

Resolving the Ethical Quagmire of the Persistent Vegetative State

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Abstract

A patient is diagnosed with the persistent vegetative state (PVS) when they show no evidence of the awareness of the self or the environment for an extended period of time. The chance of recovery of any mental function or the ability to interact in a meaningful way is low. Though rare, the condition, considering its nature as a state outwith the realm of the conscious, coupled with the trauma experienced by the patient's kin as well as health care staff confronted with painful decisions regarding the patient's care, has attracted a considerable amount of discussion within the bioethics community. At present, there is a wealth of literature that discusses the relevant neurology, that elucidates the plethora of ethical challenges in understanding and dealing with the condition, and that analyses the real-world cases which have prominently featured in the mainstream media as a result of emotionally charged, divergent views concerning the provision of care to the patient. However, there is scarcely anything in the published scholarly literature that proposes concrete and practically actionable solutions to the now widely recognized moral conundrums. The present article describes a step in that direction. I start from the very foundations, laying out a sentientist approach which serves as the basis for the consequent moral decision-making, and then proceed to systematically identify and deconstruct the different cases of discord, using the aforementioned foundations as the basis for their resolution. A major intellectual contribution concerns the fluidity of the duty of care which I argue is demanded by the sentientist focus. The said duty is shown initially to have for its object the patient, which depending on the circumstances, can change to the patient's kin, or the health care staff themselves. In conclusion, the

proposed framework represents the first comprehensive proposal regarding the decision-making processes involved in the deliberation on the provision of life sustaining treatment to a patient in a PVS.

Keywords: coma, consciousness, dignity, duty, death, family, trauma.

1 Introduction

The persistent vegetative state (PVS) (nowadays also sometimes referred to as ‘unresponsive wakefulness syndrome’ (Span-Sluyter et al., 2018; Laureys et al., 2010)), first identified by Jennett and Plum (Jennett and Plum, 1972; Aleshinloye, 2021; Shewmon, 2004), is most commonly taken to refer to the vegetative state from which a patient is unlikely to recover consciousness (Multi-Society Task Force on PVS, 1994) (though there are notable difficulties in reaching a consensus definition in the context of the present understanding of the condition (Shewmon, 2004)), the vegetative state being:

“...a clinical condition of complete unawareness of the self and the environment, accompanied by sleep-wake cycles, with either complete or partial preservation of hypothalamic and brain-stem autonomic functions...[without]...sustained, reproducible, purposeful, or voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli; ...language comprehension or expression;...”.

Most people diagnosed with PVS indeed never recover any mental function or the ability to interact with the environment in a meaningful way, though the condition of a few improves sufficiently that the diagnosis is changed to minimally conscious state (Maiese, 2022; Jennett, 2002). Although rare, with an estimated 10,000 to 25,000 adults (cc. 0.004% to 0.012%) and 4,000 to 10,000 children (cc. 0.005% to 0.014%) being diagnosed with it in the United States (Multi-Society Task Force on PVS, 1994), the nature of the PVS, seen as a disorder of consciousness and poignantly

described by Wikler (Wikler, 1988) as “not dead, not dying”, presents a minefield of ethical challenges. Consequently, the phenomenon has attracted much interest from ethicists (Andrews, 1997; Panksepp et al., 2007; Borthwick, 2005; Fox and Stocking, 1993). However, the substance of the published academic thought is rather wanting in actionable ideas, focusing on the elucidation of ethical issues surrounding the PVS (which, lest I be misunderstood, is a worthwhile pursuit, but one which is only the starting point in the quest for positive change), but offering little in terms of how these issues should be addressed in practice, in an ethically well-founded and principled manner. As Celesia (1997) resignedly put it:

“I do not have, and I believe nobody has, absolute answers to these vexing questions.”

Moreover, even within the realm of the aforementioned elucidation, there is much which is conceptually suspect, this being a consequence of the lack of the establishment of a firm ethical basis which must logically precede such discussions. A poignant illustration is the British Medical Association’s Working Party statement (BMA Working Party on Euthanasia, 1988) that the core feature of the ethos of medicine is:

“that human life is of inestimable value and ought to be protected and cherished.”,

which is but a thinly veiled vestige of theological ethics which can hardly be defended in the context of contemporary moral thought (Arandjelović, 2022). Pervasively, authors centre their attention on the person in a PVS, with their kin, the health care

staff, and the State being brought into the picture as deemed necessary. Indeed, this seems most reasonable and is consonant with the increasing degree of importance placed on patient-centred care (Pelzang, 2010). Yet, in the present work I take a different view and argue that notwithstanding the apparent breadth of opinion on display, the existing thought on the matter has a veiled *petitio principii* at its core, the said fallacy emerging from an *a priori* narrowing of the relevant ethical context and resulting in a misplaced direction and application of the duty of care. Hence, herein I start by clearly and explicitly establishing a moral framework with precise objectives at its core, then discuss the entire relevant sentient context of the problem at hand, and from these derive concrete and actionable conclusions.

1.1 Previous work & the intricate web of ethical considerations

In order to contextualize the contribution of the present article and make the significance of its conceptual novelty and practical value, I now give a brief review of the existing work in the realm of ethical discussions concerning the persistent vegetative state. Some of the issues which feature here are directly addressed by the present article; others, important as they are, are not within the scope of my inquiry. For example, I presume that the PVS is a real condition, which is questioned by some as I shall shortly discuss. Clearly, a convincing case to the opposite effect would make any specific consideration of what we deem the PVS immaterial (though some of the underlying ideas and principles ought to remain relevant in the consideration of other, related conditions).

Premised on the principle that the patient's wishes should be at the centre of any decision-making considering health care delivery (de Zulueta and Carelli, 2009), an oft raised ethical challenge concerns cases when such wishes have not been formally expressed *a priori* (given that the patient, by the very nature of the condition, is unable to express them once in a PVS), that is, when there is no existing advance directive. Thus, Weijer (2005), working from actual court cases when the value of family testimonies had to be assessed, describes the challenge of finding an acceptable solution to the question of what role surrogate decision-makers should have in such circumstances. Similar contributions, both in terms of the methodology employed and the key challenges brought to the fore, were made by Andrews (1997) as well as many others (Kitzinger and Kitzinger, 2018).

Another pervasive ethical concern is that of the credibility of the PVS diagnosis itself (Wade, 2001; McLean, 1999; Borthwick, 1996), which many other ethical considerations are consequent to; these concerns are particularly loudly voiced in cases involving children (Ashwal et al., 1992). As discussed by Dyer (2012), diagnostic doubts introduce an additional conundrum to decision-makers in resolving a conflict which results when the health care staff consider it best to cease life sustaining treatment while the patient's family believes that they have witnessed signs of consciousness and expresses hope that further improvement is possible. Worryingly, Borthwick (2005) discusses what I will argue later on can be seen as undue valuation of expertise over the actual sentient experience of undoubtedly sentient actors, noting that:

“...clinicians have in general preferred to ignore the increasingly suspect

nature of the prognosis inherent in the diagnosis of permanent (or persistent) vegetative state because they have been concerned less with issues of consciousness than with opinions about resource use.”

Yet more concerning is the inconsistency highlighted by Wade (2001), whereby:

“The law states that the patient in a permanent vegetative state has no interest but also concludes that treatment is not in the patient’s best interests.”

In the author’s words:

“If someone has no interest, how can they also have a best interest?”

A related, yet a more fundamental question raised by some, is that of the very meaningfulness of the notion of the PVS, that is, the premise that a patient in what is currently described as a PVS, is entirely non-sentient. Owen et al. (2006), for example, suggest that at least some patients diagnosed with PVS:

“...may be able to use their residual cognitive capabilities to communicate their thoughts to those around them by modulating their own neural activity.

This finding is echoed by a number of others (Monti et al., 2010b,a; Laureys et al., 2004).

In addition to questioning the methodology and the statistical strength of the literature on the topic, Borthwick (1996) questions the assumptions inherent in the functional examination of the brain, effectively asking if our understanding of the

brain is sufficiently good to draw conclusions about the absence of sentience by the presently available means. His point is valid:

“On the most straightforward level, any study that compares PVS readings on any scale only with normal readings can prove nothing. The question is not whether there is brain damage, or the nature of the brain damage; rather, it is whether such damage is such as to exclude sensation.

What is more, Panksepp et al. (2007) demonstrate that even these provide evidence that some level of mentality remains in PVS patients, and ask if this evidence opens the doors to the possibility of life support termination leading to “excruciating feelings of pure thirst and other negative affective feelings”. Such findings elevate the importance of questioning the premises that currently underlie the decision-making process regarding the withdrawal of life sustaining treatment from patients in PVS. As stated by Wade (2001):

“The law states that the patient in a permanent vegetative state has no interest...”

In this context, Celesia (1997) offers a detailed analysis of the present definition of the PVS and its differentiation from other related conditions.

Some contributors to the debate direct their attention to more abstract issues, which I would argue are, as far as ethical discussion is concerned, semantic distractions, appearing as if they have substance by virtue of the lack of clear foundational principles used to guide the discussion. Thus, Wade (2001) and McLean (1999) discussed the mode of death in cases when a withdrawal of life sustaining treatment

is opted for, while Wikler (1988) considered the difference between letting a patient die and killing them. At best, these questions have relevance in the context of the legal, as elucidated by the work of de Zulueta and Carelli (2009) who discussed the potential of criminal liability. In contrast, in the absence of a theological belief, the arguments based on the diktat in the form of proclaimed sanctity of life (McLean, 1999; de Zulueta and Carelli, 2009) has been rebutted by Arandjelović (Arandjelović, 2022), having been shown to be incoherent and without a sound moral foundation (to the extent that there has been a credible attempt at establishing such a foundation at all), a remnant of theological ethics, dissonant with contemporary ethical thought.

Lastly, the empirical work of Fox and Stocking (1993) provides a good summary and a body of evidence showing the state of disarray that the current ethical views on PVS are in, demonstrating remarkable divergence even between ethics consultants' recommendations for life prolonging treatment of patients in a PVS, and the reasons behind the said divergence.

2 Disentangling the persistent vegetative state

I have already stated that one of the central considerations that I would like to bring out in the present work is that of the full ethical context of relevance to the discussion of PVS, and hinted at the excessive (I ask the reader to bear with me for the time being) focus on the individual diagnosed with the condition, that is, the patient. Thus, I would like to explicate what I contend the correct context is.

In general, in the consideration of a case of PVS, we can recognize four different interested groups, to wit, (i) the person diagnosed with PVS, (ii) the person’s family, (iii) the clinicians, and (iv) the State. In specific instances the second group may include no person at all, and the ‘presence’ of the State may not be immediately visible (though it always is present by virtue of Law which both imposes restrictions on and grants rights to the other three groups) when no significant conflict between the other parties arises (Kitzinger and Kitzinger, 2020). The problem of interest to me in the present article concerns the ethical issues which present themselves when there *is* discord between, or indeed within, the parties regarding the provision of life sustaining treatment (Span-Sluyter et al., 2018). For example, what should happen if the family of the individual in a PVS desires the continuation of such provision when the clinical opinion is that it should be terminated?

2.1 Laying out the foundations

In contrast to previous work which is universally inattentive with respect to this issue, I contend that we must begin with an establishment of a solid and explicit grounding for our ethical framework. My starting point draws from the traditions of Epicureans and Existentialists, amongst others (Arandjelović, 2022), and focuses on *sentience*, to wit, the ability of (in this case) humans to experience pleasure on the one hand and suffering on the other. Such experiences are, if you will, *urphnomena*, the sense-experience knowledge immediately (rather than mediately), *prima facie* known to their subjects. Any other moral notions, be they that of duty (deontology), virtue, or the desirability of the hypothetical (consequentialism) can only

emerge from these in an inter-subjective manner, the inter-subjectivity arising from the *structural* similarity of our mechanisms of apprehending and experiencing the world, no matter whether that structure is biological, *in silico*, or comprised of any other material content. It is by means of this shared structure that coherent ethics can emerge, neither as a subjective nor an objective, but rather as an inter-subjective, an agreed upon set of norms and values. Clearly, this consensus has to be reached by beings which are *both* sentient *and* sufficiently cognitively sophisticated; yet, the aforementioned norms and values are projected objectively to everything sentient (thus, we do not have ethical *expectations* from dogs, say, but we do *afford their sentient experiences* regard and sympathy (Arandjelović, 2022)). The overarching goal of medicine should thus be to alleviate patients' subjectively hypostatized suffering, whatever its aetiology may be. Who, as a sentient being intimately acquainted with the experience of pleasure and pain, could object to the goal of maximizing the former and minimizing the latter? It is the most unifying fundamental, grounding principle ethics can possibly hope to find. The importance of this principle in the context of PVS will soon become clear.

In this view of the foundations of morals, I find myself very much in agreement with Schopenhauer (2009):

“Compassion is an undeniable fact of human consciousness, is an essential part of it, and does not depend on assumptions, conceptions, religions, dogmas, myths, training, and education. On the contrary, it is original and immediate, and lies in human nature itself. It consequently remains unchanged under all circumstances...”

It is in this, in the immediately experienced feelings of pleasure and suffering, that is in the respect of every one's pursuit of the former and the avoidance of the latter, that I argue the fountainhead of morality lies. Hereafter I use the term 'sentientism' to refer to this principle, distinguishing it from the weaker use of the term by most (Rodogno, 2010) which is that:

“(A) An entity has interests or wellbeing only if it is sentient;

and:

(B) The capacity to have interests or wellbeing is a necessary and sufficient condition for an entity to have moral standing.”

To elaborate, when speaking of pleasure, I subsume under the notion both the positive sentient experiences effected immediately, such as the consumption of tasty food (Kringelbach, 2015), the feeling of the warmth of the sun's rays on a clear day (An et al., 2016), or perhaps the touch of a loved person (Esch and Stefano, 2005); 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 (Moll et al., 2006), the process of imagination of future happy experiences (Addison, 1828), and even the act of sacrifice for a subjectively hypostatized worthy cause (Kustritz, 2008). The same applies to my use of the term 'suffering' (Hall et al., 2010), which also includes immediately felt unpleasantness, such as malodorous smells (Zald, 2003), loud noises (Hirano et al., 2006), or a physical injury (Bruneau et al., 2015), as well as those experienced mediately, such as due to deprivation that is the denial of pleasure (Cushing, 2007), through the expectation of fearful futures (Arandjelović, 2023), or through reflection

and the consequent sense of guilt and remorse (Morris, 1971).

For completeness, I would like to address a potential challenge to my argument of the moral primality of sentience. Some may argue that other things, such as truth, rights, or respect also must be considered on an equal footing. To this, I ask: why does truth, say, matter? I would object to this being stated as universal. Indeed, I can say that *to me* truth does not always matter, thereby immediately invalidating any claim of universality. Furthermore, if one is to claim that truth mattering is a starting principle, then considering what I just said, I would see it as an ill-founded diktat imposed onto me, a diktat that underlies much of my criticisms of the existing work in the area. On the other hand, if the claim is to be explained, i.e. reduced to more fundamental notions, then this is where we ought to start and ask what the *explanans* is. My answer to why truth usually matters is that individuals value it for one reason or another (instrumental, aesthetic, etc.) which brings us to that which I argue should be the basis of morality, namely sentient experience. Singer's observation (Singer, 2011):

“The capacity for suffering and enjoying things is a prerequisite for having interests at all, a condition that must be satisfied before we can speak of interests in any meaningful way.”

should lead to the same conclusion: to have an *interest in* truth is contingent upon sentient experience and some form of pleasure which results in truth having (or not having) value to a *specific* sentient agent. The same can be said of rights, respect, etc., which too are notions which ultimately derive their value from sentient experience rather than which exist through some form of value aseity.

To highlight the chasmic difference between the framework I am seeking to advance and the views widely accepted at present, consider the words of Gormally (1997), representative of the current zeitgeist in the field:

“It is only those who believe that the dignity and value of a now incompetent patient’s life derives wholly from the choices he made when competent who even appear to have a case for allowing those choices to override other considerations. But it is false to believe that the dignity and value of an incompetent patient’s life rest on such an infirm foundation. His fundamental dignity as a human being exists independently of the character of his prior choices. And what that dignity requires of those who care for him is that they act for his good or, as is commonly said, in his ‘best interests’. However, it will be clear that the notion of ‘best interests’ as applied to the care of patients has an **objective interpretation** within the moral framework I am articulating. What medically serves a patient’s best interests is what secures either a patient’s restoration to health, or some approximation to health, or, if the patient is dying, effectively controls distressing symptoms.” [all emphasis added]

Merely asserting as a diktat, with no foundation to rest upon, Gormally (1997) *ut supra* relies on the nebulous concept of one’s ‘fundamental dignity’ (Bagaric and Allan, 2006; Schopenhauer, 2009) as something existing outwith oneself (rather than, as I argue, as being subjectively hypostatized), or indeed the notion of inherent value in life, which is nothing short of a veiled remnant of theological morality (Arandjelović, 2022). Thereby, Gormally (1997) *imposes* a value system onto the patient, which is

an anathema to the much-lauded focus on patient-centred care. Such diktats cannot possibly win the minds of the philosophically educated or the hearts of the general public, so there is little wonder that the discord as regards PVS is not abating.

In contrast, the view I advance, one premised on a clear moral foundation, is that 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 (what Gormally (1997) sees as objectively worse for the patient), as the intensity of the patient's prior suffering in the contemplation of the opposite prohibits the alternative; and what is impossible cannot be preferable.

2.2 Duty of care

Dictatum erat, underlying much of the discussion of the PVS is the, in this context rather unexamined, concept of *duty* (de Zulueta and Carelli, 2009), which for nuanced topics such as that before us, must be approached with great care. Whence does any duty of relevance herein arise? The hastily assumed 'duty' invoked in the existing literature can be readily seen to be bequeathed in a topsy-turvy manner, not as a notion that *emerges* from a solid underlying foundation, but rather as an *imposed* diktat by an amorphous Authority, suspended in thin air and resting on nothing but an appeal to 'common sense' and emotion. Instead, any duty, which is a form of *obligation*, can only meaningfully exist as a consequence of an agreement with two parties (at present, the sole exception to this being the duty of parents to their children, which duty emerges from the presently unique situation of one-sided

decision to create new sentience¹). Indeed, the primary duty of a physician to their patient too arises from an agreement, often a tacit one, between the patient and the physician. Such an agreement exists even when dealing with an unconscious person who is unable to express their will at the time when care is called upon; for example, in jurisdictions with state provided health care the agreement is presumed (Morris, 1998), and includes the duty of non-intervention if an explicit *a priori* refusal of consent to be medically treated was made by the individual. Children, deemed incapable of making informed decisions in this regard, enter the agreement mediately, that is by virtue of their carers (usually parents) consenting to it on their behalf.

Seeing the central role that duty has in the present article, I would like to elaborate on the notion and prevent potential misunderstandings emerging from its different uses in the academic literature and colloquially, noting Schopenhauer's observation (Schopenhauer, 2009) of:

“...the mistake of giving a much too wide extension to the idea ‘Duty’...

Firstly, herein I am strictly referring to moral rather than, say, legal duty; given the focus of the present article, I am also only considering duty to other humans rather than other sentient beings, such as animals. Secondly, a duty implies a positive imperative — something that one *must* do, rather than a boundary, that is something that one *must not* do. Thus understood, duty, as positively binding, does not include Rawls's requirements not to harm or injure another, or to cause unnecessary suffering (Hart, 1973); these are not duties but, as noted, being neg-

¹In principle, the same duty would accompany any *in vitro* or *in silico* creation of sentience, if it were to become possible.

actively defined, boundaries. I also emphasise the compulsion inherent in the word ‘must’ rather than the desirable, such as may be described as ‘good’, ‘admirable’, ‘beneficent’, etc. In this I find myself again in agreement with Schopenhauer who communicates this with clarity:

“...the conception of Duty, which is so often spoken of both in Ethics and in real life, but with too wide an extension of meaning. We have seen that wrong always signifies injury done to another, whether it be in his person, his freedom, his property, or his honour. The consequence appears to be that every wrong must imply a positive aggression, and so a definite act. Only there are actions, the simple omission of which constitutes a wrong; and these are Duties. This is the true philosophic definition of the conception “Duty,”—a term which loses its characteristic note, and hence becomes valueless, if it is used...to designate all praiseworthy conduct.”

I emphatically reject any notion of a duty, understood as per the above, imposed onto another merely by virtue of being, i.e. without one’s entering an agreement, with the single exception of parental duty already commented on.

2.3 Disentangling different cases of disagreement & the change of the focus of duty

I now show how the ethical foundations I argued for in the previous section can be applied in clinical practice, leading to clear and actionable decisions in the real world. I approach the task systematically by considering the different instances of possible

disagreement with respect to the manner in which the patient in PVS should be treated, and demonstrate that despite their apparent differences, given the proposed framework they are reduced to a canonical case by virtue of the change in the object of duty central to the decision-making challenge at hand.

2.3.1 Known prior wishes (advance directives) of the patient

In the instance of an individual diagnosed with PVS, the agreement between the individual and the health care provider is either presumed or had been explicitly entered into (e.g. with a private insurer), and therefore, the foremost duty of a physician is to respect the person's wishes as regards the provision of any treatment. This does not change even if the soundness of the notion of "the patient's best interest" is denied on the basis of a lack of sentience, that is regardless of (Andrews, 1997):

“...whether the patient has any interest in living or dying...”,

which is an important issue that I will return to in more detail shortly. The reason for this lies not in the effect that acting otherwise would have on this particular patient, who indeed by definition cannot experience suffering and woe, but rather on *possible future patients*. If individuals in a society could not have faith that their health care preferences would be respected if they were diagnosed with a PVS, being by the nature of the condition unable to insist on these at such time, this uncertainty would impose mental suffering on them prior to, and indeed regardless of, any hypothetical subsequent diagnosis of a PVS. The degree to which the patient's wishes are well-founded scientifically is equally inconsequential, as demanded by the

sentientist framework I laid out — neither scientific education nor philosophical sophistication can be demanded from the public at large, nor can or should these in any way affect how an individual’s sentient experiences are valued (Arandjelović, 2022). Hence, the patient’s prior wishes must override even the clinicians’ best judgement should these find themselves at variance with one another.

2.3.2 Unknown prior wishes (advance directives) of the patient with kin

The situation becomes more intricate when the wishes of the individual diagnosed with PVS are unknown (this includes children who are considered not to have the competence in this regard (Ashwal et al., 1992)), that is when such wishes have neither been formally stated nor can be evidenced as credibly expressed privately (a matter usually settled in court (de Zulueta and Carelli, 2009)). I contend, firstly, that in this case there can be no duty *to the patient*, given the high variance in the subjective preferences of individuals as to what the right course of action under the circumstances is and the fact that *by definition*, the patient lacks sentience and the ability to experience either pleasure or pain. The adoption of the sentientist framework, focused on one’s subjective experiences, shows that the notions of ‘personhood’ (Gormally, 1993) or the patient’s dead vs alive status (Panksepp et al., 2007; Wikler, 1988), often at the centre of the debate in much of the existing work and invoked in lieu of a solid ethical grounding of arguments, can be seen to be irrelevant semantic distractions which only serve to confound the relevant considerations. However, given that there remains the *a priori* agreement (as noted before, often tacit) between the patient and the physician which puts the latter in the position of

acting power, I also argue that the duty which usually has the patient at its focus, rather than being dissolved, transforms by virtue of it changing its *object*. In particular, while the physicians' choices no longer can effect the experiences of pleasure or suffering in the patient, they certainly can in those that care for the said person, to wit, their kin (de Zulueta and Carelli, 2009; Andrews, 1997). It is towards them that the physicians' duty of care ought to be directed in this circumstance. This idea is in sharp contrast to the existing attitudes of ethicists to date, whose focus always remains on the original patient and who are thus unable to offer much more than warm words and wishful thinking in terms of the practical and actionable (Kitzinger and Kitzinger, 2020), e.g. Span-Sluyter et al. (2018) stating that:

“Management should bridge conflicts and support their staff, by developing expertise, by creating stability and by facilitating medical ethical discourses. Shared compassion for the patient might be a key to gain trust and bridge the differences from non-shared to shared decision making.”

Once the necessity of the change of the object of the duty of care is understood, the moral imperative resting on the physicians becomes clear, and it is to pursue the course of care and the kind of care, or its withdrawal, as desired by the kin (for the time being I treat the wishes of this group to be unanimous; I shall later return to the discussion of cases when within group discord exists). It is equally clear that any other notion of physicians' belief as regards the patient becomes meaningless, for a non-sentient patient cannot have interests (for completeness and lest the reader infer otherwise, I repeat here that I assume that the diagnosis of PVS is indeed correct, that is I take non-sentience as granted; by doing so, I do not dismiss concerns about

the confidence that we can have over the diagnosis; on the contrary, I recognize this as an important issue, though one outwith the scope of the present work). Consequently, I reject the relevance of disagreement between the wishes of the kin and the medical experts, by which I also reject the permissibility of intervention by the State in this case, e.g. via the judiciary system.

2.3.3 Unknown prior wishes (advance directives) of the patient with no kin

In the rare cases when the patient in PVS has not left a record of their preferences for how they would wish to be treated in the situation they are now in, and the patient has no kin who would consequently become the object of the duty of care, whom do the physicians now owe any duty? Is there any duty to be spoken of here? The answer is in the positive, the duty now being towards the very medical staff in care of the patient. To be clear, this does not mean that an individual physician now has ‘duty to oneself’, which is an ill-conceived Kantian notion (Singer, 1959) lacking in any origin of this supposed imperative (Schopenhauer, 2009), but rather *to their fellow colleagues* also tasked with decision-making power concerning the patient.

If there is no dissonance between the views of the different members of the health care staff, then the situation is simple and the right course of action is to act on the said view, be it to continue or to discontinue life support or any other additional treatment. Hence, this case only becomes problematic when there *is* a divergence of views. Then, we are dealing with a situation in which an interested group of individuals, one of the four I identified previously (see the beginning of Section 2),

hitherto considered as univocal and speaking with one voice, divides into two sub-groups, to wit, one which desire to continue providing life support to the patient, and the other which considers it best to discontinue such support. Reminding the reader of the *punctum saliens* I advocate in the present article, the focus always remains on the sentient experiences of individuals, here of the health care staff in charge of the patient.

As a means of reinforcing this point, let me address a potential objection in the form of the question why duty would not rather shift elsewhere, e.g. to other patients. To answer this, recall that the original duty, that is the duty of the health care staff to the patient, emerges from their entering an agreement with the patient. When the patient is diagnosed with PVS, if there is a unanimous agreement by the health care staff that the patient is no longer sentient and that the patient's life has no inherent value, then there is no discord to be spoken of — there remains no duty to the patient, life support can end, and the staff can direct their efforts elsewhere. However, *ex hypothesi*, herein we *are* confronted with discord. Some health care staff may doubt the diagnosis, others may consider the very notion of PVS ill-founded (as noted previously, some research questions whether PVS patients indeed do not have any sentient experiences), and yet others may have religious or spiritual beliefs about the value of life itself (remember that despite my own disagreement with this, I do not impose this belief onto others, rather the sentientist framework putting their own sentient experiences at the forefront). Moving the duty of care to other patients rather to the health care staff, some of whom for the reasons stated *still* feel duty bound, would severely transgress against the latter. Until this duty is discharged, it

cannot change focus; all refocusing of duty I advocate is consequent to a previous duty dissolving due to one cause or another.

In this first instance, it is informative to seek the root causes of the disagreement, that is to interrogate the origins of the different individuals' views. It is a different matter if these stem, e.g., from different expectations as regards the patient's recovery (a scientific question), as opposed to, e.g., from fundamental attitudes towards human life (an extra-scientific question). An understanding of such origins opens avenues for discussion, which discussion can result in a compromise, effecting a dissipation of the original disagreement. However, if an attempt at reaching a satisfactory consensus fails, thereafter the reasons as such behind the disagreement cease to be relevant: all that remains are the objective facts that the different interested individuals (health care staff, to remind the reader) have different views as to what action should be taken and that a transgression of these, considering the issue at hand, may cause suffering to them (emotional, in the present case). The question thus becomes that of making a choice as regards the patient which balances, if you will, the distress caused to the different interested individuals (Chiambretto et al., 2010).

This conceptualization of the situation makes it tempting to seek the solution in a utilitarian approach, that is, to ask what course of action produces 'the greatest good for the greatest number' (Elliott, 2007). In general, this is hardly a highly practically useful guide, admirable as its goal is, for it provides no insight as to how distress and suffering are to be quantified, how plurality is to be handled (is distress something that be can accumulated as an exercise in accounting (Arandjelović, 2022)?), etc. Although this fundamental problem of utilitarianism does not fully disappear in the

specific present case either, the *sui generis* nature of the PVS does permit a convincing argument in favour of one choice, to wit, the continuation of the provision of life support and care to the patient. In particular, consider the health care staff whose best judgement is to discontinue the aforementioned support. These individuals, *ex hypothesi*, do not consider the patient to possess the capacity for sentient experiences, their hypothetical suffering in the case of continued treatment emerging from distal effects, consequent on what they would see as imprudent use of resources, which resources are in turn denied to patients whom they do see as capable of experiencing suffering which could be helped. The key observation here lies in the observation that these hypothetically harmed patients have to be *imagined*; these hypothetical individuals lack a concretization which is crucial in triggering the kind of empathy instrumental in driving the strength of an emotional response (Levine, 1997); here, empathy is cognition based (Goldie, 2011). This is very much unlike the suffering of the staff that consider it best to continue with life supporting provision. The object of their concern, the patient in a PVS in front of them, is real and physical, with a concrete face, a concrete life, and a concrete medical history — in other words, it is a concrete person triggering the more affective, *non-cognitive empathy*, also sometimes referred to as mirroring empathy (Goldman and Jordan, 2013).

2.3.4 Divergence of views within the patient’s kin

Lastly, what remains for me to address is the case when there is disagreement amongst the patient’s kin when these are the target of the health carers’ duty of care, that is when there is no credible advance directive of the patient, as laid out in Section 2.3.2.

It goes without saying that the first course of action should be to direct effort into consensus building which would lead to the resolution of discord, thus leading to least anguish experienced by everybody; indeed, much previous work has studied how this challenge should be approached best and what particular concerns tend to create the greatest contention (Buckley et al., 2004; Nelson and Nazareth, 2013; Graham et al., 2015). My focus here is on the problem which presents itself when this resolution proves impossible. How kin disagreement should be handled in the decision-making process regarding the patient's care, is a question which has received little in terms of convincing actionable proposals. Indeed, as noted by Weijer (2005), it has been largely ignored in the literature:

“Bioethics commentators have missed an important moral question posed by the Terri Schiavo case, namely, how to deal with familial disagreement.”

The situation here bears similarities to the one considered previously, in Section 2.3.3, namely that of within group disagreement amongst the health care staff in charge of the patient. However, there are also notable differences between the two, which differences have consequences in the manner in which discord should be resolved. Firstly, while there may be disagreement as regards the different individuals' views respecting the prognosis (which may be one of the sources of different judgements about the continuation or the withdrawal of life sustaining provision), as regards the diagnosis, that is the acceptance that the patient indeed *is* in a PVS, we can reasonably assume unanimity amongst the health care staff who all have medical training and an understanding of the patient's condition. This is very much unlike

what can be expected amongst kin, amongst whom the level of understanding of the condition can vary greatly, just as can the beliefs about the possibility of sentient experience of their loved one (Span-Sluyter et al., 2018). Secondly, when it comes to the balancing act of juxtaposing the potential harm which is likely to be inflicted on others by virtue of resource use, against the possible suffering or perceived suffering of the patient, while the former are in both cases imagined individuals, whose hurt has to be mentally simulated, the latter is for the kin not only a specific person, but also a specific person to whom they have a special connection to, with whom they have shared memories and experiences, etc., this even further amplifying the emotional anguish effected by the possibility of their suffering (Deng, 2019). Lastly, while in both cases, that is both in the case of disagreement amongst the health care staff and that of disagreement amongst the kin regarding the continuation of life support provision, this disagreement is bound to result in personal conflict and impact relationships between individuals, in the former group the relevant relationships are professional in nature (Laurent et al., 2017) whereas in the latter group they are personal and thus more intensely affective (Van Audenhove and Van Humbeeck, 2003).

The differences between the challenges in dealing with within group discord amongst the health care staff and amongst the patient's kin I just highlighted, show that the source of asymmetry in the emotional harm experienced by those group members whose preferences are violated by the decision regarding the future of the patient's life sustaining care provision, and which was present when dealing with the former group allowing a concrete ethically sound resolution to be made, does not

exist when dealing with disagreement amongst the patient's kin. Such asymmetry lacking, it is difficult not to get drawn towards a utilitarian approach and consider intervention by the State, that is the Law, wherein I would consider it morally permissible, having in previous instances argued against its imposition of heteronomous values. While in this instance I do not consider such course of action to be unsound, given the necessity of a decision in practice, I would nevertheless, though cautiously and less strongly than previously, reject it on the basis that I discussed earlier, that is, the fact that here utilitarianism requires a rather *ad hoc*, unprincipled treatment of sentient experiences, these being reduced to something that can be added up as if such experiences were financial tallies. Instead, keeping the sentientist framework proposed in Section 2.1 firmly in focus, I would propose an actionable alternative, though, as just noted, with due caution and restraint with respect to its prescriptiveness, on the basis of a different *sui generis* kind of asymmetry or, rather, kinds of asymmetries depending on the specifics of a particular case.

Let us consider the different cases which arise from the different objections to the continuation of life sustaining treatment from some kin on the one hand, and the objections to its discontinuation on the other. As regards the former, there are three major underlying reasons discussed previously, to wit, (i) the unnecessary use of resources which could be allocated to other patients (the financial burden of continuing life support alone is approximately £90,000 *per annum* (Kitzinger and Kitzinger, 2017)), (ii) the perceived suffering of the person in a PVS, and (iii) the need to move on (Hamama-Raz et al., 2013; Span-Sluyter et al., 2018). On the other side, that is, when it comes to the objections to the discontinuation of a life sustaining

treatment, the principal concerns are those of the patient's potential recovery, and that of the sanctity of life. As argued in the previous section, the aetiology of the suffering that would result from the violation of the aforementioned principles — that its origin is in the concrete or the imagined, and whether it concerns a known individual or hypothetical people — provides a sound and empirically evidenced basis to weigh them on a relative basis. Thus, if all family members who object to the continuation of life support do so on the grounds of the imprudent use of resources, but any one family member wishes the support to continue on the grounds of the sanctity of life of their loved one, the latter's wishes should be respected in preference. Similarly, if any one family member objects to the continuation of life support on the basis of their perceived suffering of the patient, but all the family members who wish the support to continue do so on the grounds of a hoped-for recovery, it is the wishes of the former that should be followed, i.e. life support should be terminated. *Argumentum a pari*, the same conclusion applies to the case when either the hope of recovery by all objecting family members or the belief in the sanctity of life by some, are juxtaposed with the need of any family members of moving on. The remaining two cases are more difficult, which I recognize, and thus I offer my views in a more guarded manner. In particular, if the discord is purely based on the use of resources vs the hope of recovery, I would cautiously argue in favour of the termination of life support on the basis that in both cases we are dealing with imagined hurt, with the potential harm resulting from the denial of scarce resources to others effecting the said harm to a greater number. In addition, although I have noted that in a case like this any question regarding the objective

correctness of the views of the persons at the focus of the duty of care ceases to be relevant, the sentientist approach demanding that one's suffering is acknowledged unconditionally even if it be premised on subjectively held but objectively erroneous beliefs, some comfort can be brought to those family members whose wishes were not upheld, by compassionately communicating to them the medical opinion regarding the chances of the recovery, as well as the lack of suffering involved in the termination of life support itself. Finally, the last case, that of adjudicating between the claims of perceived suffering in the prolongation of life support and of sanctity of life, is arguably the most challenging one, given that they concern deeply rooted and highly emotional beliefs, which also relate to a specific, loved individual. Continuing to tread ever more carefully, I would argue that in this difficult case the preferable course of action is to discontinue life support. The reason behind this choice can be found in the concrete suffering perceived by the kin who would see this suffering in their loved one, the suffering thus involving both the patient and consequent on it, these family members too. In contrast, the suffering of the kin whose objection is rooted in the belief in the sanctity of life is arguably confined to within their own selves, stemming from the violation of their belief, rather than any suffering apprehended objectively.

A summary of the different cases is presented in Table 1.

Table 1: Juxtaposition of the different grounds for within kin disagreement regarding the continuation of life sustaining provision to the patient, and the recommendations argued for in each case (see the main text for detail).

Objection to terminating life support	Objection to continuing life support		
	Resources (all)	Suffering (any)	Moving on (any)
	Sanctity (any)	Continue	Terminate (?)
Recovery (all)	Terminate (?)	Terminate	Terminate

3 Summary and conclusions

The focus of the present article was on the persistent vegetative state, and in particular the gap in the extant bioethics literature concerning the resolution of the various moral dilemmas which present themselves in the consideration of the provision of life supporting treatment to patients in the condition. The range and nature of these dilemmas has been identified and delineated with much care by the previous work, but little progress has been made in terms of the practical and actionable consequent on them. To address this limitation, I start by a consideration of the very moral foundations which must be solid if the diversity of the ethical challenges is to be resolved in a principled and convincing manner. I argue in favour of a sentientist viewpoint, 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. From there, I moved on to the consideration of the concept of duty, central to the ethos underlying modern health care delivery. A clear explication of this crucial notion, and its incorporation within the contended sentientist framework, further allowed me to show how the duty of care, initially directed towards the patient in a persistent vegetative state, is required to change its object from the patient depending on the particularities of a specific case. In particular, the key considerations were the existence or lack thereof of the patient's prior directives, the preferences of the patient's kin in the absence of prior directives, and finally those of the health care staff when there are neither prior directives nor kin of the patient. The duty of care could thus assume as its object either the patient, their kin, or the health care staff. Finally, I dealt with the nearly universally overlooked challenge of discord in the wishes amongst the patient's kin or the health care staff. Again guided by a sentientist focus, I showed how our understanding of the aetiology of subjective suffering and the corresponding empirical evidence, facilitates decision-making that minimizes suffering in the individuals to whom the duty of care is due.

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