increasingly widely appreciated as an important aspect of patient-centred health care delivery, affecting not only the individuals’ perception of being cared for, but also as a factor influencing the ultimate health outcomes. Notwithstanding this apparent focus and the plethora of research resulting from it, in this article I showed that the possible scope for patient involvement in their care is presently inherently limited by the health care paradigm which underlies the current health care delivery, which paradigm is a direct result of the conception of notions such as ‘disease’, ‘illness’, ‘sickness’, ‘disorder’, and the like. In particular, we can recognize a two stage process, the first one focusing on the diagnosis of the patient, and the second (if applicable) on their treatment. The increasing attention on patient involvement mentioned earlier has been strictly confined to the realms of the latter; the former is seen as a process wherein patient involvement would not only be unnecessary but also nonsensical: the patient either does or does not have a condition, a disease, a disorder, etc. This spirit is lucidly exemplified by the words of Vahdat et al. [112]:

“Patient participation means involvement of the patient in decision making or expressing opinions **about different treatment methods**, which includes sharing information, feelings and signs and accepting health team instructions. [all emphasis added]”

In other words, the presence of disease is seen as objective (or, ‘at best’, as inter-subjective). In this article I explained why this view of disease and hence diagnosis must be rejected. I first overviewed the existing views on the conception of disease — such as nominalist, functional, statistical, and socio-cultural ones — showing them all to suffer from glaring flaws and resulting in a diagnostic process which imposes upon a patient by virtue of some higher authority, be that the medical community or the society.

Guided by the identified weaknesses, and in particular the infirmity of the foundations upon which all of the existing views of disease are founded, I proposed an alternative, built upon that which is immediately accessible to us all: sentient experience, that is, the feelings of pleasure on the one hand, and the suffering on the other. Following from this starting point, I argued that the concept of disease is unnecessary at best and likely harmful, and that the focus of health professionals should be on the alleviation of suffering, subjectively felt by the patient and mediately apprehended by the clinician, whatever its aetiology may be. I next led the reader through a series of scenarios which pose insurmountable difficulties to the current theory of disease as well as create a vehement polarization amongst the experts and the public (such as cosmetic surgery, homosexuality, transsexualism,

and life endangering paranoia), concretizing the impact that the adoption of the proposed framework would have and, by virtue of its coherence and strong foundations, demonstrating its power in resolving conflict in presently contentious situations.

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