Personhood and care in disorders of consciousness. An ontological, patient-centred perspective

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ABSTRACT

People in unresponsive wakefulness syndrome/vegetative state or minimally conscious state are characterized by the alteration – or the complete loss – of self-awareness and consciousness of the external environment. According to the functionalist and brain-centred approach, this kind of clinical situations also implies the loss of the moral status of person. This paper critically discusses this perspective and proposes an alternative paradigm of personhood concerning the disorders of consciousness (DOC). After a preliminary analysis, I will compare the function-based approach with the pragmatic perspective, arguing that the latter seems to deal better with the evaluation of the status of personhood in patients with disorders of consciousness, and specifically criticising the functionalist view from both the theoretical and ethical levels. Nevertheless, I will claim that the pragmatic view only works as a provisional approach, falling back into the functionalist perspective once the uncertainty of the clinical diagnosis is resolved or decreased. I will thus propose an ontological personalist approach that avoids the radical separation of the concepts of person and human being, considering personhood as an intrinsic condition of human existence, instead of an emerging property from certain contingent faculties or decisions made by a community of moral subjects. In this sense, the patient with DOC is understood as a human being with some damaged features (rationality, consciousness, self, etc.) but still a person worthy of care and attention precisely because of her/his human nature in a fragile and non-autonomous condition. Moreover, I will argue that such an ontological personalism could guide healthcare professionals towards a proactive attitude for the wellbeing of these patients.

RIASSUNTO

Persona e cura nei disordini di coscienza. Una prospettiva ontologica, centrata sul paziente.

Le persone in stato di veglia non responsiva/stato vegetativo o in stato di minima coscienza sono caratterizzati dall'alterazione – o dalla completa perdita – della consapevolezza di sé e della coscienza del mondo esterno. Secondo l'approccio funzionalista e neuro-centrico, questo genere di situazioni cliniche comportano anche la perdita dello statuto morale di persona. In questo saggio tale prospettiva viene discussa criticamente, e viene proposto un paradigma alternativo di persona in relazione ai disordini della coscienza. Dopo una preliminare analisi, comparerò l'approccio funzionalista e la prospettiva pragmatica e sosterrò che quest'ultima affronta in modo più adeguato la valutazione dello statuto della persona in pazienti con disordini della coscienza, con una critica specifica alla visione funzionalista sul piano sia teorico che etico. Tuttavia, l'approccio pragmatico funziona solo a livello provvisorio, in quanto, nel momento in cui l'incertezza della diagnosi clinica viene risolta o ridotta, questa prospettiva ricade all'interno del funzionalismo. Dunque, proporrò un approccio centrato sul paziente che evita la separazione radicale dei concetti di persona ed essere umano, considerando l'essere persona come una condizione esistenziale, invece che come una proprietà emergente da certe facoltà contingenti o un prodotto della decisione presa da una comunità di soggetti morali. In tal senso, il paziente con disordine di coscienza è inteso come un essere umano con alcune caratteristiche danneggiate (razionalità, coscienza, sé, ecc.) ma pur sempre una persona meritevole di cura e attenzione proprio in virtù della sua condizione di fragilità e di autonomia perduta. Inoltre, sosterrò che tale personalismo ontologico può indirizzare il professionista sanitario verso un'attitudine di cura nei confronti di questi pazienti.

Keywords: disorders of consciousness, personhood, unresponsive wakefulness syndrome, minimally conscious state, neuroimaging, anthropological dualism.

Parole-chiave: disordini della coscienza, persona, stato di veglia non responsiva, stato di minima coscienza, neuroimmagine, dualismo antropologico.

1. Introduction

Mental life is crucial for the constitution of who we are, i.e. beings capable of emotions, feelings, perceptions, desires, actions, attitudes, fantasies, memories, reason, cognition, and self-reflection; consciousness underlies these states and makes them mine and personal, i.e. referred to my own life and not to someone else's. In other words, our mental states seem embedded in a temporal psychological continuity that contributes to the development of our identity. This raises significant questions involving the meaning of our existence. What does it mean to lose consciousness? For example, when we are sound asleep dreamlessly and upon awakening, it seems like it has only been a few seconds since we went to bed. Or when we undergo major surgery and are put under general anaesthetic, so as not to feel any pain or to have any memory of the surgery. In these cases, we may assume that we are not capable of a proper mental life since we do not feel anything, we cannot dream or imagine, nor are we aware of ourselves or the surrounding environment. Undoubtedly, these situations are transitory in the sense that we lose the actual exercise of experiencing the world and ourselves just for a narrow amount of time, but we do not lose the capacity *per se*. However, in other cases, consciousness is lost persistently and with it the disposition to generate proper mental activity. This may happen when, as a result of trauma or illness, the patient is diagnosed with a disorder of consciousness (DOC), like coma, unresponsive wakefulness syndrome/vegetative state (UWS/VS), or minimally conscious state (MCS). It is now indisputable that the different altered states of consciousness are not simply a matter of all or nothing, but rather are a matter of degree, a "grey zone" [1] with different levels of awareness of oneself and the world, depending on the severity of the clinical situation and the type of treatments received (not to mention the entire clinical spectrum of DOCs) [2]. Thus, it is difficult (and dangerous) to declare without a doubt the state of consciousness in these patients based solely on one kind of clinical evaluation; however, it would be an essential mistake not to be guided in ethical reflection by neuroscientific results as well, without confusing the methodological domain with the ontological one (see below the methodological-ontological fallacy).

This paper aims to discuss the attribution of personhood based on the level of consciousness in people with DOCs, and related clinical and ethical issues concerning the application of life-sustaining treatments and end-of-life decisions. First, I will present and criticise the functionalist, brain-centred approach on personhood, according to which the loss or impairment of consciousness and self-awareness implies the loss of the moral status of person. Then, I will argue for a different concept of personhood based on an ontological personalist approach, according to which a person is not an emerging quality from some states (consciousness, rationality, etc.) but is a basic condition of human beings.

2. The attribution of personhood in DOCs

The loss (or the impairment) of consciousness in DOCs is not natural nor indu-

ced for clinical reasons (except for the medically induced coma), and this situation may persist for months or years in UWS/VS and MCS with low or no signs of recovery. Patients diagnosed with UWS/VS[1] are awake (e.g. spontaneous eye-opening and reflexive movements, normal body temperature and cyclic sleep patterns) but remain behaviourally unresponsive (e.g. no purposeful responsiveness to stimuli and no speech) [5], and show abnormal brain activity (e.g. low brain metabolic activity, abnormal functional connectivity, decreased spontaneous brain activity, disruption of the thalamocortical system, etc.). The UWS/VS becomes "persistent" after one month, and the possibility of recovery of consciousness strongly drops after three months in patients with nontraumatic aetiology (e.g. anoxia or neurodegenerative disease) and after 12 months in patients with traumatic brain injury; in these cases, clinicians apply the term "permanent" or "chronic" UWS/VS [6; 7].[2] In contrast, if the patient presents little signs of awareness, e.g. purposeful behaviour (instead of merely reflexive movements), simple command-following, simple gestural or verbal responses, then she/he may be diagnosed with MCS (or MCS- or MCS+ depending on the level of recovery) since consciousness is not completely lost still severely altered [8]. Nevertheless, it seems difficult if not impossible to draw a clear-cut distinction between the two conditions, since these diagnoses are currently based only on behavioural and neurophysiological measurements [9].

2.1 The Functionalist approach vs. the Pragmatic approach

These severe clinical situations, in particular UWS/VS, present the disruption of the mental life along with the loss of consciousness for a long period and with slight chances of recovery. This may raise ontological and ethical questions about human personhood; indeed, if our identity is constituted by the conscious continuity of mental states that normally characterises our life (with desires, memories, emotions, thoughts, etc.), once we persistently lose consciousness (and our mental unity *a fortiori*), do we still retain our own ontological and moral status of persons?

According to the standard view – the functionalist perspective – personhood is defined by a set of functions, properties or abilities, in which consciousness plays an important role. As Glannon states: «If personhood is defined in terms of the capacity for conscious awareness, then patients in a permanent VS no longer exist as persons.

1 UWS was previously defined as vegetative state (VS), but due to the pejorative connotation of this old definition (referring to a patient as being vegetable-like), the more neutral name UWS has recently been proposed [3]. However, at the moment "UWS" seems to be used only by experts, while lay people still prefer the term "VS" [4]. Other similar terminologies are "coma vigil" and "apallic state".

2 «Given the frequency of recovery of consciousness after 3 months in patients in nontraumatic VS/UWS, and after 12 months in patients with traumatic VS/UWS (including some cases emerging from MCS), use of the term permanent VS should be discontinued. After these timepoints, the term chronic VS (UWS) should be applied, accompanied by the duration of the VS/UWS. [...] Use of this term implies irreversibility, which is not supported by the current research and has implications for family counselling, decision-making, and the ethics of the field. The guideline panel suggests that the term permanent VS be replaced by the term chronic VS to indicate the stability of the condition (in keeping with other diseases that have a chronic phase)» [7, pp. 453, 455-456].

They continue to exist as human organisms because they have enough intact brainstem, cardiocirculatory, and somatic functions to remain alive in a biological sense. The fact that vegetative patients are wakeful is not crucial to this classification. Because persistently vegetative individuals may progress to the MCS, they may retain some capacity for awareness and survive as persons, at least for a limited period of time» [10, p. 158]. Some authors claim that people in chronic UWS/VS are not persons anymore since they have lost consciousness, consequently losing also the capacity to value their own lives, as well as a set of intrinsically human abilities such as sentience, self-consciousness, rational agency, etc. [11–17]. For others, likely, even patients in MCS do not reach the full moral status of persons due to the transitory and fluctuating conscious states that are associated with severe cerebral damages [18]. As I will explain later in detail, these issues do not merely concern academic philosophical debates but are concretely reflected in clinical practice.

Regarding the functionalist position, Matthew Braddock recently analysed the "PVS (Persistent Vegetative State) Nonpersonhood" thesis, arguing that the inference from «it is highly likely that PVS patients have irreversibly lost consciousness» to «it is highly likely that PVS patients are not persons» is fallacious in several points [19, p. 269]. First, the diagnosis of persistent UWS/VS does not necessarily mean the loss of consciousness, nor that it is highly likely that consciousness is lost. Braddock points out that numerous studies ranging from 1993 to 2015 have shown that about 35-45% of UWS/VS diagnoses were incorrect, as these patients were instead conscious in different degrees; and this indicates that the use of behavioural or neurophysiological analyses is not yet totally reliable. There are cases of covert awareness, where the patient is behaviourally unresponsive but an advanced clinical exam may show some relevant neuronal patterns potentially related to cognitive and/or conscious activities in response to command-following questions (in cases like cognitive motor dissociation and complete/total/functional locked-in syndrome) [20; 21]. I would also argue that even if serious damages are assessed to brain areas that are normally related to the maintenance of consciousness (e.g. ponto-thalamo-cortical tracts), there can be cases in which some relevant islands of brain activity may suggest the presence of some degree of consciousness [22]. Moreover, methodologically speaking, Piarulli and colleagues have shown that MCS patients present temporal fluctuations of brain activity with periodicities of about 70 minutes, closely resembling those of healthy participants, and related to higher and lower levels of awareness. This will help to identify the better time-window to use neurophysiological tests and/or therapeutic techniques such as transcranial magnetic stimulation. This means that applying an EEG or an fMRI test for 15-20 minutes may record only the period of low-level awareness or even a period during which the patient in MCS (or MCS-) is not conscious in that moment – hence, the possibility of false negatives [23].

The fact that more than a few patients diagnosed with UWS/VS actually are in MCS does not affect the theses of those

who, like Levy and Savulescu, consider even the fluctuation or the low level of consciousness as insufficient to define someone as a person.[3] Braddock continues his analysis, explaining how the lack of a current act of consciousness does not necessarily mean that the "dispositional nature" of the capacity to be conscious is irreversibly lost [19, p. 274]. Besides, I argue that the denial of personhood to patients in MCS consequently raises further issues about the moral status of personhood in other cases of cognitive and consciousness alterations, like people with mental disabilities, senile elderly, patients suffering from neurodegenerative diseases (e.g. later stages of Alzheimer's disease) and newborns, opening up possible scenarios of ethically questionable clinical practices. Thus, given the uncertainty of diagnosis in UWS/VS patients and the variability of awareness in MCS patients, he argues for a pragmatic approach, suggesting a "precautionary principle" instead of proposing a clear-cut distinction between person and non-person: «when it is fairly uncertain for us whether S is a person, then we should treat S as a person (as having the important rights of persons), unless we know that doing so would infringe upon the comparably important rights of individuals who are clearly persons» [19, p. 275]. This pragmatic perspective is also supported by a "moral asymmetry argument", which I suggest is similar to Pascal's wager on the existence of God. It says that it is always better to treat the unclear UWS patient as a person, since there is something to gain and much less to lose, while if we consider unclear patients as non-persons, we have nothing to gain and much to lose. This does not mean that this kind of patients possesses a sort of moral priority over other patients whose consciousness state is clear.[4] Taken together, this is a paradigmatic example of how the use of the concept of consciousness in relation to that of personhood can be extremely problematic for theoretical and scientific issues but also ethical ones.

2.2. The brainhood condition

Consciousness as a peculiar mental feature is related to other concepts such as personhood and personal identity, which intrinsically involve issues about the defi-

3 «It is important to emphasize that consciousness is not always an all-or-nothing phenomenon but may come in degrees, and what degree is sufficient for personhood is not always clear. […] What degree of consciousness is sufficient for one to continue to exist as a person? Could a patient survive as a person in a permanent MCS? This would depend on what one includes among the defining properties of consciousness. If one includes only arousal and minimal awareness of self and surroundings, then it might be plausible to say that the patient survives as a person. But if one includes the ability to meaningfully interact with others, which minimally conscious patients lack, then they do not survive as persons in a permanent MCS. Only emergence from this state is consistent with personal survival» [10, p. 158].

4 «[C]*omparably important* does not mean *equally* important. […] This qualification allows for the important rights of clear persons to take precedence in various conflict cases. [...] This does not mean we should treat the uncertain person as having little or no moral status – on the contrary, we should treat them as having significant moral status in virtue of our uncertainty regarding whether they possess the full moral status of personhood. For example, we should at least still treat them as moral patients whose welfare deserves serious moral consideration. But we should not treat them as the moral equals of clear persons» [19, p. 277].

nition of human nature. Our Western ontological and existential background is significantly rooted in the Lockean idea that connects personal identity with a continuous and unitary mental life. This opens the radical possibility of considering only a part of humankind (e.g. healthy, adult, rational, self-aware people) worthy of personhood. Braddock offers arguments against these positions, also suggesting a more pragmatic and less scientistic approach to the relationship between the presence of consciousness, the persistence of personhood in patients with DOCs, and the application of basic care and life-sustaining treatments. And yet as I will explain in the next part of the paper, I would suggest that even Braddock might be still working within the same paradigm that conceives personhood as a functional property of human beings that directly depends on the presence of a coherent and solid conscious mental life. This way of interpreting personhood and its relation to human beings and consciousness, i.e. the idea that the mental condition and contents of an individual define his/her identity, is a typical Lockean thesis that has spread over the centuries and persists in contemporary debates in philosophy of mind or bioethics, as well as in our folk psychology [24].

Indeed, another concept has been recently added to personhood-consciousness-mental life triad, due to the enormous development of neuroscience, namely the brain. The concept of consciousness nowadays seems strongly intertwined with the concept of the brain as the basis of our mental activity. Notably, the brain-mind-consciousness relation (whatever that means) is rooted in our common way of thinking as well as in the clinical context. The belief in the essentiality and centrality of our head in the determination of our mental life, subjective characteristics and personhood can be defined as "brainhood". Brainhood names the ontological condition of being (and not simply having) a brain, just as "personhood" refers to the condition of being a person, and it relates to an anthropological figure of modernity named by Fernando Vidal the "cerebral subject" [25; 26]. Indeed, it seems self-evident – at least apparently – that we are our brain and if the brain loses its normal features and activity, we may consequently lose our personhood and individuality. The intuitive power of thought-experiments like the brain-in-a-vat hypothesis or the brain transplant scenario confirms this general belief. Interestingly, the brain is here taken as the only necessary and sufficient cause of our whole existence, so much that not only the environment but also the rest of the body is left out. In this sense, concepts like mind, consciousness, but also personhood and individuality have been related to that of the brain, i.e. the mind-brain relation/problem. It is important to see how this strong relationship has emerged in both cultural and scientific contexts.

In the last decades, the brain-imaging techniques have become increasingly able to identify instances of the relationship between brain activity and consciousness, and they give us the feeling of going beyond the limits of the observable behaviour up to see what happens "inside the machine". Under the brainhood paradigm, conscious states such as perceptions, thoughts, will, emotions, pleasures and pains are considered as products of the mind, and the mind

as a genuine natural phenomenon produced in and by the brain. Everything is brought back to the brain, within the ontological and epistemological paradigm of contemporary naturalism and the empirical methodology of neuroscience. Accordingly, since we could define ourselves as individuals or persons because we possess particular features and those characteristics depend on our neural activities, someone – like Paul and Patricia Churchland – argues to be no reason to deny the fact that we are our brains, i.e. cerebral subjects with the property of being a brain.

3. The unsustainability of function-based and brain-reductive personhood

So far I presented the functionalist position, which argues that personhood depends on whether the human being possesses specific functions like a diachronically coherent mental life and a stable capacity of consciousness. These functions have been recently related to the brain, in particular to some specific cerebral structure, functionality or pattern of neural activation, depending on the position held by the many current neuroscientific theories of consciousness. Now, this part of the paper aims to critically analyse both the function-based and brain-centred approaches towards personhood, arguing that not only they are problematic from an ontological and ethical point of view, but also they can be detrimental from a practical and clinical point of view.

3.1 The methodological-ontological fallacy

The first point concerns the different neuroscientific methodologies used for the clinical assessment of consciousness in patients with DOCs. It is nowadays indisputable that the brain plays a constitutive role in the emergence and maintenance of consciousness; as said, various neuroimaging techniques are used to detect traces of consciousness in behaviourally unresponsive people. Nevertheless, it is necessary not to conflate the clinical assessment of consciousness with the ontological determination of it. The subject of the clinical and neuroscientific research is not consciousness *per se*, but rather the operationalised equivalent; the scientific concept is defined through the operations by which we indirectly measure a phenomenon via instrumental and methodological mediations. In this case, the concept of consciousness is defined through measurements that detect biological, electrochemical, structural, functional, etc. markers potentially related to the presence of consciousness. The error lies in confusing the marker with consciousness itself, passing from the scientific-clinical level to the ontological one. Hence, someone might fall into fallacies such as the mereological fallacy [27], i.e. the attribution to parts of the whole of specific characteristics and properties that belong to the whole, and the fallacy of simple location [28], i.e. the error of assuming that anything real must have a simple location in space and time. This does not affect the importance of neuroscientific analyses of consciousness, but the idea that "we are our brain" is more likely to be the result of an

approach inherited from modern culture, rather than a scientifically and logically supported position.

This may imply questionable consequences in ethics, like potentially attributing personhood to an intact brain in a vat allegedly capable of reasoning and self-consciousness, while not attributing it to someone that still preserves essential, vital functions (e.g. autonomous breathing, body temperature regulation, heart rate and blood circulation, reflexive movements, wound healing, etc.) but lacks sufficient cortical activity to be diagnosed as conscious. In this regard, the strong positions about UWS/VS and MCS held by authors like Levy, Savulescu or Singer are not so surprising, since they are based on the brainhood condition, so that if our brain stops working properly, our status as persons will also be compromised. Notably, in the recent years, an increasing amount of neuroscientific research has been questioning the sufficiency of a brain-centred approach to the mind and consciousness, arguing that the entire body (in particular the heart-brain and intestines-brain relations) and the environmental context are also important elements for the determination of consciousness [29; 30].

Even Braddock's argument risks remaining stuck into the brainhood paradigm, because if neuroscience will be able to provide a 100% certain diagnosis of permanent, irreversible UWS/VS based exclusively on the patient's brain state (assuming neuroscience will concretely be able to do this), the lack of consciousness will necessarily result in the loss of personhood. Braddock's core claims are mainly grounded on the contingent uncertainty of current neurological and clinical exams, rather than on theoretical or normative arguments (except for the moral asymmetry argument). Assuming the complete certainty of the diagnosis, it is plausible that for Braddock's non-reductivism as well what defines a person is only the brain activity, however, it is problematic to infer normative conclusions directly from scientific observations, no matter how important they are in defining the clinical state. On the ontological level, Braddock's pragmatic view remains silent about the status of patients with DOCs but it would fall within the functionalist perspective if the uncertainty of the clinical diagnosis were resolved or decreased. Thus, the pragmatic approach works well only as a provisional tool in a clinical context to deal with diagnostic uncertainty, while it falls back into the function-based approach once the diagnosis is more robust.

3.2 Mistaking selfhood with personhood

Another critical point concerns the sense of subjectivity and personal identity. Each of our experiences is shaped by a subjective perspective on the world and by a sense of self that crosses it transversally. This subjective characteristic can be generally defined as selfhood and is related to other various aspects of consciousness as explained by the phenomenological tradition: mineness, for-me-ness, pre-reflective self-awareness, ownership, perspectivalness, etc. [31]. People that are correctly diagnosed as UWS/VS – i.e. that are not patients with fluctuations of awareness or with cognitive-motor dissociation – seem to completely lose their sense of self toge-

ther with the perception of the surrounding environment. This point is still controversial since some patients diagnosed as UWS/VS may show significant brain activation induced by self-related stimuli, like the repetition of the patient's name. However, it is not clear whether this activation is associated with concrete conscious processing or merely an automatic processing of the stimuli [32-35]. Nevertheless, assuming the complete loss of self-awareness, those authors who argue for the loss of personhood in UWS/VS strictly relate selfhood with personhood, therefore falling into the fallacy of *transitus de genere ad genus*, i.e. giving a certain element of a class a property that belongs to another class.

In this case, personhood is mistaken as a phenomenal property of experience, thus ontological and ethical consequences (about the status of person) are then inferred from phenomenal premises (the absence of selfhood). However, personhood is a characteristic related to the concept of human being in different ways, e.g. socially constructed (human individuals reciprocally recognise each other as persons) or normatively constructed (by law as a legal notion with rights and responsibilities). Surely, some specific rights depend on the degree of consciousness in relation to the development of the human being; for example, freedom of movement, the rights to drive and marry cannot be guaranteed for children or mentally incapable patients, however, these rights are based on a second-level and social concept of personhood and they are not inalienable, nor rooted in the very being of a living person as such [36]. Instead, the functionalist version, arguing that the loss of phenomenal selfhood is co-occurrent with the loss of the moral concept of personhood, leads to improbable scenarios that cast doubt on the validity of the position; for example, according to this view, the life of a human being would be accompanied by the ontological property of being a person only intermittently (no personhood in new-borns and during most of the infancy, then personhood is gained during the normal development of the individual – especially in adulthood – but subsequently she/he loses personhood during a period of coma and slow recovery after brain injury; then she/he recovers personhood for another life period, to then gradually lose it due to neurodegenerative disease in old age) [37]. The functionalist perspective considers personhood in a one-dimensional way, as a property that a living being can have or not in a specific time, but this seems counterintuitive and puzzling since the way we generally consider our fellow human beings as "persons" is not so much variable and dependent on some contingent or arbitrary factors.

3.3 Anthropological dualism and the clinical implications

In addition to relying on incorrect methodological and phenomenological assumptions, the function-based and brain-centred personalism also produces problematic effects within clinical practice. This functionalist conception reveals an underlying anthropological dualism between "person" and "human being", as well as between the biological body and the conscious mind; this dualism also reverberates in the clinical context, where, for example,

the doctor may consider the patient in chronic UWS/VS as a biologically alive body without any moral status.

The consequences can be seen both in clinical practice and in the relationship between the physician and the patient's family. From the clinical point of view, the clear-cut division between human being and person in UWS/VS diagnosis may induce physicians and caregivers (e.g. nurses) to treat the UWS/VS patient differently from other patients that preserve consciousness. For example, let us consider the cost-benefit analysis in healthcare systems, where long life-sustaining treatments for patients in UWS/VS or MCS are costly, especially in situations of scarce medical resources. If these patients are considered as non-persons, it is highly likely that it is not worth persevering them with certain treatments (e.g. palliation, physiotherapy, consciousness assessment, life-sustaining treatments). Or to take another example, let us consider the phenomenon of dehumanisation in the medical context, e.g. the tendency to perceive patients as less characterised by human dignity than healthy people [38; 39]. This kind of attitude may indirectly increase in cases of chronic UWS/VS patients, where it is supposed that there is no longer any consciousness and mental continuity, and consequently no person but a mere biologically alive body;[5] indeed, such an approach that radically separates "person" and "human being" can lead to practical consequences such as the inadequate and cynical language sometimes used by physicians in describing the dramatic situation to the patient's relatives [41].[6]

This attitude might even produce a methodological vicious circle that reduces the possibility of recovery and emergence of consciousness in people with DOCs. First, as seen, function-based personhood takes the capacity of being conscious as one of the main criteria of being a person. Also, it assumes that UWS/VS patients are probably not persons, and therefore clinicians may feel less morally committed concerning what actions to take towards them. Given these premises, if people diagnosed with UWS/VS or MCS are considered as non-persons, they are likely to receive less care and attention during hospitalisation, and the clinical treatments might be reduced to the bare minimum – if not even withdrawn – in favour of patients that still possess the status of person. Now, several findings recently suggested that an enriched environment and sensory stimulation programs (i.e. stimulation addressing one or a combination of senses) enhance the condition of people with DOCs, improving the possibility of recovery [43-46]. However, these kinds of specific treatments may not be applied to patients whom physicians do not consider as persons. Therefore, people with DOCs such as UWS/VS and MCS might have less chance of recovering some degree of consciousness – and consequently regaining

5 Interestingly, through a survey conducted in New England, Gray and colleagues have found that people, in particular those with high religiosity, see UWS/VS as a state worse than death, and patients in this condition as having less mental capacities than the dead [40].

6 Someone might say that that I am arguing against the use of the concept, rather than the description of it, thus projecting normative standards regarding persons into a description of what it is to be a person. However, personhood is a value-laden concept intrinsically linked to the normative dimension, as it refers to the idea of being human as worthy of moral concern [42].

personhood – precisely because of the functionalist approach, which may indirectly favour attitudes of therapeutic nihilism and prognostic pessimism [47; 48].

4. Ontological personalism: the patient as human being (and person)

So far, I argued that the separation of the concepts of personhood and human being is highly problematic and that the functionalist paradigm may lead to discriminatory attitudes (in the sense that it divides between who is worthy of certain treatments and who is not). On the other hand, arguing for an original and ontological identity of personhood and human being might, in turn, lead to problems within clinical practice, whereby the ontological level is conflated with the normative one. Indeed, the person-human being identity could become a way to absolutise the concept of life in relation to the existence of the person, as someone might consider life as a non-disposable good in any possible case, preventing any chance of withdrawing disproportionate and futile life-sustaining treatments in patients with prolonged chronic UWS/VS. Therefore, we need to identify an approach to the person that does not develop any anthropological (human being vs. person) and neuro-centric (brain vs. body) dualism, but which at the same time does not remain stuck in the mud of the sanctity of person and life.

First, I would propose a patient-centred concept of personhood. Personhood as a pragmatic value in the way proposed by Braddock means that a patient in UWS/VS or MCS should be considered as a person since there is the possibility of partial or even total awareness [49]. However, where Braddock only considers patients in a persistent vegetative state (PVS), I believe it is appropriate to extend this approach also to people with chronic UWS/VS, given the possibility, even minimal, of covert awareness and partial recovery of consciousness over time. This attitude can limit cases of patients misdiagnosed as UWS/VS and treated as non-persons, who instead are aware of what is happening around them but are unable to communicate their status. See, for example, the case of Julia Tavalaro, a woman misdiagnosed as VS for six years, while she was instead in locked-in syndrome and conscious of the surrounding environment. During those years she was considered in a vegetative state and treated as if she were not a human person until the doctors realised that she was conscious. In this sense, despite being in relation with the surrounding world, from her written testimony we can understand that during the years of misdiagnosis she perceived herself as separated from the others, incapable of communicating to the other subjects, who instead looked at her as an object among the objects.[7]

7 «"Can you close your eyes, Mrs. Tavalaro?" With these words, *I'm shocked back into reality*. This is *no dream*. *I'm actually being spoken to*. I close my eyes. I open them and see Arlene's face. "Can you blink twice?" I do it. Silence fills the space between us. Her face shows shock and grief and happiness at once. In the previous six years, no one had thought to ask me these simple questions. "Okay, Mrs. Tavalaro. I'd like you to respond with eye movements. Can you move your eyes up, like this?" She rolls her eyes toward her forehead. I watch her do this. Then, with a quick movement of my eyes *I feel my mind rise from the ocean depths of pain*. For the first time in six years, *I feel whole*» [50, p. 121, emphasis mine]. See also [51; 52].

Then, to extend the concept of person beyond mere neuro-centric and clinical criteria, it would be appropriate to consider an approach focused on the human being as such. In this sense, the patient, even before any determination as conscious or unconscious, is a human being who needs clinical treatments; and even in the case of the futility of any treatment, the patient still requires at least an attitude of care and attention towards her/him, to protect her/him as a human being no longer autonomous and in evident need. This means that we should not care for the patient in UWS/VS or MCS based on the level of consciousness or the degree of personhood preserved, rather on the recognition and respect of the individual *per se*. In other words, although diagnosis and prognosis are necessary to decide treatments and limitation of therapeutic effort, people are not more or less worthy of care based on their state of consciousness, rather they are worthy of care as they are in human beings in need, and when someone loses autonomy and the capacity of sustain herself/himself, we are called on to protect her/him. Being a person is not an abstract quality among others emerging from a set of properties (consciousness, rationality, etc.), as argued by functionalists, but is the underlying condition intrinsically related to the status of the human being. To support this point, it is necessary to overcome a position merely focused on the patient – such as the pragmatic approach – and discuss the concept of the person on an ontological level.

In this regard, from an Aristotelean perspective, a patient in coma is not downgraded to the status of non-rational animal, rather she/he is a rational animal with damaged rationality, which is «still there as an intrinsic, albeit blocked, potential» [53, p. 4]. Similarly, personhood is not a quality that we have somehow acquired during the growth or by being accepted by someone who is already a person according to contingent criteria (as Engelhardt argues); rather personhood is the structure that characterizes us as subjects of moral concern. Ontologically speaking, personhood is here conceived as a substance sortal, i.e. it is intrinsic and essential to any individual human being, while consciousness, rationality, sensitivity, etc. are phase sortal, i.e. properties that apply only to some temporal segment of the human existence. For example, "kitten" is a phase sortal, because once the cat matures it ceases to be a kitten without the cat ceasing to exist [54]; "being a teenager" is a phase sortal as when the human being becomes older it ceases to be a teenager without ceasing to exist. Instead, a substance sortal defines what something is and what cannot cease to be without completely ceasing to exist as such.

Interestingly, as Reichlin argues, even the function-based – and the pragmatic approach consequently – claims that being a person is our substance sortal, i.e. our own identity is grounded on the fact that I exist as a person, and when I cease to be a person I cease to exist [55]. Nevertheless, according to the functionalist and pragmatic perspectives, this substance sortal is in turn dependent on properties like consciousness which can accidentally disappear or reappear. But consciousness and the mental life are phase sortals of the human organism, as they appear at a certain moment in the development of the human individual and then disappear (naturally or for some acci-

dental reason) without the human being ceasing to exist. Therefore, if being a person were a substance sortal but based on accidental properties, there would be the paradoxical situation in which a human being can lose and regain the status of person over and over again during life; this, counterintuitively, would mean that a person can begin to exist and then, at some point, she/he can cease to exist but then regain its existence, and so on. This is not merely a problem of phenomenological unity, as someone might critically argue from § 3.2, but an ontological problem concerning the reduction of substance into functions.

To sum up, "being a person" does not seem in any way similar to phase sortals like "being a teenager" and, at the same time, it does not seem reasonable to make it dependent on phase sortals such as certain mental capacities. Rather, "person" is a primitive concept [56] related to the human being as such and ontologically prior to its parts, therefore it cannot be determined by or reduced to the individual's abilities or functions. The view presented here – which is a kind of ontological personalism[8] – meets the common sense in recognizing that the condition of personhood does not lie in functions (consciousness, memory, self-awareness, etc.), but in the continuity of life, represented by the bodily continuity of the human organism. Although this kind of ontological personalism is based on the anti-reductionist perspective that rejects function- and property-based conceptions of the person, it takes into account the importance of the clinical status of the brain but nested into the biological and metabolic integrity of the entire human organism. This means also that it does not imply an anti-naturalist and anti-scientific attitude, rather, in the intrinsic relationship between personhood and human being, the latter is understood as a biological organism. So, this conception is far from supporting a substantial dualism that merely juxtaposes the person to the living body as two separate substances, without at the same time considering the person as a sort of biological property of the body. Thus, a patient with DOC is not a "non-person" as much as a defective chair is not a "non-chair". A UWS/VS patient is a person because is still an integrated human organism, even without some properties [55]. She/he is not a human body which has lost the bundle of phase sortals that defines her/his identity. In other words, being a person is not the result of a progressive development nor an abstract essence, but a concrete, individual existence that persists until the human organism ceases to function as an integrated whole, and upon which the typical qualities of the human being can develop. This means a complete reversal of the function-based approach since a person is not a human being that subsequently gains the property of personhood on the basis of additional accidental features and qualities [55; 58]. Let us consider, for example, the life of an individual who slips into an unresponsive wakefulness syndrome/vegetative state due to ischemic injury at the age of 75, and then dies at 80. According to the functionalist

8 «In summary, the idea of ontological personalism avoids the error of viewing persons as property-things. It relies on the substance view of persons, which, far from being an esoteric philosophical construct, follows from simple intuition: persons are more than the sum of their parts, and have continuity with their past» [57].

view, the human being has existed for 80 years, while the person, as a conscious subject, for about 75 years (considering also that some mental features are not yet properly developed in new-borns and during early childhood). If so, who existed for the remaining 5 years? An individual temporally divided between early childhood and late life? A depersonalized, dementalized human being? A mere human body? This is a problem that arises from the co-occurrence between certain mental states and personhood, and from the strong separation between human being and personhood, as the functionalist view argues. Thus, the intrinsic relationship between human being and person, which avoids the problem just shown, seems more reasonable than the functionalist position.

4.1 Practical implications of Ontological personalism

Ontological personalism may be useful for improving certain attitudes and ways of dealing with complex clinical and existential situations such as coma, UWS and MCS. Indeed, this perspective is based on a strong ontological commitment that consequently leads to a strong moral engagement. To better understand this point, it is important to analyze to what extent an ethical theory can change some attitudes in medical practice. Previously we briefly mentioned the cases of dehumanization present in the medical context (§3.3), indeed, acts of this kind are present or even endemic within the clinical practice [59]. Denied humanness can be interpreted as a quality that differentiates the human being from animals (human uniqueness), e.g. as the capacity to be a moral agent, and that differentiates the human being from inanimate objects (human nature), e.g. as the feature of having a subjective experience [60; 61]. When not taken to extremes, such dehumanization processes can represent some psychological dynamics typical of specific contexts, like some professional and social practices. A paradigmatic example is precisely the medical context, in which certain attitudes of dehumanization are not only typical but necessary [62].[9] If these instances of dehumanization are kept under control and counterbalanced by strategies of personification, empathic balance

9 Haque and Waytz have identified six main causes of dehumanization within this specific context, but some of these are particularly detrimental to the doctor-patient relationship, as well as to the quality of medical practice itself. The deindividuating practices that anonymize and identify the patient with a number or a disease; the impaired patient agency, i.e. perceiving the patient as incapable of its typically human autonomy; the dissimilarity between the category of healthcare professionals and that of the patient, characterized by the asymmetry in the power and control of the former over the latter. These are the three so-called "non-functional" causes of dehumanization, which are not useful and even harmful for medical practice. The other three are the mechanization of the patient's body that allows the physician to focus on the location of the pathology and the surgical practice; the empathy reduction that helps to regulate the production of harmful negative emotions, for example, for the identification of the diagnosis; the moral disengagement that allows the physician to mitigate the discomfort caused by his responsibilities in the clinic, whose practices often involve inflicting pain on patients (even if necessary). These last three causes, if contained within specific contexts, may be necessary – albeit problematic [63] – for the effective development of the dynamics of diagnosis and treatment. For example, a certain level of mechanization and the reduction of empathy can lead to a sort of "defensive dehumanization" attitude, which may psychologically protect the healthcare professional from the symptoms of burnout [64].

and moral engagement, they will not thwart effective care and the doctor-patient relationship [59].

Generally, the debate on dehumanization in medical context often focuses on conscious patients. Nonetheless, these discriminating and degrading behaviours, caused by the unconscious attribution of lower human status to other people, can only worsen in the case of patients with disorders of consciousness. This derives from an attitude of dementalization [38] intrinsically linked to the dehumanization processes described above, in which the subject incapable of a proper mental life and an agency and decision-making capacity is consequently assimilated to the inanimate object. As patients with DOCs are partially or completely unable to respond to external stimuli and social interactions, a radicalization of dehumanizing dynamics is possible, such as the mechanization of the biological body, perceived as an empty shell deprived its psychological-mental life, the increase in dissimilarity between the agency of the healthcare professional and the passivity of the patient, and the moral disengagement towards patients that cannot – apparently – feel any pain [65].

In this regard, it is reasonable to think that education based on a specific ethical perspective on personhood can influence – if not properly orient – some attitudes and habits of health professionals towards the patient. Previously, I argued that approaches such as the function-based one can increase the risk of disrespectful behaviour towards patients who are no longer considered as persons. One might argue that this is not necessarily the case, since one could still justify respectful treatment based on their professional training and norms, which impose a certain behaviour. In other words, a healthcare professional might think that patients with UWS are no longer persons, nonetheless, she/he will treat them respectfully according to some specific norm or guideline. In this regarde, the guidelines for nursing care of patients with DOCs propose a caring attitude that focuses on treating these as well as other patients, e.g. keep the privacy and avoid body exposure, maintain the patient's physical appearance (shaving, hairdressing, etc.), communicate with the patient (introducing yourself to the patient, inform him/her about each care procedure, always call him/her by his/her name regardless the level of consciousness, avoid loud talk or parallel talks with workmates, use non-verbal communication, concentrate on the relationship and the activity that is performed, etc.) [66]. In this sense, we can imagine that even without a personalist moral engagement, a physician or a nurse can deal with DOCs respectfully. For example, three palliative doctors – functionalist, pragmatic and personalist respectively – can behave adequately with a patient with DOC, avoiding dehumanizing attitudes even in the absence of responsiveness. What changes is the principle of the action, i.e. for the functionalist, following a specific professional or ethical rule; for the pragmatic, the adoption of the prudential approach; for the ontological personalist, the recognition of the status of personhood. From a consequentialist point of view, there would be no differences in the concrete action, as well as in the effects. Nonetheless, the focus is not on the single action *per se*, rather in the construction of a long-

lasting ethical-professional habitus and a proactive attitude towards patients with DOCs, which I will now describe.

As on the ontological level, the personalist perspective involves the reversal of the functionalist one (persons are not emerging from specific human qualities, but persons are human beings upon which specific human qualities can develop), on the ethical level. The patients with DOCs are not human beings who have lost their personhood, rather they require special attention precisely because they are the most vulnerable and fragile people in human society, and because we can feel a sort of similarity with them (none of us is immune to the possibility of becoming so vulnerable); consequently, we can develop an attitude of solidarity and respect for them, just as for any other healthy human being [47; 67]. Therefore, therapeutic nihilism and prognostic pessimism should be replaced with more patience and respect, more frequent attempts to communicate with the patient with the help of family members' voices (which may also improve the chance of recovery), more efforts in determining the patient's clinical state, and better care without applying futile treatments [68].

This holistic focus on the "human being-person-patient" can also direct clinical practice towards the patient as a whole, e.g. monitoring the biological and metabolic integrity of the body, the inclusion of the patient into an enriched environment and the application of stimulating treatments that might be helpful for the recovery (see §3.3). Indeed, this approach towards DOCs could induce physicians to consider specific treatments to increase the chances of recovery in UWS/VS and MCS patients [69], to frequently monitor the patient's brain activity through neuroimaging technologies as ancillary diagnostic evidence that may reduce diagnostic error [70], as well as to apply palliative treatments since it is not always clear whether and how much pain a patient with DOC may experience [71]. Nevertheless, one must be careful not to confuse respect and solidarity towards a person in difficulty with an ineluctable sense of obligation towards her/his life. Just as the functionalist view could lead to therapeutic nihilism, on the other hand, this perspective could indirectly lead to therapeutic adventurism [47], i.e. an excessive emphasis on cure, rather than care. Supporting the intrinsic relationship of human being and person does not necessarily imply strong normative conclusions such as the strict protection of human life at all costs [55]. Rather, when it is medically appropriate not to persist with disproportionate treatments, there may be the possibility to let the person die in the most dignified way possible [72], e.g. guaranteeing palliation, a compassionate approach under the care of relatives, and the consideration of any advanced healthcare directive.

5. Conclusion

Being a person means being a subject of specific moral concern and respect. According to the functionalist view combined with the brain-centred approach, personhood is defined by the state of consciousness and is radically separated from the concept of human being. This may produce coun-

terintuitive ontological issues, like the fluctuation of the essential property of "being a person" during the life-span, and ethically questionable consequences, like the reduction of patients with DOCs to the state of non-person, which may also indirectly favour attitudes of therapeutic nihilism or prognostic pessimism. Despite its practical value, the pragmatic position falls within the functionalist ontology of the person. Therefore, I here proposed to consider personhood as ontologically and intrinsically related with the integrated human being, rather than as of an emerging property from certain contingent faculties or decisions made by a community of moral subjects. In this way, patients with DOCs can be considered as human beings with some damaged qualities but still persons that, *a fortiori*, are worthy of care and attention because they are fragile and non-autonomous human beings.

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