NOTTINGHAM
TRENT UNIVERSITY

Rethinking persistent vegetative state and protection of those diagnosed as in it.

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Olabode Bamidele Aleshinloye N0662132

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Abstract

Both the concept of PVS and the treatment of those defined as having it have been the subject of considerable discussion in the literature from a variety of disciplinary perspectives. This thesis, however, aims to push the field further forward with an approach that is more intensively multidisciplinary, holistic, and critical of orthodoxies with respect to the legitimacy of the PVS concept and withdrawal and withholding of life-sustaining interventions (WWLSI) from those labelled as being PVS. Through a unique empirical study, it deepens the understanding of how healthcare professionals working with patients defined as PVS see the condition and think about / practically approach the clinical, ethical, and legal issues relating to it, including WWLSI.

One of the critically reflected orthodoxies is the medical notion that PVS is a condition involving patients who are unconscious. The empirical aspect of the thesis suggests that there is a great deal of complacency around this notion. Yet closer consideration reveals several problems with it. Firstly, functional magnetic resonance imaging (fMRI) analysis of some patients deemed PVS appears to contradict the notion that they cannot per se communicate. Secondly, no study has demonstrated any direct link between consciousness and a specific neural process in the brain of those labelled 'PVS.' Indeed, as I show as part of an epistemological exploration of the PVS concept, there is, at least beyond the narrow confines of medical practice in this field, a great deal of debate and dispute over what consciousness is and how it relates to the brain. Thirdly, as some patients are being defined as having recovered from being vegetative (reflected in the P now generally being treated as standing for persistent rather than permanent), this gives rise to the question of whether they had actually lost consciousness only to recover it or whether they had never lost consciousness in the first place (with PVS thus being more of a communication disorder).

The uncritical orthodox position towards the PVS has played into a limited conception of the interests of those labelled PVS – including notions that they have no functional interests. I posit that this has spilled over into ethico-legal analysis of how they should be treated and the specific question of WWLSI. That analysis, however, is also greatly impacted by the ethical lenses it tends to be viewed through. Furthermore, this thesis details the main ethical lenses and makes the case for preferring one that reflects respect for human worth, grounded in a particular conception of respect for human dignity and personhood. I work through the implications of this approach on law and practice relating to the treatment of those diagnosed as PVS and the legitimacy of WWLSI from such patients in particular. Besides recommending that the parameters for diagnosing PVS should be revisited and making a case for changing the governance and practice of WWLSI in PVS, I also recommended further research into the relationship between the brain and consciousness in these patients and that the law and / or professional ethical codes should protect the unconscious.

Keywords: Persistent vegetative state; human dignity; personhood.

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CHAPTER ONE

Introduction and Methodology

1.1. Overarching Aims of the Thesis.

Both the concept of persistent vegetative state (PVS) and the treatment of those diagnosed as PVS have been considered fairly extensively in the literature. However, this thesis has been developed to push the field further forward with a more intensively multidisciplinary, holistic, and progressive approach. This is particularly with respect to the legitimacy of the PVS concept and the withholding and withdrawing of life-sustaining interventions (WWLSI) from those labelled as being PVS. The thesis also aims to add to the understanding of how healthcare professionals working with patients defined as PVS see the condition and think about / practically approach the clinical, ethical, and legal issues relating to it, including WWLSI.

1.2. The Objectives of the Thesis.

1. To explore the concept of PVS and question its validity as a concept by examining whether there is proper evidence in order to support the determination of the presence or loss of upper brain function in severe brain injury and relatedly consciousness or the lack of it. In addition, to explore whether the concept of consciousness, how people diagnosed as in a PVS lose or regain consciousness, and if the relationship between brain, mind, and consciousness are well researched and understood. There will also be a critical evaluation of how the clinicians see the clinical diagnosis and management of PVS as a condition.

2. To draw on relevant philosophical theories and ethical principles to develop a benchmark for critiquing law, policy, governance, and practice concerning WWLSI in people deemed to be in a PVS.

3. To explore the law, policy, and governance concerning WWLSI in people deemed to be in a PVS in light of the following questions:

   I. Whether the claimed lack of discernible interactive capability is in some or all cases attributable to not using all the measuring tools at our disposal.
   II. Whether it is ever possible to say a person objectively lacks interactive capability given that measuring tools only ever tell us that they can or cannot measure something, which is not necessarily the same as concluding with certitude that it does or does not exist.
   III. Whether the heart of the notion of PVS – the notion of loss of upper brain function and related consciousness and a supposed potential for its recovery – is properly evidenced.

4. To explore healthcare practitioners' perspectives on the concept of PVS and the practice and governance of WWLSI in people diagnosed as in a PVS, principally through original empirical research to deepen the understanding of attitudes and practices in this field and comparing the status quo with the practitioners' perspectives.

1.3. Technical terms used in this thesis and their explanations.

I. **Persistent vegetative state (PVS):** The medical profession gives this name to people who do not appear to interact with their immediate environment after suffering severe brain damage. They open and close their eyes like normal people sleep and wake up and it is believed that their sleep-wake cycle is intact. This feature is attributed to an intact brain stem. The neuropathological problem proposed in these patients is attributed to the damaged upper part of the brain called the cerebrum. They are generally referred to as being awake but not conscious.

II. **Minimally conscious state (MCS)**: MCS, on the other hand, is a condition following severe brain injury where the brain stem function is intact like PVS and the patient exhibits a normal sleep-wake cycle. However, unlike PVS, the patient has variable interactions with environmental stimuli.

III. **Prolonged disorder of consciousness (PDoC):** Disorder of consciousness (DoC) refers to the group of patients who appears not to have conscious experience. While some literature includes locked-in syndrome (LIS), technically, LIS is not a disorder of consciousness. DoC is an umbrella term for patients diagnosed with coma, VS, and MCS. However, when the patients remain in the state for more than a month they are generally referred to as PDoC.

IV. **Interactive capability:** This term is used to describe the ability of the patient's nervous system to sense and respond to external stimuli. This property involves both the afferent (input) and efferent (output) pathways and these pathways must be intact together with the brain for the interactive capability to be normal.

V. **Reticular activating system (RAS):** It is part of the brain located in the brainstem and comprises of a network of neurons interconnecting severe parts of the brain. It is said to be responsible for the maintenance of the vegetative function of the brain and facilitates sensation and attention.

VI. **Single-photon emission computerized tomography (SPECT):** This specialised scan uses the radioactive substance in the form of gamma rays to obtain images of organs and tissues with their blood flows.

VII. **Perturbational complexity index (PCI):** This is a method of measuring brain activity (spatiotemporal complexity) by applying a magnetic pulse across the brain.

VIII. **Electroencephalogram (EEG):** is a test that measures the electrical activities of the brain and is used to detect abnormalities in the brain's electrical activities.

IX. **Functional magnetic resonance imaging (fMRI):** This is a neuroimaging technique used to evaluate the patient brain and used to detect performance on motor and spatial imagery tasks in patients with PDoC.

X. **Fluorodeoxyglucose positron emission tomography (FDG-PET):** The scan uses a radioactive substance called fluorodeoxyglucose (a simple sugar) which is ingested into the bloodstream and generates energy detected by the PET scanner. The scanner reconstructs the images and gives a picture of the tissues and organs in the body and how they work.

1.4. The state of the art and the approach the thesis takes to building on it.

It is widely acknowledged that governance and practice relating to the diagnosis and treatment of people labelled as PVS are controversial. However, some aspects of the controversy, which have a potentially very significant bearing on practice and its governance, have yet to be robustly addressed. This thesis adopts a holistic approach to exploring these issues systematically by reviewing the governance and practice of withholding and withdrawing treatment in people diagnosed as in a PVS through clinical, philosophical, governance, regulative, legal, and practitioner lenses. In this thesis, governance in relation to people diagnosed with PVS refers to the framework in the form of law and regulation by which the healthcare organisations in the UK are held accountable for the care provided to these individuals.[1] The thesis commences that process by engaging with the epistemological issues. Specifically, I briefly explore the history of use of the label PVS and examine key prevailing theories around the relationship between the brain, mind, and consciousness. PVS is widely accepted to be a real condition typically categorised as forming one of three types of disorder

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[1] Amanda Macfarlane, 'What is clinical governance?' (2019) 19(6) BJA education <https://doi.org/10.1016/j.bjae.2019.02.003> accessed 10 July 2021.

of consciousness.[2] My contention is that this acceptance is premised on complacency and that whilst those who are considered to be diagnosed as PVS do exhibit some kind of clinical issue, there is a lack of clarity in terms of the exact nature of the issue. I specifically suggest that the label PVS arises out of a narrow reductionistic medical viewpoint that is not sustained by what we understand of the relationship between consciousness and the brain and does not sit well with basic logic. I posit that neither reductionism nor the PVS label which reflects it can explain how a person who is said to have lost upper brain function can recover it and that it is important to question whether they lost it in the first place. This, in turn, raises valid questions on the use of the vegetative element of the label and thereby, the label itself. The diagnosis of PVS solely depends on the inability of the clinicians to observe any behaviour indicative of upper brain function. I will argue that this should not be taken to mean that such a function does not exist.

It is therefore imperative to explore the philosophy of the mind and consciousness in the quest to answer the lingering questions about PVS. One of the problems is the widespread palpable complacency around the notion of PVS being a real condition. The reaction to two developments illustrates this well: firstly, some patients have been observed to move from a state where they appeared unconscious and unreachable - even, in some cases, after a prolonged period - to a state where they were not.[3] Secondly, some individuals who were believed to be unconscious and unreachable were found not to be in such a condition (via developments in the use of brain scanning initiated from 2006).[4] Due to the former development, the P in PVS is treated as persistent rather than permanent, and the latter has been a factor supporting

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[2] Blessen Eapen and others, 'Disorders of Consciousness' (2017) 28(2) Physical Medicine Rehabilitation Clinics of North America <https://doi.org/10.1016/j.pmr.2016.12.003 > accessed 6 September 2020.

[3] Alessio Baricich and others, 'Recovery from vegetative state of patients with a severe brain injury: a 4-year real-practice prospective cohort study' (2017) 32(3) Functional Neurology <https://ncbi.nlm.nih.gov/pmc/articles/PMC5726348/>accessed 15 May 2021.

[4] Daniel Kondziella and others, 'Preserved consciousness in vegetative and minimal conscious states: Systematic review and meta-analysis' (2016) 87 (5) Journal of Neurology and Psychiatry <https://jnnp.bmj.com/content/87/5/485.long> accessed 11 September 2020.

increased nuance in diagnosis (with, in particular, some patients now defined as MCS when they would formerly have been defined PVS).[5] However, even the combined presence of both has not led to a fundamental appraisal of whether PVS is a valid condition, let alone causing a fundamental reconsideration of how we ought to treat those who are defined as being in this state. Against this backdrop, the original and significant contribution of this thesis is that it not only demonstrates the complacency and attempts to understand the cause of it, but also makes the case for and brings about a fundamental reconsideration of how we think about those labelled to be PVS and how we care for them.

Furthermore, by exploring the ethical principles and philosophical theories of decision-making in medicine and law as it relates to life-sustaining interventions (LSI) in this category of patient, this thesis critiques the governance of withholding and withdrawing treatment in patients deemed in PVS. The legal perspective provided through technical analysis of the law exposes the inconsistencies in the available practices' laws and regulations. Appraising the practitioner perspective, through an original empirical research of the views and opinions of healthcare practitioners helps in comparing the current practice of WWLSI in PVS to the views of the clinicians. Notably, while I use the term 'PVS patient' or 'PVS' in some sections for the sake of convenience as this is how the medical and legal establishments refer to such patients, this should be understood as meaning 'individuals diagnosed as PVS' and not be construed as an endorsement of the concept of PVS in this thesis.

Several controversies exist regarding how medical professionals label their patients as PVS and how they are subsequently cared for and, in many cases, allowed to die. The existing literature has not robustly addressed these controversies, even though they have a huge bearing on governance and practice. Jennett and Plum coined the terminology in 1972 out of a need to

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[5] Andreas Bender and others, 'Persistent Vegetative State and Minimally Conscious State: A systematic review and meta-analysis of diagnostic procedures' (2015) 112(14) Deutsches Ärzteblatt International <https://doi.org/10.3238/arztebl.2015.0235> accessed 21 January 2021.

begin the discussion on a category of patients who were emerging from a comatose state following severe brain injury by cyclically opening their eyes; however, they did not appear to be aware of their surroundings.[6] Despite defining the state mainly based on the absence of behavioural features they attributed to consciousness, they did not link any neuropathological process in the brain to the inability of these patients to exhibit the expected reactions.[7] Regardless, they asserted that a patient in that state lacked a functioning mind.[8] These characterisations became the basis upon which PVS patients are managed in clinical settings. Subsequently, the medical profession defines PVS as a condition presenting after one month of brain injury with total unawareness and a preserved sleep-wake cycle.[9] This condition is now categorised as one of the three forms of a so-called PDoC.[10] Over the years, questions have been raised about various issues with the diagnosis. However, no studies have examined the evidence behind the claim of 'lack of a functioning mind' in patients diagnosed as PVS.[11] The existing literature about this claim has been patchy.

Some researchers have theorised that the damage to the cortical brain is responsible for the behavioural features seen in these patients.[12] On the other hand, others have postulated that

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[6] Bryan Jennett and Fred Plum, 'Persistent vegetative state after brain damage: A Syndrome in Search of a name' (1972) 299(7753) The Lancet <https://doi.org/10.1016/S0140-6736(72)90242-5>accessed 1 May 2021.

[7] Ibid

[8] Ibid

[9] The Multi-Society Task Force on PVS, 'Medical Aspects of the Persistent Vegetative State' (1994) **330 (22)** NEJM <https://nejm.org/doi/full/10.1056/NEJM199405263302107> accessed 10 July 2021.

[10] Eapen and others (n 2); Spencer Septien and Michael Rubin, 'Disorders of Consciousness: Ethical Issues of Diagnosis, Treatment, and Prognostication' (2018) 38(5) Seminars in neurology <https://doi.org/10.1055/s-0038-1667384> accessed 8 July 2021.

[11] Gastone Celesia, 'Persistent Vegetative State' (1993) 43(8) Neurology <https://n.neurology.org/content/43/8/1457> accessed 22 September 2020; Gastone Celesia, 'Persistent Vegetative State: Clinical and Ethical Issues' (1997) 18(1) Theoretical Medicine <https://doi.org/10.1023/A:1005709410296> accessed 3 April 2021; Gastone Celesia, 'Conscious awareness in patients in vegetative states: myth or reality?' (2013) 13(11) Current Neurology and Neuroscience Reports < https://pubmed.ncbi.nlm.nih.gov/24048705/> accessed 11 September 2020; Lindy Willmott and Ben White, 'Persistent vegetative state and minimally conscious state: ethical, legal and practical dilemmas' (2017) 43(7) Journal of medical ethics <https://doi.org/10.1136/medethics-2017-104378> accessed 8 July 2021.

[12] Simona De Salvo and others, 'Clinical differentiation and outcome evaluation in vegetative and minimally conscious state patients: the neurophysiological approach' (2012) 27(3) Functional neurology <https://ncbi.nlm.nih.gov/pmc/articles/PMC3812768/> accessed 8 July 2021.

consciousness is associated with the neural processes of the reticular activating system (RAS) in the brainstem.[13] However, a few researchers opined that consciousness hinges on the complex interactions among the global network of neurones in the whole brain.[14] Contrary to the assertion that patients diagnosed as PVS lack a functioning cerebral cortex, few studies have shown some upper brain functions in some patients who might have been accurately diagnosed according to the prevailing criteria.[15] Despite the various advancements in medical technology and the increasing use of sophisticated tests, the PVS brain and consciousness relationship remains a puzzle.[16] In this thesis, I explore this concept from an epistemological perspective and critique the overreaching notion of PVS. Beyond this, I reach conclusions about what we can say we know and do not know about the state (wrongly) labelled PVS and then evaluate the potential significance of those conclusions in terms of how we approach law, governance, and practice in this field, including specifically WWLSI

The literature suggests that there are far-reaching implications of the claim about PVS being a valid concept without strong evidence about the understanding of the linkage between the brain and the mind or consciousness. It was not long after the concept was proposed that

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[13] Melanie Boly and others, 'Baseline brain activity fluctuations predict somatosensory perception in humans' (2007) 104(29) PNAS < https://doi.org/10.1073/pnas.0611404104> accessed 20 May 2021; Brian Edlow and others, 'Neuroanatomic connectivity of the human ascending arousal system critical to consciousness and its disorders' (2012) 71(6) Journal of neuropathology and experimental neurology <https://doi.org/10.1097/NEN.0b013e3182588293> accessed 8 July 2021; Sung Jang and others, 'Relationship between consciousness and injury of ascending reticular activating system in patients with hypoxic ischaemic brain injury' (2019) 90(4) Journal of neurology, neurosurgery, and psychiatry <https://doi.org/10.1136/jnnp-2018-318366> accessed 8 July 2021; Sung Jang and others, 'Long-term recovery from a minimally responsive state with recovery of an injured ascending reticular activating system: A case report' (2021) 100(9) Medicine <https://doi.org/10.1097/MD.0000000000023933> accessed 8 July 2021.

[14] Sonia Silva and others, 'Wakefulness and loss of awareness: brain and brainstem interaction in the vegetative state' (2010) 74(4) Neurology <https://doi.org/10.1212/WNL.0b013e3181cbcd96> accessed 8 July 2021.

[15] Steven Laureys, 'The neural correlate of (un)awareness: lessons from the vegetative state' (2005) 9(12) Trends in cognitive sciences <https://doi.org/10.1016/j.tics.2005.10.010> accessed 8 July 2021; Hai-Bo Di and others, (2007). 'Cerebral response to patient's own name in the vegetative and minimally conscious states' (2007) 68(12) Neurology <https://doi.org/10.1212/01.wnl.0000258544.79024.d0> accessed 8 July 2021.

[16] James Bernat, 'Can functional MRI detect awareness when a neurological examination does not?' (2007) 3(9) Nature clinical practice. Neurology <https://doi.org/10.1038/ncpneuro0579> accessed 8 July 2021.

researchers noticed that some people labelled as PVS started recovering from the state.[17] It then became obvious that the manner in which the diagnoses were made was ridden with problems. Several studies have shown high rates of misdiagnosis by clinicians despite using the standardised criteria.[18] Meanwhile, other studies showed that some patients that were purportedly diagnosed accurately were later found to regain consciousness.[19] These observations herald the need to redefine PDoC to include the MCS category by the Aspen Group in 2002.[20] Even with this development, there is still a significantly high rate of misdiagnosis of patients with PVS and MCS. It is unclear whether this new classification of patients is an entirely different category. Some have proposed that people who suffered a severe brain injury can move in and out of 'PVS' and 'MCS', suggesting that these two clinical entities are perhaps on the same spectrum.[21] One study, in particular, found that 37% (n 193) of patients labelled as PVS and sent for rehabilitation over five years were inaccurately diagnosed.[22]

Another study in 2009 attempted to investigate the accuracy of the diagnosis of PVS and MCS by conducting a comparative study between the consensus-based diagnosis and the

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[17] Gary Rosenberg and others, 'Recovery of cognition after prolonged vegetative state' (1977) 2(2) Annals of Neurology <https://doi.org/10.1002/ana.410020215> accessed 8 July 2021.

[18] Keith Andrews and others, 'Misdiagnosis of the vegetative state: retrospective study in a rehabilitation unit'(1996) 313(7048) *BMJ* <https://doi.org/10.1136/bmj.313.7048.13> accessed 8 July 2021; Helen Gill-Thwaites, 'Lotteries, loopholes and luck: misdiagnosis in the vegetative state patient' (2006) 20(13-14) Brain injury <https://doi.org/10.1080/02699050601081802> accessed 8 July 2021; Derick Wade, 'How often is the diagnosis of the permanent vegetative state incorrect? A review of the evidence' (2018) 25(4) European journal of neurology <https://doi.org/10.1111/ene.13572> accessed 8 July 2021.

[19] Antonio Naro and others, (2017). 'Unexpected recovery from a vegetative state or misdiagnosis? Lesson learned from a case report' (2017) 41(4) Neuro-Rehabilitation <https://doi.org/10.3233/NRE-172160> accessed 8 July 2021.

[20] Ronald Cranford, 'What is a minimally conscious state?' (2002) 176(2) The Western journal of medicine <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1071686/> accessed 22 September 2020; Ricardo Hodelín-Tablada, 'Minimally Conscious State: Evolution of Concept, Diagnosis and Treatment' (2016) 18(4) MEDICC review<https://pubmed.ncbi.nlm.nih.gov/27829654/> accessed 8 July 2021.

[21] Monica Risetti and others, 'On ERPs detection in disorders of consciousness rehabilitation' (2013) 7(775) Frontiers in human neuroscience <https://doi.org/10.3389/fnhum.2013.00775> accessed 8 July 2021; Michael Brogan and Javier Provencio, 'Spectrum of catastrophic brain injury: coma and related disorders of consciousness' (2014) 29(4) Journal of critical care <https://doi.org/10.1016/j.jcrc.2014.04.014> accessed 8 July 2021.

[22] Nancy Childs and others, 'Accuracy of diagnosis of persistent vegetative state' (1993) Neurology 43(8) <https://n.neurology.org/content/43/8/1465 > accessed 11 September 2020.

diagnosis based on the Coma Recovery Scale-Revised (CRS-R).[23] They found out that 41% (n 44) of the patients diagnosed as VS with the consensus criteria were reclassified as MCS after using the CRS-R tool.[24] Generally, the PVS diagnosis relies mainly on physical examination and assessment of the patient's behaviour which involves a degree of unpredictability.[25] Some studies have suggested other ways of assessments to improve diagnostic accuracy. One study postulated that resistance to eye-opening has a voluntary component and could be a sign of consciousness if present in a 'PVS patient'.[26] An online survey of 503 neurologists' responses to a vignette-based randomised presentation of two different forms of PDoC and non-PDoC case scenarios showed the diversity of opinions in stratifying these patients into categories.[27] Furthermore, a study in 2016 demonstrated that approximately 15% (n 1041 patients) of patients diagnosed with VS clinically were able to follow commands (which were not clinically observed) when their brains were examined using fMRI and EEG.[28] Other studies have demonstrated some neural activities in the upper cortical brain of 'PVS' patients.[29] Many other studies have undoubtedly suggested fundamental issues with the way these patients are diagnosed or the diagnosis itself.

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[23] Caroline Schnakers and others, 'Diagnostic accuracy of the vegetative and minimally conscious state: clinical consensus versus standardized neurobehavioral assessment' [2009] 9(35) BMC Neurology <https://bmcneurol.biomedcentral.com/articles/10.1186/1471-2377-9-35 > accessed 11 September 2020.

[24] Ibid.

[25] Jitka Annen and others, 'Diagnostic accuracy of the CRS-R index in patients with disorders of consciousness' (2019) 33(11) Brain injury <https://doi.org/10.1080/02699052.2019.1644376> accessed 8 July 2021.

[26] Hjalmar van Ommen and others, 'Resistance to eye opening in patients with disorders of consciousness' (2018) 265(6) Journal of neurology <https://doi.org/10.1007/s00415-018-8849-0> accessed 8 July 2021.

[27] Katja Kuehlmeyer and others, 'Diagnostic and ethical challenges in disorders of consciousness and locked-in syndrome: a survey of German neurologists' (2012) 259(10) Journal of Neurology <https://ncbi.nlm.nih.gov/pmc/articles/PMC3464386/> accessed 11 September 2020.
Around 86% of the respondents got the diagnosis right (locked-in syndrome (LiS) - (94%); VS - (79%); MCS - (87%, $p < 0.001$)

[28] Kondziella and others (n 4).

[29] De Salvo and others (n 12); Martin Monti and others, 'Willful modulation of brain activity in disorders of consciousness' (2010) 362(7) NEJM <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.464.4663&rep=rep1&type=pdf> accessed 11 September 2020.

This thesis goes beyond the existing literature on this topic to make a case that the issue of misdiagnosis lies in the complacency of the medical profession in accepting the notion of PVS as a real clinical state. Tests are routinely performed to see whether these patients lack interactive ability. However, these routine tests have not been reliable indicators as they only rule out differential diagnosis rather than evidence of the lack of consciousness.[30] Furthermore, when routine tests are not reflective of interactive ability the medical fraternity overreaches by concluding that such interactive ability is lacking, conflating this with a lack of upper brain awareness and affixing the derogatory label of vegetative. Even leaving these fundamental points to one side, the literature makes it evident that the frequency with which a conclusion of lack of upper brain awareness/consciousness is reached strongly depends on the ability of the assessor to detect the evidence of consciousness and the sensitivity of the technological modalities deployed. Many other studies have looked into misdiagnosis, late recovery, and reliability of technological modalities in use.[31] Researchers have recently tried to demonstrate an association between coordinated dynamic patterns on fMRI in MCS and healthy individuals to consciousness.[32] Some have also demonstrated patterns on EEG, which may indicate brain

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[30] A Shiel and others, 'Difficulties in diagnosing the vegetative state' (2004) 18(1) British journal of neurosurgery <https://doi.org/10.1080/02688690410001660625> accessed 8 July 2021.

[31] Keith Andrews and others, 'Misdiagnosis of the vegetative state: retrospective study in a rehabilitation unit' (1996) 313(7048) BMJ <https://pubmed.ncbi.nlm.nih.gov/8664760/> accessed 11 September 2020; Katja Kuehlmeyer and others, 'Single case reports on late recovery from chronic disorders of consciousness: A systematic review and ethical appraisal' (2013) 6(4) Bioethica Forum 137 <www.bioethica-forum.ch/docs/13_4/04_Kuehlmeyer.pdf > accessed 9 April 2019; Anna Estraneo and others, 'Clinical and neuropsychological long-term outcomes after late recovery of responsiveness: a case series' (2014) 95 (4) Archives of physical medicine and rehabilitation <https://doi.org/10.1016/j.apmr.2013.11.004> accessed 2 May 2021; Willemijn van Erp and others, 'Unexpected emergence from the vegetative state: delayed discovery rather than late recovery of consciousness' (2019) 266(1) Journal of Neurology <https://doi.org/10.1007/s00415-019-09542-3 >accessed 2 May 2021.

[32] Damien Gabriel and others, 'Substitute or complement? Defining the relative place of EEG and fMRI in the detection of voluntary brain reactions' (2015) 290 Neuroscience <https://doi.org/10.1016/j.neuroscience.2015.01.053 > accessed 2 February 2021; Athena Demertzi and others, 'Human consciousness is supported by dynamic complex patterns of brain signal coordination' (2019) 5(2) Science Advances <https://advances.sciencemag.org/content/5/2/eaat7603> accessed 8 July 2021.

activation in patients who are unresponsive clinically.[33] Whether this substantiates the presence of consciousness in these patients remains debatable.

Some researchers have combined EEG, fMRI, and FDG-PET to improve the accuracy of diagnosis of the condition.[34] Meanwhile, other studies have suggested PCI to detect consciousness.[35] Some studies argued that combining the behavioural criteria provided by Jennett and Plum with ancillary investigations like EEG and FMRI would improve the accuracy of diagnosis.[36] However, this thesis takes a unique position by arguing that understanding consciousness as an entity or perhaps as a concept is crucial to the understanding of what happens to these patients after brain injury. The existing studies have primarily focused on the physical reductionist aspect of the mind and consciousness. The attempts to explain consciousness from a pure physicalist point of view might not resolve this yet unsolved mystery. The exploration of the philosophical nuances of consciousness will undeniably shed more light on PVS discourse. Myriad philosophical theories of consciousness in the literature serve as important points of reference to the debate on PVS.[37] Even though there are a reasonable number of studies on PVS in these areas, very little research has been undertaken

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[33] Vidya Kulkarni and others, 'EEG Findings in the Persistent Vegetative State' (2007) 24(6) Journal of Clinical Neurophysiology < https://doi.org/10.1097/WNP.0b013e31815c2810> accessed 10 July 2021; Jan Claassen and others, 'Detection of Brain Activation in Unresponsive Patients with Acute Brain Injury' (2019) 380(26) The New England journal of medicine <https://doi.org/10.1056/NEJMoa1812757> accessed 8 July 2021.

[34] Daniel Golkowski, and others, 'Simultaneous EEG-PET-fMRI measurements in disorders of consciousness: an exploratory study on diagnosis and prognosis' (2017) 264(9) Journal of neurology <https://doi.org/10.1007/s00415-017-8591-z> accessed 8 July 2021.

[35] Olivier Bodart and others, 'Measures of metabolism and complexity in the brain of patients with disorders of consciousness' (2017) 14 NeuroImage Clinical <https://doi.org/10.1016/j.nicl.2017.02.002> accessed 8 July 2021; Yelena Bodien and others, 'Functional MRI Motor Imagery Tasks to Detect Command Following in Traumatic Disorders of Consciousness' (2017) 8 Frontiers in neurology <https://doi.org/10.3389/fneur.2017.00688> accessed 8 July 2021.

[36] Tim Bayne and others, 'Reforming the taxonomy in disorders of consciousness' (2017) 82(6) Annals of neurology <https://doi.org/10.1002/ana.25088> accessed 8 July 2021.

[37] Ravi Prakash and others, 'Global workspace model of consciousness and its electromagnetic correlates' (2008) 11(3) Annals of Indian Academy of Neurology <https://doi.org/10.4103/0972-2327.42933> accessed 10 July 2021; Davide Sattin and others, 'Theoretical Models of Consciousness: A Scoping Review' (2021) 11(5) Brain sciences <https://doi.org/10.3390/brainsci11050535> accessed 10 July 2021.

to assess the validity of PVS as a clinical state and how it relates to the Court's assumptions in deciding whether a PVS patient lives or dies.

The Courts have historically relied on expert evidence on the condition before making declarations on the applications put forward by the doctors, official solicitors, or even the patient’s relatives. Perhaps the most important proclamation by the medical profession that has a huge bearing on these cases is that these patients are not conscious, lack sentience capabilities, and are unlikely to regain these functions. The evidence for irreversibility was contained in a document by the Multi-Society Task Force (MSTF) on PVS published around three decades ago, which has been criticised as biased. Furthermore, the literature on these patients regaining consciousness beyond the timeframe proposed by MSTF has invited more criticisms about the way in which they are treated. A study in 2018 demonstrated consciousness in a patient diagnosed with 'PVS' for twenty years by combining standardised scale and functional neuroimaging.[38] Another study that looked into the recovery of a 15-year-old patient whom the doctors labelled as PVS for seven years before regaining full consciousness suggested that making a negative diagnosis of PVS after one year might not be in the patient’s best interests.[39] Some might have reasons to believe that we are yet to know all that is to know about consciousness among patients with severe brain injury. A study with a promising result demonstrated an improved behavioural response in a patient labelled as VS after the vagus nerve was electrically stimulated.[40]

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[38] Audrey Vanhaudenhuyse and others, ‘Conscious While Being Considered in an Unresponsive Wakefulness Syndrome for 20 Years’ (2018) 9(671) Frontiers in neurology <https://doi.org/10.3389/fneur.2018.00671> accessed 8 July 2021.

[39] Antonio De Tanti and others, ‘Recovery of consciousness after 7 years in vegetative state of non-traumatic origin: A single case study’ (2016) 30(8) Brain Injury <https://pubmed.ncbi.nlm.nih.gov/27119381/> accessed 11 September 2020.

[40] Martina Corazzol and others, ‘Restoring consciousness with vagus nerve stimulation’ (2017) 27(18) Current biology <https://doi.org/10.1016/j.cub.2017.07.060> accessed 8 July 2021.

Whether patients in VS and indeed in coma are conscious remains a contentious issue.[41] This assertion makes the standard behaviour assessment to determine consciousness insufficient to lay claims to irreversibility or permanence of VS.[42] The demonstration of brain activities by neuroimaging may not provide compelling enough evidence of the subject under investigation gaining conscious awareness as these activities may only denote neuronal stimulation, which may or may not lead to any physiologically relevant process.[43] There is a need for more studies on prognosis and recovery from PDoC.[44] Even though the P in the PVS was used to mean permanent, the medical profession realised that these patients have complex issues. The decision to terminate lifesaving treatments without any widely acceptable framework become a big issue.[45] In the nascent stages of the history of the label, some studies suggested that doctors have no ethical responsibility to continue treatment in these patients but that basic nursing care can continue.[46] There are studies into the legal, ethical, clinical, and practical implications of decisions to withdraw clinically assisted hydration and nutrition (CAHN).[47] However, in its focus on these issues, this thesis represents one of the few pieces of work that could be described as systematic and holistic. It provides a unique insight into these pertinent issues grounded on philosophical and professional reflection and an original

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[41] Morten Overgaard, 'How can we know if patients in coma, vegetative state or minimally conscious state are conscious?' (2009) 177 Progress in Brain Research <https://pubmed.ncbi.nlm.nih.gov/19818891/> accessed 11 September 2020.

[42] Ibid

[43] Gastone Celesia, 'Conscious awareness in patients in vegetative states: myth or reality?' (2013) 13(11) Current Neurology and Neuroscience Reports <https://pubmed.ncbi.nlm.nih.gov/24048705/> accessed 11 September 2020.

[44] Giuliano Dolce and others, 'Clinical signs and early prognosis in vegetative state: A decisional tree data-mining study' (2008) 22(7-8) Brain Injury <https://doi.org/10.1080/02699050802132503> accessed 11 May 2021.

[45] Ronald Cranford, 'Termination of treatment in the persistent vegetative state' (1984) 4(1) Seminars in neurology <https://doi.org/10.1055/s-2008-1041530> accessed 8 July 2021.

[46] Sylvia Oboler, 'Brain Death and Persistent Vegetative States' (1986) 2(3) Clinics in Geriatric Medicine, <https://doi.org/10.1016/S0749-0690(18)30870-X> accessed 8 July 2021; Fenella Rouse, 'Withholding or Withdrawing Treatment' (1986) 256(4) JAMA <https://doi.org/10.1001/jama.1986.03380040043013> accessed 8 July 2021; Thomas Corbett, 'Withholding or Withdrawing Life-Prolonging Medical Treatment' (1986) 256(19) JAMA <https://doi.org/10.1001/jama.1986.03380190043008> accessed 8 July 2021.

[47] Lindy Willmott and Ben White, 'Persistent vegetative state and minimally conscious state: ethical, legal and practical dilemmas' (2017) 43(7) Journal of medical ethics <https://doi.org/10.1136/medethics-2017-104378> accessed 8 July 2021.

programme of empirical research focused on the knowledge, insights, and attitudes of professionals working in the field. Several studies exist on the diversity of attitudes or actions undertaken towards WWLSI for people identified to be in a PVS state. However, none of them was based on the type of empirical approach used for this study.[48]

From the above literature review, it is evident that the language about ‘PVS’ has been constructed around a certain view of PVS that includes the use of the term consciousness as well as terms like vegetative. Indubitably, this category of people has some medical issues and appears not to interact with their surroundings. However, the problem with the conventional discourse about the label is the presumption of lack of consciousness without strong evidence to prove the evidence of lack of consciousness. Therefore, this thesis will add to the body of knowledge in the field by being the first holistic and systematic multi-disciplinary analysis of the issues around the PVS concept. Specifically, I have highlighted below some distinct and materially valuable contributions to the field.

1. The epistemological critique of the discourse/construction of knowledge in this area exposes the overreaching idea that people labelled as PVS lack upper brain function and related consciousness. This thesis critically evaluates the validity of the fundamental widespread assumptions of the clinical existence of a PVS state and the premise on which the concept is defined (the loss of upper brain function, related consciousness, and a supposed potential for its recovery) whether they are potentially grounded in ideas and theories.

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[48] Andrew Grubb and others, ‘Survey of British clinicians' views on management of patients in persistent vegetative state’ (1996) 348(9019) Lancet <https://pubmed.ncbi.nlm.nih.gov/8691931/>accessed 11 September 11, 2020; Kirk Payne and others, ‘Physicians' attitudes about the care of patients in the persistent vegetative state: a national survey’ (1996) 125(2) Ann Intern Med <https://pubmed.ncbi.nlm.nih.gov/8678363/>accessed 11 September 2020; Athena Demertzi and others, ‘Attitudes towards end-of-life issues in disorders of consciousness: a European survey’ (2011) 258(6) Journal of Neurology <https://pubmed.ncbi.nlm.nih.gov/21221625/> accessed 11 September 2020; Kuehlmeyer and others 2012 (n 27).

2. The development of a specific ethical lens to analyse issues in the field and their specific application to governance, law, and practice. Beyond the critiquing of the notion of whether PVS is a valid state or otherwise, this research further considers broader issues related to the perception of the clinical diagnosis and management of the condition. Consequently, I provide broader analysis via the provision of a systematic approach to tackling pertinent questions related to the PVS including the determination of whether some or all of those who are said to be in a PVS might be more aptly described as in fact, another state and, if so, what that state might be better described as well as the implications for the reform of governance and practice.

3. A unique empirical programme that aims to enhance the current understanding and knowledge base regarding the PVS state as provided by the original anecdotal primary evidence from various health professionals delivering care to patients deemed to be in a PVS state. Notably, this perspective enables the opportunity to compare what obtains in the practice and governance with the professional knowledge and opinions of these professionals. No research so far has looked into the interaction between the individual determinants in the patients.

4. The fourth and final significance of this thesis is in the criticism of the internal inconsistencies in the law regarding WWLSI in people diagnosed as a PVS from a unique perspective. So far, there are very limited systematic efforts to understand the interactions among several concepts including law, policy, and governance, and how PVS patients are protected in practice. Hence, this research further evaluates the complexities including the ethical dilemmas of the interrelationships between these concepts to provide new approaches for comprehending the diagnosis, prognosis, and the administration of the duty of care to individuals deemed in a PVS in the UK.

1.5. Methodology

The methodology is in part doctrinal with the analysis focused on the function of critiquing current governance and practice in the field to reflect on possible reform. Facilitating this partly entailed using the disciplines of medicine, philosophy/ethics, and law to engage in technical analysis of relevant governance related provisions and practice. However, it was also a question of evaluating the substantive positions taken in relevant governance and practice. These were examined for their coherence in the light of: a clinical and philosophical analysis of awareness, consciousness, and the brain, tailored towards PVS and specifically PVS; and the development of an ethical benchmark in the light of a philosophical analysis of the competing merits of ethical theories pertinent to medicine. To facilitate these analyses an extensive search and review of relevant hard copy and electronic sources were performed. These sources included monographs, chapters in edited collections, journal articles, public policy and legal/professional governance and guidance documents, command papers, legislation, and case law. The extensive search, review, and ongoing analysis both fostered a more complete understanding of the pertinent issues and this in turn laid the platform for identifying those specific pertinent issues which might be potentially further illuminated by empirical investigation.

The empirical research was used to explore the healthcare professionals' perspective on the concept of PVS and the treatment of people deemed to be in that state. This aspect of the thesis is important because it gives a comparative perspective on the current practice of WWLSI in PVS and the practitioners' opinions. The methodology used to explore the views of the healthcare professionals was a mixed methodology. The survey involved the use of a questionnaire with open-ended and closed-ended questions to collect information. Therefore, a mixed methodology was deemed appropriate to analyse the data. The empirical programme entailed distributing questionnaires to doctors and nurses in the National Health Service (NHS) hospitals to gather information on how the law influences their practice and their views on PVS and the practice of WWLSI. The target population was selected because they are more likely to come across PVS patients in their day-to-day practice than any other population. In order for the study to have significant statistical power, the sample size was determined before the commencement of the research, and it was calculated to be 96 (n = 96). A confidence interval (CI) of 10 and a confidence level (CL) of 95% in an estimated sample population of 1 million registered doctors and nurses in the United Kingdom (UK) were used to calculate the sample size. After determining the sample size, emergent issues from the extensive literature review were used for the synthesis of the questionnaires for this study. In addition, informed consent was sought for voluntary participation, and assurances were provided to respondents of their rights of withdrawal at any point while the protection of their privacy and upholding their confidentiality were utmost priorities.

The questionnaires, along with accompanying cover letters and consent forms (see appendix for samples of questionnaires, participant information sheet, and a consent form) were distributed to healthcare professionals, i.e., doctors, nurses, and healthcare assistants working in the medical ward and the intensive care ward at the Rotherham Foundation Trust, Rotherham, UK between February 2019 and December 2019. During that period, 120 questionnaires were handed out in person to the workers in the trust; the response rate was approximately 61.7% because only 74 questionnaires were returned, albeit 4 of the 74 were also partially completed. To achieve the necessary sample size, the conversion of the questionnaire into electronic format was achieved via the Survey Monkey website, and the website link was subsequently sent to additional 56 healthcare practitioners. The link was deactivated following the attainment of the predetermined sample size of ninety-six participants and the analysis commenced. Anybody who verbally declined to participate in the research was not included, and it was made clear to everyone that if at any point after collecting the questionnaires, they change their minds regarding participation for any reason, they can return the questionnaire unfilled or destroy it by themselves.

The questionnaire was accompanied by an information leaflet that contained vital information about the research. After reading the information sheet, the participant decided whether to go proceed with the study. If they were happy to be involved in the study, they were required to sign the consent form; for those who completed the questionnaire electronically, it was made clear that the submission of their response would be regarded as consent. The consent form was submitted separately from the questionnaires. The right not to take part, and to withdraw the participant's data from the project was made known to the participants, and they were told that they did not have to give any reasons for exercising such rights and that there would be no repercussions for doing so. There seemed to be a lot of interest in the subject topic and many of the participants said the questions were thought-provoking and that there are some things in the questionnaire that they had never thought about. Most of the informal feedback from the survey was very encouraging although there were some critical feedback on some of the controversies explored in the survey.

1.6. Thesis structure.

The thesis comprises this introductory chapter and five substantive chapters. The first substantive chapter, chapter two, covers the theory of the knowledge of PVS as a concept concerning its scope and validity and the philosophy of how it is related to consciousness or lack of consciousness. This chapter critically examines how clinicians see the clinical diagnosis and management of PVS as a condition. There is also an exploration of the various assumptions of how the physical element, the brain, is related to the mental element, the mind, or consciousness. It also offers the clinical perspective and the philosophical perspective on the mind and consciousness. Finally, it is proposed that a principled approach should be taken in the form of theory to define consciousness in people with brain injuries. Chapter three explores a variety of ethical principles and theories of philosophy that underpin the making of decisions on behalf of vulnerable adults that lack mental capacity, including those perceived to be experiencing a PVS. Particularly, the analysis of four distinct decision-making models is presented with critical appraisals of their merits and demerits. The models explored were the principlism approach, normative ethical approach, inherent worth-based approach, and human rights approach. Subsequently, the respect for human dignity and personhood approach (inherent worth-based) is proposed and used to set a benchmark for the critique of the law regarding WWLSI in people labelled as in PVS. Chapter four uses the benchmarks produced in chapter three to evaluate the law from both the chronological and technical perspectives. It concludes that the law as it is in the UK does not adequately safeguard the interests and rights of patients diagnosed in PVS. Chapter five details the original empirical research into the opinion of healthcare practitioners working in the NHS on the concept of PVS and the practice and governance of WWLSI in patients labelled as PVS. Lastly, chapter six discusses the thesis findings, conclusions, and recommendations.

1.7. Limitations of the research.

The healthcare perspectives in the empirical aspect were from a modest number of participants. Time constraints and limited resources played a big factor in limiting the sample size to a manageable level. However, with the sample size calculation made before the study started, the statistical significance of the result was pre-determined in line with the criteria adopted. Another limitation is in the scope of the empirical aspect of the research which did not include PVS patients or relatives as it would have been interesting to see the difference between the views of this cohort with the ones conducted in this study. The predicament in accessing these subjects and the constraints on time and resources meant that the scope of this study has to be limited to only healthcare professionals. Finally, the role of healthcare financing is crucial to the treatment options available to patients in the UK. Getting opinions from people working in clinical commissioning groups would have been another valuable perspective to understanding the way the policy makers treat PVS and how it affects the law and their clinical care.

CHAPTER TWO

The ‘PVS’ and the Critique of the Label

2.1. Introduction

For some time, it has been clinically normative to describe people who, in the aftermath of acute severe brain damage, are viewed following testing to be unaware of their surroundings as vegetative and are described as having a PVS where this situation is enduring.[49] PVS is often in turn categorised as a form of so-called PDoC.[50] Whilst it is widely accepted that sometimes a person may wrongly be labelled or continue to be labelled vegetative, it is also generally accepted by the medical establishment that a state of lack of awareness does exist and can, in fact, be diagnosed.[51] Ernst Kretschmer first described the condition now referred to as VS in 1940, referring to it as ‘apallic syndrome’.[52] A few years later in 1963, Arnaud and his colleagues referred to patients with a severe head injury as *‘vie végétative’*.[53] However, these attempted definitions were without descriptions of clinical features until 1972 when Jennett and Plum gave descriptions of what is today referred to as VS and proposed the concept of PVS.[54] In this, they stated that the distinction between the two terms was that patients in the VS could ascend from the state of coma to consciousness while those in the PVS had very little to no chances of regaining consciousness.[55] They also acknowledged conceded the presence of other related conditions. In 1982, the terms "persistent" and "permanent" were further redefined

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[49] Adam Boardman and Ganesh Bavikatte, ‘An overview of prolonged disorders of consciousness for the General Practitioner’ (2020) 13(1) BJMP < https://bjmp.org/files/2020-13-1/bjmp-2020-13-1-a007.pdf > accessed 25 May 2021.

[50] Ibid.

[51] Ronald Cranford, ‘Misdiagnosing the persistent vegetative state’ (1996) 313(5) BMJ <https://doi.org/10.1136/bmj.313.7048.5> accessed 2 May 2021.

[52] Ernst Kretschmer, ‘Das apallishe Syndrom’ (1940) 169(1) Zeitschrift Für Die Gesamte Neurologie Und Psychiatrie <https://doi.org/10.1007/BF02871384 > accessed 5 August 2020.

[53] Marcel Arnaud and others, ‘Etats frontières entre la vie et la mort en neuro-traumatologie,’ (1963) 6(1) min - Minimally Invasive Neurosurgery <http://doi: 10.1055/s-0028-1095424> accessed 5 August 2020.

[54] Jaak Panksepp and others, ‘Does any aspect of mind survive brain damage that typically leads to a persistent vegetative state? Ethical considerations’ (2007) 32(2) Philosophy, Ethics, and Humanities in Medicine <https://doi.org/10.1186/1747-5341-2-32> accessed 3 February 2021.

[55] Jennett and Plum (n 6).

to create a distinction.[56] This distinction was based on the probability of recovering from VS that had lasted for a period.

In 1991, the MSTF on PVS provided clinical and ethical guidance on diagnosing and treating this condition.[57] The criteria drawn by the task force remain the basis for classifying patients diagnosed with the condition. The main issue with these characterisations is that the guidance took a medical reductionist approach without giving a broad explanation of how consciousness is lost or regained in these individuals or how the lack of evidence of consciousness is regarded as evidence for its absence. Therefore, the lack of evidence of interactive ability is treated as a lack of consciousness which in turn discounts the possibility that the patient has an inner life. Moreover, some researchers have questioned the degree of bias in the evidence provided.[58] In this chapter, a more holistic approach to the critique of the concept of PVS is taken. It covers the theory of the knowledge of PVS as a concept regarding its scope and validity and how it is related to (un)consciousness. Additionally, there is a critical evaluation of the manner in which the clinicians see the clinical diagnosis and the subsequent management of PVS as a condition. Furthermore, there is an exploration of the various assumptions of how the physical element, the brain is related to the mental element, the mind or consciousness. It is then pointed out that the condition's characterisation is based on dubious suppositions about the nature of - and relationship between – consciousness and the brain and the nature of human beings more broadly and has a few specific problems with it. The final section offers the clinical and philosophical perspectives of PVS concerning the mind and the conscious mental state. Finally, a suggestion is proposed that involved taking a principled approach in the form of theory to defining consciousness in people with brain injuries.

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[56] Fred Plum and Jerome Posner, *The diagnosis of Stupor and Coma* (Philadelphia: FA Davis, 1982).

[57] The Multi-Society Task Force on PVS (n 9).

[58] Andrew Haig, 'The Persistent Vegetative State' (1994) 331(20) NEJM <https://doi.org/10.1056/NEJM199411173312015> accessed 3 May 2021.

2.2. PVS as a Clinical syndrome.

A *clinical syndrome* is defined as a collection of clinical features (symptoms and signs) used to identify a particular disease or condition.[59] In principle, these manifestations in patients diagnosed as PVS should be the direct consequence of the injury to the brain. While these manifestations might not be said to be wrong per se, the criticism of the condition lies in the conceptualisation of PVS. Therefore, understanding the clinical features of this condition would help provide clarity on what we can say we know for certain about this concept and what we do not know about it. In the extant literature, there are a few definitions of 'PVS', both in the legal and medical spheres but it appears that the legal status of the state is not well defined in several states including the UK, Canada, Australia, and the US. This is mainly attributed to the nature of debates surrounding issues pertaining to death, such as who is responsible for terminating life, and which conditions allow for termination of the life?[60] The so-called 'VS' is defined in reference to the lack of responsiveness to the environment with inconsistent and non-reproducible wakefulness. However, the understanding of 'PVS' is contingent on evidence-based information on how 'VS' is considered permanent or persistent. The word permanence refers to a word that refers to a state of affairs that is fixed rather than amenable to change. Within the context of a clinical diagnosis, it, therefore, implies irreversibility.[61] Persistent on the other hand, refers to a situation that has endured for a period of time and may continue to do but is also capable of coming to an end.

The use of persistent and permanent to qualify VS has been confusing since the MSTF on PVS brought out the twelve-month timeframe for reversibility in people diagnosed as VS.

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[59] Franz Calvo and others, (2003). 'Diagnoses, syndromes, and diseases: a knowledge representation problem' (2003) 802 AMIA Annual Symposium proceedings <https://ncbi.nlm.nih.gov/pmc/articles/PMC1480257/> accessed 16 July 2021.

[60] Royal College of Physicians, *Prolonged Disorder of Consciousness- National Clinical Guideline* (Royal College of Physicians 2013).

[61] Jennett and Plum (n 6).

The word ‘persistent’ as used in reference to the vegetative state means prolonged over a duration, whereas ‘permanent’ is defined to mean that it cannot be reversed through any means. While Jennett and Plum applied the term in a precise manner, some nebulousness has always prevailed on what the term means. First, "persistent" is an adjective referring specifically to a medical condition probably from the past and which has a perpetuating disability whose future course is uncertain.[62] Accordingly, the Persistent (VS) is described as an unconscious state whereby the patient remains wakeful and this state lasts longer than four weeks.[63] On the other hand, a permanent (VS) also implies that the condition cannot be reversed.[64] The idea is that clinical diagnoses in this field of medical practice have a basis on probabilities rather than absolution. Thus, an individual who is in a coma is labelled as being in a permanent (VS) only when there is irrefutable confirmation of an irreversible state, in which case, the chances of the individual regaining the state of consciousness in the future are almost non-existent.[65]

Modern orthodoxy with respect to patients labelled as a VS is to view them as capable of recovery. Therefore, the term persistent is typically preferred to the term permanent to describe the condition of those who are viewed as having been for a significant period. However, even after this development, the PVS label may not be impervious to criticisms because it is misleading in its suggestion of loss of upper brain function and resultant loss of awareness: It cannot be stated with certitude that these patients lack awareness since tests only confirm lack of evidence of awareness. Possibly, the available tests are not sophisticated enough to demonstrate awareness in these patients or even that awareness is not something that can be measured.

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[62] Steven Laureys and Melanie Boly, ‘What is it like to be vegetative or minimally conscious’ (2007) 20(6) Current Opinion in Neurology < https://doi.org/10.1097/WCO.0b013e3282f1d6dd.> accessed 2 February 2021.

[63] Royal College of Physicians, *Prolonged disorders of consciousness following sudden onset brain injury: National clinical guidelines* (RCP 2020).

[64] Takamitsu Yamamoto and others, ‘DBS therapy for the vegetative state and minimally conscious state’ (2005) 93 < https://pubmed.ncbi.nlm.nih.gov/15986737/> accessed 2 February 2021.

[65] Royal College of Physicians. Prolonged disorders of consciousness following sudden onset brain injury National clinical guidelines. London: RCP, 2020.

PVS diagnosis criteria and the clinical behaviour.

The MSTF on PVS laid down the criteria for diagnosing PVS as follows:[66]

1. When the patient exhibits no behavioural indication of awareness of the surroundings and the patients themselves.[67] It can be argued that the inability of the examiner to witness or evidence any behavioural activities in the patient is not enough to claim that the patient lacks consciousness.
2. When the patient is unable to produce an intentional response to stimuli from the examiner.[68] These stimuli include sensory inputs to any of the five senses (touch, smell, visual, gustatory, or auditory). The diagnosis criteria suggest that this response should be purposeful, sustained, and reproducible. However, the shortcoming of this criterium is that the inability of the examiner to elicit this response may potentially be an afferent or efferent pathway problem rather than a consciousness issue.
3. The patient's inability to comprehend or express language.[69] It might sound straightforward to say that if someone is able to speak or understand instruction from the examiner surely, then he or she is conscious. However, the inability of the patient to do this task does not necessarily confirm the absence of consciousness.
4. Evidence of intermittent wakefulness in the patient which will signify that the patient has sleep-wake cycles.[70] This feature is easy to observe in patients because it is a positive finding, unlike the three above criteria. The patients can be observed to open their eyes like they are awake sometimes and at other times, they will close their eyes like they are sleeping.

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[66] MSTF on PVS (n 9).

[67] Ibid.

[68] Bruce Day, The persistent vegetative state (prolonged post-coma unresponsiveness) and post-hypoxic brain injury. in Anthony Schapira (ed), Neurology and Clinical Neuroscience (Mosby 2007) 117.

[69] Ibid.

[70] Ibid.

5. There should be evidence of a functioning hypothalamus and brainstem which modulate the autonomic function of the body which in principle allows the patient to survive with minimal medical support and nursing care.[71] These functions can be objectively evidenced with examination and neuroimaging.
6. The patients will usually have urinary and faecal incontinence.[72] The idea behind this criterium is that the patients lack voluntary control of their bladder and bowel and that these functions are driven by the autonomic nervous system. The shortfall of this observation is that a fully conscious patient can have urinary and faecal incontinence.
7. There should be variably preservation of both the spinal and the cranial nerve reflexes which are modulated by the autonomic nervous system. This feature does not tell us anything about the consciousness of these individuals.

Bioethicists have argued that the determination of lack of consciousness in patients using these criteria is more likely an educated guess rather than evidence-based.[73] This is because the response to be elicited when making a diagnosis is contingent on the individual's willingness and/or ability to respond to the doctor.[74] Beyond this, the doctor's ability to accurately evince and appreciate the response to these criteria is very significant, especially when the available assessment tools are not very reliable in assessing consciousness.[75]

Medical Issues

The prognosis of PVS has been on default mode for many years, which implied that if twelve months had passed after the initial injury to the patients' brain, then they would have no chance of recovery and regaining reasonable brain function. However, recent advances and

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[71] MSTF on PVS (n 9).
[72] Day (n 68).
[73] Keith Andrews, 'The vegetative state – clinical diagnosis' (1999) 75(884) Postgraduate Medical Journal <https://doi.org/10.1136/pgmj.75.884.321> accessed 18 July 2021.
[74] Ibid.
[75] Ibid.

related cases show compelling evidence that point to a direction suggesting the need to review this notion.[76] Research has found evidence suggesting the need to clarify this misconception. An example is a study in 2010 that involved 50 patients diagnosed with PVS. The researchers followed the progress of these patients for two years. Importantly, 20% of these patients representing a figure of 10 patients regained minimal consciousness. A further six patients (12%) progressed to normal consciousness. Although this research is laudable, it did not consider the aetiology of the brain injury. However, these findings do support the need for a reappraisal of the 'PVS' concept.[77] Regardless of the issues with the diagnosis of 'PVS' and its conceptualisation, the patients still have some medical issues for which various researchers have proffered a plethora of care and management practices.

The initial care commences during the diagnosis process, and must never be provided in haste.[78] During the diagnosis sessions and subsequent periods, the patients should be given full medical care benefits such as proper nutrition, and surgery, if deemed fit, and necessary in order to alleviate the condition. Nursing care provided by a qualified and registered nursing practitioner is necessary to avoid undesirable complications arising due to the course of treatment. The patients are unable to eat or feed on their own, but proper and adequate nutrition should be provided through the aid of a percutaneous endoscopic tube, which forms part of a basic nursing care. The skin of the patient must also be duly attended to. For those patients who can regain consciousness, the physicians usually prefer an early and intensive rehabilitation of the neurological system. Any form of treatment provided must be carried out in the patient's best interests. Managing these patients at home is a very onerous process owing to the level of care and support they need.[79] Studies have shown that VS patients survive for anywhere

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[76] Gastone Celesia, 'Persistent Vegetative State: Clinical and Ethical Issues' (1997) 18(1) Theoretical Medicine <https://doi.org/10.1023/A:1005709410296> accessed 3 April 2021.

[77] Estraneo and others (n 31).

[78] Ibid.

[79] Fateme Goudarzi and others, 'The Resilient Care of Patients with Vegetative State at Home: A Grounded Theory' (2018) 7(3) Journal of caring sciences <https://doi.org/10.15171/jcs.2018.026> accessed 1 May 2021.

between two to five years following a head injury on average, but some of them can live for up to ten years or even more.[80]

The acute treatment of a comatose patient and someone deemed in a vegetative state is similar in many ways.[81] From the nursing perspective, both patients would require nutrition and hydration and they would require some sort of assistance because of their state of unconsciousness. Patients in both conditions are unable to move their jaws, tongue, and swallow food, although their digestive system remains fully functional.[82] Therefore, water and food are provided through a gastrostomy tube in proportions that match their metabolic demands.[83] PVS patients generally would not require assistance with ventilation unlike those in a coma. Sometimes they only require airways adjuncts for the protection and stabilisation of their airways which include nasopharyngeal and oropharyngeal airways.[84] Moreover, due to their inability, the patients also require nursing care to maintain the integrity of their skin. To prevent the occurrence of pressure sores, they are required to be placed in specialised beds and turned systematically on a regular basis. The development of ulcers would ultimately lead to the patient contracting secondary infections that may further deteriorate the quality of their health.[85] Patients diagnosed as PVS tend to develop recurrent chest and urinary infections.[86] These infections are managed with antibiotics. Most PVS patients are usually medically stable,

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[80] Bryan Jennett, 'Thirty years of the vegetative state: clinical, ethical and legal problems' (2005) 150 Progress in brain research < https://doi.org/10.1016/S0079-6123(05)50037-2> accessed 5 May 2021; Paola Chiambretto and others, 'Prolonged grief and depression in caregivers of patients in vegetative state' [2010] 24(4) Brain injury <https://doi.org/10.3109/02699051003610490> accessed 5 May 2021.

[81] The Multi-Society Task Force on PVS (n 9).

[82] Jennet and Plum (n 6).

[83] Ronald Hamel and James Walter, *Artificial nutrition and hydration and the permanently unconscious patient: The catholic debate* (Georgetown University Press 2007) 18-20.

[84] The Multi-Society Task Force on PVS (n 9).

[85] John Whyte and Risa Nakase-Richardson, 'Disorders of consciousness: Outcomes, comorbidities, and care needs' (2013) 94(10) Archives of Physical Médicine and Réhabilitation <www.archives-pmr.org/article/S0003-9993(13)00525-X/fulltext> accessed 2 February 2021.

[86] Damian Cruse and others, 'Bedside detection of awareness in the vegetative state : A cohort study' (2011) 378(9809) Lancet <www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)61224-5/fulltext>accessed 2 February 2021.

which is why the only life-sustaining treatment they require is CANH along with occasional antibiotics.[87]

The above issues are related to caring for these patients, which can be straightforward. However, when it comes to the reversibility of consciousness vs. personhood, there are variations in approach to caring for them. When the entire brain losses its function every expert agrees that the process is called brain death - however, if only the cerebral function is lost, the use of the concept of cortical brain death is not generally agreed on.[88] Some people have likened the existence of PVS to 'been dead but the body is still alive'.[89] In the past, there have been changing definitions of death and a significant difference in the way death is defined by doctors and by the Court. In light of these observations, what then should be an acceptable degree of accuracy in the diagnosis of PVS and what should the requisite standard of proof be to make this diagnosis? Given that the decision at hand is about life and death, the advocacy for a close to hundred percent accuracy becomes mandatory. It also becomes pertinent to ask if the Court's legal test for diagnosis remains the highest level of proof that is "beyond reasonable doubt?"

2.3. Background to the concept of 'PVS'.

Many experts assert that patients deemed to be in a PVS are unable to interact with their environment because they lack consciousness. The notion of consciousness with respect to PVS seems to be a view solely from a physiological perspective by the medical profession. William James described "Consciousness" in the year 1890 as a stream of thoughts or ideas and that our ability to pay attention to one thing or the other in this stream is the active element

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[87] The Multi-Society Task Force on PVS (n 9).

[88] Frank Shann, 'A Personal Comment: Whole Brain Death versus Cortical Death' (1995) 23(1) Anaesthesia and Intensive Care <https://journals.sagepub.com/doi/pdf/10.1177/0310057X9502300103> accessed 2 February 2021.

[89] Ibid.

of all consciousness.[90] Therefore, it is not farfetched to infer that according to his postulation, this stream of thoughts is always present whether one is in a dream or dreamless sleep, under anaesthesia, in coma, and perhaps in the so-called VS. His view was mainly from a psychological or metaphysical perspective although he also acknowledged the involvement of a philosophical perspective to consciousness.[91] Trying to marry the physiological perspective of consciousness to the metaphysical perspective in order to explain the concept of PVS has given rise to many difficult questions. In the literature, there are many studies that look into the challenging question of consciousness, but none has been able to give a definitive answer about how the concept works.[92] Neuroscientists give some plausible explanations about consciousness from the physiological perspective through various theories while philosophers also theorise about consciousness from the metaphysical perspective. Despite this, not enough is known or understood to make clear conclusions about these two approaches. However, conclusions on such issues are needed; this will be dealt with later in this chapter. Cognitive experiences encompass one's thoughts, memories, feelings, and sensations in relation to the environment. Many believe that consciousness requires arousal, whereas awareness requires full brain functionality.[93] However, there is overwhelming evidence that consciousness is not confined to a particular structure or region in the brain. In practice, it is rather unnerving to measure the absence of consciousness therefore, making the use of only neuroscience to explain the concept of PVS is a herculean task. The diagnosis of PVS is solely predicated on an assessment of behavioural responses, which involves a complex interplay of clinical processes in the human body. The contemporary advances in neurophysiologic studies can only

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[90] Russell Goodman, 'William James' [2017] *The Stanford Encyclopedia of philosophy* <https://plato.stanford.edu/archives/win2017/entries/james/> accessed 21 September 2020.

[91] Ibid.

[92] Daniel Dennett, 'Facing up to the hard question of consciousness' (2018) 373(1755) Phil. Trans. R. Soc. B <https://doi.org/10.1098/rstb.2017.0342> accessed 13 July 2021.

[93] Christine Blume and others, 'Across the consciousness continuum—from unresponsive wakefulness to sleep' (2015) 9(105) Frontiers in Human Neuroscience <https://www.frontiersin.org/article/10.3389/fnhum.2015.00105> accessed 1 June 2021.

be at best supportive.[94] The understanding of the philosophy of the mind is inescapably important in this regard.

Epistemologically, the relationship between the brain, the mind, and consciousness remains fundamentally unresolved. It is unclear which specific pathway in the brain is responsible for human consciousness. Some experts posit that the upper part of the brain is crucial for conscious awareness; however, others opine that this evidence is weak and that there is evidence of subcortical mediation of consciousness.[95] A study in 1999 demonstrated clinical evidence of conscious awareness in four children born without cerebral cortex (labelled as developmental VS).[96] Other related studies have suggested that the RAS in the brainstem is the brain part responsible for consciousness.[97] However, significantly, few in or outside the profession would regard the loss of upper brain function as equating to brain death.[98] The definition of brain death has changed over the years. According to the latest consensus, when there are no brain stem activities and an EEG shows no cortical activities above two microvolts after a brain injury, then the individual is said to have Electro-Cerebral Inactivity (ECI), which literally means that such a person is brain dead.[99] For both medical and legal purposes, such an individual is presumed to be clinically dead. Meanwhile, the World Health Organization (WHO) states that the other way to diagnose death is circulatory death when there is irreversible circulatory collapse.[100] On the other hand, if the brain stem reflexes are intact but the individual

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[94] Adrian Owen and others, ‘Detecting awareness in the vegetative state’ (2006) 313(5792) Science <https://doi.org/10.1126/science.1130197 >accessed 15 May 2021.

[95] Emily Sohn, ‘Decoding the neuroscience of consciousness’ (2019) 571 Nature <https://doi.org/10.1038/d41586-019-02207-1> accessed 1 June 2021.

[96] Alan Shewmon and others, ‘Consciousness in congenitally decorticate children: developmental vegetative state as self-fulfilling prophecy’ (1999) 41 Developmental Medicine & Child Neurology <https://onlinelibrary.wiley.com/doi/pdf/10.1111/j.1469-8749.1999.tb00621.x > accessed 14 July 2021.

[97] Sung Jang and others 2021 (n 13).

[98] Ofra Golan and Esther-Lee Marcus, 'Should we provide life-sustaining treatments to patients with permanent loss of cognitive capacities?' (2012) 3(3) Rambam Maimonides Medical Journal <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3678818/> accessed 15 June 2021.

[99] Seo-Young Lee and other, ‘Electroencephalography for the diagnosis of brain death’ (2017) 19(2) Annals of Clinical Neurophysiology < https://doi.org/10.14253/acn.2017.19.2.118> accessed 22 September 2020.

[100] Alex Manara and Ian Thomas, ‘Current status of organ donation after brain death in the UK’ (2020) 75(9) Anaesthesia <https://doi.org/10.1111/anae.15038> accessed 22 September 2020.

appears to be unable to interact with the environment, then they are said to be in VS.[101] Historically, PVS was sometimes used to denote a permanent vegetative state, but it has become evident that some patients who have been deemed vegetative have gone on to show purposeful goal directed behaviours after some time.[102] This has led to the P being widely used to denote persistent instead. The controversy around PVS was not limited to what P stands for in PVS. Many issues regarding misdiagnosis prompted the Aspen Neurobehavioral Conference Work Group to add another conceptual category of MCS.[103]

Patients who exhibit inconsistent but well-defined features of awareness were labelled MCS.[104] By contrast, a coma can be described as a deep state of unconsciousness that lives a person unresponsive for a limited duration that does not exceed two months.[105] In a coma, a person is viewed as unable to respond to his or her surroundings, including any stimuli that it produces, and, importantly, is unable to be awakened.[106] Thus, it is easy to view coma as the direct opposite of how we typically define consciousness in a medical sense.[107] However, even here, we might say there is room for debate – with some authors suggesting that simplifying consciousness and unconsciousness as opposites of each other might be misleading and that it is better to understand them quantitatively instead.[108] William James proposed that introspection, which is a psychological way of examining one's own conscious thought and

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[101] Maria Inzaghi and Matteo Sozzi, 'The altered state of consciousness: Clinical assessment and monitoring' (2011) 10(1) Neuropsychological Trends < www.semanticscholar.org/paper/The-altered-state-of-consciousness-%3A-clinical-and-Inzaghi-Sozzi/cbbd54708581c7bd6a5620bc984d734d867f85c2> accessed 22 September 2020.

[102] Schnakers and others (n 23).

[103] Ronald Cranford, 'What is a minimally conscious state?' (2002) 176(2) The Western journal of medicine < https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1071686/> accessed 22 September 2020.

[104] Ibid.

[105] Gastone Celesia, 'Persistent Vegetative State' (1993) 43(8) Neurology <https://n.neurology.org/content/43/8/1457> accessed 22 September 2020.

[106] Athena Demertzi and others, 'Coma, persistent vegetative state and diminished consciousness' (2009) 1 Encyclopedia of Consciousness < http://coma.ulg.ac.be/papers/vs/demertzi_VS2009.pdf> accessed 22 September 2020.

[107] Plum and Posner (n 56).

[108] Jacob Sitt and others, 'Ripples of consciousness' (2013) 17(11) Trends in Cognitive Sciences <https://pubmed.ncbi.nlm.nih.gov/24094796/> accessed 22 September 2020.

feeling, could detect consciousness.[109] Although many people have criticised that this approach is an unscientific way to measure or confirm consciousness, it remains the only fundamental way to track or define consciousness.[110] The question at this juncture is whether the notion of conscious or consciousness is different in the way we talk about it psychologically where it is associated with being thoughtful, reflective, and even spiritual to the way one might talk about it in a 'basic medical sense'. What exactly are we looking for in this basic medical sense? Is it merely about having the capacity to think or also awareness of one's environment? The ability to think hinges on the cognitive function of the brain, which involves both conscious and non-conscious processes while the ability to be aware of the environment is contingent on our basic senses.[111]

The fundamental question one would ask is that in labelling people, as in a PVS are we saying that they lack consciousness? If that is the case, then what have we tested? Is it the ability to think or awareness of one's environment? Can we say that the testing can accurately measure either parameter? Furthermore, how can a third party know that an individual is conscious when the person in question is unable to talk or express any feelings? What should be the criteria for assigning consciousness to patients in PDoC? The term, PDoC is a diffuse and general label than PVS, more interestingly; it is unclear what the term refers to in the absence of a properly understood relationship between the brain and consciousness. It becomes apparent that something is happening with the brain and its relationship with one's awareness. Nevertheless, we cannot separate these questions from how the profession defines an individual as 'human'. For example, if one is a kind of deterministic biological reductionist, one might describe consciousness as simply an emanation from the brain and dependent on its function -

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[109] Bruce Mangan, Cognition, fringe consciousness, and the legacy of William James. in Max Velmans and Susan Schneider (eds), The Blackwell Companion to Consciousness (Blackwell 2007) 671-685.

[110] David Rosenthal, 'Two Concepts of Consciousness' (1986) 49(3) Philosophical Studies <www.jstor.org/stable/4319832> accessed 23 September 2020.

[111] Sohn (n 95).

this seems to still be the dominant medical model of consciousness that is being used today.[112] Conversely, if one is of the view that we are essentially spiritual beings characterised by an awareness that is not bounded or finite (in time, space, or knowledge) and that the body is simply an aspect of creation then, the relationship between awareness and brain would be something different. Therefore, what we label different states and different disorders of consciousness would have to be understood differently.

The medical profession opines that there are three PDoC along the spectrum of consciousness. One of these disorders which seems to be somewhere at the worst end of the spectrum is characterized as VS, the other two are coma and MCS.[113] Medical experts diagnose VS when a patient is able to open his/her eyes intermittently without any evidence of purposeful eye contact after emerging out of a coma.[114] However, the diagnosis changes to MCS as soon as the patient begins to exhibit a reproducible purposeful behaviour like visual fixation, ocular pursuit movement, or the ability to follow simple commands.[115] While it is difficult to make an accurate guess on the level of consciousness that is lost or retained in patients with brain damage, the general assumption is that an MCS individual is likely to have some degree of ordered integrative processes in the brain, which is necessary for gaining conscious auditory perception. On the other hand, some experts defined VS as a state of partial arousal with no awareness of the environment.[116] Notably, the characteristic attributed to the condition by the medical profession is the loss of higher cortical function.

The MSTF on PVS proposed changing the diagnosis to PVS when an individual remains in VS for twelve months when the brain injury is due to trauma, or six months when it is due

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[112] Boris Kotchoubey,'Human Consciousness: Where is it from and what is it for' (2018) 9 Frontiers in psychology <https://doi.org/10.3389/fpsyg.2018.00567> accessed 14 May 2021.

[113] Inzaghi and Sozzi (n 101).

[114] Keith Andrews, 'the vegetative state – clinical diagnosis' (1999) 75(884) Postgraduate Medical Journal 321 <https://pmj.bmj.com/content/postgradmedj/75/884/321.full.pdf > accessed 23 March 2021.

[115] Dominic Wilkinson and Julian Savulescu, 'Is it better to be minimally conscious than vegetative?' (2013) 39(9) *Journal of Medical Ethics* < https://jme.bmj.com/content/39/9/557.long> accessed 23 September 2020.

[116] Inzaghi and Sozzi (n 101).

to a non-traumatic cause.[117] Although these timeframes are contentious, they continue to be the only yardsticks used in practice to determine reversibility in VS.[118] The peculiar characterisation of this condition is at best controversial. The features and consequently, the medical and legal treatment of the condition have remained fundamentally unchanged over time. The attempts in the past to ascribe names like apallic syndrome, coma vigil, and more recently, unresponsive wakefulness syndrome (UWS) to this category of people have done little in trying to solve the rather complicated issues around the notion of PVS.[119] The medical professionals stopped using the first two names because the term coma vigil seems like a contradiction since patients in coma generally never open their eyes and the term pallic refers to pallium meaning possessing a cortex.[120] Therefore, it will be erroneous to refer to these patients as apallic, meaning without cortex since they still have brain cortex.[121] The term UWS is mainly descriptive therefore, the features and the characteristics of the condition remained fundamentally unchanged.

2.4. The legal process relevant to the withdrawal of life sustaining treatment from PVS patient

In all UK jurisdictions, the law presumes that all adults have the capacity to make decisions and, in turn, the capacity to consent or refuse medical treatment.[122] When there are significant reasons to doubt this presumption, the treating doctor should explore all avenues to

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[117] Multi-Society Task Force on PVS (n 9).

[118] Katja Kuehlmeyer and others, 'Single case reports on late recovery from chronic disorders of consciousness: A systematic review and ethical appraisal' (2013) 6(4) Bioethical Forum < http://www.bioethica-forum.ch/docs/13_4/04_Kuehlmeyer.pdf > accessed 21 January 2021.

[119] Steven Laureys and others, 'Unresponsive wakefulness syndrome: a new name for the vegetative state or apallic syndrome' (2010) 8(68) *BMC medicine* < https://ncbi.nlm.nih.gov/pmc/articles/PMC2987895/> accessed 5 October 2020.

[120] Klaus Von Wild and others, 'Guidelines for quality management of apallic syndrome/ vegetative state' (2007) 33(3) Eur J Trauma Surg. < https://pubmed.ncbi.nlm.nih.gov/26814491/> accessed 5 October 2020.

[121] Ibid.

[122] Mental capacity act 2005.

encourage or assist the patient in making an autonomous decision.[123] The level of capacity in people varies. The degree to which capacity is required is commensurate to the implication the proposed treatment or lack of treatment has on the patient's health.[124] While many may see capacity as a binary option, the boundary between mental capacity and incapacity is blurred in practice. In addition, capacity can vary with time and fluctuate in some people. It is also decision specific.[125] The law provides that practical assistance should be given to patients to maximise their decision-making ability.[126] The assistance includes taking reasonably practicable steps to improve a patient's ability to communicate his or her decision.[127] The prevailing view in the medical and legal fields is that people diagnosed as in a PVS lack capacity. Even if we agree that they retain their consciousness, it is reasonable to assume that their capacity level would be at the lower end of the spectrum. Greater evidence of capacity is required for decisions like WWLSI, which, in turn, has serious implications for the patient.[128] Therefore, this section's discussion will focus on patients diagnosed as in a PVS being treated as adults who lack capacity.

The mental capacity act 2005 covers the legal guidance for decision-making for adults who lack capacity, like individuals with severe brain injury. In England, Wales, and Scotland, there are legal provisions for appointing welfare attorneys and court-appointed deputies who can make treatment decisions on behalf of patients who lack mental capacity.[129] In England and Wales, mentally competent adults over eighteen years can appoint a welfare attorney who

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[123] Ibid.

[124] Mental capacity act code of practice 2007.

[125] NICE UK, 'Decision-making and mental capacity' (Quality standard [QS194], 11 August 2020) <https://www.nice.org.uk/guidance/qs194/chapter/Quality-statement-3-Assessment-of-capacity> accessed 16 July 2022.

[126] NICE UK, 'Decision-making and mental capacity' (NICE guideline [NG108], 03 October 2018) <https://www.nice.org.uk/guidance/ng108> accessed 16 July 2022.

[127] Ibid.

[128] Soumya Hegde and Ratnavalli Ellajosyula, 'Capacity issues and decision-making in dementia' (2016) Annals of Indian Academy of Neurology 19(1) <https://ncbi.nlm.nih.gov/pmc/articles/PMC5109759/> accessed 15 July 2022.

[129] MCA code of practice chapters 7 & 8; The adult with incapacity (Scotland) Act 2000.

can provide or refuse consent to treatment or withdraw treatment on their behalf should they lose capacity.[130] The medical team looking after the patient should consult an attorney (if one is appointed) before life-sustaining treatment can be ceased. Where there is an unresolved disagreement between the welfare attorney and the treating team or the family of the patient, the CoP can be approached for a declaration. The Court can also appoint a deputy to decide on behalf of the patient.[131] When a deputy is appointed, such a person should be consulted about treatment decisions whenever practically possible. If there is still disagreement between the deputy and doctors and they cannot resolve it, the Court of Protection would be contacted to make a ruling on the matter.[132]

In Scotland, mentally competent individuals over the age of sixteen can appoint welfare attorneys who can act as proxy decision makers should they lose capacity.[133] In addition, the sheriff court has the authority to appoint a welfare guardian.[134] Both appointees have the legal power to consent on behalf of the incapable adult and must be consulted whenever possible.[135] Attorneys may also refuse or withhold treatment consent if it follows the general principles of The Adults with Incapacity Act 2000. Doctors treating patients who lack capacity may not override the refusal of a welfare attorney to give consent on behalf of the patient unless the Mental Welfare Commission of Scotland is asked to nominate a medical practitioner who can provide a second opinion.[136] When there is a disagreement on what is in the patient's best interests, the treating team can make an application to the sheriff for a declaration.[137]

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[130] MCA code of practice chapter 7.

[131] Ibid chapter 8.

[132] Ibid.

[133] British Medical Association, *Medical treatment for adults with incapacity: Guidance on ethical and medico-legal issues in Scotland* (2nd edition BMA London 2002).

[134] The adult with incapacity (Scotland) Act 2000.

[135] Ibid.

[136] Adults with incapacity Act 2000: code of practice for local authorities.

[137] Ibid.

In England and Wales, doctors must acknowledge and respect the patient's valid advanced directive to refuse life-sustaining treatment, including ANH.[138] The refusal of a particular treatment stated in the document does not extend to other treatments unless expressly stated. Although the advanced refusal of certain basic care like AHN is not binding on the doctors, they must still exercise their clinical judgment to decide what is in the patient's best interests.[139] There are some criteria that the directive has to meet for it to be valid. These criteria are set out in the MCA code of practice. Where there is ambiguity surrounding the validity of the advanced decision, enquiries can be made, or even applications can be made to the Court of Protection.[140] Family members or those close to the patient have no power to override a valid advance decision made by the patient. The MCA code of practice supports preservation of life wherever possible therefore, medical practitioners should always consider written requests to offer LSI like ANH. However, the code does recognise that there are some situations where the provision of such treatment would not be counterproductive.[141] Therefore, the doctors are not obliged to comply with an advance decision requesting life-sustaining treatment.

When determining the patient's best interest, the doctors should consider the general spirit, tone, and wording of an advance decision document.[142] In Scotland, the statute only covers advanced decisions concerning mental health disorder treatment.[143] However, the Code of Practice issued under the Adults with Incapacity Act states that an advanced statement made by someone competent can be used as evidence of the patient's wishes.[144] Similarly, in Northern Ireland, there is no statute regarding advanced decisions about medical treatments. This aspect of law is governed by common law. The courts in these two jurisdictions are more likely to

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[138] MCA 2005 code of practice chapter 9.

[139] Ibid.

[140] MCA 2005 code of practice chapter 8.

[141] MCA 2005 Code of practice chapter 5.

[142] Ibid.

[143] Adults with incapacity Act 2000.

[144] Scottish Executive, Adult with Incapacity (Scotland) Act 2000 Code of Practice for Persons Authorised to Carry Out Medical Treatment or Research under part 5 of the Act. SE/2002/73 (2002) [para 2.29].

take the same approach as England, which postulates that a valid advanced refusal of treatment has the same legal standing as a contemporaneous refusal.[145] When a patient has no LPA, court-appointed deputy, or advanced care directive or decision, treatment may be withdrawn if it is in their best interests. The health care professionals are required to take all necessary steps to assess what is in the patient's best interests.[146] The assessment involved considering previously expressed views and wishes of the patient, which can be obtained through those close to the person. In England and Wales, where the patient has no relatives or friends, the MCA provides that an Independent Mental Capacity Advocate (IMCA) must be involved in the decision-making.[147] Every NHS body or local authority is legally obligated to establish an IMCA service that can provide representation and support to adults who lack mental capacity and who do not have friends or relatives to speak on their behalf.[148] When 'serious medical treatment' such as withdrawing life-sustaining treatment in PVS is contemplated, IMCA must be consulted. IMCAs cannot consent on behalf of PVS patients, but the doctors should always seek their views when assessing patient's best interests.

In Scotland, treatment may be given provided the proposal per the principles of the Adults with Incapacity (Scotland) Act. There is no legal guidance in Scotland on WWLSI in patients that are not diagnosed with PVS or not imminently dying. Until 2018, doctors were legally required to obtain a court declaration before withdrawing life-sustaining treatment in patients diagnosed as PVS.[149] In Scotland, applying to the court for all cases of withdrawal of ANH from PVS patients is gratuitous. The Court of Session adjudicate these cases, but there is no formal legal requirement to refer such case to the court. Where the treating doctors are granted the authority to withdraw life-sustaining treatment by the court, they are immune from

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[145] In re T (Adult: Refusal of Treatment): CA [1992] 4 All ER 649, [1992] 3 WLR 782, [1993] Fam 95.

[146] MCA 2005.

[147] MCA 2005 Code of practice chapter 10.

[148] Ibid.

[149] An NHS Trust and others (Respondents) v Y (by his litigation friend, the Official Solicitor) and another (Appellant) [2018] UKSC 46.

prosecution. It is understandable why doctors would prefer to apply for a declaration where doubt exists. The situation regarding WWLSI in Northern Ireland is similar to England and Wales.

In summary, decision-making in PVS follows the same process as other patients who lack capacity. Healthcare professionals will follow a valid advanced directive to refuse life-sustaining interventions in PVS if one exists. However, if there is no advanced decision by the patient, the doctors will have to involve health care proxies in the form of welfare attorneys, court-appointed deputies, or IMCA. Close friends and relatives are also involved in the decision, although they are not legally allowed to refuse life-saving interventions on behalf of the patient. Where there is a lack of consensus on whether a treatment should be continued or withdrawn, a second opinion can be requested, and legal advice should be sought when in doubt. The codes of practice of the Adults with Incapacity (Scotland) Act and MCA 2005 set out the procedure to follow when deciding on adults who lack capacity. Regardless of the above legal provision, some cases would get to court; either the CoP in England and Whales, Sherriff court in Scotland, or High court in Northern Island. It is necessary to make an application for declaration before the doctors can withdraw LSI. This declaration helps provide clarity on the patient's best interests and protects the doctors from legal challenges.

2.5. Controversies around the concept of PVS and its practical use.

When Bryan Jennett and Fred Plum first described VS as a diagnosis, they defined ‘persistent’ with a timeline of a minimum of one month.[150] The term vegetative in the name referred to the preservation of the vegetative nervous functioning i.e. preserved although variable sleep-wake cycle, respiration, digestion, and thermoregulation.[151] Despite elucidating that these patients are in a PVS, they also cautioned that the name should not mean more than what they intended it to describe.[152] The scrutiny and criticism of the validity of the clinical state by various commentators have given rise to other terminologies in the field of PDoC. These other terminologies reflected a fundamental flaw in the characterisation of the ‘PVS’ label. When it became apparent that some of the patients initially diagnosed with ‘PVS’ were later found to have some interactive abilities, the Aspen Group decided to explain this by carving out a new term of MCS which might actually mark out a different state. The opportunity to question the validity of ‘PVS’ was not accepted. Other alternative terminologies to PVS exist but tend not to question the central assumption of a vegetative state. Examples include UWS and chronic vegetative state.

The feature that creates a distinction in the PVS as opposed to other PDoCs is the irregular and cyclic nature of the sleeping and waking behaviour, without any detectable behaviour.[153] In the literature, there are limited evidence-based criteria for predicting or prognosticating recovery for patients with VS or MCS. The use of ancillary investigations like magnetic resonance imaging (MRI) and EEG has not been so helpful in this regard, as we will see later in this chapter.[154] This is partly attributed to the fact that there is no specific structural neuro-

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[150] Jennett and Plum (n 6).

[151] Laureys and others (n 119).

[152] Ibid.

[153] James Bernat, ‘Chronic disorders of consciousness’ (2006) 8367(9517) Lancet <https://pubmed.ncbi.nlm.nih.gov/16616561/>accessed 21 January 2021.

[154] Andrew Peterson and others, ‘Risk, diagnostic error, and the clinical science of consciousness’ (2015) 7 Neuroimage: Clinical 588 <https://doi.org/10.1016/j.nicl.2015.02.008> accessed 2 February 2021.

pathological pattern in the brain that is pathognomonic of consciousness or awareness. The inability of the technical modalities available to measure objectively consciousness and/or awareness in patients has profound implications on how we treat them. Although these investigations may exclude other conditions, they do not necessarily confirm the diagnosis of PVS.[155]

The main issue then, is whether, in some or all cases, the claimed lack of discernible interactive capability is attributable to not using all the measuring tools at our disposal. Alternatively, the totality of measuring tools available, even if well used, may not be adequate for the task in some or all cases. That is a problem generically inherent to trying to define the absence of anything – if it cannot be found on measuring instruments all that we have proven is that it cannot be found – not that it does not exist. Researchers are currently focusing on objective approaches to diagnosis by exploring electrophysiological and radiological examinations to stimulate deep areas of the brain.[156] This could prove to be supportive of the diagnosis at some stage. While the more dynamic neurophysiologic modalities like fMRI and brain mapping look promising, their role in the routine diagnosis of PVS remains nebulous.[157] Ascribing 'persistent' or more particularly 'permanent' label to VS remains controversial as people regain some functions after months to years of being in VS. In 2017, doctors used a nerve implant to restore consciousness in a man who was said to be in PVS for about fifteen years.[158] Reports like this and many more in the literature have cast doubts in the minds of

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[155] Ibid.

[156] Estraneo and others (n 31).

[157] Hai-bo Di and others, 'Cerebral response to patient's own name in the vegetative and minimally conscious states' (2007) 68(12) Neurology <https://doi.org/10.1212/01.wnl.0000258544.79024.d0> accessed 1 May 2021.

[158] Hannah Devlin, 'Nerve implant restores consciousness' to man in persistent vegetative state' The Guardian (London, 25 September 2017) <www.theguardian.com/science/2017/sep/25/nerve-implant-restores-consciousness-to-man-in-vegetative-state> accessed 9 April 2019.

many people regarding how people deemed to be in the state are allowed to die based on the prognosticating criteria used by the medical profession.

The coma assessment tool used in practice (i.e., the Glasgow coma scale (GCS)) is limited in differentiating between PVS and MCS. Even the more specialised internationally recognised tool called the Revised Coma Recovery Scale (CRS-R) adjudged to be a superior validated scale has its shortcomings when it comes to the differentiation of PVS from MCS.[159] The evidence of this is in the significantly high rate of misdiagnosis of patients in prolonged unconscious state. A research conducted in 2015 compared the accuracy of using the ancillary investigation to diagnose PDoC against the CRS-R scale and the result was not very impressive.[160] The researchers conducted a systematic review of twenty clinical studies, which involved 470 MCS cases and 436 PVS cases to find out the modalities used to differentiate MCS from PVS and to determine the sensitivities and specificities of these tests.[161] They found that the most used techniques were quantitative EEG (90% sensitivity with 95% CI: 69% - 97%; 80% specificity with 95% CI: 66% - 90%); fMRI (44% sensitivity with 95% CI: 19% - 27%) and event-related potential (ERP) recording 59% sensitivity with 95% CI: 26% - 85%).[162] It is noteworthy that these technologies were measured against the supposed gold standard, CRS-R, which is not impervious to flaws. Even the use of positron emission tomography scans with radiotracers only aided the diagnosis in only 85% of cases (95% CI: 77% - 90%).[163] Evidently, the advent of these technologies has not really unravelled the mystery behind the controversies around the concept of PVS.

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[159] Bender and others (n 5).

[160] Ibid.

[161] Ibid.

[162] Ibid.

[163] Ibid.

The lack of coherence in the classification of PVS further widened the division in opinions on how they are treated or allowed to die.[164] Subsequently, their uncertain status as to whether they are dead or alive or in some yet unclassified clinical states has led some commentators to advocate euthanasia for them.[165] If we accept that there is a fundamental flaw in the definition of PVS and that there are other ways we can re-categorise PDoC, then these patients would be treated differently. Another systematic review of 1406 cases of chronic disorders of consciousness between 1997 and 2012 found that the erroneous conception that recovery after an arbitrary timeframe is impossible is not true in all cases.[166] In this study, fifteen patients showed clinically significant improvements in their consciousness level.[167] Similarly, in a study in 2015, a specialist team reclassified up to 43% of patients that the treating teams initially diagnosed as VS into MCS.[168] Whether these patients were misdiagnosed at the outset or they subsequently recovered is debatable. Given many other cases in the literature, is it possible that it is all down to misdiagnosis, or is it now certain that we cannot be sure of permanence even if we eliminate misdiagnosis? Should the residual label of persistent raise some fundamental philosophical questions? Does the notion of vegetative itself imply a state of permanent loss of consciousness? Therefore, would it be more appropriate to ditch the label entirely?

For practice and practical purposes, the regulatory and professional bodies in the UK weighed in on the topic as well. The Royal College of Physicians (RCP) gave guidelines on when to consider PVS as permanent, while the General Medical Council (GMC) gave ethical

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[164] Keith Andrews and others, 'Misdiagnosis of the vegetative state: retrospective study in a rehabilitation unit'(1996) 313(7048) *BMJ* 13.

[165] Stephen Holland, and others, 'Death, treatment decisions and the permanent vegetative state: evidence from families and experts' [2014] 17(3) Med Health Care Philos <www.ncbi.nlm.nih.gov/pmc/articles/PMC4078237/pdf/11019_2013_Article_9540.pdf/?tool=EBI> accessed 21 January 2021.

[166] Kuehlmeyer and others (n 118).

[167] Ibid.

[168] Bender and others (n 5).

guidance to doctors on how to make decisions for PVS patients.[169] Despite providing useful guidance to doctors, these two bodies did not adequately address the controversies around the notion of PVS or permanent vegetative state. All these guidelines did were to echo the legal reasoning in the *Bland* case that was based on the evidence and opinions of medical experts given during the proceedings.[170] Judgments in similar cases relied on the medical opinions and the guidelines given by these professional bodies, which ironically echoed the judgement in *Bland*. In 2010, the GMC attempted to give a more robust guideline on pertinent issues regarding the treatment and feeding PVS patients after the withdrawal of her earlier document in 2001.[171] However, the document failed to address the fundamental question of whether the PVS concept is valid or not. It seems from the document that the council accepted the status quo with its accompanying controversies and flaws. The guidance only gave directions on ethical principles and generals instruction on capacity. The guidance reiterated the express prohibition of mercy killing and assisted suicide concerning the underpinning principles of relevant statutory documents.[172] Despite the perceived improvements in the guidelines, there were many unanswered questions about clinically assisted nutrition and hydration (CANH) in PVS and other similar conditions. Besides, the guideline failed to adequately address other issues like the reliability of the timeframes, whether these patients can feel pain or get hungry (in which case it might be inhumane to starve them or not give adequate analgesia), and the remote possibility of misdiagnosis and recovery.

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[169] David Bates, 'The vegetative state and the Royal College of Physicians guidance' (2005) 15 (3-4) Neuropsychological Rehabilitation <https://tandfonline.com/doi/abs/10.1080/09602010443000399> accessed 21 January 2021.

[170] Sheila McLean, 'Permanent vegetative state: The legal position' (2005) 15 (3-4) Neuropsychological Rehabilitation <https://doi.org/10.1080/09602010443000272> accessed 21 January 2021.

[171] The General Medical Council, Treatment and care towards the end of life: good medical practice (GMC 2010).

[172] Mental Capacity Act 2005; Adults with Incapacity (Scotland) Act 2000; Human Right Act 1998.

The aspects of controversy that this thesis will explore will span over the clinical, ethical, legal, and philosophical issues around the practice and governance of treatment withholding and withdrawing in people deemed to be in a PVS. The first issue is whether widespread assumptions that the state clinically exists are properly evidentially grounded and what the implications for governance and practice are if it cannot be. To contextualise this element of the controversy, it is worth considering that there used to be significant debate about whether the P stood for permanent or persistent until with the passage of time it became clearer that even some patients, who according to established criteria were correctly diagnosed as being persistently vegetative, were coming out of their state; some of them even went on to lead relatively functionally 'normal' lives.[173] The need for a rethink in this light was perhaps most vividly exposed by the contrasting situations of Tony Bland and his friend Andrew Devine, both of whom were diagnosed as PVS following their involvement in the Hillsborough disaster but the former said by Lord Mustill in the House of Lords (HL)[174] to have no interests when the latter went on to recover from his state and live a normal life.[175] The move to the term persistent was an acknowledgment in this respect that notwithstanding doubts about whether it was consistent with the inherent worth or dignity of human beings to ever describe any of them as not having any interests, those diagnosed as in a PVS could undeniably be said to have an interest in potential recovery. Whilst this was all well and good, it did not lead to any kind of fundamental reappraisal of whether it was legitimate to label any living beings as vegetative. Aside from its naturally derogatory connotations, the term vegetative would seem to be problematic because it is used to define a person as not only lacking in discernible interactive

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[173] Baricich and others (n 3).

[174] [1993] 1 All ER 821 at 894.

[175] Clare Dyer, 'Hillsborough survivor emerges from permanent vegetative state' (1997) 314(993) BMJ <https://www.bmj.com/content/314/7086/993.8.full> accessed 14 October 2020.

capability but as actually objectively lacking upper brain function and, relatedly, consciousness.

When Jennett and Plum started the concept of PVS, they laid down some essential points that they put into consideration before naming the condition.[176] They pointed out that the behavioural features they observed were based on clinical grounds.[177] They also emphasised that the central feature of this condition was the inability to evidence consciousness with any neurological pattern in the brain.[178] Lastly, they remarked that the condition was likely to be a part of a spectrum of neurological dysfunction.[179] These points were fraught with logical inconsistencies as they did specify what they actually meant by a 'functioning conscious mind'. Do they mean the brain? Or something else? If it is the brain they were referring to, then how is the brain related to the mind? Furthermore, if there is no structural pattern in the brain corresponding to the behavioural features been looked for on clinical examination, how then can one evidence the lack of it? The duo might have inadvertently concluded that the inability to clinically observe behavioural features consistent with awareness is enough to confidently diagnosed people as lacking a functioning conscious mind. Therefore, it will not be farfetched to ask whether people with PVS label are unconscious or permanently in the state of unconsciousness. Nowadays it is a common assumption that anyone with a label of PVS is permanently unconscious and treated as such without asking whether the inability to detect consciousness is enough to diagnose a lack of consciousness or awareness.

The continuing advancement in technology has given rise to an increasing number of challenges facing healthcare professionals when making decisions that can or will lead to the

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[176] Jennett and Plum (n 6).

[177] Ibid.

[178] Ibid.

[179] Ibid.

death of patients.[180] It is now possible to prolong life and paradoxically extend the dying process beyond what some people will deem sensible. Such interventions carry many moral and ethical issues, while some would argue that life-prolonging interventions in publicly funded facilities like the NHS mainly follow a cost-benefit approach, others would beg to differ.[181] Conceptualising PVS patients as permanently lacking a conscious mind without well-ground evidence potentially flaws in policies and governance derived from the concept. The assumption that people deemed to be in a PVS are unable to feel pain, thirst, and hunger stems from the acceptance that they are permanently unconscious.[182] Although evidence from functional neuroimaging of the brain to sensory stimuli has supported the activation of certain areas in the brain when the subject is exposed to painful stimuli.[183] This finding may indicate that 'PVS' patients retain their affective consciousness. Anecdotal evidence from patients who were put to deep sleep by general anaesthesia may be relevant in understanding whether people who are unconscious still retain their sentient capacity. Therefore, if people deemed to be in a PVS retain these perceptive capabilities, then some moral and ethical issues must be addressed in terms of withdrawing CAHN.

Another grey area in the management of 'PVS patients' is the issue of whether to use tubes to feed them or not. There have been controversial discussions on administering nutrition and hydration through tubes. These discussions have provoked dignity and human rights arguments. In 2018, the Supreme Court in *Re Y* case ruled that CANH could be ceased in

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[180] Peter Singer, 'Medical ethics' (2000) 321 (7256) BMJ <https://doi.org/10.1136/bmj.321.7256.282> accessed 21 January 2021.

[181] Neil McHugh and others, 'Extending life for people with a terminal illness: A moral right and an expensive death? Exploring societal perspectives' (2015) 16 (1) BMC Medical Ethics <https://doi.org/10.1186/s12910-015-0008-x> accessed 21 January 2021.

[182] James McHugh, 'Principles in regard to withholding or withdrawing artificially assisted nutrition/hydration' (1990) 6 (1) Issues in law & medicine 89-93.

[183] Tao Yu and others, 'Patients with unresponsive wakefulness syndrome respond to the pain cries of other people' (2013) 80 (4) Neurology < https://doi.org/10.1212/WNL.0b013e31827f0846 > accessed 21 January 2021.

patients diagnosed as PVS without involving the Court in some situations.[184] This judgment was received with mixed emotions and some criticisms were made, which will be discussed later. It was determined in *Bland* that CAHN is a medical intervention. [185] When CANH ceases, it is not unreasonable to think that the patient will suffer from starvation and when the patient dies, he or she is more likely to die of malnutrition and dehydration rather than the underlying condition.[186] If this is indeed the case, a lot of ethical and human rights questions need to be answered. In the empirical aspect of this thesis, I examine the healthcare professionals' views on this issue to understand if there is any difference in what the law says and the clinicians' perceptions on this controversial issue.

2.6. Practical approach to diagnosing PVS and why it is flawed.

Following severe brain injury, even though individuals may me alive for all intent and purpose, they may be left oblivious of their immediate environment for a considerable period. Labelling a patient as having persistent or permanent vegetative state is intended to have a huge impact on the treatment that the patient receives afterwards. Active medical treatment may be withheld or, in extreme cases, LSIs are stopped. (Un)consciousness becomes a heavily contested issue in the absence of any reliable way of objectively measuring awareness in human beings. This section investigates how consciousness is assessed in the clinical setting and what are the things we can say that can be known for sure about patients diagnosed as PVS and the things we do not know about them. Depending on the severity of the insult to the brain, the cognitive skills are lost in a stepladder fashion during traumatic brain injury. The first skill to go seems to be the cognitive function of the brain, followed by reasoning and problem-

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[184] *An NHS Trust and others (Respondents) v Y (by his litigation friend, the Official Solicitor) and another (Appellant)* [2018] UKSC 46 para 126.

[185] *Airedale NHS Trust v Bland* [1993] AC 789.

[186] Zosia Kmietowicz, 'Woman dies two months after food withdrawal' (1997) 314(7093) BMJ < https://doi.org/10.1136/bmj.314.7093.1501e> accessed 21 January 2021.

solving skills, then memory. This, in turn, is followed by speed at which information is processed, perception and recognition of information, awareness arousal and, finally, wakefulness. Similarly, experts stratified the recovery from brain injury into ten levels.[187] In the first level, the patient demonstrates no response at all like in coma. In level two, there is a generalised response like open eye but no response to stimulation like in VS. The response in these patients is minimal, delayed, and inconsistent. [188] The patients in level three exhibit localised response like starring in direction of sound or voice, looking at pictures, grabbing towards tube and catheter or pulling away from pain.[189] This is a type of response seen in MCS.

Furthermore, level four is reserved for patients in emerging consciousness phase when the patient becomes confused and agitated.[190] At this stage, the patient requires maximum assistance. In level five the patient becomes confused, inappropriate but not agitated.[191] The patient is awake and aware of the surrounding but needs continuous prompting. This level is labelled post-traumatic state of confusion. However, patients in level six are confused but appropriate. In this state, the patient needs moderate assistance with activities of daily living (ADL).[192] This level is labelled as emerging from post-traumatic amnesia. In level seven, the patient becomes automatic and appropriate and requires minimal assistance with ADL.[193] Patients in level eight generally become purposeful and appropriate.[194] At this stage, the patient would require a stand-by assistance which would be mainly for prompting. In level nine, the patient is purposeful and appropriate but the need for a stand-by assistance will be on request.[195] The patients at this stage are able to appreciate when they require assistance and are usually

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[187] Katherine Lin and Michael Wroten, *Ranchos Los Amigos* (Stat Pearls Publishing 2020).

[188] Ibid.

[189] Ibid.

[190] Ibid

[191] Ibid

[192] Ibid

[193] Ibid

[194] Ibid.

[195] Katherine Lin and Michael Wroten, *Ranchos Los Amigos* (Stat Pearls Publishing 2020).

able to call for help. Finally, the patient becomes purposeful and appropriate in level ten, also gaining independence, albeit with some adaptations.[196]

In practice, before an individual can be labelled as being in PVS, other differential diagnoses would have been considered. The final diagnosis is made after taking a careful history, clinical examination, and ancillary investigations. Owing to the complexity of making an accurate diagnosis in this category of patients, researchers have spent a considerable number of resources in understanding the underlying reasons behind missed diagnoses and misdiagnosis. The consequence of which recommendations have been made on the guidelines to follow to standardised diagnosis and improve the accuracy of making the right diagnosis. Anecdotal evidences suggest that some people with other conditions that can mimic behavioural characteristics of VS can be misdiagnosed as PVS.[197] In addition, care should be exercised to ensure that patients are not on sedatives prior to assessments. However, if such medication is required, the dose should be limited to the minimum.[198] If there are any abnormalities causing neurological imbalance that can affect the assessment, such condition should be treated or at the very least, optimised.[199] Some medications can exert unwanted adverse effects on the neurological system.[200] These medications include antiepileptic drugs, sedatives, and drugs used to reduce spasms in VS patients.[201] Assessing a patient in a controlled posture helps in stimulating the nervous system; thus, the examiner is likely to witness observable behaviour that suggests the presence of conscious awareness in the patient.[202] Hence, the provision of a comfortable bed that offers a good sitting position is necessary to

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[196] Ibid

[197] De Salvo and others (n 12).

[198] Lucy Strens and others, ‘Misdiagnosing the vegetative state after severe brain injury: The influence of medication’ (2004) 18(2) Brain injury < https://doi.org/10.1080/0269905031000149533> accessed 21 January 2021.

[199] De Salvo and others (n 12).

[200] Strens and others (n 198).

[201] Ibid.

[202] Roger Barker, ‘The neurological assessment of patients in vegetative and minimally conscious states’ (2005) 15(3-4) Neuropsychological Rehabilitation <https://pubmed.ncbi.nlm.nih.gov/16350964/>accessed 1 May 2021.

prevent spurious muscle contractions during a clinical examination. Many doctors will examine these patients in a recumbent position even though research has demonstrated that they tend to be more alert when adopting a sitting position.[203] This may be attributed to the fact that the RAS receives more stimulation from a sitting posture compare to the supine position.[204] For this reason, the patient should be provided with a good posture support to tone the muscles properly and the facilitation of the movement of the limbs.

Furthermore, the examiner should lay emphasis on the environment where the patient is examined because it is capable of altering the outcome of the examination. The condition of the environment should be controlled to prevent sensory overload which might cause interference or damage to the tissues of their brains.[205] Thus, the activities that the patient is exposed to, such as bathing and dressing prior to assessment should be limited. Moreover, it is necessary to shorten the period of assessment to prevent fatigue. Therefore, the best way to a better accuracy with diagnosis is to examine for the shortest possible time at a time over a long period.[206] In addition, the use of therapeutic communication that affords strong interpersonal interactions must be adopted for the patient by the clinician to promote the sensitivity of the preferences and choices that would result in better outcomes.[207] In this context, since the relatives and the caregivers tend to be emotionally involved with the patient, they tend to play the role of identifying any responses. Therefore, they will easily note any responses from the

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[203] Takashi Moriki and others, 'Sitting position improves consciousness level in patients with cerebral disorders' (2013) 1(1-3) Open Journal of Therapy and Rehabilitation <http://dx.doi.org/10.4236/ojtr.2013.11001> accessed 23 May 2021.

[204] Ibid.

[205] Wakoto Matsuda and others, 'Levodopa treatment for patients in persistent vegetative or minimally conscious states' (2005) 15(3-4) Neuropsychological Rehabilitation <https://tandfonline.com/doi/abs/10.1080/09602010443000588> accessed 21 January 2021.

[206] Ibid.

[207] Rupert Ortner and others, 'Assessment and Communication for People with Disorders of Consciousness' (2017) 126(53639) Journal of visualized experiments <www.ncbi.nlm.nih.gov/pmc/articles/PMC5613801/> accessed 15 May 2021.

patient.[208] However, caution should be exercised to avoid all forms of subjectivity including prejudices. The chance of achieving a correct diagnosis is predicated on a plethora of factors which can be taken for granted in the best of situations. The features characterising the diagnosis of PVS clinically are the lack of behavioural evidence of interaction between the patient and their environment despite the preservation of their sleep-wake cycle and maintenance of essential involuntary body physiology.[209] To make a credible diagnosis, the examiner needs to demonstrate that the patient lacks this behavioural evidence.

Furthermore, the examiner must also be convinced that the patient has no comprehension of the language and are unable to express their thoughts caused by brain injury and not because of a problem in the transmission of impulses to the muscles.[210] Although this observation should be interpreted with caution because there are cases like locked-in syndrome where the patient's inability to respond to command is not a consequence of being unconscious but the inability to control the muscles necessary for phonation and movement.[211] If care is not taken these patients can be wrongly diagnosed as in a PVS. As noted above, there are various standard procedures used to make the diagnosis of PVS in clinical settings, but the fundamental issue remains how to confidently determine that a person is unconscious from a lack of behavioural evidence of conscious state when tests only tell us that they cannot measure consciousness. This critical question is the reason behind the appraisal of the concept of PVS in this thesis. The very many studies on PVS in the literature have yet to explore this line of argument. As with the locked in syndrome where unless one has a close observation, it is easy to arrive at an erroneous conclusion that patients with this condition are in PVS.

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[208] Pasquale Moretta and others, 'Family caregivers' opinions about interaction with the environment in consciousness disorders' (2017) 62(2) Rehabilitation Psychology <https://doi.org/10.1037/rep0000144> accessed 25 May 2021.

[209] Bender and others (n 5).

[210] Steven Laureys and others, 'The locked-in syndrome: what is it like to be conscious but paralyzed and voiceless?' (2005) 150 Progress in brain research <https://doi.org/10.1016/S0079-6123(05)50034-7> accessed 3 March 2021.

[211] Ibid.

In practice, the examiner will try to ascertain the cause of the chronic disorder of consciousness and relate it to the content and the level of consciousness. The causes usually include head injury, brain infections, degenerative diseases, metabolic disorders, and congenital diseases.[212] After identifying the etiology of the brain injury, all potentially reversible factors that may be responsible for this condition should be excluded. These may include persistent side effects associated with sedative drugs, such as anticonvulsants and anaesthetic or neuromuscular agents that block neuromuscular pathways.[213] Other causative agents that can be reversed include metabolic disturbances and structural lesions that are treatable.[214]The GCS is the preliminary tool used at the bedside to objectively determine the level of consciousness in a patient. The scale assesses the patient's response to pain, voice, and conversation and ranks them from 3 to 15. The lowest score is the worst possible outcome while the highest score is the best possible outcome.[215] However, this scale suffers from many limitations in affirming the absence of a conscious state when the score is at its lowest.[216] After the initial assessment of the level of consciousness, a full neurological examination is conducted to examine the sensory, motor, and autonomic functions of the patient.[217]

A positive diagnosis is made when the patient does not exhibit any evidence of either being aware of the environment that he/she is in or self-awareness and does not interact with people around him/her or respond to environmental stimuli such as light.[218] In this state, the patients fail to demonstrate continued, repeated, well intended, or voluntary responses to

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[212] Prolonged Disorders of Consciousness - National Clinical Guideline Royal College of Physicians (2013).

[213] Strens and others (n 198).

[214] Ibid.

[215] Florence Reith and others, 'The reliability of the Glasgow Coma Scale: a systemic review' (2016) 42(1) Intensive Care Med <https://pubmed.ncbi.nlm.nih.gov/26564211/> accessed 2 February 2021.

[216] Ibid.

[217] David Bateman, 'Neurological assessment of coma' (2001) 71(1) J Neurol Neurosurg Psychiatry <https://jnnp.bmj.com/content/71/suppl_1/i13> accessed 23 March 2021.

[218] Laureys and Boly (n 62).

stimuli.[219] They also reflect the inability to comprehend language or express themselves.[220] However, these patients have intermittent wakefulness in the form of sleep-wake cycles. More importantly, the brainstem functions like the cranial nerve reflexes, autonomic and hypothalamic functions remain preserved.[221] On the contrary, when making a diagnosis of MCS, the patient must demonstrate that there is observable evidence of some degrees of interaction with the immediate surroundings in the form of a non-primitive response to external stimuli initiated by the examiner. Depending on the situation, this response could be a sustained or inconsistent behaviour.[222] Nevertheless, in the differential diagnosis of the condition, certain aspects must be critically analysed. To illustrate, persons with severe intellectual disabilities and other lifelong severe disabilities accompanied by physical disabilities usually demonstrate a limited amount of ability to respond to their environment. In such cases, caregivers always keep them in a state of constant communication and awareness to make proper observations. Such persons cannot be classified to be in a PVS.

Patients diagnosed to be in PVS can make purposeless trunk movements or limb movements. Other things that they may do include occasionally smiling and shedding tears; some of them are even known to utter grunts and moan or scream at times. These motor activities can suggest a line of potentially misleading purposeful movements. However, such types of responses have been widely observed in patients labelled to be in PVS, who, are not supposed to be aware of their immediate environment according to the diagnostic criteria. Owing to the maintenance of brain stem functions, many patients in this condition have a good to almost normal regulation in their ability to see and the movement of their eyes. In other

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[219] Yamamoto and others (n 64).

[220] Laureys and Boly (n 62).

[221] Yamamoto and others (n 64).

[222] Wakoto Matsuda and others, 'Levodopa treatment for patients in persistent vegetative or minimally conscious states' (2005) 15(3-4) Neuropsychological Rehabilitation <https://pubmed.ncbi.nlm.nih.gov/16350982/> accessed 2 February 2021.

cases, a few patients may have signs of other degenerative abnormalities related to the brain. These abnormalities, in turn, may lead to the destruction of some nerves.[223]

In addition, patients in this condition exhibit some challenges in the sustainability of their visual functions. Thus, they cannot maintain focus on specific targets at any given point in time, track the path of a moving object, or even try to withdraw from a gesture that jeopardises their vision.[224] The ability of these patients to maintain visual focus might well be the early sign of emergence from the state they are in (which the medical profession labelled as PVS).[225] However, such types of patients have demonstrated a primitive ability to receive auditory reflexes; hence, at times, they slightly turn their heads towards the direction of the stimuli. Most importantly, one should exercise a lot of caution when making VS diagnosis in an individual who exhibits any amount of sustained visual response to visual stimuli.[226] Most patients in this condition who have survived for longer periods have demonstrated the ability to maintain a normal body temperature, thus indicating that their hypothalamic functions were not altered by this condition.[227] Moreover, their breathing cycles and heart rates have remained normal. In most patients, some reflexes such as those of gagging, coughing, sucking, and swallowing are maintained which makes feeding not a clinical risk to their existence. However, they are unable to chew or swallow the food, although this does not have any impact on the alimentary canal functions of digestion and absorption of food.[228]

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[223] Estraneo and others (n 31).

[224] Bernat, (n 153).

[225] Willemijn van Erp and others, 'Unexpected emergence from the vegetative state: delayed discovery rather than late recovery of consciousness' (2019) 266(1) Journal of Neurology <https://researchgate.net/publication/335948997_Unexpected_emergence_from_the_vegetative_state_delayed_discovery_rather_than_late_recovery_of_consciousness >accessed 2 May 2021.

[226] Norman Cantor, "The permanently unconscious patient, non-feeding, and euthanasia' (1989) 15(4) Am J Law Med 381.

[227] Multi-Society Task Force on PVS (n 9).

[228] Ronald Cranford, 'Neurologic syndromes and prolonged survival: when can artificial nutrition and hydration be forgone?' (1991) 19(1-2) Law Med Health Care <https://doi.org/10.1111/j.1748-720X.1991.tb01788.x> accessed 2 February 2021.

It is noteworthy that regardless of the above steps and precautions, the integrity of the diagnosis process heavily relies on an intact nerve pathway to and from the brain. When a physician attempts to communicate with an unconscious patient, the communication may be impeded by interruptions in these pathways, which have nothing to do with the integrity of the brain itself.[229] A negative response from the patient in this circumstance will only mean that the patient did not receive the sensory input from the observer but also may indicate that the relevant organ did not receive the message sent by the brain. This observation was echoed in a study in 1996 where it was found that there was a 43% (17 Patients) misdiagnosis rate in patients with PDoC.[230] Interestingly, severe visual impairment was the major cause of misdiagnosis in these patients (65%).[231] Therefore the integrity of the body's sensory and motor apparatus is crucial for any form of interaction or communication with the environment. The reliance on observation of manifestations of awareness in the patients may well be contingent on factors that are unrelated to the brain or the brain injury. Thus, it can be inferred that the overt dependence of clinical diagnosis of VS or PVS on motor behaviour and task engagement is a flawed assumption. Hence, the adoption of a more reliable approach for the detection of the capacity for the conscious mental state in patients is necessary.

Ancillary investigation

There is no specific structural neuro-pathological pattern in the brain that is pathognomonic of VS or PVS. However, investigations may be necessitated to exclude treatable causes for the patient's condition. Even though clinical/behavioural examinations

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[229] Steven Laureys and others, 'The locked-in syndrome: what is it like to be conscious but paralyzed and voiceless?' (2005) 150 Progress in brain research <https://doi.org/10.1016/S0079-6123(05)50034-7> accessed 3 March 2021.

[230] Keith Andrews and others, 'Misdiagnosis of the vegetative state: retrospective study in a rehabilitation unit' (1996) 313 BMJ <https://doi.org/10.1136/bmj.313.7048.13> accessed 2 February 2021.

[231] Ibid.

have been heavily relied upon for many years in making a diagnosis of PVS/VS, we have seen in the last few years that more and more ancillary investigations have been used. However, the diagnostic accuracy of these tests has been controversial.[232] Ancillary investigations can be divided into routine blood tests (full blood count, electrolyte, inflammatory markers, etc.), neurophysiological tests (EEG, ERP), and neuroimaging tests (fMRI, SPECT, and PET scans).[233] Some of these ancillary tests can detect evidence of brain activities in VS patients which is also seen in the normal brain and might represent evidence of awareness in the subjects. Some researchers opine that complementing good history taking and clinical examination with these ancillary tests can in principle reduce the rate of misdiagnosis.[234] The level of consciousness fluctuates from time to time in patients with a disorder of consciousness.[235] Hence, this dynamic nature of consciousness poses a big challenge to an observer trying to make a diagnosis. Therefore, concerns have been raised about the decisions made based on the diagnosis that could have been made erroneously.

Research by scientists currently focuses on more objective approaches for making a diagnosis. However, this cannot be perceived as a reliable means of diagnosing or prognosticating. Even though more dynamic neuroimaging assessments such as fMRI seem to offer promising results, they are currently not used routinely in clinical practice. Recently some researchers studied brain patterns using fMRI in healthy subjects and MCS to try and identify any specific activities that indicate consciousness.[236] They found a rich brain dynamic in a healthy pattern but the paucity of activities in the MCS patients. However, they are unable to

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[232] Damien Gabriel and others, 'Substitute or complement? Defining the relative place of EEG and fMRI in the detection of voluntary brain reactions' (2015) 290 Neuroscience <www.sciencedirect.com/science/article/abs/pii/S0306452215001104?via%3Dihub> accessed 2 February 2021

[233] Peterson (n 154).

[234] Ibid.

[235] Francesco Riganello and Walter Sannita, 'Residual brain processing in the vegetative state' (2009) 23(1) Journal of Psychophysiology <https://doi.org/10.1027/0269-8803.23.1.18> accessed 2 February 2021.

[236] Athena Demertzi and others, 'Human consciousness is supported by dynamic complex patterns of brain signal coordination' (2019) 5(2) Science Advances<https://advances.sciencemag.org/content/5/2/eaat7603> accessed 2 February 2021.

identify any specific pattern that corresponds to consciousness. Some research works have also shown features suggestive of higher cortical neuro-functioning in VS patients following stimulation with complex language or mental imagery.[237] These findings suggest that the brain of VS patients might be more complex than it was previously projected. These investigations (fMRI/ PET) might not only be used to aid the diagnosis of VS/ MCS, but they also probably have a role in predicting recovery from the states. The presence of some activities in certain areas (e.g., primary sensory cortex) of the brain during stimulation with mental imagery or complex language stimuli are associated with some recovery.[238] These activities may not confirm consciousness as some subset of VS have a similar response to these stimuli as normal brain and yet they are said to be unconscious.[239]

The advent of new technology has revealed more about the VS and evidence has emerged that some individuals regain a few functionalities after many years of being in the so-called vegetative state.[240] However, there is some ambiguity on how these modalities will improve diagnosis in the future. The criteria for diagnosing PVS imply that recovery from VS/UWS after a certain period is extremely rare, if not impossible. In an attempt to explain or rationalise misdiagnosis, some authors have come up with hypotheses to explain the unexpected recovery in PVS. However, these claims lack vital information and are misleading at best. Some researchers have claimed that there is no difference between diagnosing VS and MCS.[241] For this reason, stronger and better evidence is required to enable clinicians to be able to

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[237] Adrian Owen, 'using functional magnetic resonance imaging and electroencephalography to detect consciousness after brain injury' (2015) 127 Handbook of Clinical Neurology <https://doi.org/10.1016/B978-0-444-52892-6.00018-0> accessed 2 February 2021.

[238] Marie-Aurelie Bruno and others, 'Functional neuroanatomy underlying the clinical subcategorization of minimally conscious state patient' (2011) 259(6) J Neurol <https://doi.org/10.1007/s00415-011-6303-7> accessed 2 February 2021.

[239] Julia Crone and others, 'Altered network properties of the fronto-parietal network and the thalamus in impaired consciousness' (2014) 4 Neuroimage Clin <www.ncbi.nlm.nih.gov/pmc/articles/PMC3895618/> accessed 2 February 2021.

[240] Baricich and others (n 3).

[241] Giulia Liberati and others, 'Questioning the dichotomy between vegetative state and minimally conscious state: a review of the statistical evidence' (2014) 8 Frontiers in Human Neuroscience <https://doi.org/10.3389/fnhum.2014.00865>accessed 21 May 2021.

confidently declare the point where the prognosis is uncertain and hopeless. A neurologist claimed that neuroscience is yet to decipher the limit of the human brain abilities, where he argued that the brain is capable of "re-wiring" itself after injury.[242] He recounted the story of a patient that was misdiagnosed as PVS but was in MCS.[243] Two other patients, Martin Pistorius[244] and Juan Torres recovered from PVS and recounted that they had detailed memories of their time in the state.[245] The foreseeable implication of a PVS diagnosis includes denial of prolonged rehabilitation, physicians attempting to convince family members that the patient is unable to recover, and eventually withdrawing treatments. All these actions highlight the gross marginalisation of the vulnerable.

Why this approach to diagnosis in PVS is flawed?

This medical reductionistic approach to defining the absence of consciousness in individuals diagnosed as PVS is fundamentally flawed because consciousness can only be confirmed by the patients themselves through introspection and it would be illogical to infer that it is not present in the absence of any strong physical evidence. The determination of consciousness by a third party in a patient who for whatever reason is unwilling or unable to communicate is practically impossible through the observational method as we have in the criteria. It is evident that most of the criteria for labelling people as PVS are negative findings. These observations give room for making a clinical diagnosis on false negative premises. Some studies have claimed that PVS and MCS are two closely related conditions on the

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[242] Joseph Fins, 'Brain Injury and the Civil Right We Don't Think About' (The New York Times, 24 August 2017) <https://nytimes.com/2017/08/24/opinion/minimally-conscious-brain-civil-rights.html> accessed 5 May 2021.

[243] Ibid.

[244] Lulu Miller, 'Trapped in His Body For 12 Years, A Man Breaks Free' (NPR; All Things Considered, 9 January 2015) <https://npr.org/sections/health-shots/2015/01/09/376084137> accessed 5 May 2021.

[245] Kate Lunau, 'The story behind a vegetative patient's shocking recovery' (MacLean's, 31 December 2015) <https://macleans.ca/society/health/the-story-behind-a-vegetative-patients-shocking-recovery/> accessed 5 May 2021.

consciousness spectrum.[246] However, the delineation of these conditions is on a questionable premise. Perhaps these two manifestations are from the same pathophysiological process and the claim on whether consciousness is minimally present or not is bogus. Some studies claim that PVS patient lacks consciousness, unlike MCS.[247] It is also claimed that these patients can transition in and out of these two states.[248] However, no explanation is given on how consciousness, the entity that defines the two states is lost and regained.

Another critique of how PVS is diagnosed clinically is the manner in which the lack of behavioural response to the examination is correlated to consciousness. It can be said that taking the absence of these behaviours to mean that the patient is unconscious is an educated guess at best based since there is a physiological limitation to objectively accessing another person's thought and consequently, conscious state. Furthermore, all the test modalities in use clinically to diagnose PVS are not objective in picking up consciousness in these patients. Even advanced and specialised neuro-imaging technologies are found to be lacking in this regard. There are bound to be some non-physical elements to the concept of PVS. The next section will delve into the philosophical aspect of consciousness and how we can reconcile the physiological ideas about PVS.

2.7. The philosophical perspective of the PVS label.

The main epistemological issue with the PVS/VS label is the debatable premise of lack of consciousness, a subjective concept. Consciousness is an experience that is only witnessed by the person in question and remains inaccessible to third parties. Scientists and neurologists have continued to find evidence of how a conscious mental state is lost in the 'PVS' brain but so far, no strong evidence has been given to the relationship. No study has unequivocally

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[246] Bender and others (n 5).
[247] De Salvo and others (n 12).
[248] Ibid.

pinpointed the seat of consciousness within the brain or specified the brain activities corresponding to (un)consciousness either in a healthy human being or in those diagnosed as in PVS. The existing literature has been unable to substantiate how the biological system integrates the various sensory inputs in the brain to produce specific subjective experiences or what specific neural activities correlate to consciousness. Furthermore, as I explore later in this section, some theories postulate that consciousness is not organised in the biological system. Another question that one might ask is if it is possible to program machines in a way that they can have a conscious mental experience. This section will explore the various philosophical approaches to the concept of consciousness in relation to the brain. There will also be a critique of the prevailing physicalist approach adopted by the medical profession in defining the concept of PVS.

The idea of how mental states become conscious requires the philosophical exploration of the concept of consciousness. Thomas Nagel, in 1974, asked the question, what is it like to be conscious? His explanation of consciousness remains the most plausible notion of consciousness.[249] He claimed that every organism has a unique experience of what it feels like to be that organism; therefore, the organism can be said to have a conscious mental state even if it is inaccessible to others, like in bats (the example he gave in his article).[250] The historical account of the concept of consciousness gives an insight into how complex and controversial it can be. Since the medieval period, ancient philosophers have attempted to explain consciousness and solve the mind-body problem. Reductive physicalists believe that body physiology can explain everything about human existence.[251] Therefore, the mind resides in the body. Unfortunately, this idea has not been able to address the issue of consciousness in the

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[249] Thomas Nagel, ‘What is it like to be a Bat?’ (1974) 83(4) The Philosophical Review <https://doi.org/10.2307/2183914 > accessed 23 February 2021.

[250] Ibid.

[251] Daniel Stoljar, 'Physicalism' (Stanford Encyclopedia of Philosophy, 25 May 2021) <https://plato.stanford.edu/archives/sum2021/entries/physicalism/> accessed 12 June 2021.

PVS. Despite rapid advancements in science and technology, many things cannot be explained solely by the mechanism of the physical body's function. Plato wrote in the dialog sophist that

> "…*My notion would be, that anything which possesses any sort of power to affect another, or to be affected by another, if only for a single moment, however trifling the cause and however slight the effect, has real existence; and I hold that the definition of being is simply power…*"[252]

He seemed to be supporting the notion that consciousness can or should be explained by physicalism. However, by saying power to affect means we are dealing with something real. However, that does not imply its reality is necessarily physical or purely physical/organised from the physical. This cause-effect power was echoed in the integrated information theory (IIT) proposed by Giulio Tononi in 2015 to explain how consciousness is generated in the brain.[253] This Theory claims that consciousness is an integrated information generated by the brain from a complex of elements independent of the brain's cognitive functions.[254]

Aristotle's opinion on the nature of consciousness and perception is that perceptual awareness is both inherent and higher-order or relational to perception.[255] Rene Descartes argued that the mind is separate from the body, in the sense that the body is conceived as a physical entity compared to the non-physical entity perception of the mind.[256] This differentiation made him have some reservations about the concept of unconscious mental state. He posited that the body and the mind interact with the pineal gland.[257] Furthermore, he

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[252] Olivia Goldhill, '2,300 years later, Plato's theory of consciousness is being backed up by neuroscience' (Quartz, 18 June 2016) <https://qz.com/709969/2300-years-later-platos-theory-of-consciousness-is-being-backed-up-by-neuroscience/> accessed 3 May 2021.

[253] Giulio Tononi and Christof Koch, 'Consciousness: here, there and everywhere' (2015) 370(1668) Philosophical Transactions of the Royal Society B <https://royalsocietypublishing.org/doi/10.1098/rstb.2014.0167>accessed 25 May 2021.

[254] Ibid

[255] Victor Caston, 'Aristotle on Consciousness' (2002) 111(444) Mind <https://doi.org/10.1093/mind/111.444.751> accessed 23 February 2021.

[256] Justin Skirry, 'René Descartes: The Mind-Body Distinction' (Internet Encyclopedia of Philosophy) <https://iep.utm.edu/descmind/> accessed 3 May 2021.

[257] Ibid.

posited that one needs to be conscious for him/her to be able to think; therefore, consciousness is an essential prerequisite for thought and consequently, consciousness is inevitably confirmed through introspection.[258] John Locke echoed that the body and the mind are distinct entities, but he did not commit to a specific interaction like Descartes.[259] Unlike Locke and Descartes, G. W Leibniz refuted the claim that consciousness is required for perception.[260] He proposed the concept of non-conscious perceptions which he called petit perceptions.[261] Therefore, he inferred the existence of an unconscious mental state and furthered the argument that not all cognitive activities are conscious.[262] Hence, it remains unclear what these philosophers refer to as the 'mind'. Therefore, the reference of the mind to consciousness or otherwise is debatable. However, it is clear that their perceptions are not making any reference to the human brain. The debate here would be whether so-called PVS patients lack a mind or consciousness. Where exactly is the mind located? Or is it just an abstract concept?

The early modern philosophers gave varying but not too different opinions of the mind and mental state. Immanuel Kant characterised the mind as having two fundamental powers that form the basis for our cognitive behaviour - the power of receptivity and the power of spontaneity.[263] In his theory of knowledge, he opined that every act of knowledge begins with a receptive act (power of receptivity) but what we receive from the information is what our faculty of knowledge supplies from the information (power of spontaneity).[264] Kant's characterisation of the mind connotes that the mind can be influenced with or without external

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[258] Ibid.

[259] Angela Coventry and Uriah Kriegel, 'Locke on Consciousness' (2008) 25(3) History of Philosophy Quarterly <https://www.jstor.org/stable/27745128> accessed 23 February 2021.

[260] Ibid.

[261] Ibid.

[262] Rocco Gennaro, *Leibniz on Consciousness and Self Consciousness* (R. Gennaro & C. Huenemann edn, New York: Oxford University Press 1999) 353-371.

[263] Michael Rholf, 'Immanuel Kant' (The Stanford Encyclopedia of Philosophy, 28 July 2020). <https://plato.stanford.edu/archives/fall2020/entries/kant/> accessed 31 May 2021.

[264] Andrea Kern, 'Spontaneity and receptivity in Kant's theory of knowledge' (2006) 34(1-2) Philosophical Topics <https://jstor.org/stable/pdf/43155413.pdf?refreqid=excelsior%3Acdbff5e66bd73e3058e3cf641810f03e> accessed 21 July 2021.

prompting.[265] He, therefore, like Leibniz believed in the existence of the unconscious mental state or unconscious representation.[266] According to this notion, human beings are not directly cognisant of most of the representations in their brains.[267] Therefore, a higher-order representation would be involved for them to bring any of these representations to a conscious state.[268] Renowned psychologists like Carl Jung also support this notion. Although Wilhelm Wundt initially tried to distinguish between representations and representational acts, he later in his theory of actuality said that the two entities are different facets of the same process.[269] Later, Sigmund Freud promulgated the concept of unconscious mental state to where almost every philosopher began to embrace it.[270] William James however, believed that consciousness results from neural activities and went further to say that only careful introspection can detect it.[271] He posited that consciousness is a continuous process of changing events as brain activities shift with experiences.[272] Other philosophers define it as the summation of mental experience one has at any particular time.[273] B. F Skinner, a behavioural psychologist, claimed that the origin of consciousness is not physical; however, the brain is its physical representation.[274]

The philosophers' early views and approaches to the concepts of mind and consciousness were devoid of scientific ideas as none of them had any scientific knowledge of the manner in

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[265] Coiln Mclear, *'Kant: Philosophy of Mind'* (*Internet Encyclopedia of philosophy*) <https://iep.utm.edu/kantmind/> accessed 3 May 2021.

[266] Chong-Fuk Lau, 'Kant's Transcendental Functionalism' (2014) 68(2) The Review of Metaphysics <www.jstor.org/stable/24636348 > accessed 23 February 2021.

[267] Diogo Valadas Ponte and Lothar Schäfer, 'Carl gustav jung, quantum physics and the spiritual mind: a mystical vision of the twenty-first century' (2013) 3(4) Behavioral sciences (Basel, Switzerland) <https://doi.org/10.3390/bs3040601> accessed 23 September 2021.

[268] Lau (n 266).

[269] Kim Alan, 'Wilhelm Maximilian Wundt' (Stanford Encyclopedia of Philosophy, 10 September 2016) <https://plato.stanford.edu/archives/fall2016/entries/wilhelm-wundt/> accessed 31 May 2021.

[270] Charles Stangor and Jennifer Walinga, Introduction to Psychology (BCcampus, 2014)

[271] Mangan (n 109).

[272] Ibid.

[273] Tracy Henley, *Hergenhahn's An Introduction to the History of Psychology* (8th edn, Cengage Learning Inc 2019) 255.

[274] Burrhus Skinner, *Science and Human behaviour* (New York Macmillan1953).

which the brain functions.[275] However, over the past four decades, the knowledge of how the brain functions has significantly improved even to the point that the philosophical views on the mind and consciousness are hard to reconcile with what has been demonstrated scientifically. Even though what we know scientifically still leaves several questions open. This approach has created yet many unanswered questions in the quest to see how best the medical profession can manage people deemed to be in PVS. There are two competing views on the philosophy of the mind and consciousness.[276] The first view is materialism which holds that the brain harbours the mind and that neural activities in the brain give rise to the conscious mental state.[277] Succinctly put, the absence of these neural activities should equate to unconsciousness. This view appears to be the informed medical orthodoxy with regard to PVS. The other view, dualism supports the idea that the mental or consciousness sphere is entirely independent of the physical element.[278] These views are diametric opposites, but there is a third view. According to this notable view, rather than the qualities of reality as a whole and living systems specifically emanating from the physical, they emanate from a 'spiritual' source and include a physical dimension. This theory seems plausible because the metaphysics of the mind and consciousness remains unclear in the physical sense. The proponents of dualism believe that there is no conceptual link between the material and the mental state. The conceivability arguments that are still relevant today can be traced back to Descartes.[279] Many people regard dualism as a theologically motivated concept. Some ideas like life after death, soul, and out-of-body experience have sometimes been used to explain dualism.[280] Using materialism to

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[275] David Rosenthal, *Consciousness and Mind* (OUP, 2006) 1-34.

[276] Ibid.

[277] Ibid.

[278] Neeta Mehta, 'Mind-body Dualism: A critique from a Health Perspective' (2011) 9(1) Mens sana monographs <https://doi.org/10.4103/0973-1229.77436> accessed 23 March 2021.

[279] David Chalmers, *The Conscious Mind* (OUP, 1996)

[280] Tapani Riekki and others, 'Conceptions about the mind-body problem and their relations to afterlife beliefs, paranormal beliefs, religiosity, and ontological confusions' (2013) 9(3) Advances in cognitive psychology <https://ncbi.nlm.nih.gov/pmc/articles/PMC4158462/>accessed 2 May 2021.

explain the concept of PVS would imply the presence of modalities to measure consciousness to a reasonable level of accuracy or certainty. Since advancements in science and technology are yet to detect or isolate neural correlations of consciousness, dualism will remain a plausible view in the quest for answers on the validity of the PVS concept.

The out-of-body experience gives a relevant perspective to the mind-body dualism argument. While some have argued that it is nothing more than a form of dissociative hallucination or dream, others have affirmed the credibility of the out-of-the-body adventure.[281] In his book 'the flip', Jeffrey Kripal described 'flip' as a near-death or mystical experience which can be likened to when someone ingests hallucinogens, and everything seems like an illusion.[282] In that state, people's consciousness appears like tiny cross-sections in a vast mind called the universe. He believed every human being is conscious and cosmic and assumes that every paranormal experience coincides with reality.[283] Flippers describe humans as five-dimensional beings with spectral superpowers. Kripal also described humanities as the 'study of consciousness coded in culture'.[284] The study of the effects of hallucinogens like lysergic acid diethylamide, psilocybin (magic mushroom), peyote, DMT, and ayahuasca on the brain have also given some insights into the mind-body dualism.[285] When someone ingests these substances, the person sees vivid images, hears sounds, and sometimes feels things that seem real to them but are imaginary. Studying how these subjective perceptions are formed inside a

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[281] Mark Woodhouse, 'Out-of-body experience and the mind-body problem' (1994) 12(1) New Ideas in Psychology <https://doi.org/10.1016/0732-118X(94)90051-5> accessed 10 July 2022.

[282] Jeffrey Kripal, *The flip: epiphanies of mind and the future of knowledge* (Bellevue literary press 2016).

[283] Ibid.

[284] Ibid.

[285] Torsten Passie and others, 'The pharmacology of lysergic acid diethylamide: a review' (2008) 4(4) CNS Neuroscience & Therapeutics <https://pubmed.ncbi.nlm.nih.gov/19040555/> accessed 10 July 2022; David Nichols, 'Hallucinogens' (2004) 101(2) Pharmacology & Therapeutics <https://pubmed.ncbi.nlm.nih.gov/14761703/ > accessed 10 July 2022; Emmanuelle Schindler and others, 'Serotonergic and dopaminergic distinctions in the behavioral pharmacology of (+/-)-1-(2,5-dimethoxy-4-iodophenyl)-2- aminopropane (DOI) and lysergic acid diethylamide (LSD)' (2012) 101(1) Pharmacology, Biochemistry and Behavior. <https://ncbi.nlm.nih.gov/pmc/articles/PMC3272148/> accessed 10 July 2022; Hyeong Lee and Bryan Roth, 'Hallucinogen actions on human brain revealed' (2012) 109(6) Proceedings of the National Academy of Sciences of the United States of America <https://pubmed.ncbi.nlm.nih.gov/22308478/> accessed 10 July 2022.

hallucinating brain may give some clues to dualism. Recent scientific evidence on the impact of psychedelics on the brain has been contradicting. Some evidence shows that hallucinogenic drugs activate serotonin receptors in the brain.[286] However, it remains unclear how this activation produces an alteration in consciousness or perception.

Aldous Huxley proposed the reducing valve theory, suggesting that the brain constrains awareness and that hallucinogens inhibit this filtering mechanism when ingested.[287] He theorised that the inlet side of the valve is on the right hemisphere of the brain, and the outlet is the left brain.[288] The right hemisphere has a vast pool of possibilities regarding perception, emotions, and cognitive experiences, while the left hemisphere is where the moment-to-moment stream of experience we utilise every day is located.[289] Certain mechanisms inside the metaphorical valve streamline the character and contents of experience into human consciousness that we use for our daily activities. Researchers identified the serotonin 2A subtype (5-HT2A) in the brain as the specific receptor out of the 15 different receptors like the one that produces the effects of thought and perception alterations.[290] However, some researchers have speculated that the effect of psychedelics on the brain stems from heightened brain activities.[291] It remains unclear how this alteration affects one's consciousness. Huxley's opinion was mainly based on the physiological effect of mescaline on him after ingesting the substance.[292] Although many researchers believe that hallucinogens activate the brain, Huxley's reducing valve theory remains plausible. Despite the advent of new medical technologies, it is

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[286] Casto de Vos and others, 'Psychedelics and Neuroplasticity: A Systematic Review Unraveling the Biological Underpinnings of Psychedelics' (2021) 12 (724606) Front Psychiatry <https://ncbi.nlm.nih.gov/pmc/articles/PMC8461007/ >accessed 15 July 2022.

[287] Link Swanson, 'Unifying Theories of Psychedelic Drug Effects' (2018) 9(172) Frontiers in Pharmacology <https://doi.org/10.3389/fphar.2018.00172> accessed 15 July 2022.

[288] Aldous Huxley, '*The Doors of Perception, and Heaven and Hell*' (HarperPerennial New York 1991).

[289] Aldous Huxley, Moksha. in M Horowitz and C Palmer (eds), Aldous Huxley's Classic Writings on Psychedelics and the Visionary Experience (Park Street Press 1999).

[290] Kevin Murnane, 'Serotonin 2A receptors are a stress response system: implications for post-traumatic stress disorder' (2019) 30 (2-3) Behavioural Pharmacology <https://ncbi.nlm.nih.gov/pmc/articles/PMC6422730/>accessed 15 July 2022.

[291] Ibid.

[292] Aldous Huxley (n 289).

difficult to discard this opinion completely. Robin Carthart-Harris and David Nutt's studied the effects of psilocybin on brain activity using fMRI.[293] The medication induced its psychedelic effect by inhibiting neuronal activities in some parts of the brain. The authors concluded that consciousness is limited to the confines of the normal waking state in these brain areas.[294] This finding is in contrast to the findings of Dr Franz Vollenweider, who demonstrated increased brain activities in the areas mentioned above after administration of oral psilocybin.[295]

Iain McGilchrist also describes the differences between left and right cerebral hemispheres in humans. He proposed a more complex and interesting contrast between the two hemispheres beyond the simplified version of "emotion on the right and reason on the left".[296] McGilchrist's account of the conversation of the hemispheres proposed that the right hemisphere sees more than the left hemisphere even though there is a connection between the two hemispheres through the corpus callosum.[297] He labelled the former the "master", contrary to the traditional belief that the left hemisphere is the dominant hemisphere. He proposed that the right hemisphere is that part of the brain that does not function well in schizophrenia resulting in the pathological overdrive of the left hemisphere.[298] Each hemisphere is a unit on its own. The connection between the two hemispheres contains mainly inhibitory fibres. The right hemisphere sees a complex, interconnected living being and gives depth to life—depth in space, time, and feelings.[299] The right hemisphere is interested in the new, whereas the left hemisphere is interested in the familiar experience.[300] The left hemisphere prefers what is

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[293] Robin Carhart-Harris and others, ‘Psilocybin for treatment-resistant depression: fMRI-measured brain mechanisms’ (2017) 7(1) Scientific reports <https://pubmed.ncbi.nlm.nih.gov/29030624/> accessed 15 July 2022.

[294] Ibid.

[295] Franz Vollenweider and others, ‘Psilocybin induces schizophrenia-like psychosis in humans via a serotonin-2 agonist action’ (1998) 9 (17) NeuroReport <https://pubmed.ncbi.nlm.nih.gov/9875725/> accessed 15 July 2022.

[296] Iain McGilchrist, *The master and his emissary: The divided brain and the making of the western world* (Yale University Press 2019).

[297] Ibid.

[298] Louis Sass, *Madness and Modernism: Insanity in the light of modern art, literature and thought* (Harvard University Press 1992).

[299] Iain McGilchrist (n 296).

[300] Ibid.

certain, and the right hemisphere prefers what is possible. The right brain is interested in flow, while the left brain is interested in fixed things. The right brain does things as a whole, while the left does things in parts. The left-hemispheric world is virtual (things that have been mapped), while the right hemispheric world is the immediacy of perceptual experience.[301] When there is a right hemispheric stroke, the patient develops left inattention.[302] Following a split-brain operation, the hemispheres exhibit different personalities.[303]

Another perspective of the body-mind dualism is Julian Jaynes' notion of the bicameral mind. Jaynes explored consciousness through historical evaluation, introspection, and by studying language and metaphor.[304] He argued that consciousness is not a simple sense of perception and does not copy experience. Even though consciousness plays a role in human learning, it is not necessary for learning. A typical example is the operant conditioning phenomenon. He also said that consciousness is not necessary for thinking or reasoning and that the locus of consciousness is arbitrary.[305] In addition, the mind-space also has no location; we only assign a functional space for it. Therefore, by inference, it was impossible to trace consciousness's origin to the brain or the neural system in the human body. The concept of the bicameral mind means that human mentality is in two parts: a decision-making part and a follower part, of which none is conscious.[306] He gave four ideas about the origin of consciousness.[307] The first idea is that consciousness evolves from the power of language to make metaphors and analogies. The second idea is the bicameral mind hypothesis, which is the belief that the right hemisphere talks to the left hemisphere of the brain. The third idea is that

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[301] Ibid.

[302] Daniel Hier and others, 'Behavioral abnormalities after right hemisphere stroke' (1983) 33 (3) Neurology <https://doi.org/10.1212/WNL.33.3.337 > accessed 15 July 2022.

[303] Tim Bayne, 'The Unity of Consciousness and the Split-Brain Syndrome' (2008) 105 (6) The Journal of Philosophy <https://jstor.org/stable/20620103> accessed 15 July 2022.

[304] Julian Jaynes, *The origin of consciousness in the breakdown of the bicameral mind* (Mariner Books 2000).

[305] Ibid.

[306] Ibid.

[307] Ibid.

consciousness followed the bicameral mind and the fourth idea is the neurological model for the bicameral mind.

Another perspective of the mind-body dualism is Anil Seth's ambitious new attempt to identify the basic substrates of consciousness.[308] Anil Seth, an England-based neuroscientist, believed that the puzzle of consciousness could not be solved by neuroscience alone but by other branches of science, including philosophy. He considered David Chalmers' submission that consciousness is a "hard problem" as a pessimistic view. In his book titled "*Being you- a new science of consciousnes*s," Seth discussed how the mystery of consciousness becomes clearer as we understand its science.[309] In addition to arguing that our conscious experience comes from the predictive models of the brain rooted in the need for us to continue to live, he proposed that the free-energy principle gives a way of explaining how the brain works.[310] For one to be conscious, some brain features must function in certain ways, and understanding how these properties work in humans and other species would offer clues about the mystery of consciousness. He proposed that the brain actively constructs perceptions used for survival in all organisms.[311] Therefore, we see the world from our perspective and not necessarily the way it is. Seth also echoed the Integrated Information Theory of consciousness and said that it is necessary to further explore the integrated qualities of consciousness.[312] Although he was not entirely convinced that consciousness requires substrate, he tended to lean more towards the idea that it is substrate-dependent. Consciousness is a form of information processing that requires some sort of substrate.

William James and F. W. H. Meyers proposed the filter theory, which suggests that consciousness is outside the physical body and the mind and that the brain serves as a receiver

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[308] Anil Seth, *Being you- a new science of consciousness* (Dutton 2021).

[309] Ibid.

[310] Ibid.

[311] Ibid.

[312] A Pedro and others, 'The strength of weak integrated information theory' (2022) 26 (8) Trends in Cognitive Sciences <https://doi.org/10.1016/j.tics.2022.04.008> accessed 15 July 2022.

of consciousness.[313] The brain acts as a filter or a reducing valve that selectively from an array of experiences from the source(s). Therefore, the thoughts do not originate from the brain; the brain only collects and processes these thoughts. This phenomenon is likened to a radio or TV function, where they receive and filter signals from outside through the antenna. This theory did not explicate how the consciousness is physically located away from the body or brain, or perhaps a non-physical entity interacts with the brain. Our bodies and minds are important parts of a system that continuously interact with the environment to generate subjective realities.[314] This view is consistent with dualism. However, medical professionals are sceptical about how nonbiological explanations can be used to explain illnesses.[315] Exploring the "supraliminal" and "subliminal" consciousness, Meyers envisioned a veil between our conscious minds, the sub-conscious, and a greater consciousness outside with numerous experiences from creativity and genius to telepathy and clairvoyance, a matter of the porosity of the veil.

Several forms of body-mind dualism have been described in the literature. These views give unique viewpoints on the relationship between mental phenomena and the body and thus bring to perspective the hard problem of consciousness. Substance or Cartesian dualism echoes the views of Descartes about the mind and body interacting at the pineal gland in the brain.[316] This form of dualism is subdivided into interactionism and parallelism.[317] Interactionism, the more popular form of substance dualism holds that the body and the mind (mental state) interact in a cause-effect manner while parallelism rejects such a relationship.[318] Various philosophers

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[313] Edward Kelly and others, *Irreducible mind: Toward a psychology for the 21st century* (Rowman & Littlefield publishers, Inc 2007).

[314] Neeta Mehta (n278).

[315] Grant Duncan, 'Mind-body dualism and the biopsychosocial model of pain: What did Descartes really say?' (2000) 25 (4) Journal of Medicine and Philosophy <https://pubmed.ncbi.nlm.nih.gov/10916180/> accessed 10 July 2022

[316] Moncef Berhouma 'Beyond the pineal gland assumption: a neuroanatomical appraisal of dualism in Descartes' philosophy' (2013) 115(9) Clinical neurology and neurosurgery <https://doi.org/10.1016/j.clineuro.2013.02.023> accessed 2 May 2021.

[317] Howard Robinson, 'Dualism' (Stanford Encyclopedia of Philosophy, 11 September 2020) <https://plato.stanford.edu/archives/fall2020/entries/dualism/> accessed 31 May 2021.

[318] Ibid.

including Gilbert Ryle have criticised Cartesian dualism.[319] It has gradually fallen out of favour in the body-mind arguments mainly due to its linkage with theological views.[320] Having said that, a few philosophers like Swinburne and Foster still favour substance dualism.[321] The main challenge facing this view is how to explain the transfer of energy from the physical to the non-physical realm without violating the fundamental tenets of the conservation of energy.[322] A plausible argument would be that any diffuse damage to the brain like in PVS or localised damage to some brain regions like in a stroke would always lead to a corresponding mind disorder.

Property dualism is another form of dualism which is a modest version of the view and a rather popular form of dualism.[323] This view holds that mental properties (like beliefs and emotions) exist as well as physical properties (brains), but the former cannot be reduced to the latter and the two properties are not identical.[324] One can argue that this is not actually dualism in any proper sense but simply the rejection of physicalism that is simply described as dualism for want of the theorists concerned developing an additional classification. Since consciousness cannot be explained satisfactorily using the brain's physical properties, this view suggests that there are mental properties in or supervene on the brain to bring about a conscious mental state.[325] Therefore, saying that a patient diagnosed as PVS lacks consciousness solely based on negative evidence by physical means without regard to the mental component of consciousness is illogical. Other forms of dualism mentioned in the literature are epiphenomenalism and

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[319] Julia Tanney, 'Gilbert Ryle' (Stanford Encyclopedia of Philosophy, 12 May 2021). <https://plato.stanford.edu/archives/sum2021/entries/ryle/> accessed 31 May 2021.

[320] Ibid.

[321] John Foster, *The Immaterial Self: A Defence of the Cartesian Dualist Conception of Mind* (Routledge, 1996).

[322] Brian Pitts, 'Missing Features in Its Nature and Justification and Why They Matter' (Foundations of Science, 4 April 2020) <https://doi.org/10.1007/s10699-020-09657-1> accessed 27 June 2021.

[323] Robinson (n 317).

[324] Ibid.

[325] Jaegwon Kim, *Supervenience and Mind* (Cambridge University Press, 1993).

panpsychism.[326] The doctrine of epiphenomenalism which is credited to Thomas Huxley holds that mental states are by-products of brain events and do not exact any causal effects on the physical form.[327] These inert mental properties like sensations, ideas, and volition are called 'epiphenomena' and are said not to cause anything physical. This assertion perhaps might be misleading in the sense that science has shown us that these two realms have an interaction. Even things like not getting enough vitamins, for example, can affect one's mental state as can being punched in the head or otherwise subjected to brain trauma.[328] It is possible to acknowledge those physical influences on mental state without reductively holding them to be determinative. Panpsychism, by contrast, holds that all material things have some mental components.[329] This view is rather extreme and eccentric, which explains its lack of popularity among philosophers. However, some philosophers gave the view some consideration. David Chalmers proposed a variant of panpsychism called 'panprotopsychism', which posits that proto-consciousness rather than consciousness is fundamental and ubiquitous.[330] While phenomenal properties characterise consciousness, proto-phenomenal (these properties are not themselves forms of consciousness properties but in combination give rise to forms of consciousness) characterise proto-consciousness.[331]

The dominant view of the concept of PVS is medically reductive and philosophically concordant with the materialism (physicalism) approach to the concept of the mind which holds that the neural activities in the brain give rise to the mind. This view is popular today owing to the scientific and technological advancement of the twenty-first century, which has seen many

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[326] David Chalmers, Panpsychism and Panprotopsychism. in Torin Alter and Yujin Nagasawa (eds), *Consciousness in the Physical World: Perspectives on Russellian Monism* (Oxford University Press 2015) 246-273.

[327] William Robinson, *Understanding Phenomenal Consciousness* (Cambridge University Press, 2004).

[328] Drew Ramsey and Philip Muskin, 'Vitamin deficiencies and mental health: How are they linked?' (2013) 12(1) Current Psychiatry <https://balancewomenshealth.com/wp-content/uploads/2020/03/Vitamin-Deficiencies-and-MH-Current-psych-1.pdf> accessed 21 July 2021.

[329] Chalmers (n 326).

[330] Ibid.

[331] Philip Goff and others, 'Panpsychism' (The Stanford Encyclopedia of Philosophy, 27 May 2020) <https://plato.stanford.edu/archives/sum2020/entries/panpsychism/> accessed 21 July 2021.

philosophical postulations going out of fashion. Despite the unrelenting efforts of neuroscientists to rationalise the body-mind mystery, the physicalist view continues to attract many criticisms. A knowledge void still needs to be filled between the physical and mental state in the quest to explain consciousness in general. More specifically, there is an explanatory gap in the overall concept of PVS and its relationship to consciousness.[332] This hard question has eluded science for almost four decades.[333] Thomas Nagel and Frank Jackson acknowledged the epistemological shortcomings of physicalism view in their seminal writings.[334] We are yet to know all that there is to know about the mind and consciousness, and it appears that the missing knowledge is not embedded in the physical matter. Suppose there is a knowledge gap in our explanation of VS or PVS with the very sophisticated technologies available today. In that case, it can be logically surmised that there must be some non-physical component to it. Consciousness is intrinsic to the person experiencing it and cannot be objectively verified by a third party despite today's scientific measures. We may reasonably deduce that consciousness is an irreducible part of nature to an extent.[335]

Some critics of materialism have also argued that the hard problem is a mystery beyond human comprehension and claimed that the limitations to human understanding would make it impossible for humanity to unravel the mystery behind consciousness.[336] McGinn even claimed that science is unlikely to reveal the part of the brain or the brain's specific process, which gives rise to conscious experience.[337] However, some experts have argued that this limitation is only

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[332] Joseph Levine, *On Leaving out what it's like. In M. Davies and G. Humphreys, eds. Consciousness: Psychological and Philosophical Essays* (Blackwell 1993).

[333] Jonathan Shear, *Explaining Consciousness: The Hard Problem* (Cambridge Press 1997).

[334] Frank Jackson, 'What Mary didn't Know' (1986) 83 Journal of Philosophy <https://doi.org/10.2307/2026143> accessed 15 June 2021.

[335] David Chalmers, *The Conscious Mind: In search of a fundamental theory* (Oxford University Press 1996).

[336] Colin McGinn, 'Can we solve the Mind-Body Problem?' (1989) 98(391) Mind <https://jstor.org/stable/2254848> accessed 22 March 2021.

[337] Ibid.

temporary and that the mystery is solvable in principle.[338] There have been some promising innovations in the science of consciousness (e.g. TMS-EEG) and going by the principle of sufficient reason, there has to be an underlying mechanism for consciousness.[339] The notion of philosophical zombies in contemporary philosophy has also been used to criticise materialism. David Chalmers brought this idea to notice, and it is a notion that refers to conceivable creatures identical to human beings but lacking subjective experience.[340] The fact that there are zombies who are indistinguishable from us materially but lacks consciousness will negate the idea that consciousness comes from physical properties.[341] Although the debate on zombies is extensive in the literature, there are arguments and counterarguments to the concept.[342] But the main counterargument is that the fact that the notion is conceivable or plausible does not mean that it is possible; therefore, it should not be used to draw metaphysical inferences about the real world.

Materialism in the literature has a host of forms, but the two most popular forms are the two identity theories regarding how the mind is related to the body.[343] These theories are the type identity theories and the token identity theories.[344] The former postulated that some mental states are represented in the brain and therefore identical.[345] On the other hand, the token-token identity theory posits that every conscious mental event can be identified with some brain processes or events.[346] Token identity proposed a weaker mind-body relationship than the type identity, but identity theory is preferable among philosophers. Another interesting view is

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[338] Marcello Massimini and Guilio Tononi*, Sizing up consciousness: Towards an objective measure of the capacity for experience* (OUP Oxford 2018) 98- 120.
[339] Ibid 61.
[340] Chalmers (n 326).
[341] Massimini and Tononi (n 338) 9.
[342] Kirk, R. *Zombies and Consciousness* (Oxford University Press 2005).
[343] Charles Wolfe, 'Diderot and materialist theories of the self' (2015) 9(1) Society and Politics <https://philpapers.org/archive/WOLDAM.pdf>accessed 25 May 2021.
[344] Frank Jackson and others, 'Functionalism and type-type identity theories' (1982) 42 Philosophical Studies <https://doi.org/10.1007/BF00374035 >accessed 2 May 2021.
[345] Ibid.
[346] Ibid.

functionalism, which is a viewpoint that the components of the conscious mental state are the functional roles played within the cognitive system, and not the physical matter.[347] Some philosophers who are advocates of materialism have completely disregarded the idea of mind and mental state or at the very least claimed that the notion is flawed and that the concept of consciousness is jumbled.[348] However, not all philosophers who believe in materialism accept that consciousness can be satisfactorily explained by using only the brain's physical properties; therefore, consciousness cannot be reduced to the physical.[349] Thus, we can conclude that these philosophers are partial materialists.

Various theoretical accounts of consciousness

Historically, various postulations have been made about consciousness and its relationship to the mind and the brain. These theories are grouped into two: 1) physicalist; and 2) mentalistic terms.[350] In the physicalist term, the theories take a neurophysiological approach to explain the concept of consciousness. Contrastingly, mentalistic theories use cognitive concepts to explain consciousness. While there are various postulations about the neural correlates of consciousness (NCC) in the literature, the common denominator of these theories is that some neural mechanisms in the brain give rise to consciousness.[351] This assumption suggests that some neurochemical processes in the brain can be used to explain the conscious experience in human beings.[352] Many researchers in the past have tried to explain

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[347] Ibid.

[348] Kathleen Wilkes, 'Is Consciousness Important?' (1984) 35 British Journal for the Philosophy of Science <https://philpapers.org/rec/WILICI>accessed 25 May 2021.

[349] Robert Van Gulick, Nonreductive Materialism and Intertheoretical Constraint, In A. Beckermann, H. Flohr, J. Kim, eds. Emergence and Reduction (Berlin and New York: De Gruyter, 1992) 49-54.

[350] Donelson Dulany, 'What explains consciousness? Or…What consciousness explains?' [2014] 12(1) Mens Sana Monographs <https://ncbi.nlm.nih.gov/pmc/articles/PMC4037891/>accessed 30 May 2021.

[351] Andrea Nani and others, 'The Neural Correlates of Consciousness and Attention: Two Sister Processes of the Brain' (2019) 13 Frontiers in Neuroscience <https://frontiersin.org/article/10.3389/fnins.2019.01169>accessed 13 May 2021.

[352] Ibid.

consciousness using the neural mechanism. A study proposed that the nerves' reverberatory circuits from the visual cortex to the thalamus play are crucial to consciousness and short-term memory.[353] However, these processes can occur in the brain with or without consciousness. The concept of NCC has invited criticism from some researchers that the mere correlation of activities in the brain with consciousness is not enough to explain the concept.[354]

Representational theories are known to use mental representations to explain consciousness.[355] They proposed three major forms of mental representations which are first order (FOR), high order (HOR), and hybrid representational accounts (HRA).[356] The FOR theories were pioneered by Fred Dretske and Michael Tye but the theories later became popular with other philosophers.[357] FOR theorists postulated that the sensory representations of consciousness are directly available to the person.[358] A representation determines a conscious state therefore being conscious is a product of these representations.[359] Each representation has content, but the content is not identical to the representation.[360] Sometimes the content can be fictitious and about abstract things. The representation of phantom things explains the existence of illusions, dreams, and hallucinations. However, this theory holds that not every representation with content is conscious. Some have argued that representational properties cannot be used to explain conscious experience.[361] Phenomenal consciousness is like

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[353] Francis Crick, *The Astonishing Hypothesis: The Scientific Search for the Soul* (Scribners 1994) 249.

[354] David Chalmers, *what is a neural correlate of consciousness? in Thomas Metzinger (eds), Neural Correlates of Consciousness* (MIT Press 2000) 17-39.

[355] William Seager, *Theories of consciousness: An introduction and assessment* (Routledge London and New York 1999) 132.

[356] Ibid.

[357] Michael Tye, *Consciousness, Color, and Content* (MIT Press 2000); Fred Dretske*, Naturalizing the Mind* (The MIT Press 1997); Paula Droege, *Caging the Beast*. (John Benjamins Publishers 2003).

[358] Ibid.

[359] Neil Mehta and George Mashour, ‘General and specific consciousness: a first-order representationalist approach’ (2013) 4 Frontiers in Psychology <https://frontiersin.org/article/10.3389/fpsyg.2013.00407> accessed 2 May 2021.

[360] Fred Dretske, ‘Experience as representation’ (2003) 13(1) Philosophical Issues <https://doi.org/10.1111/1533-6077.00005> accessed 23 May 2021.

[361] Ned Block, ‘Mental paint and mental latex’ (1996) 7 Philosophical issues <https://www.jstor.org/stable/1522889 > accessed 23 May 2021.

experiencing something, for example, what is like to see an apple.[362] While reflexive consciousness is the form of awareness that gives us the ability to reflect on ourselves.[363] John Locke expressed consciousness *'...as the perception of what passes in a man's own mind*'.[364] Proponents of the higher-order theories define consciousness from the high order state's point of view which states that the object of a meta-physical state is what determines whether a mental state is conscious or unconscious.[365] This is referred to as the higher-order representation as enshrined in two fundamental theories namely the theories of the higher-order thought (HOT) and higher order perception (HOP).[366] These philosophies posit that human beings express consciousness in reference to thoughts and awareness. Higher-order theories have been described in different forms in the literature. David M Rosenthal advocated the HOR and expressed it as a form of thought while theorists like William Lycan said that HOR is a perception.[367] Although some philosophers have noted that the concept is secular in nature.[368] Regarding HOT theories, there is criticism about the need for a high cognitive function therefore, infants and people with intellectual disabilities who lack the mental sophistication required for HOT would be regarded as being unconscious.[369]

In the HOR, the higher order is said to be extrinsic to the mental state.[370] However, there are other increasingly popular accounts that these meta-psychological states are intrinsic to the conscious state. This hybrid representational account was named by Rocco Gennaro as the 'wide intrinsicality view'.[371] He said that the conscious state should be seen as a global brain

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[362] Robert Van Gulick, 'Consciousness' (Stanford Encyclopedia of Philosophy, 20 March 2018) <https://plato.stanford.edu/archives/spr2018/entries/consciousness/> accessed 31 May 2021.

[363] Mark Bickhard, 'Consciousness and reflective consciousness' (2005) 18(2) Philosophical Psychology 205-218.

[364] John Locke, An Essay Concerning Human Understanding (Ed. P. Nidditch. Oxford: Clarendon, 1689/1975).

[365] Seager (n 355) 132-152.

[366] Ibid 153-177.

[367] William Lycan, *Consciousness and Experience* (Cambridge, MA: MIT Press, 1996).

[368] Fred Dretske, *Naturalizing the Mind* (Cambridge, MA: MIT Press, 1995).

[369] Seager (n 355).

[370] Rocco Gennaro, *The Consciousness Paradox: Consciousness, Concepts, and Higher-Order Thoughts* (Cambridge, MA: MIT Press, 2012) 15.

[371] Ibid.

state that comprises perceptual input received passively together with its accompanying higher-order conceptual activity. Similarly, Robert Van Gulick emphasised and recognised the higher-order state as an integral part of an all-encompassing global state of consciousness.[372] This alternative higher-order view was called the global state of higher-order.[373] The unconscious and lower-order state have intrinsic self-awareness that facilitates the exploration as a larger state during a state of consciousness. Therefore, Rocco Gennaro and Van Gulick recognised that the global state of the brain is a representation of a conscious state that can be comprehended materialistically. Hence, the treatment of the first-order state as an integral component of a greater cortical state. Uriah Kriegel and Kenneth Williford supported this view and proposed a self-representational theory as a name for their postulation which stated that '*…mental state is conscious if and only if it represents itself in the right way…*'[374] Their argument relates to the perception of the conscious mental state as being reflexive or self-directed. David Rosenthal called these theories intrinsic higher-order theories.[375] Thomas Metzinger proposed a concept of higher-order binding, which is a process where consciousness unifies experience.[376]

There are other cognitive theories among which the multiple draft model of consciousness (MDM) and global workspace theory (GWT) seem to be the most popular theories.[377] Daniel Dennett proposed the MDM theory, which is somewhat like representationalism.[378] It states that parallel processes of interpretation in the brain are

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[372] Ibid.
[373] Ibid.
[374] Kenneth Williford and Uriah Kriegel, *Self-Representational Approaches to Consciousness* (MIT Press 2006) 1-7.
[375] David Rosenthal, *Varieties of higher-order theory. in Rocco Gennaro (ed), Higher-Order Theories of Consciousness: An Anthology* (John Benjamins Publishing Company 2004) 30-31.
[376] Thomas Sturm, 'Consciousness regained? Philosophical arguments for and against reductive physicalism' (2012) 14(1) Dialogues in clinical neuroscience <https://ncbi.nlm.nih.gov/pmc/articles/PMC3341650/> accessed 24 May 2021.
[377] Rosenthal (n 375) 230.
[378] Daniel Dennett, *Sweet Dreams: philosophical obstacle to a science of consciousness* (MIT Press 2005).

constantly reviewed, and these give various mental activities. It sees the self as a resultant effect of a narrative that occurs over a period and not as an inner observer. Dennett embraced the assumption that there is no clear demarcation between unconscious and conscious mental states. He advocated the use of a third person (heterophenomenological) approach rather than a first person (phenomenological) to investigate unconsciousness. Furthermore, Bernard Baar proposed the GWT, which is more popular with psychologists, although neuroscientists seem to be embracing the theory more these days.[379] The concept looks at the cognitive system as a form of a global workspace where unconscious and conscious processes compete for attention. Global access to specific messages in the brain results in consciousness. The quantum views to solving the mystery behind the concept of consciousness have also been explored in the literature. The idea behind this assumption is that consciousness is in some ways related or correlated to physical brain activities and that quantum theory could be used to understand the concept of consciousness.[380]

Quantum theory is the study of sub-atomic particles or the smallest particles of matter. These approaches assumed that the site of consciousness is located at a fundamental particle level. As exciting as it may seem, these approaches are rather radical and maybe a little bit too ambitious. Roger Penrose[381] and Stuart Hemeroff[382] a physicist and an anaesthesiologist respectively have been at the forefront of pushing this idea. Their fundamental principle is that consciousness is a resultant effect of the quantum phenomenon in the microtubules.[383] The complexity in this approach is that the quantum phenomenon in itself is a mysterious natural

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[379] Bernard Baars, *In the theater of Consciousness: the workspace of the mind* (New York: Oxford University Press 1997).

[380] Carlos Maldonado, 'Quantum physics and consciousness: a (strong) defense of panpsychism' (2018) 41(7) Trans/Form/Ação <https://doi.org/10.1590/0101-3173.2018.v41esp.07.p101> accessed 25 May 2021.

[381] Roger Penrose, *Shadows of the Mind: A search for the missing science of consciousness* (Oxford University Press 1994).

[382] Stuart Hemeroff, 'Quantum mathematical cognition requires quantum brain biology: The "Orch OR" theory' (2013) 36(3) Behavioral and Brain Sciences < https://doi.org/10.1017/S0140525X1200297X>accessed 3 May 2021.

[383] Ibid.

phenomenon. Therefore, using quantum to explain consciousness is like trying to use one mystery to unravel another mystery. It is no secret that science has improved our knowledge and understanding of the concept of consciousness in relation to the body and the mind. However, the science of consciousness is still lacking in many vital areas of unravelling the knowledge gap. In a similar vein, Karl Pribam theorised that the mathematical elucidations of the cell processes and their branches as well as how they interact with each other anatomically and functionally when mapped give a description similar to that of quantum events.[384] He used this to explain how the brain works and referred to the brain as escaping to higher and higher orders of complexity. This hypothesis could also be related to the early Goldstein thesis that the system is holistic – after observing the brain of injured soldiers, he saw how other parts of the brain would seek to compensate for lost functions to maximise the working of the whole brain.[385]

The quest by neuroscientists to find the NCC has produced a host of postulations, some of which are rather compelling.[386] Gerald Edelman proposed that the re-entrant cortical feedback loops in all neural circuits in the brain might be responsible for consciousness.[387] Furthermore, Hans Flohr also postulated that N-methyl- D- aspartate (NMDA) – neurotransmission of information might be responsible for conscious mental state.[388] This theory was born from the inference that since anaesthetic agents tend to abolish consciousness by disrupting the effect of NMDA on the NMDA receptors, this might be responsible for the

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[384] Shelli Joye, 'The Pribram-Bohm hypothesis: A topology of consciousness' (2016) 12(2) The journal of natural and Social Philosophy <http://cosmosandhistory.org/index.php/journal/article/view/552> accessed 25 August 2021.

[385] Ibid.

[386] Chalmers (n 354).

[387] Gerald Edelman and Joseph Gally, 'Reentry: a key mechanism for integration of brain function' (2013) 7(63) Frontiers in Integrative Neuroscience < https://frontiersin.org/articles/10.3389/fnint.2013.00063/full > accessed 3 May 2021.

[388] Hans Flohr, 'Unconsciousness' (2006) 20(1) Best Pract Res Clin Anaesthesiol. <https://doi.org/10.1016/j.bpa.2005.08.009> accessed 3 June 2021.

conscious mental state.[389] Damasio also postulated the several processes that characterise the emotive somatosensory haemostasis within the frontal lobe can lead to these phenomenal experiences.[390] While all of these theories are logical to a certain extent, they are yet to convincingly show how these pathways or activities are related to consciousness. In 2006, Victor Lamme proposed the recurrent processing theory of consciousness where he postulated that the recurrent sensory processing in the sensory regions of the cerebral cortex, which involve feed forward and feedback pathways, is responsible for perceptual consciousness whether it is accessible to the person or a third person.[391] Unlike any other organ or tissue in the body, the brain's processing of information is integrated.[392] This theoretical framework was proposed by Dr Guilio Tononi in 2004.[393] The idea behind this theory is that the brain cells have specialised properties for processing information received. When the threshold for consciousness is reached it can be used to predict the subject's quality of conscious experience. The measurement for the degree of integration of information in the brain was called 'phi'. The higher the value of phi, the more integrated the information in the system is and consequently, the more conscious the system.[394] This theory, in principle, can be used to assess consciousness in non-communicating patients like PVS. The problem with the theory is that the way information is processed by different brain regions remains unclear.[395]

All the above theories of consciousness offer a plausible explanation of the concept of consciousness. Even though there is still an explanatory gap on how consciousness emanates

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[389] Chalmers (n 354).

[390] Antonio Damasio, *The Feeling of What Happens: Body and Emotion in the Making of Consciousness* (New York: Harcourt 1999).

[391] Victor Lamme, 'Towards a True Neural Stance on Consciousness' (2006), 10(11) Trends in Cognitive Sciences <https://doi.org/10.1016/j.tics.2006.09.001> accessed 10 May 2021>; Victor Lamme, 'How Neuroscience Will Change Our View on Consciousness' (2010) 1(3) Cognitive Neuroscience <https://doi.org/10.1016/j.tics.2006.09.001> accessed 10 May 2021.

[392] Guilio Tononi, 'An information integration theory of consciousness' (2004) 5(42) BMC Neuroscience <https://doi.org/10.1186/1471-2202-5-42> accessed 10 May 2021.

[393] Ibid.

[394] Ibid.

[395] Jerome Feldman, 'The neural binding problem(s)' (2013) 7(1) Cogn Neurodyn <https://doi.org/10.1007/s11571-012-9219-8> accessed 25 May 2021.

from the brain, it is clear that the medical profession's physicalism approach to defining the PVS notion is fundamentally flawed. Philosophical psychopathology, the idea of trying to understand consciousness from how conscious mental state is affected in some disease states other than PVS, could determine the complexity of the mind-body problem. For example, in dissociative identity disorder, the individual experiences at least two distinct personalities with each state having its way of thinking. It can be argued that such persons may have more than one centre of consciousness in their bodies. Similarly, in split-brain patients where a procedure called commissurotomy (where the fibres connecting the two cerebral hemispheres are separated, this procedure is out of fashion these days) is performed for refractory epilepsy. Some have argued that the two brain hemispheres harbour two independent consciousness.[396] There is even a plausible theory that the isolated right hemisphere cannot express its conscious state because it lacks a language centre.[397] Findings in memory disorders like amnesia also give rise to questions like whether there is a requirement of some sort of autobiographical memory for consciousness. Be that as it may, there is overwhelming evidence that scientific and philosophical understanding regarding the relationship between consciousness, brain, and PVS is insufficient to answer whether PVS is a valid concept. The consequence of accepting the status quo of the PVS label in people is that such a diagnosis proposes that the individual is irreversibly unconscious and thus dismisses other possibilities. Assumptions are made that anyone diagnosed as in PVS must be unconscious; the implication is that not enough is done to protect the patient. The medical profession accepts that PVS indeed is a valid concept even though the concept of consciousness is not fully understood.

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[396] Edward H.F de Haan and others, 'Split – Brain: What we know and why this is important for understanding consciousness' (2020) 30 Neuropsychology Review <https://doi.org/10.1007/s11065-020-09439-3> accessed 1 May 2021.

[397] Michael Gazzaniga, 'The split-brain: Rooting consciousness in biology' (2014) 111(51) Proceedings of the National Academy of Science of the United States of America < https://doi.org/10.1073/pnas.1417892111> accessed 22 May 2021.

In summary, this chapter gave an overview of the knowledge of PVS as we know it today and the clinical characterisation of the condition. It critically evaluated the various views on the relationship between the mind, body, and consciousness. It then went on to propose that there is a questionable association between the brain and the mind as regards the so-called PVS label. The area of controversy explored include the validity of the PVS label, the use of a persistent or permanent label, the limitations in the use of clinical scales and ancillary investigations, sentience, as well as the controversies ensconcing the diagnosis of PVS. All these observations and arguments around the concept of PVS reveal that the notion is fundamentally flawed, which then exemplifies the need to revisit ways of a diagnosing and treating these patients. Taking a principled approach perhaps in the form of a theory to defining consciousness in people with brain injury would give a broader perspective on treating people with brain injury. This theory about how consciousness is generated in these patients' brains should recognise that the physical influences the non-physical but there is no clear evidence that it is determinative of it. Finally, this chapter concludes that the concept of PVS is not evidentially grounded. This conclusion will provide the backdrop for the empirical research in chapter 5 that would look at the health care professionals' views on all these salient issues raised in this chapter and compare their opinions to the conclusion drawn in this chapter.

2.8. Conclusion

When someone has a brain injury, he/she becomes unconscious and appears to be unable to interact with the immediate environment. The medical professionals then diagnose PVS based on criteria put forward by the MSTF on PVS. This chapter argued that the characterisation of such a state is not based on well-grounded scientific and philosophical research. The diagnosis is mainly based on the inability of the doctors to evidence clinical features associated with consciousness and the inability of the available technologies to prove otherwise. While it remained unknown how the brain is related to the mind and consciousness, it would be unnerving to make the presumption of permanence, persistence, or bad prognosis on the grounds of limited evidence. Therefore, there is a strong need to adopt a different approach to diagnosing and treating these people. It is also necessary to develop a new theoretical approach to defining consciousness in people with brain injuries. Finally, there should be a critical consideration for ditching this term and revising the professional guidelines and ethical approaches to their management owing to the prejudices associated with the term PVS.

CHAPTER THREE

Developing an ethical lens through which to critique care of those labelled PVS

3.1. Introduction

All human beings should be involved in every treatment decision being proposed or administered to them in an ideal world.[398] Patients diagnosed as PVS in practice cannot exercise this fundamental duty because of the insult to their brains unless there is a relevant advance statement that indicates things like their wishes, values, beliefs, and treatment preferences. The default situation is that the healthcare professionals will have to work out what course of action best reflects their interests, including what treatment options if any. The Courts, in some cases, have allowed life maintaining treatments to be withdrawn or withheld from PVS patients. Some judges say that these patients have no interests and therefore argue that the treatment cannot be in their best interests. The Mental Capacity Act 2005 (MCA 2005) gives guidance on how to objectively determine best interests. However, the inherently subjective nature of the concept opens it to a variety of interpretations.

In this chapter, I offer a critical discussion, analysis, and selection of potential benchmarks for how we approach people deemed to be in a PVS. The four different approaches evaluated are principlism, normative, inherent worth-based, and human rights approach. I argue that the prevailing approach used in clinical practice (principlism approach) is fundamentally inadequate in solving ethical issues PVS patients face. Rather than adding more principles to the pre-existing ones, the need of the hour is a fundamental rethink on how medical practitioners should approach these complex ethical issues. I also contend that while one might think of a human rights approach as a separate entity, it is arguably a version of principlism

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[398] Sheila McClean, 'Legal and ethical aspects of vegetative state' (1999) 52(7) Journal of Clinical Pathology <https://ncbi.nlm.nih.gov/pmc/articles/PMC501487/>accessed 25 March 2021.

because it lacks an overarching theory but entails weighing competing principles. In addition, I point out that the normative approach involves weighing theories with competing views. Although we may find common grounds in their applications, they do not have a common denominator. More importantly, their use involves extensive use of moral calculations, which makes their practical use complex. In the end, I propose a worth based approach to ethics as a lens or benchmark for decision making in patients diagnosed as PVS. This fits with the existing normative order in terms of both human rights and health law.

3.2. A principlism approach.

This approach is an applied approach to resolving ethical dilemmas by using standard principles of medical ethics as first proposed in the 'Belmont report' in 1976.[399] Beauchamp and Childress subsequently promoted this general approach used in clinical practice.[400] The analysis in this section will involve a critical appraisal of this method of bioethics to medical decision-making concerning treatment withdrawal/withholding in patients labelled as PVS. After discussing the four principles of medical bioethics, there will be a brief analysis of other ethical considerations relevant to decision making in patients diagnosed as PVS. At the end of this section, I argue that this approach is fatuous and fundamentally insufficient in dealing with the issues faced by these patients.

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[399] Kenneth Ryan and others, 'The Belmont Report Ethical Principles and Guidelines for the Protection of Human Subjects of Research' (Office for Human Research Protections, 18 April 1979) <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html> accessed 12 June 2021.

[400] Tom Beauchamp and James Childress, *Principle of biomedical ethics* (OUP 7th ed, 2013).

Medical Care Principles

As the world evolves and the ability to prolong life advances, it becomes imperative to address the complex issues arising from the practice of withholding and withdrawing treatments in patients. Since they constitute non-everyday forms of touching, medical interventions require legal justification to avoid falling foul of criminal, civil, and human rights law protection of the person. The most common justification used is the consent of the prospective subject of the intervention. Indeed, it is trite that as a general rule intervention cannot be justified without the consent of its prospective subject. However, there are exceptions, including rules that allow intervention considered to be in the best interests of the incapable adult to be justified where (s)he does not have a valid advance refusal in place. Applying the standards of best interests can be very challenging. This is not least the case with respect to disorders of consciousness where it may be impossible or impractical to ascertain from the adult what his or her preferences are and there may often at best be only limited relevant knowledge of his or her wishes, values, and beliefs PVS decisions have proved especially challenging. The role of lifesaving/maintaining interventions in ameliorating pain and suffering in PVS is still a subject of rigorous debate. It remains unclear whether these patients can feel pain or in fact experience any pleasure.

Beauchamp and Childress made a bold claim that all medical professionals can use their four fundamental bioethical principles universally.[401] However, some of their critics would disagree with this statement. Some have even argued that the principles are sets of loosely related matters that lack systematic interactions and that they often have conflicts when used to resolve moral problems in practice.[402] They alleged that the conflicts in the use of the principles have been left unsolved by the authors. Nowadays, ethical principles are deployed

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[401] Ibiid.

[402] Clouser, Danner and Bernard Gert, 'A critique of principlism' (1990) 15(2) Journal of Medicine and Philosophy <https://pubmed.ncbi.nlm.nih.gov/2351895/>accessed 25 March 2021.

in decision making regarding treatment options for patients. Several ethical approaches have been described in the literature. However, the four fundamental principles by Beauchamp and Childress seem particularly popular among healthcare professionals.[403] This approach is not self-justifying, and it is liable to varying interpretations. One of its shortcomings is the difficulty in knowing which principle should take precedence when two or more of the principles are in conflict. It can, in effect, simply reinforce existing opinions and prejudices, which would be a vacuous approach in such important cases. This pluralistic theory claimed that the four principles carry equal weight in decision-making but in reality, one appears to weigh more than the others do. For example, when using the principlism to decide whether to withdraw CANH in a PVS patient, autonomy or justice is likely to take precedence over beneficence or non-maleficence. The main issue with the application of these principles in medical practice is that there is no guidance on how to resolve tensions between competing principles. Some critics have said that these are attributed to the fact that the principles are derived from incompatible philosophical theories.[404] Furthermore, Charles Foster believes that the principles are derived from dignity and that the answer to the inadequacy of this approach is embedded in dignity as a concept.[405] This assertion has merit because those bioethical principles are somewhat a reflection of normative ethics and it would not be wrong to say they are ultimately a derivative of dignity.

Autonomy in bioethical terms is generally regarded as self-determination but a further dig into the principle will expose at least two other conceptions of autonomy.[406] The definition of autonomy in this thesis will be limited to self-determination as the other conceptions are

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[403] Beauchamp and Childress (n 400).

[404] Danner Clouser, 'Common morality as an alternative to principlism' [1995] 5(3) Kennedy Institute of Ethics Journal <https://pubmed.ncbi.nlm.nih.gov/11645307/>accessed 25 March 2021.

[405] Charles Foster, 'Putting dignity to work' (2012) 379(9831) The Lancet <https://doi.org/10.1016/S0140-6736(12)60885-X> accessed 29 July 2021.

[406] Lisa Dive and Ainsley Newson, 'Reconceptualizing Autonomy for Bioethics' (2018) 28(2) Kennedy Institute of Ethics Journal <https://muse.jhu.edu/article/700750> accessed 29 July 2021.

beyond the scope of the discourse. The respect for autonomy is the acknowledgment that everybody is entitled to know about treatment options and benefits before deciding on whether to receive it or not and they are given the freedom of choice and preferences.[407] This respect can be either a positive or a negative obligation.[408] A positive obligation involves actions that encourage patients to make an autonomous decision while a negative obligation involves no particular actions in the quest to protect autonomy.[409] While patients diagnosed as PVS cannot decide on their own, the determination of the type of treatment they get is premised on their previously expressed wishes. Binding advanced directives if relevant will help the treating team to know what the patient's wishes are when they were mentally competent. Furthermore, other legally allowed proxy health care decision-makers (e.g. welfare attorneys), and relatives may also contribute to the discussion about best interests but they cannot decide on behalf of the patient.[410]

The wishes of the patient are usually obtained from the members of the family in this instance.[411] This is because they spend most of the time with the patient and thus, they can convey the thoughts of the patient to the physician. It is in this manner that the wishes of the patient and their views about life can be reconstructed and used to arrive at a decision.[412] However, some patients might have expressed their wish to continue treatment while in the so-called vegetative state. Therefore, all actors must examine and assess all possible situations to

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[407] John Coggon and Jose Miola, 'Autonomy, liberty, and medical decision-making' (2011) 70(3) The Cambridge Law Journal <https://jstor.org/stable/41301008> accessed 2 May 2021.
[408] Pagollang Motloba and Nokukhanya Makwakwa, 'Respecting Autonomy (Part 2)' (2018) 73(7) Ethics <http://dx.doi.org/10.17159/2519-0105/2018/v73no7a7> accessed 29 July 2021.
[409] Ibid.
[410] Rebecca Dresser and John Robertson, 'Quality of life and non-treatment decisions for incompetent patients: a critique of the orthodox approach' (1989) 17(3) Law Med Health Care < https://doi.org/10.1111/j.1748-720X.1989.tb01101.x> accessed 2 May 2021.
[411] Beauchamp and Childress (n 400).
[412] Nicholas Schiff and others, 'Residual cerebral activity and behavioural fragments can remain in the persistently vegetative brain' (2002) 125(6) Brain <https://academic.oup.com/brain/article/125/6/1210/290406>accessed 2 May 2021.

determine the genuineness of the information provided. The provision of any intervening treatment is subjected to the potential benefits attached to such intervention.[413] The burdens resulting from this form of treatment are debated. However, their course of treatment imposes a heavy financial and emotional burden on the family of the patient. This financial burden is usually what drives the decisions made by the relatives of patients diagnosed as PVS as well as other chronically and terminally ill patients. Most of them would not want to appear to be financial burdens to their families, which is why would in principle prefer that their treatments be stopped when they appear to be totally dependent on others. Therefore, in as much as some believe that the patients in the PVS experience and feel nothing, they do incur the financial burden of treatment. Other factors such as religious beliefs and personal views may also influence the decision made by surrogates about treatment options. [414]

It is imperative that the doctors should give all necessary information needed by the patient (this is not feasible in PVS), relatives, or medical power of attorney in order to decide on treatment options, after which consent for treatment may be given or withheld.[415] These rights of autonomy are not limited to current situations but also applicable to future foreseeable situations, which are enabled through advance directives in conformity with the MCA 2005. Furthermore, this principle does not compel doctors to provide care that is not medically indicated or those wherein the doctor is faced with religious objections to (e.g., abortion).[416] In the UK, the right to autonomy does not permit anyone to receive assistance to commit

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[413] Bernard Lo, 'The *Wendland* case – withdrawing life support from incompetent patients who are not terminally ill' (2002) 346 NEJM < https://nejm.org/doi/full/10.1056/NEJM200205093461912>accessed 2 May 2021.

[414] David Thomasma and Joel Brumlik, 'Ethical issues in the treatment of patients with a remitting vegetative state' (1984) 77(2) The American Journal of Medicine < https://doi.org/10.1016/0002-9343(84)90725-3> accessed 2 May 2021.

[415] John Harris, 'Consent and end of life decisions' (2003) 29(1) Journal of Medical Ethics <https://jme.bmj.com/content/29/1/10> accessed 2 May 2021.

[416] Julian Savulescu, 'Conscientious objection in medicine' (2006) 332(7536) BMJ <www.ncbi.nlm.nih.gov/pmc/articles/PMC1360408/> accessed 2 May 2021.

suicide;[417] it is illegal to give such assistance, and thus the ability to obtain it is indirectly circumscribed. Similarly, a patient cannot obtain a treatment that is not medically indicated (i.e., futile, or not in their best interests). However, this assertion is somewhat debatable depending on how one defines ‘medical’. Certainly, some interventions are performed for purely cosmetic reasons, for example. Advanced directives are a form of valid consent, which can be used when someone becomes mentally incompetent to make decisions.[418] The shortfall of this form of consent in those diagnosed as PVS is that they rarely foresee this eventuality. Verbally expressed wishes can be used in the absence of written advanced directives. This form of auxiliary autonomy based on prospectively stated preferences is called prospective autonomy.[419] The other type of autonomy applicable to an individual in a PVS is substitutive autonomy, which is based on substituted judgment regarding the presumed will of the patient.[420] Appointing an appropriate surrogate to decide for a patient is the form of substituted judgement used in the US.[421] The problem with this form of autonomy is that it is the best guess of what someone would prefer, and may be influenced by ill motives by family members or even by close associates. The central questions here are who is the most appropriate surrogate? Does the decision made by the proxy reflect the patient's values? As straightforward as the principle may sound or portrayed to be, it is engulfed in a lot of complexities when dealing with an unconscious person.

Furthermore, the principle of beneficence simply means that the clinician should always strive to only perform interventions that would benefit the patients and that the patient should

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[417] Anne Donchin, ‘Autonomy, interdependence, and assisted suicide: Respecting boundaries/crossing lines’ (2004) 14(3) Bioethics <https://doi.org/10.1111/1467-8519.00190> accessed 2 May 2021.

[418] Thomas Mappes, ‘Persistent vegetative state, prospective thinking, and advance directives’ (2003) 13(2) Kennedy Institute of Ethics journal <https://doi.org/10.1353/ken.2003.0012>accessed 12 April 2021.

[419] Ibid.

[420] John Phillips and David Wendler, ‘Clarifying substituted judgement: the endorsed life approach’ (2015) 41(9) Journal of Medical Ethics < https://jme.bmj.com/content/41/9/723> accessed 2 May 2021.

[421] Ibid.

get the best service available.[422] It may well be likened to the notion that every action must be in the patient's best interests. The doctor must be satisfied that any proposed treatment has potential benefits before commencing such an intervention. The doctors always do a weighing exercise of balancing potential benefits with the risks of any proposed treatment. Equally importantly, the suffering arising from the condition of the patient must be considered. A good example is when a patient with brain damage suffers pain from spasticity. In a situation where no choice appears beneficial, a selection of less harm becomes the preferable approach. This argument brings us to the next principle called non-maleficence.[423] It is the element of medical ethics whereby healthcare providers do everything possible to avoid harming the patient in any way. Medical interventions are not without unwanted harmful effects, but they also save lives and improve outcomes. Therefore, when making choices that might lead to death, it is necessary to consider how many unwanted effects are permissible from the interventions, without disregarding the fact that death itself is a form of harm.

The last principle is justice, which ensures equitable distribution of healthcare resources.[424] It is based on the philosophy of acting impartially to settle the tensions between contending claims. Gillon categories it into distributive, right-based, and legal justice.[425] On the other hand, the principle of justice may be defined with reference to equality or equity. Bioethicists describe equity in healthcare as the '…*absence of systematic disparities in health between groups with different levels of underlying social advantage/ disadvantage…*'[426] This implies that every individual should be able to access healthcare freely irrespective of their

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[422] Tom Beauchamp, 'The Principle of Beneficence in Applied Ethics, The Stanford Encyclopedia of Philosophy (Winter 2016 Edition) <https://plato.stanford.edu/archives/win2016/entries/principle-beneficence/> accessed 2 May 2021.

[423] Christine Harrison, 'Primum non nocere is only the beginning' (2007) 12(5) Paediatrics & Child Health <http://europepmc.org/article/PMC/2528718> accessed 2 May 2021.

[424] Raanan Gillon, 'Medical ethics: four principles plus attention to scope' (1994) 309(6948) BMJ <https://doi.org/10.1136/bmj.309.6948.184> accessed 2 May 2021.

[425] Ibid.

[426] Paula Braveman and Sofia Gruskin, 'Defining equity in health' (2003) 57(4) Journal of Epidemiology & Community Health <https://jech.bmj.com/content/57/4/254.info> accessed 2 May 2021.

race, social status, gender, ethnic or religious group and that there should be no social unjust or unfair health disparities. Furthermore, equality is a social, civic, and legal concept that everybody is equal.[427] Even though sometimes the terms health inequalities and inequities are used interchangeably, the terms equality and equity are not synonymous. The concept of equality is vital in operationalizing and measuring health equity. There is no consensus on how justice in healthcare should be achieved.[428] Ethical issues are usually not formally assessed. To increase the acceptability of these ethical principles, some bioethicists have added the principle of respect for dignity[429] and the principle of veracity[430] but these principles are not generally considered part of principlism. The demerit of these values fails to give answers on how to handle certain situations.[431] The withdrawal of life-saving interventions is viewed by critics as a form of passive euthanasia or rather the deliberate intention of killing someone.[432] It is noteworthy that if healthcare professionals can prove that a form of treatment is futile, it can then ethically be withdrawn - although such a decision might be challenging even at the best of times.[433] While some have asserted that autonomy is the leading ethical principle, it is advocated that all bioethical principles must be balanced when making decisions doctors.

The wishes of patients diagnosed as in PVS are respected regardless of whether or not it can lead to death. Beneficence and non-maleficence have practical concerns, which ensure happiness is restored especially to those around the patient. However, in my opinion, the most important principle is the justice element which states that all people should be treated with

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[427] Leif Wenar, *John Rawls* (Summer 2021 edn, Metaphysics Research Lab, Stanford University 2021)

[428] Norman Daniels, 'Justice, Health, and Healthcare' (2001) 1(2) The American Journal of Bioethics <https://doi.org/10.1162/152651601300168834> accessed 12 June 2021.

[429] Alfred Allan and Graham Davidson, 'Respect for the dignity of people: What does this principle mean in practice?' (2013) 48(5) Australian Psychologist <https://doi.org/10.1111/ap.12012> accessed 2 May 2021.

[430] Ahmed Amer and Graham Davidson, 'The Ethics of Veracity and It Is Importance in the Medical Ethics' (2019) 9(2) Open Journal of Nursing <https://doi.org/10.4236/ojn.2019.92019> accessed 12 June 2021.

[431] Raanan Gillon, 'Medical ethics: four principles plus attention to scope' (1994) 309(6948) BMJ 184-188.

[432] John Keown, *Euthanasia, ethics, and public policy: an argument against legalization* (Cambridge University Press 2002) 12-13.

[433] Saric Lenko and others, 'Futile Treatment—A Review' [2017] 14 Journal of Bioethical Inquiry <https://link.springer.com/article/10.1007%2Fs11673-017-9793-x> accessed 3 May 2021.

equity. This can be about the number of resources spent on an individual over the others. For instance, when a patient diagnosed as PVS needs more resources which are also required by other patients such as cancer treatment or hip replacement not to mention other non-medical such as education, then we need to make wise decisions. In this case, the question that arises is whether it is morally acceptable to spend money on a futile treatment. The definition of futility should not be universally based on the presumption that 'PVS patients' are unconscious and unable to regain their capacity. Thus, on micro levels, the doctors solely focus on the patient, and the treatment indicated rather than focus on the justice matters directly which are perceived at the macro level. However, it needs to be made clear that macro-level decisions are also significant in healthcare as they are in other places to ensure resources are used fairly and efficiently.[434]

Most bioethicists tend to dismiss the qualification between withholding, furthermore, pulling back treatment since, they assert, they have a similar impact.[435] Clinicians, notwithstanding, largely hold that the two procedures are extraordinary and see the withdrawal of treatment to be more genuine than withholding treatment. Therefore, clinicians are occasionally hesitant to start treatment that stands a decent possibility of being withdrawn before long. One reason for this contrast between healthcare providers and bioethicists, without a doubt, comes from the reality they have distinctive foci on PVS patient care. This might be especially valid for medical care providers since they spend an extraordinary measure of time cooperating with patients in extremely personal and private settings. Indubitably, it is specifically aimed at those who have been the most disappointed with specific components of traditional bioethics, in light of an approach. A poignant example includes principals, since it neglects to address the uncommon relationship clinicians, have with their patients, which

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[434] Beauchamp and Childress (n 400).

[435] Lars Ursin, 'Withholding and Withdrawing Life-Sustaining Treatment: Ethically Equivalent?' (2019) 19(3) The American journal of bioethics <https://doi.org/10.1080/15265161.2018.1561961> accessed 25 April 2021.

depends on the thought of mind. Subsequently, someone concentrating on value or non-beneficence from a utilitarian point of view may see no good contrast in the qualification between withholding and withdrawing life bolster.

A medical attendant working with and watching over a specific individual nearing the end of their life may see a radical distinction since their work is not contingent on the "final product," however that is characterised. In this way, for instance, looking after a terminally ill patient who will not show signs of improvement is similarly as vital as taking care of a patient who will recuperate even though the care to the terminally ill patient is futile in some target, consequentialist sense. Besides, we should recall that medical caretakers are not working and identifying with theoretical standards yet as genuine individuals. On the other hand, rather, to be more exact, attendants and specialists may have little collaboration with a patient before life support is started yet regularly form tight bonds with patients after such strategies have started. This can be genuine notwithstanding when the patient does not achieve consciousness amid the whole course of this 'association.' Hence, it is little wonder that attendants and specialists tend to imagine that the withdrawal of the life support system is more genuine, ethically talking, than the underlying withholding of life support. Note that in occurrences like this, medical caregivers may much contrast from other experts; - for example, doctors since doctors ordinarily invest considerably less energy with their patients than medical caretakers do, and subsequently may not form the same sort of bond with their patients.

In practice, there are ethical issues at every stage of decision-making in patients diagnosed as in a PVS.[436] For the sake of simplicity, these stages will be arbitrarily divided into five as highlighted below:

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[436] Derick Wade, 'Ethical issues in diagnosis and management of patients in the permanent vegetative state' [2001] 322(7282) BMJ <https://dx.doi.org/10.1136%2Fbmj.322.7282.352> accessed 10 June 2021.

a) **Acknowledging PVS as a clinical state:** The very first step in the management of PVS is recognising and accepting that the state exists and considering if life-saving treatment should be forgone or withdrawn.[437] The healthcare professional's beliefs and moral inclination play a role here. In addition, the organisation's image and resource rationalisation is equally important in determining how individuals deemed to be in a PVS are treated.

b) **Diagnosing the vegetative state:** Labelling an individual as being in a vegetative state has life and death implications. The ethical issues at this stage include the scope of uncertainty with diagnosis and the clinical state of the condition, the degree of error in the diagnosis, and the availability and reliability of ancillary investigations.[438] The neuropsychological debates around the diagnosis and the philosophical discussion also assume significance.

c) **Deciding on its potential reversibility:** The ongoing debates on the validity of the timeframes for determining irreversibility in a PVS put heavy ethical weights on the clinicians making the diagnosis.[439] The question that comes to mind is, how confident is the original diagnosis? There is anecdotal evidence of late recovery in a patient deemed to be in a PVS, but it cannot be easily substantiated in all cases.

d) **Deciding to withdraw treatment:** The lack of a consistent and comprehensive ethical framework for deciding to withdraw interventions in PVS has resulted in disagreements between the treating team and the relatives of these patients.[440] Ethically, it is incumbent upon the senior clinician to look after the patient. However, one relevant question that arises is whether one should in any event be looking for a prognosis of permanence to

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[437] Peterson (n 154).
[438] Wade (n 436).
[439] Ibid.
[440] Beauchamp and Childress (n 400).

withdraw or simply something else, such as persistence - which is what the law seems to be satisfied with anyway.

e) **The process of withdrawing treatment:** When the decision is made to withdraw intervention, this does not resolve ethical issues on how this is done and the mode of death.[441] For example, when food and water are deliberately stopped, the patient can be dehydrated, and the death process can linger for days. This in itself can raise human rights questions.

Justices and resource allocation to PVS patients in light of competing interests.

The cost of care for patients with PDoC is a legitimate concern, especially in a publicly funded healthcare system like the NHS in the UK. While only a small percentage of people who suffer traumatic or non-traumatic brain injury end up in the PVS or MCS, the cost of their long-term care is disproportionately high. From an economic and resource allocation perspective, it is imperative to articulate how these costs of care can be justified, especially when there are competing interests in using the limited resources to look after patients with potentially treatable diseases such as heart attacks or more manageable chronic diseases like hypertension and diabetes. A cost-effectiveness analysis (CEA) is usually used to justify allocating resources to any particular intervention or therapy in a publicly funded healthcare setting.[442] Policymakers evaluate the benefits a particular population will derive from allocating given resources against the opportunity cost of using the same resources in other populations. NICE and NHS England use this cost-benefit analysis to manage or regulate the use of new medications and medical technologies in NHS patients.[443]

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[441] Ibid.

[442] Christopher McCabe and others, 'The NICE cost-effectiveness threshold: what it is and what that means' (2008) 26 (9) Pharmacoeconomics <https://pubmed.ncbi.nlm.nih.gov/18767894/> accessed 16 July 2022

[443] Ibid.

Paterson et al. argued that there are two inherent issues with using the CEA metric to justify the allocation of resources to PDoC patients.[444] The first issue is that the moral status of these patients is not well defined due to the prevailing ambiguity on whether they are conscious or unconscious.[445] There have been doubts cast over the value of PVS/MCS lives due to the uncertainty about the existence of conscious minds and their capacity for consciousness.[446] It remains unknown whether PVS or MCS patients retain their sentience ability. In addition, using expensive novel healthcare resources to find this out will only exacerbate the already-high cost burdens. The second predicament with using CEA in PDoC is the difficulty in measuring the benefits these patients get from the allocated resources.[447] Benefit in the economic analysis of healthcare interventions is extrapolated using metrics like quality-adjusted life-years (QALYs), disability-adjusted life years (DALYs), and other similar metrics.[448] A QALY is a measure combining health-related quality of life (QA) and length of life (LY) into a single measure of health gain—so that one year of perfectly healthy life for one person is one QALY.[449] The problem with these indices is that they are prone to different forms of bias especially cognitive bias.

In the UK, NICE sets the threshold for recommending treatment at £20,000–£30,000 per QALY.[450] The annual budget of the NHS is fixed and subject to review from time to time; therefore, there is little room for manoeuvres. Therefore, if more than £30,000 of NHS

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[444] Andrew Paterson and others, 'What justifies the allocation of healthcare resources to patients with disorders of consciousness?' (2021) 12 (2-3) AJOB Neuroscience <https://pubmed.ncbi.nlm.nih.gov/33787458/> accessed 10 July 2022.

[445] Ibid.

[446] Lucio Esposito and Nicole Hassoun, 'Measuring health burden without discriminating against the disabled' (2017) 39 (3) Journal of Public Health (Oxford, England) <https://pubmed.ncbi.nlm.nih.gov/27608970/> accessed 10 July 2022.

[447] Andrew Paterson and others (n 444).

[448] Melissa Brown and others, 'Health care economic analyses and value-based medicine' (2003) 48 (2) Survey of Ophthalmology <https://pubmed.ncbi.nlm.nih.gov/12686305/> accessed 16 July 2022.

[449] Christopher McCabe and others (n 442).

[450] Karl Claxton and others, 'Methods for the estimation of the National Institute for Health and Care Excellence cost-effectiveness threshold' (2015) 19 (14) Health Technology Assessment <https://pubmed.ncbi.nlm.nih.gov/25692211/> accessed 10 July 2022.

resources is spent to add one QALY to a patient with PDoC, it will adversely affect the opportunity cost of interventions in other patients. However, Luyten argued that even though CEA in PDoC is challenging, it is still possible to demonstrate cost-effectiveness in them.[451] If an intervention can be proven to be cost-effective, there would be enough justification for instituting it in PDoC patients. There is strong evidence that newer medical interventions can benefit patients diagnosed with PVS or MCS. While some of these interventions (like fMRI or PET scan) aid diagnosis and prognosis, notwithstanding their expensiveness, others help in improving recovery. According to some studies, serial neurobehavioral evaluation can improve diagnostic accuracy and, in turn, save cost.[452] Neuroimaging and EEG have also been shown to improve the accuracy and prognosis in PVS.[453] Although EEG is relatively inexpensive compared to the other neuroimaging modalities which use can be reserved for cases that require further evaluation.

If these interventions are proven to be beneficial in PDoC, then it would be unfair not to provide them with the opportunity to be treated. The argument would then be as follows: how can the NHS limit cost of care provided to PVS and MCS patients? Paterson et al. proposed using a stepladder approach to assessment by starting with inexpensive modalities. This cost-saving approach will screen patients who are not likely to do well and streamline the number of patients subjected to investigations or treatments that are more expensive. Paterson et al. also proposed 'piggybacking' modalities with high costs on other therapies to reduce the overall

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[451] Jeroen Luyten, ‘Rationalizing Resources for Disorders of Consciousness Care’ (2021) 12 (2-3) AJOB neuroscience <https://doi.org/10.1080/21507740.2021.1904029> accessed 10 July 2022.

[452] Ronald Seel and others, ‘Assessment scales for disorders of consciousness: Evidence-based recommendations for clinical practice and research’ (2010) 91 (12) Archives of Physical Medicine and Rehabilitation <https://pubmed.ncbi.nlm.nih.gov/21112421/> accessed 10 July 2022; Caroline Schnakers (n 23).

[453] Jan Claassen and others (n 33), Johan Stender and others, ‘Diagnostic precision of PET imaging and functional MRI in disorders of consciousness: A clinical validation study’ (2014) 384 (9942) The Lancet <https://doi.org/10.1016/S0140-6736(14)60042-8 > accessed 10 July 2022; Peter Forgacs and others, ‘Preservation of electroencephalographic organization in patients with impaired consciousness and imaging-based evidence of command-following’ (2014) 76 (6) Annals of Neurology <https://pubmed.ncbi.nlm.nih.gov/25270034/> accessed 10 July 2022; Martin Monti and others (n 29).

cost of care.[454] One might also argue that the early introduction of pharmacologic therapies that have shown some promise in the recovery process in PVS can potentially reduce the burden of disability and reduce the cost of care in a long term.[455] Studies have also shown that multidisciplinary rehabilitation decreases mortality and improves recovery in PVS.[456] Starting these treatments early in patients with brain injury will help reduce the number of patients with severe disabilities.

Cost-effectiveness in health care can be interpreted in two different ways.[457] The first interpretation is that the cost-benefit analysis of any intervention should be in line with what society sets as the threshold for health gains.[458] This refers to the amount the country is willing to pay in health costs which determines the process of resource allocation. This figure is set at £20,000–£30,000 per QALY in the UK; as discussed above, whether the cost of care of PDoC is proportionate to the QALYs gained is debatable. The other interpretation of cost-effectiveness is based on the interventions and health programs being supplied by the health system at a particular time.[459] In this situation, the cost-effectiveness of a particular intervention is determined by the threshold set by the least cost-effective program that is funded at the time. Therefore, the allocation of resources can be justified if the cost-benefit analysis of managing patients in PDoC surpasses any program. In addition, since there are studies that demonstrate

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[454] Andrew Paterson and others (n 444).

[455] Joseph Giacino and others, 2012. 'Placebo-controlled trial of amantadine for severe traumatic brain injury' (2012) 366 (9) The New England Journal of Medicine <https://pubmed.ncbi.nlm.nih.gov/22375973/> accessed 10 July 2022; John Whyte and Robin Myers, 'Incidence of clinically significant responses to zolpidem among patients with dis- orders of consciousness: A preliminary placebo-controlled trial' (2009) 88 (5) American Journal of Physical Medicine & Rehabilitation <https://pubmed.ncbi.nlm.nih.gov/19620954/> accessed 10 July 2022.

[456] Risa Nakase-Richardson and others, 'Longitudinal outcome of patients with disordered consciousness in the NIDRR TBI Model Systems Programs' (2012) 29 (1) Journal of Neurotrauma <https://pubmed.ncbi.nlm.nih.gov/21663544/> accessed 10 July 2022.

[457] Jeroen Luyten (n 451).

[458] Hans-Georg Eichler and others, 'Use of cost-effectiveness analysis in healthcare resource allocation decision-making: how are cost-effectiveness thresholds expected to emerge?' (2004) 7 (5) Value in Health <https://doi.org/10.1111/j.1524-4733.2004.75003.x> accessed 10 July 2022.

[459] Jeroen Luyten and Yvonne Denier, 'Explicit cost-effectiveness thresholds in health care: a kaleidoscope' (2019) 32 (2) Social Justice Research <https://doi.org/10.1007/s11211-018-0322-9> accessed 10 July 2022.

a significant level of waste in financing expensive projects with marginal benefit to the health system, there is always a plausible argument for resource allocation to PDoC.[460]

In summary, the broader issue of how the state spends its money on the welfare of the citizens cuts across every facet of life. These broader issues go beyond the healthcare system and cover issues like the environment, climate change, and defence, just to mention a few. Singling PVS patients out is not only appropriate but also important because people are not thinking about them and there may be a knee -jerk reaction to want to think that it is not worth spending money on them. Therefore, there is an isolated demand for rigor with regard to resource allocation to this group of patients. Everything is a trade-off but the financial knock on effect of treating them would be nothing compared to the moral and ethical knock on effect of not treating them. Adopting a utilitarian approach or ranking people (i.e. valuing people differently) will come at the cost of damaging our values. This expediency is costing us and to have a healthy and flourishing society we have to uphold good values by protecting the vulnerable members of the society.

Other relevant ethical considerations in PVS cases

The above principles are the basic principles used in the medical profession. However, when it comes to withholding and withdrawing interventions in medical practice, there are other relevant ethical principles or doctrines which are worthy of mentioning. Relevant ethical arguments in PVS include the conflict between the sanctity of life doctrine and regard for the autonomy and best interests of the individual, and between killing and letting die.[461] The following ethical perspectives are also relevant to the discourse on PVS.

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[460] William Shrank and others, ‘Waste in the US health care system: estimated costs and potential for savings’ (2019) 322 (15) JAMA <https://pubmed.ncbi.nlm.nih.gov/31589283/> accessed 10 July 2022

[461] Abdul-Rasheed Rabiu and Kapil Sugand, 'Has the sanctity of life law 'gone too far'?: Analysis of the sanctity of life doctrine and English case law shows that the sanctity of life law has not 'gone too far'' (2014) 9(1) Philosophy Ethics and Humanities in Medicine <https://peh-med.biomedcentral.com/articles/10.1186/1747-5341-9-5> accessed 3 May 2021.

I. Acts /omissions distinction

In practice when a clinician decides that a patient's prognosis is poor and the quality of life is unacceptable, the appropriateness of the interventions given is reassessed. If it is concluded that the burden of treatment or intervention is disproportionate and futile or when intervention is not considered to be in the patient's best interests, either of two things will happen.[462] The intervention is either withheld or withdrawn if it is already started.[463] Although the law in the UK makes no distinction between withdrawing and forgoing treatment, the two practices do raise different moral and practical issues. Some researchers have argued that withdrawing life-saving interventions may be preferable to withholding based on moral grounds.[464]

II. Medical Futility

This principle is frequently used to justify withdrawing and withholding treatment in medical practice even though there is no specific guideline or consensus on what chance of survival constitutes medical futility. Some ethicists have attempted to use a quantitative approach to define futility by setting a cut-off for an acceptable probability of success of a proposed intervention. Some advocated for a 1% success rate[465] while others have advocated for a 2%-5% success rate.[466] The problem with setting an arbitrary figure for futility is that at best the evidence is biased and could be self-serving. Even if we accept these cut-offs, the

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[462] *Airedale v Bland* (n 94) [877] (Lord Mustill).

[463] Ibid [866] (Lord Goff).

[464] Jean-Louis Vincent, 'Withdrawing may be preferable to withholding' (2005) 9(3) Critical care <http://ccforum.com/content/9/3/226> accessed 3 May 2021.

[465] Lawrence Schneiderman and others, 'Medical futility: its meaning and ethical implications' (1990) 112(12) Ann Intern Med <https://pubmed.ncbi.nlm.nih.gov/2187394/> accessed 3 May 2021.

[466] Paul Helft and others, 'The rise and fall of the futility movement' (2000) 343 NEJM <https://nejm.org/doi/full/10.1056/NEJM200007273430411> accessed 3 May 2021.

criteria will not be fair to some patients that will benefit from the intervention.[467] Other bioethicists have proposed a qualitative approach to defining futility, which is a value-based method and uses parameters like physiology or cost-benefit ratio.[468] Although this approach seems more practical and acceptable, some scholars have completely dismissed the futility concept as an ancient idea that has no place in modern-day medical ethics.[469] Sceptics have even labelled it a disguise for rationing healthcare resources at the end of life.[470]

III. Ordinary versus extraordinary means

This concept can be used to rationalise the practice of withholding or withdrawing interventions that are thought to be more burdensome to the patients. Ordinary means are those therapies that have reasonable expectations of benefits with little or no burdens, unlike extraordinary means where such treatments can cause considerable distress with little or no hope of benefits.[471] Other terms used to portray this concept includes simple versus complicated; proportionate versus disproportionate. Extraordinary means impose excessive burdens or expenses on the patient’s relatives or society at large. Ethically, there is a duty of care to give treatments, which are proportionate, but no obligation to consider disproportionate interventions. This principle is closely related to the non-maleficence and beneficence ethical principles.

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[467] David McGee and others, 'The patient's response to medical futility' (2000) 160(11) Arch Intern Med <https://pubmed.ncbi.nlm.nih.gov/10847247/> accessed 3 May 2021.

[468] Emily Rubin and Andrew Courtwright, 'Medical Futility Procedures What More Do We Need to Know?' (2013) 144(5) Chest Journal <https://doi.org/10.1378/chest.13-1240> accessed 3 May 2021.

[469] Paul Helft and others (n 466).

[470] Charles Plows and others, 'Medical Futility in End-of-Life Care: Report of the Council on Ethical and Judicial Affairs' (1999) 281(10) JAMA <https://doi.org/10.1001/jama.281.10.937> accessed 3 May 2021.

[471] James McTavish, 'Justice and Health Care: When “Ordinary” is Extraordinary' (2016) 83(1) The Linacre Quarterly <https://doi.org/10.1080/00243639.2015.1123891> accessed 3 May 2021.

The moral significance of acts and omissions distinction

The distinction between acts and omissions concerning withdrawing and withholding life-sustaining interventions was a key subject of discussion in Bland's case. Lord Goff and Lord Lowry gave their opinions on the legal and moral equivalence of the two approaches.[472] They both took a view that it is illogical to legally and ethically distinguish between act and omission as a doctor can withhold treatment if he or she thinks it is not in the best interests of the patient and has no legal liability. In the same vein, doctors can cease such treatment if it is futile. Some have argued that the reason that the judges posited that the withdrawal of life-sustaining treatment is an omission rather than an act was to protect the doctor involved in the case from being prosecuted.[473] Another argument is that if there is a difference in both approaches, doctors might be unwilling to institute interventions to see if they could help the patient. On the contrary, some have argued that calling the withdrawal of intervention an omission does not depict reality and common sense.[474] Despite this criticism, many bioethicists support the notion that withdrawal is an omission and that there is no ethical and moral difference between withdrawing and withholding LSI.[475]

Legally and ethically in the UK, the prevailing view is that withdrawing life-sustaining treatment (including ANH) from PDoC patients, like withholding treatment allows the patient to die from the disease or condition; therefore, both actions are deemed equivalent. Sulmasy and Sugarman rejected this claim as they consider the two actions to be morally different.[476] One might argue that from a psychological perspective, a doctor might feel easier to withhold

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[472] Airedale NHS Trust v Bland

[473] Robert Young, Medically assisted death (Cambridge University Press 2007).

[474] Patrick Hopkins, 'Why does removing machines count as 'passive' euthanasia?' (1997) 27 (3) The Hastings Center Report <https://doi.org/10.2307/3528666> accessed 9 July 2022.

[475] Andrew McGee, 'Acting to let someone die' (2015) 29 (2) Bioethics <https://doi.org/10.1111/bioe.12072> accessed 9 July 2022; Dominic Wilkinson and others, 'Withdrawal aversion and the equivalence test' (2019) 19 (3) American Journal of Bioethics < https://doi.org/10.1080/15265161.2019.1574465> accessed 9 July 2022.

[476] Daniel Sulmasy and Jeremy Sugarman, 'Are withholding and withdrawing therapy always morally equivalent?' (1994) 20 (4) J Med Ethics <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1376558/> accessed 9 July 2022.

treatment than withdraw it. A survey in 2003 showed that there is higher mortality in ICU patients when doctors withdraw treatments compared to when they withhold them.[477] Studies have shown that the two approaches are different and that doctors and nurses tolerate treatment withholding and find treatment withdrawing more difficult.[478] Some bioethicists claimed that it is more emotionally taxing to withdraw food and water through ANH.[479] Although some might argue that treatment withdrawal serves the patient's best interests more than withholding.[480] By not starting a treatment, the doctor will deprive the patient of the opportunity to benefit from it. However, there is a palpable moral and psychological difference between withdrawing and withholding LSI. Glick and Jotkowitz claimed that ethical decisions are not only based on rationality but also on emotional and intuitive considerations.[481] Those who support withdrawing and withholding treatment are ethically making the same argument that the perceived difference is due to cognitive biases and flawed reasoning.[482]

Lars Ursin argued that the two acts are not ethically equivalent and proposed revising medical guidelines to reflect this nuanced discussion.[483] Other researchers have rejected the cognitive bias argument against the opponents of the "equivalence thesis (ET)".[484] They argued that the difference in both actions might be viewed from an alternative basis for bioethics like

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[477] Charles Sprung and others, 'End-of-life practices in European intensive care units: The Ethics study' (2003) 290 (6) JAMA <https://jamanetwork.com/journals/jama/fullarticle/197049> accessed 9 July 2022.

[478] Shimon Glick and Alan Jotkowitz, 'We reject the 'Equivalence Thesis' 2019 19 (3) AJOB <https://www.ncbi.nlm.nih.gov/pubmed/31543039> accessed 9 July 2022.

[479] Emma Somers and others, 'Withholding versus withdrawing treatment: artificial nutrition and hydration as a model' (2016) 10 (3) Current Opinion in Supportive and Palliative Care <https://pubmed.ncbi.nlm.nih.gov/27348795/> accessed 9 July 2022.

[480] Jos Welie and Henk Ten Have, 'The ethics of forgoing life-sustaining treatment: theoretical considerations and clinical decision making' (2014) 9 (1) Multidisciplinary Respiratory Medicine <https://pubmed.ncbi.nlm.nih.gov/24618004/> accessed 9 July 2022; Jean-Louis Vincent (n 464).

[481] Shimon Glick and Alan Jotkowitz (n 478).

[482] Dominic Wilkinson and Julian Savulescu, 'A costly separation between withdrawing and withholding treatment in intensive care' (2014) 28 (3) Bioethics <https://pubmed.ncbi.nlm.nih.gov/22762352/> accessed 9 July 2022.

[483] Lars Ursin, 'Withholding and Withdrawing Life-Sustaining Treatment: Ethically Equivalent?' (2019) 19 (3) AJOB <https://pubmed.ncbi.nlm.nih.gov/30896350/> accessed 9 July 2022.

[484] Shimon Glick and Alan Jotkowitz (n 478).

from a cultural or religious perspective.[485] Proponents of ET argued that religious-based feelings do not have any ethical relevance in deciding treatment options.[486] Although some proponents of ET agreed that there could be situations where there could be some difference in withdrawing and withholding treatments.[487] When a doctor withdraws life-sustaining intervention the patient dies and some commentators have claimed that this action amounts to killing rather than letting die.[488] Some researchers reject this assertion claiming that both withdrawing and withholding treatment are omissions and that there is no distinction between the two acts.[489] The distinction between the two acts can be likened to killing and letting die where when there is killing the person responsible for the act carries the burden but when she allows someone to die the agent carries no responsibility. [490] However, some contended that the act of withdrawal, unlikely withholding, involves taking further responsibility. Some claimed that in most situations it is necessary to do something to allow a patient to die.[491]

Some argue that the moral difference between the two acts can be examined from the point that withdrawal can be seen as withdrawing resources from one patient for another patient's use when faced with limited resources.[492] This argument is not particularly true as withholding LSI can also be seen as keeping resources free from other patients. Beyond the resource's argument, the difference in these approaches can be viewed from autonomy, professional responsibility, and treatment status perspectives.[493] Lars Ursin argued that

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[485] Ibid.

[486] Dominic Wilkinson and Julian Savulescu (n 482).

[487] Ibid.

[488] Franklin Miller and Robert Truog, *Death, Dying, and Organ Transplantation: Reconstructing Medical Ethics at the End of Life* (New York: Oxford University Press 2012).

[489] Ben Bronner, 'Two Ways to Kill a Patient' (2018) 43 (1) Journal of Medicine and Philosophy' <https://pubmed.ncbi.nlm.nih.gov/29342284/ > accessed 10 July 2022.

[490] Joachim Asscher, 'The moral distinction between killing and letting die in medical cases' (2008) 22 (5) Bioethics <https://pubmed.ncbi.nlm.nih.gov/18447863/> accessed 10 July 2022.

[491] Steven Jensen, *Killing and letting die. In the Ethics of Organ Transplantation* (Washington, DC: Catholic University of America Press 2011) 170-91; Andrew McGee (475).

[492] Daniel Sulmasy and Jeremy Sugarman (476).

[493] Lars Ursin (n 483).

withdrawal and withholding treatments impact the patient's autonomy in different ways.[494] In addition, the professional responsibilities in the two situations cannot be weighed in the same way.[495] To continue ongoing treatment is seen in a different way than to start a new treatment; therefore, withdrawing and withholding have different statuses on the patient.[496] Wilkinson et al. argued the ET using the 'ceteris paribus" clause by claiming that withholding and withdrawing are equivalent if other things are equal.[497] Lars Ursin argued against this point by insinuating that it is hard to achieve ceteris paribus therefore, withholding and withdrawing treatment cannot be equivalent.[498] Also, Bjørn Hofmann argued against ET saying that things are not equal and contexts may provide the difference in both situations.[499] Therefore, there should be a higher moral threshold to the withdrawal of ongoing treatment than to withhold new treatment.[500]

In summary, the prevailing view of act/omission in WWLSI in PVS is logical and coherent from the legal and ethical standpoint of doctors not starting a treatment that they believe to be futile and withdrawing already started treatment for the same reason. However, the two actions are not morally equivalent as they provoke different emotions from the doctors and different reactions from the patient's relatives and can impact the patient's autonomy differently.

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[494] Ibid.

[495] Ibid.

[496] Ibid.

[497] Dominic Wilkinson and Julian Savulescu (n 482).

[498] Lars Ursin (n 483).

[499] Bjørn Hofmann, 'Categorical Mistakes and Moral Biases in the Withholding-Versus-Withdrawal Debate' (2019) 19 (3) The American Journal of Bioethics <https://pubmed.ncbi.nlm.nih.gov/31543044/> accessed 10 July 2022.

[500] Andreas Schmidt, 'Withdrawing and Withholding Treatment: What Do Medical Professionals Owe Their Patients?' (2019) 19 (3) The American Journal of Bioethics <https://pubmed.ncbi.nlm.nih.gov/31543042/> accessed 10 July 2022.

The ethics of WWLSI in patients diagnosed as PVS

Over the years, doctors have remained concerned about the ethical stances that should be adopted for patients diagnosed as PVS. For example, in many cases, concerns have been expressed about their prognosis, determination, and definition of their death according to the criteria used in neocortical procedures.[501] On the other hand, the impetus for these concerns has been raised from the rapid technology of organ transplantation whereby patients diagnosed as PVS may be thought to be a potential source for providing scarce transplantation organs.[502] However, the concerns regarding medical resource scarcity have led to the proposition that the cost of survival should be considered in ethical decisions about patients diagnosed as PVS. It is undeniable that as the costs vary, it is still costly to maintain a patient in PVS. At this point, ethical decisions about cost efficiency must be made. Notably, a patient diagnosed as PVS can survive for several years. On the other hand, the cause of death might be a direct consequence of withdrawal of the treatment and not the severity of the condition. However, when the burden of the treatments outweighs the benefits, the balance is tilted in favour of treatment withdrawal since the burdens or benefits fall on others while the patient themselves are believed to experience nearly nothing during the life support treatments.

When a doctor states that the treatment being administered is futile, serious ethical consequences come along.[503] In practice, qualitative and quantitative aspects of futility need to be considered whereby quantitative elements include the improbability of the treatment success and qualitative includes the quality of the treatment results - for instance, when intervention fails to preclude complete dependence on life support.[504] When these two are considered then

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[501] David Smith, *Legal Issues Leading to the Notion of Neocortical Death. in Richard Zaner (ed), Death: Beyond Whole-Brain Criteria* (Springer Netherlands 1988) 111-112.

[502] Grant Gillett, *'Consciousness, the brain and what matters'* (1990) 4(3) Bioethics <https://doi.org/10.1111/j.1467-8519.1990.tb00082.x > accessed 12 May 2021.

[503] John Lantos and others, *'The illusion of futility in clinical practice'* (1989) 87(1) The American journal of medicine <https://doi.org/10.1016/S0002-9343(89)80487-5> accessed 3 May 2021

[504] Lawrence Schneiderman, 'Defining Medical Futility and Improving Medical Care. Journal of bioethical inquiry' (2011) 8(2) <https://doi.org/10.1007/s11673-011-9293-3> accessed 2 May 2021.

the treatment might be considered futile.[505] When futility is described from the qualitative perspective, it involves weighing the effects and benefits of the proposed treatment. The benefit is measured as a function of the improvement in the quality of life following the intervention. There are ethical and moral debates on whether providing nutrition through artificial tubes should be optional or obligatory. The determination of whether the treatment is optional or obligatory depends on the benefits, burdens, and effects whereby some doctors might claim that artificial feeding is important to the extent that it keeps the patient alive. Although it is not clear the role this plays in the restoration of consciousness in PVS patients.[506]

The thought of withdrawing interventions such as artificial feeding for a patient deemed in PVS is likely to have drawbacks. Considering that the person is neither dead nor alive, the withdrawal of the interventions used in keeping them alive may be viewed as an intentional killing by some people. Finally, the provision of these treatments is morally obligatory.[507] Ethical controversies arise when deciding who should decide futility.[508] The legal position of decisions regarding treatments in patients with PVS remains unclear to many.[509] However, the concept of futility should involve a long-term consensus between the family, the doctors, the caregivers, or any other party involved.[510] Withdrawing the life support treatments for PVS patients may be considered beneficent and humane at some point.[511] The reality remains that we all have multiple ways to expound on how the ‘PVS patients’ look and forget how they feel in their state. Accordingly, so long as the patient does not have any pain or suffering, societal

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[505] Nancy Jecker, 'Knowing when to stop: the limits of medicine' (1991) 21(3) Hastings Center report <https://doi.org/10.2307/3563315> accessed 3 May 2021.

[506] Schneiderman and others (n 465).

[507] Robert Truog and others, 'The problem of futility' (1992) 326(23) NEJM <https://http://dx.doi.org/10.1056/NEJM199206043262310> accessed 3 May 2021.

[508] Nancy Jecker and Robert Pearlman, 'Medical futility: who decides? ' (1992) 152(6) Archives of internal medicine <https://http://dx.doi.org/10.1001/archinte.1992.00400180012002> accessed 3 May 2021.

[509] Beauchamp and Childress (n 400).

[510] Robert Truog and others, ‘Futility' as a criterion in limiting treatment: the authors reply to correspondence (1992) 327 NEJM <https://doi.org/10.1056/nejm199210223271712> accessed 3 May 2021.

[511] Richard Huxtable, ‘Dying too soon or living too long? Withdrawing treatment from patients with prolonged disorders of consciousness after Re Y’ (2019) 20(91) BMC Med Ethics <https://doi.org/10.1186/s12910-019-0424-4>accessed 15 May 2021.

values allow the provision of life preservation unless the patient does not want it, which in most cases patients diagnosed as PVS cannot say so.

Similarly, that individual can also decline life-sustaining interventions by prospective declaration when the quality of life does not meet what they expect. However, this declaration is made before they are unable to.[512] Withdrawal of the life support treatments for patients diagnosed as PVS in the UK has become complex because the interventions in medicine help in prolonging life whereas the withdrawal of these interventions ends it. It becomes more complex when the patient is at a young age. Therefore, withdrawing life sustaining interventions can be justified to some extent in those patients who are in severe pain and suffering where palliative therapy has failed to alleviate their predicaments. Nevertheless, it cannot be considered right when the Court orders the withdrawal of a life support machine from a patient who is not in distress on moral grounds.

Arguments for the Withdrawal of Treatment

Proponents of treatment withdrawal argue that this act will assist in relieving the individual from their suffering and make hospital resources free for those who can get treatment and recover. Their argument is because some patients like the PVS patients have a condition that experiences no relief and therefore they can await their natural death, and when they stay in the hospital for treatment, the treatments cost a significant amount of money hence burdensome. However, the issue of perception by PVS and MCS patients is not generally agreed on and the assessment of pain in these patients is challenging. A study conducted in 2008 showed that 68% (n 538) of paramedics and 56% (n 1166) of medical doctors believed

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[512] Mental Capacity Act 2005 Section 24.

that PVS and MCS patients could feel pains.[513] Neuroimaging studies have demonstrated distinct neurological patterns in the CNS following a noxious stimulus in PVS/MCS patients.[514] Despite these findings, a significant proportion of people still believe that they cannot perceive pain. Similarly, it is unethical to target PVS and MCS patients in healthcare resources allocation, and this should not be used as a reason for giving up treatment in PVS.[515]

Arguments against the Withdrawal of Treatment

The opponents of treatment withdrawal in patients diagnosed as PVS usually based their argument on the "slippery slope" phenomenon, whereby there is a gradual down sloping of practice from voluntary passive euthanasia to involuntary passive euthanasia. This can make the practice more common. Moreover, there is no definitive way whereby a patient's treatment can be proved futile and predict that death will occur. Another argument is that allowing a PVS patient to die of starvation is worse than if they were given medication that causes instant death like the one seen in active euthanasia. This is because death through the cessation of CAHN can take up to weeks, which leaves the patient suffering from starvation.[516] On the other hand, the withdrawal of treatment might be used for malicious reasons or somewhat wrong reasons. When the patient is incompetent to decide on their medical care, the family takes charge to make the decisions, and this is where some may have ulterior motives. Furthermore, treatment withdrawal can be used for inappropriate reasons such as to generate high-demand resources

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[513] Athena Demertzi and others, ‘Different beliefs about pain perception in the vegetative and minimally conscious states: a European survey of medical and paramedical professionals’ (2009) 177 Progress in Brain Research <https://doi.org/10.1016/S0079-6123(09)17722-1> accessed 18 May 2021.

[514] Melanie Boly and others, 'Perception of pain in minimally Conscious state with PET activation: an observation study' (2008) 7(11) Lancet Neurol <https://doi.org/ 10.1016/S1474-4422(08)70219-9 > accessed 3 May 2021.

[515] John Luce, ‘The pressure to withhold or withdraw life-sustaining therapy from critically ill patients in the United States’ (2007) 175(11) American journals of respiratory and critical care medicine <https://doi.org/10.1164/rccm.200609-1397CP> accessed 25 Marc 2021.

[516] James Rachels, Can Ethics Provide Answers? And Other Essays in Moral Philosophy (Rowman & Littlefield 1997) 69-79.

at the hospital. Incidentally, if this happens to be the desired outcome, then it can also be a significant reason for making active euthanasia legal.

In the UK there are set principles of Good Medical Practice that a doctor is supposed to abide by. The guide states that the doctor is supposed to ensure they take all the steps possible to avert pain and distress in a patient whether the cure is possible or not.[517] However, the question remains, could this also include the withdrawal of treatment for PVS patients? Conversely, cultural and religious differences complicate the decisions regarding withdrawal of treatment since beliefs vary greatly between each faith.[518] Nonetheless, the religious arguments are irrelevant to the non-believers, and hence people refer to the ethical frameworks that are traditional such as the consequentialist approach to address the withdrawal of treatment issue.

The case against the use of principlism in decision-making for PVS patients.

The use of the Beauchamp and Childress 4 principles approach to resolve ethical and moral issues in medical practice has been criticised by many experts over the years but it is fascinating why it is still widely used despite its shortcomings. Two vocal critics have been Danner Clouser and Bernard Gert, who have produced several publications to argue their points.[519] Before the principlism approach, health care professionals used moral ideas, rules, and theories to resolve moral and ethical issues in practice. The health professions' inability to satisfactorily resolve conflicts around the issue of treatment withdrawal and withholding in the PVS without resulting in going to Court in some cases is a testament to the fact that there is a

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[517] General Medical Council, Good medical practice (2013) <https://www.gmc-uk.org/-/media/documents/good-medical-practice---english-20200128_pdf-51527435.pdf?la=en&hash=DA1263358CCA88F298785FE2BD7610EB4EE9A530> accessed 25 August 2021.

[518] Maria Manalo, 'End-of-Life Decisions about Withholding or Withdrawing Therapy: Medical, Ethical, and Religio-Cultural Considerations' [2013] 7(1) Palliative care <https://doi.org/10.4137/PCRT.S10796> accessed 2 May 2021.

[519] Clouser and Gert, (n 402).

need for a rethink going forward about the adequacy of the status quo. Furthermore, Danner Clouser has argued that the conflicts seen in the use of the principles proposed by Beauchamp and Childress are because the principles did not come from any cohesive moral principles which then makes their interpretation challenging.[520] He proposed the use of common morality in professional ethics to resolve issues.[521] The problem with this suggestion is that it will take a bioethical approach to resolve ethical issues back to the pre-modern era. This approach is discussed in the next section on the normative approach to ethical issues in clinical practice. Other experts have argued that the principlism approach did not critically evaluate the relationship between mortal practice and ethical theory.[522]

Similarly, the current practice is devoid of any systematic approach to the four fundamental principles used in ethical and moral dilemmas. The heterogeneity in this ethical approach has been the primary basis for why theoretical analysis is improbable. Having discussed other ethical considerations in the treatment of PVS above, it is evident that we cannot rely solely on the four principles of ethics used today. This observation echoes the argument of Tom Walker who claimed that the principlism approach is inadequate to resolve moral and ethical issues and that there is a need to add more principles.[523] Further, Alasdair Macintyre argued that the approach failed to link the moral agent to the judgement.[524] This isolation of the act from the actor undermines the sense of moral obligation by the actor. Peter Herissone-Kelly also argued that the approach is not globally acceptable, as claimed by the duo.[525] In the quest to answer some of the criticisms raised, Beauchamp and Childress later

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[520] Danner Clouser, ‘Common morality as an alternative to principlism’ (1995) 5(3) Kennedy Institute of Ethics Journal <https://pubmed.ncbi.nlm.nih.gov/11645307/>accessed 25 March 2021.

[521] Ibid.

[522] Andrew Lustig, 'The method of 'principlism': a critique of the critique' (1992) 17(5) J Med Philos <https://doi.org/10.1093/jmp/17.5.487> accessed 3 May 2021.

[523] Tom Walker, ‘What principlism misses’ (2009) 35(4) Journal of Medical Ethics <https://jme.bmj.com/content/35/4/229.long>accessed 25 March 2021.

[524] Alasdair Macintyre, *After Virtue: a study in moral theory* (University of Notre Dame Press 1981).

[525] Peter Herissone-kelly, The Principlist Approach to Bioethics, and Its Stormy Journey Overseas (Tuija, eds edn, New York: Rodopi 2003) 65-77.

suggested an empirical approach to common morality, which was hitherto believed to be a value that everyone subscribes.[526] However, Peter Herissone-Kelly has argued that seeking conceptual justification of these norms through an empirical method would be onerous and gratuitous.[527]

Other issues lie in the vagueness of the expression of the principles and lack of in-depth explanation of each principle and how it is related to the other principles. Furthermore, the practical application of the whole concept is not feasible to solve ethical issues in treatment decisions with PVS. The concepts can be defined differently, which then complicates the logic behind any arguments made for and against the approach. Richard Davis, on the other hand, argued that various people define what moral theory means in relation to the principles differently.[528] Daniel Callahan also contended that the four principles are not equally crucial like Beauchamp and Childress claimed.[529] He also said that the approach to principlism is too narrow. Therefore, claiming that it can solve all the ethical problems faced in medical practice would be farfetched.[530] There is no doubt that some experts will tend to favour one principle over the other three principles. Charles Foster, albeit his criticism of the principlism approach, favours principle of autonomy over the others.[531] Although Pellegrino and Thomasma proposed that the beneficence principle should be the overriding principle in medical ethics, the interpretation of this principle is subjected to bias. [532] By extension, one might argue that all the four principles can be interpreted in a variety of ways when dealing with PVS patients. For

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[526] Beauchamp and Childress (n 400).

[527] Peter Herissone-Kelly, 'Determining the common morality's norms in the sixth edition of Principles of Biomedical Ethics' (2011) 37(10) Journal of Medical Ethics < https://jme.bmj.com/content/37/10/584.long > accessed 25 March 2021.

[528] Richard Davis, 'The principlism debate: a critical overview' (1995) 20(1) Journal of Medical Philosophy <https://pubmed.ncbi.nlm.nih.gov/7738461/ >accessed 25 March 2021.

[529] Daniel Callahan, 'Principlism and communitarianism' (2003) 29 (5) Journal of Medical Philosophy <https://ncbi.nlm.nih.gov/pmc/articles/PMC1733787/pdf/v029p00287.pdf> accessed 25 March 2021.

[530] Ibid.

[531] Charles Foster, *Human Dignity in Bioethics and Law* (Bloomsbury Publishing Plc, 2011) 3.

[532] Edmund Pellegrino and David Thomasma, *For the patient's good: toward a restoration of beneficence in health care* (Oxford University Press, New York 1988).

instance, when considering justice in PVS patients, one can think of distributive justice in different forms like socialism, libertarianism, or capitalism.

Some experts have called for alternative approaches to bioethics as the principlism approach is deemed to be incomplete.[533] Foster argues that the invitation of other notions in this regard will only feed on these four principles or perhaps on the concept of dignity which will be discussed in the later section.[534] The redundancy of the Beauchamp and Childress approach in solving complex ethical issues like WWLSI in PVS is evident in Foster's criticism of the approach.[535] Some claim that healthcare professionals do not directly use these principles in decision-making, even though they know and value the principles.[536] Therefore, the user can be relegated to a mere checklist application that lacks thorough ethical evaluation or reasoning.[537] The limitations of this method of decision-making have deprived people of the opportunity to use a robust ethical approach to solve real-life issues with treatment withholding and withdrawing. The complexity and the ambiguity of the principles have added more layers of confusion to clinical practice. While some have proposed approaches like feminist ethics, care-based ethics, narrative ethics, and the primacy of beneficence ethics.[538] This thesis argues that respect for human dignity and personhood is the cornerstone to tackling complex situations like the ones faced by patients diagnosed as PVS. However, before we get to this, let us critically appraise the normative ethical approach and evaluate it concerning WWLSI in patients diagnosed as PVS.

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[533] James Bernat and Richard Beresford, Handbook of clinical neurology (Amsterdam: Elsevier 2013) 1.

[534] Foster (n 531) 2.

[535] Ibid 2-4.

[536] Katie Page, 'The four principles: can they be measured and do they predict ethical decision making?' (2021) 13(10) BMC medical ethics <https://doi.org/10.1186/1472-6939-13-10> accessed 25 May 2021.

[537] Danner and Gert (n 402).

[538] Ibid.

3.3. A normative ethical approach.

This is a value judgement-based approach to medical ethics. It involves using ethical theories to determine how best to act in a moral sense when dealing with difficult decisions on whether to treat patients or not.[539] In this section, there is a critical evaluation of the two major theoretical approaches - the outcome-based philosophy and the duty-based philosophy, which many refer to as consequentialist and non-consequentialist ethics, respectively.[540] The former is a normative ethical approach, which views actions based on the consequences they produced, while the latter does not base the rightness or wrongness of actions on the outcomes but rather on what spirituality prescribes, whatever that is or means.[541] A duty-based approach appeals to the idea that it is inherently right or wrong to follow certain norms or principles, but not all versions of it are spiritually based per se. Some are deliberately secular, for example. The approach here is normative in nature in that it recommends or favours a certain type of action or motivation while critics another type of action. This approach is the most traditional ethical approach which prescribes a set of rules and norms to people. It is prescriptive in nature and can be either agent-centred (virtue theories) or act-centred (deontological theories and consequentialist theories). There are several normative theories in the literature, but this section would base the arguments on PVS on the person, motive, action, and consequences.[542] I argue that contrary to some views that these theories contradict themselves, they actually complement each other. However, their use in clinical practice is challenging as it usually involves complex philosophical debates and moral calculations.

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[539] Dietmar von der Pfordten, 'Five Elements of Normative Ethics - A General Theory of Normative Individualism' (2012) 15 Ethical Theory and Moral Practice <https://doi.org/10.1007/s10677-011-9299-2> accessed 2 May 2021.

[540] Andrew Gustafson, Consequentialism and non-consequentialism. in Heath and others (eds), The Routledge Companion to Business Ethics (Routledge Taylor and Francis Group, London and New York 2018) 79-93

[541] Ibid.

[542] Robert Taylor, 'Ethical principles and concepts in medicine' (2013) 118(3) Handbook of clinical neurology <https://researchgate.net/publication/258250395_Chapter_1_Ethical_principles_and_concepts_in_medicine> accessed 3 May 2021.

The consequentialist approach to difficult decisions in healthcare

The technology used these days in medical practice has created opportunities for more people than ever before with limited mental and physical capacities to survive and live for longer periods than it would have been possible some years prior. For the patients labelled as PVS with the accompanying presumption of a diminished chance of survival as adjudged by the treating clinicians, the question of withholding/withdrawing life-prolonging interventions including ANH then becomes an ethical dilemma. Even though the law lays down the minimum acceptable actions in such a situation, the approach to normative ethics is not that straightforward. Caregivers as moral agents can have acts that are lawful but unethical. Questions have been raised as to what constitutes appropriate medical care, whether such treatments bear any benefits to the patient, or whether prolonged intrusive procedures become burdensome to persons in that state. The practice of medicine involves making decisions and judgments that affect the lives of other people, and of which at times certainty of their outcomes is not usually guaranteed.[543] The current ethical approach used in clinical practice may be inadequate to resolve complex issues arising from the current practices. Therefore, there is a need for medical practitioners to comprehend and understand more objective and formal rationale forms of reasoning.[544] These formal approaches comprise ethical theories, professional codes of conduct, and moral principles.

Consequentialist ethical theories maintain that nothing is ethically right or wrong in itself and that the morality of an action is determined through the outcomes that it produces.[545] Applying this approach to how society treats patients in PVS would mean that the rightness or

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[543] John Ellershaw and others, 'Dehydration and the dying patient' (1995) 10(3) Journal of Pain and Symptom Management <https://jpsmjournal.com/article/0885-3924(94)00123-3/pdf> accessed 3 May 2021.

[544] Rachels (n 516).

[545] Dale Jacquette, *Pathways in Philosophy: An Introductory Guide with Readings* (New York: Oxford University Press 2004) 318-320.

wrongness of any actions would be assessed based on the outcome of such actions. Thus, an action is considered morally good if the intentions behind it are geared towards producing the greatest ratio of happiness among the people it affects over unhappiness or the best long-term consequence on all the available options. This theory is best applicable where there are conflicting interests and the consideration that what benefits an individual may be at the expense of another.[546] The two main forms of consequentialism approach to ethics are ethical egoism and utilitarianism. According to these theories, the origins of morality lie in the moral agent's self-interest rather than in some universal moral laws or theology.

Ethical egoism promotes what is in one's interest by weighing the good produced by an action over the evil in the interest of the moral agent.[547] While this approach could be viewed as selfish there are instances where an egoist would act in a selfless way. The latter approach is referred to as enlightened egoism which was a concept adopted by Thomas Hobbes in the seventeenth century.[548] In other words, ethical egoism can take either an individual or a universal approach. In individual ethical egoism, a person only looks out for his or her own personal interests.[549] Therefore, their concern for others only applies to the extent that their interests are fully sorted out first. In the universal ethical egoism, every person is obligated to act only in their own best interest, and they can get concerned about others only to the extent that it directly contributes to their interests. This theory advocated for looking out only for self-interests while ignoring those of the rest. For instance, when a decision about whether to treat a patient is being made, the family and the medical practitioners will focus on their interests and disregard those of their patients. That decision may be influenced by their personal values

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[546] Donna Dickenson, 'Are medical ethicists out of touch? Practitioner attitudes in the US and UK towards decisions at the end of life' (2000) 26(4) J Med Ethics <http://ncbi.nlm.nih.gov/pmc/articles/PMC1733246/ > accessed 3 May 2021.

[547] Darin Gates, 'Self-interest, ethical egoism, and the restored gospel' (2013) 52(2) BYU Studies Quarterly <https://www.jstor.org/stable/43039915 > accessed 21 June 2021.

[548] Thomas Hobbes, *The English works, vol III* (Leviathan 1651) 113.

[549] James Fieser, *Moral Philosophy through the Ages* (California: Mayfield Publishing Company 2001).

and options. The family will most likely put into consideration the financial burden of sustaining the treatment and thus opt for a decision that favours its withdrawal. The hospital management may be influenced by the desire to carry out more research and thus opt to continue the therapy. In both instances, the actions do not consider the patient wishes. Some critics will see this approach as morally wrong and unethical.

On the other hand, utilitarianism advocates pleasure for the good of everyone. This approach is essential in the provision of healthcare services especially when the limited resources must be used in a way that benefits the majority. Utilitarianism is closely associated with Jeremy Bentham, John Stuart Mill, and Henry Sidgwick.[550] Bentham's perspective of utilitarianism is called 'act utilitarianism' where morality is assessed based on the amount of good or evil an act produces.[551] According to this version of the ethical theory, the pleasure of the majority of people overshadows the pain of the minority. This ideology was however rejected by many philosophers. In other to overcome this problem, John Mill modified the 'act utilitarianism' to 'rule utilitarianism' where he added that behavioural rules should not be broken for past situations where happiness has been maximised and pain minimised.[552] The version of the theory used nowadays is Peter Singer's version which rejects the hedonistic nature of the traditional utilitarians.[553] This is mainly because people have varying opinions on what happiness means to them.[554] This version judges action according to the maximum satisfaction it brings to everyone. If one were a proponent of this theory, then one would question the morality of artificially sustaining an individual in a permanently unconscious state

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[550] Walter Sinnott-armstrong, 'Consequentialism' (Stanford Encyclopedia of Philosophy, 2019) <https://plato.stanford.edu/archives/sum2019/entries/consequentialism/> accessed 3 May 2021.

[551] Jeremy Bentham, *Introduction to the principles of moral and legislation in John Stuart Mill, Utilitarianism* (Fontana 1985) 33.

[552] John Mill*, Utilitarianism* (Longmans, Green and Company 1879) 276.

[553] Peter Singer, *Practical Ethics* (6th edn, Cambridge University Press 2013).

[554] Mill (n 552) 135.

because of the associated drain on the limited resources.[555] The same argument can be forged for a patient deemed in a PVS on life support but what then happens if the patient is no longer on life support and is living in a nursing home or rehabilitation centre with only tube feeding?

The justification of action or group of actions by the net good effects or happiness they produce may seem straightforward but it is a complex task in practice. The first issue is deciding what a good effect is and what a bad effect is, so if a patient with the diagnosis of PVS (which is open to debate) dies after cessation of treatment. Would the death be a good effect or a bad effect? Who is this good or bad effect related to - the patient, the family, or society? The theory considers the happiness of the greatest number as the greatest good. This argument begs the question, does stopping a treatment that keeps someone alive lead to the happiness of anyone? Death in itself causes pain and suffering to the immediate family members and friends. Moreover, proponents of this theory will argue that if something is difficult then it is not tenable.[556] Thus, the possibility of the cessation of treatment of these patients causing harm and pain cannot be ruled out entirely. Some people have struggled to find the ethical or moral grounds on which artificial nutrition can be withdrawn or withheld from any living human being. In addition, the fact that withholding treatment or withdrawing nutrition will ultimately lead to the death of these patients goes against the reasoning behind this theory and raises another question, which is a more desirable outcome, or the benefits of the patient- between living and dying.

In finding the answer to that question, it is imperative to scrutinise what ‘quality of life’ really means. This term is frequently used in the medical arena but it lacks a definitive description. By adopting utilitarian reasoning, one may define the term based on the number

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[555] Kerby Anderson, 'Utilitarianism: The Greatest Good for the Greatest Number' (Probe for answers, 27 May 2004) <https://probe.org/utilitarianism-the-greatest-good-for-the-greatest-number/> accessed 3 May 2021.

[556] Ibid.

of years lived. Therefore, medical practitioners can employ this in determining which patients or which kind of treatment will put the limited health resources into good use. However, this practice will be highly unethical and goes against the professional code of ethics guiding medical practitioners.[557] Hence, this necessitates defining the term from another perspective. The determination of what represents a good quality of life can be viewed from both objective and subjective perspectives.[558] Practically, one cannot decide on another person's quality of life objectively without having a basis on their own personal view and without allowing their values to take precedence over the needs, wants, beliefs, and aspirations of the party being judged. Therefore, the argument about the quality of life is heavily criticised by many commentators. This is because decisions made on behalf of mentally incompetent persons such as those deemed in a PVS generally exclude their subjective input and thus do not represent their true wishes. The person making decisions for the patient tends to draw on their personal values and beliefs to come up with conclusions.

The other challenge with the adoption of classic utilitarianism is that most actions have both intrinsic good and bad effects on them.[559] Therefore, a singular action can produce both good and bad effects simultaneously. In such cases, there would be a need to do a balancing exercise to tilt the favour in one direction or the other. Similarly, the action may produce a good effect on some people and produce a bad effect on other people. Perhaps the most challenging issue with the theory is that it is rather difficult to predict what effect an action would have on people beforehand. The term "good' in this context could be pleasure

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[557] Richard Playford, 'Deontological and utilitarian ethics: a brief introduction in the context of disorders of consciousness' (2015) 37(21) Disability and Rehabilitation <https://doi.org/10.3109/09638288.2014.989337> accessed 2 May 2021.

[558] Glenda Meeberg, 'Quality of life: A concept analysis' (1993) 18(1) Journal of Advanced Nursing <https://doi.org/10.1046/j.1365-2648.1993.18010032.x> accessed 3 May 2021.

[559] Ibid.

(hedonism), happiness, welfare, or desire for satisfaction.[560] In the pluralist sense, the maximum good is focused on how the good is distributed.[561] Some commentators have criticised consequentialism as not demanding enough on one hand and as excessively demanding on the other hand. Perhaps the most relevant criticism of this discourse is what it seems to permit. Some acts like those that killing of innocent people in certain circumstances, lying, and deprivation (of food or material things) can be permitted if it produces greater benefits for others. Putting this into context, the deliberate killing of PVS or even euthanasia of anyone for that matter can be conceivably justified as long as it is more beneficial for others.

Indeed, some philosophers like Bentham and Quinton introduced the concept of positive and negative duties to consequentialism.[562] The implications are that health professionals have legal, ethical, and professional duties and responsibilities to act within the level of professional expertise and competence to make better and optimal actions that promote positivity for the world around them. Bentham criticised the hedonism approach of classic utilitarianism by saying that the concept diminishes human beings to an instinctive level comparable to the one found in animals.[563] Alexander proposed that consequentialism should not be based on the acts but rather on the theory that directly assesses the rules indirectly evaluates the act (with reference to the rules).[564] Rule consequentialism, which is the commonest form of indirect consequentialism is also known as the second principle approach.[565] This approach introduced by John Mills is a way of assessing the rightness of an act based on the consequence of the rule guiding the action.[566] Although advocates of direct consequentialism have argued that judging

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[560] Julia Driver, 'The History of Utilitarianism' (Stanford Encyclopedia of Philosophy (Winter 2014 Edition), Edward N Zalta (ed), 22 September 2014) <https://plato.stanford.edu/archives/win2014/entries/utilitarianism-history/> accessed 14 June 2021.

[561] Ibid.

[562] Gerald Jones and others, *Moral philosophy: a guide to ethical theory* (Hodder education 2006) 59-86.

[563] Ibid.

[564] Ibid.

[565] Mill (n 552).

[566] Marcus Singer, *Generalization in Ethics* (New York: Knopf 1961).

an act by the consequence of a rule is a convoluted way of assessing the act and they find this implausible.[567] Mills then put forward a list of moral rules like do not lie, do not cause harm to others, and so on.[568] This approach is seen as a way of combining the good aspects of consequentialism with deontology.[569] Following the rule, utilitarian approach helps avoid the need for complex calculations involved in act utilitarianism to decide which act is morally right.

The deontological approaches to difficult decisions in healthcare

This is a non-consequentialism approach to ethics which unlike the consequentialism approach categorically forbids some actions (like killing innocent people) regardless of what good they can or liable to produce.[570] This ethical analysis permits people to chase their goals in life without having to think about making other people well off. The theories are different from teleology because they hold that actions are perceived as intrinsically right or wrong irrespective of their outcomes. The primary value of deontology theories is the duty to do what is adjudged 'good' with such duty accompanied by a right. In the case of a doctor looking after an individual deemed to be in a PVS, the doctor has a duty or compulsion to bring about 'good' in this person. Some commentators may refer to this duty to do good as a duty of beneficence. With this duty comes the right to be treated in a good way. The early account of deontology can be traced back to the Ten Commandments in the Bible.[571] However, Immanuel Kant gave a non-religious account of the theories in the eighteenth century. This approach was criticised

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[567] John Smart, 'Extreme and Restricted Utilitarianism' (1956) 6(25) The Philosophical Quarterly <https://doi.org/10.2307/2216786> accessed 3 May 2021.

[568] Mary Warnock, Utilitarianism and on Liberty: Including Mill's 'Essay on Bentham' and selections from the writings of Jeremy Bentham and John Austin, Second Edition (Blackwell Publishing Ltd 2003) 88-100.

[569] Ibid.

[570] Larry Alexander and Michael Moore, 'Deontological Ethics' (The Stanford Encyclopedia of Philosophy (Winter 2020 Edition), 30 October 2020) <https://plato.stanford.edu/archives/win2020/entries/ethics-deontological/> accessed 3 May 2021.

[571] The Bible (King James Version) Exodus 20:3-17.

by the utilitarian philosophers, but others such as H. A Prichard and W D Ross have defended the approach.[572] The two popular forms of deontology are the divine command ethical approach and the Kantian ethical approach.[573]

The divine ethics is premised on the ground that the actions commanded or directed by God are morally right while the ones condemned by God are morally wrong.[574] This approach is rooted in the belief that a creator exists, and that the creator has a will which is the yardstick to determine what is right. According to this command ethics, it is irrelevant if the command is cruel or unjust, the ethical standards are derived from the divine lawmaker.[575] The critique of forgoing or ceasing life-sustaining or prolonging interventions in this theory going by Pope John Paul II's sentiments regarding the matter.[576] A few months before he passed on, the pope made an address termed '*Care for Patients in a PVS*', that was presented at an international conference on VS.[577] The address opened up a debate about CAHN that will surely have far-reaching consequences in the future. His stance was that '…*the administration of water and food, even when provided by artificial means, always represents a natural means of preserving life, not a medical act…*'.[578] This statement implies that CAHN for those in a PVS should be a moral obligation. The address has given rise to questions pertaining to whether this allocution applies only to individuals labelled as PVS or other mentally incompetent individuals, and if Catholics are obliged to adhere to it.

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[572] Alexander and Moore (n 570).

[573] Ibid.

[574] Avi Sagi and Daniel Statman, 'Divine Command Morality and Jewish Tradition' (1995) 23(1) The Journal of Religious Ethics <https://www.jstor.org/stable/40015197> accessed 2 May 2021.

[575] Ibid.

[576] John Paul ii, 'Care for patients in a 'permanent' vegetative state' (2004) 33(43) Origins <https://pubmed.ncbi.nlm.nih.gov/15139351/> accessed 3 May 2021.

[577] Kevin Miller, 'Artificial nutrition and hydration and the permanently unconscious patient: The catholic debate' (2015) 82(1) The Linacre Quarterly < https://ncbi.nlm.nih.gov/pmc/articles/PMC4313428/>accessed 19 April 2021.

[578] Paul ii (n 576).

Kantian ethics, on the other hand, does not have any root in the commands of God but rather, the moral law emanated from reasoning.[579] Kant believed that moral actions are duty-bound and the recognition of this duty by a moral agent makes it moral. He said that every human being is bound by categorical imperatives and that there is a maxim (principle of action) behind every act.[580] Some have argued that these moral duties can be formed based on reasoning alone. Therefore, behaviour in the Kantian theory is governed by obligation. A behaviour that results from obligation is perceived to be ethical. Kant further gave a golden rule which states that '*…acting such a way that it is possible for one to will that the maxim of one's actions should become a universal law…*'[581] In addition, Kant insisted that human beings should not be treated '*…as a means to an end…*'[582] Therefore, according to the view of this theory, availing CAHN to patients labelled as PVS is a moral duty and thus ethical while withholding nutrition and any other life-sustaining treatment is unethical. This view comes from the perspective that if an action is considered right then it becomes a universal law.[583] Therefore, if doctors forgo CAHN in VS or PVS then this should be done across the board for all patients lacking mental capacity.

The virtue of ethical approaches to difficult decisions in healthcare

Virtue ethics differs from the above two ethical approaches in that it focuses on the individuals rather than the act.[584] Some philosophers have sometimes described it as an agent-centred ethics. [585] Virtue ethics has been around since ancient Greece, but it was not until a few

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[579] Andrews Reath, *In M Gregor (Trans), Kant: Critique of Practical Reason* (Cambridge University Press 2015).

[580] Herbert Paton, *The moral law: Kant's Groundwork of the metaphysic of morals* (Hutchinson 1972) 65.

[581] Robert Johnson and Adam Cureton, 'Kant's Moral Philosophy' (Stanford Encyclopedia of Philosophy (Spring 2021 Edition), Edward N Zalta (ed), 25 February 2021) <https://plato.stanford.edu/archives/spr2021/entries/kant-moral> accessed 14 June 2021.

[582] Ibid.

[583] Ibid.

[584] Rosalind Hursthouse and Glen Pettigrove, 'Virtue Ethics' (Stanford Encyclopedia of Philosophy, 9 December 2018) <https://plato.stanford.edu/archives/win2018/entries/ethics-virtue/> accessed 3 May 2021.

[585] James Sterba, *Philosophy: The Big Questions* (2nd edn, John Wiley and Sons 209) 311-312.

decades ago when philosophers like Macintyre and Pellegrino started promulgating it as an alternative to the above-mentioned ethics.[586] The concept of good among the ancient Greek philosophers is in relation to function (i.e., one is good if one functions well).[587] The virtue ethics in ancient Greece was based on Plato and Aristotle's theories.[588] The two theories shared views on the link between virtues, happiness and morality but there are fundamental differences in their ethical positions. While Plato posited those virtues emanate from the knowledge of the world of forms, Aristotle believed that one can only be virtuous by appreciating what one's function was and outrivalling in the right ways.[589] Natural law ethics emanates from the writings of Aristotle. He says, '… *All things aim at some good and for this reason, the good has been rightly declared that at which all things aim …*'[590]

St Thomas Aquinas in the thirteenth century adapted Aristotle's theory by integrating it into a Christian context and called it the natural law, which according to him, actions in human nature are meant to fulfil God's will and commandments.[591] The basic principle that underlines the natural law ethics is premised on the need for the administration of good and the avoidance of evil acts.[592] Good tantamount to acting according to what God commands. God commands us not to kill. Therefore, an act that may result in the death of others knowingly is tantamount to passively 'killing' the patient and thus going against the commandment of God. Aristotle defined good as something that satisfies natural need such as food and water.[593] The Stoics further delved into that natural law by stating that it was possible for humans to be happy

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[586] Edmund Pellegrino and David Thomasma, *The Virtues in Medical Practice* (OUP, New York 1993).

[587] Richard Parry and Harald Thorsrud, 'Ancient Ethical Theory' (Stanford Encyclopedia of Philosophy (Spring 2021 Edition), Edward N Zalta (ed), 5 February 2021) <https://plato.stanford.edu/archives/spr2021/entries/ethics-ancient/> accessed 14 June 2021.

[588] Ibid.

[589] Ibid.

[590] Douglas Soccio, *Archetypes of Wisdom: An Introduction to Philosophy* (8th edn, Wadsworth Publishing Co Inc 2012).

[591] Ibid.

[592] Mark Murphy, 'The Natural Law Tradition in Ethics' (Stanford Encyclopedia of Philosophy, 26 May 2019) <https://plato.stanford.edu/archives/sum2019/entries/natural-law-ethics/> accessed 12 June 2021.

[593] Ibid.

without the need for external goods such as clothes and luxury but placed the emphasis on rationality to govern human emotions.[594] Therefore, when our actions are guided by proper reason, then the sanctity of life will be preserved through the provision of CAHN to patients in the VS/PVS rather than the regard for financial burden and economic good.

Practical application of the normative ethics

The fact that the two classes of ethical theories have opposite concepts means that they cannot be solely reliably applied in making withholding or withdrawing decisions.[595] Over time, the consequentialism approach to ethics has tried to mimic some good aspects of non-consequentialist ethics. Both are known to have far-reaching shortcomings. However, a combination of good concepts derived from both theories can be used for ensuring best practices. Objectively, in the preservation of life, some of the concepts that can be derived from both theories are the need to be responsible in the delivery of the duty of care to achieve the best possible outcomes for the preservation of life in accordance with the will of God.[596] According to Gillion[597] and Beauchamp & Childress[598] Fundamental principles of healthcare ethics, some of these concepts have been reflected and need to be considered when ethical judgments are made. Withdrawing artificial nutrition and hydration in principle can cause harm to the person, even though we may presume that they do not feel pain or hunger, but it is well established that the act leads to death.[599] Likewise, withdrawing life-sustaining treatment. All decisions should benefit the patient and consider all those affected. It is sometimes difficult to make objective ethical decisions. Many doctors wrestle with the dilemma of reconciling ethical

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[594] Ibid.

[595] Rachels (n 516).

[596] Scott Rae, *Moral Choices: An Introduction to Ethics* (2nd edn, Zondervan Publishing House 2000).

[597] Raanan Gillion, *Philosophical Medical Ethics* (John Wiley & Sons, Chichester 1986).

[598] Beauchamp and Childress (n 400)

[599] Mackenzie Graham, 'Can they Feel? The Capacity for Pain and Pleasure in Patients with Cognitive Motor Dissociation' (2019) 12 Neuroethics <https://doi.org/10.1007/s12152-018-9361-z> accessed 25 May 2021.

theories and professional principles which can be in conflict. This explains the conflicting decisions made by physicians across the domain. The obligation to make decisions when an ethical dilemma has been solely laid upon physicians and raises another issue of withdrawal and withholding CAHN.

The issue of withdrawal of CAHN is highly controversial even in a situation when the patient is considered to be approaching the terminal stage of life.[600] The decision on which course of action to take for a mentally incompetent patient, in the absence of a reliable surrogate, or a written or verbal wish represents a big ethical dilemma especially when the outcome of action or omission is the patient’s death. However, ensuring that the patient’s autonomy is respected remains a fundamental person-centred principle amidst these ethical dilemmas. The analysis of burden over benefit showed to be untenable, not unless if consideration is made that death is preferred over life. The principle of the quality of life is of little significance in determining whether death can be a likely benefit.[601] The philosophical-oriented debate whether CAHN should be withdrawn from PVS patients will be important in the applicable contexts if the reality is brought into account and other ways of ending the life of PVS patients are accorded an ethical consideration.

Criticism of the normative ethical approach in decision-making for PVS patients.

The issue with the theological approach to ethics is that it is based on the will of a creator which is God.[602] Many have queried the source of the will in the sense that it is not very clear

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[600] Roschelle Heuberger, ‘Artificial Nutrition and Hydration at the End of Life’ (2010) 29(4) Journal of Nutrition for the Elderly <https://doi.org/10.1080/01639366.2010.521020> accessed 23 May 2021.

[601] Leslie Scheunemann and Douglas White, ‘The ethics and reality of rationing in medicine’ (2011) 140(6) Chest <https://doi.org/10.1378/chest.11-0622> accessed 25 May 2021.

[602] Lawrence Pasternack, And Courtney Fugate, 'Kant’s Philosophy of Religion' (Stanford Encyclopedia of Philosophy (Summer 2021 Edition), Edward N Zalta (ed), 19 April 2021). <https://plato.stanford.edu/archives/sum2021/entries/kant-religion/> accessed 14 June 2021.

how these wills are obtained. The other issue is that even if this is accepted as being from God, how then do we expect everybody to abide by these obligations even for those that do not believe in any religion? The theory must also assume that the divine creator is benevolent and therefore, the will is good and caring. But what about the existence of the devil or evil? If good is associated with God, if there is no God then there will not be any obligation to do good. It is well known that atheists are not evil doers. They have a morality that they follow. How does divine ethics cover the advancement in technology in medicine, with issues like cloning and organ donations? On the other hand, there have been criticisms of the Kantian approach to ethics which involves the use of logical reasoning to determine what is moral. However, the major drawback to this approach is the fact that not all universal maxims are moral and not all maxims can be universalised.[603] How about how we differentiate a social etiquette from a moral obligation?

Conversely, the utilitarian approach promotes a calculative approach to morality and ethics which can be complex and time-consuming. Also, it may not be practicable in every healthcare decision process. Further, it is unclear how utilitarians will decide if withdrawing treatment in PVS is wrong or right because they are seen as being unable to experience pain or pleasure. Therefore, on what grounds will the amount of good or bad be based? The issue with natural law ethics revolves around the definition of 'natural'. The theory heavily depends on viewing the universe through a teleological telescope. Today, science has significantly changed people's perspectives about the universe and therefore, the teleological views of the Aristotle era have become obsolete. Furthermore, Aquinas' views on natural law theory relied on Christian theology which made it unacceptable to everyone. The law is also seen as reactionary in nature. The norm is seen as the morality that is obtained up to a certain point and when the norm changes people tend to reject that law and move to the next norm. It is unclear how the

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[603] Jones (n 562) 45.

philosophers determine what is morally right or wrong by just looking at nature. How were they able to distinguish between natural and unnatural events?

In summary, the normative ethical approach involves having virtues and learning the application of moral rules and duties to resolve ethical dilemmas. As simple as the last statement may sound, the application of normative ethics in practice is complex, especially in contentious debates such as the issues around the management of patients diagnosed as PVS. How can bioethics decide the virtues or vices in the treatment of PVS patients? Virtue ethics seems to be an imprecise way of resolving dilemmas in healthcare settings. From the above argument, it seems that the application of normative ethics to the issues around the treatment of people diagnosed as in a PVS may be inadequate. Unless one is committed to a certain ethical perspective, choosing among these theories with competing views seems impossible because each theory has its good and not-so-good features. Even though sometimes we may find a common ground during their applications they do not have a common denominator.[604]

3.4. An inherent worth-based approach.

The notion that all human beings have inherent worth has formed part of the foundation of many forms of thought across time, including all of the major world religions. In Western thought, it has been reflected in certain conceptualisations of dignity and personhood – albeit contradicted by others. These conceptualisations have a specific poignancy for those diagnosed as having PVS because of the threat posed to the notion that they are persons/have interests/are of equal value posed by certain other conceptualisations of dignity and personhood as well as by utilitarian thought. This section will not only focus on personhood and dignity as proxies for worth but will also refer critically to versions of personhood and dignity that are not

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[604] Thomas Nigel, *The fragmentation of value' in mortal Questions* (Canto 1992) 132.

consistent with inherent worth. In addition, there will be an appraisal of the valuation of human life and more specifically, the sanctity of life as it is relevant to PVS and it is more of a specific aspect of recognition of dignity and personhood.

Human dignity as a proxy for worth.

The concept of dignity has been criticised by some philosophers as useless and perhaps not fit for purpose.[605] Some have said that the concept is too vague, not possible to accurately define, and not practical to apply.[606] However, this thesis takes a strongly different view on these assertions. More importantly, the approach to the dignity argument here involves exploring the concept from its history and its meaning and applying it specifically to people diagnosed as in PVS. The main dignity argument concerning the PVS concept is whether an individual with a deteriorated quality of life still has dignity and what form of dignity. Further, whether such dignity should be respected.

Dignity is expressed in a lot of ways in the literature; while some experts have attempted to define and classify it others have only managed to explain what it is and what it's not without any explicit definition. The vagueness in the definition of the concept has made arguments about dignity a complicated task. Unless there is an agreement on the form of dignity one is referring to, the usage will only offer more questions than answers when deployed to resolve complex ethical issues. As such, the concept of dignity has always been seen to appear vague and abstract, and thus its application in real-life situations has been controversial. Although the Courts in the UK are starting to use the concept more as a part of the legal principles in PVS cases, it is broad and difficult to define in a precise manner. While many

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[605] Ruth Macklin, 'Dignity is a useless concept' (2003) 327(7429) BMJ <https://doi.org/10.1136/bmj.327.7429.1419>accessed 25 May 2021.

[606] Doris Schroeder, 'Dignity: two riddles and four concepts' (2008) 17(2) Camb Q Healthc Ethics <https://doi.org/10.1017/S0963180108080262> accessed 2 May 2021.

philosophers/bioethicists shy away from the use of dignity in an ethical coherent way to tackle complex ethical issues in medical practice, a handful of them, like Charles Foster, hold a strong view that dignity holds the key to unlocking all problems in bioethics and medical ethics.[607] The argument on human dignity in this thesis shares the sentiment that dignity forms the basis upon which rights and norms are formulated. As such, it is pivotal to protecting the rights of individuals labelled as PVS.

Some have argued that dignity is not lost even at death, while others believe that a life of deteriorated quality lacks dignity.[608] Death signifies the end of life, dignified or not, which could be the end of dignity depending on the school of thought to which one belongs. As much as it is required of a human being to live a life that is full of dignity, the process of dying should also carry as much dignity as life itself. Death, therefore, should not warrant indignity to any person.[609] In other the safeguard the rights of patients diagnosed as PVS we must agree that they retain their dignity and the accompanying respect should be a basis for decision-making. Even if we agree that they are dying for the sake of argument, there is still the need for them to have their dignity respected. Thus, PVS patients should maintain their status as human beings even to the point of death and perhaps thereafter. The dignity of these individuals can be violated in a few ways regardless of what definition we hold about the concept. Treating them in a degrading or humiliating manner will deprive them of their rights to dignity. Also, using them as a source of obligation would amount to instrumentalization with would violate their dignity. In addition, making them superfluous would also violate their dignity. The last and perhaps the most important is by not allowing them to flourish like every other human being

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[607] Foster (n 531) 19 -21.

[608] Ruth Horn and Angeliki Kerasidou, 'The Concept of Dignity and Its Use in End-of-Life Debates in England and France' (2016) 25(3) Cambridge quarterly of healthcare ethics <https://doi.org/10.1017/S0963180116000050> accessed 25 May 2021.

[609] Ibid.

will also violate their dignity. One of the compelling interpretations of dignity is allowing humanity to flourish.[610]

Although the origin of human dignity is not very clear in the literature, the early philosophical account of the concept can be traced to the writings of Petrarch and Manetti in the fourteenth and the fifteenth centuries, respectively.[611] However, the notion was later popularised by the Italian philosopher Pico della Mirandola.[612] He argued that we need to explore the history of creation to understand the scope of the concept.[613] Pico della Mirandola posited that man acquires dignity from his God-given ability to make a free choice.[614] The journey of the concept to today's discourse on human rights and the constitution has not been smooth all the way. Some philosophers have taken a strongly negative view of the concept. As a case in point, Arthur Schopenhauer believed that human dignity is a form of flattery and that the concept has no substance.[615] Furthermore, Ruth Macklin, in her BMJ article in 2003, made a bold remark that dignity has no value in medical ethics and that the concept is a mere slogan or, at best, a form of respect for autonomy.[616] In a similar vein, Doris Schroeder added that the concept is unfit to be used in ethical debate due to its nebulousness, claiming that the concept could have four different meanings.[617] The four forms of dignity she mentioned are the dignity we have due to our reasoning or free will (Kantian dignity), rank (Aristocratic dignity), good behaviour (Comportment dignity), and the one associated with virtue (Meritorious dignity).[618]

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[610] Foster (n 531) 8 -14.

[611] Aharon Barak, *Human dignity: The constitutional value and the constitutional right* (Cambridge University Press 2015) 24.

[612] Lukman Harees, *The mirage of dignity on the highways of human dignity- the bystanders' perspective* (Authour House, 2012) 54.

[613] Francesco Borghesi and others, *Pico della Mirandola: Oration on the Dignity of Man: A New Translation and Commentary* (Cambridge University Press 2012) 52-65.

[614] Barak (n 611) 24.

[615] Michael Rosen, *Dignity: its history and meaning* (Harvard University Press, 2012) 1-3.

[616] Ruth Macklin, 'Dignity is a useless concept' (2003) 327(7429) BMJ <https://doi.org/10.1136/bmj.327.7429.1419>accessed 25 May 2021.

[617] Doris Schroeder, 'Dignity: two riddles and four concepts' (2008) 17(2) Camb Q Healthc Ethics <https://doi.org/10.1017/S0963180108080262> accessed 2 May 2021.

[618] Ibid

However, Suzy Killmister dismissed Macklin and Schroeder's argument by saying they are wrong to view human dignity from such a narrow perspective.[619] She said that human dignity could mean autonomy in a way, but its broader meaning and application serve to value human life; therefore, all its distinct roles are connected.[620] The argument of human dignity as a proxy for worth in this thesis shares similar sentiments with Killmister's view on dignity. In this research, human dignity is considered a useful concept but the ultimate relevant question here is whether it is specifically useful in PVS. The discussion of human dignity in this thesis and the analysis of its application show that it is a useful concept. The issue with Macklin's argument against dignity is that she premised her argument partly on the notion that other principles would do the job better.[621] However, the principles she was referring to in her article are neither complete as a set to cover health/medical ethics and law issues and without worth nor some proxy for it lacks any reference point for their prioritisation. This inadequacy is the principal problem/limitation with reliance on any set of non-generic principles (i.e. with reliance on any form of principlism).

The second issue with Macklin's criticism is that it is possible to work out a schema of principles that flow from the protection of inherent worth/dignity and for these to have reasonable specificity and clarity of application and be clearer boundary wise as between them because they reference back to inherent worth or dignity. Take, for example, equality. If one follows it as an isolated principle, as Macklin suggests, one can give it virtually any meaning one likes. It could, for example, reference outcome or sameness of treatment or require differences in treatment that reflect differences between individuals or differences in treatment that make up for historic disadvantages endured by the class of person in question.

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[619] Suzy Killmister, 'Dignity: not such a useless concept' (2010) 36(3) J Med Ethics 160-164 <https://doi.org/10.1136/jme.2009.031393> accessed 25 August 2021.

[620] Ibid.

[621] Macklin (n 616).

Alternatively, it could be a mix. Referencing inherent worth or dignity is not going to give one a complete answer about what to do. However, it does at least help provide a bit of guidance – for example. It tells one at a minimum that one's approach should avoid interfering with the equal valuation of all members of the species and should endeavour to protect that positively.

Other philosophers have taken a less dramatic approach when it comes to dismissing the concept. For instance, James Griffin also likened dignity to autonomy, while Joel Feinberg claimed that human dignity is simply a form of respect for people's rights.[622] This research postulates that dignity should be a fundamental right of everyone irrespective of the quality of life possessed by an individual. The notion of important life decisions takes different forms to the extent that critics have said that the concept does not have an intelligible meaning by itself.[623] For instance, the dignity argument has been used to argue against euthanasia, while the same dignity, in a different sense, has been used to argue that people should die with dignity through controversial practices like assisted suicide.[624] In discussions involving ethics in general and bioethics in particular, human dignity is a concept that carries much weight. Dignity has always been associated with supreme holiness.[625] It is an acceptable quality an individual should have to make autonomous decisions in life. The different views or interpretations of human dignity are based on different philosophical opinions, religious beliefs, and social perspectives. Regardless of the complexity of the concept, it takes nothing away from its importance in the decision-making process. The ideas underpinning the concept are not straightforward; therefore, a systematic approach should be used to understand the reasoning behind different usage.

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[622] Rosen (n 615) 5.

[623] Ibid 6.

[624] Ronald Dworkin, *life's dominion: An argument about abortion, euthanasia and individual freedom* (Vintage Books, 1994) 238.

[625] Rosen (n 615) 2-3.

Religion has been pivotal in the history of the development of human dignity.[626] Although various world religions recognise the concept, western religions have had the greatest impact on the concept.[627] Judaism recognised '*kavod*', which means dignity/honour as an attribute of God extended to man through creation.[628] Moreover, that human dignity takes precedence over autonomy and liberty.[629] Christianity adopted the Judaic view that human dignity is a notion that God created human beings to exude His image on earth.[630] Although Islam does not believe that man was created in God's image, her believers still acknowledge that man is God's creation, consequently the evidential proof of God's existence.[631] Therefore, human dignity should be bestowed on human beings in honour of God. In Hinduism, '*Dharma*' defines a person and her responsibilities; this bestows dignity on the person; however, understanding the human dignity concept in Hinduism remains debatable.[632] Furthermore, in Buddhism, the equivalence of dignity lies in the way they value human life as a very precious entity.[633] There are correlates of the western world concept of human dignity. In Africa, the humanity concept called *Ubuntu* shares some fundamental parallels to human dignity.[634] Mohandas Gandhi introduced a concept called *Sarvodaya* in the early twentieth century in India, which means universal uplifting.[635] This social movement encompasses dignity of labour, egalitarianism, and freedom. In the Chinese tradition, the concept '*Zun Yan*' posits that people have human dignity due to their innate virtues.[636]

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[626] Sigrid Müller, 'Concepts and Dimensions of Human Dignity in the Christian Tradition' (2020) 6(1) Interdisciplinary Journal for Religion and Transformation in Contemporary Society <https://doi.org/10.30965/23642807-00601003>accessed 25 May 2021.

[627] Barak (n 611) 18–23.

[628] Harees (n 612) 60–64.

[629] Ibid.

[630] Barak (n 611) 21.

[631] Ibid 20 -23.

[632] Harees (n 612) 62–63.

[633] Ibid.

[634] Ibid.

[635] Harees (n 612) 74.

[636] Ibid 72.

Dignity as a concept started as a social construct whereby the people in the high social stratum are accorded respect and honour.[637] Cicero introduced the conventional status approach where he claimed that human being has dignity, not because of his ability to reflect but because he was made in God's image.[638] This status approach to dignity transcended into the early Christian era. There was a shift in how respect was accorded to people. A change from giving a few people respect because of their status to giving everybody all together. Thomas Aquinas later popularised this theological approach to dignity by positing that dignity is an intrinsic value possessed by everyone because of the human link to God as the creator.[639] Following the reasoning of Aquinas, whether the medical profession or the law sees individuals deemed in PVS as dying or severely disabled, they retain their dignity from conception to death. People have argued that self-awareness and the capacity to make free, informed choices accord humanity its dignity. This approach to dignity was the secular conception that humans' ability to reason is the basis for their dignity during the Middle Ages.[640] This argument becomes very critical in the debate about the worth of the lives of people in the state of the PVS. However, this should not be the basis to accord indignity to persons in a VS or the dying process. Kant's approach to dignity is somewhat like Aquinas' because the value of something is on its account.[641] However, the difference in their ideas is that while Aquinas' intrinsic value of human beings is related to God, Kant's idea is related to morality, humanity, and natural law.[642] Therefore dignity is a non-conditional and unique inherent value possessed by all humans. Kant's dignity is related to a human being's ability to make an autonomous decision.[643]

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[637] Rosen (n 615) 11.

[638] Ibid 11–13.

[639] Ibid 16-71.

[640] Harees (n 612) 55.

[641] Bernard Baertschi, 'Human dignity as a component of a long-lasting and widespread conceptual construct' (2014) 11(2) Journal of bioethical inquiry <https://doi.org/10.1007/s11673-014-9512-9> accessed 15 April 2021.

[642] Barak (n 611) 22.

[643] Ibid 26–28.

Friedrich Schiller, through his essay on grace and dignity, introduced the notion of grace into the dignity discourse. He posited that when human beings act instinctively, it is called grace, but the ability to resist our natural predispositions and act morally is dignity.[644] This definition of dignity is different from possessing intrinsic value because someone can lack this form of dignity and still have dignity as an extension of her humanity. Therefore, dignity, according to Schiller, is a function of an individual's action.[645] Another form of dignity is the one campaigned for during the French Revolution to oppose slavery. This notion was an egalitarian approach to worth which then superseded the privileged approach in the aristocracy's dignity, which dignity associated with rank or status.[646] A hierarchical approach to dignity was seen in the nineteenth-century Catholic Church practice, where dignity is accorded to people based on their order in society.[647] Furthermore, Joel Feinberg's concept of human dignity is simply the respect for other people's rights.[648] Hence, if we respect one's dignity, we invariably acknowledge that the person has dignity. Jeremy Waldron brought the early years' notion of dignity as rank and status to the modern-day discourse, but the context in which he approached it was different.[649] Waldron argued that all human beings have a high and equal rank, which he called human dignity.[650] The concept's susceptibility to different interpretations has made critics say that it is vague, and its use in the Court can be subjected to a wide range of interpretations.[651]

The modern-day concept and usage of dignity started after World War II when the idea of human dignity as free and equal rights of everyone was enshrined in many international

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[644] Rosen (n 615) 35.

[645] Lydia Moland, 'Friedrich Schiller' (Stanford Encyclopedia of Philosophy (Summer 2021 Edition), Edward N Zalta (ed), 26 April 2021) <https://plato.stanford.edu/archives/sum2021/entries/schiller/> accessed 12 June 2021.

[646] Rosen (n 615) 38-40.

[647] Ibid 48 – 49.

[648] Ibid 57-58.

[649] Meir Dan-cohen, *Jeremy Waldron: Dignity, Ranks, and Rights* (Oxford University Press 2012) 13–18.

[650] Ibid.

[651] Barak (n 611) 9.

conventions and the constitutions of various countries.[652] This heralded the usage of the human dignity notion in legal discourse. The preamble of the Charter of the United Nations recognised the dignity and worth of every human being and that everyone has equal rights.[653] In 1948, the UN General Assembly adopted the Universal Declaration of Human Rights (UDHR), which contained in it the acknowledgement of the intrinsic dignity of every human being.[654] After the Geneva Convention, the concept of human dignity found its way into some countries' constitutions. Germany became the first country to incorporate human dignity into her constitution, wherein article one states that '*the dignity of man shall be inviolable*'.[655] While human dignity is a constitutional value in some countries like the US, Canada, and Spain, human dignity is a constitutional right in other countries like Germany, Colombia, Russia, Switzerland, South Africa, and Israel.[656] The transition of human dignity from a socio-philosophical concept to a legal one seemed to begin around the middle of the twentieth century. There have been criticisms that dignity in the law is not always consistent with its definition in other documents.[657] These criticisms do not take away anything from the meaning of the concept from the legal perspective. The law protects human dignity indirectly by upholding human rights laws and treating people as dignified agents of society.[658] After the three documents mentioned above, human dignity has appeared in a host of international conventions (ICCPR art. 10(1), ICESCR art. 13(1), UNESCO, and Convention on the Rights of Person with Disabilities, among others), European conventions and the constitutions of some

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[652] Doron Shulztiner and Guy Carmi, 'Human Dignity in National Constitutions: Functions, Promises and Dangers' (2014) 62(2) The American Journal of Comparative Law <http://www.jstor.org/stable/43668212> accessed 15 June 2021.

[653] United Nations Charter <https://www.un.org/en/about-us/un-charter/full-text> accessed 25 May 2021.

[654] Universal Declaration of Human Rights <https://www.un.org/en/about-us/universal-declaration-of-human-rights> accessed 25 May 2021.

[655] Basic Law (Grundgesetz) of 23 May 1949, the constitution of the Federal Republic of Germany, article 1.

[656] Barak (n 611) xvii – xix.

[657] Dan-cohen (n 649) 15.

[658] Waldron, Jeremy, How Law Protects Dignity (December 15, 2011). NYU School of Law, Public Law Research Paper No. 11-83 <http://dx.doi.org/10.2139/ssrn.1973341> accessed 25 May 2021.

countries. In countries where it is not written in the constitution, there are provisions within the constitution to safeguard the dignity of the citizens. Certainly, in countries like the UK, where there is no codified constitution, there are legal provisions to protect the dignity of the people.

As rightly observed by Doris Schroeder, human dignity can have at least four meanings.[659] According to the first one, dignity is an inherent value in the Kantian way or the Catholic way.[660] The other idea is dignity as a status held by human beings based on humanity.[661] The third idea is when dignity is seen as behaviour[662], and lastly, the idea of dignity as a form of treating people with respect.[663] Importantly, it would be prudent to view all these ideas as complementary rather than contradicting. The pre-modern era idea of dignity as a rank was modified by Jeremy Waldron to connote that everybody has a high rank/status, which he called human dignity.[664] A concept that derived its meaning somewhere along a spectrum between honour and worth.[665] The dignity argument in PVS should involve all considerations that put the individual as a moral agent with inherent worth regardless of the disabilities the condition confers. In deciding the value of life, priority should be accorded to the welfare of the patient. All parties are required to uphold the interests of the patient, which may be a daunting task. The value and quality of life depend on how it is defined and who defines it. Opinions are divided on the difference between letting a person die and engaging in activities that may lead to that person's death.[666] The dignity argument supports that everyone has an inherent worth and that no life should be terminated because of diminished quality. Another argument is that given the circumstances under which the quality of life of a person

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[659] Killmister (n 619).
[660] Ibid.
[661] Ibid.
[662] Ibid.
[663] Ibid.
[664] Jeremy Waldron, ‘How law protects dignity’ (2021) 71(1) The Cambridge Law Journal <http://www.jstor.org/stable/23253794> accessed 15 April 2021.
[665] Dan-cohen (n 649) 4.
[666] UNESCO, 2011. Casebook on Human Dignity and Human Rights, Bioethics Core Curriculum Casebook Series, No. 1, UNESCO: Paris, 144.

is, let us say, unacceptably deteriorated. Then such life should not be prolonged to prevent more suffering, even though there are actions that could be undertaken to prolong such life.[667]

Personhood as a proxy for worth.

The personhood approach to the management of patients labelled as PVS would be based on the philosophical approach to defining who a 'person' is? To answer this question is to agree on how medicine and the law should treat PVS patients. The main philosophical notions of personhood in the literature are whether a person is defined based on mental abilities or being a human being or based on the relationship with others. The day-to-day usage of the term 'person' means a human - however, the philosophical approach to defining the term is that someone has moral status worthy of moral claims.[668] The personalism approach defines a person based on the possession of characteristics that are associated with mental capabilities like the ability to think or communicate.[669] However, it completely disregards those characteristics as long as one is a member of the human species, that individual is regarded as a 'person'.[670] By contrast, the relational account holds that people's moral status is dictated by their relationships with the other members of their species.[671] This section argues that it is morally challenging to base life and death decisions on characteristics like possession of mental capacity or the relationship between an individual with others and that these approaches are not congruent with human beings having a moral agent with inherent dignity. Therefore, the personalism approach should be advocated to protect the rights of PVS patients.

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[667] Hume Adams and others, 'The neuropathology of the vegetative state after an acute brain insult' (2000) 123(7) Brain <https://doi.org/10.1093/brain/123.7.1327> accessed 3 May 2021.

[668] Frederick White, 'Personhood: An essential characteristic of the human species' (2013) 80(1) The Linacre quarterly <https://doi.org/10.1179/0024363912Z.00000000010> accessed 15 April 2021.

[669] Austen Garwood-Gowers, *Medical use of human beings: Respect as a basis for critique of Discourse, law and practice* (Taylor & Francis group 2019) 12.

[670] Ibid.

[671] Charles Foster and Jonathan Herring, *Identity, personhood and the law* (Springer international publishing AG, 2017) 35.

Personhood in bioethics and philosophy is a theoretical concept of how human beings are valued and why they are given more rights than animals. It is a claim of moral value to the biological entity called human beings. Some experts defined a person as 'a self-conscious or rational being' who can think and make rational decisions.[672] The concepts of personhood and self-awareness are elastic and subject to cultural variations. For instance, slaves and women were not regarded as persons, according to Aristotle.[673] Instead, the intelligent and rational actions of slaves and women were considered to be an extension of their master's intelligence and rationality. Concerning this, people from subordinate groups have historically been treated with epistemic priority. This treatment does not mean that they do not meet the criteria to be accorded the status of personhood, but it is merely because they belong to a subordinate group. The boundaries of personhood are determined by many arbitrary factors, including political beliefs and socioeconomic status.[674] Therefore, it can be concluded that the academic discourse on consciousness, rationality, and personhood is filled with bias, with rampant goalpost shifting to protect imminent scientific prejudices.

The imminent biases set the grounds for criticism of the concept of personhood as a basis for moral standing and criteria for the determination of a person as being meaningful. History has demonstrated that the casualties of these tests are the less privileged in society, like people in PVS, the elderly who require expensive treatment, foetuses, and new-born with disabilities. Lately, it has been the turn of animals. Just how much can they pass the test? In addition, animals have no moral standing if they fail the test. Both utilitarian and rights theorists view persons and human beings as being morally privileged. However, the disagreements between the two groups are the criteria to differentiate a person from a non-person. In some

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[672] Randall Auxier, 'Personalism Revisited: Its Proponents and Critics' (2005) 19(1) Journal of Speculative Philosophy <http://dx.doi.org/10.1353/jsp.2005.0003.> accessed 3 May 2021.

[673] Maryanne Horowitz, 'Aristotle and woman' (1976) 9(2) Journal of the History of Biology <http://dx.doi.org/ 10.1007/bf00209881> accessed 3 May 2021.

[674] White (n 668).

schools of thought, it is permissible to kill, experiment upon, or harm non-persons, even though not many people will agree with this assertion if the subject is a foetus or someone labelled as PVS.[675] Based on the apparent prejudices, we might think that we have some special qualities that children with downs syndrome, the severely brain-damaged, barbarians, foetuses, and any other being different from us, do not have. Thus, personhood considers some arbitrary criteria such as freedom, self-consciousness, morality, language, and rationality.[676] Therefore, the approach to personhood can either be an inherent approach or a capacity-based approach.

Thomas Aquinas defined the concept of personalism as 'The individual substance (or subsistence) of a rational nature (*persona est naturare rationalis individual substantia*).'[677] Giubilini and Minerva argued that a foetus and a new-born baby are human beings with the potential of being persons.[678] Peter Similarly, Peter Singer defended infanticide using this argument.[679] Though this argument has proved controversial amongst many philosophers and bioethicists, it goes to show the other side of the argument and what the potential consequences of that view may be in practice.[680] Personalism underpins the reasoning behind their argument; thus, when putting the subject of a moral right to life, neither foetus nor infant can be considered a 'person. Here, a 'person' is referred to as someone who can attach values to her existence. This definition may imply that some animals would be considered 'persons' while not all human beings accord the same qualifier. Therefore, being a human being alone is not enough for one to be called a person. Thus, the right to life may not be ubiquitously applicable. This

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[675] Ibid.

[676] Foster and Herring (n 671) 23.

[677] Johan De Tavernier, 'The historical roots of personalism' (2009) 16(3) Ethical perspectives <http://dx.doi.org/10.2143/EP .16.3.2042719> accessed 3 May 2021.

[678] Alberto Giubilini and Francesca Minerva, 'After-birth abortion: why should the baby live?' (2013) 39 Journal of Medical Ethics <http://dx.doi.org/10.1136/medethics-2011-100411> accessed 3 May 2021.

[679] Trevor Stammers, 'Peter Singer's Ethics: A Critical Appraisal' (2018) 24(3) The new bioethics <https://doi.org/10.1080/20502877.2018.1487698 > accessed 15 April 2021.

[680] Charles Camosy, 'Concern for Our Vulnerable Prenatal and Neonatal Children: A Brief Reply to Giubilini and Minervans ' (Practical ethics, 2 March 2012) <http://blog.practicalethics.ox.ac.uk/2012/03/concern-for-our-vulnerable-prenatal-and-neonatal-children-a-brief-reply-to-giubilini-and-minerva/> accessed 31 May 2021.

argument would be favoured in places where practices like abortion, research on embryos, and capital punishment are legal.[681] In essence, the text explicitly dehumanises those mentally disabled and those in PVS, as they are put in an indistinguishable category from animals. The characteristics attributed to personalism include self-determination, subjectivity, dignity, and relational ability.[682] Other characteristics are self-awareness or consciousness, identity, and the ability to value one's life.[683]

There are a few fundamental issues with the personalism concept of personhood. The use of mental capacity as a yardstick to define a person would mean that animals with mental capacity and even computers with sufficiently sophisticated artificial intelligence would be regarded as a 'person'.[684] On the other hand, if someone becomes mentally incapable, then the person would cease to be a person. How about when we go to sleep or when we are under anaesthesia? Is it the case that every human being ceases to be a person for at least 6-8 hours every day when we go to bed? Under this criterion, babies will not be regarded as persons until they attain a certain age, and incapable adults who would have been regarded as persons will, after some time, cease to be. Another issue would be the threshold for which the mental capacity is acceptable. Someone with high mental capacity would be accorded the same value as someone who barely crosses the threshold in this situation. This blanket categorisation brings the issue of equality to question. What is it about the cognitive ability that is crucial to determine one's moral value? The assessment of mental capacity or mental experience of the individual from a third party might not be reliable since understanding the brain function

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[681] Alberto Giubilini and Francesca Minerva, 'After-birth abortion: why should the baby live?' (2013) 39 Journal of Medical Ethics <http://dx.doi.org/10.1136/medethics-2011-100411> accessed 3 May 2021.

[682] Williams, Thomas D. and Jan Olof Bengtsson, "Personalism", The Stanford Encyclopedia of Philosophy (Spring 2020 Edition), Edward N. Zalta (ed.), <https://plato.stanford.edu/archives/spr2020/entries/personalism/> accessed 3 May 2021.

[683] Foster and Herring (n 671) 23.

[684] James Rachels, *Created from animals: the moral implications of Darwinism* (Oxford University Press 1990) 173.

concerning consciousness is not fully understood.[685] Therefore, it remains unknown how the individual values her life and her opinions on whether to continue living or end the life.[686]

The relational approach to defining a person attaches moral status to individuals based on their relationships with others.[687] Foster and Herring opined that our relationships with others accord people their high moral value and consequently their entitlement to moral claims.[688] This argument favours the PVS patients since their definition as persons from the philosophical view would not be based on their mental abilities but rather their relationship with their relatives and carers. Jennifer Nedelsky also contends that people derive their moral values from their relationships with other people.[689] Similarly, Kenneth Gergen argues that people gain their identities as humans through their interaction with other members of the human race.[690] The counterargument to this approach would be that other animals care for themselves, thereby sharing the relational qualities with human beings.[691] The possession of this ability to look after themselves would then mean that these animals could be regarded as having the same moral value as human beings. This argument perhaps does not take anything away from the relevance of the relational approach of personhood to protecting the rights of PVS patients. Another perspective would be in a situation where people are in an abusive relationship with other people.[692] For example, a PVS patient whom a family member exploits would be regarded as having high moral value due to the exploitation; this assertion would be morally wrong.

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[685] Simo Vehmans, ‘Newborn infants and the moral significance of intellectual disabilities’ (1999) 24 (2) Research and Practice for Persons with Severe Disabilities <https://doi.org/10.2511%2Frpsd.24.2.111> accessed 15 June 2021.

[686] Sarah Chan, *Human Animals and Nonhuman Persons. in Tom Beauchamp and Raymond Frey (eds), The Oxford Handbook of Animal Ethics* (Oxford University Press 2011) 307.

[687] Foster and Herring (n 671) 35–41.

[688] Ibid.

[689] Jennifer Nedelsky, *Law’s relations: A relational theory of self, autonomy, and law* (Oxford University Press 2011) 77.

[690] Kenneth Gergen, *Relational Being: Beyond Self and Community* (Oxford University Press Inc, 2009) 95.

[691] Foster and Herring (n 671) 38.

[692] Ibid 40.

This study favours the personalism approach to personhood because it is necessary to treat human beings with dignity and respect. There should be no discrimination against anyone based on his or her disabilities. The disadvantage of people living with disabilities is how society caters to their needs rather than what nature confers on them.[693] Although this approach has also been criticised by Peter Singer, Simon Cushing, and other experts as a form of speciesism or racism, the basis for their arguments is not grounded on a well-balanced moral principle.[694] Speciesism in this regard is not a derogatory approach to attributing worth to human beings.[695] For example, it is a well-established fact that members of a particular species share common characteristics that differentiate them from other species. Therefore, attributing value or worth to all human beings, including those diagnosed as PVS, would not be considered a moral blunder. Regarding the racism argument, racism is discrimination premised on a misleading and egregious distinction within the human race, while the difference between human beings and other species is a matter of scientific facts. Thomas Scanlon has argued that being a human being is enough for everyone to be given the same value and respect that every member of the species has, and to prejudice that with the speciesism argument would be an unfounded claim.[696] Richard Playford and Diane Playford have emphasised the need for clinicians to understand the philosophical approach to defining who a person is and how to value their lives and help them make a balanced decision on treatment options in patients diagnosed as PVS.[697] In essence, this research affirms that the personalism approach is logical and straightforward and, therefore, easy for clinicians to apply in practice.

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[693] Ibid 28.

[694] Simon Cushing, 'Against 'Humanism' Speciesism, personhood, and preference' (2003) 34(4) Journal of Social Philosophy < https://doi.org/10.1111/1467-9833.00201> accessed 16 June 2021.

[695] Foster and Herring (n 671) 30 -31.

[696] Thomas Scanlon, *what we owe each other* (Harvard University Press 2000) 185.

[697] Richard Playford and Diane Playford, 'What am I? A philosophical account of personhood and its applications to people with brain injury' (2018) 28(8) Neuropsychological Rehabilitation <https://doi.org/10.1080/09602011.2018.1456939 > accessed 15 June 2021.

Worth and the life of those diagnosed as PVS

The value we put on human life goes a long way in determining how it is treated in our day-to-day situations. Before looking at the valuation of human life, let us try to define what life is by looking at the three main philosophical approaches to defining life. Some commentators believe that life cannot be defined, as living things are materially continuous from non-living things.[698] Evidence from evolution and biology proves this assertion is misleading at best. The first philosophical approach to defining life is Aristotle's view of life as animation, where he first provided a few definitions of the soul before defining what life is.[699] He claimed that the soul is the cause of life.[700] Aristotle proposed that living things exist in a hierarchical form where human beings are at the top of the hierarchy.[701] The reason for this hierarchical position is that they have the power above everything to reason since reasoning is the highest form of rationality. According to him, the human body cannot be separated from the soul, and if that happens then the body loses its function.[702] It is unclear how the body and soul are related in this definition and how this can be used in decision-making in real situations.

The second philosophical view of life is that of Rene Descartes who viewed living things as a machine and therefore defined life as a mechanism.[703] He argued that the mind and the body are not two discrete entities, since the former cannot exist independent of the latter.[704] He equated human beings to animals owing to their functionality, but thought that human beings are superior due to their ability to reason.[705] Reasoning, according to him, requires the

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[698] Margaret Boden, *The Philosophy of Artificial Life* (Oxford University Press 1996) 303-314.
[699] Marc Cohen, 'Aristotle on the Soul' (History of Ancient Philosophy, 23 September 2016). <https://faculty.washington.edu/smcohen/320/psyche.htm> accessed 3 May 2021.
[700] Ibid.
[701] Juliet Clutton-Brock, 'Aristotle, The Scale of Nature, and Modern Attitudes to Animals' (1995) 62(3) Social Research <http://www.jstor.org/stable/40971103> accessed 25 May 2021.
[702] Ibid.
[703] Justin Skirry, 'René Descartes: The Mind-Body Distinction' (Internet encyclopedia of philosophy: A peer-reviewed academic resource) <https://iep.utm.edu/descmind/> accessed 3 May 2021.
[704] Ibid.
[705] Ibid.

intervention of a thinking substance which he called 'the soul'.[706] Therefore, to him, any person who cannot reason lacks a soul and therefore, is not a human being. For the physicalists, the soul he is referring to here is the brain and by inference, if the brain is unable to reason like we see in PVS then, according to Descartes, these patients may be treated as a non-living entity. However, if 'the soul' is defined from a dualist or spiritualist point of view, then the functionality of the brain will be irrelevant to the definition of life in patients diagnosed as PVS.

Lastly, Kant's perspective is that life can be seen as an organization.[707] Kant's theory resonates with the current ideals of human rights that promote the perception of the treatment of humanity as a worthy end in itself.[708] In his theory, he posited that human comprehension largely led to the emergence of the general laws of nature that structure human experiences, which also allows humans to abide by the moral laws that formed the basis of the beliefs in freedom, immortality and God.[709] Despite these philosophical views of life, biology and evolution have unequivocally confirmed the existence of life and defined various forms of life as originating from a common form and changing over time through the law of natural selection.[710] The understanding of the above perceptions about life remained fundamental to the placement of intrinsic value on human lives.

Three main competing notions of the value of human life have been described in the literature. These are 'vitalism'; the 'sanctity/ inviolability of life', and 'Quality of life'.[711] The

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[706] Ibid.

[707] Eduardo Molina, 'Kant and the Concept of Life' (2010) 10(3) The New Centennial Review <https://researchgate.net/publication/236768520_Kant_and_the_Concept_of_Life > accessed 25 May 2021.

[708] Andrew Reath, 'Value and Law in Kant's Moral Theory' (2003) 114(1) JSTOR <https://doi.org/10.1086/376715> accessed 3 May 2021.

[709] Ibid.

[710] Muhammad Ashraf and Maliha Sarfraz, 'Biology and evolution of life science' (2016) 23(1) Saudi Journal of Biological Sciences <https://ncbi.nlm.nih.gov/pmc/articles/PMC4705322/> accessed 3 May 2021.

[711] John Keown, *Euthanasia, Ethics and Public Policy, An argument against legalisation* (Cambridge University Press 2005) 39.

understanding and the interpretation of how valuable a certain life is, remains a challenge to doctors, bioethicists, and even the Court. The issue with patients who remain unconscious for a protracted period (thereby labelled as PVS) is trying to weigh the intrinsic value of life against its extrinsic value. Interestingly, the frequently used notion ‘sanctity of life’ has not been used in a legally coherent way or better still in an ethically sounded way in medical practice. The way the Courts apply the sanctity of life doctrine can be at times controversial. Some experts argue that the application of this doctrine may have gone too far. In a review by Raanan Gillon, he criticised the judgment of Justice Baker in the W v M, where he claimed that the judge’s decision to reject the authorisation to withdraw ANH in an MCS patient did not consider the principle of distributive justice and the previously held autonomy.

Subsequently, Rabiu and Sugand refuted Gillon’s arguments by claiming that Professor Gillion erroneously assumed that sanctity of life law existed in the English common law. They went further to say that the sanctity of life doctrine as applied in the judgments involving treatment withdrawal and withholding usually considers the limited resources available and respects autonomous decisions by a competent adult. There is no doubt that the value society places on human life goes a long way in determining how people in that society are allowed to die. There are effectively notions of the sanctity of life that are close to vitalism but the way the concept is understood in English law reflects a more nuanced acceptance of the limits to maintaining life (vis autonomy, the interests of those unable to make their own decisions and ultimately to some extent even resources). Vitalism as a doctrine holds a view that our lives as human beings have supreme value and as such, it should not be shortened at all costs regardless of any pain or suffering the disease or treatment imposes on the patient.[712] Unlike sanctity of life, this value is absolute and is held by the Catholics. Vitalism’s view of life in bioethics faces

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[712] Rob Heywood and Alexandra Mullock, 'The value of life in English law: revered but not sacred?' (2016) 36(4) Legal Studies <http://dx.doi.org/10.1111/lest.12131> accessed 3 May 2021.

many difficulties because it is fundamentally an epistemological rather than an ethical theory. The sanctity of life doctrine also sees life as having an intrinsic good regardless of the form it takes and that it is wrong to end it intentionally. It prohibits intentions and conducts that are aimed at the shortening of human life although in certain situations some jurisdictions tolerate practices like abortion and euthanasia.[713]

Although the origin of the doctrine remains unclear, however, John Sutherland Bonnell appears to be the first person to use the phrase while he was making a case against euthanasia from the Christian's perspective.[714] Some renowned bioethicists like Peter Singer and Helga Kushe had opposed the idea and pushed for quality-of-life ethics when making cases about abortion and end-of-life decisions.[715] The doctrine is defined as a religious concept given by God as a gift to humanity, which further lay credence to the fact of the need to value and place utmost respect for humans' lives from the non-religious perspective.[716] Kulshe claimed that the principle has a Christian origin.[717] Therefore, its use in legal reasoning may be controversial since not everybody shares the Christian faith. In practice, when decisions are weighed about artificially prolonging a patient's life against the quality of that life, there is a danger of inadvertently passing a message that some lives are worthless. This, in turn, can lead to discrimination especially when we consider people with disabilities in society. There are no universally agreed criteria on what is the minimum acceptable quality of life as this changes from person to person depending on their attached values to some aspects of life, which tends to change with time and circumstances.

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[713] David Gushee, 'The Sanctity of Life' (The center for bioethics & human dignity, 15 June 2015) <https://cbhd.org/content/sanctity-life> accessed 3 May 2021.

[714] Heike Baranzke, 'Sanctity-of-Life—A Bioethical Principle for a Right to Life?' (2012) 15(3) Ethical Theory and Moral Practice <https://doi.org/10.1007/s10677-012-9369-0> accessed 25 March 2021.

[715] Ibid.

[716] Kenneth Boyd and others, *New Dictionary of Medical Ethics* (BMJ Books, 1997) 228.

[717] Ibid.

The doctrine of the Quality of life (the capital letter 'Q') assesses the worthiness of the patient's life while that of quality of life (small letter 'q') weighs the patient's condition to decide the worthiness of the proposed treatment.[718] There seems to be an arbitrary threshold for the quality of life, which can be affected by diseases, injuries, or disabilities.[719] When that threshold is not met, the life is deemed to be not worthy of living. The question one would ask is as follows: is it morally justified to allow the person to die either by acts or by omissions? The only person who determines the worthiness of life is the owner of such a life. Thus, there should be no justification whatsoever for withholding lifesaving treatment because of the assessment of poor quality by someone else.[720] Being in VS may not be classified as being terminally ill, as there is still an ongoing debate on the claim that recovery is impossible after a specific timeframe. Nowadays, there have been tremendous improvements in the technology used in sustaining life in medicine but the categorisation of PVS is still pegged on one made almost fifty years ago even though clinical diagnosis can be enhanced through the application of technology. [721] In principle, life can be preserved to a certain degree but the extent to which this is done depends largely on the value we place on such life and the expected outcome of such intervention. However, the question of whether the condemnation of a negative act of killing necessarily means the positive duty of preserving life is worth considering.

Arguments in favour of the worth-based approach to decision-making for PVS patients.

The worth-based argument for protecting patients deemed to be in a PVS is broad and cut across the individual concepts described above. The appreciation that human lives have value

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[718] Keown (n 711) 43-44.

[719] Ibid 43.

[720] UNESCO, 2011. *Casebook on Human Dignity and Human Rights*, Bioethics Core Curriculum Casebook Series, No. 1, UNESCO: Paris, 144 pp.

[721] Helen Gill-thwaites, 'The Sensory Modality Assessment Rehabilitation Technique--a tool for assessment and treatment of patients with severe brain injury in a vegetative state' (1997) 11(10) Brain Injury <https://doi.org/10.1080/026990597123098> accessed 3 May 2021.

or worth is crucial in the decision-making process for anyone labelled as PVS. Even though some may argue that the sanctity of life notion has some religious inclination, not many people would deny that it is generally wrong to take life either by act or by omission (albeit taking life is acceptable for self-defence, during war, or as a punishment for certain crimes). Using the term like the inviolability of life may be more acceptable. The concept of vitalism may seem extreme, but the underlying motive remains the same as the inviolability of life. Furthermore, the notion of quality of life can be a bit controversial just because it is at the mercy of the person defining it. However, if we all agree that every life has intrinsic value, then the use of quality-of-life evaluation would take a back seat when discussion about life-prolonging intervention is taking place. Human worth cuts across every sphere of human life and the appreciation of this reality is the basis for protecting human beings in general.[722] In saying so we can agree that respect for human worth is a basis for constraint when making life and death decisions.

The worth-based personhood argument favours the personalism approach which describes all human beings as having inherent value. Adopting this position would compel us to protect these values that all humans have in them. The use of attributes such as self-consciousness, rationality, intellectual abilities, and many other attributes that a functionalist would consider as a prerequisite to be labelled ‘a person’ will result in the marginalisation of the vulnerable members of society including those diagnosed as PVS.[723] Persons with the PVS label are particularly vulnerable since they lack the cognitive ability to express their needs and defend their personal space. At times, the abuse may be physical, financial, or even sexual. This may originate from family, professionals, paid carers, or from other quarters. Some argue that what makes a human being a person is perhaps the ability to think and behave rationally. Persons deemed to be in PVS appear to lack the criteria that will accord them the qualifier

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[722] Garwood-Gowers (n 669) 12-41.

[723] Allen Buchanan, ‘Moral Status and Human Enhancement’ (2009) 37(4) Philosophy and Public Affairs <https://www.jstor.org/stable/40468461>accessed 25 March 2021.

‘person’ according to the personalism argument but in reality, they are not any less of a human being than other members of society are. The observation exposes this argument as being erratic as it discriminates against those who are less fortunate than the rest, and excludes our moral obligation to such people in doing so.

3.5. Human rights approach.

This approach is about the prioritisation of respect for human worth in overarching human rights and legal norms. The relevant human rights obligations own by the state to everyone in the UK are contained in the Human Rights Act 1998. These are fundamental rights and freedom of all citizens. For patients diagnosed as PVS, these obligations more specifically involve but are not limited to rights like rights to life, rights to bodily integrity, rights to autonomy, rights to equality (non-discrimination), and the rights to benefit from scientific progress. This section explores how these rights are respected in patients diagnosed as PVS and to what degree. It also argues as patients designated as disabled do not have more legal rights than a dying patient, a human-rights approach to decision-making in PVS might not be adequate in safeguarding their best interests.

Disability is a condition whether physical, cognitive, or mental that impairs one’s ability to perform tasks and activities that are considered typical.[724] A good number of PVS patients can be seen as disabled as opposed to actively dying. Evidence from the literature is in support of a significant proportion of these patients living for years after diagnosis. For example, Karen Quinlan, Nancy Cruzan, and Terri Schaivo (all in the United States) lived for nine, seven, and fourteen years respectively after the initial injuries.[725] Furthermore, Eluana Englaro in Italy

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[724] David Wasserman, 'Disability: Definitions, Models, Experience' (Stanford Encyclopedia of Philosophy (Summer 2016 Edition), Edward N Zalta (ed), 23 May 2016) <https://plato.stanford.edu/archives/sum2016/entries/disability/> accessed 14 June 2021.

[725] Bruno Marie-aurelie and others, Coma and disorders of consciousness. in JL Bernat and R Beresford (eds), Ethical and legal issues in neurology (Elsevier BV 2013) 206.

lived for seventeen years after the brain injury before she was allowed to die in February 2009.[726] If anything, a 'PVS patient' should be seen as someone trapped in her own body, with or without the capacity to appreciate what is going on in the surroundings and unable to make purposeful movements or communicate. Some may argue that as there is no known cure for this condition, it is of no use to keep these patients alive. This argument is only right to the extent of what we know about this condition however, there is still a lot to know about how they lose or regain consciousness and how we may assist them to communicate with technology if indeed they never lose their consciousness at all. One study demonstrated specific brain activity (which might correlate to consciousness) in a 'PVS patient' in response to calling his name.[727] There is a moral obligation to treat patients diagnosed as PVS as they are people with a unique form of disability that the medical world is yet to fully understand.

The right to life is routinely protected in human rights instruments, including the ECHR, art. 2 of which states that everybody is entitled to live (right to life), and this right must be protected by law. Notwithstanding arguments to the contrary, it is clear that from a legal point of view that 'PVS patients' are alive and as entitled to that protection as any other living human being. It is also clear that human rights instruments routinely protect the dignity of human beings either with direct provisions or indirectly through provisions covering such matters as the right to private life (part of ECHR art. 8(1)) and freedom from inhumane and degrading treatment (part of ECHR, art. 3). Amongst other things, this should be seen to entail respecting the wishes of such patients, where known, and protecting their interests. By choosing to cease CAHN in a patient diagnosed as PVS, one decides to override the interests of the patient and plan based on what one thinks is best for the patient. Decisions made around

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[726] Ibid.

[727] Wolfgang Staffen and others, 'Selective brain activity in response to one's own name in the persistent vegetative state' (2006) 77 Journal of Neurology, Neurosurgery & Psychiatry <http://dx.doi.org/10.1136/jnnp.2006.095166> accessed 11 August 2021.

these patients are made for them, thereby stripping them of their freedom of choice. In addition, we can argue that human life is valued because of the consciousness that is demonstrated through sane decision-making and the ability to choose and respond to things going on around us.

The respect for life is undeniably married to the impression that humans have a personality that is very much linked to the quality of life that they live. However, when it comes to the treatment of patients diagnosed as PVS, the treating doctors who reach their decision after careful thoughts and observation decide the medical treatment that is agreed upon.[728] This can be viewed as a way of observing respect for the sick patient that is not in a position to make medical decisions on his own. In addition, decisions concerning the patient are made after researching and finding out their values, wishes, and character (through those that lived with him before the ailment). As such, the option to continue with artificial feeding is adopted or rejected. A detailed plan to withdraw care is drawn to ensure that the patient transitions devoid of any pain or distress and their dignity is maintained to the last minute. When we accept one practice that was up to this time unaccepted, then we will invariably accept more currently unacceptable practices in the future. Hard lines must be drawn between practices that affect the health of patients that have minimal ability to make choices on their own. Cases involving decisions about the life of a person are to be regarded seriously and should be heard before the Court to ensure that an ethically and legally coherent balancing exercise is made. The slippery slope is a concern that will have been addressed when the outcome of this law justifies it and brings forth benefits that may not have been realised before. These benefits include a broader budget for the NHS to focus their limited resources on patients that are ailing from more manageable ailments.

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[728] John Saunders, 'Assisted dying. Reflections on the need for law reform' (2008) 8(6) Clinical Medicine <https://doi.org/10.7861/clinmedicine.8-6-629> accessed 25 June 2021.

The NHS is crucial to the maintenance of the health and wellbeing of all the people living in the UK regardless of their disabilities.[729] The body is independent and handles its budget, planning, and ways of delivering their services under the Department of Health and Social Care. In relation to PVS patients, their continued treatment costs a lot because of these patients' level of dependency. Although there is no database for PVS in the UK, estimates as of 2015 stated that there could be between 4000 and 16000 people diagnosed as PVS with an even larger number with MCS diagnosis potentially up to three-time of PVS.[730] This figure may have underestimated the condition's actual prevalence since there is no methodological approach to the epidemiology of the condition. In the United States, the incidence of patients diagnosed as PVS is around 4200 with a lifetime cost for caring for them in the excess of one million dollars per patient.[731] The Court rulings treated these patients with utmost dignity and also gave due consideration to available resources within the NHS and the social care service all over England.[732] Patients are often taken care of by overzealous relatives who are unduly optimistic about the recovery of their loved ones. Sometimes they have unrealistic expectations and hopes of recovery despite the clear symptoms that do not change or that change ever so slightly. Prolonged and extensive treatment of a patient in PVS causes a lot of emotional distress on the part of the family and friends of the person concerned. Thus, jobs are lost or abandoned in order to look after the patient, who is then seen as a burden causing underlying bitter feelings. The provision of disability support for the patients will go a long way in ensuring that whenever WWSLI are withdrawn in these patients, it would not be because they are 'in PVS' but rather the decision is truly in their best interests.

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[729] Vicky Bailey and others, *The NHS's role in the public's health A report from the NHS Future Forum* (NHS Future Forum 2012) 10-14. <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216423/dh_132114.pdf> accessed 31 May 2021.

[730] Huxtable (n 511).

[731] Joseph Giacino and others, Practice guideline update: Disorders of consciousness (American Academy of Neurology, 2018) 11.

[732] Ibid.

Human rights issues related to PVS.

The global protection for disabled individuals was put in place by the United Nations Convention on the rights of persons with disabilities (CRPD) in 2007.[733] This convention advocated treating anyone with a disability as human beings with inherent rights as opposed to using them as objects of charity, medical treatment, and social protection.[734] This involves making sure that all individuals with disability enjoy the same human rights and freedom as every other member of society. Similarly, the International Bill of Human Rights (IBHR) also ensures that everybody is treated with equal dignity and rights.[735] The bill comprises the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights (ICESCR), and the International Covenant on Civil and Political Rights (ICCPR).[736] In Europe, the European Convention on Human Rights (ECHR) covers all human rights issues for everyone. The same thing applies to the Human Rights Act 1998 in the UK. The treatment of PVS potentially raises some human rights issues. There are arguments for the use of a conceptual framework of fundamental human rights in deciding for these patients. The law and policies in the UK may have negative effects on people with severe brain injuries especially the ones labelled as in a PVS or MCS. The human rights approach to PVS and MCS focuses on dignity and equality.

The Universal Declaration of Human Rights echoed the importance of inherent dignity when dealing with everybody.[737] Similarly, the CRPD affirmed the rights to dignity by persons with disability. The treaty advocated the human rights model of disability. Over the years, there have been several models of disability in the literature. The medical, social, and economic models have been to advocate for rights for people with disability. On the other hand, the

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[733] United Nations Convention on the rights of persons with disabilities.

[734] Ibid.

[735] The International Bill of Human Rights.

[736] Ibid.

[737] Universal Declaration of Human Rights, G.A. Res. 217A (III) (1948), preamble.

medical model views disability as an impairment that requires treatment and/or rehabilitation. The social model of disability views the individual's inability to fully function as a member of society as a social construct developed through discrimination and oppression. This model sees impairment as a condition of the body or the mind while disability is the way society responds to these impairments. Some would consider disability as a variation in the continuum of human variation. The discrimination of anyone based on their physical or mental deficiency is a violation of their dignity and their personhood.[738] The current treatment of PVS patients may be argued to be insufficient in fulfilling all the obligations the state has in protecting their human rights. Some of the rights relevant to PVS in the context of their disabilities are evaluated below.

Right to life with dignity

The right to life by individuals with disabilities, including PVS, is fundamental and should be protected by the law. This right may be violated if the patient is allowed to die without being given the opportunity to benefit from treatments that might potentially keep them alive or make them recover from the underlying condition.[739] The ECHR also recognises this right in article 2. Furthermore, ICCPR and CRPD also echoed the right of everyone to life.[740]. The Universal Declaration of Human Rights article 3 and CRPD underscore the need for every state to treat everybody equally, including people with disabilities, when it comes to the right to life. People in PVS seem not to benefit from this right due to other overriding arguments.

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[738] Convention on the rights of persons with disabilities, G.A. Res. A/RES/61/106 (2006), preamble (h).

[739] Joseph Fins, 'Affirming the right to care, preserving the right to die: Disorder of consciousness and neuroethics after Schiavo' (2006) 4(2) Palliative and supportive Care <https://doi.org/10.1017/s1478951506060238> accessed 10 January 2021.

[740] ICCPR art 6; CRPD art 10.

Right to health

Everybody is entitled to enjoy reasonable health and both physical and mental wellbeing. Article 12 of the ICESCR states that ‘*everybody has the right to enjoy the highest attainable health standard*’.[741] CRPD also echoed this right and went further that this right must not be violated based on disability.[742] People with PVS should be able to enjoy the highest possible health they can be provided within the limits of the available technology. They should not be discriminated against based on their diagnosis. The ECHR, in article 14 of the convention, also prohibits discrimination of any form. Furthermore, the United Nations Committee on Economic, Social, and Cultural Rights (para. 12) reiterated that quality health care must be made available to the most vulnerable and the marginalised people in society.

Right to benefit from scientific progress

The popular arguments for withdrawing life-saving interventions in people diagnosed with PVS are that they are unlikely to recover from the state and that the treatments administered to them are futile. It can be argued that if technological innovations would be used to understand the disease process more and potentially be treated, these people are deprived of the opportunities to potentially be sustained until a time in the future. ICESCR in article 27 made provision for availing everyone to benefit from the progress of scientific advancements. The CRPD in article 4 obliges the state to provide an enabling environment for research and development that may benefit people living with disabilities and make these new technologies available to them.

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[741] ICESCR art 12.

[742] CRPD art 26.

Right to equality

It is not farfetched to say that people diagnosed with PVS are generally not treated fairly and equally when it comes to the extent to which the medical profession would go to sustain their lives. Equality is fundamental to human rights, and this is why the UDHR proclaims that everybody is born with dignity and rights.[743] It also declares that everybody is equal and that the application of the law should equally protect everybody without any discrimination.[744] This provision also finds mention in the ICCPR and the CRPD documents.[745] The provision for the right to equality in these conventions buttresses the fact that people living with disabilities, including PVS, have human dignity.

Arguments against the use of human rights approach.

Human rights are fundamental rights which are inherent in everyone regardless of race, gender, sexual orientation, social status, or disabilities. These rights cannot be acquired and similarly cannot be taken away from anyone. Human rights may be restricted in some exceptional circumstances, but it is generally agreed upon that they are unconditional rights. The human rights approach to PVS (If the patients are seen as having one form of disability or the other) would do more to protect these patients from some of the decisions made on the wards or in the courtrooms. The human rights approach to decision-making in PVS seems a great idea to resolve some of the contentious decisions in PVS. The main issue with this approach is that while many would agree that individual with severe brain damage (whether named PVS or MCS) is disabled, the medical profession sometimes treats them as if they are approaching the end of life. It is unclear if using the human rights approach in decision-making would confer any added protection to these patients. Human rights protect everybody

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[743] Universal Declaration of Human Rights art. 1.

[744] Art. 7.

[745] ICCPR art. 26; CRPD art. 5.

regardless of whether one is disabled. The empirical section of this research explores the perspective of the healthcare professionals on whether PVS patients are seen as severely disabled or approaching the end of life.

3.6. Conclusion.

In conclusion, this chapter looked at four ethical approaches to decision-making in patients in a state of prolonged unconsciousness and labelled as PVS. These approaches are principlism, normative ethical approach, worth-based approach, and the human rights approach. It was argued that the principlism approach only provided general ethical principles and remains devoid of any systematic conceptualisation. When there are conflicts between competing principles, there is no guidance on how to resolve the tension. Hence, the four principles approach risks being little more of a reification and ex-poste justification of an individual's pre-existing views. For example, the instinctively more libertarian minded doctor will more heavily weigh the autonomy principle, whilst the instinctively more paternalistic doctor will more heavily weigh beneficence and non-maleficence. Moreover, the ethical arguments used in the cases involving PVS in the Courts have mainly focused on autonomy. The principles of beneficence and non-maleficence are generally assumed even though it might not necessarily be the case. The principle of justice infrequently appears in the argument, but the meaning is usually ambiguous. Other ethical principles apart from the above four principles have been used in arguments around treatment decisions in PVS. Relying on the four principles may not be sufficient to protect the patients. The normative ethical approach was also criticised in this chapter. Even though this approach offers a more robust argument in the determination of the morality of the actions of the doctors towards the PVS patients, it is argued that the approach is complex and can be contradictory in some sense. Further, there are many ambiguities in this ethical approach to complex cases like withholding and withdrawing treatment in an unconscious patient like those diagnosed as PVS.

It was also pointed out that the worth-based approach provides a more pragmatic way to dealing with a complex and difficult decision in treatment withdrawing and withholding in PVS. Respect for dignity and personhood has always been the bedrock of human rights law. This approach promotes inherent dignity and acknowledges people diagnosed as in a PVS as human beings with equal rights. This argument about a worth-based approach to ethics fits with the existing normative order in terms of both human rights and health law and many experts in the field have highlighted the consistency of medical/health law with worth/dignity. Lastly, I contended that although the human-rights approach to ethics seems plausible, the main challenge with the approach is that 'PVS patients' are invariably viewed from the point of somebody without consciousness who is neither dead nor alive. Therefore, it is easy to waive their human rights with other overriding legal principles. However, if they are treated as human beings living with disabilities then the argument will be different. Thus, it can be seen that no theory supplies a definition of PVS as a disability. Even though it looks like it fits well into the definition of disability from all indications, people in a PVS have customarily been treated as if they are approaching the end of life. Further, the point about the human rights approach is the same as the point about principlism where there is no inbuilt weighing mechanism. The notions of how to weigh competing rights and interests are developed through jurisprudence. Human rights are nonetheless important– and especially so in this context. Hence, dignity or worth informed enforcement of them could be considered apposite.

CHAPTER FOUR

A critique of the English law approach to safeguarding people labelled PVS.

4.1. Introduction

An adult with a sound mind may refuse medical intervention that could potentially prevent him from dying.[746] This legal principle was echoed by Lord Donaldson MR and Dame Butler-Sloss LJ in the *Re T (Adult: Refusal of Treatment)* and Re *MB (An Adult: Medical Treatment)* cases, respectively.[747] Therefore, informed consent is a prerequisite to any medical intervention. Whilst this is blithely stated, it is not really true even judicially. The circumstances in which one can treat without consent are limited; mostly the rights of other contexts but also treatment for mental disorders, in the majority of jurisdictions.[748] Nevertheless, the principle of autonomy requires that respect must be accorded to the patient's treatment choice, irrespective of its prudence or the lack thereof, so far as it does not pose any risk to society.[749] However, autonomy requires mental capacity as a precondition. The patient's right to autonomy is protected by the HRA 1998 and ECHR.[750] The MCA is of the view that all adults have the mental capacity to decide about their medical treatment until proven otherwise.[751] If someone loses his mental capacity for whatever reason, and there are no valid advanced directives or appointed lasting powers of attorney (LPA), others will have to decide for the

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[746] *Re T (Adult: Refusal of Treatment)* [1993] Fam 95.

[747] [1992] 3 WLR 782, {786}; [1997] 2 FCR 541, {549}.

[748] Austen Garwood-Gowers and Solvita Olsena, Informed consent. in Andre den Exter (eds), European Health Law (Maklu Publishers 2017) 245-272.

[749] The Mental Capacity Act 2005, section 2(3).

[750] European Convention on Human Rights art. 8.

[751] The Mental Capacity Act 2005, section 2(3).

person.[752] In the UK, doctors are not legally obliged to provide or continue to provide treatment that is not clinically indicated.[753]

For patients diagnosed as PVS, the main predicament is the clinicians' inability to know what the patient would decide if they had been competent, and more importantly, how to determine what would be in their best interests in an objective way. When the doctors decide to WWLSI in any patient, it is generally taken to be the right decision for the person. This assumption is not always the case when it comes to a patient diagnosed as PVS. The three preceding chapters of this thesis laid out the issues with diagnosing PVS as a condition and the complexity of the decision-making process regarding treatment and more particularly, WWLSI. It is generally agreed that whatever decision the clinicians make on behalf of any incapable patient, it should be in his/her best interests. However, the limitations in the determination of best interests lie in its vulnerability to varying interpretations. In chapter three, a case was made for the use of a worth-based approach to determine the best interests of PVS patients. In this chapter, however, I critique the English law approach to WWLSI in patients diagnosed as PVS from both chronological and technical perspectives. This involves an appraisal of the historical evolution of the relevant doctrines and statutory framework used in the decision-making process and the analysis of relevant PVS (and some relevant non-PVS) cases. Furthermore, I evaluate the impact of the Court's judgments on the policy and governance of WWLSI in 'PVS patients' in the UK. Lastly, I contend that the current approach to the law in the UK regarding WWLSI is inadequate to safeguard the interests of the patients labelled as PVS.

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[752] Ibid sections 4 & 9.

[753] R. (on the application of Burke) v GMC [2005] EWCA Civ 1003; [2006] Q.B. 273.

4.2. The historical evolution and technical analysis of the English law affecting PVS.

An individual who is diagnosed to be in a PVS, regardless of whether this is a valid condition or not, is incapable of making any decisions by virtue of being unable to interact with the immediate surroundings. This assertion is reflected in practically all the judgments involving PVS or MCS even though there are questions about whether the so-called PVS patient is actually a person whose brain is intact in terms of consciousness but simply struggles to communicate or there is an actual loss of conscious experience. Practically speaking, communication is not necessary for decision-making. However, legally speaking, a disorder of the brain combined with the inability to communicate would be enough to find a person incapable.[754] However, the assertion that 'PVS patients' are unable to communicate might not be entirely true as research has shown that some patients diagnosed as PVS have been able to communicate via sophisticated dynamic technologies like fMRI.[755]

As argued in chapter two, much more still needs to be learned about the functionality of the brain in patients diagnosed as PVS regarding whether or not they retain their consciousness. The MCA 2005 has largely been used to make decisions for incapable patients, but it can be argued that the role of the Act in PVS limits the autonomy of these patients. The decisions made on their behalf might protect them further if a human rights-based approach is developed to consider factors such as liberty, physical well-being, and dignity. Additionally, there should be a way of monitoring decisions made on their behalf and exploring ways of affording them the opportunity to propose or refuse treatment, regardless of their incapacity. PVS denotes a special category of patients because they are neither brain dead nor approaching the end of life. This peculiar characteristic was reflected in *Airedale NHS Trust v Bland* and

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[754] MCA 2005 section 2(1).

[755] Jennifer Chandler and others, 'Online public reactions to fMRI communication with patients with disorders of consciousness: Quality of life, end-of-life decision making, and concerns with misdiagnosis' [2017] 8(1) AJOB empirical bioethics <https://doi.org/10.1080/23294515.2016.1226199> accessed 15 May 2021.

subsequent cases. *Bland* was the first case in the UK to have examined the legality of WWLSI from a PVS patient.[756] *Prima facie*, this act would have violated the doctor's legal obligation of the duty of care and the doctor may have been liable in a civil lawsuit or a criminal lawsuit (manslaughter or murder).[757]

Withdrawing is physically an act but legally, it is the discontinuation of an act (excepting Lord Goff's comment about interlopers in *Bland*). Continuation needs justification just as discontinuation does where it will result in death. In most cases, justification is premised on the fact that whilst life is of value (in line with the Sanctity of life principle), it is not always justifiable to act/continue an act to treat even if the doing of so will extend the life of the individual concerned. Due to the absence of any legislation regarding the treatment of such cases, the Court relies on the accepted legal principles that are relevant to the case. There is no widely accepted theoretical model for the Court to rely on when making treatment decisions for these people. Owing to the absence of such a theoretical model, the Court uses expert opinion and a legal framework to ascertain the best means of deciding what is best for these patients. Currently, it is not entirely clear that the law fully safeguards PVS patients' autonomy more so that it is generally agreed that the threshold for capacity is not reached. It might be argued that the binary classification of people into mental capable or incapable is not a fair approach as capability is a continuum and these patients can fall on any point on the spectrum. Legal principles are deployed in the Court when making rulings in these cases Relevant legal principles deployed have already been discussed in the last chapter with regards to treatment withdrawal in PVS; however, these doctrines would be used to critique the judgments in this chapter.

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[756] *Airedale NHS Trust v Bland* [1993] A.C. 789.

[757] Ibid.

In recent times, the determination of best interests has been strongly predicated on deciding whether ceasing intervention in a PVS patient is ethical or not.[758] This approach is the surrogate way of ensuring that the individual's autonomy is respected to a certain extent.[759] The MCA 2005 outlines the steps a healthcare professional should take when deciding on treatment options for an incapable adult.[760] Traditionally, depending on the jurisdiction where the doctor is practicing, there are a couple of ways to make decisions for incapable adults. In Ireland, England and Wales, the best interests test is adopted while in the US, the substituted judgment standard is embraced.[761] Some may liken the best interests test to a form of soft paternalism if decisions are made with little analysis and few safeguards.[762] The MCA 2005 attempts to combine these two standards with limited success. As the focus of discussion is the United Kingdom, the substituted judgment standard will not be discussed in detail in this thesis, although there may be some reference to it during the course of the arguments around best interests and treatment withdrawal in PVS.

The Best Interests test

The best interest's standard dates back to the early British case law when the Court exercised the *parens patriae's* power to protect the autonomy of the vulnerable individuals in the country.[763] The origin could be traced back to the statements in the *Prerogative Regis* legislative law of the fourteenth century.[764] This doctrine was a protective jurisdiction intended

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[758] MCA 2005 section 1(5).

[759] John Coggon, 'Mental Capacity Law, Autonomy, and best Interests: An Argument for Conceptual and Practical Clarity in the Court of Protection' [2016] 24(3) Medical Law Review <https://doi.org/10.1093/medlaw/fww034> accessed 17 June 2021.

[760] MCA 2005 section 4.

[761] Daniel Sulmasy and Lois Snyder, 'Substituted Interests and Best Judgments: An Integrated Model of Surrogate Decision Making' [2010] 304(17) JAMA < https://doi.org/10.1001/jama.2010.1595>accessed 17 June 2021.

[762] Giles Birchley, 'The theorisation of 'best interests' in bioethical accounts of decision-making' (2021 22(1) BMC medical ethics <https://doi.org/10.1186/s12910-021-00636-0> accessed 23 June 2021.

[763] Margaret Hall, 'The Vulnerability Jurisdiction: Equity, Parens Patriae, and the Inherent Jurisdiction of the Court' [2016] 2(1) CJCCL < https://core.ac.uk/download/pdf/55293353.pdf> accessed 13 June 2021.

[764] Prerogativa Regis. Of the King's Prerogative (temp. incert.) (1322).

to protect the person and estate from adults with unsound minds. It was based on a doctrine of allowing the state to act as a parent or guardian for children, the mentally ill, elderly, disabled, and incompetent individuals who are unable to care for themselves, although the standard used for substitute decision-making under this jurisdiction in the early cases remains unclear.[765] However, the jurisdiction was abolished on 1 November 1960 following the passing of the law on mental health in 1959.[766] The Mental Health Act of 1959 provided regulations to manage the incapacitated person's property and affairs but was lacking in the welfare jurisdiction.[767] The guardianship powers in the act appear to provide welfare protection but these powers were not extensive enough.[768] Subsequently, there was a hiatus in the welfare jurisdiction following the abolition of *parens patriae* jurisdiction.[769] The ruling in the *Re F (Mental Patient Sterilisation)* case filled this hiatus by using the inherent jurisdiction of the High Court.[770] This then made it acceptable for the Court to make declarations on the legality of some medical procedures that were brought before the Court. Prior to this case, the Court used the legal principle of necessity in making declarations to allow doctors to treat their patients.[771] The HL in *Re F* used the *Bolam* test standard to determine whether the proposed intervention, in this case, sterilisation, was in her best interests. The *Bolam* standard was also used in other cases like *Airedale NHS Trust v Bland* and *Re T*.[772] The utilisation of the best interests' standard in cases involving incapable adults only became apparent in *Re F* case.[773] The language used

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[765] Antal Szerletics, *Best Interests Decision-Making Under the Mental Capacity Act Essex Autonomy Project Green Paper Report* (Essex Autonomy Project, University of Essex, 2011) <http://autonomy.essex.ac.uk/best-interests-decision-making-under-the-mental-capacity-act> accessed 2 May 2021.

[766] Ibid.

[767] Mental Health Act 1959.

[768] *Re F (Mental Health Act: Guardianship)* [2000] 1 FLR 192, CA.

[769] Re F [2000] 2 F.L.R. 512.

[770] [1990] 2 AC 1.

[771] Michael Dunn and others, 'Constructing and Reconstructing Best Interests: An Interpretative Examination of Substitute Decision-making under the Mental Capacity Act 2005' [2007] 29 Journal of Social Welfare and Family Law 119.

[772] [1993] AC 789; [1993] Fam. 95.

[773] [1990] 2 AC 1.

before this case was ‘benefit’ rather than best interests.[774] It is unclear if these two terms meant or referred to the same thing. Published in 1991, the Law Commission paper made a clear distinction between ‘best interests’ and ‘substituted judgement’ standards.[775] The paper sought to look at the distinction between the best interests’ standard and substituted judgment standard. The Paper stated that:

> ‘*Two different tests have been developed for making decisions on behalf of a mentally incapacitated adult. The 'best interests' standard is derived principally from childcare law and represents the more paternalistic and at times restrictive approach: the decision taken is that which the decision-maker thinks are best for the person concerned. It was adopted in Re F [1990] 2 A.C. 1. Under the 'substituted judgment' standard, decisions made for an incapacitated person attempt to arrive at the choice that particular person would have made had he been competent to do so. This has, for example, been adopted as the correct standard for the execution of a statutory will*’.[776]

The publication seemed to favour a substituted judgment standard but the shortfall in using this standard is that people’s past perspectives on healthcare choices are difficult to predict in the absence of any written documents on them, which are rare. These unresolved issues led to the publication of the second consultation paper which claimed that the concept of ‘best interests' is fundamentally different from that of 'substituted judgment’ and therefore, the standards are not the same.[777] The paper advocated a test where best interest is modified to include a requirement of substituted judgment as a prerequisite. Hoffmann LJ echoed this

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[774] Szerletics (n 765).

[775] Law Commission Consultation Paper No. 119 (1991) (Mentally Incapacitated Adults and Decision-Making: An Overview).

[776] Ibid para 4.22.

[777] Law Commission Consultation Paper No. 128 (1993) (Mentally Incapacitated Adults and Decision-Making: A New Jurisdiction) para. 2.14.

opinion in the *Airedale v Bland*.[778] The report was accepted after a four-year-long consultation with an integrated approach to best interests incorporated into the MCA 2005.[779] If a doctor treats an incapable adult without consent, the doctor risks a dilemma of potential civil or criminal liability.[780] Informed consent signifies an important precondition to medical intervention, without which a charge of assault may be levied against the attending physician.[781] Further, treating a capable patient contrary to an expressed wish can result in civil charges and nominal awards can be made as a result.[782] Even when the decisions are clearly imprudent, it does not prevent the individual from getting his/her wish.[783]

For the sake of medical decision-making, anyone over the age of sixteen is presumed to have capacity per the MCA 2005, but they are still legally a child per the Children Act 1989 until eighteen.[784] Therefore, if someone is sixteen and over and becomes mentally incompetent for whatever reason, the doctors will need to determine best interests in accordance with the MCA 2005. The doctor would not incur any criminal or civil liability for treating such patient as long as the doctor takes reasonable steps to determine if the patient has the capacity and believed that the treatment is in the patient's best interest.[785] Law in the UK specifies that a third party cannot make a decision for an incapacitated adult.[786] If the patient does not have a relative or welfare attorney, the doctor is duty-bound to appoint an IMCA who can represent and support the patient.[787] Although the MCA offers guidance on how to ascertain best interests, it does not clearly define the concept.[788] In the absence of a clearly laid down

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[778] [1993] AC 789 [833].
[779] Law Commission Report on Mental Incapacity No. 231 (1995) para. 3.25.
[780] *Re F (Mental Patient: Sterilisation)* 2 WLR 1025 (HL).
[781] *Re T (Adult: Refusal of Treatment)* [1993] Fam 95 (CA) [99].
[782] *Ms B v. An NHS Hospital Trust* [2002] All ER (D) 362 (FD).
[783] *Re C (an adult: refusal of treatment)* [1994] 1 All ER 819 (FD); MCA s 1 (4).
[784] Family Law Reform Act 1969, section 8; MCA, s 2 (5).
[785] MCA 2005 s.5.
[786] *Re F (Mental Patient: Sterilisation)* 2 WLR 1025 (HL).
[787] MCA 2005 s. 37(6).
[788] Ibid s.4.

definition, the use of the principle as a legal standard for making decisions on behalf of incapable patients can be construed in a few different ways, as highlighted below:

1. The first interpretation is what the clinicians feel are the clinical needs of the patient in question. Lord Phillips MR referred to this form of best interests as the objective test.[789] Some critics might argue that this approach is a form of soft paternalism.[790] The Justices of appeal in *Aintree v David James* adopted this approach to best interests' determination.[791]
2. The second interpretation, which Dame Butler-Sloss and Munby J elucidated in *Re SL,* and *Burke v GMC* respectively, is what the treating team considers to be the best social and wellbeing predilection for the individual beyond the clinical needs.[792] Although this is a broader perspective in comparison to the first interpretation, there is more subjectivity element to it. Furthermore, it is a more patient-centred approach but still may not necessarily reflect what the patients' preferences would have been if they were able to communicate their needs.
3. Arden LJ described another interpretation in *Aintree v David James* where the team uses what a reasonable person's preference would be in a similar situation.[793] This approach totally ignores the view of the person involved in the best interest's determination. This is usually done when nothing is known about the individual's past views and preferences. Some people would consider this approach to be more objective.
4. The fourth interpretation was the one given by Lord Brandon in the HL judgment in *Re F*.[794] This form of best interests is the one used when the treating team considers the

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[789] *R (on the application of Burke) v. General Medical Council* [2005] All ER (D) 445 (Jul) (CA) [29].

[790] Birchley (n 762).

[791] [2013] EWCA Civ 65 (CA).

[792] [2000] All ER (D) 683 (CA). [683]; EWHC 1879 (QBD) [88]-[97].

[793] [2013] EWCA Civ 65 (CA) [59].

[794] [1989] 2 WLR 1025 (HL).

patient's clinical and welfare needs before concluding what is best for the patient. This approach is more sophisticated since there are various important factors involved in the process.

The MCA 2005 gives statutory guidance on the doctrine of best interests. These include guidance on how the doctor will assess the patient's best interests. This includes getting to know the past and present feelings, values, beliefs, and other related aspects of the patient's life.[795] More importantly, the Act makes it mandatory that in assessing best interests, the doctors must ensure that they put in reasonable efforts to consider the opinions of the patient's relatives, carers, or other advocates.[796] Legally speaking, the introduction of the MCA helped provide weight to emotional, social and medical considerations in determining best interests. Even though the assessment of best interests is supposed to be objective, this legislation opens up a wide range of subjective considerations. It is apparent that legislation alone is inadequate in providing a holistic legal framework that is objective when dealing with complex cases like PVS. It is also evident that as important as the best interests test is, the fact remains that it is difficult to define the concept. However, over the years, its use has made it easy to identify the various clinical and non-clinical factors relevant to the determination of best interests.

One of the factors is the relevance of the proposed treatment or treatment withdrawal to the patient's condition. This factor is arguably the starting point for the decision about treatment withdrawal and withholding. Whether the proposed treatment is relevant to the patient at the material time or in the future is an equally important factor. In Re R, the trust applied for a declaration that it would be lawful to withhold resuscitation in the case of cardiac arrest and antibiotics for a life-threatening infection in a 23-year-old man with cerebral palsy and a low

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[795] MCA 2005 section 4(6).
[796] MCA 2005 section 4(7).

level of awareness.[797] The Court granted the former application but rejected the latter stating that the application should be made when the situation arises.[798] Given that the success of cardiopulmonary resuscitation largely depends on the patient's comorbidities and physiological reserve, the procedure will be futile if patients are not carefully selected. Therefore, DNAR (Do Not Attempt Resuscitation) orders are usually made in advance. Another factor is the patient's clinical status and the proposed action's impact on the patient. In Re J (A Minor) (Wardship: Medical Treatment) [1990] 3 All ER 930, the doctors applied for a declaration that it would be lawful not to put a 5-month-old baby with severe brain damage on the ventilator again if the baby collapses. The child was born prematurely with profound physical and mental disabilities. The child was deemed too frail, and the interventions were too invasive. The application was granted in the HC, and the appeal was upheld in CA.[799]

Another important factor is the wishes and the previously expressed views of the patient in question. Moreover, the views and wishes of the partners and next of kin are also deemed relevant in deciding what would be in their best interests. This consideration is discussed in the relevant cases later in this chapter. At times, some discordances emerge among the family members concerning their wishes and views. Similarly, there could be disparities in the account of the patient's previously expressed views and wishes. The diagnosis of PVS or other conditions is also pertinent to the best interests' test. In patients diagnosed with PVS, the label seems always to tilt the determination of best interests in favour of WWLSI. In *PCT v CW*, Ryder J inferred that if the diagnosis of PVS is accurate, then the continuation of interventions in such patients would not be in their best interests.[800] Baker J echoed this assertion in *W v M*

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[797] *Re R (Adult: Medical Treatment)* [1996] 2 FLR 99.

[798] Ibid.

[799] Other relevant cases are: Re C (A Minor) (Medical Treatment) [1998] Lloyd's Rep Med 1; An NHS Trust v A and SA [2005] ECWA CIV 1145 CA; Portsmouth NHS Trust v Wyatt [2004] ECHC 2247 (Fam) Fam Div (Hedley J).

[800] *A Primary Care Trust v CW* [2010] EWHC 3448 (Fam).

by pointing out that best interests will fall in the direction of treatment withdrawal in PVS.[801] The label of PVS appears to portray an impression that the patients diagnosed as PVS have no interests. Lastly, one factor that is not generally talked about is resources or economic consideration, which may passively influence decision-making both at micro and macro-economic levels.

4.3. An overview of the Legal Developments.

The role of the Court in withholding and withdrawing intervention in mentally incapable patients was defined in the early non-PVS cases.[802] However, the Court's approach to the PVS cases differs to a certain degree. While this section will explore the legal development in PVS cases, the section on the exploration of the non-PVS cases later in the chapter will evaluate the role of WWLSI in non-PVS cases and how they are to be distinguished from patients diagnosed as PVS. Various significant legal developments have taken place from the first time when the involvement of the law was sought to inform the determination of whether to continue or terminate medical treatments in PVS in the UK. Following the enactment of the MCA 2005, the MCA Code of Practice was published to give guidance on issues not directly covered by the Act. Paragraphs 5.31 and 5.33 are the sections of the Code of Practice most relevant to the cessation of interventions in patients in prolonged unconscious state. Section 5.31 provides that clinicians must make efforts to prolong these patients' lives unless such intervention is futile or too burdensome.[803] However, section 5.33 goes further, stating that law does not require

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[801] *W v M and Others* [2011] EWHC 2443 (Fam).

[802] *Re Arthur* (1981) 12 BMLR was a case of a doctor who withheld treatment in a baby with Down's syndrome and was charged with murder. The doctor was later found not guilty by the Court. In another case later that year, *Re B (A minor) (wardship: Medical Treatment*) [1981] 1 WLR 1421, the Court authorised a surgical procedure in a baby with Down's syndrome stating that the patient's life expectancy with the surgery would be 20 to 30 years and without it the patient will suffer pain and progressive disability. Arguably, there are some similarities with PVS patients in that they also can live for up to 20 years with nutrition and hydration and optimal nursing care. In terms of pain, there are still controversies around their sentience ability.

[803] Mental Capacity Act Code of Practice section 5.31.

doctors to continue to provide futile interventions.[804] The legal development in this area has witnessed various arguments and the use of established principles with reference to earlier judges' reasoning in other relevant cases. However, the analysis of the case laws revealed some internal inconsistencies in the way some of these legal doctrines are applied.

The CoP's Practice Direction 9E which was withdrawn a few years back mandated seeking the approval of the Court before the cessation of CANH. [805] However, the subsequent legal developments have seen the removal of the reliance of the physicians and patient's family on the Court's approval before they take such actions in some situations.[806] In addition, this legal development changed the guidance for medical practitioners concerning the treatment of patients with prolonged unconscious state in the UK. Recent legal judgments have determined that the treating physician is not obliged to make application to the Court before withdrawing CANH in cases where professional guidelines have been adhered to, and the treating teams and the patient's family or surrogates all agree that the continuation of intervention may not serve the best interests of the individual.[807] Even though paragraphs 6.18 and 8.18 of the MCA Code of Practice still put that obligation on the clinicians, the High Court has ruled that the paragraphs were informed by case law at the time. Moreover, the code can be put aside in cases where all the professional guidelines have been adhered to, and the involved parties agree to the proposed line of action.[808]

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[804] Ibid section 5.33.

[805] Mary Donnelly, 'Best Interests, Patient Participation and the Mental Capacity Act 2005' [2009] 17 Med L Rev 1-29.

[806] NHS Trust v Y [2018] UKSC.

[807] Ibid.

[808] Donnelly (n 805).

The first High-Profile Case: Airedale Hospital v Bland

This case was the first high-profile case to bring clarity to the position of the law concerning the cessation of LSI for patients in a prolonged unconscious state. The ruling of this case set legal precedence that existed for several years. Although some legal developments have taken place since *Bland*, cases involving the withdrawal of treatment for PVS patients had to be presented before the CoP for a declaration before the treating physician could take such action. On the 15th of April 1989, Nottingham Forest was playing against Liverpool Football Club in the Football Association Cup semi-finals at the Hillsborough Stadium.[809] Only six minutes into the game, there occurred a crowd rush which led to the injury of over seven hundred and fifty fans, of which 96 of them sadly passed away.[810] Amongst the injured fans was Anthony David Bland who sustained various injuries, including severe brain injury. He was resuscitated and received various invasive treatments. Unfortunately, he developed brain anoxia and was diagnosed to be in PVS after some months.[811] In August 1989, Bland's parents and his treating physician Dr Howe agreed that the interventions he was receiving were no longer beneficial to him.[812] This decision, however, triggered police interest in the case and the treating team was reminded of the criminal liability of the proposed action.[813] The trust made an application to the Court for a declaration of the lawfulness of the intentions. This application received the support of the lower Court. However, the official solicitor appealed the ruling of the lower Court but the Court of Appeal (CA) did not grant the appeal.[814] Then, this case was taken to the HL for deliberation. The Lords who had been appointed to review the case unanimously dismissed the appeal.[815] The case, which had elicited considerable interest from

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[809] *Airedale NHS Trust v Bland* [1993] AC 789 [795].

[810] Ibid.

[811] Ibid.

[812] Ibid [796].

[813] Ibid.

[814] *Airedale NHS Trust v Bland* [1993] AC 789.

[815] *Airedale NHS Trust v Bland* [1993] 1 All ER 821.

both professional and lay audiences, was eventually concluded in 1993 when the doctor was permitted to cease all interventions and Tony Bland was allowed to die.[816]

The arguments, in this case, led to the development of legal precedent regarding how such cases should be handled by the treating physicians. This development resulted from the realisation that the patient in PVS is both legally and literally incapacitated to make any decisions. Therefore, it is imperative for the medical practitioner to seek a Court declaration before any action that could result in the demise of the patient. The requirement resulted from the determination of the HL to limit the scope of its ruling and take away decisions of this nature from the clinical discretion of doctors. The judges stressed that this ruling only applied to people with the diagnosis of PVS.[817] They also stressed that diagnosis only qualified as accurate under their ruling if it had been made by two doctors working independently in a time frame of not less than twelve months.[818] This time frame was adopted from the evidence given during the proceedings. They, therefore, advised that in future cases, a Court declaration must be obtained before the treating team could withdraw interventions from PVS patients.[819]

From a technical standpoint, the reasoning used by the judges in the case to arrive at the final ruling exhibited some level of inconsistencies and incongruence with the broader doctrines underpinning the decision despite being underpinned by numerous doctrines. The concept of consent to treatment was one of the ways in which the case was considered. In the first place, Tony Bland did not consent to the treatments he was receiving, some of which were largely invasive.[820] The treatments he received may have violated his right to autonomy even though these were initiated under the principle of necessity.[821] Autonomy gives everyone the

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[816] Ibid.

[817] *Airedale NHS Trust v Bland* [1993] AC 789.

[818] Ibid.

[819] Ibid.

[820] Airedale NHS Trust v Bland [1993] 1 All ER 821 [894].

[821] *Re F* (Mental patient: Sterilisation) [1990] 2 AC 1.

right to decide what happens to them, including medical treatment without being influenced by the healthcare provider. Tony Bland was unconscious when he was taken to the hospital and legally did not consent to the treatments. It was thus illogical to reason that the treatments should be withdrawn because he had not consented to them *ab initio*. Doctors have a duty of care to treat every patient in an emergency situation if the person is unable to give consent, and can use the principle of necessity as a defence.[822] If the ethical aim is to respect the individual, then unless one takes an extreme libertarian approach, it could be concluded that if an individual cannot decide for themselves, they should have one made for them in a way that protects their interests - albeit with the caveat that one would probably want to respect an advance refusal should one that is relevant exist.

Another perspective that judges used to reach the final judgment was arguments on the principle of best interests. They arrived at the conclusion that the treatments could only continue if they are in the best interests of the recipient. In so reasoning, they determined that the continuation of treatment for a patient in PVS did not serve his best interests.[823] This view was consistent with beneficence, the basic principle of medical ethics. Beneficence as a principle of medical ethics requires that procedures performed on a patient should be aimed at benefiting him/her. Since they concluded that Tony Bland could not recover from his state, the treatments were not offering him any benefits, and hence, their withdrawal was justified. This ethical principle will only be valid if the assumption that recovery from a 'PVS patient' is impossible is right. Some cases of late recoveries from PVS have recorded in the literature- what if the initial diagnosis was wrong? The manner in which best interests were determined in this case raises pertinent questions on how they arrived at what is best for Anthony owing to the emergence of conflicting views on the topic at the time the case was decided. The Lords

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[822] Ibid.
[823] Airedale NHS Trust v Bland [1993] 1 All ER 821 [896].

did not benefit from the guidance of the MCA 2005 since the case preceded the act. This sort of assessment requires a careful balancing of several factors before the final decision is made. Notably, two of the CA judges asserted that Tony Bland had an interest in dignity whereas, by contrast, in HL Mustill seemed to view him as having no interests due to only considering experiential interests and applying them in a very negating way – he considered patients said to be in PVS to lack such interests – which is both a negating view of their capacity for the inner life and of their capacity for recovery (he conflated a diagnosis of persistent with a de facto state of permanence).[824] The concept of futility with regard to the intervention received by the patient is fraught with complexities.[825] If the usefulness or otherwise uselessness of the treatment is linked to the recovery of consciousness, then the approach to best interests will weigh heavily on the withdrawal of such interventions. For instance, the provision of food and water through tube feeding may not be deemed futile if it is giving the patients the recommended daily allowance of energy and keeping the patient alive. However, if the usefulness of CAHN is based on the overall recovery of the patient from the state he or she is, then the balance will tilt to the other side of the argument.

In this case, where the issue involved the withdrawal of CANH, the Court ought to have systematically weighed the pros and cons of continuing or ceasing the tube for food and water for the patient. However, this was not done in this case. Lord Goff argued that balancing exercise is not necessary in the case of patients in PVS since in whatever case, the scale would always tip in favour of treatment withdrawal.[826] He added that the treatments no longer imparted any therapeutic benefits to the patient. The treatment was effectively futile since it only served to sustain an unconscious patient.[827] This view is based on a certain type of narrow

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[824] Airedale NHS Trust v Bland [1993] 1 All ER 821.
[825] Ibid [845] [871].
[826] Ibid [870] [871].
[827] Ibid.

conception of interests, differing from the broader view that views interests as extending beyond one's ability to experience life - encapsulated by the notion of dignity used by Hoffman and Butler Sloss. This is a narrow application of a narrow conception as well – i.e. – that it does not reflect the fact that fMRI analysis has shown us that de facto at least some patients defined PVS do have an inner life and that it is, therefore, erroneous to blithely conclude that they do not have experiential interests in that as well as an experiential interest in the possibility of recovery. According to Hoffman J, both autonomy and dignity survive even in the face of loss of consciousness.[828] Butler J echoed this in her remarks that Bland has the right to avoid unnecessary and degrading treatments if there are not serving any good purpose.[829] Notwithstanding the views used to declare the final ruling, the judgement favoured the withdrawal of nutrition and hydration in this case in congruity with the principles of beneficence and patient autonomy.

Wherever possible, the law always protects life, which is the reason behind the existence of a strong presumption that favours attempts to extend life. In granting the permission to withdraw the treatments for Bland, their Lordships may have deviated from the principle of inviolability of life being absolute. This may be misconstrued as inferring that death was in his best interests to the lay person. If the intervention was adjudged to be futile, then an argument could be made for exploring other options instead of just ceasing it without any replacement. If we refer to the dictionary definition of futile here as pointless, this might be misleading because there are several points to treating. This, in turn, is attributed to the fact that there are several aspects of interest at stake. The only way to viably argue that continuation is not in the best interests is to make the case that it is counter-productive for the individual, and not that it is not productive at all. The judgment did not explicitly clarify whether futility in this context

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[828] Heywood and Mullock (n 712).

[829] [1993] 1 All ER 821 at 848C (CA).

referred to the efficacy of the treatment given or Anthony's quality of life. However, the ruling was made because the Lords had sufficient evidence to believe that his life was not worth living rather than the treatment not achieving its purpose.[830] To avoid violating the principle of the inviolability of life, one might wonder whether CANH was a form of treatment and whether it was worthwhile instead of referring to the quality of life of the individual. Those strongly committed to the inviolability of life/sanctity of life will always remain critical of the judgment.[831] However, as discussed in chapter three, a distinction needs to be made between the sanctity of life and vitalism. For instance, if the question is, 'is the tube feeding worthwhile?' there may still be a compelling argument to stop it. The assessment of futility as a benefit versus burden balancing exercise by the judges in subsequent cases after *Bland* took a different approach, as will be seen below. While some chose to focus more on the benefits of the treatment, others adopted a broader approach. Those focussing on the benefits of treatment tend to see reasons to preserve life while those taking a different approach usually favour withdrawal of treatment.

The Second High-Profile Case: W v M and Others

This case was heard after the MCA 2005 was enacted into law in the UK; therefore, the parties had the benefit of the guidance of the Act on best interests. Although it was a MCS case, the approach and the legal principles adopted were similar to those of Anthony Bland. The case involved a 43-year-old lady who was deemed to be in a MCS following a severe viral brain infection in 2003.[832] After some years of treatment, the doctors decided that she was unlikely to regain full consciousness but was said to be minimally conscious (although she was initially thought to be in a PVS).[833] This medical opinion prompted her family to apply for two

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[830] Keown (n 711) 340.
[831] Airedale NHS Trust v Bland [1993] AC 789.
[832] W v M and others [2011] EWHC 2443 (Fam) [1].
[833] Ibid [2].

declarations from the High Court. According to the first declaration sought by them, she was mentally incapable of making any decision about her treatment and future.[834] The second declaration they sought was that the cessation of medical interventions (Nutrition and hydration) administered to M would be lawful.[835] A High Court judge, Sumner J made the first declaration on the 23rd of January 2007 and transferred the proceedings to the CoP for the second declaration.[836] However, judge, rejecting the application for the withdrawal of nutrition and hydration, Baker J stated that M still has sentience capacity and that withdrawing her nutrition and hydration would not be in her best interests.[837]

Case Critique

The outcome of this case is interesting given the decision in the earlier case of Anthony Bland. Baker J relied on all the considerations proposed by the MCA 2005 while he was assessing what would be the best decision for M in wake of the prevailing circumstances. He took into consideration all advantages and disadvantages of withdrawal of CANH for M and settled on the preservation of life to arrive at his final decision.[838] While his ruling was consistent with the principle of inviolability of life, he may not have sufficiently laid out why continuing the interventions is more beneficial to the patient. Whereas M's treatment indeed had the prospect of some therapeutic benefits, there is ambiguity on whether those benefits outweighed the burdens associated with the continuation of treatment. Since medical evidence indicated that M was near a mid-range of consciousness, a continuation of treatment would have sustained her in an indeterminable pain, which would progressively get worse as she

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[834] Ibid.
[835] Ibid.
[836] Ibid [17].
[837] W v M and Others [2011] EWHC 2443 (Fam).
[838] Ibid [6] – [9].

continued to develop awareness courtesy of the positive prospects of the treatment.[839] With the clarity provided by medical evidence in terms of the burdens, how was the decision to continue CAHN arrived at? Baker J in this judgment might have taken a narrow view to best interests and given preference to the sanctity of life.[840] Even though the MCA 2005 encourages taking a broader approach which includes the patient's values, beliefs, and known past preferences.[841]

The introduction of the MCA 2005 came with the challenge of how the law determines where the quality-of-life threshold should be set and who should define this threshold.[842] This determination is subjective and should be judged only based on how the individuals would have valued their lives.[843] Judging this concept based on the values that a patient attaches to his/her life is rendered complicated by the fact that it is difficult to adjudge how someone would be able to handle a particular situation.[844] The best interests test is assumed to be objective - however, judges are faced with the challenge of objectively assessing inherently subjective factors. The assessment is thus subjected to varying interpretations, which may lead to conclusions that are incongruent with the expectations of the patients. In this particular case, there was clear evidence of what the patient's wishes are regarding the situation.[845] The family claimed that she had previously said that she would prefer not to go through the same situation as *Bland.*[846] These claims fall within the requirements of the MCA and should have been enough to determine the best line of treatment she should receive from the treating physician.[847]

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[839] Ibid [238].

[840] Richard Heywood 'Withdrawal of treatment from minimally conscious patients' (2012) 7(1) Clin Ethics 10–16; Alexander Mullock, 'Deciding the fate of a minimally conscious patient: an unsatisfactory balancing act? (2012) 20(3) Med L Rev 460–469.

[841] MCA 2005 Section 4(6).

[842] Alexandra Mullock 'Best interests and the sanctity of life after W v M' (2013) 39(9) J Med Ethics 553–554 <https://doi.org/10.1136/medethics-2012-100907> accessed 25 August 2021.

[843] Ibid.

[844] Ibid.

[845] W v M and Others [2011] EWHC 2443 (Fam) [6].

[846] Ibid [107].

[847] MCA 2005 Section 4(6).

Even though Baker J considered these wishes and factored them in during the balances exercise, he evidently placed very little emphasis on them relative to the preservation of life. While this legislation requires judges to consider the prior wishes of patients in their judgments, judges can never be certain about how a patient would perceive their current situation. When placed in real situations as opposed to hypothetical ones, there is a fair chance that the individuals can change their decisions. However, in the presence of convincing evidence that supports what a patient would have wished for, then such wishes should be pivotal and not marginalized as Baker J had done. If the patients' wishes are afforded the appropriate weight, it demonstrates that the law recognizes that patients have varying opinions on the treatment that would allow in different situations.

The manner in which Baker J treated the views of M’s family is another aspect of Baker J's balancing exercise in this case which was open for debate. M's family members, including her partner, wanted her treatment withdrawn. Even though Baker J gave his consent to these views, it is not clear why in his final judgment; the wishes of M’s caregivers took precedence over those of her family. In some cases, especially for individuals in a long-term facility, caregivers may develop closer relationships with the patients than the patients’ own families. In such cases, the views of the caregivers might be justified to take precedence over those of the relatives. However, this did not seem to happen in M’s case since her family members remained close to her while in the care home.[848] Baker J, therefore, may have erred in placing more emphasis on the wishes of M's caregivers at the expense of those of her family. In any case, the judgment gave a proviso that if her condition deteriorated and she needed treatment for even trivial infections it might be appropriate to not initiate treatment.

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[848] W v M and Others [2011] EWHC 2443 (Fam) [111].

The third High-Profile Case: Aintree University Hospitals NHS Foundation Trust v David James and Others

This was another high-profile case involving a request for a Court declaration by the hospital. The Court held that the hospital can lawfully withhold cardiopulmonary resuscitation, invasive circulatory support, and renal replacement therapy in the event that the patient deteriorates.[849] Even though David James was said to be in MCS, the description portrayed a patient who had a higher degree of awareness of the immediate than *M* in the above case.[850] Furthermore, the interventions, in this case, are more invasive than the ones in *M*. Mr James was receiving circulatory support and renal replacement therapy which involved the passage of invasive lines.[851] The CoP decided the case barely two years after it had refused to grant a similar declaration in *M*. Technical analysis of the final judgment and the balancing exercise undertaken in this case point towards several internal inconsistencies with the broader underlying doctrines. The case highlighted many controversial issues resulting from allowing PDoC patient to die through medical means. More importantly, it shed light on the complications that can occur when decisions about the treatment of patients are taken away from the four walls of healthcare settings and put in the hands of judges and the law. The CA ruling on the case included some notable remarks.[852] It demonstrates that the best interest's decision clearly involves the assessment of the quality of life. This is particularly disturbing as the empirical research conducted in this study revealed that 85% (n-95) of the healthcare providers opined that PVS patients could just be severely disabled. The detail of this is in

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[849] *Aintree University Hospitals NHS Foundation Trust v James* [2012] EWHC 3524 (COP) [8].
[850] Ibid [33].
[851] Ibid [13].
[852] *Aintree University Hospitals NHS Foundation Trust v James* [2013] EWCA Civ 65.

chapter five. It also shows that the value judgment made on people's lives can lead to slippery slopes and that the MCA 2005 has not really helped in this regard.

Case History

The patient in the case, having battled with colon cancer for a prolonged period of time, was admitted to the hospital with constipation and acquired some infections which led to multiple organ failure and a stroke. This resulted in brain damage and subsequent diagnosis of MCS.[853] The treating team looking after him applied for a declaration by the CoP that the withdrawal of treatment would not be unlawful in the event that there was further clinical deterioration. However, Peter Jackson J rejected the application, stating that the treatments *DJ* was receiving at the time could not be considered to be unnecessary or futile.[854] The case subsequently went to the CA and the decision of the CoP was overturned on the ground that the CoP's view of futility in the case had been too narrow.[855] The declaration sought by the hospital was thus granted shortly before the patient died. After his death, the Supreme Court with a panel of five justices considered the case and reached a unanimous decision.[856] Lady Hale confirmed that the legal position of keeping individuals alive in their best interests is not absolute. She agreed with the decision of the CA to discontinue treatment at the time as Mr James's condition had deteriorated when the case got to the Court - however, her stance changed on how they determined the best interests in this case. She said that Jackson J was right in his broad approach of considering futility from a subjective (using the patient's apparent wishes and what the patient would consider a worthwhile treatment) rather than an objective perspective. If the patient considers some benefits a worthwhile treatment despite the limited clinical value, will that be enough to allow such treatment to continue? The decision in

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[853] *Aintree University Hospitals NHS Foundation Trust v James* [2012] EWHC 3524 (COP) [16] – [19].

[854] Ibid [84].

[855] *Aintree University Hospitals NHS Foundation Trust v James* [2013] EWCA Civ 65.

[856] *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67.

R (Burke) v GMC supports that there should be an objective appraisal of all treatments to weigh the benefits against the burdens of any medical intervention.[857]

Case Critique

During the balancing exercise at the CoP, factors on both sides were evidently few. The judge highlighted the factors in support of the continuation of treatment as follows. The first factor was the inviolability of life, and he reasoned that treatment could have prolonged the patient's life.[858] The second factor was quality of life, which Jackson J believed that DJ had a measurable quality.[859] The third was the family's wishes and what they thought the patient would prefer.[860] They believed that the patient would have preferred to receive treatment until the treatment proved hopeless. The family felt this point of hopelessness had not been reached.[861] The factors in favour of treatment withdrawal included: unchallenged diagnosis indicated the patient was less likely to regain independence, the treatment was invasive, and each of its setbacks placed the patient at a further disadvantage, the treatment was less likely to work, enduring such interventions would bring unnecessary burden to the patient, and that the patient would face a prolonged undignified death.[862] The judge after settling for treatment futility and claiming that the treatment could not be said to be futile failed to justify why this factor overrode all the other factors.

The CA judge, Sir Alan Ward, took note of the inherent problems in the concept of treatment futility.[863] Thus, he analysed the meaning of this concept from a wider perspective

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[857] [2005] EWCA Civ 1003 CA.

[858] *Aintree University Hospitals NHS Foundation Trust v James* [2012] EWHC 3524 (COP) [79].

[859] Ibid.

[860] Ibid.

[861] Ibid.

[862] Ibid.

[863] *Aintree University Hospitals NHS Foundation Trust v James* [2013] EWCA Civ 65 [33].

than the CoP judge had done.[864] He took a utilitarian approach to assess the need for the interventions. Thus, the question of the goal of life-saving treatment arose. The Court identified various goals of the life-saving treatment, including preventing the imminent death of the patient; extending life even if briefly, providing a minimum quality of life, and offering therapeutic benefit to the patient by curing the ailment he/she is suffering from.[865] Sir Allan Ward focused on this goal when assessing the futility of treatment. Sir Allan's assessment of treatment futility also weighed the potential burdens of the treatment against the therapeutic benefits.[866] His judgment was thus justified since even though the treatment would have imparted some therapeutic benefits to the patient, they were extremely vexatious. English judges dealing with the question of the need for interventions or otherwise in either PVS or MCS have understandably avoided relying on the evaluation of the worth of life to inform their judgment.[867] They have approached this question with a lot of caution, but there is some degree of scepticism when they say the evaluation excluded an assessment of the worth of life.[868] While some people may take a view that they are actually evaluating the worth of life there is a counterargument that what judges are doing is saying all life is inherently worthwhile, but that some life-extending measures may be counterproductive in some circumstances.

This CoP's judgment thus had a further positive element since even though the judge was aware that the question of the quality of a patient's life was fraught with difficulty - he went ahead and considered it.[869] His judgment, therefore, featured the concept of intolerability which is a notion that it would not be in the patient's best interests to continue providing a particular

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[864] Ibid [34] [35].
[865] Ibid [36].
[866] Ibid [37].
[867] Richard Heywood, 'Parents and Medical Professionals: Conflict, Cooperation, and Best Interests' [2012] 20 Med L Rev 29.
[868] Ibid.
[869] *Aintree University Hospitals NHS Foundation Trust v James* [2013] EWCA Civ 65 [36].

treatment because it poses an intolerable burden on the patient.[870] Holman J condemned this approach in *NHS Trust v MB, Mr. and Mrs. MB*[871] by saying that the tolerability test seems to connote a conclusion rather than a test. This was a case of an application for the withdrawal of ventilation in an 18-month-old child with spinal muscular dystrophy.[872] Therefore, the reliance on this notion puts the judge at the risk of having to assess an inherently subjective question objectively, thereby ending up with decisions that do not necessarily reflect the individual's beliefs and values. It is also difficult to detach objectively defined intolerability from the facts presented by the medical experts in the case. The judges should endeavour to broaden their views of intolerability in relation to the condition and the accompanying treatments. Sir Allan Ward rightly recognized that in the event a patient suffers an additional setback in his/her condition, then the burden and risks of sustaining his life are disproportionate to the dwindling chances for him to enjoy life.

Furthermore, the judgment also considered the fact that certain sections of the MCA 2005 require the assessment of the quality-of-life questions that are pertinent in the examination of the patient's previously expressed wishes.[873] While assessing these wishes, a judge is essentially considering desires and opinions that the individual might have previously expressed and guided by the values which he/she placed on own life. This is a subjective exercise since judges usually embark on trying to ascertain their thoughts on what those wishes would have been without any indications of what the wishes would have been.[874] Although evidence suggests that the patient would have preferred to continue receiving treatment, the

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[870] Nuffield Council on Bioethics, Critical care decisions in fetal and neonatal medicine: ethical issues (Nuffield Council on Bioethics 2006) xvii.
[871] [2006] EWHC 507 (Fam) [17].
[872] Ibid.
[873] Ibid [45].
[874] Heywood (n 867).

lack of clear indication led the Court into assuming that the individual would prefer the option that seemed rational and would therefore not which to prolong his life amidst the burdens.

Other relevant cases: PVS and non-PVS involving WWLSI.

In the past, there have been several cases of people in a state of prolonged unconsciousness and there will be many more in the future as medical knowledge and technology continue to advance. A few of these cases will be discussed to understand how the legal principles have evolved. *Briggs v Briggs* is a landmark case as regards the use of a holistic approach to best interests to resolve a clash between the sanctity of life and autonomy.[875] The best interests approach used in this case gave much weight to Paul Briggs' past wishes, his feeling, values, and beliefs as provided by the MCA 2005.[876] The case was very instrumental in bringing some clarity to the use of the MCA and addressing the underlying discordances between various interpretations of best interests that were highlighted earlier in this chapter.

Briggs v Briggs (by his litigation friend, the Official Solicitor) and others

The case was heard from 28th November to 1st December 2016 in the CoP.[877] In 2015, Paul Briggs had a severe brain injury in a motor vehicle accident on his way to work and subsequently remained in MCS.[878] Sixteen months after the injury, the case was heard as his wife, Lindsey Briggs, took the proceedings to Court because she believed that Paul would have wished not to be kept in that state. She disagreed with the stance taken on CAHN by the hospital, the CCG, and the official solicitor.[879] The medical expert was of the view that Paul was still in the early phase of the MCS and that there were significant chances of improvement

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[875] [2016] EWCOP 53.

[876] MCA 2005 s 4(6).

[877] Lindsey Briggs v Paul Briggs (By his litigation friend, the Official Solicitor), The Walton Centre NHS Foundation Trust, Wirral Clinical Commissioning Group [2016] EWCOP 53.

[878] Ibid [1].

[879] Ibid [4].

in his consciousness level. However, they were not confident that the level of improvement would be to the extent that he would be physically and mentally independent. According to the diagnosis report, Mr Briggs sustained various injuries, including traumatic brain injury. The CT scan revealed that the accident had resulted in diffuse axonal injury and cerebral atrophy. In February 2016, he had a SMART test to determine whether he was in MCS or PVS, and it turned out that he was in MCS minus.[880] Medical analysis showed that Mr Briggs had Paroxysmal Sympathetic Hyperactivity (PSH), which was due to a brain injury that he sustained after the accident.[881]

While looking at what would be in Paul Briggs' best interests, the Court found out that he would not want to have his life prolonged unnecessarily. Reference was made to comments made by Paul during the last days of the life of Lindsey's mother - he felt that she endured some degrees of unnecessary suffering while undergoing interventions that were eventually futile. At some point when he was mentally competent, Paul had conversations about Tony Nicklinson, Tony Bland, and Michael Schumacher.[882] He concluded that he would not like to undergo the pain that Tony Nicklinson had gone through.[883] In addition, he made comments about the victims who sustained severe injuries due to traffic accidents. The determination of best interests, according to the provisions of the MCA 2005, requires the judges to duly consider all pertinent factors.[884] On this occasion, the Court gave significant weight to the patient's well-accounted views on life on a life support machine over the principle of preservation of life. In his judgment, Charles J reiterated the non-absolute nature of the sanctity of life principle, even though it may be fundamental to everyone. In this case, the judge gave

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[880] Ibid [32].
[881] Ibid [33].
[882] Ibid [109].
[883] Ibid.
[884] MCA 2005 s 4 (2).

precedence to autonomy.[885] This judgment underscores the significance of self-determination in decision-making whenever it is possible. If the Court is satisfied, with what the individual would have decided, the decision must be respected, regardless of whether it is in favour of preserving life. This scrutiny will give confidence to the public that the voice of their relatives in PVS or MCS would be heard if they have previously voiced their opinion on not being kept alive in that state. A study in 2013 showed that a number of these patients were kept alive even though they have previously made contrary views to a 'fate worse than death'.[886]

The practical implications of this judgment on policy and practice became apparent quickly. It was observed that the MCA 2005 did not give any practical guidance on how to weigh an individual's previously expressed views against the preservation of life when determining best interests. As evidenced by the cases below, *Briggs v Briggs* later became a prototypical reference for defining a holistic approach to best interests. MCA's best interests test does not determine what one would have done in a particular scenario; it only weighs a range of factors and presumes what would be best for the individual. This decision may not necessarily be what the individual would choose if he or she were to be mentally capable. However, if the decision that the person would have made can be ascertained with confidence, then such a decision would supersede the presumption of preserving life if it favours withdrawal of treatment.[887] This case also established that MCA 2005 does not prevent the Court from making orders to withdraw interventions, which may result in the demise of the patient.[888] The MCA Code of Practice addresses the withdrawal of life-sustaining intervention

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[885] Lindsey Briggs v Paul Briggs (By his litigation friend, the Official Solicitor), The Walton Centre NHS Foundation Trust, Wirral Clinical Commissioning Group [2016] EWCOP 53 [8].
[886] Jenny Kitzinger and Celia Kitzinger, 'The 'window of opportunity' for death after severe brain injury: family experiences' [2013] 5(7) Sociology of Health and Illness < https://doi.org/10.1111/1467-9566.12020> accessed 23 June 2021.
[887] Briggs v Briggs [2016] EWCOP 53 [62].
[888] MCA 2005 s.4(5).

in paragraphs 5.31 and 5.33.[889] Munby J – in *R v GMC* stated that even though the law encourages the doctors to explore all options in support of the preservation of life when making CAHN or other lifesaving intervention decisions, there are certain situations where it is acceptable for the doctors to deviate from this obligation.[890] In some situations, the dignity of the patient bears greater significance to them than the unnecessary prolongation of life by artificial means.[891] Eleanor King LJ in the CA judgment in *Briggs v Briggs* proposed that if there is no dispute regarding withdrawing CAHN in an incapable adult, the treating teams could cease the intervention and not suffer any legal liabilities.[892] Nevertheless, the Court's guidance must be sought when there is disagreement.[893]

4.4. Withdrawal of CAHN: The need for Proceedings

Following the *Briggs* case, the comment of King LJ signalled the end to the practice of NHS trusts, official solicitors, and sometimes the family of PVS/MCS patients, of making applications to the Court in order to seek a declaration from the CoP to withdraw CAHN from patients even when the parties reach an agreement. The next two cases heralded the end of the practice Direction 9E, and such cases are no longer required to go to Court anymore.

M -v- A Hospital[894]

This landmark ruling by Mr Justice Peter Jackson in *M -v- A Hospital* gave more clarity to the need to get a Court's declaration by the treating clinician before they can cease CAHN in PVS and MCS patients in the UK.[895] This, similar to the aforementioned case of *Briggs v*

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[889] Briggs v Briggs [2016] EWCOP 53 [75].
[890] *R (on the application of Burke) v. General Medical Council* [2005] All ER (D) 445 (Jul) (CA).
[891] Sampath Karnik and Amar Kanekar, 'Ethical Issues Surrounding End-of-Life Care: A Narrative Review' (2016) 4(2) Healthcare <https://doi.org/10.3390/healthcare4020024> accessed 23 May 2021.
[892] [2017] EWCA Civ 1169 [108].
[893] MCA 2005 s. 15-17.
[894] [2017] EWCOP 19.
[895] *M -v- A Hospital* [2017] EWCOP 19.

Briggs, was a deprivation of liberty challenge. Nonetheless, the judge was asked to make a ruling on whether decisions about withdrawal of CAHN in PVS/MCS should be decided by the Court in every case as provided by Practice Direction 9E.[896] Following the submissions of all parties involved, the judge made his rulings based on the facts of the case. In particular, Jackson J outlined the conditions that needed to be fulfilled before the feeding tubes can be withdrawn and gave a useful analysis of whether an application is needed or not.[897] Following the ruling, the patient was placed on palliative management, and she subsequently died eleven days after the CAHN was withdrawn.[898]

M lived with Huntington's disease for years and subsequently progressed to MCS.[899] She was admitted to the hospital in 1994, and by 2003, she was utterly dependent on PEG feeding to maintain her obligatory nutritional requirements.[900] She was totally dependent on other people and had been bedridden ten years before the date the case was heard in Court. Her family members and the hospital had agreed that continuing feeding through a PEG tube is not doing any good to her and would like to discontinue it.[901] According to her mother, Mrs B, M was in a peculiar situation where her body was just lying in bed.[902] She was unable to interact with the environment or even recognise her immediate family members anymore. She was said to be perpetually unconscious. During the Court proceedings, Dr Wild confirmed that the patient was in VS.[903] The judge noted that regardless of whether a patient has the capacity, he or she must be protected by the ECHR[904] and other relevant conventions (right to autonomy,

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[896] Ibid [5] [28].
[897] Ibid [36] – [38].
[898] Ibid [2].
[899] Ibid [6].
[900] Ibid [7].
[901] Ibid [10]– [12]; [15]– [17].
[902] Ibid [9].
[903] Ibid [16].
[904] ECHR articles 2 & 3.

and inherent dignity).[905] These rights must be protected to avoid undue discrimination as a result of her disability.[906] Peter Jackson J approached the case using the universal framework, in which he said that the patient's interests must be considered when making any treatment decision irrespective of the diagnosis, condition, and aetiology of the condition.[907] However, the wording of the judgment may suggest otherwise - the emphasis was placed on the clinical state of the patient and the prognosis. If the Court wants to ascertain what the individual will choose in the condition he or she is in, then this cannot be done in a vacuum.

The MCA 2005 provides guidance on the assessment of best interests in these patients, s 1 (5); s 4 (5) – (7) are particularly relevant in this case. PVS/MCS is fully protected by ECHR and CRPD. Usually, the Court commences from the fundamental presumption of upholding the sanctity of life in cases like this. However, where it is evident that prolonging life will not serve the individual's best interests, then this doctrine takes a back seat, as seen in *Aintree v James*.[908] How do we determine if a life is worth living or not? Alternatively, who determines when life is worthless? In *Re J*, it was clear that only the individual could make such decisions.[909] The judgment in *R (Burke) v GMC* reiterated that there is no prerequisite of legal authorization from the Court before stopping CANH. [910] While each case has its facts, the general principles could apply, especially when all parties agree on the intended treatment options.[911] Deliberating on a PVS case, the European Court of Human Rights (ECtHR) declared that authorizing the withdrawal of CAHN did not violate the patient's rights (art. 2) so far as the state has measures in place to safeguard people's lives. [912]

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[905] UN Convention on the Rights of Persons with Disabilities.
[906] [*M -v- A Hospital* [2017] EWCOP 19 [21].
[907] Ibid [25].
[908] [2013] UKSC 6 [35].
[909] [1991] Fam 33.
[910] [2005] EWCA Civ 1003 at [67-80].
[911] Ibid [38].
[912] *Lambert v France* Appn 46043/14.

NHS Trust v Mr Y and Mrs Y[913]

The case was presided over by O'Farrell J on 13th November 2017. The central claim of the case was that it is not mandatory for a declaration under CRP part 8 to withdraw CANH from the people in the state of prolonged unconsciousness when all the parties agree on the decision.[914] Following a cardiac arrest from myocardial infarction, Mr Y had hypoxic brain damage because of prolonged resuscitation.[915] In the aftermath of this brain damage, he became incapable and unable to decide on his future care. Even though Mr Y had only been in that state for five months when the case was argued in the Court (and, therefore, he was not technically classified as PVS according to the guideline)[916]- the two medical experts assessing him concurred that his level of responsiveness was low with no awareness of his environment and that he was unlikely to regain his lost neurological function.[917] It would be interesting to know what evidence-based criteria were used to determine the irreversibility of his neurological function. Notwithstanding, it was on this basis that he was treated as being in PVS. He did not have any formal advanced directives or lasting powers of attorney, but the family articulated that he would not want to be in the state he was in due to the reported poor prognosis. The treating trust and the family concurred that it was in his best interests to have the CAHN withdrawn with the prospect that he would die in 2 to 3 weeks.[918] The trust made an application for a declaration, as there is no dispute, and there is no statutory or common law obligation to refer cases like this to the Court.[919] The official solicitor acting on behalf of Mr Y submitted

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[913] [2017] EWHC 2866 (QB).

[914] Ibid [1].

[915] Ibid [2].

[916] Ibid [10].

[917] Ibid [3].

[918] *NHS Trust v Mr Y and Mrs Y* [2017] EWHC 2866 (QB) [5].

[919] Ibid [7].

that there is a common law obligation to bring an application for the proposed action in order to protect his ECHR articles 2 and 6.[920]

O'Farrell J held that the cessation of CAHN in this patient was in his best interests. However, he said that it would not be necessary or appropriate to make a declaration beyond that case.[921] The judge noted that their Lordship's decision in *Bland* only said that proceedings should only be initiated as a matter of practice and did not say that withdrawal of CAHN in PVS will only be lawful if sanctioned by the Court.[922] The argument of whether or not CAHN is a medical treatment or simply a fundamental human need makes withdrawing it a complicated grey area. Many continue to opine that it is necessary to have a sound knowledge of the brain's neural reaction and adaptability to injuries before removing the safeguards to avoid the slippery slope phenomenon. Independent oversight of the process should be obligatory. As with other cases, one of the legal principles applied in this case, is the sanctity of life - although it was noted, as in other cases, that this is not absolute (see *Airedale NHS v Bland)*.[923] Whether the Court should sanction cases involving CAHN or not - remains a matter of practice and not an obligation.[924] In reality, these cases are both time consuming and financially draining in equal measure. Therefore, if it is agreed that CAHN is not achieving any benefit in the patient, then going to Court may well subject the individual to unnecessary intervention for months. Alternative safeguards perhaps could be an independent ethics committee, tribunal, or medico-legally oriented dispute resolution committee. Parliament did not consider it necessary to insert into the MCA a requirement that there should be an oversight

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[920] Ibid.
[921] Ibid [54 -55].
[922] Ibid [37].
[923] *Airedale NHS Trust v Bland* [1993] AC 789 (HL) [859B-D] (Lord Keith); [866G]-[868E] (Lord Goff); [877B] (Lord Lowry); [884G] – [885B] (Lord Browne-Wilkinson); [897F] – {898A (Lord Mustill).
[924] Ibid [859E-G] (Lord Keith); [873F]-[874D] (Lord Goff); [875F]-[876A] (Lord Lowry); *R (Burke) v General Medical Council* [2005] EWCA Civ 1003 [70], [71] and [80]; In *Director of Legal Aid Casework v Briggs* [2017] EWCA Civ 1169 [108] (King LJ).

by the Official Solicitor and the Court in these cases. The Supreme Court hearing case took place in February 2018 (26th and 27th), and the judgment was delivered on the 30th of July 2018 where the appeal was rejected.[925] Therefore, the judgment removed the legal obligation to seek Court approval in every case where CAHN was to be withdrawn.

PL (by her litigation friend, SL) v Sutton Clinical Commissioning Group and another.

This case involved P, a 79-yr. old who became mentally incompetent after a massive cerebrovascular accident.[926] Following the acute stroke management, she was moved to a care home and kept alive with CAHN via PEG.[927] Technically, she was not considered to be MCS, but she had some features of MCS.[928] Her son was concerned about her state and requested that the doctors should discontinue the CAHN. After arguments and counterarguments, Cobb J ruled in favour of the patient's past wishes and feeling on LSI as expressed by her friends and family.[929] These views were expressed clearly, and considerable weight was placed on them against the sanctity of life. The judge ruled that continuing the intervention would not be in her best interests. A similar case was that of NHS Trust v AW in 2013, which involved a woman in her fifties who had a subarachnoid haemorrhage in 1992 with a resultant restriction in some activities of daily living, but she continues to be active.[930] However, she suffered another episode in 2008. However, this time, she became unconscious and was admitted to ICU, but she did not recover. Following several assessments and reviews by the specialist, she was diagnosed as being in PVS. The trust sought a declaration to have her CAHN withdrawn after being in PVS for over four years.[931] All parties, including the official solicitor, agreed to the

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[925] *NHS Trust v Y* [2017] EWHC 2866 (QB).

[926] *PL (by her litigation friend, SL) v Sutton Clinical Commissioning Group and Another [2017] EWCOP 22* [1].

[927] Ibid [20;21].

[928] Ibid [26-28].

[929] Ibid [81].

[930] [2013] EWHC 78 (COP).

[931] Ibid [20].

decision. Jackson J granted the application, the CAHN was withdrawn, and she subsequently passed away.

Why is withdrawing nutrition and hydration controversial in 'PVS patients'?

Lady Black, while dismissing the appeal of the official solicitor in *NHS v Y*, said:[932]

> "*If the provisions of the MCA 2005 are followed and the relevant guidance observed, and if there is agreement upon what is in the best interests of the patient, the patient may be treated in accordance with that agreement without application to the Court".*[933]

This Supreme Court judgment turned out to be contentious. Many feared that the extra layer of protection given to patients in PVS and MCS patients has effectively been stripped away, while others think it is a fair judgment. Professor Foster argues that this judgement will promote medical paternalism and make medical guidelines and doctors the quasi-final arbitrator in deciding the 'best interests' of patients diagnosed as PVS (and other non-capable individuals).[934] However, Professor Wade opines that enough safeguards exist in the process of decision-making and best interest's determination that court application would not be necessary in all cases.[935] Regardless of which side of the argument one belongs to, one cannot but think that there will be someone somewhere who will need a Court application for justice to be properly served. Many people seem to disregard the fact that categories of patients should be treated differently from other patients. The presence of myriad grey areas in the characterisation of this condition is enough to make whoever is making decisions for them

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[932] An NHS Trust and others (Respondents) v Y (by his litigation friend, the Official Solicitor) and another (Appellant) [2018] UKSC 46.

[933] Ibid [126].

[934] Charles Foster, 'The rebirth of medical paternalism: An NHS Trust v Y' (2019) 45(1) Journal of Medical Ethics <https://doi.org/10.1136/medethics-2018-105098> accessed 18 August 2021.

[935] Derick Wade, 'Commentary on Charles Foster's 'The rebirth of medical paternalism: An NHS Trust v Y' (2019) 45(1) Journal of Medical Ethics <https://doi.org/10.1136/medethics-2018-105200>accessed 18 August 2021.

tread with caution. The above case of *Mr Y vs NHS Trust* was fast-tracked to the Supreme Court and during the process, he suffered a heart attack and died.[936] However, because it was agreed that the issue raised in the application was pertinent to the legal development in this area, his death did not halt the proceedings. This judgment made the withdrawal or withholding CANH permissible in some circumstances. So, why was CANH hitherto treated differently from other interventions used in patients in PVS or MCS to keep them alive?

The Court determined in *Bland* that CANH should be treated as a medical intervention.[937] Whether this assertion is true or not remains in the realm of conjuncture. Similarly, this judgment again rejected the argument that tube feeding is not a medical treatment.[938] For individuals who are unconscious, complex coordination of the reflexes is involved in the swallowing of food and water to help maintain their obligatory physiology. More pertinently, the individual should be awake enough to physically put their food in the mouth and consciously chew the food using the muscles involved in mastication. PDoC patients are unable to do this, which is why they need assistance in either getting the food into the stomach or getting nutrients directly into the bloodstream. This can be achieved either by passing tubes through the nostril to the stomach or directly from the anterior abdominal wall to the stomach.[939] In some situations, special tubes called 'lines' are inserted directly into the peripheral veins in the arms or a larger central chest or neck vein (total parenteral nutrition).[940] These devices deliver nutrients and hydration to the patients. When CANH is withdrawn from a patient, it would not be unreasonable to infer that the patient will suffer from starvation. When the patient dies, he or she is more likely to die of malnutrition and dehydration than the

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[936] [2017] EWHC 2866 (QB).

[937] Air*edale NHS Trust v Bland* [1993] AC 789.

[938] An NHS Trust and others (Respondents) v Y (by his litigation friend, the Official Solicitor) and another (Appellant) [2018] UKSC 46 [21].

[939] Gwen Sayers and others, 'Parenteral nutrition: ethical and legal considerations' (2006) 82(964) Postgraduate medical journal <https://doi.org/10.1136/pgmj.2005.037127> accessed 25 May 2021.

[940] Ibid.

underlying problem (in this case, PVS). If this is the case, a lot of ethical and human rights questions are raised.[941] A good example of such a situation was May Ormerod, an elderly woman who died in August 1995, two months after her GP instructed the nurses in her care home to stop feeding her.[942] Having suffered a series of strokes between 1987 and 1994, she was left severely debilitated.[943] Following Mrs. Ormerod's death, the doctor was arrested and investigated for murder, but the Director of Public Prosecutions (DPP) dropped the case seven months later. Mrs Ormerod weighed 25kg only at the time of her demise. The coroner ruled that she died of natural causes, but malnutrition contributed to her death.[944]

The coroner's submission in the case seems to be nebulous in the sense that, in one breath, he said the death was due to natural cause, and in the other breath, malnutrition contributed to her death. The post-mortem revealed that bronchial pneumonia was the cause of her death.[945] Lack of nutrition will make her body's natural defences unable to fight this infection even in the presence of potent antibiotics. The sight of an old frail 85-year-old woman wasting away without food for two months potentially raises many human rights issues. Despite the DPP dropping a murder case against the GP, the GMC suspended him for six months for 'serious professional misconduct'.[946] Could this case have been treated differently if the patient was labelled as in PVS? Medicine is a growing field that is characterised by new inventions and new ways to treat illnesses. In the past, brain injuries have been the leading cause of PVS and the advances taking place in the field of medicine will increase the prevalence of MCS. Patients who had tragic accidents now have a higher chance of surviving, even when that means that they will show minimal or no signs of self-awareness. Advances in medical

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[941] Ibid.

[942] Kmietowicz (n 186).

[943] Ibid.

[944] Ibid.

[945] Ibid.

[946] Clare Dyer, 'Withdrawal of food supplement judged as misconduct' [1991] 318(7188) BMJ <https://europepmc.org/article/med/10102845> accessed 2 June 2021.

technologies have enabled the prolonging of the lives of PVS patients.[947] These patients are sustained by artificial feeding despite having the faintest chance of recovery. The argument about legalising the withdrawal of care in PVS in the UK dates back to 1993 in *Bland*.[948] However, it was not until the Supreme Court judgment in *NHS vs Y* that it was confirmed that there was no need to take all cases to Court in order to seek permission to withdraw CANH.[949]

It may be argued that by permitting the cessation of care for 'PVS patients', the law has eased the burden for families that would otherwise have had to make hard decisions about their loved ones. The law recognises that an unconscious patient does not benefit from assisted feeding through tubes in all cases.[950] However, the decision requires a pragmatic approach to ensure that the rights and the dignity of these patients are safeguarded sufficiently to prevent any mishaps. When artificial feeding and nutrition are withdrawn, in many people's opinions, it 'hastens death.' One might argue that the patient is already being deprived of life by not being aware of what is happening and lacking the freedom to make choices, even concerning his health. One could also argue that withdrawal of care should be a best interests' decision.[951] In any case, the law seems to offer a somewhat objective way of handling the patients in a PVS by seemingly stepping back and giving an emotion-free perspective on the way things should be handled. Not only do families feel less pressured and guilty, but they also feel better knowing that the decision to withdraw care was made by someone who was not emotionally involved and who only considered facts to reach their conclusion. In a way, the Court's jurisdiction helps the relatives not feel responsible for the death of their loved ones despite believes by some of

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[947] Kartina Choong and Mahmood Chandia, 'Technology at the end of life: "Medical futility" and the Muslim PVS patient' (2013) 2 International Review of Law <http://dx.doi.org/10.5339/irl.2013.9> accessed 21 March 2021.

[948] *Airedale NHS Trust v Bland* [1993] A.C. 789.

[949] NHS Trust & ORS (Respondents) v Y (by his litigation friend, the official solicitor) (Appellants) [2018] UKSC 46

[950] Celia Kitzinger, 'Serious Medical Treatment and the Law Concerning Patients in a Permanent Vegetative State' (A Coma and Disorders of Consciousness Research Centre, 2015) <https://cdoc.org.uk/wp-content/uploads/2014/05/Overview-Law-PD9e-v.1-2072932.pdf> accessed 24/06/2021.

[951] Emily Jackson, 'The minimally conscious state and treatment withdrawal: W v M' (2013) 39(9) Journal of Medical Ethics < https://doi.org/10.1136/medethics-2012-100981> accessed 24 June 2021.

them that they are not technically alive. Instead of viewing the law as the enemy that only recognises PVS patients as dying, it should be seen as an instrument protecting the citizens. Furthermore, it recognises the importance of every human being to die ’a good death’ and ensures that the patient dies with dignity and respect, irrespective of how difficult a decision that might be for the family involved.[952]

Lord Goff said in the judgment in *Re F* that a treatment given to a mentally incompetent patient can be discontinued at any time during the care if it is determined that the patient is not getting any significant benefit from it.[953] This is a case of an intellectually disabled woman in a long-term mental health facility for over two decades. She started having a sexual relationship with another patient and the hospital management raised concerns about the impact conceiving and having a child would have on her and the unborn child.[954] Since other contraceptive methods were not practicable in her case, the hospital applied for a declaration for sterilisation. She was unable to consent to the procedure and did not understand the implications of not taking precautions against unwanted pregnancy. Acknowledging that it was in her interests to have the intervention, the Court reiterated that such a procedure should not be carried out without the opinion or guidance of the Court.[955] The Court then established that applying to the Court for some decisions on behalf of incapable patients is essential in this case.

Similarly, the same principle should be applied to the issue of artificial feeding in the PVS patient. The Court acknowledged that continuous technological advancement in medicine has blurred the hitherto certain distinction between life and death.[956] Therefore, the question of whether or not to feed a patient will remain a complex one. The use of artificial methods to

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[952] Paquita de Zulueta and Francesco Carelli, ‘Permanent vegetative state: comparing the law and ethics of two tragic cases from Italy and England’ (2009) 2(2) London journals of primary care <https://doi.org/10.1080/17571472.2009.11493266> accessed 2 May 2021.

[953] [1990] 2 AC 1 [867].

[954] Ibid.

[955] *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1 [79].

[956] *Airedale NHS Trust v Bland* [1993] A.C. 789 [878].

administer food and water to patients exacerbates the complexities in an already contentious argument. In *Airedale v Bland*, artificial feeding through tubes was said to be a medical intervention. Therefore, from a legal standpoint, there is a difference between drinking water directly and pushing it down a nasogastric tube simply due to the involvement of some technology. The argument in support of this view was that the public could not undertake this method of feeding in a non-clinical environment.[957] This argument is not entirely convincing as we continue to see patients with swallowing issues been giving PEG tubes, and they manage it by themselves at home. Sir Thomas Bingham MR of the Appeal Court opined that the position is likely to change as knowledge and practice advance in the future. Therefore, a Court application for withdrawal of CANH would not be necessary in every case.[958] However, Lord Browne-Wilkinson took a more cautious approach in his judgment by saying that the declaration was made with the knowledge that the future may bring a possibility of innovations.[959] Furthermore, the Law Commission report stated an artificial method of sustaining an unconscious patient with no higher cortical function and no prospect of recovery, e.g., a PVS patient, should not be withdrawn without the approval of the Court.[960] In addition, the MCA code of practice included the proposed withholding and withdrawal of treatment in PVS as one of the serious treatment decisions that require Court permission before it is carried out.[961]

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[957] *Airedale NHS Trust v Bland* [1993] AC 789.
[958] Ibid.
[959] Ibid [885].
[960] The law commission report No 231 on mental incapacity [6.21].
[961] Mental Capacity Act 2005 code of practice [6.18].

Cases where there are disagreements between parties.

Salford Royal Foundation Trust v Mrs P and Q.

This case was presided over by Hayden J in 2017. It involved Mrs P, 72 years old woman who became mentally incompetent and unable to communicate her wishes to the treating doctors after suffering from a brain injury in 2016.[962] The trust applied for a declaration to allow the doctors to insert a PEG tube for feeding. She was said to be in an MCS with minimal awareness of the environment.[963] Mrs P had a fall in the car park in 2016. Following an evaluation with a CT scan, she was found to have a subarachnoid haemorrhage (bleeding into the brain). She was following evaluation with a CT scan- she was found to have a subarachnoid haemorrhage (bleeding into the brain). She was then transferred to Salford Royal Hospital to undergo a neurosurgical procedure. On arrival, she was unconscious with a GCS score of 3/15, which is the lowest level of consciousness on that scale. By virtue of the clinical state she was in, she was referred to as having a disorder of the mind and brain,[964] and according to MCA 2005, anyone with a disorder of the mind or brain shall be deemed to lack capacity.[965]

The trust made a compelling argument as to why the patient needed to have CANH through a PEG tube.[966] The clinical team stated that the procedure was claimed to be reasonable and clinically indicated given the patient's condition. During the hearing, the patient's children hinted that their mother did not want to live in such a devastating state.[967] The two experts reporting on the case agreed that she would not regain her mental capacity.[968] The Court

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[962] Salford Royal Foundation Trust v Mrs P (by her litigation friend, the Official Solicitor) and Q [2017] EWHC EWCOP 23 (Fam) [1].

[963] Ibid [16].

[964] Ibid [3].

[965] MCA 2005 s 2(1).

[966] Salford Royal Foundation Trust v Mrs P (by her litigation friend, the Official Solicitor) and Q [2017] EWHC EWCOP 23 (Fam) [1].

[967] Ibid [12].

[968] Ibid [4] [19].

declined the trust's application for the insertion of PEG for CAHN. It was accepted that there have been occasions that she had mentioned her view on not to live a 'travesty life' even though P did not have a documented advanced care directive to refuse treatment. In this case, autonomy/self-determination was giving weight over the sanctity of life.

Cumbria NHS CCG v Miss S and Ors

In *Cumbria NHS CCG v Miss S and Ors*, Miss S's mother, brother, daughter, and the treating team agreed that continuing to provide CAHN to her would not be in her best interests.[969] Interestingly, the PEG tube fell out where the application to withdraw CAHN was in Court, and the medical team had to put another tube in her. S was said to be a healthy person since her childhood; however, her life was darkened with a depressive illness that resulted in alcohol abuse since her teenage years.[970] In August 2012, she took an overdose of glucoside, which is an oral hypoglycaemic agent. This medication has a strong tendency to lower the blood glucose level. Due to dangerously low glucose levels, she had a seizure and subsequently developed brain damage from hypoxemia.[971] It was unclear whether the overdose was accidental or deliberate. S was found unconscious and was rushed to Furness General Hospital. She was investigated and treated acutely with tracheostomy and gastrostomy and then discharged to a nursing home for neurological rehabilitation.[972] After a few months, the family stated that she would not want to be in that state and that they would like the PEG tube to be discontinued. There was a family meeting around eight months after the injury, and the doctors told the family that they would require another three months before being labelled as PVS.[973]

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[969] [2016] EWCOP 32.

[970] Ibid [2].

[971] Ibid [4].

[972] Ibid [5].

[973] Jenny Kitzinger and Celia Kitzinger, 'Causes and consequences of delays in treatment-withdrawal from PVS patients: a case study of Cumbria NHS Clinical Commissioning Group v Miss S and Ors [2016] EWCOP 32' [2017]. 43 J Med Ethics <https://jme.bmj.com/content/medethics/43/7/459.full.pdf> accessed 27 May 2021.

Four years after the injury, the case was concluded in Court, the CAHN was discontinued, and the patient was put on a palliative care pathway.

An NHS Trust v D

An NHS Trust applied to the Court for a declaration to cease CAHN from patient D, who was said to be in PVS. [974] The family and the medical staff agreed with the application made by the hospital. D developed a malignant thyroid lesion which required surgical intervention.[975] Even though the operation was complicated with a cardiac arrest, he was resuscitated. However, he subsequently had brain damage from a lack of adequate oxygen supply to the brain during the resuscitation. He was on organ support in the intensive therapy unit and was later having assisted feeding and hydration. A diagnosis of PVS was made, and it was determined that the CAHN was no longer serving any beneficial purpose therefore, according to *Airedale v Bland* continuing such futile intervention would not be in his best interests.[976] However, prior to the surgery, D wrote a letter to his sister authorising her to act on his behalf should he become incapable. He explicitly stated that he would not want any invasive procedure, including a feeding tube if the purpose is to prolong his life with unacceptable quality. Unfortunately, D was not aware of the MCA 2005 provisions for advanced care directives and that such a directive to refuse life-saving treatment must be witnessed.[977] Since his letter was not legally binding, the Court had to determine his best interests. The Court agreed with evidence provided by the NHS Trust that he is in a PVS, that continued treatment has no benefits to his health, and that he is unaware of himself. The subsequent Court ruling in relation to the withdrawal of CANH did not violate D's wishes. In addition, the NHS Trust and the family had agreed on the withdrawal of CANH since it was not beneficial to the patient.

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[974] [2012] EWHC 885 (COP); [2012] EWHC 886 (COP).

[975] An NHS Trust v D [2012] EWCOP 885.

[976] [1993] 1 AC 789.

[977] MCA 2005 s.25.

Even though D’s wishes were clear and known, it took nine months for the proceedings that eventually led to the withdrawal of the PEG feeding.

Abertawe Bro Morgannwg University Local Health Board v RY & CP.

Mr Hayden J also echoed the significance of the sanctity of life doctrine in the determination of best interests analysed by Justice Charles J in the *Briggs v Briggs* in this judgement. This case was for an application for withdrawal of LSI in a PVS patient. RY was an 81-year-old patient who suffered a cardiac arrest due to cardiac rhythm abnormality.[978] While he was being resuscitated, he fractured his ribs and subsequently developed hypoxic brain injury, which resulted in him being in PVS.[979] In an extempore judgment, the Court consented on his behalf to have a tracheostomy, which is a procedure that connects a tube through the neck to deliver oxygen into the lungs, bypassing the nose and the upper part of the throat.[980] In 2017, the case was taken back to Court. At that time, his life expectancy was said to be six months, and he was said to have progressed to MCS.[981] Unlike in *Briggs v Briggs*, Mr RY’s daughter, CP said that she believed that her father would have wanted his life preserved at all costs (this account was found to be unreliable).[982] However, the determination of his best interests was difficult because of the lack of sufficient evidence to ascertain his past wishes and feelings.[983] In this case, the main issue was to determine whether deep suctioning of RY through the tracheostomy tube would be in his best interests. As his wishes on this issue were not known, Hayden J was reluctant to assume that sanctity of life should take precedence over an individual’s autonomy.[984] Usually, when decisions are made about living or not living are

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[978] Abertawe Bro Morgannwg University Local Health Board v RY & CP [2017] EWCOP 2 [3].
[979] Ibid.
[980] [2016] EWHC 3256 (Fam).
[981] [2017] EWCOP 2.
[982] Ibid [11].
[983] Ibid [41].
[984] Ibid.

to be made in the Court, the general instinct lies in favour of preserving life, although there are other strong considerations as well.[985] Cases like *Re N,*[986] *Pretty v United Kingdom,*[987] and *Airedale NHS Trust v Bland*,[988] are useful references as echoed in the earlier judgment. The question then was whether the intervention could be rationalised been appropriate or not for the doctors to ascertain what would be in his best interests. His Lordship concluded that the intervention did not serve any life-prolonging or quality improvement purpose beyond clearing secretions. Since the intervention is accompanied by discomfort and sometimes pain, it cannot be justified to cause harm without purpose as doing so will compromise RY's integrity and dignity.[989] In this case, unlike *Briggs v Briggs*, it was challenging to know what RY wishes and feelings, so alternatives were explored.

<u>A summary of the observation drawn from the above cases.</u>

1. Almost all the PVS cases that have gone to Court have resulted in CAHN withdrawal, regardless of whether the parties involved (the family, clinician, and the official solicitor) agreed or disagreed on the proposed action.
2. Considerable delay exists between the injury and when the CAHN is withdrawn, even though the family may have told the clinician that the patient would not want to be in that state or when, in some cases, there is even written documentation of that by the patient (including non-legally valid advanced directives or LPA).
3. Even though the judges have said that best interest's assessment is a broad concept not determined by diagnosis, the judgment had been adjourned in some cases because of

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[985] [2016] EWHC 3256 (Fam) [6].
[986] [2015] EWCOP 76.
[987] [2002] 35 EHRR 1.
[988] [1993] AC 789.
[989] Ibid [53].

getting a second and another expert opinion on PVS diagnosis. E.g., in *Cumbria NHS CCG v S and Ors*, the case was adjourned by two months.[990]

4. The label PVS has a negative influence on the outcome of the judgment. Once a diagnosis of PVS is made, there is an assumption of futility and hopelessness in the patient's chances of recovery. Not enough has been done to look into the evidence underpinning the diagnosis and prognostication.
5. The concept of futility used in the judgments is about the overall prognosis of the condition. Technically speaking, the purpose of the CAHN is to deliver nutrition and hydration to maintain the body's physiology. This purpose was met in all the cases, but it was said to be futile.

Non-PVS Cases

Although the cases discussed above were not exclusively PVS, there were some MCS cases as well. This is because of the overlap in the diagnosis of these two conditions. However, in this section, there will be an evaluation of cases in other non-PVS/MCS contexts with a discussion about the relevance of patients' wishes, values, and beliefs.

B v D (by his litigation friend, the official solicitor) and The Ministry of Defence.

This case concerned capacity, best interests, non-NHS funders, and cross-jurisdictional issues.[991] The presumption that best interests are what the treating team finds beneficial for the patients is not always correct as seen in some of the aforementioned cases that best interests' assessment goes beyond the patient's clinical need. This judgment showed that in some situations the Court could favour interventions that are not clinically proven to have benefits

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[990] Kitzinger and Kitzinger (n 973).

[991] *B v D (by his litigation friend, the official solicitor) and The Ministry of Defence* [2017] EWCOP 15 [1].

and decide against the opinion of the clinical team as long as it is the patient's preference. This case involved D, a 27-year-old soldier who was assaulted by another regiment member and subsequently suffered a brain injury.[992] The legal issue, in this case, was that Mrs B, who is D's mother, wanted her son to undergo stem cell treatment in Belgrade however, the official Solicitor declined the request.[993] The assault took place in a bar in Afghanistan and following which he was diagnosed with an axonal injury. In addition, he also had bleeding in the brain.[994] B had to seek a declaration from the Court to order stem cell treatment for her son. During the hearing, D expressed a desire to be healthy and live a normal life like other people.[995] In addition, D assured the Court that he was keen to be flown to another country for treatment. In this case, the principle of best interests was applied. It was evident that D was aware of the proposed treatment and to a reasonable extent understood that there was a good chance of it not working however, he was optimistic.

More importantly, he was said to be aware of the risks that might come with the proposed treatment. Although the psychiatrist looking after him said that he could not make decisions about his treatment, it seems that the Court gave weight to his expressed wishes during the proceedings. Pointing out that he was struggling to cope, she felt that the procedure could potentially be beneficial to him. She added that his desperation to get better informed his interest in pursuing the experimental treatment proposed. The best interests' argument made by the treating team was that the proposed treatment is experimental and has not gone through the normal rigorous process of scientific and ethical approval.[996] They added that it is unclear that Swiss Medica was adhering to rules and regulations governing the expansion of cells.

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[992] Ibid [3].
[993] Ibid [1].
[994] Ibid [3].
[995] Ibid [14].
[996] *B v D (by his litigation friend, the official solicitor) and The Ministry of Defence* [2017] EWCOP 15 [28].

Therefore, they did not believe that the procedure would serve his best interests.[997] The approach here should focus on the patient's wishes since he appears to understand, to an extent, what the treatment is about and how it might benefit him together with the potential risks accompanying the procedure. The principle of autonomy should have taken precedence in this instance. The Court gave provisional consent (albeit with conditions) at the end of the proceedings to D to travel for the experimental treatment. This ruling was on the basis that D would be more depressed if he were to be denied this opportunity, and it was highly likely that he would begin to exhibit a hostile reaction that could delay his rehabilitation.[998]

The relevance of this case to the discourse on PVS is that in this case, the patient suffered brain injury like PVS however, the patient remains conscious even though he was adjudged by the psychiatrist to have lacked the capacity to make decisions related to the treatment. During the proceedings, he expressed his wishes to have the treatment regardless of the risks.[999] Even though it cannot be said that the Court was entirely satisfied that he had capacity, the Court appears to have given more weight to his wishes. The argument thus is that PVS patients are treated differently because they are considered unconscious despite the absence of evidence that they are unconscious. To interrogate their brains and get information about their wishes at the material time, it is necessary to explore avenues of using technologies. It is probably not very relevant as we have seen in this case whether the patient has the capacity or not as long as they are able to articulate their wishes.

***W Healthcare NHS Trust v H and Another* [2004] EWCA Civ 1324.**

This case is an appeal to a judgment by Coleridge J, which allowed the re-insertion of a PEG tube for a 59-year-old woman, KH, who had multiple sclerosis and was said to be mentally

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[997] Ibid [54].
[998] Ibid [60].
[999] Ibid [28].

incapable for about 20 years.[1000] She has been living in a nursing home and has been fully dependent, but she was said to be conscious even though she could not recognise anybody. The official solicitor supports the trust application both at the lower Court and at the CA. KH's brother Mr H and P, her daughter, took the case to the Court of Appeal. After her PEG tube of five years fell out at the nursing home, she was admitted to the hospital. The treating doctors believed it was in her best interests to re-insert the tube since she had no concurrent infection and was clinically stable, albeit the PEG tube falling out. One of her daughters said that her mother told her that she would not want to be kept alive by machines.[1001] In the past, KH had also said that she would not want to be kept alive if it came to the point that she could no longer recognise her children and that she would not like to be a burden to them.[1002] As highlighted in the judgment, even though all the family members recounted KH's wishes about sustaining her life only when the quality of life is reasonable, she did not specifically mention PEG feeding.[1003] In addition, there was no indication of her knowing the implication of PEG withdrawal viz slowly starving to death. Also, there was no evidence that she made a well-balanced decision at that material time.[1004]

In the judgment, the Court acknowledged no valid advanced directives albeit previously expressed wishes by KH. However, these wishes were not clearly articulated with regard to PEG feeding. The Court was not satisfied that KH made a well-informed decision regarding death by starvation.[1005] While the appeal was diagnosed, there are two interesting remarks in the judgment. The first remark is that the Court was not convinced that sustaining KH's life by ANH would make her life intolerable.[1006] This assertion is an interesting point when compared

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[1000] W Healthcare NHS Trust v H and Another [2004] EWCA Civ 1324.
[1001] Ibid [6].
[1002] Ibid [8].
[1003] Ibid [17].
[1004] Ibid.
[1005] Ibid.
[1006] Ibid [26].

to the remarks on tolerability in PVS judgments. According to the second remark, the Court cannot sanction death by starvation in any individual unless the person is in a PVS or has clear legally valid advanced directives or the person's condition is intolerable beyond doubt.[1007] It might be argued that the only difference between this patient and someone diagnosed as PVS is that the doctors believed KH is conscious. At the same time, there is a general presumption that PVS patients lack consciousness and sentience ability which is why the Court would make a judgment in the support of the preservation of life in patients other than PVS.

***RAO v ROO* [2018] EWCOP 33.**

ROO had a subarachnoid haemorrhage complicated by hydrocephalus in 2008.[1008] The pressure in the brain was relieved with a ventriculo-peritoneal shunt and was discharged home with nursing care after the acute management.[1009] However, she suddenly deteriorated in 2012, and the husband claimed that the cause of the deterioration was not adequately investigated.[1010] However, he believed that it was due to the malfunctioning of her shunt. She deteriorated further and was admitted into a nursing home in 2018 as a permanent resident.[1011] She continued to refuse food, water, and medications. The husband made an emergency Court application when she was admitted to the hospital with pneumonia, and the treating team was unable to pass a nasogastric tube.[1012] The husband claimed that she was placed on palliative care, but it was found that she was continuing to have antibiotics and other treatments. The husband sought three declarations from the Court.[1013] The first declaration was that it would not be in ROO's best interests to be discharged from the hospital in the clinical state she was

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[1007] Ibid [22].
[1008] *RAO v ROO* [2018] EWCOP 33.
[1009] Ibid [4-5].
[1010] Ibid [6].
[1011] Ibid [8-9].
[1012] Ibid [9].
[1013] Ibid [11].

at the time. The second declaration was that it was in her best interests to be taken off palliative care and be investigated to ascertain the cause of her deterioration in 2012. The last declaration was that she should be offered temporary artificial nutrition and hydration until she could eat by herself. The trust made a case that ROO has vascular dementia and her neurological function is progressively deteriorating, and she is unlikely to recover her function.[1014] The team said her deterioration was not from malfunctioning shunt, but progressive changes as a sequel of the stroke compounded with acute events.

There was limited evidence regarding ROO's wishes and feeling regarding artificial feeding and life-sustaining interventions.[1015] William J agreed with the evidence given by the expert that she has dementia, and there is no prospect of her recovering her neurological function to the extent that she would be able to eat enough to maintain her body physiology.[1016] In addition, the guidance on artificial nutrition in dementia did not support artificial feeding. Therefore, the RAO application was rejected as it was not found to be in her best interests to have artificial feeding. It was also not in her best interests to have further investigations in the quest to find another diagnosis since she already has one.[1017] It was found that discharging her to a nursing home to have a more conducive environment to spend with the family and be looked after would serve her best interests.[1018] This judgment is fairly straightforward as the diagnosis is not in dispute, and there was comprehensive guidance on the management of artificial feeding in dementia. Therefore, determining best interests in this case with no advance directives or clear wishes and views on artificial feeding is not as daunting as in PVS.

[1014] Ibid [22b].
[1015] Ibid [58].
[1016] Ibid [75].
[1017] Ibid.
[1018] Ibid.

Human rights cases on PVS.

The HRA 1998 and the ECHR have a role in WWLSI in PVS like in other cases involving end of life issues. Relevant articles of the ECHR are article 2, which compels the state to take reasonable positive steps to protect the lives of the citizen; and article 3, which protects against inhumane or degrading treatment and to some extent article 8, the respect for private and family life. Various human rights instruments protect every human being's right to life. From the ICCPR internationally to the ECHR regionally down to the HRA 1998 in the UK. ICCPR in article 6(1) provides that:

> '*Every human being has the inherent right to life. This shall be protected by law. No-one shall be arbitrarily deprived of his life.*'[1019]

Similarly, according to article 6(1) of the Convention on the Rights of the Child (CRC), every state needs to recognise that every child has the inherent right to life. In addition, the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families provides in article 9 that the right to life of migrant workers and members of their families shall be protected by law. Article 2 of the ECHR also echoes the right to life of everybody; HRA 1998 gives domestic effect to the ECHR rights. The states have both positive and negative obligations to protect this right.

In *Lambert v France*, a PVS in France human rights case involved a 32-year-old gentleman named Vincent Lambert. A road accident resulted in him being in a chronic vegetative state and tetraplegic.[1020] The accident occurred in 2008, and he was kept alive on life support but with little or no clinical improvement.[1021] In 2013, the treating doctors decided

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[1019] ICCPR art. 6(1).

[1020] Lambert v France [2015] App No 46043/14.

[1021] Ibid.

to withdraw artificial nutrition and reduce hydration after following the professional guidelines.[1022] His wife and some members of his family agreed with the decision. However, his parents and two of his siblings strongly disagreed with the doctor's decision because they believed that the interventions should be continued. They sought an injunction to stop the clinician from withdrawing his ANH. The *Conseil d'État* dismissed their application, and they subsequently applied to the ECtHR relying on article 2 of the Convention to prevent the doctors from withdrawing the interventions. The Commission held that the withdrawal did not violate article 2 of the ECHR. It was stated in the judgement that for decisions like this to be made, there should be a balancing exercise between the protection of the patient's right to life and the protection of their right to respect for their private life and personal autonomy.[1023] The Court was satisfied that France complied with both its negative and positive article 2 obligations.[1024]

The main argument was whether the withdrawal of nutrition and reduction of hydration in this patient violates his article 2 rights. The judgment focussed on the decision-making process and the available safeguards in French law. The withdrawal of ANH was not treated as euthanasia but rather as an omission. It was stated that the treating team complied with all the requirements of the Leonetti Act procedure.[1025] The *Conseil d'État* judgment ruled that the ANH could be withheld on the grounds of unreasonable obstinacy.[1026] ECtHR ruled that the judgment complied with the positive obligation of France under the ECHR article 2.[1027] Under article 2, reasonable positive steps should be undertaken to protect life. However, these steps do not include providing treatments that would contravene article 3 of the Convention.[1028] The state's positive obligation to preserve life under ECHR art. 2 is discharged when a responsible

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[1022] Ibid.
[1023] Ibid.
[1024] Ibid.
[1025] Ibid.
[1026] Ibid.
[1027] Ibid.
[1028] *NHS Trust A v M; NHS Trust B v H* [2001] 1 All ER 801.

doctor decides to withdraw treatment per the professional guidelines and in the patient's best interests. In Widmer v. Switzerland, it was held that the Commission does not consider death caused by the withdrawal of medical treatment as a crime.[1029] In addition, article 3 of the Convention cannot be used as a basis to demand a treatment that is not medically indicated. It would be illogical to argue that not providing treatment that doctors deemed futile would amount to inhumane treatment.

In these cases, the relevance of article 8 of the Convention is its involvement in the balancing exercise of protecting the article 2 rights of the patient. The patient's wishes, values, and feelings, where known, should always be used to determine what would be their best interests. By so doing, the clinicians will be protecting their right to respect their private life and personal autonomy under article 8. In the UK, the MCA 2005 provides the legal framework for protecting incapable patients' autonomy.

4.5. Overarching analysis of current English law relating to those labelled PVS.

PVS is one of the most contentious medical conditions, raising various issues for the medical profession. An individual in this state requires gastrostomy feeding for nutritional support, and the inevitable happens when this is withdrawn. PVS patients cannot give consent for treatments given and are unable to get involved in any subsequent medical decisions. This section will analyse the protection afforded to individuals in PVS in the UK by evaluating the interaction between the law and policies and discussing how governance has impacted the management of people labelled with PVS.

The interaction between the law and policies regarding PVS in the UK.

[1029] Widmer v Switzerland [1993] Appl 20527/92 (comm).

The debate on PVS has always focused on the appropriateness of either continuing with the life-sustaining treatments or terminating them. There is a diversity of opinions on this topic which are largely guided by religion, law, ethics, and practice guidelines. The legal positions on many of these issues are somewhat clear but the legal reasoning behind these positions is sometimes questioned by bioethicists. Doctors and nurses owe their patients the duty of care and they must provide the best care available in order to prevent them from dying from the disease or condition if possible. Therefore, it is paradoxical that the same professionals would abandon these responsibilities and advocate for measures that would potentially end the life of the people they are meant to protect. According to the analysis of the rulings on PVS cases, the Courts do not take a view that the life of these patients should be prolonged at all costs if there are compelling arguments against such action. The law states some of the circumstances where withdrawing and withholding a life support system/treatment would be legal and establishes some principles which are highlighted below.

1. An act whereby the healthcare provider's chief purpose is to end a patient's life would be illegal.[1030]
2. The act of withdrawing and withholding treatment are both regarded as an "omission" and not an "act" by law.[1031]
3. An adult that is deemed by the clinician to have mental capacity has the legal right to decline treatment even when it results in death or harm to the person in question.[1032] The health caregivers are bound to respect the decision regardless of how unwise it may seem.

[1030] *An NHS Trust v D* [2000] 2 F.L.R.

[1031] *Airedale NHS Trust v Bland* [1993] A.C. 789 [866] (Lord Goff) [877] (Lord Mustill).

[1032] *Re T (Adult: Refusal of treatment)* [1993] Fam 95.

4. Doctors are not legally obliged to continue interventions that are assessed to be burdensome and futile.[1033] In doing this, the doctors have the responsibility to weigh all evidence and consult the available professional guidance before arriving at a conclusion.[1034]
5. A quality of life assessment is generally undertaken to decide for an incompetent adult whether a certain treatment is futile and not beneficial.[1035]
6. Court declaration is only required for CAHN to be withdrawn if there is any doubt or dispute in the proposed course of action.[1036]
7. Finally, the duty to decide what treatments a patient receives rests on the doctor; however, the family or guardian should be carried along in the process. Neither the patients if mentally competent nor the relatives of incapable patients have the legal right to demand treatments that are not indicated.[1037]

A patient's autonomy is a fundamental right. The paradigm of the concept in the common law has shifted from the tolerance of paternalism, which is a notion that doctors know it all, to promoting individualism. The legal position on this matter is the requirement for informed consent before treatment. Informed consent implies that the patient should understand the condition he/she is suffering from and the risks, benefits, and alternatives to any proposed intervention.[1038] The position of the law on PVS applies this requirement and makes it

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[1033] [2005] EWCA CIV 1003.

[1034] *Airedale NHS Trust v Bland* [1993] A.C. 789 [890].

[1035] Ben White and others, 'What does "futility" mean? An empirical study of doctors' perceptions' (2016) 204(8) MJA <https://mja.com.au/journal/2016/204/8/what-does-futility-mean-empirical-study-doctors-perceptions> accessed 2 June 2021.

[1036] An NHS Trust and others (Respondents) v Y (by his litigation friend, the Official Solicitor) and another (Appellant) (2018) UKSC 46.

[1037] Benjamin Davies, 'Responsibility and the limits of patient choice' (2019) 34(5) Bioethics <https://doi.org/10.1111/bioe.12693> accessed 15 June 2021.

[1038] Daniel Hall and others, 'Informed consent for clinical treatment' (2012) 184(5) Canadian Medical Association journal <https://doi.org/10.1503/cmaj.112120> accessed 25 May 2021.

mandatory that patients consent to any medical intervention for their conditions.[1039] However, patients in the PVS cannot give consent, at least as far as we know today. As such, the best interest's standard is the minimum requirement for any intervention given or withheld.[1040] The advances in science have increased the complexity of medical cases going to Court these days, and consequently, there is a greater move towards patient autonomy. The enactment of the HRA 1998 has stimulated a move away from medical paternalism and protects fundamental human rights.[1041] Although professional bodies are trying to clarify relevant issues by publishing guidelines and guidance, the Courts remain the final arbitrator in these cases.

The legal development through the various Court cases posits that the treatments that aim to prolong patients' lives but fail to benefit them will not be in their best interests.[1042] It is not against the law to discontinue life-prolonging treatment in these patients if there is no dispute between the parties involved. The position, however, does not in any way make the discontinuation mandatory. The law in the UK now does not require the Court's involvement in every instance of determining whether to withdraw treatment.[1043] Presently, the Courts are only involved if there is a controversy between the involved parties. In cases where all the parties involved agreed on the individual's best interests and the healthcare professions have followed all the prevailing professional guidelines, the doctors can withdraw the treatment without having to consult the Court.[1044]

[1039] Richard Huxtable, *Law, ethics, and compromise at the limits of life: to treat or not to treat?* (Routledge, 2012).

[1040] British Medical Association, *Withholding and withdrawing life-prolonging medical treatment: guidance for decision making* (John Wiley & Sons, 2008).

[1041] Human Rights Act 1998.

[1042] Ibid.

[1043] Jill Manthorpe and others, 'Early days': knowledge and use of the Mental Capacity Act 2005 by care home managers and staff' [2011] 10(3) Dementia < https://doi.org/10.1177/1471301211403970> accessed 11 May 2021.

[1044] An NHS Trust and others (Respondents) v Y (by his litigation friend, the Official Solicitor) and another (Appellant) [2018] UKSC 46.

Various professional bodies have issued guidance on the issues around treatment options for PVS patients. However, these documents have only echoed legal judgments especially the ones in *Bland*. It is interesting that rather than having guidance based on balanced ethical arguments we tend to see an extension of Court rulings. The GMC oversees the activities of all doctors in the UK. The Council publishes guidance and guidelines on how to make decisions to withdraw and withhold treatment in incapable patients like the PVS. It also published a related document on '*end-of-life care*' in 2010. The BMA also published a '*guidance on withholding and withdrawing life-prolonging medical treatment'* which gave a more comprehensive guidance for doctors.[1045] Notably, there has been criticism of the publication. John Keown said that the argument given in the guidance about tube feeding being a medical treatment is weak and that the reason given for not treating or tube-feeding PVS patients, severely demented patients, and the ones with serious stroke, undermines BMA's position against euthanasia and assisted suicide.[1046] Lastly, he said that the guidance heavily relied on legal precedence rather than ethical reasoning.[1047] There are a few ethical issues that the guidance has incoherently tried to unravel such as the issue of passive euthanasia versus withholding and withdrawing treatment in PVS patients. While the former is killing a life that is adjudged worthless, the latter is stopping a treatment that is adjudged worthless. There is no grounded explanation on why withdrawing and withholding life-saving interventions are ethically the same. What about starving a patient to death by withdrawing CAHN? How is this different from injecting a lethal substance to a patient as seen in *Cox*[1048] or other cases of mercy killing?[1049]

[1045] British Medical Association, *Withholding and withdrawing life-prolonging medical treatment: guidance for decision-making* (3rd edn, Blackwell publishing 2007).

[1046] John Keown, 'Beyond Bland: a critique of the BMA guidance on withholding and withdrawing medical treatment' [2006] 20(1) legal Studies <https://doi.org/10.1111/j.1748-121X.2000.tb00133.x> accessed 22 June 2021.

[1047] Ibid.

[1048] R v Cox (1992) 12 BMLR 38.

[1049] R v Dr Bodkins *Adams [*1957] Crim LR 365.

The law and professional guidelines significantly interact to shape the legal development to what we see today. After *Bland,* the BMA published its guidance on treatment withdrawal in PVS patients. However, the guidance mainly endorses the ruling. Notably, the Lords took a cautious approach in delivering the judgment by limiting it to PVS patients only. When the 1999 edition of the document came out, the guidance was extended to patients with severe dementia and catastrophic stroke. This potentially set up a 'slippery slope' phenomenon since the Court always relies on a 'responsible body of medical opinion' like BMA; we risk being trapped in a vicious circle. On the other hand, if the professional guidance is clear, well-articulated, and grounded in ethical and moral principles, which is why it will help in tackling many of the never-ending issues. Where the treating doctors adhere to the available professional guidelines, they are unlikely to be culpable of any criminal or tort of negligence charges.[1050] The law, permitting termination of treatment without the involvement of the Courts makes it mandatory that the treating physician must adhere to all the prevailing professional guidelines. The position of the law is therefore that even if all the parties agree on withdrawing life-sustaining intervention, the act cannot be lawful unless the treating physician adheres to the prevailing professional guidelines.[1051] The same requirement for strict adherence to professional guidelines is also held by policies issued by various policy groups that review the professional guidelines on the treatment of individuals in PVS.

Impacts of Policy and Governance on the Practice of Treatment Withholding and Withdrawing for Patients in PVS

Patients in PVS need to be kept alive through artificial nourishment and other treatments. However, there have been many concerns raised regarding whether the physicians and family members of patients in this state should continue the pursuit of such treatments to maintain the

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[1050] *Bolitho v City and Hackney Health Authority* [1998] AC 232.

[1051] Ibid.

patient's permanently unconscious existence. These concerns have led to lawsuits, the rulings of which have informed the development of legal policy and governance guidelines that have had a significant impact on the practice of withholding or withdrawing interventions from these patients. The legal position on the treatment of patients in PVS has had various impacts on the practice and governance of management of these patients. The first impact of this policy has been to reduce the complexity of the process involved in allowing these patients to die when it is agreed that such a step would be in their best interests. In the early days when the legal position on this matter was not clear, patients would be kept in PVS for years through treatment, even when there was evidence that they would themselves not want their lives to be prolonged in such states. Even when the patient's family and surrogates agreed that the treatments needed to be terminated, they still had to apply through the Court before treatments are terminated. This however changed with the recent Court cases and the formulation of the policy that guides withdrawal of treatment for such patients.[1052] As a result, the process of withdrawing treatment for PVS patients has been made easier since Court determination is only sought when there is a disagreement between the concerned parties.

Policy and governance have also reduced the criticism of the practice of forgoing or ceasing treatment in PVS patients. In the past, the practice was heavily criticised since the legal position on the matter was not very clear, even to physician themselves. However, policy and governance stemming particularly from the decisions of judges hearing cases on this matter have brought light to the arguments. With criticism for the practice of withdrawal or withholding treatment for patients in PVS reduced and the process made easier, the practice has significantly increased in popularity. The NHS does not publish data on the number of patients in PVS under its care. However, rough estimate figures obtained from professionals

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[1052] Huxtable (n 1039).

working with the NHS indicate that there could be thousands of such patients on whom the NHS spends millions. Healthcare professionals admit that the number of patients in this state is on the rise. Contrary to the situation two decades ago when they would apply for Court determination before withdrawing treatment, physicians now rely solely on the consent of the family or surrogates of the patient to terminate treatment.

4.6. Conclusion

In conclusion, the discussions about the patient in the PVS have dominated bioethical and medical law debates. Various medical groups around the United Kingdom, such as the British Medical Association, have adopted clear policy statements regarding decision-making in PVS. The law, particularly concerning medicine, is faced with adapting to technological and scientific innovations. This clash between the law and therapeutic advances has been largely witnessed in the cases where many believed that more could be done with the avalanche of biotechnology available today. From the early 1970s, when the diagnostic category of PVS was developed, legal systems in the United Kingdom as elsewhere have to contend with some of the hardest issues ever raised in the history of medical law. One of these questions, which form part of the focus of this paper, has been whether we are doing enough to protect these patients from practices like the termination of the life-sustaining treatments in PVS patients. From the analysis of the cases above, it is evident that English law has undergone significant legal developments regarding its view on forgoing or ceasing treatments in patients with PVS labels. The law has seen significant developments in this regard, from the development of the requirement that cases of treatment withdrawal should be presented before a Court for determination to the introduction of the MCA and finally the withdrawal of the CoP’s Practice Direction 9E, which mandated the Court’s involvement in such cases. The principles used to inform the various judgments also exhibit some internal inconsistencies and incongruence with the broader doctrines underpinning them. While some would say that the law is fit for purpose, others will argue that there is still a lot to be done to adequately safeguard these subsets of people in our society, in this case, PVS/MCS. PVS patients do not meet the capacity threshold prescribed by the MCA 2005 under their limitation in function due to the disruption in the normal brain function. Therefore, the law and medical practice should go far and beyond to ensure that all that is to be done is done to protect them from unfair and unjust practices.

CHAPTER FIVE

An empirical study of healthcare professional's view on the management of PVS patients under English law.

5.1. Introduction

This chapter discusses the empirical aspect of this thesis which analyses the views of healthcare professionals on the issues raised in the earlier chapters. These are issues around diagnosis, prognosis, and care of patients diagnosed with PVS. In addition, issues around recovery, artificial nutrition, withdrawal of treatments and the process of withdrawal are also explored. The exploration was done by using a structured questionnaire to gather information about the healthcare professionals' perspectives on these issues. The data obtained were analysed and used to test the research hypotheses. A mixed-method that integrates the quantitative and the qualitative data obtained from the closed-ended and open-ended questions in the questionnaire was used to obtain a holistic understanding of these issues. While several questions were asked and explored, the three main research questions of the empirical aspect of this thesis are:

1. Is PVS a valid concept?
2. Is there any relationship between accuracy of diagnosis and the way PVS patients are treated?
3. Does the UK law adequately protect individuals diagnosed as in a PVS?

5.2. Data Collection and analysis

The questionnaire used for the survey was a four-page document, which contained questions on demographics, and 30 questions divided over three vignettes covering the three main issues highlighted above. After designing the questionnaire, it was sent to the Nottingham Trent University Research Ethics Committee for approval. A consent form and participant information sheet were also designed to give the respondents information on the study and tell them about their rights (see appendix). The questionnaire has three hypothetical scenarios followed by questions on the scenarios. The first scenario was about acknowledging PVS as a clinical state and the controversy around making a diagnosis of PVS. This section was intended to collect the respondents' opinions on the definition of VS, determination of persistence, pain/hunger perception, reversibility, disability and end-of-life issues as they relate to PVS. These questions were used to test the associations between diagnosis of PVS and technological modalities, the associations between diagnosis and clinical state and associations between disability and end of life.

The second scenario was about determining permanence in VS patients. This section asked about the reliability of timeframes in PVS. In addition, whether the healthcare professionals think that late recovery in PVS is due to misdiagnosis *ab initio* or whether the patients recovered from the initial insult. Lastly, it asked about the appropriate terminology to describe VS (persistent or permanent) and whether they believe that withdrawing CAHN shortens life. These questions were used to find associations between diagnosis, misdiagnosis and treatment of PVS. The third scenario was about treatment withdrawal and the withdrawal process. There are questions about whether withholding and withdrawing interventions are in the patients' best interests or if the respondents agree that these patients do not have interests. These questions were used to determine any associations between these actions and their best interests. There are also questions on morals, ethics and human rights relating to how PVS patients are managed. These questions were used to find out if there are any associations with these variables. Finally, all these vignettes were used to determine associations between the protection the law in the UK gives to PVS patients and the perception of the condition, whether or not it is a real clinical state.

Analysis of the empirical data

1. Issues around diagnosis, prognosis and care of PVS patients.

This section analyses the responses to the survey on the diagnosis of PVS. Ninety-six responses were obtained from the distributed questionnaires containing a hypothetical scenario divided into three headings. The first heading of the scenario was carefully written to mimic the issues highlighted in chapter two. There were ten closed-ended questions (Q1 –Q10a) and one open-ended question (Q10b). The closed-ended questions were analysed using IBM SPSS statistics software, while the open-ended question (Q10b) was analysed using the thematic qualitative analysis method. These analyses were used to answer the first main research question: **Is PVS a valid concept?**

The tables below display the respondents' demographics (age, profession and area of practice). Table 1a shows the number of respondents who filled the question on age and the number who omitted the question. Table 1b shows the age distribution of the respondents. Table 2a shows the number of responses to the question on profession and the number of missing answers, while table 2b shows the statistical distribution of their professions. Table 3a shows the number of respondents who answered the question on the practice area versus missing answers. Table 3b shows the statistical distribution of the area of practice. Lastly, Table 4 shows the statistical distribution of all the above demographical data obtained in this study.

N	Valid	89
	Missing	7

Table 1a: Number of responses to the question on age.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	21-30	28	29.2	31.5	31.5
	31-40	26	27.1	29.2	60.7
	41-50	29	30.2	32.6	93.3
	51-60	5	5.2	5.6	98.9
	61-71	1	1.0	1.1	100.0
	Total	89	92.7	100.0	

Table 1b: Statistics of the age distribution.

Statistics

Profession

N	Valid	90
	Missing	6

Table 2a: Number of responses to the question on profession.

Profession

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Doctor	61	63.5	67.8	67.8
	Nurse	27	28.1	30.0	97.8
	Health care assistant	2	2.1	2.2	100.0
	Total	90	93.8	100.0	

Table 2b: statistics of the profession of the respondents.

N	Valid	90
	Missing	6

Table 3a: Number of responses to the question on area of practice.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Anaesthetics	27	28.1	30.0	30.0
	Medicine	56	58.3	62.2	92.2
	A&E	2	2.1	2.2	94.4
	Others	5	5.2	5.6	100.0
	Total	90	93.8	100.0	

Table 3b: Statistics on the area of practice.

	N	Minimum	Maximum	Mean	Std. Deviation
Age	89	2.00	6.00	3.1573	.97583
Profession	90	1.00	3.00	1.3444	.52277
Area of practice	90	1.00	4.00	1.8333	.72282
Valid N (listwise)	89				

Table 4: Descriptive Statistics of the demographics.

Results

Heading 1: Acknowledging PVS as a clinical state and making a diagnosis

… 'Mr XY was involved in an accident while playing rugby; he became unconscious and was admitted to the intensive therapy unit, where he was stabilised. After a few weeks, he was noticed to be in a state of partial arousal but unaware of his immediate environment. He was subsequently deemed to have lost his higher cortical brain function but still has an intact brainstem'…

This vignette was used to answer questions 1 to 10, and below are the questions and the responses given.

Q1. Mr XY can be said to be in a vegetative state.

The first question (Q1) was about acknowledging VS as a clinical state. Opinions can be divided on the timeframe, although the scenario only described the features of the condition without any timeframe. Some researchers argued that what characterises the condition is partial wakefulness with no awareness of the environment.[1053] This study shows that 70.84% (n - 96) of the respondents agreed with the definition of VS, while 21.9% (n - 96) disagreed with the statement. 8.3% (n - 96) of the respondents neither agreed nor disagreed with the definition (see table 5b). Based on this finding, it is reasonable to conclude that the description of VS is clear to healthcare professionals.

N	Valid	96
	Missing	0

Table 5a: Total response to Q1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	9	9.4	9.4	9.4
	Disagree	10	10.4	10.4	19.8
	Somewhat disagree	2	2.1	2.1	21.9
	Neither agree nor disagree	8	8.3	8.3	30.2
	Somewhat agree	24	25.0	25.0	55.2
	Agree	22	22.9	22.9	78.1
	Strongly agree	21	21.9	21.9	100.0
	Total	96	100.0	100.0	

Table 5b: Response to the question on diagnosis of VS (Q1)

Q2. If Mr XY remains in this state for 12 months, he can be labelled as been in persistent vegetative state

Question two (Q2) was about diagnosing PVS based on timeframes. The guideline states that when a VS persists for more than six months (for non-trauma aetiology) and twelve months (for traumatic aetiology), the patient can be labelled 'PVS'.[1054] The results showed that many healthcare professionals seemed to agree with the twelve months timeframe in traumatic aetiology 75% (n - 96). Although a handful of them disagreed with this timeframe, 15.6% (n -

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[1053] Caroline Schnakers and Steven Laureys, Coma and disorders of consciousness (2nd edn, Springer International Publishing 2018) 4-6.

[1054] Joseph Giacino and Kathleen Kalmar, 'Diagnostic and prognostic guidelines for the vegetative and minimally conscious states' [2005] 15(3-4) Neuropsychologic Rehabilitation <https://doi.org/10.1080/09602010443000498> accessed 25 May 2021.

96) and 9.6% (n - 96) neither agreed nor disagreed (see table 6b). It is not surprising to see that majority of the respondents agreed with the status quo.

N	Valid	96
	Missing	0

Table 6a: Total response to Q2.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly agree	5	5.2	5.2	5.2
	Disagree	6	6.3	6.3	11.5
	Somewhat disagree	4	4.2	4.2	15.6
	Neither agree nor disagree	9	9.4	9.4	25.0
	Somewhat agree	12	12.5	12.5	37.5
	Agree	32	33.3	33.3	70.8
	Strongly agree	28	29.2	29.2	100.0
	Total	96	100.0	100.0	

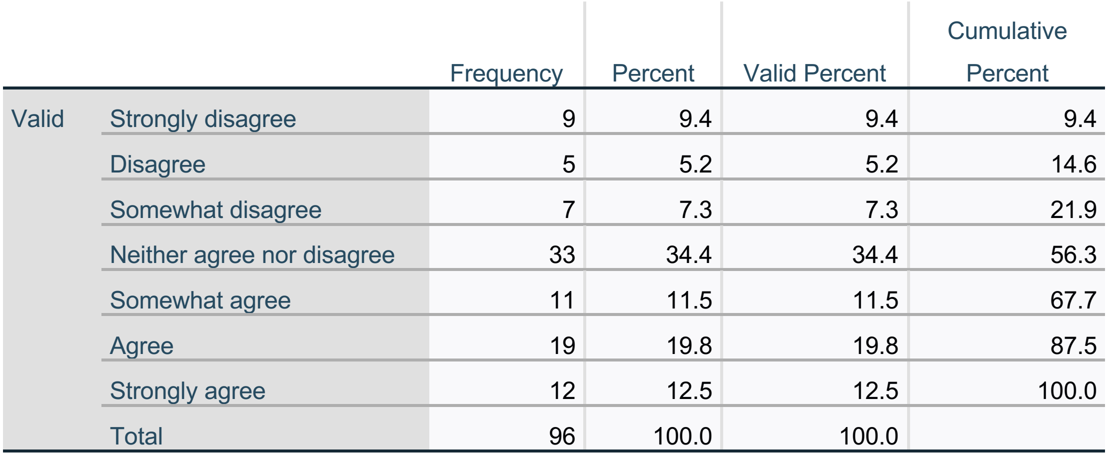
Table 6b: Response to the question on diagnosis of PVS of traumatic aetiology (Q2).

Q3. If Mr XY's cause of brain injury is non-traumatic, 6 months is enough to label him as being in persistent vegetative state.

In question three (Q3), even though more respondents agreed with the six months timeframe for defining PVS in a non-traumatic aetiology, the percentage is significantly less than the one for the traumatic aetiology seen in Q2, i.e. 44.21% (n-96). It seems that the remaining respondents chose to sit on the fence on this one (34.4% neither agree nor disagree with this), while 21.9% (n - 96) disagreed with the statement (see table 7b).

N	Valid	96
	Missing	0

Table 7a: Total response to Q3



		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	9	9.4	9.4	9.4
	Disagree	5	5.2	5.2	14.6
	Somewhat disagree	7	7.3	7.3	21.9
	Neither agree nor disagree	33	34.4	34.4	56.3
	Somewhat agree	11	11.5	11.5	67.7
	Agree	19	19.8	19.8	87.5
	Strongly agree	12	12.5	12.5	100.0
	Total	96	100.0	100.0	

Table 7b: Response to the question on diagnosis of PVS of non-traumatic aetiology (Q3).

Q4. Even though Mr XY is unaware of the environment, he may still be able to feel pain or get hungry.

Question four (Q4) is about the contentious issue of whether or not these patients can respond to some basic physiological stimuli like hunger and pain. External stimuli like pain could well discredit the assertion that they are unaware of their surroundings since responding to pain is part of the criteria when assessing GCS. Only 6.3% (n - 95) of the respondents disagreed with this assertion while, 7.4% (n - 95) neither agreed nor disagreed with the statement. However, 86.3% (n - 96) of the respondents agreed with the statement. This finding raises a very important question of how ethical it would be to forgo or cease nutrition from patients in PVS, no matter what the argument for doing this might be (see table 8b).

N	Valid	95
	Missing	1

Table 8a: Total response to Q4

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	1	1.0	1.1	1.1
	Disagree	4	4.2	4.2	5.3
	Somewhat disagree	1	1.0	1.1	6.3
	Neither agree nor disagree	7	7.3	7.4	13.7
	Somewhat agree	11	11.5	11.6	25.3
	Agree	38	39.6	40.0	65.3
	Strongly agree	33	34.4	34.7	100.0
	Total	95	99.0	100.0	

Table 8b: Response to the question on the ability of PVS patient to feel pain and hunger (Q4)

Q5. Mr XY may never recover from this state after 12 months.

Question five (Q5) is still on the assumption of permanence of the VS after twelve months. This criterium is the basis for the definition of PVS, and it seems that most of the decisions on life-sustaining interventions rely on this assumption.[1055] Interestingly, around 27% (n - 96) of the respondents neither agree nor disagree with this statement. Nonetheless, almost 60% (n - 96) agreed with the statement and only 13.5% (n - 96) of the respondents disagreed with the statement (see table 9b).

N	Valid	96
	Missing	0

Table 9a: Total response to Q5

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	7	7.3	7.3	7.3
	Disagree	3	3.1	3.1	10.4
	Somewhat disagree	3	3.1	3.1	13.5
	Neither agree nor disagree	26	27.1	27.1	40.6
	Somewhat agree	12	12.5	12.5	53.1
	Agree	25	26.0	26.0	79.2
	Strongly agree	20	20.8	20.8	100.0
	Total	96	100.0	100.0	

Table 9b: Response to the question on recovery from PVS after 12 months (Q5).

[1055] Multi-society Task Force on PVS (n 9).

Q6. Mr XY may be considered as being severely disabled.

Some may consider VS/PVS/MCS patients severely disabled and treated as such. Although the 'disabled' designation does not give them more legal rights than a dying patient, if treated as approaching end-of-life, some practices like CAHN would be tolerated.[1056] Question six (Q6), therefore, looked at the response to this assertion. Notably, 85.2% (n – 95) of the respondents agreed that these individuals are severely disabled, while 8.4% (n – 95) disagreed with the statement. 6.3% (n – 95) of the respondents neither agreed nor disagreed (see table 10b).

N		
	Valid	95
	Missing	1

Table 10a: Total response to Q6

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	7	7.3	7.4	7.4
	Somewhat disagree	1	1.0	1.1	8.4
	Neither agree nor disagree	6	6.3	6.3	14.7
	Somewhat agree	6	6.3	6.3	21.1
	Agree	23	24.0	24.2	45.3
	Strongly agree	52	54.2	54.7	100.0
	Total	95	99.0	100.0	

Table 10b: Response to the question on whether PVS patients could be considered as being severely disabled (Q6).

Q7. Mr XY may be considered as approaching the end of his life.

Question seven (Q7) focused on whether these patients can be treated as if they are approaching the end of life. If so, it may be that some of the end-of-life practices might apply to them, and it may be that the family and the public could be more amenable to the decisions that can lead to the patient's demise. Perhaps palliative care could be something to consider. 41.5% (n – 94) of the respondents disagreed with this statement, while 31% agreed with the statement (see table 11b).

[1056] Joseph Fin and others, 'Late recovery from the minimally conscious state: ethical and policy implications' (2007) 68(4) Neurology <https://doi.org/10.1212/01.wnl.0000252376.43779.96> accessed 23 May 2021.

N	Valid	94
	Missing	2

Table 11a: Total response to Q7

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	17	17.7	18.1	18.1
	Disagree	16	16.7	17.0	35.1
	Somewhat disagree	6	6.3	6.4	41.5
	Neither agree nor disagree	25	26.0	26.6	68.1
	Somewhat agree	14	14.6	14.9	83.0
	Agree	8	8.3	8.5	91.5
	Strongly agree	8	8.3	8.5	100.0
	Total	94	97.9	100.0	

Table 11b: Response to the question on whether PVS patients could be considered as approaching end of life (Q7).

Q8. Mr XY may be aware of his environment, but the technological modalities cannot detect this awareness.

Question eight explored the possibility of the patient being conscious. The inability to detect consciousness by clinical examination and thorough investigations does not necessarily mean it is not there. 61% (n – 95) of the respondents believed this was possible, while 13.7% (n – 95) of the respondents disagreed with the statement. (See table 12b).

N	Valid	95
	Missing	1

Table 12a: Total response to Q8

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	4	4.2	4.2	4.2
	Disagree	3	3.1	3.2	7.4
	Somewhat disagree	6	6.3	6.3	13.7
	Neither agree nor disagree	24	25.0	25.3	38.9
	Somewhat agree	15	15.6	15.8	54.7
	Agree	29	30.2	30.5	85.3
	Strongly agree	14	14.6	14.7	100.0
	Total	95	99.0	100.0	

Table 12b: Response to the question on whether PVS patients have awareness that may not be detected by available technology (Q8).

Q9. The diagnosis may not be PVS (it could be any other form of PDoC)

Given that there have been issues with misdiagnosis in the literature,[1057] this question (Q9) sought to determine whether the clinical syndrome of PVS might not be what it is generally believed to be. The responses showed that 47.9% (n – 94) of the respondents felt that the diagnosis might not be PVS, while 20.2% (n – 94) thought it was unlikely that the diagnosis is another form of PDoC (see table 13b). This finding echoes the plethora of research on misdiagnosis in PDoC patients.

N	Valid	94
	Missing	2

Table 13a: Total response to Q9

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	3	3.1	3.2	3.2
	Disagree	7	7.3	7.4	10.6
	Somewhat disagree	9	9.4	9.6	20.2
	Neither agree nor disagree	30	31.3	31.9	52.1
	Somewhat agree	19	19.8	20.2	72.3
	Agree	15	15.6	16.0	88.3
	Strongly agree	11	11.5	11.7	100.0
	Total	94	97.9	100.0	

Table 13b: Response to the question on the possibility of misdiagnosing a patient with PVS (Q9).

Q10. A Persistent vegetative state is a real clinical state.

The question of whether PVS is a real clinical state was asked in a closed-ended format, and then an open-ended follow-on question was asked on why the respondent believed that it is a real clinical state or otherwise. The response to the first part of the question is highlighted in table 14b below. The response showed that 73.7% (n – 95) of the respondents believed that PVS is a real clinical state, while only 11.6% disagreed with this statement (see table 14b).

N	Valid	95
	Missing	1

Table 14a: Total response to Q10.

[1057] Chandler and others (n 755).

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	3	3.1	3.2	3.2
	Disagree	5	5.2	5.3	8.4
	Somewhat disagree	3	3.1	3.2	11.6
	Neither agree nor disagree	14	14.6	14.7	26.3
	Somewhat agree	6	6.3	6.3	32.6
	Agree	41	42.7	43.2	75.8
	Strongly agree	23	24.0	24.2	100.0
	Total	95	99.0	100.0	

Table 14b: Response to the question on whether PVS is a real clinical state (Q10).

The response rate to the follow-up question to Q10 is comparatively low at 38. This figure reflects that response rates are generally lower for open-ended questions compared to multiple-choice ones. The response was analysed using the thematic qualitative analysis later in the analysis section below.

Analysis

The analysis of the above data will be presented in two ways. The descriptive analysis of the response to the questions (see figure 1, tables 15 and 21) and then a Spearman's rank-order correlation (tables 16 to 20) calculates a coefficient rs or p (rho) of the data. Spearman's rank-order correlation, in statistical terms, measures the strength and direction of the association between two variables. In order to use Spearman's correlation for analysis, the data should pass at least two of the three assumptions (i.e. assumption I & 2 +/- assumption 3).[1058] Assumption 1 is that the data must have two continuous or ordinal variables. Assumption 2 is that the two variables should represent paired variables, while assumption 3 is that the relationship between the variables should be monotonic. The data in this study passed the first two assumptions, but the scatterplot graph did not show a monotonic relationship between the variables. In any case, since this is not an essential criterion, Spearman correlation will still be

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[1058] Carl Spearman, 'The proof and measurement of association between two things' (2010) 39(5) International Journal of Epidemiology <https://doi.org/10.1093/ije/dyq191> accessed 22 October 2020.

appropriate to demonstrate whether there are any associations between these paired variables.[1059] Table 15 below shows the descriptive statistics of the response to questions 1 to 10. The formula represents the null hypothesis to be tested: $H0: \rho = 0$, the correlation coefficient is equal to zero in the population.[1060] At the end of the analysis in this section, there would be a descriptive analysis of Q26, which asked whether PVS is a valid concept.

Descriptive Statistics

	N	Minimum	Maximum	Mean	Std. Deviation
Q1	96	1	7	4.85	1.930
Q2	96	1	7	4.43	1.734
Q3	96	1	7	5.34	1.752
Q4	95	1	7	5.83	1.334
Q5	96	1	7	4.96	1.722
Q6	95	1	7	5.96	1.682
Q7	94	1	7	3.63	1.878
Q8	95	1	7	4.96	1.543
Q9	94	1	7	4.53	1.522
Q10	95	1	7	5.42	1.582
Valid N (listwise)	91				

Table 15: The descriptive statistics of the response to questions 1 to 10.

Null hypothesis 1: There is no relationship between VS diagnosis and the idea that PVS is a real state.

Analysis: A Spearman's rank-order correlation analysis was done to assess the relationship between making a VS diagnosis and viewing PVS as a real clinical state. Table 16 below shows

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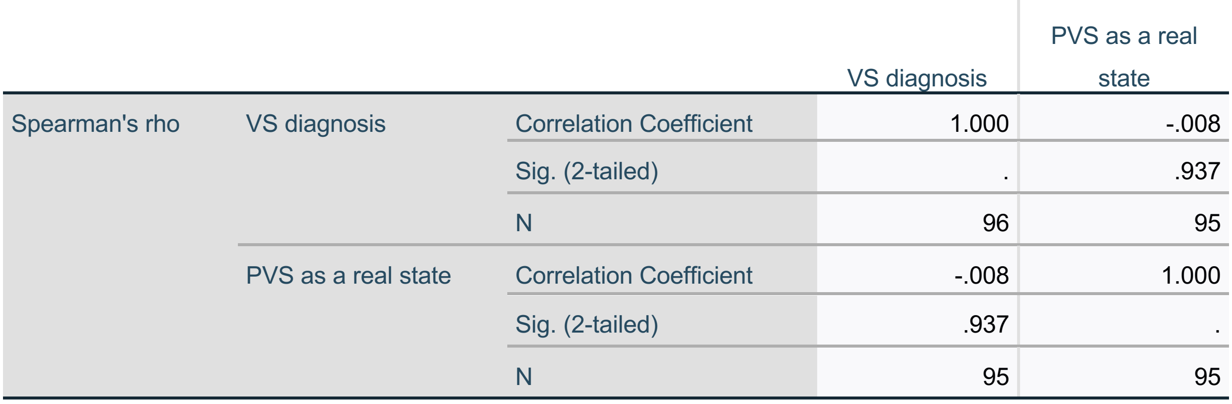
[1059] David Sheskin, Handbook of parametric and nonparametric statistical procedures (5th edn, Chapman and Hall/CRC 2011).

[1060] Where ρ (rho) is the population correlation coefficient and H_0 is the null hypothesis.

that the Spearman coefficient (r_s) is -.008, which means a negative correlation between these two variables. The two-tailed significance level (p-value) of the correlation coefficient is .937 (i.e., $p > .05$).

Conclusion: Spearman's correlation was not statistically significant; therefore, we cannot reject the null hypothesis and cannot accept the alternative hypothesis. Therefore, there was no statistically significant correlation between VS diagnosis and viewing PVS as a real clinical state, $rs(93) = -.008, p = .937$.



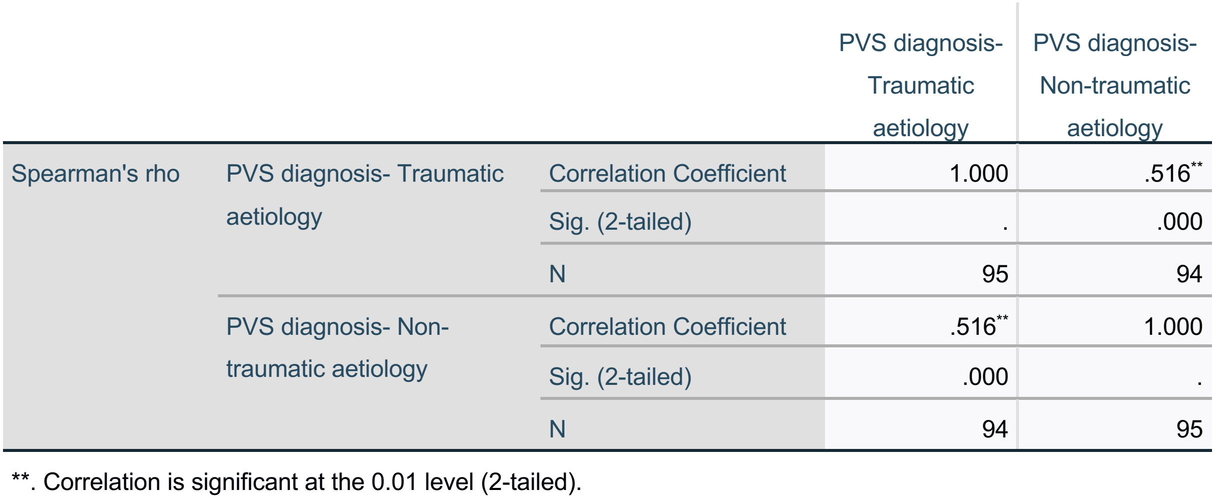
			VS diagnosis	PVS as a real state
Spearman's rho	VS diagnosis	Correlation Coefficient	1.000	-.008
		Sig. (2-tailed)	.	.937
		N	96	95
	PVS as a real state	Correlation Coefficient	-.008	1.000
		Sig. (2-tailed)	.937	.
		N	95	95

Table 16: Spearman correlation between VS diagnosis and PVS as a real state.

Null hypothesis 2: No relationship exists between traumatic and non-traumatic aetiology when diagnosing PVS.

Analysis: A Spearman's rank-order correlation analysis was run to assess the relationship between traumatic and non-traumatic aetiology in PVS patients. Table 17 below shows that the Spearman coefficient (rs) is .516 and the two-tailed significance level (p-value) of the correlation coefficient is .000 (i.e., $p < .05$).

Conclusion: Spearman's correlation was statistically significant; therefore, we can reject the null hypothesis and accept the alternative hypothesis. Therefore, there was a statistically significant correlation between the two acquired aetiologies of PVS, $rs\ (92) = -.008, p = .000.$



			PVS diagnosis- Traumatic aetiology	PVS diagnosis- Non-traumatic aetiology
Spearman's rho	PVS diagnosis- Traumatic aetiology	Correlation Coefficient	1.000	.516**
		Sig. (2-tailed)	.	.000
		N	95	94
	PVS diagnosis- Non-traumatic aetiology	Correlation Coefficient	.516**	1.000
		Sig. (2-tailed)	.000	.
		N	94	95

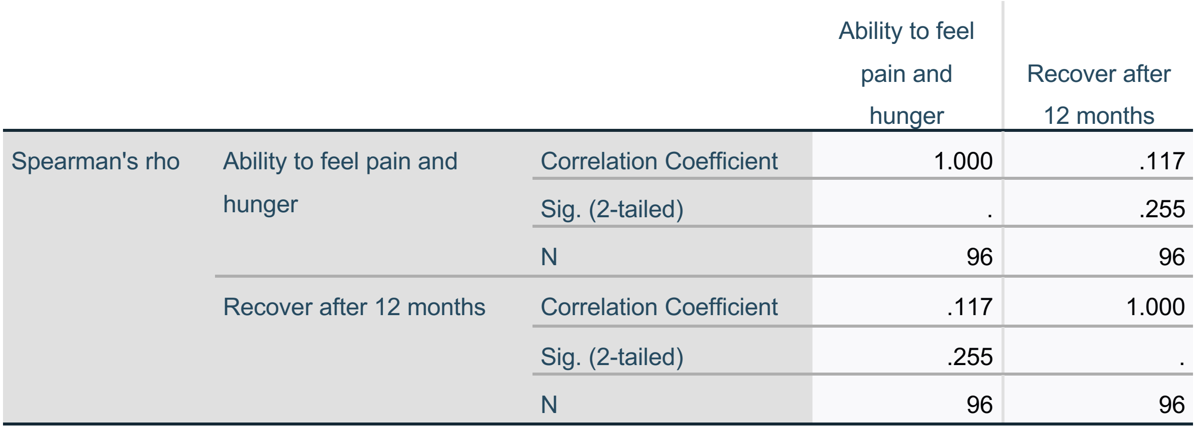
**. Correlation is significant at the 0.01 level (2-tailed).

Table 17: Spearman correlation between traumatic and non-traumatic aetiology in PVS patient.

Null hypothesis 3: There is no relationship between sentience ability in PVS patients and recovery after 12 months of diagnosis.

Analysis: A Spearman's rank-order correlation was run to assess the relationship between sentience in PVS patients and recovery after 12 months of diagnosis. Table 18 below shows that the Spearman coefficient (*rs)* is .117, which is a positive correlation. However, the two-tailed significance level (p-value) of the correlation coefficient is .255 (i.e., $p > .05$).

Conclusion: Spearman's correlation was not statistically significant; therefore, we cannot reject the null hypothesis and cannot accept the alternative hypothesis. Therefore, there was no statistically significant correlation between the ability to feel pain and hunger in PVS patients and recovery after 12 months of diagnosis, *rs(94) = .117, p = .255.*



			Ability to feel pain and hunger	Recover after 12 months
Spearman's rho	Ability to feel pain and hunger	Correlation Coefficient	1.000	.117
		Sig. (2-tailed)	.	.255
		N	96	96
	Recover after 12 months	Correlation Coefficient	.117	1.000
		Sig. (2-tailed)	.255	.
		N	96	96

Table 18: Spearman correlation between ability to feel pain and hunger in PVS patients and recovery after 12 months of diagnosis.

<u>Null hypothesis 4:</u> There is no relationship between seeing PVS as disabled and being considered to be approaching the end of life.

<u>Analysis:</u> A Spearman’s rank-order correlation was run to assess the relationship between seeing PVS as being disabled and being considered as approaching the end of life. Table 19 below shows that the Spearman coefficient (*rs)* is -.015, which is a negative correlation between these two variables, and the two-tailed significance level (p-value) of the correlation coefficient is .887 (i.e., $p > .05$).

<u>Conclusion:</u> Spearman’s correlation was not statistically significant; therefore, we cannot reject the null hypothesis and cannot accept the alternative hypothesis. Therefore, there was no statistically significant correlation between seeing PVS as being disabled and being considered as approaching the end of life, $rs(91) = -.015, p = .887$.

			PVS considered disabled	PVS considered approaching EOL
Spearman's rho	PVS considered disabled	Correlation Coefficient	1.000	-.015
		Sig. (2-tailed)	.	.887
		N	95	92
	PVS considered approaching EOL	Correlation Coefficient	-.015	1.000
		Sig. (2-tailed)	.887	.
		N	92	93

Table 19: Spearman correlation between seeing PVS as being disabled and being considered as approaching end of life.

<u>Null hypothesis 5:</u> There is no relationship between the inability of technology to detect consciousness and the misdiagnosis of PVS.

<u>Analysis:</u> A Spearman’s rank-order correlation was run to assess the relationship between the inability of technology to detect consciousness and misdiagnosis of PVS. Table 20 below shows that the Spearman coefficient (*rs)* is .206 and the two-tailed significance level (p-value) of the correlation coefficient is .046 (i.e., $p < .05$).

Conclusion: Spearman's correlation was statistically significant; therefore, we can reject the null hypothesis and accept the alternative hypothesis. Therefore, there was a statistically significant correlation between the inability of technology to detect consciousness and misdiagnosis of PVS, *rs(92) = -.206, p = .046.*

			Inability of technology to detect consciousness	Misdiagnosis
Spearman's rho	Inability of technology to detect consciousness	Correlation Coefficient	1.000	.206*
		Sig. (2-tailed)	.	.046
		N	95	94
	Misdiagnosis	Correlation Coefficient	.206*	1.000
		Sig. (2-tailed)	.046	.
		N	94	94

*. Correlation is significant at the 0.05 level (2-tailed).

Table 20: Spearman correlation between the inability of technology to detect consciousness and the misdiagnosis of PVS.

Lastly, a question was asked on whether PVS is considered a valid concept or not. Below are the descriptive statistics on the response to the question. Figure 1 below is a bar chart of the response. 88.9% (n – 81) of the respondents agreed that PVS is a valid concept, while 11.1% (n – 81) disagreed with the statement.

N	Valid	81
	Missing	15
Mean		1.1111
Median		1.0000
Mode		1.00
Sum		90.00

Table 21: Descriptive statistics on the question: PVS a valid concept

PVS a valid concept

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	72	75.0	88.9	88.9
	No	9	9.4	11.1	100.0
	Total	81	84.4	100.0	
Missing	System	15	15.6		
Total		96	100.0		

Table 22a: Frequency table for question 10

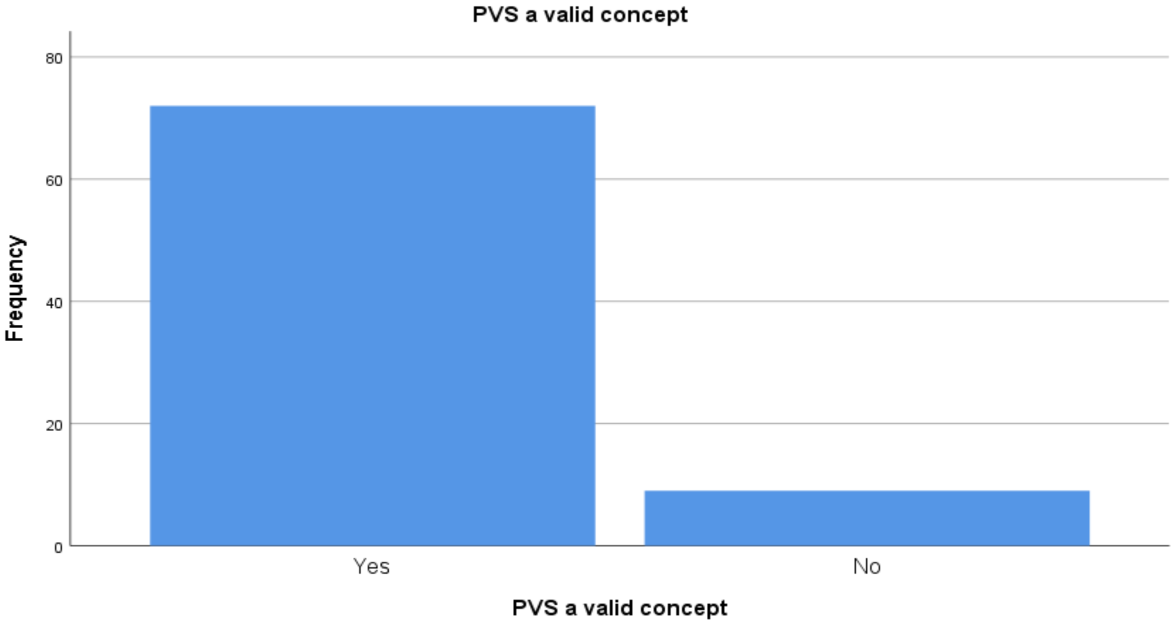


Figure 1: Bar chat for question 27

A follow-on question was asked on why the respondents agreed or disagreed with the assertion that PVS is a valid concept.

<u>Thematic analysis of responses to Q10b.</u>

This section is the qualitative analysis of why the participants believed that PVS is a real clinical state. The table below shows the questions' responses' themes and properties.

How PVS is diagnosed.	**Disordered process associated with PVS.**	**The knowledge of the condition.**	**Manifestations of the condition.**
Clinical diagnosis. Clinical syndrome. Defined criteria exist. Through Tests. Through other conditions. Signs and presentation. Validated tools.	Loss of cognitive function Brian stem not intact. Intact Brain stem. Damage to parts of the brain. Loss of cortical function. Neuroanatomy. Loss of RAS. Brain damage.	Lack of knowledge Previous experience. No previous experience.	Recovery unlikely Recovery is possible. Lack of awareness. Disorder of consciousness. Loss of function is real.

Thematic framework for the questionnaire response

Reporting

Despite the scepticism about PVS diagnosis and the overall notion of the condition, it is generally accepted by medical professionals to be a real concept, and the law treats it as such.[1061] However, this question was designed to understand the healthcare professionals' perspectives regarding the notion. The question asked the respondents to state why they agreed or disagreed with the statement that said PVS is a real state. The thematic analysis method was used to group the responses into four themes, as highlighted below.

1. **How PVS is diagnosed**: This is an important approach to understanding any medical diagnosis and its concept. The theme shows how the participants viewed the way the condition is diagnosed to the concept's validity. Some participants agreed that the condition is a valid state because it is well recognised clinical diagnosis or clinical syndrome, and those standard criteria are available to aid the diagnosis. Although some

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[1061] Multi-society Task Force on PVS (n 9).

of them may have well believed that it can be diagnosed using ancillary tests. The role of ancillary tests in diagnosing is to rule out other conditions. Some participants said the availability of validated tools and the signs and presentation of the condition are the reasons to believe it is a valid state. In contrast, others think it is through the manifestation of other conditions. These are examples of some of the responses under this theme:

Participant Q1007 wrote, '…*defined criteria exist...patients can be in or out of the state*….'

Another participant (Q1016) wrote, '…*being in a vegetative state is a clinical state as it is a clinical diagnosis which needs to be recognised.*...'

Participant Q1029 wrote, '…. *specific symptoms, signs and investigation results that classify the diagnosis*….'

2. **The disordered process associated with PVS**: The pathophysiology of PVS is very important in validating the concept. There is a general assumption that the loss of cortical brain function is why these patients are in the state.[1062] Some participants attributed the validity of the condition to the presence of disordered processes in the brain. They believed the loss of cognitive function could be why the concept should be right. The presence of an intact brain stem, the loss of cortical function and the structural evidence in neuroanatomy are enough to evidence the lack of consciousness. Some have mentioned the damage to the brain stem and the reticular activating system; some are non-specific about the area of the brain affected. The responses under this theme are very intriguing.

   Participant Q1005 wrote, '…*damage to cortical hemispheres causing loss of higher cognitive function but with normal brain stem function*….'

[1062] Inzaghi and Sozzi (n 70).

Participant Q1030 wrote, *'…it can be explained from our neuroanatomy knowledge….'*

Participant Q1037 wrote *'…it is loss of reticular formation system* (in the brain stem) *….'*

3. **The knowledge of the condition**: The healthcare professional's knowledge of the condition is important in diagnosing PVS. The critique of the concept will largely depend on the knowledge and experience in managing the condition. Some participants' knowledge of the condition is rudimentary as they said they lack knowledge about it due to no direct experience with PVS patients. Some commented on the lack of knowledge about the possibilities of retaining sentience ability in PVS. Below are examples of the responses given by the participants:

   Participant Q1006 wrote, *'…lack of knowledge of brain stem injuries….'*

   Participant Q1011 wrote, *'...previous clinical experience….'*

   Participant Q1024 wrote, *'…I agree it is difficult to say because we do not know to what extent he feels things or what his emotions are….*'

4. **Manifestations of the condition:** The features of the condition are crucial in categorising the condition and understanding the pathophysiology of the disease condition. Some participants believed that the condition's manifestations, like lack of awareness, are enough to evidence the validity of the condition. Others said that the loss of function is observable by the clinicians and that he possibly can recover from a real clinical state.

   Participant Q1020 wrote, '…lack of awareness in this condition/state.…'

   Participant Q1021 wrote, '…*PVS is a clinical state of disorder of consciousness…. …. awake person showing no signs of awareness….'*

   Participant Q1023 wrote, *'…lasting signs/presentations with no neurological changes….'*

In summary, what defines the vegetative state is a conglomeration of clinically identifiable features of being awake but unable to interact with the surroundings.[1063] Regardless of the aetiology, the lack of objective markers to assess the lack of consciousness puts doubts in people's mind about the accuracy of diagnosis of PVS. This diagnosis is purely clinical because it depends on assessing behavioural responses. The clinical features demonstrated by the patient are usually intricate, which is why it takes an experienced specialist to have confidence in the diagnosis and the subsequent course of care. Certainly, this is not the kind of diagnosis that can be made in a single assessment session without a considerable amount of undisputable supportive evidence from a team comprising specialists who have expertise in different disciplines and are adequately experienced in the management and care of severe brain damage. At best, current advances in neurophysiologic investigations can only be supportive and not diagnostic. Prognostic predictors in PDoC, like short-latency afferent inhibition, which can be used to predict recovery and functional outcomes in the patient, have been studied. However, all these efforts are way off the reality of being used clinically to improve the current situation.[1064] There have also been efforts to develop clinical signs that can improve the accuracy of consciousness assessment to predict outcomes reliably. [1065]

Despite several research studies, it remains unclear whether or not PVS is a true clinical condition. However, the term has continually been associated with a negative connotation. Over the years, it has been in use because it has created confusion by posing a risk of developing underside contrasts between vegetables and the patient. Moreover, the term has created a notion of persistence from the moment a positive diagnosis is made. It is noteworthy

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[1063] Ibid.

[1064] Luana Billeri and others, 'Looking toward predicting functional recovery in disorders of consciousness: can sensorimotor integration help us?' [2019] 33(3) Brain Injury <https://doi.org/10.1080/02699052.2018.1553309> accessed 21 May 2021.

[1065] Jean-Michel Pignat and others, 'Outcome Prediction of Consciousness Disorders in the Acute Stage Based on a Complementary Motor Behavioural Tool' [2016] 11(6) PLOS ONE <https://dx.doi.org/10.1371/journal.pone.0156882> accessed 21 May 2021.

that this condition describes patients who have failed to demonstrate cognitive brain function in the presence of wakefulness. This state can either indicate the patient's recovery or the irreversibility of the brain damage. The empirical study showed that most healthcare professionals acknowledged the existence of VS as a clinical entity and agreed with the timeframe. This finding is not surprising, as clinicians usually adhere to guidelines given by the governing bodies. Many healthcare practitioners believe that PVS patients retain their sentience capabilities, so, interestingly, they would still support withdrawing CAHN. More than half of the respondents agreed that PVS patients might never recover from the state after 12 months. However, a good number still believe these patients can recover after such a timeframe. An interesting observation is that a significant percentage feels that PVS patients are severely disabled rather than approaching the end of life. Almost two-thirds of the respondents also believed that the reason for misdiagnosis could be that the technology available is not superior enough to detect the patient's awareness. The subsequent analysis of the results revealed an association between PVS diagnosis and the condition's aetiology.

Furthermore, there is also an association between the inability of technology to detect consciousness and misdiagnosis. However, there is no association between 'PVS patients' being seen as severely disabled and being considered approaching the end of life, nor was there an association between the ability to feel pain and hunger and recovery after 12 months. Finally, almost 90% of the respondents believed that PVS is a valid concept. In addition, most believe that while PVS is a real clinical state, the main issue with the concept is that it is liable to misdiagnosis. The reason for this lies in the inability of the available technology to detect consciousness. Furthermore, there is a need for further evidence-based research into the timeframe for determining irreversibility. Until then, it will be prudent to use terminologies like unresponsive wakeful syndrome, which only describes the condition and does not indicate prognosis or irreversibility.[1066]

2. __Issues around recovery and artificial nutrition__

This section analyses the responses to the survey on deciding permanence, misdiagnosis, late recovery, and withdrawing CAHN in PVS. Ninety-six responses were obtained from a hypothetical scenario, carefully written to bring to light the issues around recovery in PVS and artificial nutrition. The data analysis was used to answer research question two: **Is there any relationship between the accuracy of diagnosis and the way PVS patients are treated?**

Heading 2: Deciding 'permanence'

The doctors looking after Mr XY assessed him. They conducted a series of investigations and then diagnosed him to be in VS and, after a year, PVS. Mr XY's family was concerned about the possibility of stopping his life-sustaining interventions, so they asked for a second opinion. They also raised the question of misdiagnosis and late recovery in individuals with a similar diagnosis. This vignette was used to answer questions 11 to 15.

Table 23a shows the number of valid answers to the reliability of the timeframes used in defining permanence in PVS patients. The response revealed that 93 of the 96 respondents answered the question (Q11). Table 23b shows that 45% (n – 93) of the respondents agreed that the timeframes used in diagnosing PVS are evidence-based, while 12.9% (n – 93) of the respondents disagreed with the statement.

N	Valid	93
	Missing	3

Table 23a: The number of valid answers to question 11

[1066] Willemijn van Erp and others, 'Unresponsive wakefulness syndrome: Outcomes from a vicious circle' (2020) 87(1) Annals of neurology, 87(1) <https://doi.org/10.1002/ana.25624> accessed 18 August 2020.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	3	3.1	3.2	3.2
	Disagree	8	8.3	8.6	11.8
	Somewhat disagree	1	1.0	1.1	12.9
	Neither agree nor disagree	39	40.6	41.9	54.8
	Somewhat agree	16	16.7	17.2	72.0
	Agree	16	16.7	17.2	89.2
	Strongly agree	10	10.4	10.8	100.0
	Total	93	96.9	100.0	

Table 23b: The timeframe used to define permanence of vegetative state is reliable and evidence based.

Furthermore, table 24a shows the number of valid and invalid answers to question 12 of the questionnaire, which is a question on the reason for late recovery in PVS. The question asserted that late recovery might be due to misdiagnosis. Table 24b shows that only 16.1% (n - 93) of the respondents disagreed with this statement, and 54.9% (n - 93) of the respondents agreed that misdiagnosis could be the reason for late recovery.

N	Valid	93
	Missing	3

Table 24a: The number of valid and invalid answers to question 12

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	6	6.3	6.5	6.5
	Disagree	3	3.1	3.2	9.7
	Somewhat disagree	6	6.3	6.5	16.1
	Neither agree nor disagree	27	28.1	29.0	45.2
	Somewhat agree	22	22.9	23.7	68.8
	Agree	22	22.9	23.7	92.5
	Strongly agree	7	7.3	7.5	100.0
	Total	93	96.9	100.0	

Table 24b: Late recovery in PVS may be due to misdiagnosis of the initial condition.

On the other hand, 47% (n - 93) of the respondents agreed that late recovery could be due to technological advancements, while 21.5% (n - 93) disagreed with the assertion.

N	Valid	93
	Missing	3

Table 25a: The number of valid and invalid answers to question 13.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	6	6.3	6.5	6.5
	Disagree	4	4.2	4.3	10.8
	Somewhat disagree	10	10.4	10.8	21.5
	Neither agree nor disagree	29	30.2	31.2	52.7
	Somewhat agree	23	24.0	24.7	77.4
	Agree	15	15.6	16.1	93.5
	Strongly agree	6	6.3	6.5	100.0
	Total	93	96.9	100.0	

Table 25b: Late recovery in PVS may be due to advancement in technology from the point of diagnosis.

In diagnosing PVS, the full meaning of P, whether persistent or permanent, is significant in assuming prognosis. Question 14 asked whether the use of persistent is more appropriate than permanent. 74.3% (n – 93) of the respondents agreed, while only 12.9% (n – 93) disagreed.

N	Valid	93
	Missing	3

Table 26a: The number of valid and invalid answers to question 14.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	2	2.1	2.2	2.2
	Disagree	7	7.3	7.5	9.7
	Somewhat disagree	3	3.1	3.2	12.9
	Neither agree nor disagree	12	12.5	12.9	25.8
	Somewhat agree	14	14.6	15.1	40.9
	Agree	34	35.4	36.6	77.4
	Strongly agree	21	21.9	22.6	100.0
	Total	93	96.9	100.0	

Table 26b: The term ‘persistent’ is more appropriate than the term ‘permanent’ when referring to individual in vegetative state after 1 year.

Lastly, question 15 was whether the withdrawal of CAHN in PVS shortens life expectancy. 67.1% (n – 91) of the respondents agreed that withdrawing nutrition and hydration ultimately leads to the demise of the patients in PVS, while 13.2% (n – 91) disagreed with the assertion.

N	Valid	91
	Missing	5

Table 27a: The number of valid and invalid answers to question 15.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	2	2.1	2.2	2.2
	Disagree	8	8.3	8.8	11.0
	Somewhat disagree	2	2.1	2.2	13.2
	Neither agree nor disagree	18	18.8	19.8	33.0
	Somewhat agree	13	13.5	14.3	47.3
	Agree	27	28.1	29.7	76.9
	Strongly agree	21	21.9	23.1	100.0
	Total	91	94.8	100.0	
Total		96	100.0		

Table 27: The life expectancy of individual in PVS is usually cut short by withdrawing nutrition and hydration

In addition, table 28 below shows the descriptive statistics of the response to questions 11 to 15. The analysis of these questions will be presented in section 3.6.2 below.

	N	Minimum	Maximum	Mean	Std. Deviation
PVS timeframe reliable and evidence based	93	1.00	7.00	4.5591	1.47782
Misdiagnosis is the reason for late recovery	93	1.00	7.00	4.6344	1.53074
Technological advancement is the reason for late recovery	93	1.00	7.00	4.3763	1.48846
Persistent more appropriate than permanent	93	1.00	7.00	5.3333	1.59028
CAHN cuts PVS life short	91	1.00	7.00	5.1758	1.63703
Valid N (listwise)	91				

Question 15 (Q15) was in two parts: The response to the closed-ended question, which asked whether withdrawing CAHN cuts life short, was represented in table 27 above. However, the follow-on question, an open-end question, asked why the respondent agreed or disagreed with the statement. The individual response to this question is presented in the table below. This data will be analysed using the thematic analysis later in the analysis section below.

Analysis

The following analyses were run using Spearman's rank-order correlation to determine if there were any relationships/associations between two variables from the questionnaire. The null hypothesis is stated first, followed by the scatter diagram, then analysis and finally, the conclusion.

Null hypothesis 6: There is no relationship between the reliability of PVS diagnosis timeframe and the preference for persistent or permanent in PVS.

Analysis: A Spearman's rank-order correlation was run to assess the relationship between the reliability of PVS diagnosis timeframe and the preference for persistent or permanent in PVS. Table 30 below shows that the Spearman coefficient ($r_{s)}$ is -.127, which is a negative correlation between these two variables, and the two-tailed significance level (p-value) of the correlation coefficient is .937 (i.e., $p > .05$).

Conclusion: Spearman's correlation was not statistically significant; therefore, we cannot reject the null hypothesis and cannot accept the alternative hypothesis. Therefore, there was no statistically significant correlation between the reliability of PVS diagnosis timeframe and the preference for persistent or permanent in PVS, $r_s(91) = -.127, p = .227.$

			PVS timeframe reliable and evidence based	Persistent more appropriate than permanent
Spearman's rho	PVS timeframe reliable and evidence based	Correlation Coefficient	1.000	-.127
		Sig. (2-tailed)	.	.227
		N	93	93
	Persistent more appropriate than permanent	Correlation Coefficient	-.127	1.000
		Sig. (2-tailed)	.227	.
		N	93	93

Table 30: Correlation table between the reliability of PVS diagnosis timeframe the difference in the use of persistent or permanent qualifier in the name.

Null hypothesis 7: There is no relationship between misdiagnosis and technological advancement being the reason for late recovery.

Analysis: A Spearman's rank-order correlation was run to assess the relationship between misdiagnosis and technological advancement being the reason for late recovery. Table 31 below shows that the Spearman coefficient (r_s) is .022, a positive correlation between these two variables. However, the two-tailed significance level (p-value) of the correlation coefficient is .833 (i.e., p > .05).

Conclusion: Spearman's correlation was not statistically significant; therefore, we cannot reject the null hypothesis and cannot accept the alternative hypothesis. Therefore, there was no statistically significant correlation between misdiagnosis and technological advancement being the reason for late recovery, $r_s(91) = .022, p = .833$.

			Misdiagnosis is the reason for late recovery	Technological advancement is the reason for late recovery
Spearman's rho	Misdiagnosis is the reason for late recovery	Correlation Coefficient	1.000	.022
		Sig. (2-tailed)	.	.833
		N	93	93
	Technological advancement is the reason for late recovery	Correlation Coefficient	.022	1.000
		Sig. (2-tailed)	.833	.
		N	93	93

Table 31: Correlation table between misdiagnosis or technological advancement being the reason for late recovery.

Null hypothesis 8: There is no relationship between the reliability of timeframe in making a PVS diagnosis and the belief that withdrawing CAHN cuts life short.

Analysis: A Spearman's rank-order correlation was run to assess the relationship between the reliability of timeframe in making a PVS diagnosis and the belief that withdrawal of CAHN cuts life short. Table 32 below shows that the Spearman coefficient (r_s) is .195, which is a weak correlation but the two-tailed significance level (p-value) of the correlation coefficient is .063 (i.e., p > .05).

Conclusion: Spearman's correlation was not statistically significant; therefore, we cannot reject the null hypothesis and cannot accept the alternative hypothesis. Therefore, there was no statistically significant correlation between the reliability of timeframe in making a PVS diagnosis and the belief that withdrawal of CAHN cuts life short, $r_s(89) = .195, p = .063$.

			PVS timeframe reliable and evidence based	CAHN cuts PVS life short
Spearman's rho	PVS timeframe reliable and evidence based	Correlation Coefficient	1.000	.195
		Sig. (2-tailed)	.	.063
		N	93	91
	CAHN cuts PVS life short	Correlation Coefficient	.195	1.000
		Sig. (2-tailed)	.063	.
		N	91	91

Table 32: Spearman's correlation table between the reliability of timeframe in making PVS diagnosis and the belief that withdrawal of CAHN cuts life short.

Null hypothesis 9: There is no relationship between the acknowledgement of the GMC guidance on treating PVS patients and its effectiveness.

Analysis: A Spearman's rank-order correlation was run to assess the relationship between the acknowledgement of the GMC guidance on treating PVS patients and its effectiveness. Table 33 below shows that the Spearman coefficient (r_s) is -.331, which is a negative correlation, and the two-tailed significance level (p-value) of the correlation coefficient is .007 (i.e., p < .05).

Conclusion: Since there is a strong negative correlation between the two variables, we cannot reject the null hypothesis and cannot accept the alternative hypothesis. Therefore, there was no statistically significant correlation between the acknowledgement of the GMC guidance on treating PVS patients and how helpful it is, $r_s(64) = -.331, p = .007$.

			Aware of GMC guidance	Is the GMC guidance helpful?
Spearman's rho	Aware of GMC guidance	Correlation Coefficient	1.000	-.331**
		Sig. (2-tailed)	.	.007
		N	90	65
	Is the GMC guidance helpful?	Correlation Coefficient	-.331**	1.000
		Sig. (2-tailed)	.007	.
		N	65	66

**. Correlation is significant at the 0.01 level (2-tailed).

Table 33: Spearman's correlation table between the acknowledgement of the GMC guidance on treating PVS patients and its effectiveness.

Null hypothesis 10: There is no relationship between misdiagnosis and preference for persistent as the more appropriate word to qualify VS.

Analysis: A Spearman's rank-order correlation was run to assess the relationship between misdiagnosis and preference for persistent as the more appropriate word to qualify VS. Table 34 below shows that the Spearman coefficient (r_s) is 277, a positive correlation and the two-tailed significance level (p-value) of the correlation coefficient is .008 (i.e., $p < .05$).

Conclusion: Spearman's correlation was statistically significant; therefore, we can reject the null hypothesis and accept the alternative hypothesis. Therefore, there was a statistically significant correlation between misdiagnosis and preference for persistent as the more appropriate word to qualify VS, $r_s(91) = 277, p = .008$.

			Misdiagnosis	Persistent more appropriate than permanent
Spearman's rho	Misdiagnosis	Correlation Coefficient	1.000	.277**
		Sig. (2-tailed)	.	.008
		N	94	92
	Persistent more appropriate than permanent	Correlation Coefficient	.277**	1.000
		Sig. (2-tailed)	.008	.
		N	92	93

**. Correlation is significant at the 0.01 level (2-tailed).

Table 34: Spearman's correlation table between misdiagnosis and preference for persistent as the more appropriate word to qualify VS.

The thematic analysis for the questionnaire's response to Q15b

This section is the qualitative analysis of why the participants believed that the life expectancy of a PVS patient is cut short by withdrawing nutrition and hydration or otherwise.

Nutrition and hydration are essential to PVS life expectancy.	**Nutrition and hydration are not essential to PVS life expectancy.**	**Limited knowledge.**	**Contributory factor.**
Obligatory. Causation. Organ failure. Essential for life. Hasten death. Starvation.	Futile. Sentience. Clinical state. No recovery.	Paucity of knowledge. No evidence basis. Experience.	Secondary. Severe disability. Brain part affected. Inhumane.

Thematic framework for the questionnaire response to Q15b

Reporting

The issue of nutrition and hydration in PVS has been the most contentious.

1. **Nutrition and hydration are essential to PVS life expectancy:**

Some participants agreed that the withdrawal of nutrition and hydration in PVS will directly lead to death because they believe that nutrition and hydration are obligatory and essential for life. Furthermore, their withdrawal would lead to starvation, thus hastening death. This action can cause organ failure, and when the patients die, their death is not directly due to PVS but the consequence of the CAHN withdrawal. Below are some of the responses to the question:

Participant Q1516 wrote, '*…it seems reasonable to imagine that if someone is entirely dependent on assisted hydration and nutrition, then withdrawing will hasten death….*'

Another participant, Q1519 wrote, '*…without nutrition life expectancy will be cut down….*'

Participant Q1533 wrote, '*…. if a PVS is not fed or hydrated, he dies of starvation….*'

2. **Nutrition and hydration are not essential to PVS life expectancy**:

On the other hand, some participants who disagreed that withdrawal of nutrition and hydration cut life short stated that if CAHN is deemed futile, stopping it would only allow the natural course of the disease to progress. Another remark was that people could not recover from the PVS state; therefore, the provision of CAHN is irrelevant. Participants also believed that the lack of sentience ability in PVS is why CAHN is unnecessary. Below are examples of the responses given by the participants:

Participant Q1507 wrote, '*…the life expectancy of these patients is short due to their clinical state ….*'

Participant Q1517 wrote, '*…if the likelihood of recovery is slim, withdrawing treatment not likely to significantly reduce life expectancy….*'

Participant Q1531 wrote, '…*the principle would suggest that life cannot be sustained without nutrition and hydration* ….'

3. **The knowledge of the condition**:

Understanding the PVS condition is required for balanced decision-making in these patients. A few of the respondents had little knowledge about the issues raised in this study. Also, a lack of statistical evidence about these issues makes the decision-making process a little bit more subjective. Below are some of the responses given to the question:

Participant Q1504 wrote, '…*lack of knowledge of brain stem injuries*.….'

Participant Q1509 wrote, '…*I do not know relevant statistics or research to support agreeing or disagreeing with this statement* ….'

Participant Q1508 wrote, '…*permanent suggests a clinical condition that is unlikely to change, persistent suggests even though long-standing things might change*.….'

4. **Contributory factor:**

Some participants relied on some contributory factors in deciding whether the withdrawal of food and water in individuals deemed in PVS causes death. Some believe that it can contribute to the demise of the patients. Others believe that because they are severely disabled, the provision of nutrition and hydration should be ensured, and failure to do that would result in the inhumane treatment of the patients. Below are some of the responses given:

Participant Q1521 wrote, '…*severe disability so unable to self-administer nutrition and hydration* ….'

Participant Q1532 wrote, '…*it depends on the areas of the brain damage. If proper technique is used to detect the area of damage and a definitive diagnosis is made, a conclusion can be reached independently of the time frame*.…'

Participant Q1534 wrote, '…*inhumane* …

The above analysis shows that healthcare professionals grapple with ethical and moral dilemmas, particularly when withdrawing CAHN in PVS patients. The dilemma of whether or not to treat can be compounded when there is insufficient evidence regarding diagnosis and prognosis. Determining the acceptable quality of life is controversial since this is not a straightforward binary option. Therefore, decisions made on behalf of PVS patients depend on best interests, but what is in the patient's best interests varies from individual to individual. Many patients have reduced quality of life, but death is a distant reality if nutrition and hydration continue. While some may spontaneously recover some neurological function over time, many would require medical intervention to achieve a fair outcome. However, if the CAHN is withdrawn at any point, then death is inevitable. It is, therefore, medically obvious that the cause of death should be the withdrawal of CAHN. When a patient dies in the hospital, and the doctors issue the death certificate, they have to formulate the likely cause of death; however, if the cause is unknown, the coroner issues the death certificate (which usually involves conducting a post-mortem). It is unlikely that starvation would be written on the legal certification of the cause of death. This issue poses an even more serious ethical question about how we address the sequel of the act of withdrawing CAHN.

3. __Issues around withdrawal of treatments and the process of withdrawal.__

This section was used to analyse the response to the third heading in the scenario given in the questionnaire. These are questions about the legal principles of withdrawing LSI and the process of withdrawing treatments.

Heading 3: Deciding to withdraw treatment and the process of withdrawal

After 36 months, Mr XY did not make any significant improvement in his clinical condition. He was still on artificial nutrition and hydration (ANH) with occasional antibiotics treatment. He was fully dependent on other people for all activities of daily living. Consequently, the doctors *looking after him suggested that the ANH used to sustain him should be withdrawn. The family objected to the proposed action and the case was taken to Court. The Court declared that it was not in Mr XY's best interests to continue ANH and that it would not be unlawful for the doctor to withdraw such intervention. The intervention was discontinued and he subsequently died.* This vignette was used to answer questions 16 to 25 and below are the statistics for the responses to the questions.

Results

Table 35b below shows the statistics of the response to question 16 of the questionnaire, which asked whether withholding and withdrawing LSI is in a PVS patient's best interests. Table 35a shows the number of respondents who answered the question and those who did not. 78.3% (n – 92) of the respondents agreed that this might be in their best interests, while 10.9% (n – 92) of the respondents disagreed with the statement.

N	Valid	92
	Missing	4

Table 35a: Response to question 16.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	6	6.3	6.5	6.5
	Disagree	3	3.1	3.3	9.8
	Somewhat disagree	1	1.0	1.1	10.9
	Neutral	10	10.4	10.9	21.7
	Somewhat agree	11	11.5	12.0	33.7
	Agree	34	35.4	37.0	70.7
	Strongly agree	27	28.1	29.3	100.0
	Total	92	95.8	100.0	

Table 35b: WWLSI is in PVS best interests

Meanwhile, question 17 approached the issue of withdrawing and withholding LSI from the ethical point of view by asking whether the practice can be ethically justified. 81.4% (n –

91) of the respondents agreed that the practice could be ethically justified, while only 14.3% (n – 91) of the respondents disagreed.

N		
	Valid	91
	Missing	5

Table 36a: Response to question 17.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	3	3.1	3.3	3.3
	Disagree	5	5.2	5.5	8.8
	Somewhat disagree	5	5.2	5.5	14.3
	Neutral	4	4.2	4.4	18.7
	Somewhat agree	15	15.6	16.5	35.2
	Agree	32	33.3	35.2	70.3
	Strongly agree	27	28.1	29.7	100.0
	Total	91	94.8	100.0	

Table 36b: WWLSI is ethical

Question 18, on the other hand, asked whether withdrawing and withholding LSI in PVS could be morally justified. It is not surprising that 78.3% (n – 92) agreed that the practice could be morally justified, while only 13% (n – 92) of the respondents disagreed.

N		
	Valid	92
	Missing	4

Table 37a: Response to question 18.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	2	2.1	2.2	2.2
	Disagree	2	2.1	2.2	4.3
	Somewhat disagree	8	8.3	8.7	13.0
	Neutral	8	8.3	8.7	21.7
	Somewhat agree	18	18.8	19.6	41.3
	Agree	31	32.3	33.7	75.0
	Strongly agree	23	24.0	25.0	100.0
	Total	92	95.8	100.0	

Table 37b: WWLSI is moral

Furthermore, question 19 asked if PVS patients have interests. Around 65% (n – 92) of the respondents agreed that PVS patients have interests, while 1.4% (n – 92) thought they did not.

N		
	Valid	92
	Missing	4

Table 38a: Response to question 19.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	27	28.1	29.3	29.3
	Disagree	21	21.9	22.8	52.2
	Somewhat disagree	12	12.5	13.0	65.2
	Neutral	16	16.7	17.4	82.6
	Somewhat agree	3	3.1	3.3	85.9
	Agree	8	8.3	8.7	94.6
	Strongly agree	5	5.2	5.4	100.0
	Total	92	95.8	100.0	

Table 38b: PVS has no interests.

On a different note, question 20 asked whether an individual in PVS has human rights and whether these rights should be protected. About 83.6% (n – 91) of the respondents agreed that PVS patients have human rights, while only 9.9% (n – 91) of the respondents disagreed with this statement.

N		
	Valid	91
	Missing	5

Table 39a: Response to question 20.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	6	6.3	6.6	6.6
	Disagree	1	1.0	1.1	7.7
	Somewhat disagree	2	2.1	2.2	9.9
	Neutral	6	6.3	6.6	16.5
	Somewhat agree	6	6.3	6.6	23.1
	Agree	27	28.1	29.7	52.7
	Strongly agree	43	44.8	47.3	100.0
	Total	91	94.8	100.0	

Table 39b: PVS has human rights.

The next question was included to know how many respondents were aware of the GMC document on treatment and care towards the end of life. Surprisingly, 63.3% (n – 90) of the respondents were aware of this guideline, while 36.7% (n – 90) of the respondents were unaware of the document. The bar graph below shows the distribution for easy representation.

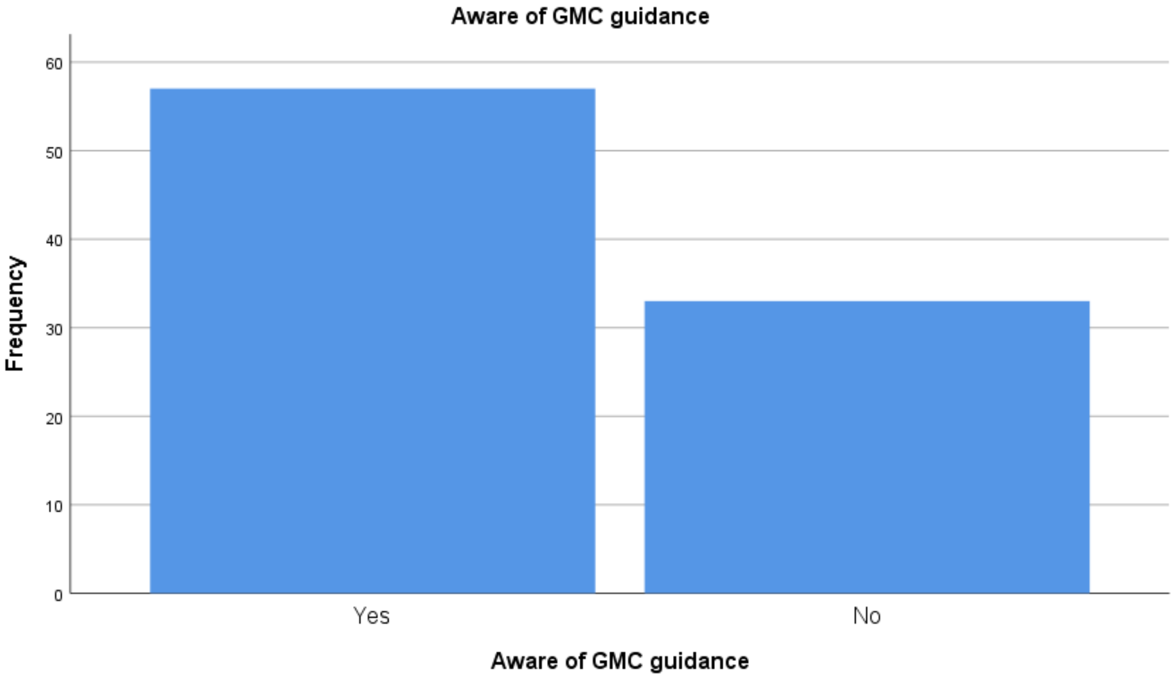
N	Valid	90
	Missing	6

Table 40a: Response to question 21.

Aware of GMC guidance

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	57	59.4	63.3	63.3
	No	33	34.4	36.7	100.0
	Total	90	93.8	100.0	

Table 40b: Healthcare professionals who were aware of the GMC guideline.



The next question was whether this ethical guideline helps doctors in making decision in challenging cases. 54.6% (n – 66) of the respondents agreed with the statement, while only 4.5% (n – 66) of the respondents disagreed with this statement.

N	Valid	66
	Missing	30

Table 41a: Response to question 22.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Disagree	2	2.1	3.0	3.0
	Somewhat disagree	1	1.0	1.5	4.5
	Neutral	27	28.1	40.9	45.5
	Somewhat agree	15	15.6	22.7	68.2
	Agree	11	11.5	16.7	84.8
	Strongly agree	10	10.4	15.2	100.0
	Total	66	68.8	100.0	

Table 41b: Is the GMC guidance helpful?

Question 23 was whether withdrawing artificial nutrition and hydration in PVS can be likened to starvation and therefore seen as inhumane treatment. Only 29.2% (n – 89) of the respondents agreed with this assertion, while 41.6% (n – 89) of the respondents disagreed with it.

N	Valid	89
	Missing	7

Table 42a: Response to question 23.

Valid	Strongly disagree	15	15.6	16.9	16.9
	Disagree	12	12.5	13.5	30.3
	Somewhat disagree	10	10.4	11.2	41.6
	Neutral	26	27.1	29.2	70.8
	Somewhat agree	10	10.4	11.2	82.0
	Agree	11	11.5	12.4	94.4
	Strongly agree	5	5.2	5.6	100.0
	Total	89	92.7	100.0	

Table 42b: Withdrawing CAHN is inhumane

Question 24 asked if withholding and withdrawing LSI in PVS are ethically the same. 41% (n – 90) of the respondents agreed with this statement, while 36.7% (n – 90) of the respondents disagreed.

N		
	Valid	90
	Missing	6

Table 43a: Response to question 24.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	10	10.4	11.1	11.1
	Disagree	12	12.5	13.3	24.4
	Somewhat disagree	11	11.5	12.2	36.7
	Neutral	20	20.8	22.2	58.9
	Somewhat agree	13	13.5	14.4	73.3
	Agree	20	20.8	22.2	95.6
	Strongly agree	4	4.2	4.4	100.0
	Total	90	93.8	100.0	

Table 43b: WWLSI are ethically the same.

In the same vein, question 25 asked if withholding and withdrawing LSI in PVS are morally the same. 45.6% (n – 90) of the respondents agreed with the statement, while 28.9% (n – 90) of the respondents disagreed with the statement.

N		
	Valid	90
	Missing	6

Table 44a: Response to question 25.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	8	8.3	8.9	8.9
	Disagree	8	8.3	8.9	17.8
	Somewhat disagree	10	10.4	11.1	28.9
	Neutral	23	24.0	25.6	54.4
	Somewhat agree	20	20.8	22.2	76.7
	Agree	16	16.7	17.8	94.4
	Strongly agree	5	5.2	5.6	100.0
	Total	90	93.8	100.0	

Table 44b: WWLSI are morally the same.

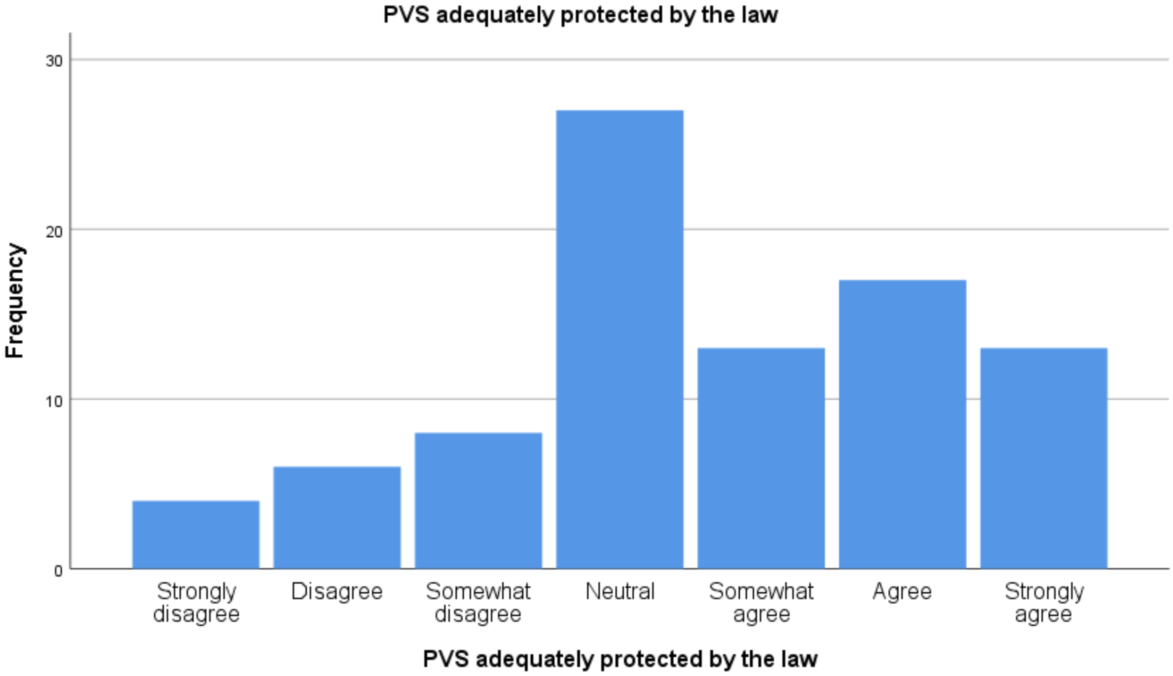
Lastly, question 26 asked whether the respondents believed the law adequately protects PVS patients. Approximately 48% (n – 88) of the respondents agreed that the law adequately protects PVS patients, while 20.5% (n – 88) of the respondents disagreed.

N	Valid	88
	Missing	8

Table 45a: Response to question 26.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	4	4.2	4.5	4.5
	Disagree	6	6.3	6.8	11.4
	Somewhat disagree	8	8.3	9.1	20.5
	Neutral	27	28.1	30.7	51.1
	Somewhat agree	13	13.5	14.8	65.9
	Agree	17	17.7	19.3	85.2
	Strongly agree	13	13.5	14.8	100.0
	Total	88	91.7	100.0	

Table 45b: PVS adequately protected by the law.



Analysis

In this section, Spearman’s correlation analysis of the responses to the above questions will be used to answer the third research question: Does the law adequately protect PVS patients. Firstly, table 46 below shows the descriptive statistics for the individual questions. 1.00 represent strongly disagree while 7.00 represent strongly agree on a scale of 1 to 7.

	N	Minimum	Maximum	Mean	Std. Deviation
WWLSI is in PVS best interests	92	1.00	7.00	5.4674	1.68674
WWLSI is ethical	91	1.00	7.00	5.4945	1.61502
WWLSI is moral	92	1.00	7.00	5.4239	1.46935
PVS has no interests	92	1.00	7.00	2.9022	1.84009
PVS has human rights	91	1.00	7.00	5.8352	1.68169
Withdrawing CAHN is inhumane	89	1.00	7.00	3.6404	1.78534
WWLSI are ethically the same	90	1.00	7.00	4.0000	1.76737
WWLSI are morally the same	90	1.00	7.00	4.1889	1.64142
Valid N (listwise)	87				

Table 46: Descriptive statistics for questions 16 to 25.

The null hypothesis to be tested in this section will be itemized as follows:

Null hypothesis 11: There is no relationship between the idea that withdrawing LSI in PVS is in their best interest and the belief that PVS patients have no interests.

Analysis: A Spearman's rank-order correlation was run to assess the relationship between the idea that withdrawing LSI in PVS is in their best interest and the belief that PVS patients have no interests. Table 47 below shows that the Spearman coefficient ($r_{s)}$ is -.146, which is a negative correlation, and the two-tailed significance level (p-value) of the correlation coefficient is .166 (i.e., p >.05).

Conclusion: Since there is a negative correlation between the two variables and P > .05, we cannot reject the null hypothesis and cannot accept the alternative hypothesis. Therefore, there was no relationship between the idea that withdrawing LSI in PVS is in their best interest and the belief that PVS patients have no interests, $r_s(90) = -.146, p = .166.$

			WWLSI is in PVS best interests	PVS has no interests
Spearman's rho	WWLSI is in PVS best interests	Correlation Coefficient	1.000	-.146
		Sig. (2-tailed)	.	.166
		N	92	92
	PVS has no interests	Correlation Coefficient	-.146	1.000
		Sig. (2-tailed)	.166	.
		N	92	92

Table 47: The Spearman's correlation table between the idea that withdrawing LSI in PVS in in their best interest and the believe that PVS patients have no interests.

Null hypothesis 12: there is no relationship between the assumptions that withdrawing/ withholding LSI in PVS is ethical and that the practice is moral.

Analysis: A Spearman's rank-order correlation was run to assess the relationship between the assumptions that withdrawing and withholding LSI in PVS is ethical and that the practice is moral. Table 48 below shows that the Spearman coefficient ($r_{s)}$ is .611, which is a strong positive correlation and the two-tailed significance level (p-value) of the correlation coefficient is .000 (i.e., p < .05).

Conclusion: A strong positive correlation exists between the variables and the p-value is significant. We can reject the null hypothesis and accept the alternative hypothesis. Therefore, there was a statistically significant correlation between the assumption that withdrawing and withholding LSI in PVS is ethical and that the practice is moral. $r_s(90) = .611, p = .000.$

			WWLSI is ethical	WWLSI is moral
Spearman's rho	WWLSI is ethical	Correlation Coefficient	1.000	.611**
		Sig. (2-tailed)	.	.000
		N	91	91
	WWLSI is moral	Correlation Coefficient	.611**	1.000
		Sig. (2-tailed)	.000	.
		N	91	92

**. Correlation is significant at the 0.01 level (2-tailed).

Table 48: Spearman correlation table between the assumption that withdrawing/ withholding LSI in PVS is ethical, and that the practice is moral.

<u>Null hypothesis 13:</u> There is no relationship between the idea that the act of withdrawing CAHN in PVS is inhumane and the assumption that PVS patients have human rights.

<u>Analysis:</u> A Spearman's rank-order correlation was run to assess the relationship between the idea that the act of withdrawing CAHN in PVS is inhumane and the assumption that PVS patients have human rights. Table 49 below shows that the Spearman coefficient (r_s) is -.165, which is a negative correlation, and the two-tailed significance level (p-value) of the correlation coefficient is .123 (i.e., p > .05).

<u>Conclusion:</u> Since there was no significant statistical correlation, we cannot reject the null hypothesis and cannot accept the alternative hypothesis. Therefore, there was no relationship between the idea that the act of withdrawing CAHN in PVS is inhumane and the assumption that PVS patients have human rights, $r_s(89) = -.165, p = .123$.

			Withdrawing CAHN is inhumane	PVS has human rights
Spearman's rho	Withdrawing CAHN is inhumane	Correlation Coefficient	1.000	-.165
		Sig. (2-tailed)	.	.123
		N	89	88
	PVS has human rights	Correlation Coefficient	-.165	1.000
		Sig. (2-tailed)	.123	.
		N	88	91

Table 49: Spearman's correlation table between the idea that the act of withdrawing CAHN in PVS is inhumane and the assumption that PVS patients have human rights.

<u>Null hypothesis 14:</u> There is no relationship between the idea that withholding and withdrawing LSI are ethically the same and the idea that withholding and withdrawing LSI are morally the same.

<u>Analysis:</u> A Spearman's rank-order correlation was run to assess the relationship between the idea that withholding and withdrawing LSI are ethically the same and that withholding and withdrawing LSI are morally the same. Table 50 below shows that the Spearman coefficient

(r_s) is .761, which is a strong positive correlation and the two-tailed significance level (p-value) of the correlation coefficient is 000 (i.e., p < .05).

Conclusion: Since there is a statistically significant correlation between the two variables, we can reject the null hypothesis and accept the alternative hypothesis. Therefore, there was a significant association between that withholding and withdrawing LSI are ethically the same and the idea that withholding and withdrawing LSI are morally the same, $r_s(88) = 761, p = .000$.

			WWLSI are ethically the same	WWLSI are morally the same
Spearman's rho	WWLSI are ethically the same	Correlation Coefficient	1.000	$.761^{**}$
		Sig. (2-tailed)	.	.000
		N	90	90
	WWLSI are morally the same	Correlation Coefficient	$.761^{**}$	1.000
		Sig. (2-tailed)	.000	.
		N	90	90

**. Correlation is significant at the 0.01 level (2-tailed).

Table 50: The Spearman's correlation table between the idea that withholding and withdrawing LSI are ethically the same and the idea that withholding and withdrawing LSI are morally the same.

Null hypothesis 15: No relationship exists between the assertion that PVS patients are adequately protected by the law and the idea that PVS is a real clinical state.

Analysis: A Spearman's rank-order correlation was run to assess the relationship between the assertion that PVS patients are adequately protected by the law and the idea that PVS is a real clinical state. Table 51 below shows that the Spearman coefficient (r_s) is .166, which is a positive correlation; however, the two-tailed significance level (p-value) of the correlation coefficient is .122 (i.e., p > .05).

Conclusion: Since there is no statistically significant correlation between the two variables, we cannot reject the null hypothesis and cannot accept the alternative hypothesis. Therefore, there was no significant association between the assertion that PVS patients are adequately protected by the law and the idea that PVS is a real clinical state, $r_s(93) = .166, p = .122$.

			PVS adequately protected by the law	PVS as a real state
Spearman's rho	PVS adequately protected by the law	Correlation Coefficient	1.000	.166
		Sig. (2-tailed)	.	.122
		N	88	88
	PVS as a real state	Correlation Coefficient	.166	1.000
		Sig. (2-tailed)	.122	.
		N	88	95

Table 51: Spearman's correlation table between the assertion that PVS patients are adequately protected by the law and the idea that PVS is a real clinical state.

Null hypothesis 16: There is no relationship between the assertion that PVS patients are adequately protected by the law and the idea that PVS patients have human rights.

Analysis: A Spearman's rank-order correlation was run to assess the relationship between the assertion that PVS patients are adequately protected by the law and the idea that PVS patients have human rights. Table 52 below shows that the Spearman coefficient (r_s) is .221, which is a positive correlation and the two-tailed significance level (p-value) of the correlation coefficient is .040 (i.e., $p < .05$).

Conclusion: Since there was a statistically significant correlation between the two variables, we can reject the null hypothesis and accept the alternative hypothesis. Therefore, there was an association between the assertion that the law adequately protects PVS patients and the idea that PVS patients have human rights, $r_s(89) = .221, p = .040$.

			PVS adequately protected by the law	PVS has human rights
Spearman's rho	PVS adequately protected by the law	Correlation Coefficient	1.000	.221*
		Sig. (2-tailed)	.	.040
		N	88	87
	PVS has human rights	Correlation Coefficient	.221*	1.000
		Sig. (2-tailed)	.040	.
		N	87	91

*. Correlation is significant at the 0.05 level (2-tailed).

Table 52: Spearman’s correlation table between the assertion that PVS patients are adequately protected by the law and the idea that PVS patients have human rights.

Null hypothesis 17: There is no relationship between the assumption that PVS is a valid concept and how the law protects PVS patients.

Analysis: A Spearman’s rank-order correlation was run to assess the relationship between the assumption that PVS is a valid concept and how the law protects PVS patients. Table 53 below shows that the Spearman coefficient (rs) is -.166, which is a negative correlation, and the two-tailed significance level (p-value) of the correlation coefficient is .140 (p > .05).

Conclusion: Since there was no statistically significant correlation between the two variables, we cannot reject the null hypothesis and cannot accept the alternative hypothesis. Therefore, there was no significant association between the assumption that PVS is a valid concept and the way the law protects PVS patients, $r_s(86) = -166, p = .140$.

			PVS a valid concept	PVS adequately protected by the law
Spearman's rho	PVS a valid concept	Correlation Coefficient	1.000	-.166
		Sig. (2-tailed)	.	.140
		N	81	80
	PVS adequately protected by the law	Correlation Coefficient	-.166	1.000
		Sig. (2-tailed)	.140	.
		N	80	88

Table 53: Spearman’s correlation table between the assumption that PVS is a valid concept and the way PVS patients are protected by the law.

The thematic analysis for the questionnaire's response to Q25b

This section is the qualitative analysis of why the participants believed that the law adequately protects individuals in PVS.

Moral obligations	**Legal Principles**	**Medical evidence**	**Rights and laws**
Advocacy Equality	Legal proceedings Best interests Surrogate decisions Legal precedence	Lack of knowledge uncertainty Evidence based	Human rights Statutory instrument Specific laws Other rights

Thematic framework for the questionnaire response to Q25b

Reporting

The laws around withholding and withdrawing treatments in people diagnosed with PVS aim to safeguard these individuals. However, opinions regarding the adequacy of these laws vary depending on which side of the argument one supports. This question was intended to the views of the healthcare professionals on how well they think the law protects PVS patients. The thematic analysis of their response is grouped under four themes below:

1. **Moral obligations:**

The participants believed that the doctors' moral obligation is to protect the PVS patients. While some believed that there should be increased advocacy on protecting PVS patients' rights, others felt that there are enough protections in the law for these patients. Below are some of the comments to the question:

Participant Q2501 wrote, '…*they have no voice* ….'

Participant Q2535 wrote, '…. *As long as they live, caregivers are mandated to treat them as they treat other human beings*….'

2. **Legal Principles**:

Some of the participants believed that the application of the various legal principles has helped in safeguarding the interests of PVS patients. Some also believe that surrogate decision-making is regulated and that the legal proceedings and legal precedence are instruments to protect PVS patients. Below are some of the comments to the question:

Participant Q2508 wrote, '…*patients have to be brain stem dead before the withdrawal is acceptable and this takes multiple opinions and Courts if there are issues* ….'

Participant Q2503 wrote, '…*Court hearings are used in ethically challenging cases*….'

Participant Q2504 wrote, '…*difficult to assess best interests; however, quality of life will differ between individuals* ….'

3. **Medical evidence**:

The availability of evidence and the knowledge of the condition is important in ensuring that the law protects the patients. The uncertainty around recovery and prognosis is an important drawback in protecting their best interests. Below are some of the comments to the question:

Participant Q2523 wrote, '…*law can measure objective evidence. PVS has much unmeasurable evidence that can be felt only by his or her relative. Hence it will be difficult to protect a person in PVS by law* ….'

Participant Q2512 wrote, '…*there is no clear evidence-based decision making which we can depend on decision making in case of PVS* ….'

Participant Q2533 wrote, '…*I am not sure of the legal protections afforded*….'

4. **Rights and laws:**

The respondents have also mentioned the roles of specific laws and statutory instruments in protecting the rights of PVS patients. Some pointed out human rights law specifically. Below are some of the comments to the question:

Participant Q2513 wrote, '…*they come under human rights act but unsure if adequately cover* ….'

Participant Q2516 wrote, '…*they cannot decide for themselves so specific laws have to be used to avoid abuse* ….'

Participant Q2518 wrote, '…*still have rights under the law as any other patients* …

Participant Q2534 wrote, '…*they are not classified as having human rights as they have no cognitive functions* …

The thematic analysis for the questionnaire's response to Q26

This section is the qualitative analysis of why the participants considered PVS to be a valid concept

Defined criteria	**Evidence based medicine**	**Clinical presentation**	**Anatomical**
Timeframe Established concept. Terminology Descriptive	Research Syndrome	Clinical experience Ethics Clinical entity	Cortical function

Thematic framework for the questionnaire response to Q26

Reporting

This question was intended to view the opinions of healthcare professionals on why they would consider PVS a valid concept. The thematic analysis of their response is grouped under four themes below:

1. **Defined criteria:**

Some healthcare professionals believe that the concept of PVS is valid because clinicians recognise the concept with its medical description and that the terminology is characterised in the literature. In addition, the timeframe for the definition is another reason for accepting the concept.

Below are some of the comments to the question:

Participant Q2626 wrote, '*…it is a valid concept because the criteria for making such diagnosis are well explained and outlined ….*'

Participant Q2616 wrote, '…. *PVS is a concept of disorder of consciousness and wakefulness which refer to neurocognitive status following brain injuries*….'

Participant Q2624 wrote, '…*it is a loose term to describe a complete dependency on medical treatment at a high level to sustain physiological life*….'

2. **Evidence-based medicine**:

According to some participants, the concept's validity is based on the evidence and the research done in the area.

Below are some of the comments to the question:

Participant Q2606 wrote, '…*research has taken place around the subject area*….'

Participant Q2612 wrote, '…*based on research*….'

Participant Q2618 wrote, '…*explains syndrome in easy to understand manner and broad to cover causes*….'

3. **Clinical presentation**:

Other respondents said that the concept must be valid since there are clinical presentations typical of the condition.

Below are some of the comments to the question:

Participant Q2628 wrote, '…*it is clinically demonstratable* ….'

Participant Q2607 wrote, '…*previous clinical experience*….'

Participant Q2622 wrote, '…*I cared for a wife in PVS ...after a while, I could feel there is something there, but cannot explain*….'

4. **Anatomical:**

Lastly, some believed that the presence of an anatomical representation of the condition is a testament to the validity of the state.

Below are some of the comments to the question:

Participant Q2608 wrote, '…*I feel this is relevant to patients whose brain stem is intact….*'

Participant Q2632 wrote, *'…PVS is unique and is an irreversible state of unawareness… we should have a low threshold to allow natural death in them in their best interests…*

5.3. Conclusion

In summary, the finding from the empirical research suggests that the timeframe given by the MSTF on PVS in defining permanence in VS could be reliable. This finding is in line with research done in the past. Despite the majority of the respondents agreeing with the timeframe used in diagnosing PVS, they thought that persistent would be the more appropriate term for describing this condition. A significant percentage of the respondents believed that the reasons for late recovery seen in the literature is not due to these timeframes but misdiagnosis and technological advancements from the time of diagnosis. However, the analysis of the data revealed that there was no statistically significant correlation between misdiagnosis/ technological advancement and late recovery. It was also found that two-thirds of the respondents agreed that withdrawing CAHN would result in death. However, there was no statistically significant correlation between the reliability of the timeframe used in defining PVS and the assertion that withdrawal of CAHN cuts PVS life short. The analysis of the data obtained revealed that there was no statistically significant correlation between the reliability of the time criteria for defining PVS and the use of persistent or permanent in describing VS. In addition, there is no statistically significant correlation between the acknowledgement of the GMC guidance on the treatment of PVS and the usefulness of the guideline. Finally, there was a statistically significant correlation between misdiagnosis and the preference for persistent as the more appropriate word to qualify VS. It is therefore concluded that there is a relationship between the accuracy of diagnosis of PVS and how these patients are treated in the UK.

Furthermore, four out of every five respondents agreed that WWLSI in PVS could be in their best interests and that the practice could be morally and ethically justified. In addition, two out of every three respondents agreed that PVS patients have interests and that the law should protect these interests. Around 84% also agreed that they have human rights which should be protected. Interestingly, only one in every three respondents was aware of the GMC guideline on managing patients in PVS. However, just over half of them agreed that the guideline helps make decisions in challenging cases. Three out of every ten respondents agreed that withdrawing CAHN can be likened to starvation and should be seen as inhumane treatment. In comparison, four out of ten respondents disagreed with this assertion. Around 41% of the respondents agreed that withholding LSI is ethically the same as withdrawing LSI, while 36.7% disagreed with this statement. Similarly, 45.6% of the respondents agreed that withholding LSI is morally the same as withdrawing LSI, while 28.9% disagreed with the assertion. Furthermore, around 48% of the respondents agreed that the law adequately protects PVS patients in the UK. However, a sizeable 20.5% still believed that the law does not adequately protect these patients.

Further, the data analysis using Spearman's ranking correlation coefficient showed no relationship between withdrawing LSI and the idea that PVS has no interest. Similarly, there was no relationship withdrawing CAHN and human rights. In addition, there was no relationship between whether PVS is considered a real clinical state and the protection the patients received under the law. Moreover, there is no relationship between whether PVS is a valid concept and the protection PVS patients get under the law. However, there is a relationship between the ethical and moral stance of withholding and withdrawing LSI in PVS. In addition, it was concluded that withholding and withdrawing LSI are ethically and morally the same. There is a relationship between the protection received by PVS in the UK and the assumption that they have human rights which should be protected.

In conclusion, the healthcare professionals agreed that overall, the law in the UK recognises that PVS patients have human rights and interests. However, there are still controversies over withdrawing/withholding nutrition and hydration. Many believed that, in some cases, WWLSI might be in their best interests and, therefore, ethically and morally justified. The most intriguing finding in this study is that the way the law treats PVS patients in the UK is independent of whether PVS is a real clinical state or a valid concept. Therefore, it would not be farfetched to say that even though the law protects PVS patients, there is still a lot to be done to understand this clinical condition and improve the law to protect these patients adequately. Lastly. the high proportion of response saying neither agree nor disagree buttress the point that there is a lot of uncertainty regarding the medical, ethical, and moral status of these patients such that answering a straightforward yes or no question might not be enough to tackle the daily issues confronted by healthcare practitioners when caring for patients with PDoC. Asking a yes or no question will not tease out the emotions behind the answers and is likely to lead to reduced response rate to questions where the respondents neither agree nor disagree. It will then be difficult to understand why they left the question unanswered. Therefore, putting the answer on a scale gives more perspectives to the responds from the participants.

CHAPTER SIX

Overarching discussion, Conclusions, Reflections and Recommendations

6.1 Discussion

Controversies around PVS in the UK are an ongoing and unresolved issue in the bioethical and medical law fields. Medical bodies like BMA and GMC have adopted policy statements regarding the treatment of and care for such patients, but this has done little to resolve the tension between patients' relatives and caregivers.[1067] The mystery around this debate is how it has managed to persist despite available consensus about the decision-making process. This recent consensus posits that treatments can be held back or withdrawn from these patients provided the healthcare professional follows the appropriate decision-making processes.[1068] The decision-making processes referred to in this consensus entail ways of trying to find out what the patient would have wished. Some of the common ways endorsed for the determination of the patient's wishes in this consensus include advance directives, contemporaneous decisions, or surrogate decisions.[1069] Why, then, is this consensus not adequate in the cases of patients in PVS to determine whether to continue medical treatments? Medical ethics involves attempting to come to terms with scientific discoveries. The same is true for medical law, which evolves significantly to accommodate emerging scientific discoveries. The law-medicine relationship is confronted with the challenge of having to technological and scientific innovations.[1070] Medicine is a scientific field that is not static. Innovations often arise with continuous research and technological advancements. Sometimes, a therapeutic advancement in medicine may pose a problem for the law, thereby challenging the law to evolve to accommodate such therapeutic advances. This clash between the law and

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[1067] John Harris, The Value of Life (Routledge London, 2009).

[1068] An NHS Trust and Others v Y and Another [2018] UKSC 46.

[1069] MCA 2005 sections 4 & 9.

[1070] University of California - Los Angeles, 'Scientists jump-start two people's brains after coma' (ScienceDaily, 27 January 2021) <www.sciencedaily.com/releases/2021/01/210127140035.htm> accessed 27 June 2021.

therapeutic advances is evident in the case of the increasing ability of the medical profession to prolong lives.

Ever since PVS has been described in the literature, the legal system has grappled with some of the hardest questions ever raised in the history of medical law.[1071] One of these questions is whether or not the law should allow the termination or continuation of life-sustaining treatments for patients in PVS. Criticism of the law generally focuses on the inconsistencies within the law and the underpinning doctrines. The fundamental question of how long a patient should stay in VS before he or she can be labelled as PVS has remained controversial. The MSTF proposed a timeframe of six months following a non-traumatic aetiology and one year following a traumatic aetiology.[1072] This proposal was given after the outcomes of 434 patients in VS after head injury were studied over a period of time. Notably, 46 percent of the patients recovered after six months and 52 percent after 12 months.[1073] Seven patients recovered after 12 months, and only one patient at 30 months. For non-traumatic aetiology, 11% (n-169) recovered within three months of injury while an additional 2% recovered at six months. In one year, 15% had recovered, 32% remained in PVS, and 53% had died.[1074] Although subsequent studies have exhibited an improvement in survival and outcomes over time, the diagnostic guidelines remain unchanged.[1075] Some studies proposed that the average survival in VS is 3-4 years, while some of them can live for up to 20 years, there have been reports of someone living for 40 years.[1076] However, they usually die within 9 to 14 days after the removal of nutrition and hydration.[1077] The extent and scope of the controversy around

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[1071] Singer (n 679).
[1072] The Multi-Society Task Force on PVS (n 9).
[1073] Ibid.
[1074] Ibid.
[1075] Elena Aidinoff and others, 'Vegetative state outcomes improved over the last two decades' [2018] 32(3) Brain Injury <https://doi.org/10.1080/02699052.2017.1418535> Accessed 25 March 2021.
[1076] Keown (n 1046).
[1077] Jenny Kitzinger and Celia Kitzinger, 'Deaths after feeding-tube withdrawal from patients in vegetative and minimally conscious states: A qualitative study of family experience' (2018) 32(7) Palliative medicine <https://doi.org/10.1177/0269216318766430> accessed 21 June 2021.

the scope of the concept of PVS have been understated. This thesis, however, has shed more light on these issues by examining them through the clinical, philosophical, governance, legal, and practitioners' perspectives.

The inability to detect consciousness in these patients remains a source of concern to many people because the fact that the available technology cannot detect consciousness does not necessarily mean that the patients are unable to sense what is going on around them. The prevailing approach to diagnosis is the medical reductionist approach, which confidently affirms that despite the lack of well-researched evidence of absence of consciousness, these patients lack awareness. Over the years, many researchers have posited that the seat of consciousness is somewhere in the cerebral cortex but recently researchers are now beginning to look at the brainstem (the RAS in the brainstem).[1078] Perhaps there is more to the science of consciousness than just the physical. At this stage, it is important not to discard the philosophical perspectives of the relationship between the brain, mind, and consciousness. The medical approach to consciousness postulated the existence of PVS as a real clinical state. This view is echoed in the practitioner's perspective from the analysis of data obtained in the empirical aspect of this research. However, the evidence from the systematic review of a wide range of views on consciousness tends to suggest that the PVS might not be a valid concept.

There were few studies in the literature which dealt with issues of classification of individuals with protracted unconscious state. A study in 2017 looked into the categorisation of patients with severe brain and proposed changing criteria for classifying Patients with PDoC.[1079] Earlier, a study in 2004 demonstrated the effects of medications on the conscious state of patients with brain injuries which might mimic a vegetative state.[1080] A study revised

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[1078] Mark Solms, *The hidden spring: A journey to the source of consciousness* (Profile Books, 2021).

[1079] Tim Bayne and others, 'Reforming the taxonomy in disorders of consciousness' [2017] 82(6) Annals of neurology <https://doi.org/10.1002/ana.25088>accessed 23 May 2021.

[1080] Strens and others (n 198).

a patient's diagnosis after 20 years of being labelled PVS.[1081] It was found that the patient was fully conscious after repeated standardised behavioural examinations complimented with neuroimaging studies, and the researchers revised the diagnosis to partial locked-in syndrome. Similarly, a study found that the predictors for recovery were too vague, which thus cast doubts on the reliability of these criteria.[1082] Another recent study showed that around 46% of patients (n-50) recovered from the state of unconsciousness following both traumatic and non-traumatic brain injuries between 64 to 1197 days.[1083] Interestingly, these criteria only focused on how long the patient has been in VS and the aetiology of the injury; however, there are other equally important factors such as age, co-morbidities, and availability of relevant technology. There are no studies on how VS patients lose or regain consciousness. It is doubtful if they lose consciousness; perhaps it is there, but the technology available is unable to pick it up.

Withholding and withdrawing treatment is not an unusual practice in medicine, but what makes the practice contentious in PVS is the lack of a well-grounded evidential basis for the clinical syndrome of the disorder of consciousness. When patients are dying, it is not unusual to cease futile and burdensome treatment. There are clear guidelines on managing patients at the end of life and the role of palliative care in this stage.[1084] However, there are several reasons why this practice may appear to be controversial in PVS. These reasons were evaluated in this thesis. Since PVS patients are technically not approaching the end of life, even though they might be treated as such, then acts or omissions that may shorten their lives need to be carefully

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[1081] Audrey Vanhaudenhuyse and others, 'Conscious While Being Considered in an Unresponsive Wakefulness Syndrome for 20 Years' (2018) 9(671) Frontiers in neurology <https://doi.org/10.3389/fneur.2018.00671>accessed 2 May 2021.

[1082] Inga Steppacher and others, 'Will time heal? A long-term follow-up of severe disorders of consciousness' (2014) 1(6) Annals of Clinical and Translational Neurology <https://doi.org/10.1002/acn3.63>accessed 2 May 2021.

[1083] Hoo Young Lee and others, 'Neurobehavioral recovery in patients who emerged from prolonged disorder of consciousness: a retrospective study' (2020) 20(198) BMC Neurology <https://doi.org/10.1186/s12883-020-01758-5> accessed 23 May 2021.

[1084] NICE Guideline, 'End of life care for adults: service delivery ' (National Institute for Health and Care Excellence, 16 October 2019) <https://nice.org.uk/guidance/ng142/resources/end-of-life-care-for-adults-service-delivery-pdf-66141776457925> accessed 24 June 2021.

examined. The principlism approach to decision-making used by clinicians has been criticised by a few bioethicists. These principles can be used to guide clinicians in decision-making, but when there are clashes between these principles, there is no guidance on how to resolve these clashes.[1085] Other bioethical principles in the literature were also looked into in this thesis but their usefulness, by and large, remains equivocal.

The critique of the relevant case laws involving the withdrawal of LSI and CAHN in PVS/MCS using ethical and philosophical benchmarks revealed that legal doctrines used in these cases are largely limited to autonomy/best interests, futility, and quality of life and to a limited extent, the sanctity of life. There are also some inconsistencies in the application of these legal principles. Other approaches to balanced decision-making in PVS were explored as well. The normative-ethical approaches were promising but the complexities of the thought process involved with the use of these philosophical theories curtail their practical utilisation. In this context, the ethical calculations involved in the process are complex and more importantly, some critics have said that the two main approaches (consequentialism and non-consequentialism) are not mutually exclusive.[1086] The human rights approach to decision-making in PVS seems credible but it is not impervious to some drawbacks. For example, even though many people would agree that PVS patients are severely disabled, they are often treated as if they are dying. They are, therefore, not usually covered by the human rights protections enjoyed by people living with a disability.

A worth-based approach to decision-making for PVS was suggested by this study. There are various views on the worth of human life, human dignity, and personhood. The idea of personhood as it relates to rationality, self-awareness, and consciousness was explored together

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[1085] Walker (n 523).

[1086] Sheila Bonde and Paul Firenze, 'A Framework for Making Ethical Decisions' (Brown University, May 2013) <https://www.brown.edu/academics/science-and-technology-studies/framework-making-ethical-decisions> accessed 24 June 2021.

with the notion of human dignity. It was postulated that respect for human dignity and personhood would guide decision-makers to making a well-balanced treatment decision for people labelled as in a PVS. Although there are a lot of unanswered questions about consciousness (or its absence) in the patients labelled with PVS which researchers will continue to explore, the acknowledgement that everyone has dignity and therefore be treated as a person with inherent worth will change the way PVS are cared for in the UK.

The main significance of this thesis lies in the exploration of the concept of PVS, which is widely acknowledged to be controversial. However, some aspects of the controversies which have a potentially very significant bearing on practice and its governance have not yet been robustly addressed in the existing literature. These include - whether widespread assumptions that the state clinically exists are properly evidentially grounded and what the implications for governance and practice are if it cannot be. To contextualise this element of the controversy, it is worth reflecting back on the fact that there used to be significant debate about whether the P stood for permanent or persistent until it became evidentially clearer over time that even some patients who, according to established criteria were correctly diagnosed as being persistently vegetative, were coming out of this state. Some of them even went on to lead relatively functionally 'normal' lives. During the Court proceedings in *Bland,* Hoffman L.J. said that we only have interests in things that we have conscious experience.[1087] The move to the term persistent was an acknowledgment in this respect that, notwithstanding doubts about whether it was consistent with the inherent worth or dignity of human beings to ever describe any of them as not having any interests, those in PVS could undeniably be said to have an interest in potential recovery. Whilst this was all well and good, it did not lead to any kind of fundamental reappraisal of whether it was legitimate to label any living beings as vegetative. Aside from its naturally derogatory connotations, the term vegetative would seem to be problematic because

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[1087] *Airedale National Health Service Trust v Bland* [1993] AC 789 [829] (Hoffman LJ).

it is used to define a person as not only lacking in discernible interactive capability but as actually objectively lacking upper brain function and, relatedly, consciousness. The significance of this has not been explored by practice, its governance, or even the literature. In the course of this thesis, I exposed and critically explored the implications of these issues which I set out in my research objectives at the outset of this research:

1. Whether the claimed lack of discernible interactive capability is in some or all cases attributable to not using all the measuring tools at our disposal;
2. Whether it is ever possible to say a person objectively lacks interactive capability given that measuring tools only ever tell us that they can or cannot measure something which is not necessarily the same as determining for certain that it does or does not exist;
3. Whether the heart of the notion of PVS – the notion of loss of upper brain function and related consciousness and a supposed potential for its recovery – is properly evidenced.

In this context, there are questions about what is meant by consciousness (neither it nor the concept of awareness has been well researched or understood), whether there is any actual concrete evidence as to its being lost, or whether supposed cases of its returning might actually evidence that it does not go away (casting doubt of the extent and very existence of the state as defined respectively) in these cases or more generally, what possible inferences or assumptions are being made about consciousness, brain, and their interconnectedness, as well as how these inferences or assumptions relate to or are potentially grounded in ideas and theories about the nature of what it means to be human. By addressing these issues in detail, the thesis was able to provide a more considered and holistic answer to the questions of whether some or all individuals in deemed in PVS might be more aptly described as in fact, another, state and, if so, what that state might be better described and what, if any, implications this might have for the reform of governance and practice.

A second aspect of the significance of the thesis concerns the way it adds to our understanding of what professionals who work with patients deemed in PVS know, experience, and think, via an original programme of research conducted with a significant number of them. This aspect of the research is important because it brings into perspective the importance of all the issues raised about the concept of PVS, how practitioners see them, and what effects they have on their practice. Furthermore, it gives a comparative lens to what they know, feel and experience against what they should know about the subject. Besides enriching our understanding of the notion of PVS in relation to the law, the empirical aspect of this research aimed to strengthen our understanding of the interaction of professional attitudes, practice, policy, and governance since they pertain to the diagnosis and treatment of people deemed to be in PVS. The three main research questions asked in this empirical programme focused on: Issues around diagnosis, prognosis, and care of PVS patients; issues around recovery and artificial nutrition; and issues around withdrawal of treatments and the process of withdrawal. It is anticipated that this holistic approach would stimulate a rethink in the practice of treatment withholding and withdrawing in PVS.

6.2. Conclusions and reflections.

Following an extensive literature review of the origin of the concept of PVS and related lack of consciousness in this research, there is substantial doubt in the conceptualisation of the PVS notion. The characterisation and classification of the condition with a timeframe are based on research that was not well grounded. The hard question of where consciousness emanates from in the brain and how it is temporarily lost or deactivated in dreamless sleep, under general anaesthesia, and in the aftermath of brain injury remains unaddressed. The use of modern-day technology like fMRI, PET scan, and EEG has yet to give any answers. Even some invasive procedures like the stimulation of deep brain substances have not yielded any positive results in this regard. A philosophical exploration of the PVS concept suggests that there is a mental component to the consciousness/ brain debate which is yet to be fully explored. Therefore, there is no strong evidence to support the assumption that the loss of the upper brain function in brain injury is attributed to the lack of consciousness. There is emerging evidence to support the assertion that the claimed lack of discernible interactive capability in some of these patients is because the modalities available are not superior enough to detect objective evidence of consciousness. It is possible that in the future, the advancement in technology would reach a point where clinicians can objectively measure or detect evidence of consciousness in the brain. Until then, it is necessary to revisit how we define these people and how we treat them.

The critical appraisal of how the clinicians diagnose the condition in practice showed that there are a lot of subjective pieces of evidence relied on by them to make the diagnosis. Even standard scales and scores used, the lack of modalities to confidently evidence lack of consciousness has increased the rate of misdiagnosis. The exploration of the law revealed internal inconsistencies in the application of legal principles. Furthermore, the application of the MCA 2005 in assessing best interests has subjective elements to it and is, therefore, open to varying interpretations. Furthermore, the definition of CAHN and its withdrawal remains controversial. Human dignity arguments and human rights arguments are rarely used in these cases. The governance related to the practice of withholding and withdrawing LSI in PVS is fraught with inconsistencies. The critique of the professional guidelines and ethical principle suggested that the principlism approach utilised by the clinician in making decisions for these patients after a positive diagnosis of PVS is made is insufficient when it comes to addressing a plethora of moral and ethical questions raised. The PVS patients are treated like they are approaching the end of life even though research suggests that some of them live for more than 10 years.

The findings of the empirical aspect of this research are highlighted below.

1. There was a strong association between the two aetiologies of brain injuries in PVS (p=.000). Therefore, the cause of the brain injury in PVS patients has no bearing on the fundamental flaw in the characterisation of the condition.
2. There was a statistically significant correlation between the inability of the available technology and misdiagnosis of PVS (p=.046).
3. There was a statistically significant correlation between misdiagnosis and preference for persistent as the more appropriate word to qualify *(*p=.008).
4. There was also a statistically significant correlation between the assumption that withdrawing and withholding LSI in PVS is ethical and that the practice is moral. (p=.000).
5. There was a significant association between the idea that withholding and withdrawing LSI are ethically the same and the idea that withholding and withdrawing LSI are morally the same *(*p=.000).
6. There was an association between the assertion that PVS patients are adequately protected by the law and the idea that PVS patients have human rights *(*p=.040).

It was therefore concluded in the empirical aspect that there is a fundamental flaw in the criteria for defining irreversibility in patients with VS. Furthermore, the reason for misdiagnosis is the inability of the available technology to detect consciousness. The majority of the healthcare professionals who participated in the study agreed that PVS is a real condition and, therefore, a valid concept. However, less than half of the respondents concurred with the timeframe used in defining irreversibility in PVS, and two-thirds of the respondents agreed that withdrawing nutrition and hydration in PVS patients shortens life. Spearman’s correlation revealed an association between misdiagnosis and irreversibility. Therefore, it was concluded that there is a relationship between the accuracy of the diagnosis of PVS and the manner the law treats these patients in the UK. The majority of these respondents agreed that PVS patients have human rights which need to be protected, but four out of every ten respondents believed that withdrawing nutrition and hydration could be likened to starvation and thus, seen as inhumane treatment. However, no relationship was found between the idea that the act of withdrawing CAHN in PVS is inhumane and the assumption that PVS patients have human rights. There was no relationship between views on the way the law protects PVS patients and whether PVS is a valid concept or not. It is indubitable that the law safeguards the human rights of PVS, but a lot needs to be done in the aspect of treatment withdrawal, especially with hydration and nutrition.

In summary, it is concluded that even though PVS is being acknowledged by the medical profession as a real clinical state, there are compelling reasons to query the validity of the notion. Consciousness is both a contested and not well-understood concept and it is difficult to reach a consensus on what we should measure when trying to evidence its absence. The absence of a specific neurophysiological pattern in the brain that is pathognomonic of consciousness makes its successful measurement improbable. This measurement problem undermines claims of the absence of consciousness when the measuring instruments cannot detect it, which does not prove its absence. The empirical aspect of the research showed that the inability of the available technology to detect consciousness is the reason for misdiagnosis in PVS. Furthermore, the empirical study also revealed an association between the accuracy of PVS diagnosis and how the law treats PVS patients. Thus, the thesis also concluded that the vegetative label gives a derogatory impression of a condition that is not well understood in terms of how people lose and regain consciousness. Owing to the above reasons and the internal inconsistencies of the law in the way PVS patients are treated, it can be surmised that much more work still needs to be done in order to ensure that the law adequately protects PVS patients in the UK. Further research is needed to understand the concept of consciousness and how it can be objectively measured in the clinical setting and how we can communicate with these patients who appear to be unreachable following brain injury. Furthermore, the policymakers are recommenced to establish an independent body to review the ethics of withdrawing treatment in PVS on an individual basis to protect their interests further.

6.3. Recommendations

1. This research has exposed some fundamental issues with the notion of PVS and how they affect the diagnosis and the subsequent management of the patients deemed in PVS. The lack of a well evidenced theoretical approach to consciousness concerning the PVS label calls for revisiting the classification of patients with prolonged unconsciousness. The term vegetative gives a derogatory connotation to the patients - it is, therefore, recommended that the labels vegetative, vegetative state, and persistent vegetative state no longer be used, ideally being replaced by a phrase that reflects both the fact that the lack of awareness of surroundings has been identified and the fact that it is not possible to make conclusions about consciousness from this. It is possible to adequately address the epistemic uncertainties regarding PDoC if we can prove beyond reasonable doubt that the proposed treatment withdrawal or withholding is in the patient's best interests. However, the problem here is that the assessment of the best interests of PDoC patients is difficult because it is impossible to know for certain how they are feeling. Their best interests cannot be discussed with certitude when we do not know how they are feeling. How can we prove beyond reasonable doubt that something is in the patient's best interests? At best we can say that any assessment of best interests in the context of PVS is purely speculative especially when it comes to WWLSI. Since we don't know what is going on in PVS there should be a demand for robust evidence that the best interests are served by WWLSI. The evidence should not be marginal but should be strongly in favour of WWLSI and the burden of proof for best interests should not be based on the balance of probability. There

is an uncontroversial presumption in favour of the preservation of life in the UK; however, what does it mean in the context of PVS when we do not have an understanding of what is going on in the person. Unless there is advanced refusal, there should be robust evidence of WWLSI. Notwithstanding what PVS means, it is their will to continue or forfeit lifesaving treatment if they have the capacity or advanced directive that matters. Beyond that, it is difficult to see any situation where WWLSI should be justified. If one doesn't know what their state, is it is difficult to comment on their quality of life.

2. There is a need for further research into the relationship between the brain and the associated absence of consciousness or otherwise in patients with brain injuries. Firstly, we need to understand how people temporarily lose consciousness in a normal physiological process like dreamless sleep and how they momentarily gain it back. Then an exploration into what happens when people are put to sleep medically, such as during general anaesthesia. This will provide clues as to what happens in pathological states like PVS. It is anticipated that more research in this field will shed more light on the inadequacy of the existing diagnostic criteria of PDoC and perhaps confirm that these patients have an innate conscious mental state which is never lost. This, in turn, will lead to a fundamental reappraisal of the clinical and legal management of PDoC patients. In addition, research into developing more sophisticated dynamic neuroimaging technologies and even the use of artificial intelligence in this area of medicine will improve the understanding of the mystery of consciousness in relation to brain.

3. There should be a change in the governance and practice of treatment withdrawal and withholding in PVS patients. The ethical principles should be revised to show respect for inherent human dignity and personhood. Furthermore, the policymakers should look into setting up multidisciplinary panels that can decide on treatment options for patients with severe brain injury on a case-by-case basis. This will improve the way decisions are made and reduce the unnecessary delays and financial burden incurred when cases go to Court. Setting up

nationwide multidisciplinary panels to adjudicate the management of PDoC cases will help improve the decision-making process and improve the general public confidence in the medical decision-making regarding PDoC. Each panel should consist of a neuro-rehabilitation specialist or neurologist, two representatives from the family, an Allied health worker (Occupational therapist, physiotherapist, or social worker), bioethicist and a lawyer. Putting a lawyer and a bioethicist on the panel would help give direction on legal and ethical issues around the proposed course of action. In addition, having two family members in the family would ensure that they don’t feel isolated. The job of the panel is to work out what would be in the patient’s best interests and agree on treatment options. As it stands, there is no comparable panel in NHS today. There are informal MDT discussions at the hospital level which usually comprise doctors, nurses and allied health, and possibly the patient’s relative. The proposed panel will represent a formalised robust system with added experts who will give advice on ethics and law regarding WWLSI. The panel will arrive at a decision by a two-thirds majority show of hands and contribution from each group of representatives should be weighted equally. This means that if the clinicians agree on a course of action then they will need at least the lawyer and the bioethicist to agree with them. There is a risk of uniformity in clinical option even if the family disagree, at the very least the bioethicist and the lawyer should agree. The length of time needed to reach a decision should be decided on a case by case basis. This stakeholder panel will be relevant to the judicial process in the sense that the judges will take into account what has happened in the panel. The panel would be seen as a robust setting that is capable of making a well-balanced decision. The cases emanating from these panels would carry much weight from the judiciary's point of view. Such decisions would be treated as more persuasive. Since there is a strong presumption in the favour of preserving life, the danger of the panel is that it could be used to provide legitimacy for preserving life. My view is that anything that falls short of advanced refusal, all cases should be treated unless the court says that withdrawing treatment is in the patient's best interests.

4. Every human has inherent dignity, and most of what we are is the unconscious. How every person perceives the world around them is only accessible to them regardless of how they look to others or what other people think about them. Consciousness should not be a yardstick to measure whether someone would receive treatment or not. Therefore, the unconscious should be protected by the law and professional ethical codes.

Lastly, the proposed changes in this thesis will positively impact the governance and practice of withholding and withdrawing treatments in a patient with severe brain injury in the UK in the following ways.

I. By revisiting the professional guidelines on the management of patients with severe brain injury and the diagnosis criteria of PVS (or better still, ditching the 'PVS' altogether), decision-making about treatment options would be easier as there would be less emphasis on whether or not they are conscious.

II. By adopting a nationwide robust best interests' determination and decision-making body to adjudicate on the issues of withholding and withdrawing LSI, the level of confidence in the decision-making process would be increased and fewer and fewer cases would end up in courts which in turn will reduce time and resources spent on the legal process. Streamlining the process of decision-making will reduce time and cost.

III. By adopting a dignity and personhood approach to decision-making in severely brain-injured patient, every patient is given the benefit of doubt and have a fair chance of recovery from the brain injury. Unless there is a binding advanced decision to refuse LSI, all "PVS" patients would be treated like any other adults who lack capacity.

IV. The proposed changes will affect the manner in which patients are investigated and treated. By adopting a stepladder approach to ancillary investigation and treatment, the overall cost of managing patients with severe brain injury would reduce. Furthermore, expanding the scope of early neurorehabilitation will reduce long-term disability.

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Participant information sheet

Dear respondent,

My name is Dr. Olabode B Aleshinloye, a Doctoral Researcher in Health Law and Ethics, at the Nottingham Law School, Nottingham Trent University, Nottingham. I am conducting an empirical research on the issues around diagnosis and treatment of patients deemed to be in persistent vegetative state (PVS). The title of my project is ***'A critical analysis of the protection afforded to individual in PVS with reference to withdrawing and withholding interventions'*** and I would like to invite you to participate in the empirical aspect of it via filling in the enclosed questionnaire and related consent form and returning them to the designated place as provided by the person handing over the questionnaire to you. The questionnaire will take you approximately 10-15 minutes to complete. You are by no means under any obligations to participate in the study. Should you choose to participate, it is envisaged that this would contribute to improving understanding of the nature of the views of doctors and nurses working in the NHS as they pertain to the diagnosis and treatment of patients in PVS and how these views interact with professional attitudes, practice, policy, governance and law. I am looking for your opinions/views on this subject matter and not your explanation or understanding of the position that the law takes on any of the issues raised in the questionnaire.

Be assured that if you choose to participate any information you share through filling in and returning the questionnaire and consent form will be kept completely confidential, and you will not be identified in any way. Please return the questionnaire and the signed consent form in separate envelopes. Participation is entirely voluntary. You will not be prejudiced in any way if you choose not be involved in the study. More importantly, you have the rights not to take part, and to withdraw from the study without having to give any reason for doing so and there will be no repercussions exercising this right. Withdrawal from the study can be achieved by not returning the questionnaire. However, your return of the questionnaire and the consent form will serve as a statement of consent that you agree to take part in the study. Finally, this participants information sheet only gives an overview of the research project. Should you have any questions, please contact:

Dr. Olabode B Aleshinloye (Principal investigator)
Doctoral Researcher in Health Law and Ethics, Nottingham Trent University, Nottingham
Email: olabode.aleshinloye2015@my.ntu.ac.uk; Phone: +447534368959

In case of any complaints or queries please contact: Dr. Austen Garwood-Gowers
Reader, Nottingham Law School, Nottingham Trent University, Nottingham.
Email: austen.garwoodgowers@ntu.ac.uk; Phone: +44 115 84 86107

Thank you most sincerely for your help.

Consent Form

I voluntarily consent to participate in this study. In completing this form, I certify that I am 18 years of age or older. I shall be given a copy of this consent form to keep.

__________________________ ____________________
Participant's signature Date

I certify that I have presented participant information sheet to the participant

__________________________ ____________________
Researcher's signature Date

……………………………………………………………………………………………….....................

A SURVEY ON THE DIAGNOSIS AND TREATMENT OF PATIENT IN PERSISTENT VEGETATIVE STATE

Dear respondent,

This questionnaire contains brief scenarios of hypothetical persistent vegetative state (PVS) case followed by a mixture of both open ended and close ended questions. Please tick or circle the box that corresponds to your view/opinion on the close-ended questions and write your views in the space provided for the open-ended questions.

Scenario 1: Acknowledging PVS as a clinical state and making a diagnosis

> *Mr XY was involved in an accident while playing rugby, he became unconscious and was admitted to the intensive therapy unit where he was stabilized. After a few weeks he was noticed to be in a state of partial arousal but unaware of his immediate environment. He was subsequently deemed to have lost his higher cortical brain function but still has an intact brainstem.*

Use the above scenario to answer questions 1 to 10 on a scale of 1 to 7; 1 if you strongly disagreed, 4 if you neither agree or disagree and 7 if you strongly agreed.

1. Mr XY can be said to be in a vegetative state.

1	**2**	**3**	**4**	**5**	**6**	**7**

2. If Mr XY remains in this state for 12 months, he can be labelled as been in persistent vegetative state.

1	**2**	**3**	**4**	**5**	**6**	**7**

3. If Mr XY's cause of brain injury is non-traumatic, 6 months is enough to label him as been in persistent vegetative state.

1	**2**	**3**	**4**	**5**	**6**	**7**

4. Even though Mr XY is unaware of the environment, he may still be able to feel pain or get hungry.

1	**2**	**3**	**4**	**5**	**6**	**7**

5. Mr XY may never recover from this state after 12 months.

1	**2**	**3**	**4**	**5**	**6**	**7**

6. Mr XY may be considered as being severely disabled.

1	**2**	**3**	**4**	**5**	**6**	**7**

7. Mr XY may be considered as approaching the end of his life.

1	**2**	**3**	**4**	**5**	**6**	**7**

8. It is possible that Mr XY is aware of his environment but the technological modalities used are not able to detect this awareness.

1	**2**	**3**	**4**	**5**	**6**	**7**

9. The diagnosis may not be PVS (it could be any other form of prolonged disorder of consciousness).

1	**2**	**3**	**4**	**5**	**6**	**7**

10. Persistent vegetative state is a real clinical state.

1	**2**	**3**	**4**	**5**	**6**	**7**

Please state the reason why you agree or disagree with the last statement (Question 10).

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Scenario 2: Deciding 'permanence'

The doctors looking after Mr XY assessed him and conducted a series of ancillary investigations then diagnosed him to be in a vegetative state and after a year, persistent vegetative state. Mr XY's family were concerned about the possibility of stopping his life-sustaining interventions, so they asked for a second opinion. They also raised the question of misdiagnosis and late recover in individuals with similar diagnosis.

Use the above scenario to answer questions 11 to 15 on a scale of 1 to 7; 1 if you strongly disagreed, 4 if you neither agree or disagree and 7 if you strongly agreed.

11. The timeframe used to define permanence of vegetative state is reliable and evidence based.

1	**2**	**3**	**4**	**5**	**6**	**7**

12. Late recovery in PVS may be due to misdiagnosis of the initial condition.

1	**2**	**3**	**4**	**5**	**6**	**7**

13. Late recovery in PVS may be due to advancement in technology from the point of diagnosis.

1	**2**	**3**	**4**	**5**	**6**	**7**

14. The term ‘persistent’ is more appropriate than the term ‘permanent’ when referring to individual in vegetative state after 1 year.

1	**2**	**3**	**4**	**5**	**6**	**7**

15. The life expectancy of individual in PVS is usually cut short by withdrawing nutrition and hydration.

1	**2**	**3**	**4**	**5**	**6**	**7**

Please state the reason why you agree or disagree with the last statement (Question 15).

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Scenario 3: Deciding to withdraw treatment and the process of withdrawal

After 36 months, Mr XY did not make any significant improvement in his clinical condition. He was still on artificial nutrition and hydration (ANH) with occasional antibiotics treatment. He was fully dependent on other people for all activities of daily living. Consequently, the doctors looking after him suggested that the ANH used to sustain him should be withdrawn. The family objected to the proposed action and the case was taken to court. The court declared that it was not in Mr XY’s best interests to continue ANH and that it will not be unlawful for the doctor to withdraw such intervention. The intervention was discontinued and he subsequently died.

Use the above scenario to answer questions 16 to 25 on a scale of 1 to 7; 1 if you strongly disagreed, 4 if you neither agree or disagree and 7 if you strongly agreed.

16. Withholding and withdrawing life-saving interventions in PVS may be in Mr XY’s best interests.

1	**2**	**3**	**4**	**5**	**6**	**7**

17. Withholding and withdrawing life-saving interventions in PVS can be ethically justified.

1	2	3	4	5	6	7

18. Withholding and withdrawing life-saving interventions in PVS can be morally justified.

1	2	3	4	5	6	7

19. An individual in PVS has no interests.

1	2	3	4	5	6	7

20. An individual in PVS has human rights and these should be respected.

1	2	3	4	5	6	7

21. Are you aware of the ‘Treatment and care towards the end of life: good practice in decision making” guidance issued by the General Medical Council (GMC).

Y/ N

If your answer to the above question (Q21) is yes, would you say that the professional ethical guideline is helpful in making withdrawing and withholding decisions in PVS.

1	2	3	4	5	6	7

22. Withdrawing artificial nutrition and hydration in PVS can be likened to starvation and therefore seen as inhumane treatment.

1	2	3	4	5	6	7

23. Withholding and withdrawing intervention in PVS are ethically the same.

1	2	3	4	5	6	7

24. Withholding and withdrawing interventions are morally the same as regards PVS.

1	2	3	4	5	6	7

25. Human beings in PVS are adequately protected by the law.

1	**2**	**3**	**4**	**5**	**6**	**7**

Please state the reason why you agree or disagree with the last statement (Question 25).

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26. Overall, would you consider PVS to be a valid concept? Y/ N

Please briefly state the reason for your choice to the above question (Question 26)

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Demographics: *Please tick or circle as applicable.*

Age:

18-20	21-30	31-40	41-50	51-60	61-70

Profession:

Doctor	Nurse	Health care assistant	Others (specify)

Area of practice:

Anaesthetics	Medicine	A&E	Others (specify)