

University of Southampton

Faculty of Social Sciences

Law

**In Need of Reappraisal? Examining the Defensibility of the
Established Definition and Determination of Death Through its
Implications for Persons with Prolonged Disorders of Consciousness**

by

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Thesis for the degree of Doctor of Philosophy

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Abstract

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The practice of defining and determining 'who is dead' is no longer a medical or biological determination. It is instead a moral standpoint on what lives are not worth living; the traditional definition of death has been redefined and now retains merely a single foothold in biology. That single foothold seems to be the capacity to voluntarily respond above the level of reflex and may therefore explain how life support withdrawal is deemed defensible from living patients, even where their subsequent death is foreseen. Therefore, the practice impacts cognitive disability on the whole and not only those with prolonged disorders of consciousness, i.e., vegetative and minimally conscious state patients (PDOC patients). For example, how else could antibiotics be withdrawn from a dementia patient knowing that they will succumb to deadly infection? Nevertheless, this thesis explores the moral and legal justifiability of life support continuation decisions via a case study on PDOC patients. It seems that life support discontinuation from living patients who have lost the capacity to voluntarily respond also lose their personhood status: the recognition and endowment of equal moral and legal protection for those holding that inherently valuable characteristic of human life and may also demonstrate why the judgments' often-noted moral inconsistency cannot be explained by intention or causation-based arguments alone.

Therefore, the thesis argues that at the heart of best interests decision-making regarding life support continuation is a hidden war on personhood in which further skirmishes include: identifying the indicia of personhood, the justifiability of life support withdrawal from (living) PDOC patients and assessing whether best interests assessments are indirectly discriminatory to them. The answers to these questions are vital for exploring whether the definition and determination of death needs to be reappraised by legislators and medical regulatory bodies. The thesis' core question asks: is the definition and determination of death in England and Wales defensible, given its implications for PDOC patients? That core question is set within a philosophical framework to enable fair assessment which may also help answer whether such judgments can be accurately described as dilemmatic cases that employ values-based decision-making. Accordingly, the relationship between death, cognitive impairment and personhood is explored to challenge the adopted theory of social justice and demonstrate why it is not enough to assume that they are persons, nor that death's definition and determination does not impact PDOC patients in law and medicine.

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Research Thesis: Declaration of Authorship

Print name: Elizabeth Catherine Redrup

Title of thesis: In Need of Reappraisal? Examining the Defensibility of the Established Definition and Determination of Death Through its Implications for Persons with Prolonged Disorders of Consciousness

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signature:

Date:

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Definitions and Abbreviations

Note that concepts are defined in the "Glossary of Terms" at the back of this thesis.

Key Definitions

Awareness is the capacity to have or of having, experience of self and environment. It is used synonymously with "consciousness" in the medical literature as those who are asleep are still recognised as aware or capable of awareness, despite not being "awake".

Brain Death has two recognised forms, whole brain death (adopted in the US) and brainstem death (adopted in the UK). Both forms lack awareness, wakefulness and the capacity to independently breathe. The difference between brainstem death and whole brain death is that whole brain death requires ruling out all electrical brain activity, whereas brainstem death requires only the loss of brainstem reflexes because it is the part of the brain thought responsible for both the capacity to breathe and for awareness.

Clinically assisted nutrition and hydration is more commonly recognised as a feeding and hydration tube. It is used in PDOC patients' treatment to bypass the capacity to swallow which has been lost in such patients. Antibiotics are sometimes needed to fight infections that occur from having a foreign body inserted. It was formerly known as assisted nutrition and hydration (ANH).

Coma is a state of absent awareness and wakefulness where the patient demonstrates no response to painful stimuli. Sometimes the patient continues to breathe unassisted. The patient's reflexive level of responsiveness is also normally severely reduced. It is often a transitive state where the patient either improves or worsens within a few weeks.

Consciousness is a state of wakefulness and awareness. Wakefulness is a state where the eyes are open and there is a degree of motor arousal. Awareness is the capacity to have or of having, experience of self and environment.

Glasgow Coma Scale is a system designed to objectively assess the state of a patient's consciousness at initial injury and subsequent assessments.

Higher Brain Death is a theory that once the higher functions of the brain (associated with awareness) are lost, the individual should also be considered "dead" from a moral and

Definitions and Abbreviations

legal perspective. The theory can be split into two further camps of advocates: mentalist and embodied consciousness theorists.

Locked-in syndrome causes a disruption in the capacity to voluntarily control movement without abolishing wakefulness or awareness. Such patients are severely paralysed but are fully conscious and able to communicate through eye or eyelid movements. It is thought to arise from damage to the brainstem.

Minimally conscious state is a condition of severely altered consciousness in which minimal but definite behavioural evidence of self or environmental awareness is demonstrated. The disorder is less frequently referred to as the "cortically mediated state".

Permanent/ persistent VS have been used simultaneously as the acronym (PVS). Permanence is a diagnosis only given after six months of no improvement regardless of aetiology or whether the patient is in MCS (including irrespective of MCS plus or MCS minus) or VS. Persistence should no longer be used according to medical guidelines and instead "continuing" should be used to denote those who have been in a VS for more than four weeks.

Prolonged disorders of consciousness are disorders of awareness lasting more than four weeks (or more accurately responsiveness) and collectively refers to coma, vegetative and minimally conscious state patients. The patient shows wakefulness and a reflexive level of responsiveness to self and environmental stimuli, sometimes showing some voluntary responses. Voluntary response is more commonly referred to as "awareness" and is further used synonymously with "consciousness". Patients are generally young and may live for a decade or more.

Sensory Modality Assessment and Rehabilitation Technique is a clinical tool used to identify potential awareness in those who have sustained brain damage. Note that the term "SMART assessment" is used as a generic shorthand for formal structured assessment. It is not essential that SMART is used over GCS or WHIM according to the PDOC 2020 guidelines.

Terminal decline of consciousness (TDOC) refers to those at end of life with progressive degenerative brain damage, such as dementia, Parkinson's or those who have suffered

multiple strokes. Such patients are not expected to live more than 1-2 years with no potential for improvement.

Vegetative state is a consciousness disorder characterised by complete absence of behavioural evidence for self- or environmental awareness. Such patients breathe independently and require CANH to be fed and hydrated as they cannot consistently swallow without assistance. Such patients also demonstrate facial movements, grimace in pain, laugh, and cry without obvious stimuli. The disorder is sometimes referred to as "unresponsive wakefulness syndrome".

Wakefulness is a state where the eyes are open and there is a degree of motor arousal.

Wessex Head Injury Matrix is another clinical tool for assessing and monitoring the recovery of cognitive functions after head injury.

Abbreviations

AD(s) Advance Decision(s)

ANH assisted nutrition and hydration

AOMRC Academy of Medical Royal Colleges

BMA British Medical Association

CANH clinically assisted nutrition and hydration

CEDAW Convention on the Elimination of All Forms of Discrimination Against Women
1981

CMRC Conference of Medical Royal Colleges

Committee CRPD Committee on the Rights of Persons with Disabilities

COPR Court of Protection Rules

CRC Convention on the Rights of the Child 1989

CRPD Convention on the Rights of Persons with Disabilities 2006

DBD Donation after Brainstem Death (Heart-Beating Donation)

Definitions and Abbreviations

DCD Donation after Circulatory Death

DNACPR(s) Do Not Attempt Cardiopulmonary Resuscitation Order(s)

DOLs Deprivation of Liberty Orders

DROM Doctrine of Relativity of Morals

EBM evidence-based medicine

ECHR European Convention of Human Rights 1950

ECtHR European Court of Human Rights

EU European Union

E&W England and Wales

fMRI functional magnetic resonance imaging

GCS Glasgow Coma Scale

HRA Human Rights Act 1998

ICCPR International Covenant on Civil and Political Rights 1966

ICESCR International Covenant on Economic, Social and Cultural Rights 1966

ICERD International Convention on the Elimination of All Forms of Racial Discrimination
1969

ICU intensive care unit (UK)

IMCA Independent Mental Capacity Advocate

ITU intensive treatment unit (USA)

LIS locked-in Syndrome

LPA(s) Legal Power of Attorney(s)

MCA Mental Capacity Act 2005

MCS minimally conscious state

OBM opinion-based medicine

PD Practice Direction (of the Court of Protection Rules)

PDOC prolonged disorders of consciousness

PDOC patient(s) patient(s) with prolonged disorders of consciousness

PVS permanent/ persistent vegetative state

RAS reticular activating system

RCP Royal College of Physicians

RCT(s) randomised clinical trial(s)

REBM real evidence-based medicine

RCP Royal College of Physicians

SMART Sensory Modality Assessment and Rehabilitation Technique

TDOC terminal decline of consciousness

UDHR Universal Declaration of Human Rights 1948

UN United Nations

VS vegetative state

WHIM Wessex Head Injury Matrix

Definitions and Abbreviations

Thesis Introduction

A. Overview

This thesis' overarching question specifically asks whether the definition and determination of death in English and Welsh medical practice and law is defensible, given its implications for patients with prolonged disorders of consciousness. Patients with prolonged disorders of consciousness (PDOC patients) include comatose, vegetative (VS) and minimally conscious state (MCS) patients who are the central case study of this thesis.¹ The thesis' findings suggest that as a consequence of how death is defined and determined in practice (as opposed to officially in statements made by medical regulatory bodies) that PDOC patients' personhood status is in question.² Therefore, running consistently throughout the thesis and alongside the concern that death's definition and determination needs to be reappraised is a normative investigation: are PDOC patients legal persons?

The core of the thesis starts with a hypothesis on the currently adopted model of social justice. Beginning with some basic suppositions about defining and determining death, it explores if death is a moral standpoint that has used personhood theory to redraw the boundary between the living and the "dead".³ Consequently, the thesis investigates the possibility that only those with voluntary responsibility (above the level of reflex) are respected as persons.⁴ Such a hypothesis suggests PDOC patients (specifically VS and MCS patients) are impacted by the definition and determination of death as individuals that have lost that valued characteristic and consequently can have their life-supporting treatment withdrawn.⁵ The thesis' legal hypothesis investigates if those with cognitive impairments hold an equally recognised right to life by exploring the moral and legal permissibility of the current law on life support discontinuation from living human persons.

¹ Royal College of Physicians, *Prolonged Disorders of Consciousness Following Onset of Sudden Injury: National Clinical Guidelines* (2020) (PDOC 2020).

² See specifically Chapter Two, Sections 2.2 and 2.4 and Chapter Three, Section 3.2.

³ As explored throughout Chapter Two.

⁴ As discussed in Chapter Two, Sections 2.3 and 2.4.

⁵ A key finding of Chapter Two, Section 2.4.

Introduction

Consequently, the thesis examines how the law upholds PDOC patients' presumed unquestionable status as legal persons.⁶ It goes straight to the battlefield of best interests decision-making and unpicks the anatomy of the specific best interests test used in PDOC patients' declaratory relief proceedings that determine whether life support should be continued or not.⁷ Further still, it examines claims in the human rights literature that personhood (or more specifically legal capacity) has been conflated with cognition which has possibly led to discriminatory denials of legal capacity for those with cognitive disability, such as PDOC patients.⁸ Therefore, it examines the possibility that if legal capacity is denied on a frequent enough basis and in all its instantiations (decision-making, agency and liberty), that PDOC patients' personhood status in its entirety is called into question.⁹ It therefore examines the adopted model of social justice: are PDOC patients legally respected persons in more than nominal status only? And if not, whether the denial of their personhood status in practice can be explained by an examination of the way in which death is defined and determined in England and Wales and its relationship with life support continuation decisions for biologically living non-persons.¹⁰ For fair assessment, it adopts a methodology based on philosophical guidance to enable and explain how "defensibility" is to be assessed in Chapter One as the thesis question's key investigatory term.

Defensibility is the ideal of moral and legal decision-making.¹¹ The struggle for achieving defensibility in the context of life-and-death-defining decisions can be

⁶ As explored throughout Chapter Three.

⁷ See specifically, Chapter Three, Sections 3.2 and 3.4.

⁸ John Dawson, 'A Realistic Approach to Assessing Mental Health Laws' Compliance with the UNCRPD' (2015) 40 International Journal of Law and Psychiatry 70; Wayne Martin, Sabine Michalowski, Timo Jütten and Matthew Burch, Achieving CRPD Compliance. Is the Mental Capacity Act of England and Wales Compatible with the UN Convention on the Rights of Persons with Disabilities? If Not, What Next? (Essex Autonomy Project Paper, 22 September 2014) (EAP 2014); Eilionóir Flynn and Anna Arstein-Kerslake, 'Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity' (2014) 10 (1) International Journal of Law in Context 81; Gerard Quinn, 'Personhood and Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD' (HPOD Conference at Harvard Law School, 20 February 2010)

<[https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/archive/Submission-on-Legal-Capacity-to-the-Oireachtas-Committee-on-Justice,-Defence-&-Equality-\(August,-2011\).pdf](https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/archive/Submission-on-Legal-Capacity-to-the-Oireachtas-Committee-on-Justice,-Defence-&-Equality-(August,-2011).pdf)> accessed 1 June 2019. See specifically Chapter Four, Section 4.2.

⁹ As discussed in Chapter Four, Subsection 4.2.2.

¹⁰ See specifically Chapter Four, Section 2.4 and Chapter Three, Section 3.2.

¹¹ Helga Kuhse, Udo Schüklenk and Peter Singer, *Bioethics: An Anthology* (3rd edn, Wiley Blackwell Publishing 2015). A methodology for assessing defensibility is outlined in Chapter One.

particularly acute. Yet, that struggle to "know" death, to define its boundaries with biological indicators and to determine when it has been realised is no longer the objective of medical science.¹² Since the 1960s medicine has adapted to the burdens of medical advancement that have blurred the commonly thought, clear boundary between life and death.¹³ For example, how could a doctor¹⁴ know if a patient had stopped breathing if the ventilator continues to push air into a patient's lungs? Further still, how could the ventilator be removed to examine if the patient's cardiopulmonary function had ceased without attracting a charge of murder where removal of the ventilator itself caused his cardiopulmonary function to cease if the offence of murder is not redefined?¹⁵ To adapt, medicine redefined and redrew death's boundaries.¹⁶ Defining and determining death is now accepted among brain death theorists to be a philosophical standpoint on what lives are worth living with merely a 'single foot resting in biology',¹⁷ rather than a science with clear biological indicators as workable safeguards. The consequence is that defining and determining death has much less to do with biology and much more to do with attributing or denying moral and legal status to some over others.¹⁸

In response to these medical advancements the law was presented with a further problem: how to justify an invasion of a non-autonomous patient's bodily integrity where consent is unavailable and judicial powers to consent on their behalf is not possible.¹⁹ By the time that the courts in England and Wales first heard a decision regarding continuation of life support for a VS patient,²⁰ it had been established that a decision to

¹² As explored in Chapter Two, Section 2.4.

¹³ Harvard Medical School, 'Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, 'A Definition of Irreversible Coma'' (1968) 205 (6) *Journal of American Medical Association* 337.

¹⁴ Note that the label "doctor" is used loosely throughout this thesis to denote a relevant healthcare practitioner more generally.

¹⁵ First hypothesised in Chapter One, Subsection 1.4.4, and subsequently analysed in Chapter Two, Section 2.4 and Chapter Three, Section 3.2.

¹⁶ Harvard Report 1968 (n 13).

¹⁷ Stuart J Younger and Robert M Arnold, 'Philosophical Debates About the Definition of Death: Who Cares?' (2001) 26 (5) *Journal of Medicine and Philosophy* 527, 532.

¹⁸ Robert M Veatch, 'The Death of Whole-Brain Death: The Plague of the Disaggregators, Somaticists, and Mentalists' (2005) 30 (4) *Journal of Medicine and Philosophy* 353.

¹⁹ *F v West Berkshire HA* [1990] 2 AC 1 (HL) (*re F*). The history and extent of the revocation of *parens patriae* is noted in *Airedale NHS Trust v Bland* [1993] AC 789 (HL) (*Bland*) at pages 862 (Lord Goff), 876 (Lord Lowry), 883 (Lord Browne-Wilkinson) of the judgment. Note Lord Browne-Wilkinson provides the most comprehensive analysis of *parens patriae*.

²⁰ *Bland* [1993] (n 19).

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continue treatment must be in the best interests of the patient or treatment would amount to assault.²¹ Therefore, although the moral question can be phrased as a question of life support withdrawal, the legal question adds a further consideration to be overcome: whether the continuation of treatment would amount to an assault on the patient.²² Consequently, and from a moral perspective, the judges in *Airedale Trust v Bland* [1993] (*Bland*) ostensibly faced a moral dilemma as a result of two conflicting moral requirements: do not kill a living human person and do not assault non-autonomous persons by continuing medical treatment without authorisation.²³

Moreover, defensibility is also a loaded term. To be accused of indefensible decision-making tarnishes a decision-maker with blameworthiness and culpability.²⁴ For example, if defensibility is nothing more than an intuitive judgement passed by others onto that decision-maker the judgement will be harsh and dogmatic.²⁵ Likewise, if defining death is a presumed science and the law is presumed to be a body of practice solely applying doctrinal rules then the question must be asked: why does morality come into such decisions at all?²⁶ This thesis' question is therefore embedded in the moral philosophical methodology outlined in Chapter One which seeks to explore how to measure the defensibility of such decision-making and how to cope with the inevitable fallout of making life and death decisions.

The stakes are high for any potential fallout. If PDOC patients are persons there seems to be no moral justification for withdrawing life support and consequently, the defensibility of legal reasoning in such judgments will also be weakened. Further still, a claim of indefensibility raises concerns of culpability, wrongdoing and blame. But such judgements are too harsh without considering the epistemic limitations and pressure faced in answering (with any degree of accuracy or consistency) the existential questions of life and death.²⁷ Interestingly, philosophers have explained that some decisions

²¹ *re F* [1990] (n 19).

²² *ibid*; *Bland* [1993] (n 19). This crucial legal question is addressed throughout Chapter Three.

²³ The nature of a moral dilemma is primarily discussed in Chapter One, Section 1.4, Chapter Three, Subsection 3.4.3 and finally answered in Chapter Five, Section 5.3.

²⁴ See Chapter One, Section 1.4.

²⁵ As discussed in Chapter One, Section 1.2.

²⁶ As explored in Chapter One, Section 1.3.

²⁷ These limitations are first discussed in Chapter One, Sections 1.3 and 1.4, and specifically identified in Chapter Three, Section 3.4 and Chapter Four, Section 4.3.

irrespective of 'wrongdoing' still evoke feelings of 'regret' or even 'self-blame' in its reasoners.²⁸ Therefore, emotive cases do not and will not necessarily indicate wrongdoing by themselves, or whether a case is dilemmatic or more accurately occurs due to conflicting moral values.²⁹ Consequently, Chapter One explores what makes cases genuinely dilemmatic and what the minimums of defensible decision-making are, as key components of assessing the defensibility of the current practice of defining and determining death.³⁰

Therefore, it is also necessary to explore if defining death in medical science is a science at all,³¹ and whether declaratory relief proceedings³² are ordinary examples of legal decision-making that merely apply common law precedent.³³ If they are not, moral philosophy can provide guidance on ethical decision-making and how to cope with the fallout of difficult choices.³⁴ Therefore, Chapter One also explores the difference between moral conflicts and dilemmas to explore whether the often-noted moral inconsistency in such decisions arises because they are genuinely dilemmatic cases.³⁵ Consequently, Chapter Five draws the thesis' findings together and answers its central question using the methodology built throughout Chapter One.³⁶

To be clear, the thesis' moral hypothesis that those with cognitive impairments (specifically PDOC patients) do not hold an equally protected right to life and personhood status does not seek to suggest that no life support withdrawal is permissible (legally or morally). Instead, it suggests that the law's demonstrable imbalance needs to be addressed. It is imbalanced because in a pluralistic society it is fair to assume that not all

²⁸ Charles C Hinkley, *Moral Conflicts of Organ Retrieval: A Case for Constructive Pluralism* (Rodopi 2005) 16 (paraphrasing); Terrance C McConnell, 'Moral Residue and Dilemmas' in H E Mason (ed), *Moral Dilemmas and Moral Theory* (OUP 1996).

²⁹ *ibid*. As explored in Chapter One, Subsection 1.4.2.

³⁰ See specifically Section 1.2 for this analysis.

³¹ See Chapter One, Subsection 1.3.3.

³² A declaratory relief proceeding is a particular type of legal judgment that seeks to resolve legal uncertainties for the litigants. They are used in the context of life support withdrawal determinations to resolve disagreement between the parties or any legal uncertainty on a proposed course of action.

³³ As preliminarily explored in Chapter One, Section 1.4 and further explored in Chapter Three, Sections 3.3 and 3.4.

³⁴ See Chapter One, Sections 1.3 and 1.4.

³⁵ See Chapter One, Section 1.4.

³⁶ For the specific aims of all the thesis' chapters refer to Part C of the introduction.

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cognitively impaired individuals would see continued treatment as worse than death, and the starting legal presumption (that continued treatment is unfavourable) is being treated as non-rebuttable by anything other than third party representations of what the individual would allegedly want.³⁷ On an orthodox legal interpretation it suggests a conflation of bodily autonomy and integrity has occurred that overlooks the importance of established law on how a duty of care/ medical necessity is clinically and legally indicated.

B. Parameters

This thesis has been structured in such a way that Chapter One acts as an introduction that presents the problem and outlines a methodology. Therefore, this introduction will only briefly outline the thesis' parameters, question and aims. Jurisdictionally it examines relevant medical practice and law specific to E&W. On occasion the UK is mentioned because some medical practices are not limited to E&W only.

The thesis also examines the moral and legal inconsistencies in *Airedale Trust v Bland* [1993] because it is the first legal and seminal case where life support was discontinued from a living patient.³⁸ Briefly, *Bland* arose out of the Hillsborough Football disaster in 1989, where overcrowding in the stadium led to 96 persons being killed in a fatal crush and Bland survived, but was left in a vegetative state (VS) as a result of his injuries.³⁹ The question before the court was whether his doctors would be legally responsible for his death if they removed his feeding and hydration tube and withheld any antibiotics from him, which would result in his foreseeable death.⁴⁰ However, the crucial question according to the court was whether continued treatment was in his best

³⁷ Prolonged disorders of consciousness are more accurately responsivity (as opposed to consciousness disorders) and are therefore not too dissimilar from locked-in syndrome (see medical evidence in Chapter Two, Section 2.3). The lived experiences of those with locked-in syndrome indicate that not all people with responsivity impairments would want to die. See Nick Chisholm and Grant Gillett, 'The Patient's Journey: Living with Locked-In Syndrome', (2005) 331 (7508) British Medical Journal 94; Jean-Dominique Bauby, *The Diving Bell and the Butterfly* (first published in French 1997, Jeremy Leggatt tr, Vintage 1998). I am therefore interested in seeing how the balance can be better struck under existing law and legal mechanisms.

³⁸ *Airedale NHS Trust v Bland* [1993] AC 789 (HL) 887 (Lord Mustill) (*Bland*). See Chapter Three, Section 3.2. Note that *Bland* was a minor at the time of injury and therefore would not have been able to complete advance planning even if the MCA 2005 has been in place at the time.

³⁹ *ibid*.

⁴⁰ *ibid* 879 (Lord Browne-Wilkinson), 887 and 889 (Lord Mustill).

interests.⁴¹ Whilst deciding *Bland*, Lord Mustill noted that despite the success of its answer to the legal question regarding invading bodily integrity, the judgment resulted in a law that was 'morally and intellectually misshapen'⁴² and foresaw that the courts would revisit the issue because some VS patients would be found to have increased capacity for awareness, thereby adding further moral complexity to the crucial continuation question.⁴³

Nevertheless, although the case is frequently referred to because it remains the seminal criminal authority for dis/continuing life-supporting treatment from PDOC patients, I do not seek to over-emphasise its importance to the exclusion of subsequent legal developments.⁴⁴ Instead, I seek to explore why these cases are dilemmatic and if they are resolvable (superficially dilemmatic) via the relationship between death's definition, personhood and the potential conflation of bodily autonomy and integrity.⁴⁵ Moreover, in assessing the impact of the definition and determination of death on PDOC patients, for comparative purposes the thesis briefly looks at other patients with impacted cognitive and mental impairments.⁴⁶ The fact that comparison can be drawn with them highlights how far reaching *Bland* has been in endowing life support withdrawal with legal authority more generally and also how PDOC patients are an apt case study because they are at the very heart of this aptly characterised 'proxy war on personhood'.⁴⁷

⁴¹ *ibid.*

⁴² *ibid* 887 (Lord Mustill).

⁴³ *ibid* 879 (Lord Browne-Wilkinson), 887 and 889 (Lord Mustill). Note Lord Mustill predicted and was concerned that the case would be extended to those with 'glimmerings of awareness' ie MCS patients at page 899 in the *Bland* judgment.

⁴⁴ The subsequent key judgments are *W v M and S (A NHS Primary Care Trust)* [2011] EWHC 2443 (Fam) (*W v M*); *M v N* [2015] EWCOP 76, [2015] 11 WLUK 514 (*M v M*); *Re Briggs (Incapacitated Person) (Medical Treatment: Best Interests Decision)* [2016] EWCOP 53, [2017] 4 WLR 37 (*Briggs (No.2)*; *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [2014] AC 591 (*Aintree*); *An NHS Trust v Y* [2018] UKSC 46, [2018] 3 WLR 751 (*NHS Trust v Y*). As discussed in Chapter Three, Section 3.3.

⁴⁵ See Chapter Three for an in-depth discussion of these issues and the defence of this argument.

⁴⁶ I could not hope to cover these patients also and how death's definition and determination has specifically impacted them to any significant degree. For example, those with intellectual disability and also those with other cognitive impairments, who the PDOC 2020 guidance (n 1) now refers to as TDOCs "terminal decline of consciousness patients". The term TDOC includes those with progressive degenerative brain damage, such as dementia, Parkinson's disease or multiple stroke patients who have a shorter life expectancy than PDOC patients, who are often younger and otherwise healthier than TDOC patients.

⁴⁷ A descriptively apt phrase borrowed from Gerard Quinn's speech presented to the University of British Columbia in April 2011, where he described the war over legal capacity as a proxy war over personhood. See Gerard Quinn, 'Rethinking Personhood: New Directions in Legal Capacity Law and Policy' (University of British Columbia, 29 April 2011)

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The exploration of how to measure the defensibility of the adopted and existing practice of defining and determining death is explored in Chapter One. The chapter explores decision-making standards that can be described as minimums that have to be met to be morally defensible.⁴⁸ Those minimums are 'factual accuracy' and 'consistency' which can helpfully indicate when a decision is 'intuition-based' and consequently being made on the basis of a subjective viewpoint.⁴⁹ It has also explored policy limitations that arise in translating a consistent moral standpoint into law and medical practice and has taken such limitations into account where necessary.⁵⁰ It has also looked at legal standards on medical decision-making to assess defensibility. Moreover, what 'ought to be' done must be something that 'can be done',⁵¹ therefore it is not enough to state that a practice is indefensible if no alternatives exist. Chapter Four consequently explores what alternatives might exist before a conclusory assessment of defensibility is undertaken in Chapter Five.⁵² Additionally, this thesis does not explore the purported problem of defining and determining death from a binary "deontological versus consequentialist" argument. Instead, it delineates a methodology that is neutral and capable of accepting any moral philosophically-based theory as long as the standpoint itself is found to be factually accurate and consistent.⁵³

On a further preliminary note, because coma is often transitive where a comatose patient will either worsen into brain or cardiopulmonary death or improve through the other PDOCs and possibly regain full consciousness within a few weeks, this thesis therefore specifically focuses on the VS and MCS.⁵⁴ I also appreciate that some of the nomenclature on consciousness disorders and death are insensitive and are used solely because they are still the used technical medical terminology.⁵⁵

<http://citizenship.sites.olt.ubc.ca/files/2014/07/Gerard_Quinn_s_Keynote_-_April_29__2011.pdf> accessed 1 June 2019.

⁴⁸ See Chapter One, Section 1.2.

⁴⁹ Helga Kuhse, Udo Schüklenk and Peter Singer, *Bioethics: An Anthology* (3rd edn, Wiley Blackwell Publishing 2015) 1 (paraphrasing).

⁵⁰ See Chapter One, Sections 1.2 and 1.4; and further examined in Chapter Five, Subsection 5.2.2.

⁵¹ Henry Sidgwick, *The Methods of Ethics* (6th edn, MacMillan & Co Ltd 1901) 3 (paraphrasing).

⁵² See Chapter Four, Section 3.4 and Chapter Five, Section 5.2.

⁵³ As explored throughout Chapter One.

⁵⁴ PDOC 2020 (n 1); David Bates, 'The Prognosis of Medical Coma' (2001) 71 (1) British Medical Journal i20.

⁵⁵ See PDOC 2020 (n 1) at 23. In response to increasing awareness of its insensitivity, the PDOC 2020 guidelines and academic commentary have sought to salvage the terminology by reference to

C. Outline of the Thesis' Question and Aims

The core question of the thesis asks whether the way in which death is currently defined and determined is defensible, given its moral and legal implications for PDOC patients.⁵⁶ For greater accuracy, the analysis in Chapter Two explores the definition of death deductively by mapping how death is determined in practice. Notably, the analysis explores the timing of different death behaviours to indicate the moral standing of such patients. Consequently, I argue that death behaviours indicate the accurate definition and determination of death in E&W medical and legal practice. To understand death behaviours and death's definition/determination as separate concepts enables the harm that the current definition of brainstem death does to those on the cognitive disability spectrum, because it overlooks the fact that even the 'brainstem dead' are not biologically dead under the officially adopted definition of death by the UK medical profession. Consequently, it enables a false sense of security that the definition of death is unrelated to, and does not currently harm those with consciousness disorders. Hence, the overarching aim is to explore whether medicine and law need to reappraise their practice of defining and determining death. Accordingly, each chapter explores or evaluates an aspect of the thesis' question and is presented as an "aim".

To answer the thesis' question, Chapter One addresses the first aim, to outline a neutral methodology that can assess defensibility whilst considering limitations in doing so and mitigating them as far as possible. Chapter Two explores the second aim, to discover how death is defined and determined and how it specifically impacts PDOC patients. Chapter Three, investigates the third aim (to see whether death's definition and determination in medicine has seeped into E&W law's continuation proceedings, and whether this can explain the often-noted moral inconsistency.⁵⁷ It will consequently

its Aristotelian meaning, see Zoe M Adams and Joseph J Fins, 'The Historical Origins of the Vegetative State: Received Wisdom and the Utility of the Text' (2016) 26 (2) *Journal of the History of Neurosciences* 140.

⁵⁶ This question is continually assessed throughout and finally answered in Chapter Five, Sections 5.2 and 5.3.

⁵⁷ John Coggon, 'Ignoring the Moral and Intellectual Shape of the Law After Bland: The Unintended Side-Effect of a Sorry Compromise' (2007) 27 (1) *Legal Studies* 110; Andrew McGee, 'Finding a Way Through the Ethical and Legal Maze: Withdrawal of Medical Treatment and Euthanasia' (2005) 13 *Medical Law Review* 357; John Keown, 'Restoring Moral and Intellectual Shape to the Law After

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explore the anatomy of the best interests test employed in such declaratory relief proceedings to assess the accuracy and consistency of their judicial decision-making.⁵⁸ The fourth aim explores “what could be” by examining the shared decision-making model and the impact pervading views on PDOC patients’ recently challenged and supposed non or minimal awareness is having on the eradication of substituted decision-making.⁵⁹ I acknowledge that the model adopted under the Mental Capacity Act 2005 is based on shared decision-making, however its judicial application has in recent years come under fire for, in effect, amounting to a substituted decision-making approach.⁶⁰ The fourth aim examines the best interests test’s underlying justification for use in decisions that determine whether life support should be continued in light of equality and non-discrimination provisions in international human rights law.⁶¹ Finally, the fifth chapter draws the findings together to assess defensibility of current practice and if a reappraisal by legislators and medical regulatory bodies is needed,⁶² as well as the fallout of the assessment’s findings itself.⁶³ Consequently, this thesis evaluates whether medicine and law in reality recognise PDOC patients as legal persons in more than a nominal status, where their rights are guaranteed and respected.⁶⁴

Bland’ (1997) 113 Law Quarterly Review 481; John M Finnis, ‘Bland: Crossing the Rubicon?’ (1993) 109 Law Quarterly Review 329.

⁵⁸ As explored throughout Chapter Three.

⁵⁹ As explored in Chapter Four, Section 4.3.

⁶⁰ House of Lords Select Committee on the Mental Capacity Act 2005, *The Mental Capacity Act 2005: Post-Legislative Scrutiny* (HL Paper 139, 2014).

⁶¹ See Chapter Four, specifically, Section 4.2 and 4.4.

⁶² As analysed in Chapter Five, Section 5.2.

⁶³ As analysed in Chapter Five, Section 5.3.

⁶⁴ The answer to this question is provided and defended in Chapter Five.

Chapter 1 Indeterminacy in Moral Reasoning:

Outlining Minimums and Recognising Inherent Limitations of an Applied Ethics Methodology

1.1 Chapter Introduction and Aims

Moral philosophy has recognised and attempted to grapple with limitations in "knowing" in order for moral agents (loosely, the decision-maker in a given context) to make a defensible choice.¹ That choice is more commonly referred to in moral philosophy as a 'moral requirement' or 'ought statement'.² These limitations in knowing seem more acute in dilemmatic cases where defining and determining death is one such case.³ Moreover, Hinkley suggests that in applied ethics disciplines such as law and medicine, the pressure decision-makers feel to make a choice may lead to poor decision-making.⁴ The medical judgements in Chapter Two on defining brain death and diagnosing loss of consciousness, as well as the legal judgments in Chapter Three, have seemingly relied on 'moral precepts'⁵ to arrive at a decision in determining whether someone is "dead" or "alive", and whether life support withdrawal is morally permissible.⁶ Determining and defining death is

¹ Terrance C McConnell, 'Moral Residue and Dilemmas' in H E Mason (ed), *Moral Dilemmas and Moral Theory* (OUP 1996). Note decision-maker and moral agent are used interchangeably in this thesis and these terms refer to any decision-making agent such as doctors, judges or even legislators in a given context.

² Henry Sidgwick, *The Methods of Ethics* (6th edn, MacMillan & Co Ltd 1901) 2. Note moral requirements require, 'in a strong binding sense', an agent to do one particular action. See eg Charles C Hinkley, *Moral Conflicts of Organ Retrieval: A Case for Constructive Pluralism* (Rodopi 2005).

³ McConnell (n 1). Dilemmas are discussed in Section 1.4.

⁴ Charles C Hinkley, *Moral Conflicts of Organ Retrieval: A Case for Constructive Pluralism* (Rodopi 2005) 64-65.

⁵ A moral precept is a single moral "rule", usually from a larger and established moral code such as Christian morality, that guides a moral agent on what to do in a particular situation. See eg Ruth Barcan Marcus, 'Moral Residue and Dilemmas' in H E Mason (ed), *Moral Dilemmas and Moral Theory* (OUP 1996).

⁶ What these moral precepts are will be explored in Section 1.4.

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both 'ontologically'⁷ and 'phenomenologically'⁸ challenging: how can the living accurately know anything about a phenomenon they are yet to "experience"? Nevertheless, it is a dilemma doctors are faced with on a day-to-day basis and judges have sought to regulate.

This chapter will explore three core questions: how 'defensibility' is to be measured (as the core analytical term in the thesis title and question)?⁹ How doctors and judges "know" and reason to make informed judgements about death?¹⁰ What are moral dilemmas (how are they identified and how do they differ from moral conflicts)?¹¹ And, what guidance can moral philosophy provide to guide judges and doctors to tackle or mitigate them?¹² In doing so, this chapter recognises that there are existing limitations that have not yet been resolved in philosophy. It therefore attempts to delineate a methodology for how doctors and judges should acknowledge those limitations and mitigate them in order to defensibly make decisions when facing a moral dilemma. The chapter draws on the guidance in the philosophical literature to assess a chosen moral requirement's defensibility whilst recognising that although no perfect answer exists, there exists sufficient guidance to arrive at a methodology that can assess the defensibility of a decision. The findings of the chapter will then be implicitly borne in mind throughout chapters Two, Three and Four, until Chapter Five where defensibility will be assessed.

⁷ Ontology is essentially the study of, or search for, objective existence outside of consciousness or perception, and how these "things" in existence relate to each other. A classic example of an ontological question in philosophy is: "Is there a God?" This search for existence has to occur outside of phenomenological experience and therefore is not without its own difficulties. See for further explanation: Stanford Encyclopedia of Philosophy, 'Logic and Ontology' (11 October 2017) <<https://plato.stanford.edu/entries/logic-ontology/#Ont>> accessed 18 December 2019.

⁸ Phenomenological approaches in philosophy use knowledge derived from experience through consciousness and awareness of the world around us. Its study of existence and knowing what exists and how, therefore relies on perception. See for further explanation: Stanford Encyclopedia of Philosophy, 'Phenomenology' (16 December 2013) <<https://plato.stanford.edu/entries/phenomenology/>> accessed 18 December 2019.

⁹ As discussed in Section 1.2.

¹⁰ As explored in Section 1.3.

¹¹ As discussed in Section 1.4.

¹² Further discussed where relevant throughout Chapter One.

1.2 How to Measure the Defensibility of a Purported Moral Requirement

1.2.1 Section Introduction

In order to measure defensibility, it is necessary to define what ethics is. The celebrated philosopher Henry Sidgwick states that, 'ethics is the Science of Practice or Conduct'.¹³ Alternatively, to define what ethics is, others start by stating what it is not: 'Many people assume ... that ethics is subjective ... a matter of opinion ... But if ethics were a matter of taste why would we even attempt to argue about it?'¹⁴ Therefore, for applied ethicists who seek to ensure and practice ethical decision-making, a phenomenological or ontological study of "death" is a luxury that doctors on the front line of life and death decisions do not have. Consequently, the moral agents' (doctors) attempt in Chapter Two to define and determine death are not seeking to know "death" in the same manner a philosopher may want to explore the phenomenon. Therefore, this thesis is not assessing the accuracy of how close doctors have come to defining death (although it does assess the accuracy of medicine purporting to have answered this question¹⁵). Instead, it assesses the moral requirement adopted by medicine in what it suggests are or is the most valuable characteristics of human life which once lost means "death" has occurred.¹⁶

1.2.2 Achieving Defensible Moral Requirements

Simply put, a moral requirement or ought statement is, 'in a strong binding sense', a decision by a moral agent on the most defensible course of action.¹⁷ For a deontologist this will be the action which is right or good itself.¹⁸ For a utilitarian it will be the action

¹³ Sidgwick (n 2) 1.

¹⁴ Helga Kuhse, Udo Schüklenk and Peter Singer, *Bioethics: An Anthology* (3rd edn, Wiley Blackwell Publishing 2015) 1.

¹⁵ Chapter Two, Section 2.2.

¹⁶ This fundamentally personhood-based argument is explored in Chapter Two, Section 2.4.

¹⁷ Hinkley (n 4) 47; Sidgwick (n 2).

¹⁸ Immanuel Kant, *Groundwork of the Metaphysics of Morals* (first published 1785, J W Semple tr, 3rd edn, T & T Clark 1871).

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that maximises utility.¹⁹ However, applied ethicists' reliance on these rational calculi such as deontology or utilitarianism,²⁰ is misguided because such doctrines do not match the realities of how people reason in day-to-day life, including doctors or judges.²¹ Therefore I suggest moving away from the assessment of whether a decision is justifiable because it has adopted a utilitarian or deontological perspective. Such perspectives start to falter for being fundamentally opinion-based on what the valuable end-goal of decision-making is, such as to maximise utility or "do right". Moreover, such an approach is particularly problematic for disciplines that regulate conduct in pluralistic societies due to the legitimate concern of coercing those of different moralities to ascribe to a conflicting morality.²² For example, its members may vastly disagree on when a person should be defined as dead or when organ donation is permissible.²³

Alternatively, Kuhse, Schüklenk and Singer have asserted that moral philosophy is not concerned with debating opinions.²⁴ Instead, they suggest that to produce a coherent ethical position that, 'consistency, at least, is a requirement of any defensible ethical position, and thus sets a limit to the subjectivity of ethical judgements'.²⁵ Factual accuracy and consistency are therefore "minimums" of assessing the defensibility of a moral requirement adopted in law and medicine. Therefore, although Sidgwick's concise definition gives an indication of what the study of ethics is, Kuhse, Schüklenk and Singer's starts to develop a methodological approach to help measure the defensibility of an adopted moral requirement in law and medicine.

Kuhse, Schüklenk and Singer do not provide a definition of 'factual accuracy'²⁶ and therefore it should be interpreted as it is commonly understood, at its face-value meaning.

¹⁹ Jeremy Bentham, *An Introduction to the Principles of Morals and Legislation* (first published 1789, Dover Classics 2007); John Stuart Mill, *Utilitarianism* (first published 1861, Roger Crisp (ed), OUP 1998).

²⁰ A rational calculus is employed in moral philosophy to weigh competing moral values against each other to arrive at an 'ought statement' of the most defensible course of action. The calculus will normally have a defined end or 'good' that it is seeking to achieve. See for example W D Ross, *The Right and The Good* (first published 1930, P Stratton-Lake (ed), OUP 2002).

²¹ Guy Kahane, 'Sidetracked by Trolleys: Why Sacrificial Moral Dilemmas Tell Us Little (or Nothing) About Utilitarian Judgment' (2015) 10 (5) Social Neuroscience 551, 554.

²² H Tristram Engelhardt Jr, *The Foundations of Bioethics* (2nd edn, OUP 1996).

²³ *ibid.*

²⁴ Kuhse, Schüklenk and Singer (n 14) 1.

²⁵ *ibid.*

²⁶ *ibid.*

To assess the factual accuracy of defining and determining death, I will therefore assess 'what is'²⁷ death: what does medical science ontologically and phenomenologically know about death? And how does this knowledge match "death" as it is defined and determined in law and medicine? It is important to note that the law in England and Wales has not stipulated a definition of death, instead the legal definition is the judicial adoption and application of its medical definition.²⁸ Therefore, Chapter Two will focus specifically on how medicine has defined and determined death. Consequently, in asking "what is death" this thesis does not attempt to suggest a more accurate definition of the phenomenon. Instead, it assesses the factual accuracy of the likeness of the current definition and determination of "death" with the phenomenon "death" because of medicine's implicit assertion that its definition and determination match the phenomenon of "death".²⁹

Consistency, in the sense that it is intended by Kuhse, Schüklenk and Singer, suggests that any moral precept must be universally applicable without contradiction.³⁰ A moral precept is a principle of a particular moral code. Moral codes can either be 'universal' (shared by all moral communities) or 'non-universal' (adopted by professions).³¹ Kuhse, Schüklenk and Singer provide further guidance on its interpretation: 'if I say, "it is always wrong to kill another human being" and "abortion is not always wrong" then I am committed to denying that abortion kills a human being'.³² Consequently, this thesis will assess the position adopted in medicine that brain dead patients are "dead" and that patients with prolonged disorders of consciousness (PDOC patients) are "alive".³³

Finally, and in the context of law, they stipulate that consistency is given a wider berth of discretion than its application in ethics due to the 'wider ramifications [the law

²⁷ Sidgwick (n 2) 2.

²⁸ Elizabeth Wicks, 'The Legal Definition of Death and the Right to Life' in Shane McCorristine (ed), *Palgrave Historical Studies in the Criminal Corpse and Its Afterlife. Interdisciplinary Perspectives on Mortality and its Timings. When is Death?* (MacMillan Publishers 2017); Hazel Biggs, *Euthanasia, Death with Dignity and the Law* (Hart Publishing 2001).

²⁹ Academy of Medical Royal Colleges, *A Code of Practice for the Diagnosis and Confirmation of Death* (2008) (AOMRC 2008). See D Alan Shewmon, "'Recovery from Brain Death': A Neurologist's Apologia' (1997) 64 (1) The Linacre Quarterly 30, in which he assesses and questions the likeness of brain death with the phenomenon of death.

³⁰ Kuhse, Schüklenk and Singer (n 14) 1.

³¹ Tom L Beauchamp and James F Childress, *Principles of Biomedical Ethics* (7th edn, OUP 2013) 3. Discussed further in Section 1.4.

³² Kuhse, Schüklenk and Singer (n 14) 1.

³³ AOMRC 2008 (n 29). Discussed in Chapter Two, Sections 2.2 and 2.3.

has] than the consequences of personal choice'.³⁴ They add that, 'as paradoxical as this position may appear ... it is not straightforwardly inconsistent'.³⁵ This wide berth of discretion suggests that it is necessary to assess how medicine and law "know" or reason in defining and determining death. Hence, it is important to not only assess consistency but also suggest how wide that berth of discretion should be and why it is necessary that judges and doctors should have a possible moral defence in grappling with moral dilemmas. Finally, Sidgwick suggests that before a moral agent can make an ought statement there is an implicit limitation and expectation in ethics that says: 'what I ought to do must be something that I can do'.³⁶

1.2.3 Section Conclusion

This section has explored what the study of ethics is and has found that it is not concerned with opinion, instead its central aim is to guide moral agents to achieve defensible decision-making. Kuhse, Schüklenk and Singer's minimums of defensible moral decision-making therefore helpfully set some parameters to assess the defensibility of a decision or policy. First, a decision must be based on accurate facts and secondly it must be universally applicable (consistent). The factual accuracy element can either be a phenomenological study (knowing from conscious experience) or an ontological study (knowledge from outside of conscious existence) of "what is". The consistency element is important because it eliminates subjective or intuition-based decision-making.

This section also introduced some key philosophical concepts. A moral precept is a single principle within a moral code. Moreover, moral codes can either represent universally agreed upon mores³⁷ or non-universal mores followed by a specific moral community and its members. Additionally, the concept of a rational calculus was introduced and described as concept employed by moral reasoners to weigh conflicting moral values (or precepts).³⁸ However, the calculus will set the sought-after end. Finally, a

³⁴ Kuhse, Schüklenk and Singer (n 14) 6.

³⁵ *ibid.*

³⁶ Sidgwick (n 2) 3.

³⁷ Morals belonging to a particular moral community.

³⁸ Moral values can be thought of as umbrella terms for moral precepts that can be grouped together. For example, moral precepts such as "do not kill" and more generally "do not steal" would

moral requirement (also known as an ought statement) is the outcome and imperative demand (course of action) that the moral agent should take after weighing the conflicting moral precepts. These concepts amount to the basic building blocks and terminology of moral reasoning.

1.3 Ensuring Consistency and Factual Accuracy in Medical Law Cases

1.3.1 Section Introduction

This section will explore how the minimums of factual accuracy and consistency are upheld in law and medicine's reasoning and decision-making processes. It will also draw from the thesis's case study of defining and determining death and its implications for PDOC patients to exemplify limitations in applied ethics methodologies. In doing so, it will also outline inconsistencies and inaccuracies that will be analysed in subsequent chapters and deduce the most defensible medical decision-making standard for Chapter Three's legal assessment.

1.3.2 Ensuring Consistency and Factual Accuracy in English and Welsh Medical Law

Sidgwick's starting question of 'what is?' is explored in Chapter Two and outlines how death is defined and determined, and also how non or minimal awareness is diagnosed in PDOC patients. It is an important starting question because the slightest change in the facts can alter the defensibility of any 'ought statement' made.³⁹ The first minimum of factual accuracy in medical law cases is largely deferred to the medical profession and therefore will more specifically be addressed in 1.3.3.⁴⁰ However, there is still a legitimate

come under "do no harm", which is more commonly recognised as the moral value of non-maleficence.

³⁹ Sidgwick (n 2) 2.

⁴⁰ Medicine's exploration of "what is" in ascertaining the most defensible diagnosis, prognosis and treatment plan is assessed in Subsection 1.3.2.

question in identifying what those allegedly competing moral values are in PDOC patients' life support continuation decisions.⁴¹

To start with, the law holds a unique constitutional role in ensuring consistency in any attempt to regulate conduct within its jurisdiction.⁴² That role is unique because ostensibly inconsistent (different) treatment, even in similar cases, may legitimately be distinguished on the basis of public policy reasons.⁴³ Based on this understanding, the distinctions made between seemingly similar cases is still consistent even in instances that can be described as alike.⁴⁴ Such an understanding of how the law upholds consistency is particularly relevant for the findings of Chapter Four which aims to assess whether PDOC patients' status as legal persons is threatened by a *prima facie* discriminatory definition and determination of death. The question of discrimination can arise not just from different treatment but also from same treatment.⁴⁵ Therefore, the question of discrimination implies that inconsistency can arise from treating like cases alike and different cases differently, and, in treating different cases alike and like cases differently. To resolve such issues the law procedurally relies on constitutional principles,⁴⁶ international

⁴¹ This question has been explored by: Camillia Kong and others, 'Judging Values and Participation in Mental Capacity Law' (2019) 8 Laws 3; Richard Huxtable and Giles Birchley, 'Seeking Certainty? Judicial Approaches to the (Non-) Treatment of Minimally Conscious Patients' (2017) 25 (3) Medical Law Review 428.

⁴² Kuhse, Schüklenk and Singer (n 14) 6.

⁴³ *ibid.*

⁴⁴ *ibid.*

⁴⁵ For example, it is for this reason as Marcia Rioux argues that human rights law must be both pluralistic and assimilationist to combat all forms of discrimination, as discussed in Chapter Four, Section 4.2. See Marcia H Rioux, 'Towards a concept of Equality of Well-Being: Overcoming the Social and Legal Construction of Inequality' in Marcia H Rioux and Michael Bach (eds) *Disability is not Measles: New Research Paradigms in Disability* (Roeher Institute 1994).

⁴⁶ The *Magna Carta* is thought to be the basis for constitutional principles such as equality before the law, transparency in law and a right to fair trial. See King John of England, *Magna Carta* (1215, Callender Press 2013).

guidance and conventions,⁴⁷ common law precedent and 'rules of statutory interpretation,⁴⁸ to assess the purported consistency of a legal approach.

However, the academic commentary on PDOC patients' life support continuation decisions note that the courts have abandoned the procedural rule of common law precedent that upholds consistency.⁴⁹ For example, recent academic commentary has begun to criticise best interests assessments in such cases for not following the ordinary rules of legal precedent.⁵⁰ This is problematic because the fairness and impartiality of the judgments may be called into question.⁵¹ Another noted criticism is the subsumption of extra-judicial values.⁵² For example, such proceedings are thought to be based on the assessment of balancing competing moral values against one another, such as sanctity of life over autonomy.⁵³

However, the analysis on such cases in 3.2 and 3.3 suggests that there is no evidence of a rational calculus being used by judges to determine which value can defensibly be prioritised (representing a moral and legal requirement) in a given case. Therefore, there is an overarching question of how these judgments are being decided and on what basis, where some have started to speculate that they are intuition-based which in turn questions how consistency and factual accuracy are being upheld.⁵⁴ For example, after

⁴⁷ See for example, the international guidance on discrimination formulated by the United Nations Human Rights Committee or the European Convention on Human Rights 1950: United Nations Human Rights Committee, *General Comment 18 on Non-Discrimination* (10 November 1989) UN Doc HRI/GEN/1/Rev6 (General Comment 18) paragraph 13; Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols 11 and 14, supplemented by Protocols 1, 4, 6, 7, 12 and 13, Nov. 4, 1950, Europ. T.S. No. 5, 213 U.N.T.S. 221.

⁴⁸ See *Duport Steels Ltd v Sirs* [1980] 1 WLR 142 (HL) at 157 where Lord Diplock outlines the 'literal rule'; *Grey v Pearson* (1857) 10 ER 1216 (QB) at 1234 where Lord Wensleydale outlines the 'golden rule'; *Heydon's Case* (1584) 76 ER 637 (KB) at 638 where Lord Coke outlines the 'mischief rule'.

⁴⁹ Kong and others (n 41); Huxtable and Birchley (n 41). As discussed in Chapter Three, Section 3.4.

⁵⁰ *ibid.*

⁵¹ *ibid.* Discussed in Chapter Three, Section 3.3.

⁵² Kong and others (n 41).

⁵³ John Keown, 'Restoring Moral and Intellectual Shape to the Law After Bland' (1997) 113 Law Quarterly Review 481; John M Finnis, 'Bland: Crossing the Rubicon?' (1993) 109 Law Quarterly Review 329. The concept of autonomy is further qualified later in this subsection. In cases concerning PDOC patients' care, autonomy is heavily qualified and is likened to welfare as opposed to self-determination or even informed consent, as discussed later in this Subsection 1.3.2 and Chapter Three, Section 3.2.

⁵⁴ Kong and others (n 41); Huxtable and Birchley (n 41).

applying the philosophical theory on how to weigh competing moral values it becomes evident that these proceedings are not always undertaking an accurate rational calculus.

Briefly, a rational calculus is employed in moral philosophy to weigh competing moral values against each other to arrive at an 'ought statement'.⁵⁵ For example, a utilitarian calculus aims at maximising utility.⁵⁶ Simply put, the utilitarian moral reasoner inputs the identified competing values in a given case and assesses which will bring "the most happiness to the most people".⁵⁷ Hinkley argues that an important starting consideration is whether the values are commensurable, meaning that the 'value of the options must be comparable'.⁵⁸ Values are thought to be commensurable under the 'Trichotomy Thesis' if they can provide a clear answer that one is either: 'better than' (more defensible); 'equal to' (defensible); or 'less than' (indefensible) the other.⁵⁹ Chang suggests that the question posed must have a neutral covering value to add intelligibility to the answer sought: "is philosophy better than pushpin?"⁶⁰ where the covering consideration seeks to measure 'intrinsic worthwhileness'.⁶¹ Therefore, in any decision involving moral value conflict a further check is to assess whether the options available to a moral agent are sufficiently comparable. To help assess if this is the case the question itself must be neutral and suitable to provide an intelligible answer.

The greatest criticism of the seminal case on PDOC patients' life support continuation (*Bland*) is that it is 'morally and intellectually misshapen'.⁶² The commentary on *Bland's* moral incongruity has largely focussed on resolving whether sanctity of life should have been upheld, or in subsequent legal developments whether such cases can be

⁵⁵ Sidgwick (n 2) 2.

⁵⁶ Bentham (n 19); Mill (n 19).

⁵⁷ *ibid.*

⁵⁸ Hinkley (n 4) 49.

⁵⁹ Ruth Chang, 'The Possibility of Parity' (2002) 112 (4) *Ethics* 659, 660-661.

⁶⁰ *ibid* 666.

⁶¹ *ibid.*

⁶² *Airedale NHS Trust v Bland* [1993] AC 789 (HL) (*Bland*) 887 (Lord Mustill). Lord Mustill's words have since been used in the titles of academic commentary on the moral incongruity in such cases, for example: John Coggon, 'Ignoring the Moral and Intellectual Shape of the Law After Bland: The Unintended Side-Effect of a Sorry Compromise' (2007) 27 (1) *Legal Studies* 110; John Keown, 'Restoring Moral and Intellectual Shape to the Law After Bland' (1997) 113 *Law Quarterly Review* 481.

morally supported by deducing what the patient would have wanted.⁶³ However, there is evidence in *Bland* that suggests that no real weighing of the values of sanctity of life and "autonomy" occurred.

To start, autonomy in law differs from philosophy which interprets the principle as self-determination.⁶⁴ In law, autonomy is primarily, closely associated with informed consent.⁶⁵ However, where autonomy is invoked to protect those who lack mental capacity and who are sometimes non-responsive, it is done in the interests of protecting the patient's interest in their own current and future welfare.⁶⁶ Therefore, because Anthony Bland was regarded as having 'no interests' at all,⁶⁷ it cannot be said that the judgment sought to value his autonomy (even in the limited sense of holding interests in his own welfare) because he was deemed to have 'no welfare interests' as he was wholly unaware.⁶⁸ In fact, the case suggests that his doctors thought that his cerebral cortex (purported to be where awareness of self and the environment manifests in the brain⁶⁹) had been liquified.⁷⁰ He was therefore considered unable to 'see, hear or feel anything'.⁷¹

Moreover, sanctity of life was referred to as 'not absolute', possibly in an attempt to downplay its significance in such cases because medicine deemed continued treatment to be futile, and thus the law responded by adding a presumption that continued treatment would not be in the patient's best interests and would amount to an assault on the basis of previous legal precedent.⁷² Hence, the futility of continued life-supporting treatment is what is being assessed in such cases.⁷³ I acknowledge futility's interpretation has

⁶³ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [2014] AC 591 (*Aintree*).

⁶⁴ Note that this interpretation has also been critiqued as a misinterpretation of Kant and Mill's work by Onora O'Neill, 'Some Limits of Informed Consent' (2003) 29 *Journal of Medical Ethics* 4.

⁶⁵ *ibid*.

⁶⁶ John Harris, 'Consent and End of Life Decisions' (2003) 29 *Journal of Medical Ethics* 10. Note that Lord Goff discusses self-determination and autonomy in terms of the patient's wishes and interest in welfare. See *Bland* [1993] (n 62) 862-867 (Lord Goff) (paraphrasing). The resulting implications of this view are discussed in Chapter Three, Sections 3.3 and 3.4.

⁶⁷ *Bland* [1993] (n 62) 897 (Lord Mustill) (paraphrasing). The facts of this case are relayed in the Thesis Introduction and in Chapter Three, Section 3.2.

⁶⁸ *ibid* 856 (paraphrasing).

⁶⁹ Explored in Chapter Two, Section 2.3.

⁷⁰ *Bland* [1993] (n 62) 856.

⁷¹ *ibid*.

⁷² *ibid* 864 (Lord Goff) (paraphrasing); *F v West Berkshire HA* [1990] 2 AC 1 (HL) (*re F*).

⁷³ The concept of futility is explored in Chapter Three, Sections 3.2 and 3.3.

drastically changed in post-Mental Capacity Act 2005 cases, from being a medical determination to reflect the patient's subjective view of the value of living in their current state of existence,⁷⁴ such distinctions are explored further in Chapter Three. For current purposes, it is enough to say that a decision to discontinue life support from patients who lack capacity and hold no welfare interests cannot arise from a rational calculus assessment that compares the competing moral values of autonomy against sanctity of life or any other alleged competing value.

Moreover, the legal question (whether the continuation of life-supporting treatment is within the best interests of a PDOC patient?⁷⁵) does not ascribe a neutral covering value (purportedly best interests). In both *Bland* and subsequent cases, futility is the determining factor.⁷⁶ In other words, the question in such cases is better phrased as: is the continuation of life-supporting treatment futile? However, no two values are being compared and the question is not phrased in such a way that two values could be. Additionally, because the question was determined on the basis of medical futility,⁷⁷ there is a strong argument that suggests that its alleged defensibility will largely rely on the accuracy of medicine in determining the futility of continued life-supporting treatment.⁷⁸ Others have picked up on the fact that no moral values are being weighed despite what the best interests test purports to do, explaining why some have criticised the judgments for more often than not returning the answer that withdrawal is in the patient's best interests.⁷⁹

No other values or considerations were weighed in *Bland* other than whether continued treatment was futile. In other words, the best interests test in such cases seems

⁷⁴ *Aintree* [2013] (n 63).

⁷⁵ *Bland* [1993] (n 62) 868 (Lord Goff) (paraphrasing).

⁷⁶ *ibid* 868-869 (Lord Goff) (paraphrasing); *Aintree* [2013] (n 63) at [39]-[40] (Lady Hale). Note the most significant of the large number of cases that came after *Bland*, and their differing approaches are first discussed in Chapter Three, Section 3.3.

⁷⁷ *Bland* [1993] (n 62) 868-869 (Lord Goff) (paraphrasing).

⁷⁸ Assessed in Chapter Two, Sections 2.2 and 2.3.

⁷⁹ *W v M and S (A NHS Primary Care Trust)* [2011] EWHC 2443 (Fam) (*W v M*; *M v N* [2015] EWCOP 76, [2015] 11 WLUK 514 (*M v N*); *A Hospital v SW* [2007] Med LR 273 (COP); 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 (7) *Journal of Medical Ethics* 459. This assertion and its counterarguments are discussed in Chapter Three, Subsection 3.3.1.

devoid of competing moral values, at least as applied in the sense it was in *Bland*.⁸⁰

Additionally, even as the legal test for futility changes in later legal developments to prioritise the patient's subjective view of what makes life worth living,⁸¹ the question posed is not as value neutral as it may seem.⁸² Donnelly for example criticises the use of subsections 4(6) and 4(7) Mental Capacity Act 2005 (MCA) to construct a view of what the patients would want (their subjective view of what is futile).⁸³ Therefore, the resulting question (addressed in Chapter Three) was whether futility should be a medically defined concept or defined by the patient's own notion of dignity.⁸⁴

The assumption that such cases undertake a rational calculus between autonomy and sanctity of life has led to an important but nonetheless frustrating endeavour to assess what moral values are being weighed and what procedural safeguards exists in any assessment that withdrawal is morally and legally required. The findings suggest that these cases are ultimately intuition-based judgments that draw on extra-judicial values and fail to follow the established procedural safeguard of common law precedent.⁸⁵ Such findings ultimately question how the law is upholding consistency and accurately identifying the moral basis for discontinuation in such cases as the vital components of defensible decision-making.⁸⁶ Consequently, because it is unclear how futility is being consistently interpreted and safeguarded, the question of 'continuation'⁸⁷ at the heart of

⁸⁰ Note this assertion is further explored to see if it remains "true" in respect of the key cases that came after *Bland*, as explored in Chapter Three, Sections 3.3 and 3.4.

⁸¹ *Aintree* [2013] (n 63) at [39]-[40] (Lady Hale). For example, post-*Bland* the test is medically objective and post-*Aintree* the test is subjective to the patient. Futility is therefore the term for that legal test and also happens to be a medical judgement that the patient has lost personhood ie "has died" (see Chapter Two, Section 2.4).

⁸² The specifically noted problems of *Aintree*'s subjective test for futility in the literature will be assessed in Chapter Three, Section 3.3 and Chapter Four, Section 4.3.

⁸³ Mary Donnelly, 'Best Interests in the Mental Capacity Act: Time to Say Goodbye?' (2016) 24 (3) Medical Law Review 318.

⁸⁴ *Aintree* [2013] (n 63) at [39]-[40] (Lady Hale). This point will be specifically addressed in Chapter Three, Subsection 3.4.1. The problems of defining dignity have been noted by Charles Foster, *Choosing Life, Choosing Death: The Tyranny of Autonomy in Medical Ethics and Law* (Hart Publishing 2009); Ruth Macklin, 'Dignity is a Useless Concept' (2003) 327 British Medical Journal 1419, and are further outlined in Chapter Four, Subsections 4.2.3 and 4.4.2.

⁸⁵ Kong and others (n 41); Huxtable and Birchley (n 41). As further explored in Chapter Three, Sections 3.3 and 3.4.

⁸⁶ *ibid.*

⁸⁷ Note in *Bland* [1993] (n 62) at 868 Lord Goff states that: 'the question is whether the doctor should or should not continue to provide his patient with medical treatment or care which, if

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these cases fails to provide sufficient scope to be answered by a 'more than', 'less than' or 'equal to' answer.⁸⁸ Therefore, because no competing moral values are being weighed it seems there is scope to suggest that the single consideration of 'futility' is what determines these cases but is being inconsistently interpreted.⁸⁹

This has culminated in the central problem this thesis tackles: that futility is not just the legal test used to determine whether life support continuation is permissible from living but severely cognitively impaired individuals,⁹⁰ futility also seems to be how death is defined and determined in E&W, and has therefore been found to hold a proximate and dangerous relationship with cognitive impairment.⁹¹ Chapter Two explores the distinction between "brain dead" and PDOC patients, and has found that the reliance on PDOC patients' capacity to breathe independently is not scientifically supported and thus cannot be used to draw a defensible distinction between the two patients' moral treatment: the brain dead as "dead" and PDOC patients as living.⁹² Moreover, academics studying the human rights of cognitively impaired persons have begun to question the link between end of life practices and a diagnosis of severe cognitive impairment.⁹³ These academics argue that cognitively impaired persons have historically been given a second-class personhood status which has given rise to a worrying pattern of behaviour that threatens their right to life and other legal rights that protect them from abuse within and outside of the home.⁹⁴

continued, will prolong his patient's life ... The question is not whether it is in the best interests of the patient that he should die.'

⁸⁸ Based on the "Trichotomy Thesis". See Chang (n 59) at 660-661.

⁸⁹ Explored in Chapter Two, Section 2.3 (medical basis) and Chapter Three, 3.2 and 3.3 (adoption in law).

⁹⁰ A finding of Chapter Three, Sections 3.2 and 3.3.

⁹¹ See Chapter Two, Sections 2.2 and 2.3.

⁹² As explored in Chapter Two, Section 2.2.

⁹³ As discussed in Chapter Four, Sections 4.2 and 4.3. See for example: Eilionóir Flynn and Anna Arstein-Kerslake, 'Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity' (2014) 10 (1) International Journal of Law in Context 81; Gerard Quinn, 'Rethinking Personhood: New Directions in Legal Capacity Law and Policy' (University of British Columbia, 29 April 2011) <http://citizenship.sites.olt.ubc.ca/files/2014/07/Gerard_Quinn_s_Keynote_-_April_29_2011.pdf> accessed 1 June 2019; Rosemary Kayess and Phillip French, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8 (1) Human Rights Law Review 1; Amita Dhanda, 'Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future' (2007) 34 Syracuse Journal of International Law and Commerce 429; Rioux (n 45).

⁹⁴ *ibid.*

However, if futility is how death is defined and determined in England and Wales-- and if futility is also how life support continuation is determined in law and medical ethics-- why was a purported rational calculus between autonomy and sanctity of life presented in *Bland*? Perhaps, as Hinkley argues, the practical demands of making a decision in applied ethics disciplines mean that applied ethicists feel pressured to pick a value and hold onto it to justify any decision made, rather than recognising inherent limitations in doing so (e.g. knowing death).⁹⁵ Such demanding circumstances suggest that the moral agents (doctors or judges) face a moral dilemma.⁹⁶

This thesis explores whether that purported moral dilemma is evidenced by the inconsistency and the factual inaccuracy of justifications which intend to distinguish PDOC patients from brain dead patients. Or more specifically, explores the implied view in medicine and law that a different interpretation of futility is occurring in life support withdrawals from brain dead patients than in cases concerning PDOC patients. The findings suggest that the same interpretation of futility is used for both brain dead and PDOC patients' life support decisions and consequently has given rise to the moral dilemma associated with *Bland*. This in turn questions whether PDOC patients are also "dead" or alternatively whether the brain dead are also "alive". In both patients' situations, the legally held status of being "alive" or "dead" makes no difference to the permissibility of a practice (life support withdrawal) which results in their foreseen biological death.⁹⁷ Yet it is this distinction which is legally vital for protecting healthcare practitioners who discontinue life support from attracting criminal liability for murder.⁹⁸

⁹⁵ Hinkley (n 4) 64-65.

⁹⁶ Explored in Section 1.4.

⁹⁷ Explored in Chapter Two, Sections 2.2 and 2.4.

⁹⁸ The inconsistency of the legal sophistry in *Bland* has been specifically analysed by: Keown (n 53); Andrew McGee, 'Finding a Way Through the Ethical and Legal Maze: Withdrawal of Medical Treatment and Euthanasia' (2005) 13 Medical Law Review 357; John Harris, 'The Concept of the Person and the Value of Life' (1999) 9 (4) Kennedy Institute of Ethics Journal 293; Finnis (n 53).

1.3.3 Ensuring Consistency and Factual Accuracy in Medicine

Medicine fact finds by drawing knowledge from a whole host of sources.⁹⁹ These sources range from the scientific to phenomenological.¹⁰⁰ From the mid-1990s a debate has arisen on how to defensibly diagnose patients and formulate a prognosis, or more specifically which of these sources of knowledge should take precedence over others.¹⁰¹ The debates focus on three theoretical models: opinion-based medicine (OBM-- experiential knowledge); evidence-based medicine (EBM-- the scientifically proven evidence e.g. from clinical trials (RCTs)); and real evidence-based medicine (REBM-- bridging the best of the older two models). Opinion-based medicine is the oldest form of medical decision-making and draws knowledge from clinical experience and patient narrative to formulate informed judgements.¹⁰² Conversely, evidence-based medicine was championed by Archie Cochrane in the 1970s.¹⁰³ He advocated that randomised clinical trials (RCTs) led to more defensible medical decision-making than OBM methods because of the greater certainty scientific evidence brought.¹⁰⁴ However, due to the poor translation of RCT results into non-clinically controlled settings there seems to be a consensus that REBM is the best way forward because of its focus on patient-centred and tailored care.¹⁰⁵ Notably, EBM has been criticised for its impracticality and poor translation into patients' care plans who are not confined to controlled settings and where the exercise of judgement still plays a crucial role. For example, the existence of patient 'multimorbidity'¹⁰⁶ and individual physiological differences cannot be accounted for in a 'one management strategy'

⁹⁹ Catherine Pope, 'Resisting Evidence: The Study of Evidence-Based Medicine as a Contemporary Social Movement' (2003) 7 (3) *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* 267.

¹⁰⁰ *ibid*. Note randomised clinical trials, patient narratives, experiential knowledge of symptoms and pathological development are some examples given in this article.

¹⁰¹ Trisha Greenhalgh, Jeremy Howick and Neal Maskrey, 'Evidence Based Medicine: A Movement in Crisis?' (2014) 348 *British Medical Journal* g3725; Rita Charon, 'Where does narrative medicine come from? Drives, diseases, attention and the body' in Peter L Rudnytsky and Rita Charon (eds), *Psychoanalysis and narrative Medicine* (State University of New York Press 2008); Pope (n 98); John R Hampton, 'Evidence-Based Medicine, Opinion-Based Medicine, and Real-World Medicine' (2002) 45 (4) *Perspectives in Biology and Medicine* 549; David L Sackett and others, 'Evidence Based Medicine: What it is and What it isn't' (1996) 312 *British Medical Journal* 71.

¹⁰² Charon (n 101) at 23-36 discusses the importance of patient narrative; Hampton (n 101).

¹⁰³ Pope (n 99); Hampton (n 101).

¹⁰⁴ Pope (n 99).

¹⁰⁵ Greenhalgh, Howick and Maskrey (n 101); Pope (n 99); Hampton (n 101).

¹⁰⁶ Greenhalgh, Howick and Maskrey (n 101) g3725.

approach,¹⁰⁷ regardless of what the results of a scientifically produced clinical trial suggest.¹⁰⁸ Such results alone rarely produce practical clinical guidance that could be universally applied.¹⁰⁹

Greenhalgh, Howick and Maskrey have ironically highlighted how EBM negates the need for critical thinking and fosters an over-reliance on bureaucratic rules, leading to robotic-like decision-making as RCT results were adopted into clinical guidelines.¹¹⁰ There were also issues of subjectivity in interpreting trial results,¹¹¹ where the vested interests of drugs companies and others are concealed by the misleading use of the 'quality mark' that EBM provides and leads to the distortion of results.¹¹² The EBM process has also provided too much evidence for clinicians to manage.¹¹³ An 'audit in 2005' identified '3679 pages of national guidelines (an estimated 122 hours of reading)', questioning the practicality of doctors being able to manage the amassing results from RCTs and the appropriateness of transposing RCT results into individuals' care management strategies.¹¹⁴ Conversely, Hampton argues that even though clinical guidelines are thought to be based on the results of RCTs they are still heavily composed of 'opinion', a point that he suggests is 'often overlooked'.¹¹⁵ His point questions how widely EBM has been adopted as the primary method of clinical decision-making and suggests that some balance between EBM and OBM has been maintained.¹¹⁶ Therefore, in the literature there seems to be a consensus that EBM alone is insufficient for defensible decision-making; clinical experience, expertise and opinion are all essential to the ascertainment of accurate clinical "fact-finding".¹¹⁷

¹⁰⁷ Hampton (n 101) 564.

¹⁰⁸ Greenhalgh, Howick and Maskrey (n 101).

¹⁰⁹ *ibid.*

¹¹⁰ *ibid* g3726.

¹¹¹ Hampton (n 101).

¹¹² Greenhalgh, Howick and Maskrey (n 101) g3725.

¹¹³ *ibid.*

¹¹⁴ *ibid* g3726.

¹¹⁵ Hampton (n 101) 559.

¹¹⁶ *ibid.*

¹¹⁷ Greenhalgh, Howick and Maskrey (n 101); Dennis R Wenger, 'Limitations of Evidence-Based Medicine: The Role of Experience and Expert Opinion' (2012) 32 (2) *Journal of Pediatric Orthopaedics* S187; Charon (n 101); Morley D Glicken, *Improving the Effectiveness of the Helping Professions: An Evidence-Based Approach to Practice* (Sage Publications 2005); Pope (n 99); Hampton (n 101); Sackett (n 101).

This finding is important for another reason. Commentators have begun to question the view that medicine can accurately be described as a science.¹¹⁸ An enquiry into the epistemology of medicine and the belief or view that medicine is a science is enlightening for highlighting its decision-making accuracy and consistency limitations. For example, the insightful work of Montgomery has advocated a move away from the EBM paradigm which she argues is harmful to patients, doctors and society.¹¹⁹ She argues that 'medicine is not a science' in the sense of 'a positivist what-you-see-is-what-there-is representation of the physical world',¹²⁰ 'despite its reliance on scientific knowledge and technological advancement'.¹²¹ Adding, that even where scientific experimentation ameliorates but 'does not eliminate medicine's uncertainty', the uncertainty that arises from collective differences (such as multimorbidity, unique patient history and differing reactions due to patients' different physiology among others) cannot be accurately diagnosed by looking at the narrow results of RCTs.¹²²

Instead, a doctor needs to exercise critical thinking that draws on the experiences and the opinions of their fellow doctors.¹²³ Medicine is therefore more accurately described as a 'practice' where the perspective that medicine as a 'positive' or 'Newtonian science' is idealised and inaccurate.¹²⁴ Moreover, even where the idealised view of medicine as a 'science ... cement[s] confidence', it harms all stakeholders.¹²⁵ Holding medicine to the standard of positive science removes critical thinking and patient-centred care which is harmful for patients, distressing for physicians (who are the first point of call in any fall out or dispute) and leads to misled lawsuits.¹²⁶ Interestingly, Montgomery also draws parallels with law and ethics suggesting that due to the very nature of these

¹¹⁸ Kathryn Montgomery, *How Doctors Think: Clinical Judgment and the Practice of Medicine* (OUP 2006); Pope (n 99).

¹¹⁹ Montgomery (n 118).

¹²⁰ *ibid* 6.

¹²¹ *ibid* 4.

¹²² *ibid*.

¹²³ *ibid*.

¹²⁴ *ibid*.

¹²⁵ See *ibid* at page 6 where Montgomery argues that, 'misunderstanding the epistemology of medicine – how doctors know what they know—has damaging consequences for patients, for the profession of medicine, and the physicians themselves ... The costs are great. It has led to a harsh, often brutal education, unnecessarily impersonal clinical practice, dissatisfied patients, and disheartened physicians'.

¹²⁶ *ibid*.

disciplines, like medicine, they all require practical reasoning to ascertain facts and assess consistency.¹²⁷ Specifically for this thesis, it cannot be denied that doctors have a 'particular familiarity with death',¹²⁸ however, medicine needs to continually draw on experiential knowledge and review end-of-life practices because they frequently deal with "the unknown". For example, determining death, the permissibility of vital organ donation or abortion (and other perennial problems of bioethics¹²⁹) all present, to differing degrees, moral dilemmas for a doctor.

Moreover, the law has also added further restrictions on the deference shown to the medical profession in their decision-making exercises. In *Bolam* [1957] McNair J stated that a doctor:

is not guilty of negligence if he has acted in accordance with a practice accepted as proper by a responsible body of medical men skilled in that particular art ...

Putting it the other way round, a man is not negligent, if he is acting in accordance with such a practice, merely because there is a body of opinion who would take a contrary view. At the same time, that does not mean that a medical man can obstinately and pig-headededly carry on with some old technique if it has been proved to be contrary to what is really substantially the whole of informed medical opinion.¹³⁰

However, in *Bolitho* [1998],¹³¹ the court reiterated that agreement or consensus from others is not enough. The House of Lords emphasised that the adjectives 'responsible, reasonable and respectable-- all show that the court has to be satisfied that the exponents of the body of opinion relied upon can demonstrate that such an opinion has a logical basis.'¹³² The Court also turned attention to *Hucks v Cole* [1993] where a decision was taken not to give a patient penicillin.¹³³ In that case the Court of Appeal held that a

¹²⁷ *ibid.*

¹²⁸ *ibid.*

¹²⁹ Engelhardt 1996 (n 22).

¹³⁰ *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582 (QB) 587.

¹³¹ *Bolitho v City and Hackney Health Authority* [1998] AC 232 (HL).

¹³² *ibid* 241-242 (Lord Browne-Wilkinson).

¹³³ *Hucks v Cole* [1993] 4 Med LR 393 (CA).

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divergence in opinion no matter how small the risk must be examined by the court.

Moreover:

the fact that other practitioners would have done the same thing as the defendant practitioner is a very weighty matter to be put on the scales on his behalf; but it is not ... conclusive. The court must be vigilant to see whether the reasons given for putting a patient at risk are valid in light of any well-known advance in medical knowledge, or whether they stem from a residual adherence to out-of-date ideas.¹³⁴

Bolitho therefore added that: 'if, in a rare case, it can be demonstrated that the professional opinion is not capable of withstanding logical analysis, the judge is entitled to hold that the body of opinion is not reasonable or responsible'.¹³⁵

Consequently, in defining and determining "death" or even in defining and determining loss of awareness (wholly or minimally lost) for PDOC patients, it would not be enough to state that a decision is defensible because it is based on an established practice. This also applies to life support continuation decisions in PDOC patients (i.e. futility decisions). *Bolitho* adds a further stipulation that the law will intervene where a practice, even if it holds a consensus, fails to be logically supported. Therefore, there is certainly scope to suggest that doctors should be wary of dogmatic practices that run counter to their experiential knowledge. Evidence of a responsible body of medical opinion and consensus is not necessarily sufficient to escape liability for negligence or assault. The practice must also be logical and reasonable. The test for defensible medical decision-making must therefore be well-reasoned and supported by the variety of sources that build experiential knowledge.

Some may view the *Bolitho* judgment as an unwarranted interference by the law into medical decision-making standards. For example, and disconcertingly for doctors, the case arose in a 'climate where medical practice was increasingly becoming litigious'.¹³⁶

¹³⁴ *ibid* 397 (Sachs LJ).

¹³⁵ *Bolitho* [1998] (n 131) 243 (Lord Browne-Wilkinson).

¹³⁶ Ash Samanta and Jo Samanta, 'Legal Standard of Care: A Shift from the Traditional Bolam Test' (2003) 3 Clinical Medicine 443, 443 (paraphrasing).

However, after analysing Montgomery's and Pope's view¹³⁷ on defensible medical decision-making standards, it seems to amount to a mere reinforcement of what medicine already views to be defensible decision-making. Hence, defensible medical decision-making is a contemplative and reflective practice, similar to the Aristotelian concept of '*phronesis*': the reflective practice of critically analysing and reasoning through the best course of action.¹³⁸

Furthermore, this view of medicine as a practice also means that doctors need to be given breathing space to make mistakes. Montgomery argues that part of viewing medicine as a practice or an art rather than a positive science, is acceptance that doctors will make mistakes which are an essential part of building better decision-making practice.¹³⁹ Therefore, not only is viewing medicine as a practice better for patients it is also fairer to doctors because they are not held to the stricter scientific standard which inaccurately reflects how they garner knowledge and form defensible decisions.¹⁴⁰ *Phronesis* can therefore be understood as the pre-existing moral translation of the current legally accepted standard for medical decision-making to provide or continue to provide treatment. To be held negligent or liable under *Bolitho*, the doctor would have failed to reflect and adapt in the face of new evidence that has questioned old and consequently erroneous practices.

1.3.4 Section Conclusion

This section has assessed how judges and doctors make decisions. It has looked at how their unique decision-making practices ensure consistency and factual accuracy (as the minimums of achieving defensible decision-making). Consistency is ensured in law via specific processes such as constitutional principles, common law precedent, statutory rules of interpretation and supranational guidance. Moreover, the question of factual accuracy in medical law is often left to doctors out of respect for their expertise.

¹³⁷ Pope (n 99).

¹³⁸ Montgomery (n 118) 33 and 41.

¹³⁹ ibid 31-32 and 41.

¹⁴⁰ Montgomery (n 118); Pope (n 99).

In the late 1990s and early 2000s medical literature was produced on how doctors could best use the information sources available to them to make the most defensible decisions in how to treat (or stop treating) a patient. It was shown that the most defensible exercise of medical decision-making draws from a whole host of information sources and practices what Aristotle coined *phronesis*. Moreover, it seems that this practice is also reflected in law, particularly after the *Bolitho* judgment that warned against following consensus for the sake of consensus. Furthermore, the realisation that medicine is also a practice and not a science also fosters better decision-making in the interest of patients and doctors.

Additionally, in 1.3.2 it was shown that philosophy adds some further qualifications on weighing moral values. First, a neutral covering value must exist in the question posed, and secondly, that the values weighed must be sufficiently commensurable to give an intelligible answer, such as 'better than', 'equal to' or 'worse than'.¹⁴¹ Where there is no evidence of this taking place it suggests no moral values are in conflict. However, there may alternatively be a moral dilemma.

1.4 Moral Dilemma or Moral Conflict?

1.4.1 Section Introduction

This section will explore whether the dilemma at the heart of PDOC patients' life support continuation decisions amounts to a genuine dilemma or more accurately can be described as a moral conflict. To do so, it will explore the seminal case of *Bland*, its reference to a dilemma at its heart and also the philosophical literature on indicators of genuine dilemmas. Note that this analysis is undertaken from a moral rather than legal perspective.¹⁴² The answer to this question may further debates in the literature that have sought to resolve the moral inconsistency in such cases.

¹⁴¹ Chang (n 59) 660-661; Hinkley (n 4) 49.

¹⁴² The particulars on the legal arguments are discussed in Chapter Three, Section 3.2.

1.4.2 Indicators of a Genuine Moral Dilemma

Both Lord Browne-Wilkinson and Lord Mustill referred to the moral and legal conflict that *Bland* presented as a 'dilemma'.¹⁴³ For Lord Browne-Wilkinson the dilemma arose because of the difficulty of determining life and death after advancements in life-saving technology: 'death in the traditional sense was beyond human control ... The time and manner of death is no longer dictated by nature but can be determined by human decision ... what is meant now by "life" in the moral precept which requires respect for the sanctity of life?'¹⁴⁴ It is therefore not only arguable that the definition of death required reappraisal more than 25 years ago but that *Bland* and PDOC patients' life support continuation decisions present a moral dilemma.

Moreover, Lord Mustill's reference to the 'dilemma' that *Bland* presents also refers to the suffering such cases stir in those around the patient and directly involved in their care, such as his family and healthcare staff: 'this combination of sympathy and respect can but yield an urgent desire to take up the burden, to reach a conclusion on this deep moral issue of life and death, and to put that conclusion into effect as speedily and humanely as possible.'¹⁴⁵ Lord Mustill also adds that, 'the pressure created by this very extreme case may distort the law in a way which leads to a false conclusion in situations where the issues are similar but more finely balanced, and may ... create unforeseen anomalies in criminal cases far removed from the present.'¹⁴⁶

It is therefore possible to distill what Lord Mustill and Lord Browne-Wilkinson thought were some identifiable features of a purported moral dilemma. First, that they arise from two equally impermissible actions; the indignity and potential assault of his continued life support and the impermissibility of granting others permission to take actions which end the patient's life.¹⁴⁷ Secondly, a dilemma arises from a conflict in moral values (sanctity of life and autonomy (in the sense of welfare/ dignity)). Thirdly, that the pressure to make a choice out of these equally impermissible options distresses those facing the dilemma. Finally, that the dilemma at least partially arises from limitations in

¹⁴³ *Bland* [1993] (n 62) 865-866 (Lord Mustill) and 877 (Lord Browne-Wilkinson).

¹⁴⁴ *ibid* 878 (Lord Browne-Wilkinson).

¹⁴⁵ *ibid* 865-866 (Lord Mustill).

¹⁴⁶ *ibid* 866 (Lord Mustill).

¹⁴⁷ *ibid* 886-887 (Lord Mustill) and 878-879 (Lord Browne-Wilkinson).

"knowing", for example, knowing the line between life and death for those who are non-responsive but nonetheless breathing such as PDOC patients.

The concept of a moral dilemma has a particular meaning in philosophy.¹⁴⁸ Although the concept's definition is controversial, it is clear that a moral conflict does not qualify as a moral dilemma.¹⁴⁹ Instead, McConnell suggests that a 'moral dilemma is a situation in which each of two things ought to be done but both cannot be done'.¹⁵⁰ Or better still, 'a situation in which, according to the true principles of morality, a moral agent was obliged both to perform an action of a specified kind and simultaneously not perform it'.¹⁵¹ Greenspan also adds that some dilemmas can be negative in nature, requiring a moral agent to choose between equally forbidden actions.¹⁵² Further still, 'in order for a moral conflict to count as a genuine dilemma, the conflicting obligations or 'moral requirements'¹⁵³ must at least be such that neither overrides the other'.¹⁵⁴ Therefore, Lord Browne-Wilkinson's and Lord Mustill's description of a dilemmatic case so far matches philosophical authority on indicators that a dilemma exists because two conflicting moral (and legal) requirements plausibly exist; continued treatment is an assault and indignity, and, to kill another living human being is wrong.

McConnell adds, 'genuine moral dilemmas are ontological, not merely epistemic; the truth of the conflicting ought-statements is independent of the agent's beliefs'.¹⁵⁵ In other words, 'we find ourselves in dilemmas not because of limited knowledge about what we ought to do, but because life has made impossible moral demands on us'.¹⁵⁶ In *Bland*, Lord Browne-Wilkinson pointed out that advances in medical technology had eroded the previously held certainty that doctors had in determining when a human being had died. It is certainly arguable that knowing "death" is more than a phenomenological limitation

¹⁴⁸ Alan Donagan, 'Moral Dilemmas, Genuine and Spurious: A Comparative Anatomy' in H E Mason (ed), *Moral Dilemmas and Moral Theory* (OUP 1996) 11-12.

¹⁴⁹ H E Mason, *Moral Dilemmas and Moral Theory* (OUP 1996) 3.

¹⁵⁰ McConnell (n 1) 36.

¹⁵¹ Donagan (n 148) 13.

¹⁵² Patricia A Greenspan, 'Moral Dilemmas and Guilt' (1983) 43 (1) *Philosophical Studies* 117.

¹⁵³ Hinkley (n 4) at page 7 defines a moral requirement as, '[in] a strong binding sense a reason to perform an action or to adopt an attitude'. Note that the use of "moral conflict" here is not referring to a moral value conflict and uses "conflict" to loosely mean a problem.

¹⁵⁴ McConnell (n 1) 36.

¹⁵⁵ *ibid.*

¹⁵⁶ Hinkley (n 4) 9.

(limitations in knowing through one's own conscious experiences and interactions with the world); death exists independently from our conscious experience. This point does not need to be examined further as it would require exploring whether death exists outside of our conscious experience which is outside the ambit of this thesis. For current purposes, it is safe to say that Lord Browne-Wilkinson's reference to limitations in knowing death could plausibly extend to an ontological limitation in "knowing" death as a phenomenon.

However, as assessed at the beginning of this subsection, Lord Browne-Wilkinson and Lord Mustill's understanding seems to suggest that a dilemma exists and that it arises between a conflict in moral values. From a philosophical perspective this understanding would be incongruous. It is clear that sanctity of life is one clearly identified moral value in the case. However, the identity of the other value is less clear and (as previously argued in 1.3.2) it seems that no two moral values can be identified in *Bland*. For arguments' sake it seems to be closer to welfare or non-maleficence.¹⁵⁷ It seems therefore that one moral value is present, non-maleficence for both protecting from assault (generally) and the most serious assault of homicide. Ultimately, philosophers stipulate that conflicting moral values amount to a moral conflict, not a moral dilemma.¹⁵⁸ They argue that genuine dilemmas only exist between competing moral requirements (ought statements).¹⁵⁹ Where moral values conflict, they argue that this scenario is more accurately described as a moral conflict because either only one moral requirement will arise or none at all, and in that sense the purported dilemma cannot be a dilemma because it is resolvable.¹⁶⁰ Either *Bland* presents a moral dilemma (with conflicting ought requirements) or it presents a moral conflict (with conflicting values): it cannot be both.¹⁶¹ Consequently, a moral dilemma seems to have arisen on two conflicting moral requirements on the basis of the same law (treating/touching another is an ostensible assault and its most serious form reflected in the law against murder).

¹⁵⁷ This welfare interest or interpretation of autonomy has been explored by Harris 2003 (n 66). This point is also analysed in more depth in Chapter Three, Section 3.2.

¹⁵⁸ Hinkley (n 4) 5; Mason (n 149).

¹⁵⁹ *ibid.*

¹⁶⁰ Mason (n 149).

¹⁶¹ Mason (n 149).

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To give an example of a possible moral dilemma from the philosophical literature, Greenspan refers to the novel *Sophie's Choice*¹⁶² and the dilemma Sophie faces.¹⁶³ Sophie and her two children are Polish prisoners at Auschwitz. When a Nazi officer at the camp accuses Sophie of being a communist, Sophie fears for the lives of herself and her two children. In an attempt to appease him, she informs him that she is Polish and Christian. He then demands that she choose which of her children will live and that if she refuses to choose, both will die. She chooses her son's life and gives up her daughter who is the youngest of the two. She is left to live with the overwhelming guilt of her choice.

Moral philosophers disagree on whether a moral dilemma can genuinely exist, even in the acutely agonising circumstances Sophie finds herself in.¹⁶⁴ This disagreement has wider implications than amounting to an abstract theoretical quandary. The possibility that true dilemmas exist suggests that the greatest moral theories developed are useless because they fail to guide a moral agent in all scenarios.¹⁶⁵ Therefore, those who have attempted to salvage moral doctrines such as utilitarianism and deontology from the wreck have attempted to deny the possibility of genuine dilemmas' existence.¹⁶⁶ Albeit a rudimentary example, possible deontological and utilitarian failings for Sophie's dilemma could be that Kantian deontology's uncompromisingly steadfast categorical imperatives would likely result in both of Sophie's children dying because it is 'wrong to kill',¹⁶⁷ and likewise, a possible utilitarian argument that sought to commensurate the children's lives on the basis of their future utility to the world would falter under any attempt to accurately ascribe value to their lives.¹⁶⁸

¹⁶² William Styron, *Sophie's Choice* (Bantam 1980). Note the dilemma can be found at page 589.

¹⁶³ Greenspan (n 152).

¹⁶⁴ For example, Barcan Marcus (n 5) defends the view that genuine moral dilemmas can exist and that this does not necessarily mean moral theory is ineffective. Alternatively, Donagan (n 148) argues that thought dilemmas arise where the moral principles used are either not as relevant as first thought or have been inconsistently formulated. Instances of their work on this point can be found in Mason (n 149).

¹⁶⁵ Mason (n 149).

¹⁶⁶ Peter Railton, 'The Diversity of Moral Dilemma' in H E Mason (ed), *Moral Dilemmas and Moral Theory* (OUP 1996).

¹⁶⁷ Mason (n 149); Donagan (n 148). See also the counterargument from Thomas E Hill Jr, 'Moral Dilemmas, Gaps and Residues: A Kantian Perspective' in H E Mason (ed), *Moral Dilemmas and Moral Theory* (OUP 1996).

¹⁶⁸ Mason (n 149); Donagan (n 148).

Alternatively, for those who argue that genuine moral dilemmas cannot exist because these moral doctrines can indicate a single moral requirement still fail to account for moral residue (the guilt and blameworthiness a moral agent feels after making an impossible choice¹⁶⁹). Ultimately, 'dilemma defenders have difficulty exonerating persons trapped in dilemmas, whereas dilemma opponents have difficulty accounting for all forms of residue.'¹⁷⁰ For example, there are noted instances in the philosophical literature where guilt may be felt by a moral agent without wrongdoing.¹⁷¹ Some have sought to reconcile this problem by distinguishing between sensations and emotions to provide some clarity on whether guilt or remorse is in fact being felt or some similar less culpable emotion.¹⁷²

The possibility of feeling moral residue (guilt, regret or remorse) when no wrongdoing is committed flies in the face of dilemma defenders who argue that moral agents, 'can feel remorse or guilt no matter what they do, or refrain from doing.'¹⁷³ McConnell therefore sought to separate guilt and remorse from regret. For example, doing so may explain 'Survivor's Guilt' which entails no wrongdoing,¹⁷⁴ or harm to others outside of one's own control, such as parental anguish caused by 'severe [congenital] birth defects in children'.¹⁷⁵ McConnell also suggests that even appropriate remorse does not necessarily entail wrongdoing, for example killing a child in a traffic accident may give rise to such an emotive response.¹⁷⁶ Ultimately, McConnell successfully demonstrates 'a vast array of appropriate negative emotions in response to an alleged dilemma' and therefore, the presence of moral residue cannot itself 'establish the presence of a dilemma'.¹⁷⁷ In fact, Sinnott-Armstrong who is a supporter of dilemmas' existence agrees with McConnell that remorse can be appropriate in situations where no wrongdoing occurred on the part of

¹⁶⁹ Hill Jr (n 168) 167.

¹⁷⁰ Hinkley (n 4) 4.

¹⁷¹ McConnell (n 1).

¹⁷² Bas C van Frassen, 'Values at the Heart's Command' in Christopher Gowans (ed), *Moral Dilemmas* (OUP 1987); Hinkley (n 4).

¹⁷³ Hinkley (n 4) 15-16; McConnell (n 1).

¹⁷⁴ Hinkley (n 4) 14.

¹⁷⁵ *ibid* 15. I have presumed that the word congenital should be added here because other defects would imply wrongdoing, for example, harm inflicted on the child in pregnancy by the mother, which is inconsistent with the point being made.

¹⁷⁶ McConnell (n 1) 36. Also discussed by Hinkley (n 4) at 15-16.

¹⁷⁷ Hinkley (n 4) 16.

the moral agent.¹⁷⁸ It therefore is apparent that feelings of regret, remorse or some other such negative emotion cannot by themselves indicate the existence of a moral dilemma. In relation to *Bland*, the argument previously made (that no real moral conflict between competing moral values occurred) may indicate that *Bland* can accurately be described as a genuine dilemma.¹⁷⁹ Consequently, the next step in establishing if a genuine dilemma exists is to examine whether two equal or hierarchical moral requirements can be found in the law protecting against infringements of bodily integrity to assess its resolvability.

1.4.3 Mitigating Problems Faced in Adopting Moral Requirements in Law

It is plausible to assume that some laws are created because they reflect universally accepted principles of morality such as 'do not kill'.¹⁸⁰ Therefore, a necessary preliminary step to find if *Bland* presented two conflicting moral requirements, is to explore how the law may reflect universally agreed upon moral requirements or alternatively which are universal or non-universal moral precepts. The law holds a complex relationship with morality.¹⁸¹ Its relationship is also further complicated because modern society is pluralistic.¹⁸² Raz, for example, indicates that, 'no state or legal system can manifest to their highest degree all the virtues or all the vices there are.'¹⁸³ It is generally accepted that laws (at least theoretically) should be 'content thin' or neutral.¹⁸⁴ Nevertheless, one way of achieving content-full morality, or "value neutrality" in pluralistic societies is through commonly agreed upon mores. For example, Beauchamp and Childress distinguish 'universal' from 'non-universal moralities'.¹⁸⁵ For these proponents universal morality refers to 'norms about right or wrong human conduct that are so widely shared that they form a

¹⁷⁸ ibid. Note Hinkley is referring to Walter Sinnott-Armstrong, 'Moral Dilemmas and Rights' in H E Mason (ed), *Moral Dilemmas and Moral Theory* (OUP 1996).

¹⁷⁹ This question will be answered in Chapter Five, Section 5.3.

¹⁸⁰ Beauchamp and Childress (n 31) 2-3.

¹⁸¹ Roger Cotterrell, 'Common Law Approaches to the Relationship Between Law and Morality' (2000) 3 (1) Justice in Philosophy and Social Science 9. Note I do not intend to explore in detail law's relationship with morality and only mention the relationship here to the extent that is necessary.

¹⁸² Engelhardt 1996 (n 22).

¹⁸³ Joseph Raz, 'About Morality and the Nature of Law' (2003) 48 (1) The American Journal of Jurisprudence 1, 4.

¹⁸⁴ Engelhardt 1996 (n 22).

¹⁸⁵ Beauchamp and Childress (n 31) 2-3.

stable social compact' such as, 'do not kill' and 'do not steal'.¹⁸⁶ Alternatively, non-universal moralities bind only 'specific communities or groups,' such as a 'profession' and its codes of professional conduct.¹⁸⁷ Additionally, Beauchamp and Childress add that non-universal moralities 'are not morally justifiable if they violate norms in the common morality.'¹⁸⁸

Engelhardt's postmodernist 'permission' theory attempted to grapple with the idea that content-full morality can be achieved among different moral communities via his 'permission principle'.¹⁸⁹ He argues that value pluralism among different moral societies raises the difficulty of applying ought statements to multiple agents from differing moral communities or what he calls 'moral strangers' (members of different moral communities who do not share the same view on morality), arguing that any attempt to do so would lead to oppression of one or more moral communities.¹⁹⁰ He also suggests that the Enlightenment thinkers who sought to advocate 'rational thinking' as a way of resolving moral disputes ultimately failed in their task to delineate a 'content-full' moral code that was acceptable and applicable to all.¹⁹¹

To avoid the brink of 'nihilism'¹⁹² he suggests that 'permission' (the consent of all moral (stranger) communities) is needed at the level of law and policy to prevent oppression and provide a 'content-full' and 'secular' moral code.¹⁹³ It could be argued that the democratic Parliamentary process in England and Wales incorporates Engelhardt's permission principle by electing representatives who vote on, create and amend law and policy on the general public's behalf. However, this is not quite what Engelhardt means by the permission principle which is more extensive than our current model of democracy allows, because under the current democratic process it is not possible to have all communities represented. His theory is laudable for its inclusivity and attention to the

¹⁸⁶ ibid.

¹⁸⁷ ibid 3.

¹⁸⁸ ibid 5.

¹⁸⁹ Engelhardt 1996 (n 22).

¹⁹⁰ ibid 7.

¹⁹¹ ibid 9.

¹⁹² Nihilism is a philosophical doctrine that rejects all moral and religious values or precepts; a belief that nothing has meaning (nihilism) is a common criticism of postmodernist theories. See Hinkley (n 4) 41-42.

¹⁹³ Engelhardt 1996 (n 22) 9 and 123.

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limitations of a universally adopted and content-full moral code in pluralistic societies, which has arguably been overlooked in applied ethics.¹⁹⁴ However, it is too idealistic to be implemented without huge constitutional upheaval and even then, there is no guarantee that a workable agreement with all moral communities could or would be reached.¹⁹⁵

Sidgwick raises a further point of concern that is applicable to those raised by Engelhardt and provides a more practical method for those delineating an applied ethics methodology. Sidgwick starts by arguing that, if the aim of ethical enquiry is generally 'not the study of what is, but what ought to be', where studying 'what is' is a necessary step to ascertaining 'what ought to be', 'what ought to be' may have no objective existence.¹⁹⁶ If ought statements are nothing more than ideals and entities that do not objectively exist, it is questionable whether "ought" can amount to anything more than the feelings, intuitive arguments or mere opinions of the moral agent.¹⁹⁷ This concern helps reinforce the importance of (whilst recognising the albeit noted difficulty of applying) Engelhardt's permission principle. Consequently, an important question is raised. Merely identifying the purpose of ethical enquiry as obtaining good ends is not enough.¹⁹⁸ The more difficult question is how to defensibly reach that end?¹⁹⁹ One possible answer is provided by the Doctrine of the Relativity of Morals (DROM).²⁰⁰ This doctrine may help applied medical ethicists to defend any moral code or theory adopted because it provides another method of finding a consensus and is practically more achievable than Engelhardt's Permission Principle. DROM also achieves defensibility because it avoids oppression of 'moral strangers'²⁰¹ and subjective arguments of what ought to be.

The Doctrine of Relativity of Morals (DROM) indicates what the moral code or theory is to be applied in a given scenario to produce a moral requirement or ought statement and thereby resolve the moral problem.²⁰² It suggests that whenever a particular moral

¹⁹⁴ See Hinkley (n 4) 39-43.

¹⁹⁵ *ibid.*

¹⁹⁶ Sidgwick (n 2) 2.

¹⁹⁷ *ibid.*

¹⁹⁸ Ross (n 20).

¹⁹⁹ *ibid.*; Sidgwick (n 2).

²⁰⁰ Sidgwick (n 2).

²⁰¹ Engelhardt 1996 (n 22) 9.

²⁰² Sidgwick (n 2) 6.

problem presents itself that a moral reasoner²⁰³ must assume that the agent has consented to the moral code that is being applied to weigh the particular problem.²⁰⁴ This is similar to Beauchamp and Childress' non-universal morality that professions adopt.²⁰⁵ Such a moral code is justified because it is adopted by people who reason 'in common'.²⁰⁶ Therefore, there is an implicit assumption that the agent in the scenario has assumed or agrees with the underlying moral code by which the scenario is being judged. Consequently, Sidgwick suggests that DROM is fundamental in applied ethics because without this assumption there would be no way of resolving ethical conflicts or dilemmas.²⁰⁷ Those evaluating the defensibility of the decision made would be left guessing the moral code each moral agent lives by, rendering the whole exercise impractical.²⁰⁸

However, non-universal moralities can also be problematic. Beauchamp and Childress suggest that because professional standards and obligations are 'often vague', there is an assumption that if guidelines are followed that all moral obligations have been covered by a member.²⁰⁹ This assumption relies on the expectation that guidelines are: easily identifiable; comprehensive enough to apply in all cases; specific enough to be commensurable (weighed against one another); and are able to provide defensible resolution.²¹⁰ Therefore, to avoid indefensible decision-making (for example the robotic-like application of EBM-based guidelines) doctors should practice *phronesis*, where in any given scenario they will reflect and draw on a mixture of their experiential knowledge and the available scientific evidence to arrive at a professional judgement on the best course of action.²¹¹

Moreover, and importantly for the principal aim of this thesis, Beauchamp and Childress also suggest that due to the vagueness and sometimes inapplicability of certain

²⁰³ A term I use here to mean the philosopher who is attempting to problem solve and suggest what the agent should do. The label is also used synonymously with moral agent or decision-maker.

²⁰⁴ Sidgwick (n 2) 6.

²⁰⁵ Beauchamp and Childress (n 31) 3.

²⁰⁶ Sidgwick (n 2) 6.

²⁰⁷ *ibid* 7.

²⁰⁸ *ibid*.

²⁰⁹ Beauchamp and Childress (n 31) 8.

²¹⁰ *ibid* (paraphrasing).

²¹¹ Montgomery (n 118) 33 and 41. Discussed in Subsection 1.3.3.

guidelines to guide moral decision-making in all scenarios, it is important to ask whether the codes specific to areas of science, medicine and healthcare are, 'coherent, defensible and comprehensive within their [respective] domain[s]'.²¹² Having outlined the basic building blocks of addressing moral decision-making limitations (DROM, that universal will trump non-universal moralities, and that moral agents employing non-universal moralities will have to critically analyse the competing options before applying guidance); I will now assess if *Bland's* competing and purported moral requirements are resolvable, e.g. they will be resolvable and consequently non-dilemmatic if one is found to be a non-universal moral precept and one a moral requirement.

1.4.4 Is *Bland's* *Cri de Coeur* Indicative of a Moral Dilemma?

This subsection will assess the moral dilemma at the heart of *Bland* -- its '*Cri de Coeur*'.²¹³ From a legal perspective, an easily identifiable moral requirement present at the time *Bland* was decided is reflected in the law on murder (sanctity of life). Further still, it is reasonable to suggest that the law on murder reflects a universal moral requirement accepted in most known cultures, religions and jurisdictions: killing other human beings is wrong.²¹⁴ Murder is a common law offence defined in Sir Edward Coke's *Institutes of the Laws of England* 1797 as: 'when a man of sound memory, and of the age of discretion, unlawfully killeth within any country of the realm any reasonable creature [human being] under the King's [or Queen's] peace, with malice aforethought, either expressed by the party or implied by law'.²¹⁵ However, the definition of murder has since been qualified. For example, *Rance v Mid-Downs Health Authority* (1991),²¹⁶ and *AG Ref No 3 of 1994* (1997),²¹⁷ held that only human beings born and breathing independently, 'without

²¹² *ibid* 8.

²¹³ Finnis (n 53) 329.

²¹⁴ Beauchamp and Childress (n 31) 2-3. Noting also its elevated status as a 'non-derogable right' in international human rights law treaties eg Article 2 of the European Convention on Human Rights 1950 (Convention for the Protection of Human Rights and Fundamental Freedoms 1950).

²¹⁵ Sir Edward Coke, *The Third Part of The Institutes of the Laws of England: Concerning High Treason and Other Pleas of the Crown and Criminal Causes* (E and R Brooke in 1797) 47 (paraphrasing).

²¹⁶ *Rance v Mid-Downs Health Authority* (1991) 1 All ER 801 (QB). Note however, the law on abortion is more nuanced, for example abortion is not a legalised practice, instead a statutory defence is provided if certain factors are met such as, the mother's own life would be at risk from having the child. See the Abortion Act 1967.

²¹⁷ *AG Ref No 3 of 1994* (1997) 3 All ER 936 (HL).

deriving any of its living or power of living by or through any connection with its mother',²¹⁸ could be murdered.²¹⁹ Moreover, Coke's definition references 'unlawful killing' and 'King's peace';²²⁰ therefore throughout English legal history further exceptions have been made. For example, the death penalty amounted to one such exception.²²¹ Likewise, reference to peacetime excludes killing in time of war. Additionally, self-killing or self-murder, i.e. suicide, has also since 1961 been a stipulated exception.²²²

However, at the time *Bland* was decided there existed no exception in law that permitted in Lord Mustill's words: 'one group of citizens to terminate the life of another'.²²³ What *Bland*'s doctors proposed (to withdraw Anthony Bland's life-supporting treatment) amounted to *prima facie* murder;²²⁴ *Bland* was a living and independently breathing human being. Based on this understanding there is no legal conflict. Moreover, if it is accepted that killing human beings is a universal moral precept enshrined in law, it is also plausible to suggest that therefore only one moral requirement existed because no other equally obvious moral requirement is found. Such findings suggest that *Bland* does not present a genuine moral dilemma at all because there exists only one moral requirement in such cases.

However, such analysis overlooks the fact that there is at least an ostensible competing legal requirement which is crucial to the legal question in *Bland* and subsequent life-supporting treatment decisions: unjustifiable touching of another's person amounts to assault.²²⁵ Consequently, all medical treatment must be justified. In such cases it seems that a lesser (albeit still serious) assault (battery) is competing against the most

²¹⁸ *Rance* (1991) (n 216) 621 (Brooke J).

²¹⁹ *AG Ref No 3 of 1994* (1997) (n 217). Interestingly, the Court held in this case that the defendant could be charged with constructive manslaughter because only causation had to be proved. The fact the foetus was not yet deemed a human being at the time of the attack (referring to *Rance* and the capability to live independently) was not a requirement under this offence.

²²⁰ Coke (n 215) 47 (paraphrasing).

²²¹ Murder (Abolition of the Death Penalty) Act 1965.

²²² Suicide Act 1961.

²²³ *Bland* [1993] (n 62) 886 (Lord Mustill). Note the case attempts to maintain the position that this is still the case in English and Welsh law as all forms of euthanasia (eg voluntary, involuntary and non-voluntary) are illegal, but as explored in Chapter Three, Section 3.2, perhaps this assertion is not as morally straightforward.

²²⁴ This was also the advice given by the Coroner and argued by the Official Solicitor Mr Munby at page 797 and reiterated at page 813 of the *Bland* [1993] (n 62) judgment.

²²⁵ *re F* [1990] (n 72).

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serious form of assault (killing another). Both of these laws are instantiations of the right to bodily integrity. Therefore, the moral and legal dilemma in *Bland* has arguably arisen from two conflicting laws both protecting the moral precept of non-interference with another's person, i.e. non-maleficence (which is enshrined in its highest instance in the law against murder). Its resolvability therefore hinges on the status of these conflicting laws: are they hierarchical or equally valued in law?²²⁶ However, for current purposes, it is necessary to ask whether protection from assault is considered an equally important moral precept as the wrongfulness of killing. As Chapter Two will demonstrate, the debate on brain death can help indicate whether protection from being assaulted is given equal moral status as the right to life because it provides a clear example of when they are in conflict.

Brainstem death was arguably the first instance where the law was presented with a change from the original definition of cardiopulmonary death. Therefore, its acceptance as another means of determining whether a "person" is dead is crucial to the legal consideration of a person's right to bodily integrity: if this determination of death is accepted as "death" no assault arises from subsequent medical action or inaction (omission). Conversely, if it is not accepted as "death", any subsequent action or inaction amounts to *prima facie* assault. Moreover, if law reflects commonly agreed upon mores, the law can indicate the universal mores of its society.²²⁷

Interestingly, very few jurisdictions accept the UK's concept of "brainstem death", suggesting that in other jurisdictions, the right to life holds a higher status of legal protection than the moral precept to do no harm (reflected in the law against assault).²²⁸ Alternatively, in E&W, both laws seemingly represent equally valued moral requirements. However, if they were equally valued the law against euthanasia and assisted dying would have changed, suggesting that the universally accepted moral requirement not to kill is treated as context-specific in law. Therefore, the crucial legal question of assault only

²²⁶ This question and the law's protection from assault and murder will be discussed in Chapter Three, Section 3.2.

²²⁷ It seems possible to have a 'universal more' even if a compromise has been reached, such as the way in which certain abortions are provided a statutory defence rather than "legalised" in the E&W, in consideration of the moral communities both for and against abortion.

²²⁸ See Chapter Two, Section 2.2 for an overview of the history of brain/ brainstem death and its cultural adherents.

seems to be dilemmatic when the individual's status as a living human being and "person" is in question, i.e. there is hesitation in defining them as "dead". Furthermore, that would suggest that both purported requirements are in fact non-universal moral precepts because their parameters are defined by medicine according to their professional code of morality, not society's.

Moreover, if medicine defines death, perhaps the law has simultaneously adopted both a universal and non-universal interpretation of "do not kill other human beings" than the sanctity of life ethic propounded by religionists would suggest. For religionists, being human (an ensouled being) means having a 'spark of the divine'²²⁹ and therefore membership of the human race for religionists means that human life is more valuable than any other species.²³⁰ The law on murder did not originally include the words "human being". Instead, the phrase 'reasonable creature in *rerum natura*' was included.²³¹ These words possibly indicate a more exclusive interpretation of human being than membership of the human race which may translate better to "beings who reason".

To support this view, this subsection earlier demonstrated that the law already qualifies the term "human being" to limit the law on murder to only born human beings who live independently.²³² However, that case (*Rance*) admittedly states that, 'anencephalic children born partially or wholly without the cerebral hemispheres of their brain' are defined as born alive human beings and are thus capable of being murdered.²³³ Moreover, as will be explored in 2.2 and 2.3, neurology asserts that the cerebral cortex is responsible for responsibility and awareness. Consequently, this specific example of anencephalic children ostensibly seems to thwart my reasoning; the capacity to reason is not a legal prerequisite to be capable of being murdered. Moreover, the implicit reference throughout Coke's account of the law on murder (that only human beings can be murdered) does not directly suggest it is only those who can reason that can be "murdered".²³⁴ Even today, animals, who at least meet the strict translation of the Latin

²²⁹ Ngaire Naffine, *Law's Meaning of Life: Philosophy, Religion, Darwin and the Legal Person* (Hart Publishing 2009) 23.

²³⁰ *ibid.*

²³¹ Coke (n 215) 47.

²³² *Rance* (1991) (n 216); *AG Ref No 3 of 1994* (1997) (n 217).

²³³ *Rance* (1991) (n 216) 621 (Brooke J) (paraphrasing).

²³⁴ Coke (n 215).

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'*rerum natura*'²³⁵ cannot be murdered, that offence is more akin to destruction of property.²³⁶ Therefore, although in law there exists restrictions on the meaning of the phrase 'human being' that are more limited than acknowledgment of belonging to the human race, there does not seem to be an explicit suggestion that the capacity to reason is a further requirement.

However, Coke wrote his *Institutes of the Laws of England* between 1628-1644 and published in 1797. Therefore, contextualising Coke's phrase in philosophical thought at the time will likely bring an even more nuanced interpretation to "reasonable creature". Coke's work was published during the Enlightenment period (17th and 18th Centuries) whose greatest philosophical thinkers sought to argue that reason was the source of morality. For example, Nietzsche and his famous exclamatory point: 'God is Dead ... and we have killed him' is in reference to the idea that rationalism, as morality derived solely from reason, had allegedly purged Christianity from moral theory.²³⁷ Although Engelhardt persuasively argues that such Enlightenment thinkers or "rationalists" failed to fully remove Christian morality from their moral code (for example Kant and Kirkegaard's work evidently rely on Christian morality) the Enlightenment determined that the capacity to reason is what separates humans from other species.²³⁸

Therefore, perhaps 'reasonable creature' could better translate to those capable of reason or "reasoning beings". For example, Kant's theory on the wrongfulness of killing as a categorical imperative is justified on the basis that to kill another or even one's self is to kill the "person". Notably, Kant also uses the (similarly to Coke's) phrase 'reasonable being' synonymously with 'person' to refer to a particular class of 'intelligent' individuals.²³⁹ In fact, he emphasises that it is the denial of another's personhood that explains why killing is

²³⁵ ibid 47. '*Rerum natura*' means beings in existence.

²³⁶ There are also prosecutorial differences in the severity of the sentence of charging a person who "kills" an animal under the Criminal Damage Act 1971, which results in criminal court proceedings, versus offences under the Animal Welfare Act 2006, which are heard in a Magistrates Court. The former will bring charges in a criminal court perhaps reflecting a severer punishment than the Animal Welfare Act 2006, paradoxically suggesting that bringing a property offence claim will result in harsher punishment than acknowledging that animals are beings in existence.

²³⁷ Friedrich Nietzsche, *The Joyful Wisdom* (Oscar Levy (ed), Thomas Common (tr), The MacMillan Company 1924) 168.

²³⁸ Engelhardt 1996 (n 22).

²³⁹ Kant (n 18) 40-41.

universally wrong.²⁴⁰ To do so, treats the other being as a thing, and as a means and not an end in themselves: 'every intelligent nature exists as an end in itself ... so act that humanity, both in thy own person and that of others, be used as an end in itself and never as a mere mean.'²⁴¹ Furthermore, in reference to the wrongfulness of killing Kant states:

he who proposes to commit suicide, has to ask himself if his action be consistent with the idea of humanity as an end in itself. The man who destroys his own organic system to escape from sorrow and distress, makes use of his person as a mean toward the supporting himself in a state of comfort and ease until the end of his life. But humanity is not a thing ... but is that which must at all times be regarded as an end in itself.²⁴²

Therefore, according to Kant, even to relieve suffering, killing the humanity in one's self (or in others) is treating that human being as a means and denies their person. Moreover, there is scope to suggest that 'person' has a further implicit qualification as 'intelligent beings'.²⁴³

This is just one example of how Enlightenment thinkers saw value in those who can reason (rational beings). Additionally, given the historically abusive treatment of those with cognitive and mental disability at that time,²⁴⁴ it also seems plausible that 'reasonable creature' in Coke's definition of murder only extends to those capable of being wronged because they hold the revered capacity to reason and thus are persons. It is at least possible that the law adopted a more nuanced interpretation of the common (religionist) moral requirement that killing human beings is wrong. In fact, it is entirely possible that English and Welsh law has adopted the Kantian or rationalist interpretation of wrongful killing.²⁴⁵ This relationship between the wrongfulness of killing and personhood status will

²⁴⁰ *ibid* 42-43; Iain Brassington, 'Killing People: What Kant Could Have Said About Suicide and Euthanasia But Did Not' (2006) 32 (10) *Journal of Medical Ethics* 571.

²⁴¹ Kant (n 18) 42.

²⁴² *ibid* 43.

²⁴³ *ibid* 42- 43.

²⁴⁴ Piers Gooding, 'Change and Continuity in Mental Health Law: The Long Road to the United Nations Convention on the Rights of Persons with Disabilities and its Implications for Mental Health and the Law Today' (2014) 20 (3) *European Journal of Current Legal Issues* <<http://webjcli.org/article/view/367>> accessed 26 June 2019.

²⁴⁵ Incidentally, Kant also suggests that those who kill should be killed by the death penalty, and that suicide is wrong—both of which had historically been reflected in law, see *Murder (Abolition of*

be explored throughout the rest of the thesis. Consequently, it is possible that *Bland* presents a moral dilemma because the law has adopted medicine's non-universal moral precept on what amounts to harm/ assault (professional deference shown in delineating a duty of care/ necessity as explored in 1.3.3) and likewise death in a medical context (see 2.3), whilst simultaneously advocating that all born human beings are persons.

Coincidentally, the law in some respects records historical development in medical policy and practice. *Bland* refers to a change in medical practice that had occurred before the case was heard in the way in which medicine defines and determines death; where the definition of death was no longer solely determined by cardiopulmonary criteria.²⁴⁶ Indeed, it is at least likely that death needed to be redefined to permit vital organ donation from living human beings: how else could non-ischemic vital organs be obtained and be feasible for successful transplantation?²⁴⁷ Nevertheless, the law treats brain dead individuals as "dead" despite their beating hearts because medicine defines such individuals as "dead".²⁴⁸ The law also accepts brainstem death despite no statutory definition, universal acceptance of its clinical criteria or consideration of different moral views on its acceptability.²⁴⁹ For example, neurologists since the late 1990s have questioned just how "dead" the brain dead are, and whether they are defined as "dead" on the basis of moral instead of biological criteria.²⁵⁰

the Death Penalty) Act 1965 and Suicide Act 1961. See Kant (n 18) 40-43; Iain Brassington, 'Killing People: What Kant Could Have Said About Suicide and Euthanasia But Did Not' (2006) 32 (10) Journal of Medical Ethics 571.

²⁴⁶ *Bland* [1993] (n 62) 878-879 (Lord Browne-Wilkinson).

²⁴⁷ As explored in Chapter Two, Subsection 2.2.2. See also Jeffrey P Bishop, *The Anticipatory Corpse: Medicine, Power, and the Care of the Dying* (University of Notre Dame Press 2011); Mita Giacomini, 'A Change of Heart and A Change of Mind? Technology and the Redefinition of Death 1968' (1997) 44 (10) Social Science and Medicine 1465.

²⁴⁸ Wicks 2017 (n 28) 121.

²⁴⁹ Butler-Cole V and Tanel B, 'Brain Death and the Law' (Mental Capacity Law and Policy, February 2020) <<https://www.mentalcapacitylawandpolicy.org.uk/wp-content/uploads/2020/03/Brain-death-talk-VBQC.pdf>> accessed 1 April 2020; Robin S Howard, 'Coma and Brainstem Death' (2012) 40 (9) Medicine 500; M D Dominic Bell, Edward Moss and Paul G Murphy, 'Brainstem Death Testing in the UK—Time for Reappraisal?' (2004) 92 (5) British Journal of Anaesthesia 663; James L Bernat, 'A Defense of the Whole-Brain Concept of Death' (1998) 28 (2) Hastings Centre Report 14.

²⁵⁰ Robert M Veatch, 'The Death of Whole-Brain Death: The Plague of the Disaggregators, Somaticists, and Mentalists' (2005) 30 (4) Journal of Medicine and Philosophy 353. As explored further in Chapter Two, Section 2.3.

It would not be the first time that doctors independently provoked a change in the law by pushing its boundaries. In 1938, Dr Bourne handed himself into police after performing (what was then) an illegal abortion.²⁵¹ He had performed an abortion on a 14-year-old girl who had been gang-raped and was suicidal. He believed some exceptional circumstances existed where abortion should be permissible. The case therefore led to the exception that where the pregnancy risked harm to the life of the mother that abortion was legally permissible. He was therefore acquitted. Yet, doctors' attempts to provoke legal change do not always end favourably. The case of *R v Cox* [1992] is one such example.²⁵² In that case Dr Cox administered a lethal dose of potassium chloride to his elderly patient to relieve her pain. The prosecution held that the administration of potassium chloride in that dosage had lethal, not analgesic effects. It was only the fact that her body had been cremated that meant that he was alternatively convicted of attempted murder.

Ultimately, it is entirely possible that the current definition and determination of death has been constructed to permit a different moral requirement on what lives are worth living (or saving). As explained in *Bland*, the change to the definition of death was both justified on the basis of the emotional distress such severe disability places on families and the necessary resources of keeping such individuals alive. Hence, the difference between *Bourne* and *Cox*, *Nicklinson*²⁵³ and *Bland* is that the individuals concerned all hold different personhood statuses impacting the wrongfulness of interfering with their bodily integrity (killing/ assault).

In cases where a clash arises between assault from continued treatment (or existence in the case of abortion) and murder from withdrawing it, the law has failed to answer the patient's personhood status. As 4.2 will demonstrate, the medical history of treating those with cognitive and mental impairments is represented by an oscillating battle over their personhood. *Bland* occurred post-1980s when international human rights movements had been fighting for the equal recognition of those with disability as legal persons. Likewise, Chapter Two demonstrates that the concept of brain death was borne

²⁵¹ *R v Bourne* [1939] 1 KB 687 (KB).

²⁵² *R v Cox* [1992] CLY 886 (unreported) (*Cox*).

²⁵³ *R (on the application of Nicklinson) v Ministry of Justice; R (on the application of Lamb) v Ministry of Justice; R (on the application of AM) v DPP* [2014] UKSC 38, [2015] AC 657.

out of a view that such lives did not hold equal value and has extended to those further up the cognitive impairment spectrum. This may explain why euthanasia/ assisted death is prohibited but the morality of withdrawing life support is lawful on the basis that such patients are no longer persons. Therefore, the moral and legal dilemma reflected in the moral precepts “to do no harm” and “to not kill” (bodily integrity) are dilemmatic where the individual’s personhood status is in question; in all other circumstances, the right to life is considered a universal moral requirement that would trump any or negate any question of assault from continued treatment.

However, because the question of assault is determined by doctors (no duty of care/ medical necessity to treat) in the context of life-supporting treatment decisions and even the determination of death, to trump the universal moral requirement that all born humans are persons, the standard of medical certainty must be very high in pluralistic societies where the lives of those with disability are to be equally valued. Where this standard has not been met, the assault consideration becomes a non-universal moral precept (specific to a profession) and therefore should arguably be trumped by the universal requirement on the sanctity of life. The key question for this thesis is to examine how death is defined and determined in medicine and law. If the moral dilemma has arisen from an inconsistent interpretation of personhood, the purported dilemma would be resolvable and thus not a genuine dilemma because a choice between the two interpretations could be made: are those with cognitive disability persons? Consequently, it could also possibly help further explain the often-noted moral inconsistency at the heart of *Bland* (discussed in 3.2) and PDOC life support continuation cases more generally (discussed in 3.3).²⁵⁴

Finally, although this chapter has focussed on *Bland*, this thesis does not entirely focus on the case to the exclusion of other developments. Where it is a focus, it is because it is the seminal case where the purported moral dilemma arose and where life support withdrawal from PDOC patients became required in law. The case is therefore a necessary starting point. Revisiting and reappraising the definition and determination of death is

²⁵⁴ John Keown, ‘A Futile Defence of Bland: A Reply to Andrew McGee’ (2005) 13 (3) *Medical Law Review* 393; McGee (n 98); Harris 1999 (n 98); Keown 1999 (n 53); Finnis (n 53). The answer to this question is provided in Chapter Five, Section 5.3.

therefore vital to assess if its rationale amounts to a personhood-based determination for death which has consequently impacted those with cognitive disability. This thesis' question therefore furthers knowledge on why *Bland* and similar cases are dilemmatic, but also how the relationship between death's determination in E&W and the personhood status of those with cognitive disability can further explain how PDOC patients' thought unquestionable status as persons is being threatened.

1.4.5 Section Conclusion

This section has found that a purported moral dilemma exists in life support continuation decisions because of an inconsistency in the personhood status of the individual in question. In turn, their personhood status determines whether sanctity of life or protection from assault is prioritised in law in a given case. In other words, a purported moral (and legal) dilemma has arisen in such cases because two laws (against murder and against assault) are both fundamentally based on the morally and legally protected right to not be assaulted/ right to bodily integrity. Furthermore, this suggests that in certain contexts the lesser (albeit still serious assault) of life support continuation can trump the individual's right to life. Consequently, the problem presented is nonsensical from both a legal and moral perspective unless the individual in question has lost personhood. In turn, this would suggest that the crucial legal question of continuation obscures the fact that personhood is what is actually being determined on the basis of medicine's view of what amounts to harm, who is capable of being harmed and to what extent. Consequently, the *Bolitho* decision plays a crucial role in protecting cognitively impaired persons' personhood status and right to life in life support continuation decisions.

1.5 Conclusion

This chapter has sought to outline an applied ethics methodology to assess the defensibility of a moral standpoint on defining and determining death. In doing so, it outlined that for any standpoint to be defensible it must at least be factually accurate and consistent. The chapter also explored basic philosophical concepts that help moral decision-makers make defensible decisions. Along the way, further limitations (and ways of mitigating them) were introduced that exist in the process of translating moral requirements into law because modern society is pluralistic and consists of several

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different moral communities, each with their own moral values or precepts. The chapter therefore introduced Beauchamp and Childress' distinction between universal and non-universal moralities, Engelhardt's permission principle, and the doctrine of the relativity of morals (DROM)— all of which provide further guidance for those assessing the defensibility of any purported moral requirement arrived at by a moral agent.

The chapter also importantly explored how judges and doctors reason. In doing so, it explored how (as moral agents) they accurately ascertain facts and how they uphold consistency in the application of those found moral requirements to avoid intuition-based judgements. It seems that medicine is also more accurately described as a practice rather than a science. That finding is important because it enables and provides a fairer assessment of defensible decision-making by identifying the unique limitations and pressures faced in medical moral reasoning. For example, it is vital to give doctors greater breathing space to make mistakes in order for them to improve their decision-making skills. Moreover, it seems that similarly the case of *Bolitho* places an appropriate limit on the deference shown to the medical profession because as long as doctors are critically reflecting on and implementing best practice techniques, no harmful dogmatic practices should occur. Furthermore, encouraging doctors to reason in this manner is also more beneficial for patients because it will more likely lead to patient-centred and tailored care.

Additionally, the chapter examined the inference in *Bland* that the case arose due to the existence of a moral dilemma. It found that a purported (not genuine) moral dilemma exists in such cases because of a failure to determine the personhood status of the individual in question. The answer to that question in turn resolves the dilemma by indicating whether right to life can be trumped by protection from assault, or more accurately still, that because they would no longer hold a right to bodily integrity, no question of assault would arise. Therefore, not only has this chapter explored the limitations of, and set minimums for assessing "defensibility", it has also begun to unpick why the definition and determination of death may need to be reappraised because of its potential basis in personhood theory as opposed to biology. Chapter Two will consequently explore that hypothesis.

Chapter 2 Defining Death: “What’s in a Name?”

Non-Conscious or Non-Responsive?

2.1 Chapter Introduction and Aims

This chapter explores how death is defined and determined under UK medical practice. In particular, it examines who is defined and determined as dead and on what basis. Consequently, its findings begin to indicate the possible implications of the current practice of defining and determining death for patients with prolonged disorders of consciousness (PDOC patients) such as comatose, vegetative state (VS) and minimally conscious state patients (MCS). Crucially, the chapter will argue that loss of consciousness is fundamental to defining and determining death, but that it is an ambiguous, elusive and exclusory term. Furthermore, that the definition and determination of death and its relationship with consciousness is better supported by philosophical ideas on the value of life than by biological or scientific evidence.

To do this, each section will address a presupposition either on the question of how death is defined or determined and/ or on the current medical understanding of consciousness to answer the following questions: How is death defined? How is the definition of death related to consciousness? What is the difference between consciousness and responsivity? The answers to these questions provide the preliminary groundwork to answer the chapter’s core question concerning how the definition and determination of death impacts PDOC patients. The chapter will largely focus on the medical and philosophical debates and introduce legal issues where necessary as the following two chapters specifically focus on the practice’s legal impact.

2.1.1 Overview of Defining “Consciousness” and its Terminology

Consciousness is defined under the Royal College of Physician’s *Prolonged Disorders of Consciousness Guidelines* (PDOC 2020) as a combination of ‘wakefulness’ and

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'awareness'.¹ Wakefulness 'is a state in which the eyes are open and there is a degree of motor arousal' and 'contrasts with sleep—a state of eye closure and motor quiescence'.² Awareness, 'is the ability to have, and the having of, experience of any kind'.³ There are currently three recognised consciousness disorders, coma, VS and MCS, which are accepted as diagnosable markers along a neuropathological spectrum between brain death and full consciousness.⁴ Coma is also a recognised PDOC but because it is a transitive state that either worsens or improves within a few weeks this thesis focuses attention on VS and MCS.⁵ See Figure 1, which demonstrates where each new disorder marks an increased change in either the patient's demonstrable degree of awareness, wakefulness or both (increasing from left to right).⁶

¹ Royal College of Physicians, *Prolonged Disorders of Consciousness Following Onset of Sudden Injury: National Clinical Guidelines* (2020) 23 (PDOC 2020 guidance).

² ibid.

³ ibid.

⁴ ibid 25. Note the 2020 guidance at page 25 also notes that the distinct categorisation between these states is no longer as legally relevant as it was in 2013, when the previous guidance was published.

⁵ David Bates, 'The Prognosis of Medical Coma' (2001) 71 (1) British Medical Journal i20, i21. Note "permanent" or "irreversible coma" was the original labelling of the state now known as brain death, and is not officially treated as comatose state. See Section 2.2 for further discussion.

⁶ This diagram was drawn pulling the definitions of brain death from the Harvard Committee Report 1968 and the UK from the Medical Royal Colleges Report 1976, which established whole and brainstem death, and the PDOC 2020 guidelines. See PDOC 2020 (n 1) 25; Harvard Medical School, 'Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, 'A Definition of Irreversible Coma' (1968) 205 (6) Journal of American Medical Association 337 (Harvard Report 1968) 337; Conference of Medical Royal Colleges, 'Diagnosis of Brain Death: Statement Issued by the Honorary Secretary of the Conference of Medical Royal Colleges and their Faculties in the United Kingdom on 11 October 1976' (1976) 2 British Medical Journal 1187 (CMRC 1976).

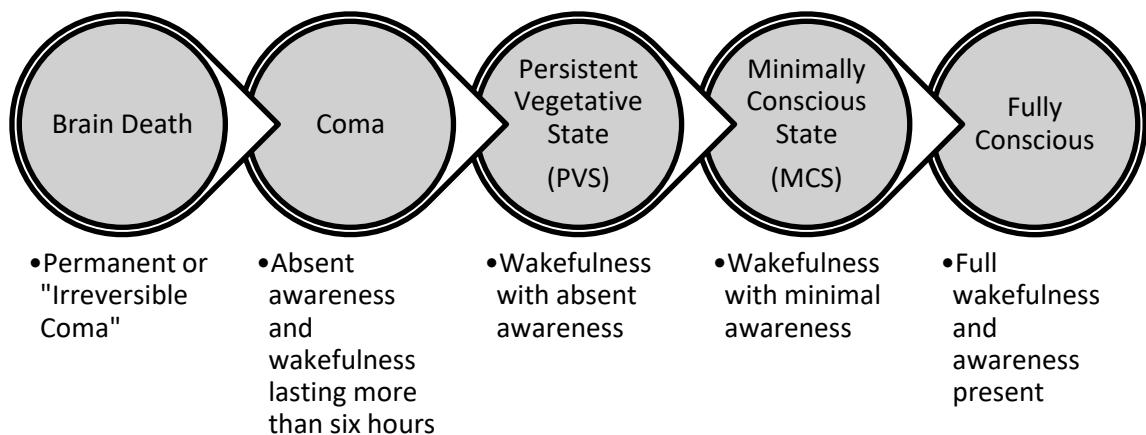


Figure 1- From Brain Death to Full Consciousness

The disorders are difficult to discern and are diagnosed through tests such as the Sensory Modality Assessment and Rehabilitation Technique (SMART), Wessex Head Injury Matrix (WHIM) or Glasgow Coma Scale (GCS).⁷

Each of the prolonged disorders of consciousness have differing degrees of either wakefulness and awareness, or both. To demonstrate the differences in wakefulness and awareness in each disorder, a comatose patient demonstrates no signs of wakefulness or awareness and is defined as being in, 'a state of unarousable responsiveness, lasting more than 6 hours in which the person: cannot be awakened; fails to respond normally to painful stimuli, light or sound; lacks a normal sleep-wake cycle, and does not initiate voluntary actions.'⁸ Those in a vegetative state (VS), or the more recently discussed terminology 'unresponsive wakefulness syndrome'⁹ are described as being in: 'a state of wakefulness without awareness in which there is preserved capacity for spontaneous or stimulus-induced arousal, evidenced by sleep-wake cycles and a range of reflexive and

⁷ PDOC 2020 (n 1) 46-52.

⁸ ibid 25.

⁹ See PDOC 2020 (n 1) at 23. This updated terminology was approved by the European Task Force on Disorders of Consciousness but has yet to receive unanimous support from the relevant UK Medical Colleges. See also Steven Laureys and others, 'Unresponsive Wakefulness Syndrome: A New Name for the Vegetative State or Apallic Syndrome' (2010) 8 BMC Medicine 68 (European Task Force).

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spontaneous behaviours.¹⁰ Moreover, patients in 'VS have spontaneous respiration and circulation and their eyes are open spontaneously for periods of the day, giving the appearance of a sleep-wake cycle'.¹¹ Furthermore, 'they may also exhibit a range of spontaneous movements and/or reflex responses' including 'facial movements', 'purposeless movements of limbs', 'shedding tears' and 'grimaces'.¹²

The nomenclature "vegetative state" (VS) has been criticised for its pejorative use of 'vegetative', leading to some calling for the disorder to be renamed as 'unresponsive wakefulness syndrome'.¹³ Additionally, it is difficult to distinguish in the literature if an academic or doctor is determining that a patient is in a permanent or a persistent vegetative state due to the unhelpful yet commonly used acronym "PVS".¹⁴ For example, in response to Dyer's article on the legal developments regarding PVS, Laureys noted the (previous) legal and moral importance of this distinction in academia by clarifying that decisions regarding withdrawal of artificial feeding only applies to those in a permanent vegetative state.¹⁵ However, developments over the past 10 years have removed permanence as a safeguard for determining who can have their life support questioned (now permissible on both VS and MCS irrespective of "permanence"),¹⁶ including clinically assisted nutrition and hydration (CANH) and antibiotics (referred to collectively throughout the thesis as "PDOC life support continuation decisions" unless stated otherwise¹⁷).

¹⁰ PDOC 2020 (n 1) 25.

¹¹ *ibid* 28.

¹² *ibid*.

¹³ Steven Laureys and others, 'Unresponsive Wakefulness Syndrome: A New Name for the Vegetative State or Apallic Syndrome' (2010) 8 *BMC Medicine* 58 (European Task Force). Note the PDOC 2020 (n 1) guidance at page 23 now refers to further literature which seeks to explain, by reference to the Greek origin of the term "vegetative", that its meaning has been distorted and should not be viewed as an offensive term.

¹⁴ For this reason I will refer to the disorder as "VS" and where necessary "Permanent VS" or "Continuing VS" throughout this thesis. The reader can also review, Ken Mason and Graeme Laurie, 'The Management of the Persistent Vegetative State in the British Isles' (1996) 4 *Juridical Review* 263, for the distinction and difficulties of 'persistent' and 'permanent' terminology.

¹⁵ Clare Dyer, 'Human Rights Act Does Not Affect the Law on PVS' (2000) 321 *British Medical Journal* 916; Steven Laureys response (17th October 2010) is available in the responses tab.

¹⁶ Those developments are analysed in Chapter Three, Subsection 3.3.1. The current legal irrelevance of permanence is also noted in the PDOC 2020 guidance (n 1) at page 36.

¹⁷ "Clinically assisted nutrition and hydration" (CANH) used to be known as "assisted nutrition and hydration" (ANH), for laypersons this treatment would be more commonly recognised as a "feeding tube".

Furthermore, the PDOC 2013 Guidance suggested that 'permanence' is a diagnosis only given after 6 months of no improvement in non-traumatic brain injury and twelve months in traumatic brain injury for the VS.¹⁸ This has since been updated to after 6 months regardless of aetiology or whether the patient is in a VS or MCS, but can only be determined by a physician who meets the criteria of an 'Expert PDOC physician', which is defined by further annexed guidance.¹⁹ Additionally, instead of 'persistent' the term 'continuing' should be adopted where patients have been in this state of consciousness for 'more than four weeks' to help clarify the use of the acronym PVS.²⁰

Finally, the minimally conscious state (MCS) was officially recognised in 2002 and is defined as, 'a condition of severely altered consciousness in which minimal but definite behavioural evidence of self or environmental awareness is demonstrated.'²¹ More precisely: 'in MCS cognitively mediated behaviour occurs inconsistently, but is reproducible or sustained long enough to be differentiated from reflexive behaviour.'²² However, there are also discrepancies in diagnosing permanence in MCS patients; in an attempt to more accurately indicate the severity of MCS, further research has suggested introducing a dual-distinction between MCS patients (MCS+ and MCS-) to decipher their specific level of awareness, which also plays an integral role in deciphering a patient's responsiveness to pain.²³ Similarly to VS, the nomenclature "minimally conscious state" is also contentious where Naccache, for example, suggests renaming MCS the 'cortically mediated state' to more accurately reflect the nature of the disorder.²⁴

¹⁸ Royal College of Physicians, *Prolonged Disorders of Consciousness: National Clinical Guidelines* (2013) 23-24.

¹⁹ PDOC 2020 (n 1) 37.

²⁰ PDOC 2013 (n 18) 9-10; PDOC 2020 (n 1) 36.

²¹ Joseph T Giacino and others, 'The Minimally Conscious State: Definition and Diagnostic Criteria' (2002) 58 (3) *Neurology* 349, 350-35. Note that neurologists were aware of a possibility of a new state which they began to label and recognise as the "minimally conscious state" in the late 1990s. See Ronald E Cranford, 'The Vegetative and Minimally Conscious States: Ethical Implications' (1998) 53 *Suppl1 Geriatrics* S70.

²² *ibid* 351.

²³ Marie-Aurélie Bruno and others, 'From Unresponsive Wakefulness to Minimally Conscious PLUS and Functional Locked-in Syndromes: Recent Advances in Our Understanding of Disorders of Consciousness' (2011) 258 (7) *Journal of Neurology* 1373.

²⁴ Lionel Naccache, 'Minimally Conscious State or Cortically Mediated State' (2017) 141 (4) *Brain: A Journal of Neurology* 949. See also: Tim Bayne, Jakob Hohwy and Adrian M Owen, 'Response to 'Minimally Conscious State or Cortically Mediated State?' (2018) 141 (4) *Brain: A Journal of Neurology* e26, which analyses whether Naccache's suggested name change is necessary.

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However, these debates on the accuracy of the nomenclature of consciousness disorders indicate something more problematic about their diagnosis and prognosis than representing a superficial or pedantic linguistic exercise. As I will show throughout 2.2 and 2.3 the neuroscientific knowledge on “consciousness” has rapidly developed in the past 20 years and neurologists have begun to question the accuracy of coining those with consciousness disorders “non-aware” or “non-conscious”.²⁵ More specifically, they have begun to suggest that although PDOC patients are unable to respond and thus communicate voluntarily, this does not mean they are not inner-aware (conscious) of themselves, or the environment around them.²⁶ Furthermore, some have gone as far as to suggest that consciousness disorders are not disorders of consciousness (awareness) at all and are more accurately akin to a super locked-in state.²⁷

This is important, especially in relation to defining and determining death. The debate on consciousness is fundamental to how death is defined and determined in England and Wales (E&W) under both cardiopulmonary and “brain death” criteria; medicine in E&W does not recognise two separate states of death, just two ways of diagnosing the phenomenon.²⁸ Additionally, alongside the discussions on the accuracy of the term “consciousness”, the debates on how alike biological death and “brain death” are, have in the past 20 years eroded any defence that seeks to support the idea that biological death is the same as brain death.²⁹ Most notably, somaticists (that argue loss of integrative functioning between the brain and body is what defines death) have been unable to convince commentators that brain death patients have irreversibly lost integrative functioning between the brain and body.³⁰

The result is that “consciousness” has been pedestalled as the most morally significant function of human life, suggesting that to lose it (irrespective of residual brain

²⁵ Discussed in Section 2.3.

²⁶ *ibid.*

²⁷ *ibid.*

²⁸ Elizabeth Wicks, ‘The Legal Definition of Death and the Right to Life’ in Shane McCorristine (ed), *Palgrave Historical Studies in the Criminal Corpse and Its Afterlife. Interdisciplinary Perspectives on Mortality and its Timings. When is Death?* (MacMillan Publishers 2017) 119; John Oram and Paul Murphy, ‘Diagnosis of Death’ (2011) 11 (3) Continuing Education in Anaesthesia, Critical Care and Pain 77.

²⁹ Discussed in Section 2.2.

³⁰ *ibid* and Section 2.4.

or bodily functioning) equates with "death".³¹ Therefore, this thesis explores the impact that loss of consciousness (as the fundamental criteria in diagnosing death) has on consciousness disorder patients and as persons deserving of equal moral and legal protection as those with "consciousness". The following analysis will therefore explore the conceptual link between defining and determining death, and consciousness.

2.2 Defining Death is No Longer a Biological and Medical Prerogative

2.2.1 Section Introduction

This section will assess the importance of somatic integrative functioning between the brain and body, more specifically the importance of loss of cardiopulmonary functioning in defining or determining an individual as dead. The section therefore undertakes the first step in assessing whether the Academy of Medical Royal College's two components of the definition death are equally important: 'the irreversible loss of those essential characteristics which are necessary to the existence of a living human person ... the irreversible loss of the capacity for consciousness, combined with irreversible loss of the capacity to breathe'.³² The section's findings are significant because the starting presumption that, "the brain dead are dead and that PDOC patients are alive", is based on the belief that retaining cardiopulmonary functioning is essential to be defined as living.³³

2.2.2 Pushing the Boundaries of Death: The Introduction of Transplantation and Ventilatory Technology

Medical understanding of consciousness is fundamentally based on two taught 'dogmas' of neurology.³⁴ These are that, 'the brain is the central integrator of the body', and that

³¹ Discussed in Section 2.4.

³² Academy of Medical Royal Colleges, 'A Code of Practice for the Diagnosis and Confirmation of Death' (2008) (AOMRC) 11. Note the AOMRC oversees the medical royal colleges across the UK and Ireland to standardise medical guidance.

³³ For example, this rationalisation was used in *Airedale NHS Trust v Bland* [1993] AC 789 (HL) 856 (*Bland*) to distinguish VS from brainstem death, and in current medical guidance on defining and determining death, see AOMRC (n 32) at 11.

³⁴ D Alan Shewmon, "'Recovery from Brain Death": A Neurologist's Apologia' (1997) 64 (1) The Linacre Quarterly 30, 35.

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awareness (as consciousness) is located in the cortex and wakefulness is manifested by the reticular activating system of the brainstem.³⁵ As Shewmon argues, 'these principles are so fundamental and so universally accepted as established beyond doubt, that their truth is simply taken for granted in professional circles.'³⁶

The starting presupposition of this chapter is that, 'all "disorders of consciousness" are quite distinct from "locked-in syndrome" or "brainstem death".'³⁷ Ostensibly, one could therefore argue that consciousness disorders are wholly unrelated to the definition of death. For example, the PDOC 2020 guidance suggests that the core difference between brainstem death and consciousness disorders is that brainstem death patients '[lose] spontaneous respiratory effort in response to rising carbon dioxide levels' due to the loss of brainstem functioning.³⁸ The guidance also suggests that locked-in syndrome patients (LIS) are distinctly different from PDOC patients, where LIS patients are 'substantially paralysed' but conversely to PDOC patients, 'conscious', as is indicated by blinking in response to questions asked.³⁹ In other words, the justification underlying the starting presupposition can be clarified as: brainstem dead patients are physiologically dead, whereas comatose, VS and MCS patients are alive but not fully conscious.

Currently, the way in which death is determined in E&W has largely been left to the medical profession, where '[judges apply] the current medical definition of death',⁴⁰ provided by the Academy of Medical Royal Colleges' (AOMRC) guidelines. Death is defined by the AOMRC as: 'the irreversible loss of those essential characteristics which are necessary to the existence of a living human person ... the irreversible loss of the capacity for consciousness, combined with irreversible loss of the capacity to breathe'.⁴¹ The view that defining death is a question for biological science therefore seems uncontentious. It also seems that it is something medicine can measure with a defensible degree of certainty because it is a (measurable) science. Nevertheless, there are two ways of determining whether a person has died because mechanical ventilatory support masks the

³⁵ ibid.

³⁶ ibid.

³⁷ PDOC 2020 (n 1) 24.

³⁸ ibid. However, see the phrenic nerve analysis in Subsection 2.2.3.

³⁹ PDOC 2020 (n 1) 24.

⁴⁰ Wicks 2017 (n 28) 119.

⁴¹ AOMRC 2008 (n 32) 11.

ability to see if a patient has spontaneously stopped breathing.⁴² Some commentators stress that this does not mean there are two types of death, just two ways of diagnosing whether the phenomenon has occurred.⁴³

Traditionally, death was determined by cardiorespiratory criteria that evidenced the cessation of a heartbeat and a lack of circulatory 'pulsatile flow'.⁴⁴ This view was uncontentious because when the heart irreversibly stopped beating nothing (such as organ donation) would interrupt the natural dying process, by which even "life" at a cellular level would eventually cease.⁴⁵ However, the introduction of ventilatory techniques in the 1950s led to the discovery of patients who had suffered 'intracranial catastrophes' but whose cardiopulmonary system could be maintained for longer than expected periods of time.⁴⁶ Neurologists termed this condition 'le coma dépassé',⁴⁷ or 'irreversible coma',⁴⁸ 'a state of profound and irreversible apnoeic coma ... whose heart[s] continued to beat for as long as mechanical ventilation continued'.⁴⁹ Therefore, in 1968 the Ad Hoc Committee of Harvard Medical School published a paper (Harvard Report) calling for irreversible coma patients to be redefined as "dead", for the purpose of permitting practices that were only morally and legally permissible on patients who were dead, such as vital organ donation and life support withdrawal.⁵⁰ To clarify, the Harvard Report 1968 had not discovered a

⁴² Alexander Capron and Leon Kass, 'A Statutory Definition of the Standards for Determining Human Death: An Appraisal and a Proposal' (1972) 121 University of Pennsylvania Law Review 87.

⁴³ Wicks 2017 (n 28) 119; Oram and Murphy (n 28).

⁴⁴ Oram and Murphy (n 28) 80.

⁴⁵ Oram and Murphy (n 28). Note Christiaan Barnard carried out the first human heart transplant in 1967, just one year before the adoption of the neurological criteria for death (brain death) in the Harvard Report in 1968, as explained by, Raymond Hoffenberg, 'Christiaan Barnard: His First Transplants and their Impact on Concepts of Death' (2001) 323 British Medical Journal 1478 at pages 1478-80.

⁴⁶ *ibid* 77. See also Arthur R Slutsky, 'History of Mechanical Ventilation: From Vesalius to Ventilator-Induced Lung Injury' (2015) 191 (10) American Journal of Respiratory and Critical Care Medicine 1106, where at pages 1108-9 he discusses the benefits of positive pressure ventilation that later helped develop mechanical ventilation technology used today, and which arose out of the events of the 1951 Polio Epidemic in Copenhagen. Slutsky notes that its introduction led the mortality rate of such patients to drop from approximately '87% to 40%, almost overnight'. The Polio Epidemic in Copenhagen is the first recorded case of mechanical ventilation being used widely.

⁴⁷ Oram and Murphy (n 28) 77.

⁴⁸ Harvard Medical School, 'Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, 'A Definition of Irreversible Coma'' (1968) 205 (6) Journal of American Medical Association 337, 337 (Harvard Report 1968).

⁴⁹ Oram and Murphy (n 28) 77.

⁵⁰ Harvard Report 1968 (n 48) 337.

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new mode of dying, instead they sought to redefine death where the consequence of such a redefinition would be to label a certain class of biologically living patients as "dead".⁵¹ Adding further confusion to the definition or "re-definition" of death, some medical professionals sought to provide reasoning that brought the question of defining death back within the territory of medical science.⁵² These medical professionals are collectively known as 'somaticists',⁵³ due to their focus on the core integrative functioning of the brain: the organ thought to be responsible for bridging and integrating the vital functions of both the brain and body. It therefore made sense that if the brain had "died" then the patient had also.⁵⁴

The next section presents somaticist reasoning that, brain death is "death", and demonstrates how their attempts to make the definition of death solely a medical question failed, leading to the stark conclusion that defining death is primarily (and has been since the 1960s) a philosophical and legal issue.⁵⁵ However, before presenting somaticist theories and exploring why they failed, it is first necessary to outline the two rationales presented in the Harvard Report 1968 which allegedly necessitated such a radical re-definition. The first rationale relates to the emotional burden on families and the limited resources of medicine to sustain such patients' lives.⁵⁶ The second rationale is that the old criteria for determining death was obsolete and needed to be revised for the purposes of vital organ donation and life support withdrawal.⁵⁷

It is at least arguable that the necessity of creating a new definition of death was primarily due to the second rather than first rationale. For example, heart transplantations had been made possible the year before the Harvard Report in 1967 by Christiaan Barnard's research and would not have been legally or morally possible on a patient whose heart continued to beat, even if they were "brain dead".⁵⁸ Additionally, Bishop

⁵¹ Shewmon 1997 (n 34) 41; Robert M Veatch, 'The Death of Whole-Brain Death: The Plague of the Disaggregators, Somaticists, and Mentalists' (2005) 30 (4) *Journal of Medicine and Philosophy* 353, 360.

⁵² *ibid.*

⁵³ Veatch 2005 (n 51).

⁵⁴ Shewmon 1997 (n 34) 43-44.

⁵⁵ *ibid.*

⁵⁶ Harvard Report 1968 (n 48) 337.

⁵⁷ *ibid.*

⁵⁸ Raymond Hoffenberg, 'Christiaan Barnard: His First Transplants and their Impact on Concepts of Death' (2001) 323 *BMJ* 1478.

provides a damning historical account of these key years, arguing that the concept of "brain death" was introduced to manipulate who could be defined as "dead" to legally and "morally" advance transplantation.⁵⁹ Bishop adds that the first rationale based on familial distress was not important enough to deserve attention in the medical literature until transplantation became an option (in the same year as Barnard's first heart transplant), and where such patients' "treatability" had previously not been questioned or thought futile.⁶⁰ He references Giacomini's work,⁶¹ arguing that patients in deep coma 'were never portrayed as virtually "dead", or even questionably alive ... [nor] as costly, time-consuming burdens ... caring for these unfortunate people in *le coma dépassé* was part of routine care'.⁶² It was only after the Harvard Report 1968 and Barnard's push for the permissibility of heart transplantations that 'brain death' and 'irreversible coma' were used 'interchangeably' and that these rationalisations came to the fore.⁶³

Some, such as Shewmon, have criticised the view that brain/neurological death was constructed solely for the purpose of organ donation and transplantation advancements.⁶⁴ He terms this view a 'pseudo-rationale',⁶⁵ yet does little to explain why such a view is false, instead focussing much of his paper on attacking somaticism.⁶⁶ Bishop also indirectly undermines the PDOC 2020 guidance's claims that brain death is distinct from other consciousness disorders (PODC patients).⁶⁷ He argues that *le coma dépassé* included what we now know as coma, vegetative and minimally conscious states, where the distinctions were only developed later, demonstrating a close historical relationship

⁵⁹ Jeffrey P Bishop, *The Anticipatory Corpse: Medicine, Power, and the Care of the Dying* (University of Notre Dame Press 2011) ch 5, 141-167.

⁶⁰ *ibid* 156.

⁶¹ Mita Giacomini, 'A Change of Heart and A Change of Mind? Technology and the Redefinition of Death 1968' (1997) 44 (10) Social Science and Medicine 1465, 1465 (paraphrasing).

⁶² Bishop (n 59) 156.

⁶³ *ibid*.

⁶⁴ Shewmon 1997 (n 34).

⁶⁵ *ibid* 42-43.

⁶⁶ *ibid*. Note I have assumed Shewmon views such an account as false due to the fact that he groups it under rationalisations that he labels 'pseudo-rationales' and claims at page 43 that this rationalisation has failed to be convincing to much of society and many healthcare practitioners. He also later states his own discomfort at such a finding because he was, before and at the time of writing, 'on the faculty of a major transplant referral centre' at page 75.

⁶⁷ PDOC 2020 (n 1) 24. Referring back to a starting presupposition of this section (Section 2.2).

between these states.⁶⁸ It therefore seems likely that death was redefined for the more pressing need of vital organ transplantation than familial distress.

2.2.3 Identifying the Vital “Biological” Factor in Defining Death

The very first line on the Harvard Report 1968 stipulates that brain death is not a newly discovered state but a redefinition of “death”: ‘our primary purpose is to define irreversible *coma* as a new criterion for death’.⁶⁹ Under such a definition, irreversible or “permanently” comatose patients were now to be redefined as “dead”. To be clear, comatose patients are not biologically dead,⁷⁰ therefore any attempt to justify that those in permanent coma (in other words brain dead patients) are biologically dead is counterintuitive.⁷¹ Despite this, the somaticists’ theory, that seeks to prove that brain dead or irreversibly comatose patients are biologically dead, started almost immediately after the Harvard Report 1968. The somaticists’ theory ultimately rests on the idea that the brain’s death, as the central integrating organ of the body, consequently rules out the operational capacity of all vital functions of the brain and body.⁷² For example, Capron and Kass, and Bernat, advocate that brain death is the same as traditionally defined cardiopulmonary death.⁷³ For these advocates, neurological death is included within traditional death or similarly, that traditional death includes neurological death hence, according to them, there is no conceptual difference.⁷⁴

However, although a consensus exists among somaticists that not every cell in the brain needs to die for a patient to be declared brain dead (primarily due to the impracticality of proving that every cell had died and that waiting for this event would render transplantation impossible⁷⁵), there is less consensus on what functions are significant enough to say the patient has “died” against those that are thought

⁶⁸ Bishop (n 59) 156.

⁶⁹ Harvard Report 1968 (n 48) 337.

⁷⁰ Henry K Beecher, ‘Ethical Problems Created by the Hopelessly Unconscious Patient’ (1968) 278 New England Journal of Medicine 1425; Shewmon (1997) (n 34).

⁷¹ Shewmon 1997 (n 34).

⁷² *ibid* 43-44. The most notable examples of somaticist advocates are Alexander Capron and Leon Kass, and James L Bernat, Charles M Culver and Bernard Gert.

⁷³ Shewmon 1997 (n 34); Capron and Kass (n 42); James L Bernat, Charles M Culver and Bernard Gert, ‘On the Definition and Criterion of Death’ (1981) 94 (3) Annals of Internal Medicine 389.

⁷⁴ *ibid*.

⁷⁵ Shewmon 1997 (n 34).

insignificant.⁷⁶ Furthermore, the task of distinguishing vital from non-vital functions for brain death inherently undermines their theory of "whole-brain death": 'one cannot simultaneously claim to be holding a whole-brain death view and still consider those who have only lost part of their brain functions "dead"— even if the remaining functions are believed to be "insignificant".'⁷⁷ Consequently, the debate on brain death is essentialist:⁷⁸ what functioning of the mind and body holds such moral significance and value that losing it renders the individual no longer deserving of moral (and legal protection)? It was therefore unsurprising to learn from Beecher's paper that lawyers at the time were reluctant to support the introduction of brain death in law and medical practice.⁷⁹ For example, the obvious impact on the law's establishment of factual causation for murder arises due to the causal link between the doctors' actions (in vital organ donation or life support withdrawal) and the patients' subsequent deaths, which was, and arguably still is, problematic.⁸⁰

Fundamentally, as it is not necessary that every cell has to die for an individual to be defined as brain dead, it is therefore possible that brain dead patients have residual brain and body functioning.⁸¹ Moreover, what residual functions remain will likely be different in each patient due to the nature of how brain damage occurs.⁸² Shewmon states that, 'like any other bodily tissue', when it is injured the brain starts to swell and because the 'brain is enclosed in the skull' where 'initially the brain volume increases at the expense of blood and cerebrospinal fluid compartments', 'if the swelling is severe, intracranial pressure

⁷⁶ ibid; Veatch 2005 (n 51).

⁷⁷ Veatch 2005 (n 51) 358.

⁷⁸ Shewmon 1997 (n 34). In philosophy, essentialism investigates the properties a being or thing must have to be considered what it is thought to be, eg what makes a pencil, a pencil? The aim is to rule out all its accidental properties until its essential property is discovered. For further explanation see Stanford Encyclopedia of Philosophy, 'Essential vs Accidental Properties' (18 April 2016) <<https://plato.stanford.edu/entries/essential-accidental/>> accessed 24 March 2019.

⁷⁹ Beecher 1968 (n 70). Note Bishop (n 59) at 70 argues that in the early days of vital organ transplantation and the need to establish brain death at the Cape Town Conference on 1968, cardiac surgeons expressed disdain at having legal, philosophical and, to a lesser extent, even neurological experts' input in such discussions.

⁸⁰ Chapter Three, Section 3.2 examines the legal issues arising from causation in life support withdrawal from PDOC patients. For brain death patients, the problem lies in their moral as opposed to legal defensibility, which is assumed to have been resolved, as discussed in Chapter Five, Section 5.2.

⁸¹ Shewmon 1997 (n 34) 40.

⁸² ibid.

begins to rise sharply'.⁸³ The brain then attempts to maintain its blood supply by increasing arterial pressure, 'but beyond a certain point this compensation fails' and the blood supply becomes increasingly limited.⁸⁴ Additionally, the lack of blood being supplied to the brain results in ischemia (where the tissue starts deteriorating due to the lack of oxygen) which further damages the brain, resulting in further swelling.⁸⁵ He adds, 'the brain is the organ most sensitive to ischemia' and where mechanical ventilation can 'restore the heartbeat quickly but not quite quickly enough, only the brain will be supracritically damaged'.⁸⁶ Brain damage is therefore a 'vicious' and 'self-destructive' cycle.⁸⁷

Moreover, even where total brain infarction occurs (where blood clots further limit oxygen supply, leading to the death of local tissue), regardless of aetiology (origin or cause for the damage), 'the other organs are relatively left intact'.⁸⁸ This means that organ transplantation is often still possible in such patients and that it is common to find 'dead brains in otherwise relatively intact bod[ies] in intensive care units'.⁸⁹ However, due to 'inhomogeneities in pressure', 'islands of sick but not totally necrosed brain tissue sometimes remain', 'even in the face of proven brain herniation and intracranial circulatory stasis, isolated brain functions can occasionally persist'.⁹⁰ Therefore, no two brain deaths or brain injuries are necessarily the same.

This is likely to be problematic because brain dead patients have been reported to demonstrate: hypothalamic pituitary functions; blood pressure and heart regulation; brainstem reflexes such as jaw jerk or snout reflexes; residual electroencephalographic activity; cardio-vascular hormonal responses to surgical incision for organ retrieval; spontaneous respiration-like movements; "goose flesh" and shivering movements; spontaneous jerks of limb; decerebrate spasms; present muscle tone; and complex

⁸³ ibid 39. For further explanation, see Allan H Ropper and Mark A Rockoff, 'Physiology and Clinical Aspects of Intracranial Pressure' in Allan H Ropper (ed), *Neurological and Neurosurgical Intensive Care* (3rd edn, Raven Press 1993).

⁸⁴ Shewmon 1997 (n 34) 39.

⁸⁵ ibid.

⁸⁶ ibid 39-40.

⁸⁷ ibid 39.

⁸⁸ ibid 40.

⁸⁹ ibid.

⁹⁰ ibid.

movements such as the "Lazarus sign", where patients raise their arms and drop them crossed on their chest.⁹¹ Despite the fact these responses are categorised as reflexive,⁹² they call into question the certainty that brain dead patients are non-sentient because of the problem of distinguishing reflex from what medicine coins "voluntary response". The significance of which is explained in 2.3. Consequently, 'where virtually every commentator agreed that not every single cell in the brain had to be destroyed', there was little consensus on which vital functions were significant for life, and moreover, which were indicative of a "living person" deserving of moral and legal protection.⁹³ A consensus was at least officially acknowledged by the President's Commission 1981.⁹⁴ However, given that this is a UK, specifically English and Welsh focused thesis, the somaticist theory most pertinent to the UK and in need of further exploration is brainstem death.⁹⁵

In 1971, Mohandas and Chou published a paper that purportedly established two points: first, that the brainstem is vital for the capacity for consciousness and cardiopulmonary functioning, and secondly that its "death" can be established 'solely on clinical grounds'.⁹⁶ Their findings suggest that if the brainstem has "died", for all important purposes the individual had also died.⁹⁷ Subsequently, at the Conference of Medical Royal Colleges 1976, the UK officially adopted brainstem death as the clinical criteria for determining whether brain death had occurred.⁹⁸ Brainstem death's adoption in the UK seems scientifically sound 'as the brainstem includes the reticular activating system (RAS) where its destruction loses somatic integration [integrative unity of vital organs] but also

⁹¹ *ibid.* See Shewmon's 1997 paper (n 34) at page 40 for the list of scientific research on each of these noted responses in the literature.

⁹² *ibid.*

⁹³ *ibid* 44.

⁹⁴ *ibid* 43.

⁹⁵ Conference of Medical Royal Colleges, 'Diagnosis of Brain Death: Statement Issued by the Honorary Secretary of the Conference of Medical Royal Colleges and their Faculties in the United Kingdom on 11 October 1976' (1976) 2 *British Medical Journal* 1187 (CMRC 1976).

⁹⁶ A Mohandas and Shelley N Chou, 'Brain Death: A Clinical and Pathological Study' (1971) 35 *Journal of Neurosurgery* 211, 211.

⁹⁷ Shewmon 1997) (n 34) 44.

⁹⁸ CMRC 1976 (n 95). See Academy of Medical Royal Colleges, 'About us' (Academy of Medical Royal Colleges, 14 March 2019) <<http://www.aomrc.org.uk/about-us/>> accessed 14 March 2019, which states that the CMRC 1976 (n 95) also established the Academy of Medical Royal Colleges (AOMRC) in 1974 to provide clinical guidance across all the 24 UK and Irish medical bodies.

causes permanent coma'.⁹⁹ However, because the RAS is solely responsible for the wakefulness part of consciousness, the "known"¹⁰⁰ cortical function of awareness (and the key component of consciousness) is ignored.¹⁰¹ As Shewmon argues, 'it made as much theoretical sense as that of a conscious corpse' due to a disassociation between the brainstem and cortex;¹⁰² the brainstem theory of neurological death does not include the loss of (full) capacity for consciousness, requires no further testing to rule out residual (and arguably important functions),¹⁰³ such as awareness.¹⁰⁴ For example, Mohandas and Chou's paper suggests that clinical testing of brainstem reflexes and the ruling out of other interfering causes is the only necessary method of testing.¹⁰⁵ Therefore, brain scans are not required to demonstrate the loss of residual electrical activity which itself indicates that other brain functions are deemed insignificant.¹⁰⁶

The concept of brainstem death has not had 'many policy adherents' outside of the UK.¹⁰⁷ This is due to the concept's further exclusivity by its rejection of additional functions than the already contentious whole-brain death theory.¹⁰⁸ Brainstem death has also been more recently questioned by UK-based anaesthetists and neurologists concerned about the accuracy of brainstem reflex tests among other potential flaws.¹⁰⁹ The consciousness aspect of brainstem death is further explored in 2.3. For current purposes, not only does

⁹⁹ Shewmon 1997 (n 34) 44 (paraphrasing); Christopher Pallis, 'From Brain Death to Brain Stem Death' (1982) 285 British Medical Journal 1487.

¹⁰⁰ This is in double quotation marks because it is a point later challenged by further evidence in Section 2.3.

¹⁰¹ Shewmon 1997 (n 34) 45 and 50.

¹⁰² *ibid* 51-52.

¹⁰³ CMRC 1976 (n 95) 1188; Mohandas and Chou (n 96).

¹⁰⁴ Note how important awareness as a component of consciousness is in the findings of Section 2.3, further demonstrating how paradoxical the rationalisation for adopting brainstem death is in the UK.

¹⁰⁵ CMRC 1976 (n 95) 1188; Mohandas and Chou (n 96).

¹⁰⁶ *ibid*.

¹⁰⁷ James L Bernat, 'A Defense of the Whole-Brain Concept of Death' (1998) 28 (2) Hastings Centre Report 14, 14. As far as I am aware this is still the case where the only potential exception is India, where a law sought to legalise brainstem death in 1994. However, it seems that not all of India's states adopted the legislation in practice, see Anant Dattatray Dhanwate, 'Brainstem death: A Comprehensive Review in Indian Perspective' (2014) 18 (9) Indian Journal of Critical Care Medicine 596 at pages 596-597.

¹⁰⁸ M D Dominic Bell, Edward Moss and Paul G Murphy, 'Brainstem Death Testing in the UK—Time for Reappraisal?' (2004) 92 (5) British Journal of Anaesthesia 663; Robin S Howard, 'Coma and Brainstem Death' (2012) 40 (9) Medicine 500.

¹⁰⁹ Howard (n 108) 502; Bell and others (n 108).

the brainstem theory not accurately rule out the possibility of awareness, it does not rule out the somatic integrative function of the “irreversible” loss of the capacity to breathe either.¹¹⁰ Capron and Kass’s famous explanation of the role of mechanical ventilators argues that mechanical ventilation merely mimics life in brain dead patients.¹¹¹ Shewmon disagrees, explaining that the ventilator replaces the function of the diaphragm, not the heart or lungs.¹¹² He argues that the damaged phrenic nerve is what undermines their capacity to breathe.¹¹³ That nerve receives signals from the brain to move the diaphragm allowing the lungs to fill with oxygenated air.¹¹⁴ Hence why (as Shewmon goes on to argue) the functioning of the heart and lungs to process and pass deoxygenated/oxygenated blood in and out the body is unaffected:¹¹⁵ fundamentally, the heart and lungs are functional. Additionally, he suggests quite a striking implication for proposing that patients who have lost phrenic nerve functioning are dead and that the visible heartbeat and movement of air passing in and out of the lungs is mimicked by the ventilator:

although all these vital functions would soon cease if the blood were to become deoxygenated due to apnea, such dependence *per se* on the mechanical ventilator is no more an argument for equating “brain death” with death than for equating any other cause of apnea (cessation of breathing) with death.¹¹⁶

Moreover, Kaufman, Bauer and Brown’s recent paper on reconstruction of phrenic nerves potentially further undermines claims that brainstem dead patients on ventilators have “irreversibly” lost the capacity to breath.¹¹⁷ Brainstem death is therefore not a defensible standard for equating the brain damage sustained with the phenomenon of biological death.

¹¹⁰ Shewmon 1997 (n 34) 43-44.

¹¹¹ Capron and Kass (n 42).

¹¹² Shewmon 1997 (n 34) 43-44.

¹¹³ Matthew R Kaufman, Thomas L Bauer and David P Brown, ‘Surgical Treatment of Phrenic Nerve Injury’ (UpToDate, 27 June 2018) <<https://www.uptodate.com/contents/surgical-treatment-of-phrenic-nerve-injury/print>> accessed 6 March 2019.

¹¹⁴ *ibid.*

¹¹⁵ Shewmon 1997 (n 34) 43-44. Interestingly, this description of the role of the mechanical ventilator was similarly, and in *obiter*, recognised in *R v Malcherek and Steel* [1981] 2 All ER 422 (CA) at page 693 by Lord Lane CJ. Note the consequence, although unacknowledged in this case, is that circulation (capacity to breathe) becomes irrelevant in determining death.

¹¹⁶ *ibid.*

¹¹⁷ Kaufman, Bauer and Brown (n 113).

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Furthermore, not only is the belief that the brainstem is vitally responsible for both the capacity to breathe and for consciousness (awareness) undermined, Shewmon further demonstrates how the brain is not central to the somatic integration of the body.¹¹⁸ He explains that, 'the somatic integrative functions that do not depend on the brain are actually considerably greater in number than those that do.'¹¹⁹ He also lists the medical interventions needed to sustain brain dead patients' lives and argues that it is not an 'inordinate amount' and is 'considerably less than that required by many patients in ITU'.¹²⁰ In turn, the attack on somaticism also better explains how and why brainstem dead patients have been known to: 'gestate foetuses'; develop through puberty; heal their wounds and fight infections. It also explains why so much of the endocrine system continues to function independently of the hypothalamus.¹²¹ Nevertheless, in the UK these noted functions are not regarded as brainstem dependent and therefore are considered insignificant signs of life.¹²²

Shewmon also addresses the immediate concern of poor survival rates of brain dead patients.¹²³ Shewmon found two reasons why some survived longer than others.¹²⁴ First, it may be specific to their aetiology; it seems that those whose brain damage is caused by cardiac arrest or multiple trauma seem to die quicker despite support because they were dead by virtue of supracritical multi-organ damage rather than brain failure alone.¹²⁵ Secondly, and perhaps thematically for the rest of this thesis, 'a declaration of brain death strongly tends toward a self-fulfilling prophecy with respect to somatic death'.¹²⁶ For example, 'if organs are donated they are dead afterwards if not before [and] if ventilatory support is discontinued they will die'.¹²⁷ Additionally, in Japan (a culture strongly against brain death) the 'mere addition of epinephrine and vasopressin increased survival times

¹¹⁸ Shewmon 1997 (n 34).

¹¹⁹ *ibid* 66.

¹²⁰ *ibid*. Note ITU "intensive treatment unit" is known as ICU "intensive care unit" in the UK.

¹²¹ *ibid* 66-68. Note the case of *Mail Newspapers Plc v Express Newspapers plc* [1987] FSR 90 (HC) where a woman "Mrs B" was being kept alive after a brain haemorrhage at 24 weeks pregnant to give birth to her unborn child despite being suspected to be "brain dead", however no clinical tests had been undertaken to confirm her death.

¹²² *ibid*.

¹²³ Shewmon 1997 (n 34).

¹²⁴ *ibid*.

¹²⁵ *ibid* 68-69.

¹²⁶ *ibid* 69.

¹²⁷ *ibid*.

from 24 hours to 23 days (approximately).¹²⁸ Further still, in a study in the US, 161 cases of individuals reliably categorised as whole-brain dead continued to survive for varying times: 67 (2 weeks); 32 (4 weeks); 15 (2 months); 7 (6 months) and one survived 14 years.¹²⁹ Such examples, 'provide a blow to the view that even with 'aggressive intervention brain dead patients die invariably within hours or days.'¹³⁰ Such findings also evidence how little the brain has to do with somatic integrative function.¹³¹ Consequently, Shewmon suggests that this self-fulfilling prophecy rules out the 'opportunity to learn how long survival ... might have been, ... for such a simple treatment to make such a profound difference in survival, the underlying somatic substrate must be fairly well integrated already.'¹³²

Importantly for the starting presupposition of this section, once the biological basis for brain death was undermined, there is little if any reason left to suggest that brainstem dead patients are different from PDOC patients. The brain damage they have sustained is certainly more severe but they are also not physiologically dead and their cardiopulmonary system is significantly less impaired than it is purported to be. Consequently, we have come full circle: 'if bodily or somatic integration is the decisive feature of being alive, then Shewmon has defeated the defenders of the whole-brain death [and consequently brainstem death] view'.¹³³ Furthermore, it is not just Shewmon that convincingly argues against the somaticist theories. In 2001, the *Journal of Medicine and Philosophy* published several papers that further attacked the somatic integration defence of brain death as "death": Potts;¹³⁴ Halevy;¹³⁵ Halevy and Brody;¹³⁶ Dagi and

¹²⁸ ibid.

¹²⁹ D Alan Shewmon, 'Chronic "Brain Death": Meta-Analysis and Conceptual Consequences' (1998) 51 *Neurology* 1538; Stuart J Younger and Robert M Arnold, 'Philosophical Debates About the Definition of Death: Who Cares?' (2001) 26 (5) *Journal of Medicine and Philosophy* 527.

¹³⁰ Younger and Arnold (n 129) 530 (paraphrasing).

¹³¹ Younger and Arnold (n 129).

¹³² Shewmon 1997 (n 34) 69 (paraphrasing).

¹³³ Veatch 2005 (n 51) 355.

¹³⁴ Michael Potts, 'A Requiem for Whole Brain Death: A Response to D. Alan Shewmon's 'The Brain and Somatic Integration'' (2001) 26 (5) *Journal of Medicine and Philosophy* 479.

¹³⁵ Amir Halevy, 'Beyond brain death?' (2001) 26 (5) *Journal of Medicine and Philosophy* 493.

¹³⁶ Amir Halevy and Baruch Brody, 'Brain Death: Reconciling Definitions, Criteria, and Tests' (1993) 119 (6) *Annals of Internal Medicine* 519.

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Kaufman;¹³⁷ Younger and Arnold;¹³⁸ and Campbell,¹³⁹ agree that the somaticist defence of brain death no longer stands.¹⁴⁰ Therefore, the result of the attack on somaticism is clear: brain death is not biological death.

The endeavour to explore the evidence that brain death is death was therefore circular. As explained in the Harvard Report 1968, brain death is a philosophical standpoint on when life is deemed to no longer be "worth living" or no longer holds moral value. Veatch therefore explains that, 'calling someone "dead" has little, if anything, to do with the way we use the terms "living" and "dead" in biology. It has everything to do with moral (and legal) status'.¹⁴¹ Therefore, there are biologically living human beings who medicine, since the 1960s and 1970s, has determined as "dead" for having lost full moral standing.¹⁴² As Veatch explains:

people we normally perceive to be living human beings are sometimes said to possess a special moral status. It can be called "full moral standing" ... a cluster of rights ... is said to accrue to each individual with full moral standing. Alternatively, we can say that other humans have certain duties toward these individuals.

Beginning in the 1960s, we assigned a word to those who have lost full moral standing. Taking a word that originally had rather different meaning, we called these individuals "dead." I have from the beginning of the definition of death debate in the 1960s always held that the ... debate is important because it is really a debate over when humans lost the status of possessors of full moral standing. Thus, calling someone "dead" has little, if anything, to do with the way we use the terms "living" and "dead" in biology. It has everything to do with moral (and legal) status.¹⁴³

¹³⁷ Teodoro F Dagi and Reinhorn Kaufman, 'Clarifying the Discussion on Brain' (2001) 26 (5) *Journal of Medicine and Philosophy* 503.

¹³⁸ Younger and Arnold (n 129).

¹³⁹ Courtney S Campbell, 'A No-Brainer: Criticism of Brain-Based Standards of Death' (2001) 26 (5) *Journal of Medicine and Philosophy* 539.

¹⁴⁰ Veatch 2005 (n 51) 354.

¹⁴¹ *ibid* 360. See Subsection 2.4.3 for moral standing's definition (or the "Glossary of Terms") and the consequential impact for PDOC patients.

¹⁴² The defensibility of this move will be assessed throughout the final chapter (Chapter Five).

¹⁴³ Veatch 2005 (n 51) 360.

Consequently, the debate on brain death did not redefine the biological or physiological state known as death, it redefined death on the basis of moral (and legal) standing.¹⁴⁴ It was only the subsequent endeavour of the somaticists (to equate brain death with biological death) that confused and obscured the original purpose of the Harvard Report 1968. As explained previously, the rationale for redefining death in that report was to facilitate 'death behaviours'¹⁴⁵ or more specifically, determine when certain death behaviours (such as life support withdrawal or organ donation) are permissible on biologically living but morally "dead" individuals.¹⁴⁶

These 'death behaviours' hold a consensus that at least some of them mark when an individual has lost moral standing to be treated with the full moral (and legal) respect of the "living".¹⁴⁷ Where there is less consensus, is whether these behaviours themselves can be used to determine a new "event" of (brain) death.¹⁴⁸ Briefly, the 'disaggregator theory' attempted to disaggregate death behaviours and see which must remain aggregated to a moment of death depending on their moral permissibility.¹⁴⁹ However, as Veatch argues, the theory has not been able to solve the problem of defining death because 'there will remain a core cluster of death behaviours that must remain aggregated because precisely the same rationale will be seen as justifying these behaviours'; they demarcate death and therefore will 'be inappropriate to attach to the living'.¹⁵⁰ Veatch has also identified some of the behaviours that are permissible to undertake before a patient is biologically dead: 'withholding or withdrawing life support treatment; procuring "life-prolonging" organs; beginning the mourning process; and initiating property and insurance proceedings.'¹⁵¹

For the purpose of this thesis, the permissibility of these death behaviours therefore indicates that a change has occurred in the individual's moral (and perhaps legal)¹⁵²

¹⁴⁴ ibid. Note legal standing has a particular meaning in law as *locus standi*; here I intend legal standing to mean legally recognised respect. This legally recognised respect is later described and explained to be personhood in Section 2.4.

¹⁴⁵ ibid. Note 'death behaviours' are practices or procedures that occur just before, during and after biological death as explained in the "Glossary of Terms".

¹⁴⁶ Harvard Report 1968 (n 48) 337.

¹⁴⁷ Veatch 2005 (n 51) 360.

¹⁴⁸ Veatch 2005 (n 51).

¹⁴⁹ ibid 358.

¹⁵⁰ ibid 358-360.

¹⁵¹ ibid 358 (paraphrasing).

¹⁵² To be explored in Chapter Three.

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status.¹⁵³ More specifically, I am interested in examining their legal and moral status when life support is withdrawn.

I will explore PDOC patients' moral standing as it is indicated in law in 2.4.3 and 3.2. However, to introduce the topic, English and Welsh law since the late 1980s determined that life support withdrawal is only permissible on those who are medically defined as "dead",¹⁵⁴ which on the basis of this chapter's findings thus far amounts to moral death; what is thought to be biological death and still is accepted as biological death in law. For example, in *R v Malacherek and Steel* [1981] the court accepted brainstem death as death (even if only implicitly) by determining that the doctor's subsequent action of removing their mechanical ventilation was not a *novus actus interveniens* because the patients were already "dead".¹⁵⁵ Likewise, in *Re A (A Minor)* [1992] the removal of a boy's mechanical ventilation was permissible because the boy was "dead", there was no need to obtain court approval that the doctor's actions would not amount to murder.¹⁵⁶ This has been subsequently reaffirmed in the more recent case of *Re A (A Child) (Medical Treatment: Removal of Artificial Ventilation)* [2015].¹⁵⁷ What these cases suggest is that life support removal is legally permissible and justified on the basis that the patient is "dead" at the time of removal. So far, the legality of life support removal is therefore seemingly uncontentious: no question of assault arising from withdrawing or continuing treatment arises.¹⁵⁸

¹⁵³ Veatch 2005 (n 51).

¹⁵⁴ *R v Malcherek and Steel* [1981] 2 All ER 422 (CA) (*Malcherek and Steel*).

¹⁵⁵ *ibid.*

¹⁵⁶ *Re A (A Minor)* [1992] 3 Med LR 303 (Fam); Hazel Biggs, *Euthanasia, Death with Dignity and the Law* (Hart Publishing 2001). This case represents the courts' official recognition of brainstem death even though *R v Malacherek and Steel* [1981] decided the similarly relevant issue of criminal responsibility for a brainstem dead patient's death after assault.

¹⁵⁷ *Re A (A Child) (Medical Treatment: Removal of Artificial Ventilation)* [2015] EWHC 443, [2015] 2 WLUK 445.

¹⁵⁸ Note that in *Re A (A Child) (Medical Treatment: Removal of Artificial Ventilation)* [2015], the child's parents contested the permissibility of his brainstem dead status on religious grounds. The case is important because the Coroner asserted jurisdiction over the body (as is the formality in the US to force removal). However, the Hayden J asserted that in cases of dispute in the England and Wales, such disagreements are to be resolved by the High Court not coronial powers. This is significant because it means brainstem death is also a best interests determination and no longer a fact of medical science, as discussed in Chapter Three.

But what about those who are not legally or medically (morally) dead? Those with consciousness disorders, cognitive or even mental impairments for whom life support withdrawal is legally permitted, even where the courts explicitly acknowledge their moral and biological status as "living"?¹⁵⁹ This section's analysis makes it apparent that the assumed certainty of the rationale that "the brain dead are dead" and that these cognitively impaired persons are "alive" by default of their cardiopulmonary functioning, is questionable. Moreover, for the purpose of this thesis, this finding may further support the explanation of why moral and legal inconsistency exists in life support continuation decisions of severely impaired, living persons such as PDOC patients.¹⁶⁰

Consequently, there is an inconsistency in the moral justification for withdrawing life support: if continuation amounts to assault on the grounds of a lack of medical necessity and duty of care, the patient must be "living". Yet, if they are living, how is their foreseen subsequent death and greater assault of "killing" then rationalised on both a legal and moral basis? It is possible that PDOC cases have pushed the view that no duty of care or medical necessity exists a step too far. For PDOC patients, the legal presumption that such treatment be withdrawn, despite their apparently indisputable status as "living", seems to have begun to unravel the neat distinction between brainstem dead and biological death, and consciousness disorders from brainstem dead patients. Life-supporting treatment seemingly should only be withdrawn where the patient is "dead", making the question of assault at the heart of continuation considerations redundant. Further still, perhaps *Airedale Trust v Bland* [1993] is morally inconsistent because it inadvertently elucidated that the medical rationale for withdrawal was unsupported in law: E&W do not have an officially recognised law permitting mercy killing by omission (irrespective of patient

¹⁵⁹ The UK has recently been criticised by the Committee on the Rights of Persons with Disability for failing to prevent learning disability being placed as a justification for non-resuscitation on "do not attempt cardiopulmonary resuscitation" (DNACPR) forms. See United Nations Committee on the Rights of Persons with Disabilities, *List of Issues in Relation to the Initial Report of the United Kingdom of Great Britain and Northern Ireland*, (20 April 2017) CRPD/C/GBR/Q/1 (Committee CRPD Preliminary List of Issues)

<https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fGBR%2fQ%2f1&Lang=en> accessed 19 September 2019, Part A subparagraph 1 (f) and Part B subparagraph 19 (f).

¹⁶⁰ These often-noted criticisms of *Airedale NHS Trust v Bland* [1993] AC 789 (HL) (*Bland*) are analysed in Chapter Three, Section 3.2.

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consent).¹⁶¹ It is therefore vital to explore the medical rationale that no duty of care or medical necessity exists where doctors seek to discontinue life-supporting treatment from PDOC patients in 2.3.

As death has little to do with biology in terms of somatic integrative functioning or cardiopulmonary functioning, and as commentators are agreed that defining death is still anchored to some biological characteristic, it is necessary to understand what that characteristic is. For example, Younger and Arnold aptly state: 'certainly, the determination of death in our society has at least one foot resting in biology. Nonetheless, philosophy, religion, psychology, politics, and even economics play major roles in how individuals and groups interpret the biological facts. Death is ultimately a social construct.'¹⁶² I suggest that because cardiopulmonary functioning has been ruled out, the only component left in the official definition of death by the AOMRC is 'irreversible loss of consciousness'.¹⁶³ It is important to remember that the brain dead have beating hearts and functioning lungs.¹⁶⁴ Likewise, the cardiopulmonary dead have no apparent consciousness either. Therefore, whether a patient has cardiopulmonary function or not, it has little to do with the defining and determining death. Consequently, defining death has everything to do with the moral value of consciousness.

If this is the case it is problematic for PDOC patients. The remaining 'foot [of the definition and determination of death] resting in biology'¹⁶⁵ seems to be loss of consciousness. Of course, PDOC patients are "awake"; they demonstrate sleep-wake cycles and can open and shut their eyes, and even laugh, cry and grimace in pain, but these responses are categorised as reflexive.¹⁶⁶ Additionally, the disturbing list of responses of

¹⁶¹ Note even in cases where a patient autonomously refuses treatment with foresight of death, the judges in *Bland* [1993] (n 160) at page 864, Lord Goff made clear that such circumstances do not amount to a question of the patient's suicide or medical personnel having aided or abetted it; *R (on the application of Nicklinson) v Ministry of Justice*; *R (on the application of Lamb) v Ministry of Justice*; *R (on the application of AM) v DPP* [2014] UKSC 38, [2015] AC 657. Therefore, assisted suicide and euthanasia are distinguished from autonomous refusals and mercy killing cannot be the underlying justification for withdrawal from non-autonomous persons, only continued treatment deemed not to be in their best interests, again emphasising mercy killing is not a permitted justification.

¹⁶² Younger and Arnold (n 129) 532.

¹⁶³ AOMRC 2008 (n 32) 11.

¹⁶⁴ The medical evidence for this assertion has been explored in Subsection 2.2.2.

¹⁶⁵ Younger and Arnold (n 129) 532.

¹⁶⁶ PDOC 2013 (n 18) 3. As discussed in Subsection 2.1.1.

brain dead patients noted earlier in this section are also thought reflexive. Therefore, the question that needs to be answered is: just how important is "wakefulness" in medicine's valuation of the capacity for consciousness? Wakefulness may just be the safety net upholding the fine purported legal and moral distinction between PDOC patients and the "morally dead".

2.2.4 Section Conclusion

This section has taken the official definition of death and examined its defensibility (consistency and factual accuracy) in light of its neuroscientific challenges. It has found that death is defined and determined on the basis of loss of consciousness alone and that death is ultimately a social construct that permits otherwise impermissible behaviours on those no longer considered to have sufficient moral standing to be protected in law. Two questions have therefore arisen: what is consciousness and are its components of wakefulness and awareness equally valued in medicine? And, does the legal presumption in favour of life support withdrawal from PDOC patients suggest they are also morally "dead"?

2.3 "What's in a Name?" Consciousness or Responsivity?

2.3.1 Section Introduction

This section will assess how consciousness is defined and determined in medicine. Fundamentally it will assess how important wakefulness is and if it is as equally valued as awareness. To do so, it will explore the neuroscientific literature on how medicine defines and determines irreversible loss of consciousness with the purpose of assessing whether PDOC patients' wakefulness is enough to prevent them also being deemed morally dead. In this sense, wakefulness is being assessed to see if it can appropriately act as a moral and medical safeguard to prevent PDOC patients being morally and legally treated like the dead. Therefore, "Awareness" also seems to be the basis for establishing whether medical necessity and a duty of care exist or not, as a requirement to continue such treatment. Additionally, the section will explore inherent limitations in measuring consciousness, and what has been proven about consciousness and what remains conjecture.

2.3.2 Cortical Brain Damage and its Conceptual Ties to Consciousness

Awareness at least in medicine, is arguably the core component of what it means to be conscious: the ability to experience the environment around oneself and the capability for self-awareness.¹⁶⁷ To better explain the difference between its two components of wakefulness and awareness, the PDOC 2020 guidance defines wakefulness as, 'a state in which the eyes are open and there is a degree of motor arousal'.¹⁶⁸ 'It contrasts with sleep—a state of eye closure and motor quiescence'.¹⁶⁹ Whereas 'awareness' is defined as 'the ability to have, and the having of, experience of any kind'.¹⁷⁰ Both VS and MCS have wakefulness, therefore the term "consciousness" implicitly and more specifically, refers to awareness as opposed to wakefulness. Further evidencing this point, is the general and well-known consensus in the medical literature that it is accurate to describe VS patients as having 'wakefulness with absent awareness'¹⁷¹ and MCS as having 'wakefulness with minimal awareness'.¹⁷² Consequently, awareness is what is lost and is being assessed in disorders of consciousness.

The cerebral cortex is the core area of the brain that is damaged in PDOC patients.¹⁷³ It is purported to be the area of the brain responsible for consciousness (awareness) and therefore its damage is responsible for PDOC patients' non or minimal ability for experiential awareness.¹⁷⁴ However, one of the most surprising findings in Shewmon's paper, *Recovery from "Brain Death": A Neurologist's Apologia*, is the results of his literature search for the 'experiment' or 'case' that 'definitively established the cortical basis for consciousness'.¹⁷⁵ It is therefore helpful to recount his findings and then assess whether such a striking account has been disproven or bolstered by more recent research.

¹⁶⁷ PDOC 2020 (n 1) 23-25.

¹⁶⁸ ibid 23.

¹⁶⁹ ibid.

¹⁷⁰ ibid.

¹⁷¹ ibid 25.

¹⁷² ibid.

¹⁷³ PDOC 2020 (n 1); Shewmon 1997 (n 34).

¹⁷⁴ Shewmon 1997 (n 34). Note wakefulness is associated with the brainstem, specifically the reticular activating system, as noted in Subsection 2.2.3.

¹⁷⁵ ibid 59.

In Shewmon's search for finding the 'seminal case, experiment or observation [that] ... definitively establish[ed] the cortical basis of consciousness',¹⁷⁶ he found that:

no such case, study or article existed. Rather, a variety of speculations on the neuroanatomical localization of consciousness were batter around in the mid-1900s and then during the 1970s the cortical theory began to be repeated long enough and loudly enough by prestigious enough experts that it eventually came to be taken for granted by everyone else as an established fact ... [Moreover] the evidence turned out to be of an exclusively negative nature: patients with diffuse cortical destruction do not manifest clinical signs of awareness of self or environment. But there was no positive evidence that such patients are not inwardly conscious.¹⁷⁷

Conversely, he presents proven knowledge on what medicine knows about the functions of the cerebral cortex,¹⁷⁸ and argues that research on diffuse cortical damage has proven that it results in communication and comprehension impediments, making it 'inherently impossible'¹⁷⁹ for a VS (and to a lesser extent a MCS) patient to respond to commands to prove they are 'inwardly conscious'.¹⁸⁰ Worryingly, all the core PDOC diagnostic tests (WHIM, SMART, GCS¹⁸¹) currently rely on the ability for a patient to respond to demonstrate inner-awareness.¹⁸² They therefore inherently rely on responsivity as the means of proving awareness and yet responsivity (to comprehend and communicate a response to a command) is the exact impairment PDOC patients have.¹⁸³ As Shewmon explains:

¹⁷⁶ ibid.

¹⁷⁷ ibid.

¹⁷⁸ Shewmon 1997 (n 34).

¹⁷⁹ ibid 59.

¹⁸⁰ ibid.

¹⁸¹ As mentioned in Section 2.1.1. This limitation is also acknowledged in the PDOC 2020 guidance (n 1) at page 23 where the guidance states: 'there is no simple single clinical sign or laboratory test of awareness. Its presence must be deduced from a range of behaviours which indicate that an individual can perceive self and surroundings, frame intentions, and interact with others.'

¹⁸² ibid.

¹⁸³ Shewmon 1997 (n 34) 59.

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diffuse cortical destruction results in spastic quadriplegia and pseudobulbar palsy,¹⁸⁴ apraxia¹⁸⁵ of whatever little motor control remains, global aphasia,¹⁸⁶ dementia,¹⁸⁷ cortical blindness,¹⁸⁸ etc. How could anyone with such a disability possibly externally manifest inner consciousness convincingly, even if it were present?¹⁸⁹

Therefore, according to Shewmon, any attempt to try to measure inner awareness via physically demonstrable behavioural responses will be inaccurate if not unsafe.¹⁹⁰ He therefore suggests that PDOC patients have awareness because their inner awareness has never been disproven.¹⁹¹ Furthermore, not only 'had [this] never been done [by the very nature of the problem] nor could it ever be done.'¹⁹² The only way of widely testing inner awareness is via responsivity.¹⁹³ He therefore suggests that such patients are better described as being in a 'super-locked-in' state.¹⁹⁴

Therefore, it is pertinent to ask why reflexive responses are not respected as responses capable of evidencing awareness. Conscious individuals grimace in pain just like

¹⁸⁴ Defined as 'impairment of voluntary movements of tongue and facial muscles and emotional lability'. See the National Centre for Biotechnology Information Advances Science and Health, 'Pseudobulbar Palsy' (NCBI, 16 March 2019) <<https://www.ncbi.nlm.nih.gov/mesh?Db=mesh&Cmd=DetailsSearch&Term=%22Pseudobulbar+Palsy%22%5BMeSH+Terms%5D>> accessed 16 March 2019.

¹⁸⁵ Defined as 'an inability to make voluntary motor movements'. See WebMD, 'Apraxia: Symptoms, Causes, Tests and Treatments' (WebMD, 16 March 2019) <<https://www.webmd.com/brain/apraxia-symptoms-causes-tests-treatments#1>> accessed 16 March 2019.

¹⁸⁶ Defined as 'the severest type of aphasia ... the person has difficulty speaking and understanding words. In addition, the person is unable to read or write'. See WebMD, 'An Overview of Aphasia' (WebMD, 16 March 2019) <<https://www.webmd.com/brain/aphasia-causes-symptoms-types-treatments#1>> accessed 16 March 2019.

¹⁸⁷ Defined as 'problems with thinking, memory and reasoning'. See WebMD, 'What is Dementia?' (WebMD, 16 March 2019) <<https://www.webmd.com/alzheimers/types-dementia#1>> accessed 16 March 2019.

¹⁸⁸ Blindness caused by a lesion in the visual cortex, which can be temporary or permanent and some patients are unaware of their blindness due to neurological miscommunication. See Sashank Prasad and Jonathan D Trobe, 'Cortical Blindness' (Medlink Neurology, 6 June 2018) <http://www.medlink.com/article/cortical_blindness> accessed 16 March 2019.

¹⁸⁹ Shewmon 1997 (n 34) 59.

¹⁹⁰ ibid.

¹⁹¹ ibid 59-60.

¹⁹² ibid 60. See Subsection 2.3.3 for an up-to-date understanding of how close neurology has come to proving this.

¹⁹³ PDOC 2020 (n 1); Shewmon 1997 (n 34).

¹⁹⁴ Shewmon 1997 (n 34) 59-60.

VS and MCS patients do,¹⁹⁵ yet responses that are shown by PDOC patients are often put down to non-voluntary reflex responses.¹⁹⁶ Consequently, an often quoted "fact" about VS patients is that they cannot feel pain,¹⁹⁷ however, there is research to suggest that this assertion is also erroneous:

all treatises on the neurophysiology of pain traced the anatomical pathway from the cutaneous nociceptors centrally, invariably ending not at the cortex by the thalamus ... [this explains why cortical stroke patients can feel pain¹⁹⁸] ... Neither is there any cortical region stimulation of which produces a subjective sensation of pain ... but in the PVS literature these well-known phenomena are systematically ignored. PVS patients often grimace to noxious stimuli and manifest primitive withdrawal responses. Advocates of the cortical theory write off such behaviours as mere brainstem or spinal reflexes, but that dismissive attitude is based more on an *a priori* assumption than a scientific conclusion.¹⁹⁹

These findings therefore question the distinction made between VS, MCS and locked-in syndrome in the PDOC 2020 guidance.²⁰⁰

2.3.3 Down the Rabbit Hole: Distinguishing Reflex from Voluntary Response

Moreover, some research papers have sought to evidence PDOC patients' inner awareness via functional magnetic resonance imaging (fMRI) scans,²⁰¹ where blood supply increases around areas of neural activity demonstrating an ability to map or see patients' inner

¹⁹⁵ PDOC 2020 (n 1).

¹⁹⁶ *ibid.*

¹⁹⁷ Shewmon 1997 (n 34) 60.

¹⁹⁸ *ibid* 59-60.

¹⁹⁹ Shewmon 1997 (n 34) 60.

²⁰⁰ PDOC 2020 (n 1) 24.

²⁰¹ Lorina Naci and Adrian M Owen, 'Making Every Word Count for Vegetative Patients' (2013) 70 JAMA Neurology 1235; Davinia Fernandez-Espejo and Adrian M Owen, 'Detecting Awareness After Severe Brain Injury' (2013) 14 Nature Reviews Neuroscience 801; Damian Cruse and others, 'Detecting Awareness in the Vegetative State: Electrocephalographic Evidence for Attempted Movements to Command' (2012) 7 (11) PLOS One e49933; Damian Cruse and others, 'Bedside Detection of Awareness in the Vegetative State: A Cohort Study' (2011) 17 378 (9809) Lancet 2088; Martin M Monti and others, 'Wilful Modulation of Brain Activity in Disorders of Consciousness' (2010) 362 New England Journal of Medicine 579; Adrian M Owen, 'Detecting Awareness in the Vegetative State' (2006) 313 Science 1402.

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awareness.²⁰² The results were thought-provoking and some argue that they have the potential to reduce the infamous misdiagnosis rate between MCS and PVS.²⁰³ Briefly, Owen and others demonstrated brain activity in VS patients that was 'indistinguishable'²⁰⁴ from conscious (and responsive) control subjects when asked to imagine themselves playing tennis or walking around their house.²⁰⁵ For these neurologists, the evidence demonstrates the patient's ability to mentally and voluntarily follow command(s).²⁰⁶ Additionally, Staffen and others argue that their fMRI scan experiment demonstrates that VS patients can distinguish their name from others and that they hoped the results could be important for future 'rehabilitative attempts'.²⁰⁷

However, such tests have not been met with unanimous support. One criticism is that not every subject was able to demonstrate voluntary responsivity via fMRI scans.²⁰⁸ This has led to an interesting and often overlooked point in current attempts to prove awareness: negative results do not necessarily prove that those who are aware, according to fMRIs, are anomalous findings. Instead, a likely reason why they demonstrate no response may be that the patient in question has global aphasia, or is cortically deaf or blind, meaning they cannot understand or pick up the command in the first place,²⁰⁹ not that they are thus proven to be non or minimally aware.

Therefore, results such as Monti and others', whose research showed 5 out of 54 were able to wilfully modulate their brain activity,²¹⁰ actually bolsters the significance of Shewmon's claim that no two brain damages are the same, and therefore comprehension and responsivity capabilities will be different in two different but similarly diagnosed VS

²⁰² Hannah Devlin, Stuart Clare and Irene Tracey, 'Introduction to fMRI' (Nuffield Department of Clinical Neurosciences, 16 March 2019) <<https://www.ndcn.ox.ac.uk/divisions/fmrib/what-is-fmri/introduction-to-fmri>> accessed 16 March 2019.

²⁰³ Monti 2010 (n 201).

²⁰⁴ Adrian M Owen and others, 'Detecting Awareness in the Vegetative State' (2006) 313 (5792) Science 1402, 1402.

²⁰⁵ *ibid.*

²⁰⁶ See Monti 2010 (n 201) at page 579, where the "voluntariness" of these responses has been debated.

²⁰⁷ W Staffen and others, 'Selective Brain Activity in Response to One's Own Name in the Persistent Vegetative State' (2006) 77 (12) Journal of Neurology, Neurosurgery and Psychiatry 1383, 1384.

²⁰⁸ George A Mashour and Michael S Avidan, 'Capturing Covert Consciousness' (2013) 381 The Lancet 271, 271.

²⁰⁹ Shewmon 1997 (n 34).

²¹⁰ Monti 2010 (n 201) 579.

(or MCS patients).²¹¹ For example, although the cortex is damaged to the same severity in two VS patients, the inhomogeneities in pressure sustained during injury will mean that not the exact same cortical damage will be sustained. Consequently, some have begun to question the essential difference between reflexive and voluntary responses, with no further concrete ground being made on what type of response is morally significant for consciousness.²¹²

Moreover, some neurologists have thought the evidence presented by fMRI's too passive to be demonstrative of inner awareness.²¹³ For these critics, the mere presence of brain activity is not sufficient in and of itself to demonstrate what is thought to be complex "awareness". Stins has drawn an analogy between both sides of this debate with debates in AI consciousness, and more specifically the debate had between Alan Turing's 'Turing Test' and John Searle's 'Chinese Room Argument'.²¹⁴ However, such debates go further into essentialist arguments on consciousness and what makes human consciousness unique than is required here. For example, the neuroscientific literature has approached consciousness from a variety of approaches and with differing goals. Some such as Mashour and Hudetz,²¹⁵ as well as Crick and Koch,²¹⁶ have focused on experiential consciousness, what was referred to earlier as the 'Holy Grail of neuroscience':²¹⁷ the

²¹¹ Shewmon 1997 (n 34). As discussed in Subsections 2.2.3 and 2.3.2.

²¹² John Banja, 'Interactive But Not Conscious; Conscious But Not Interactive: Lessons Learned From Slime Molds and Bartleby Scrivener' (2013) 4 (4) AJOB Neuroscience 40; David B Fischer and Robert D Truog, 'Conscientious of the Conscious: Interactive Capacity as a Threshold Marker for Consciousness' (2012) 4 (4) AJOB Neuroscience 26.

²¹³ Parashkev Nachev and Masud Husain, 'Comment on "Detecting Awareness in the Vegetative State"' (2007) 315 Science 1221a; Melanie Boly and others, 'When Thoughts Become Action: An fMRI Paradigm to Study Volitional Brain Activity in Non-Communicative Brain Injured Patients' (2007) 36 NeuroImage 979.

²¹⁴ John F Stins, 'Establishing Consciousness in Non-Communicative Patients: A Modern-Day Version of the Turing Test' (2009) 18 Consciousness and Cognition 187; John Searle, *The Rediscovery of the Mind* (MIT Press 1992); John Searle, 'Minds, Brains and Programs' (1980) 3 Behavioural and Brain Sciences 417; Alan Turing, 'Computing Machinery and Intelligence' (1950) 59 Mind 433.

²¹⁵ George A Mashour and Anthony G Hudetz, 'Neural Correlates of Unconsciousness in Large-Scale Brain Networks' (2018) 41 (3) Trends in Neuroscience 150.

²¹⁶ Francis Crick and Christof Koch, 'A Framework for Consciousness' (2003) 6 (2) Nature Neuroscience 119; Francis Crick and Christof Koch, 'Towards a Neurobiological Theory of Consciousness' (1990) 2 The Neurosciences 263.

²¹⁷ William R Klemm, 'Where Neuroscience Stands in Understanding Consciousness' (Psychology Today, 2 April 2018) <<https://www.psychologytoday.com/gb/blog/memory-medic/201804/where-neuroscience-stands-in-understanding-consciousness>> accessed 18 March 2019.

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answer to "how one experiences anything". The literature overall has a variety of different approaches to achieving this, for example, studying neural correlates or neural mechanisms;²¹⁸ or 'descriptive' versus 'normative' accounts,²¹⁹ where normative accounts are sometimes criticised for being intuition-based (a point I made earlier in this section whilst commenting on the starting presumption that the cortex is responsible for awareness). Conversely, others have taken a much more descriptive approach to focusing on what they call the 'primary role' of consciousness which is to 'serve the somatic nervous system'.²²⁰ Finally, since the 1980s there has been an interesting theory (whose methods have recently improved to demonstrate ostensibly the same point):²²¹ that our brains react several seconds before we are aware of a decision being made,²²² suggesting that responsivity 'is just the tip of the iceberg' for consciousness and our understanding of it.²²³ It also suggests that a large majority of what we think of as "consciousness" is happening without our awareness of it (is reflexive).²²⁴ This conclusion fundamentally questions the value neuroscience, and more specifically the PDOC 2020 guidance, has put on distinguishing reflex from voluntary responsivity.

Ultimately, such a problem has left some neurologists referring to such patients as 'hopelessly conscious'.²²⁵ Despite the current stalemate on responsivity's equation with awareness, there seems to be a growing consensus among neurologists to change the

²¹⁸ Mashour and Hudetz (n 216); Crick and Koch 2003 (n 216); Crick and Koch 1990 (n 216).

²¹⁹ Ezequiel Morsella and others, 'Homing in on Consciousness in the Nervous System: An Action-Based Synthesis' (2016) 39 Behavioural and Brain Sciences e168, e168. Note this article defines normative accounts as 'construing processes in terms of how they should function' as opposed to descriptive accounts that 'describ[e] the products of nature as they evolved to be' at page e168.

²²⁰ *ibid.*

²²¹ Benjamin Libet and others, 'Time of Conscious Intention to Act in Relation to Onset Cerebral Activity (Readiness-Potential). The Unconscious Initiation of a Freely Voluntary Act' (1983) 106 (3) *Brain* 623.

²²² Chun Siong Soon and others, 'Unconsciousness Determinants of Free Decisions in the Human Brain' (2008) 11 *Nature Neuroscience* 543.

²²³ Kerri Smith, 'Brain Makes Decisions Before You Even Know It: Brain Activity Predicts Decisions Before They Are Consciously Made' (*Nature: International Weekly Journal of Science*, 11 April 2008) <<https://www.nature.com/news/2008/080411/full/news.2008.751.html>> accessed 29 March 2019. The website quotes Soon and others' paper (n 223) stating that their findings suggest brain activity can happen at up to 'ten seconds' before we consciously make the decision.

²²⁴ *ibid.*

²²⁵ Mashour and Avidan 2013 (n 208) 271. The original phrase, the 'hopelessly unconscious patient', originates from Beecher's 1968 paper (n 70) at page 1425.

nomenclature to responsiveness disorders.²²⁶ However, although the PDOC 2013 and 2020 guidance recognised the flaw in relying on responsiveness tests to determine inner awareness,²²⁷ the disorders have not been relabelled to reflect their "minimal responsiveness" as opposed to "consciousness". Therefore, the disorders are still officially described as "disorders of consciousness". For example, despite the attempt by the European Task Force on Disorders of Consciousness to replace "vegetative state" with the name "unresponsive wakefulness syndrome" in 2010,²²⁸ this was not specifically adopted in the PDOC guidance in 2013 or 2020.²²⁹ The reason being that 'unresponsive wakefulness syndrome' fails to capture the complexity of the disorder.²³⁰ As a provided example, an implication of labelling the disorders, "disorders of responsiveness", was that this term also encapsulates reflexes.²³¹ Perhaps it is for this reason that the PDOC 2020 guidance maintains a distinction between PDOC and locked-in syndrome patients, despite Shewmon's description of PDOC patients being in a 'super-locked-in state'.²³²

The argument on whether responsiveness can be equated with awareness will either prove responsiveness is awareness (even reflex or fMRI response) and if not, responsiveness will be proven to be an unsafe standard to state with any degree of certainty that a being is not inner-aware. Therefore, the importance of this debate is whether neuroscience's reliance on responsiveness is accurate and consistent enough to determine that no continued duty of care exists on the basis of loss of the key function required to hold moral standing, and morally and legally permit life support withdrawal. The question of continuation therefore does not just answer whether continued treatment amounts to assault, but the establishment of no duty of care in this context delineates moral standing (defines who is "dead").

²²⁶ Steve Majerus and others, 'Behavioural Evaluation of Consciousness in Severe Brain Damage' in Steven Laureys (ed), *The Boundaries of Consciousness: Neurobiology and Neuropathology* (Elsevier 2005) 384; Steven Laureys, 'Death, Unconsciousness and The Brain' (2005) 6 *Nature Reviews: Neuroscience* 889, 904; Stefanie Blain-Moraes, Eric Racine and George A Mashour, 'Consciousness and Personhood in Medical Care' (2018) 12 *Frontiers in Human Neuroscience* 306.

²²⁷ PDOC 2020 (n 1) 23-24; PDOC 2013 (n 18) 2 and 19-22.

²²⁸ Laureys and others 2010 (n 13).

²²⁹ PDOC 2020 (n 1) 23-24; PDOC 2013 (n 18) 2 and 19-22.

²³⁰ PDOC 2020 (n 1) 23; PDOC 2013 (n 18) 2-3.

²³¹ *ibid.*

²³² *ibid.*; Shewmon 1997 (n 34) 60. Note Shewmon claims at page 60 that capping the manifestation of responses in VS at reflexes is based on an '*a priori* assumption than a scientific conclusion'.

Returning to the cortical theory of consciousness, no further research has been able to prove where consciousness (awareness) is localised in the brain.²³³ Moreover, some of those attempts may have been undermined by a flawed 'input/ output' methodological approach.²³⁴ Such issues are important because they further demonstrate the inherent problem of proving awareness via responsivity tests, and because the search for where awareness is located in the brain continues, the localisation of awareness is still not known or factually proven. Therefore, there is at least scope to doubt whether awareness is a cortical function at all, meaning that any attempt to state one is definitively non-conscious/ aware seems to be a guesstimate at best.

Moreover, definitively proving awareness is the 'Holy Grail of [neuro]science'²³⁵ and is unlikely to be proven under responsivity-reliant techniques, perhaps in part this is also due to the multi-functionality of brain networks.²³⁶ In a similar line of thought, Crick and Koch argue that, 'cognitive methods are undoubtedly important [but] doubt[ed] whether they [would] by themselves ever be sufficiently compelling to explain consciousness in a convincing manner.'²³⁷ Importantly they add, 'attempting to infer the internal structure of a very complex system using a 'black-box' approach (i.e. manipulating the input variable while observing the output) will never lead to a unique answer.'²³⁸ The closest researchers have come to proving a cortical role in awareness via a neural correlates approach was a further Harvard paper in 2016.²³⁹ The paper suggests that the rostral dorsolateral pontine tegmentum in the brainstem had a role in consciousness,²⁴⁰ which the researchers then, using a brain connectivity map, linked to two further regions in the cortex (the anterior insula and the pregenual anterior cingulate cortex).²⁴¹ The results are significant because a

²³³ Mashour and Hudetz (n 215) 150.

²³⁴ Crick and Koch 1990 (n 216).

²³⁵ Klemm (n 217).

²³⁶ *ibid.*

²³⁷ Crick and Koch 1990 (n 216) 263.

²³⁸ *ibid.*

²³⁹ David B Fischer and others, 'A Human Brain Network Derived from Coma-Causing Brainstem Lesions' (2016) 87 (23) *Neurology* 2427.

²⁴⁰ *ibid.* This part of the brainstem is responsible for sleep/wake cycles and some aspects of respiratory function.

²⁴¹ *ibid.* These cortical links seem to suggest that the cortex does in fact play a role in the capacity for awareness. However, such a theory would also need to prove responsivity is the same as awareness, which as Shewmon 1997 (n 34) argues, is impossible due to the fact that without responsivity others cannot know if another is inner-aware.

cortical link with the brainstem (known for its role in wakefulness) has possibly been established and may save somaticism. However, more results were needed to definitely prove that this neural correlate is, and solely is (given multifunctionality) responsible for awareness.²⁴² Finally, more recent papers have also suggested a further schism between researchers who believe consciousness is located in cortical regions against those who believe it is more likely subcortical.²⁴³

Ultimately, it seems that medical or neurological knowledge on consciousness is still in its infancy and moreover, for the purposes of this thesis' central question, any theory on moral standing or defining death that seeks to rely on the idea that holding or lacking consciousness can be proven, is unsafe, if not indefensible. This section has shown that the view that death amounts to the loss of consciousness alone neither holds an official consensus in medicine, nor can it be described as holding a logical basis under the *Bolitho*²⁴⁴ standard of medical decision-making, because the evidence that PDOC patients are possibly inner-aware is often dismissed at the expense of evidence which does not, and cannot, definitively prove their non or minimal awareness.²⁴⁵ Such a conclusion is crucial for assessing the continued legal defensibility of life support discontinuation on the basis of loss of voluntary responsibility where such patients are deemed legally alive.

2.3.4 Section Conclusion

This section's findings have shown that awareness is more highly valued than wakefulness, in the sense that when a patient is diagnosed as non or minimally conscious, doctors are stating that the patient has none or very few voluntary responses to stimuli. This means that the possible medical safeguard of wakefulness to distinguish PDOC patients from brain dead patients is inconsequential. It seems that the hypothetical argument that PDOC patients are not "dead" because they are demonstrably awake (as discussed above) is treated as an almost irrelevant biological factor in the task of defining and determining death. Moreover, there is a conceptual problem with the conflation of responsibility and

²⁴² ibid.

²⁴³ Morsella (n 219) e172.

²⁴⁴ *Bolitho v City and Hackney Health Authority* [1998] AC 232 (HL). *Bolitho*'s medical decision-making standard was discussed in Chapter One, Subsection 1.3.3.

²⁴⁵ Shewmon 1997 (n 34); Owen and others 2006 (n 204).

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awareness. Definitively disproving inner awareness is currently unsafe because the consciousness diagnostic tests rely on the patient's capacity to demonstrate voluntary responsiveness, and that is exactly what has been impacted in the sustained injury to the cortex for PDOC patients. Finally, whilst neuroscience continues to grapple with the conflation of responsiveness with consciousness, the factual accuracy of stating that PDOC patients are non or minimally aware is inaccurate. The loss of voluntary responsiveness as a basis for discharging their duty of care and establishing a lack of medical necessity for legal purposes is therefore a seemingly dubious practice, potentially threatening those with cognitive disabilities' equal right to life.

Furthermore, there is no moral consistency in maintaining that the brain dead are "dead" and PDOC patients are "alive" on the basis of difference in cardiopulmonary function (as established in 2.2) or consciousness (wakefulness or awareness). Awareness is the "Holy Grail" that neurology is still searching for and evidently wakefulness is not considered morally valuable enough to be what prevents life support withdrawal from living PDOC patients being permissible. The seemingly moral insignificance of wakefulness is assumed because of the fact that life support is also permissible from PDOC patients, because of their thought non or minimal awareness alone (irrespective of wakefulness or cardiopulmonary functioning). Therefore, voluntary responsiveness is the most morally valuable biological characteristic of human life in this context and because PDOC patients also lack this characteristic, they are also at risk of being morally defined as "dead". Consequently, the section's title "what's in a name?" refers to the moral value difference between wakefulness and awareness, and further still, between awareness with responsiveness.

The next section will look at arguments that have been put forward in the literature that support consciousness (responsivity) as the most important characteristic of human life, both in debates on defining death not yet discussed and personhood. The section will also return to the second question that was left at the end of 2.2, on whether the permissibility or impermissibility of death behaviours on certain patients could indicate such patients' moral standing status, and consequently, their status as "living" or "dead" individuals in medical practice (and law).

2.4 Consciousness and its Practical (Not Just Theoretical) Ties to Personhood

2.4.1 Section Introduction

This section explores the final brain death theory of higher brain or "neocortical death". It does so on the basis that the last two sections indicate that the only biological foothold in defining and determining death, in practice, seems to be loss of consciousness (specifically loss of voluntary responsivity). It therefore looks at the criticisms of higher brain death and its association with being a personhood view of death that is both ontologically and biologically incongruous with doctors and laypersons' experiential knowledge of death. The section therefore has the potential to finally break the assumed ties that PDOC patients' capacity to breathe and be awake are enough to distinguish them as alive, and be appropriately morally and legally protected persons. Breaking these ties will enable a more accurate analysis of their legal and moral protection in medical practice and in law in subsequent chapters.

2.4.2 'Higher Brain Death' or 'Embodied Consciousness':²⁴⁶ Implications for the 'Hopelessly Conscious Patient'²⁴⁷

Higher Brain death (or neocortical death) was a third and final theory to emerge out of the debates on death in the late 1960s and early 1970s.²⁴⁸ Veatch is one of its most often quoted proponents; however he argues that he is often misquoted because so few academic commentators give higher brain death the attention he thinks it deserves.²⁴⁹ From the outset it is not difficult to understand why this is. For example, one of the first papers advocating higher brain death in 1971 defined the theory as the permanent loss 'of those higher-functions of the nervous system that demarcate man from lower primates'.²⁵⁰ Higher brain death commentators criticise the traditional cardiopulmonary-centric view of

²⁴⁶ Veatch 2005 (n 51) 370.

²⁴⁷ Mashour and Avidan 2013 (n 208) 271. The original phrase the, 'hopelessly unconscious patient', originates from Beecher's 1968 paper (n 70) at page 1425.

²⁴⁸ Laureys 2005 (n 227); Shewmon 1997 (n 34).

²⁴⁹ Veatch 2005 (n 51) 356.

²⁵⁰ J B Brierley and others, 'Neocortical Death After Cardiac Arrest. A Clinical, Neurophysiological, and Neuropathological Report of Two Cases' (1971) 2 (7724) *The Lancet* 560, 565.

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death on the basis that consciousness (as the capacity to think, be self-and-environmentally aware, and to participate in social interaction) is what differentiates humanity from other species, not the capacity to breathe.²⁵¹ Accordingly, higher brain death debates were not, and are not, focused on biological death but a radical redefinition of death.

Higher brain death theories sought to single out the most valuable characteristic of human life.²⁵² That singular characteristic would require both moral and legal protection from harm above all others.²⁵³ As Laureys argues, higher brain death propounded 'that consciousness, cognition and social interaction, not bodily physiological integrity, are the essential characteristics of human life.'²⁵⁴ Furthermore, higher brain death has a dangerous association with eugenics. It is therefore not difficult to understand why whole-brain and brainstem death (somaticist) theorists seek to distance themselves from the theory. Higher brain death has particularly impacted severely disabled persons, such as hydranencephalic children, VS and MCS patients.²⁵⁵ The theory is also associated with the debasement of human life for its parity with animals (offending religionists), and for animal rights activists (naturalists) holds a dangerous elitist attitude that threatens animal welfare.²⁵⁶ Moreover, the fact that a Californian Bill in 1986 sought to declare hydranencephalic children "dead", for the purposes of increasing organ transplantation, is demonstrative of the type of ideologies that became associated with higher brain death.²⁵⁷

²⁵¹ ibid.

²⁵² Laureys 2005 (n 226).

²⁵³ Higher brain death is therefore an essentialist theory that seeks to find the singular characteristic that makes human life valuable.

²⁵⁴ Laureys 2005 (n 226) 904.

²⁵⁵ ibid; Shewmon 1997 (n 34).

²⁵⁶ Note Ngaire Naffine, *Law's Meaning of Life: Philosophy, Religion, Darwin and the Legal Person* (Hart Publishing 2009) gives a good overview of these different groups of personhood theorists eg religionists, naturalists etc.

²⁵⁷ Note Shewmon 1997 (n 34) at pages 54-59 presents an extraordinary study on how increased interaction enabled hydranencephalic children (thought to be "brain absent" due to the fact their cortex had not developed) were able to develop motor skills, rudimentary sight and interact with the world around them. His findings were put down to the plasticity of children's neurological system. However, increased stimulation and interaction is a method encouraged for patients with brain related pathologies because of its capacity to increase and induce such functions, see PDOC 2020 (n 1).

Therefore, the general and most often quoted understanding and implication of higher brain death for PDOC patients can be stated as, 'according to the consciousness- or personhood-centred neocortical definition of death, persons in a vegetative state are considered dead'.²⁵⁸ In summary, higher brain death's greatest criticisms are that, it ignores 'bodily physiological integrity theories',²⁵⁹ targets severely disabled persons and 'despite its theoretical attractiveness to some, this concept of death cannot be reliably implemented using anatomical criteria nor in reliable clinical testing'.²⁶⁰

However, somaticism's defence of whole-brain and brainstem death failed.²⁶¹ The findings of 2.2 and 2.3 were that even whole-brain and brainstem death theories are ultimately also reduced to a form of higher brain death because in practice they (even if inadvertently) prioritise the importance of awareness (responsivity) over all other vital functions. Those sections demonstrated that the integrative somatic functions brain dead patients were thought to have lost are not lost. It is therefore important to be open to the idea that perhaps in the UK, the lives of cognitively disabled persons (such as PDOC patients) are also just as at risk, if not more so than if the UK adopted higher brain death as its official policy stance.²⁶² Consequently, Veatch's clarification of his interpretation of higher brain death is pertinent and deserves further exploration.²⁶³

Veatch suggests that whilst there are some proponents in the higher brain death camp who argue that only mental functioning is sufficient for death,²⁶⁴ he is not one of them.²⁶⁵ He instead splits higher brain death advocates into two camps, naming himself to be a proponent of the latter theory: 'mentalist' and 'embodied consciousness' theorists.²⁶⁶

²⁵⁸ Laureys 2005 (n 226) 889.

²⁵⁹ *ibid* 904. Such as the somaticists defence of whole-brain and brainstem death theories discussed in Sections 2.2 and 2.3.

²⁶⁰ See Laureys 2005 (n 226) where he refers to the implications of adopting higher brain death for VS, MCS and hydranencephalic patients.

²⁶¹ Veatch 2005 (n 51); Potts (n 134); Halevy 2001 (n 135); Dagi and Kaufman (n 137); Campbell (n 139); Halevy and Brody 1993 (n 136).

²⁶² Note I write "if not more" because there is possibly a higher risk of indefensible practices slipping through if official policy is assumed to be based on a wholly different theory and moral justification.

²⁶³ In reference to his arguments in Veatch 2005 (n 51).

²⁶⁴ See, for example, Michael B Green and Dan Wikler, 'Brain Death and Personal Identity' (1980) 9 (2) *Philosophy and Public Affairs* 105; Eric J Cassell, *The Healer's Art* (Penguin Books 1979).

²⁶⁵ Veatch 2005 (n 51) 370.

²⁶⁶ *ibid*.

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According to Veatch, some of the most common criticisms that higher brain death theory receives are that it would amount to: burying a living body;²⁶⁷ that medicine is currently unable to accurately diagnose loss of higher brain functioning;²⁶⁸ and most significantly, that all higher brain death proponents are of the opinion that only the mind is sufficient for higher brain death.²⁶⁹ His responses are quite convincing.

First, in response to the argument that "brain death would amount to burying a living corpse", Veatch argues that none of the brain death theories (including both higher brain death camps) support the idea that as soon as an individual is defined as "morally" or "medically" dead, burial is appropriate on the basis of having lost moral standing.²⁷⁰ He suggests that those who believe that higher brain death theorists believe burial is defensible, fail to understand that not all death behaviours become appropriate at the moment loss of moral standing occurs.²⁷¹ Accordingly, there is a distinction between permissible death behaviours when the patient is biologically dead (e.g. burial and disposal of remains) and morally dead (e.g. withdrawal of life support and vital organ donation). For example, I mentioned in 2.3 that a core cluster of death behaviours will remain aggregated to biological death and that burial is one such behaviour according to all groups of death theorists.

In response to the second criticism, "that higher brain death is an unpractical theory because higher brain functioning cannot be reliably measured", the permissibility of life support withdrawal from PDOC patients suggests that such a view contradicts current medical practice.²⁷² Despite the noted and known problems with accurately diagnosing a PDOC patient as non or minimally conscious in 2.3, PDOC patients are still diagnosed and categorised into Coma, VS and MCS.²⁷³ Therefore, such an assertion undermines the very premise that the permissibility of life support withdrawal from VS and MCS rests on.²⁷⁴ I

²⁶⁷ ibid 368-369.

²⁶⁸ ibid; Laureys 2005 (n 226) makes this argument at page 904.

²⁶⁹ Veatch 2005 (n 51) 370.

²⁷⁰ ibid.

²⁷¹ ibid.

²⁷² ibid.

²⁷³ ibid.

²⁷⁴ Note I agree with Laureys point here that disorders of consciousness cannot be reliably diagnosed on the basis of the evidence in 2.3, but it flies in the face of established medical practice to use it as an argument against higher brain death.

therefore agree with Laureys point here that consciousness disorders cannot be reliably diagnosed as evidenced in 2.3,²⁷⁵ but it flies in the face of established medical practice to use it as an argument against higher brain death. It is for this reason I find Veatch's response on this point convincing. Additionally, brainstem death testing is not certain either and has been criticised in recent years; for example, the awareness component of consciousness (higher brain function) is largely ignored.²⁷⁶

The third and final response to, "all higher brain death theorists believe mental functioning is the only function that needs to be lost to lose moral standing, and be defined as dead",²⁷⁷ has led to some further interesting conclusions that deserve more attention than they have received. However, there are certain aspects of embodied consciousness theories that raise further implications for the 'hopelessly conscious patient'²⁷⁸ and require further clarification. Veatch argues that he supports the idea of embodied consciousness which he defines as 'the minimal somatic functions and the minimal mental functions that are necessary for full moral standing to be present'.²⁷⁹ He adds that, 'when and only when these are jointly present, then the sufficient conditions for full moral standing are present.'²⁸⁰ It seems that the most attention embodied consciousness has received is largely from philosophers debating the experimental idea of detached or "disembodied consciousness": proponents Veatch refers to as 'mentalists'.²⁸¹ For example, theories on whether a person has "died" or has been "killed" if consciousness could be downloaded into a computerised memory bank and detached from the body, have engaged with the concept of disembodied consciousness.²⁸² Importantly for this section, this debate aptly illustrates the clear distinction between mentalist theories that Veatch points to, where he argues that mentalists would conclude that the individual is still alive.²⁸³ Conversely Veatch argues: 'a disembodied mind that has been downloaded from a previous embodiment but remains capable of thinking, feeling, remembering, and

²⁷⁵ Laureys 2005 (n 226) 904.

²⁷⁶ Howard (n 108) 502; Bell and others (n 108). As explored in Subsection 2.2.3.

²⁷⁷ Veatch 2005 (n 51) 370.

²⁷⁸ Mashour and Avidan 2013 (n 208) 271. As explained in Subsection 2.3.3, the original phrase the 'hopelessly unconscious patient' originates from Beecher's 1968 paper (n 70) at page 1425.

²⁷⁹ Veatch 2005 (n 51) 370.

²⁸⁰ *ibid.*

²⁸¹ *ibid* 370-371.

²⁸² *ibid.*

²⁸³ *ibid.*

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so forth, would surely have some important moral standing, but, so [he] claim[s], it would not be the same human as it was when it was embodied.²⁸⁴

A further theory that Veatch uses to demonstrate the distinction between mentalists and embodied consciousness is the hypothetical problem of 'mind-switching'.²⁸⁵ The aim of this theory is to determine whether the original individual resides in the body or mind.²⁸⁶ Veatch argues, 'consistent mentalists would have to conclude that it is the mind that counts so that what has occurred is, in effect, a "body-switch"'.²⁸⁷ Instead, he argues that under embodied consciousness theory two new people have been created using the 'two original essential features of the previous people', adding, 'creating new individuals would be ... immoral, essentially ending the lives—killing—the original people and creating new chimeras'.²⁸⁸ However, what is unclear in Veatch's embodied consciousness theory is what the minimal somatic and mental functions are. Instead, he suggests in another paper (with Ross) that death (on the basis of embodied consciousness theory) should be left to the individual to decide for themselves.²⁸⁹ There are practical and enforcement issues I foresee with such an approach that will not be addressed here (despite its attractiveness for postmodernist philosophers).²⁹⁰ For current purposes, the findings suggest that the way in which death is defined and determined in the UK (for the purpose of life support withdrawal) is a mentalist (disembodied consciousness) understanding of the moral value of human life. Under such an interpretation somatic function is less important than the loss of awareness (responsivity). Consequently, it seems that the legal question in both brainstem death and PDOC patients' life support continuation decisions should be homogenous. It seems incongruous (on the basis of the law's current stance) for it to develop a different legal question on the basis of assault for

²⁸⁴ ibid.

²⁸⁵ ibid.

²⁸⁶ ibid.

²⁸⁷ ibid

²⁸⁸ ibid.

²⁸⁹ Robert M Veatch and Lainie F Ross, *Defining Death: The Case for Choice* (Georgetown University Press 2016).

²⁹⁰ For example, the legal ramifications arising from coronial investigations where the person's adopted definition of death is disputed and would thus be unlawful because a doctor had misunderstood the individual's own definition of death. Additionally, the same issues of recording and validity that advance planning instruments currently face may possibly arise, as outlined in Chapter Three, Section 3.3 and Chapter Four, Section 4.3.

those who are recognised as living whilst the law does not permit any form of euthanasia or assisted suicide.

So far, this chapter has assessed the factual accuracy of the bipartite somatic and mental components of the official definition of death and found that only the mental element is reflected in practice, to permit life support withdrawal (and even organ donation although this is not discussed in this thesis). To demonstrate the consistency of such a conclusion, locked-in syndrome patients have moral standing and are "deemed alive" under current practice because they can respond (eye or eyelid movements²⁹¹) and are therefore demonstratively aware and conscious. It is also consistent that in law, those with degenerative neurological disorders are denied voluntary assisted death and euthanasia because their awareness (responsivity) is demonstrably intact up until they can no longer request physician assisted suicide. Likewise, the brainstem dead are dead, not because of loss of integrative somatic functions but because they are not demonstrably aware (responsive). The capacity for voluntary responsivity is what fundamentally determines the permissibility of life support withdrawal and determines "death".

This conclusion exposes the currently drawn line for moral standing (and possibly personhood²⁹²) by delineating when a duty of care no longer exists even where death is foreseen. It also highlights how VS, and to an extent MCS patients, are on the precipice of such a decision and are often simultaneously denied and attributed moral standing on the basis of the alleged differences between reflex and voluntary responses. For example, palliative care is continued after life support withdrawal from PDOC patients,²⁹³ yet it is not in brainstem dead patients.²⁹⁴ Also, life support is withdrawn before the PDOC patient succumbs to death by dehydration which leads to suprarectal 'multiorgan damage' and makes organ donation impossible,²⁹⁵ but not in brainstem dead patients. For brainstem dead patients, organ donation is possible because death is determined before life support

²⁹¹ PDOC 2020 (n 1) 24.

²⁹² This will be further explored in the following subsection (2.4.3) and in Chapter Three, 3.2 and Chapter Four, Subsection 4.2.2.

²⁹³ PDOC 2020 (n 1). Details of appropriate palliative care treatment are outlined at pages 151-165 of the 2020 guidance.

²⁹⁴ AOMRC 2008 (n 32).

²⁹⁵ PDOC 2020 (n 1) 157.

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is withdrawn, therefore maintaining oxygen supply to the organs.²⁹⁶ Moreover, in recent years a debate arose on the meaning of “best interests” to decide the legal permissibility of continued mechanical ventilation to allow transplant teams to arrive before ischemia set in.²⁹⁷ There is therefore a moral inconsistency that is most evident in the case study of PDOC patients on the order and timing of permissible and prohibited death behaviours. Their moral existence can therefore be described as an “in-between state” or a ‘no man’s land paradox’,²⁹⁸ where they are biologically alive, and simultaneously have lost and hold moral standing.

Medicine’s endeavour to hold onto loss of minimum somatic integrative functioning is likely due to the fact that loss of moral standing, on the basis of loss of voluntary responsiveness (as the definition of death), is both ‘biologically’ and ‘ontologically’ incongruous with doctors’ and laypersons’ experiential knowledge of death.²⁹⁹ The definition is perhaps most clearly intellectually and morally incongruous in the case of consciousness disorders: PDOC patients are “awake” and independently breathe (and are only unable to swallow).³⁰⁰ This in turn questions why they also can have life support withdrawn on the basis of being morally “dead”.

Consequently, to be morally defensible, medicine will need to re-evaluate the definition of death as it is employed in practice. To maintain some minimum somatic function as necessary is morally indefensible for being factually inaccurate and inconsistent with current practice. First, there is a lack of supporting evidence in practice that somatic integrative function is important, and secondly, there is a lack of consensus on what that minimum should be to salvage brain death as a defensible practice, and still maintain that consciousness disorders are different from brainstem death and are morally “alive”.³⁰¹ The foreseeable consequence and resulting question of how to salvage the

²⁹⁶ AOMRC 2008 (n 32). As discussed in Subsection 2.2.2.

²⁹⁷ David Price, ‘End-Of-Life Treatment of Potential Organ Donors: Paradigm Shifts in Intensive and Emergency Care’ (2011) 19 Medical Law Review 86; John Coggon and others, ‘Best Interests and Potential Organ Donors’ (2008) 336 British Medical Journal 1346.

²⁹⁸ Note the phrase ‘no man’s land paradox’ has been borrowed from Have and Welie’s book on euthanasia and assisted dying in the Netherlands. See Henk A M J ten Have and Jos Welie, *Death and Medical Power* (OUP 2005) at page 8.

²⁹⁹ Josie Fischer, ‘Re-Examining Death: Against a Higher Brain Criterion’ (1999) 25 Journal of Medical Ethics 473, 473.

³⁰⁰ PDOC 2020 (n 1).

³⁰¹ As discussed in Sections 2.2 and 2.3.

defensibility of death after brain death organ donation (DBD) is outside the scope of this thesis. However, one possible way to do so would be to equally emphasise wakefulness with loss of awareness (responsivity). In other words, to steer clear from the tightrope of determining what responses amount to reflex as opposed to voluntary responsivity and assert that wakefulness is equally important. This seems to be the clearest way to separate consciousness disorders from the brain dead but would invariably mean that life support withdrawal from PDOC patients would no longer be permissible. The findings of this section ultimately suggest that for the purposes of life support withdrawal, a mentalist interpretation of defining and determining death is all that is required in practice.

The moral question of life support withdrawal from PDOC patients will now be addressed. There seems to be an implicit justification in the practice of withdrawing life support from PDOC patients that it is necessary and defensible, which has invariably been supported on the grounds of futility.³⁰² However, before exploring what futility means in law in Chapter Three,³⁰³ there is a further concept that links the concept of consciousness (as responsivity) to defining death: the deafening presence of personhood and its conceptual ties with death.

2.4.3 Consciousness' Conceptual Ties with Personhood

Looking back to Younger and Arnold's conclusion that defining death is a moral, legal and economic decision with 'at least one foot resting in biology',³⁰⁴ it seems that the definition and determination of death is based on moral standing and personhood theories. These concepts therefore need to be defined. To claim a being has moral standing is to argue that they are inherently valuable, deserving of respect from others, hold protectable interests, and that it is morally wrong to use them for the benefit of others: 'an entity with moral standing is one that can be morally wronged'.³⁰⁵ Feinberg argues that to have moral standing means to hold interests that should not be harmed:

³⁰² *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [2014] AC 591; *Bland* [1993] (n 160); PDOC 2020 (n 1). The interpretation of futility is discussed in Chapter Three, Sections 3.2 and 3.4.

³⁰³ The concept of futility is discussed in Chapter Three, Sections 3.2 and 3.4.

³⁰⁴ Younger and Arnold (n 129) 532.

³⁰⁵ Geoffrey P Goodwin, 'Experimental Approaches to Moral Standing' (2015) 10 (11) *Philosophy Compass* 914, 914.

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mere things have no conative life: no consciousness, no wishes, desires, and hopes; or urges and impulses; or unconscious drives, aims and goals [have no moral standing] ... Interests must be compounded somehow out of conations; hence mere things have no interests. *A fortiori*, they have no interests to be protected by legal or moral rules.³⁰⁶

However, Veatch has argued that the definition and determination of death has nothing to do with personhood because it leads to a paradoxical conclusion that it is possible to have a 'living non-person'.³⁰⁷ Whilst I understand his concern for using personhood as a basis for establishing biological death, the term 'civil death'³⁰⁸ has existed for some time and from a legal perspective has been used to demarcate who is "harmable" (and possibly even "killable" as explored in 1.4) from those that are not.³⁰⁹ I therefore believe a distinction needs to be recognised, namely that using personhood theories to investigate the ontological and phenomenological state of biological death is useless, however, it cannot be denied that there is at least a possibility that personhood has been used to justify who is capable of being harmed, is determined as dead in medical practice and even lawfully killed.³¹⁰ Moreover, the findings of 2.2 and 2.3 seem to indicate that medicine has also moved away from biological death because it could not itself justify certain "death behaviours" on living human beings. I therefore understand his statement to mean that the concept of personhood is unhelpful for defining and determining biological death only.

The conflation of determining "death" with personhood is possibly what has permitted otherwise impermissible death behaviours on biologically living and at least reflexively responsive human beings. It is for this reason that higher brain death theorists

³⁰⁶ Joel Feinberg, 'The Rights of Animals and Unborn Generations' in William T Blackstone (ed) *Philosophy and Environmental Crisis* (Prometheus Books 1974) 49-50.

³⁰⁷ Veatch 2005 (n 51) 367 (paraphrasing).

³⁰⁸ See, for example, Clíona de Bhailís and Eilionóir Flynn, 'Recognising Legal Capacity: Commentary an Analysis of Article 12 CRPD' (2017) 13 (1) International Journal of Law in Context 6, 10-11; Gerard Quinn, 'Rethinking Personhood: New Directions in Legal Capacity Law and Policy' (University of British Columbia, 29 April 2011)

<http://citizenship.sites.olt.ubc.ca/files/2014/07/Gerard_Quinn_s_Keynote_-_April_29_2011.pdf> accessed 1 June 2019, 11; George Szmukler, "Capacity", "Best Interests", "Will and Preferences" and the UN Convention on the Rights of Persons with Disabilities' (2019) 18 (1) World Psychiatry 34, 35.

³⁰⁹ *ibid.*

³¹⁰ Some examples were explored in Chapter One, Section 1.4.

have argued that death is a sociological as opposed to biological determination.³¹¹ However, they differ to different degrees on whether that has anything to do with personhood.³¹² Personhood and its distinction and relationship with moral standing therefore needs to be defined and explored. It is a notoriously difficult term to define because it has been used for several different meanings and purposes.³¹³ Therefore, the following analysis uses deductive reasoning to obtain an understanding of the difference between moral standing and personhood.

Starting with moral standing, Feinberg indicates that to have moral standing is to hold a morally valuable characteristic.³¹⁴ On the basis of the previously quoted paragraph, for Feinberg, that seems to be a particular interpretation of autonomy; to have self-deterministic wishes, goals, desires and interests.³¹⁵ Interestingly, Engelhardt has similarly prioritised the capacity to 'reason' for moral recognition and protection.³¹⁶ For these proponents, moral standing is the 'indicia'³¹⁷ of personhood; the singular characteristic that enfranchises an individual to personhood status.

To add further confusion, there exist two disciplinary-specific conceptualisations of personhood: moral and legal personhood.³¹⁸ Moral personhood seems to be solely characteristic dependent, where the specified characteristic is a pre-requisite to be "harmable".³¹⁹ For example, a 'rationalist',³²⁰ like Engelhardt, argues that the capacity to 'reason' is the characteristic required to be morally protectable against others and for rights bearance.³²¹ For a 'naturalist', moral standing should be attributed to any being with

³¹¹ Veatch 2005 (n 51); Younger and Arnold (n 129).

³¹² Veatch 2005 (n 51) 366-367.

³¹³ *ibid.*

³¹⁴ Feinberg (n 306).

³¹⁵ *ibid.*

³¹⁶ Note H Tristram Engelhardt Jr, *The Foundations of Bioethics* (1st edn, OUP 1986) at page 107 claims the capacity to reason is what makes an individual capable of personhood.

³¹⁷ Gerard Quinn, 'Personhood and Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD' (HPOD Conference at Harvard Law School, 20 February 2010) <[https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/archive/Submission-on-Legal-Capacity-to-the-Oireachtas-Committee-on-Justice,-Defence--&-Equality-\(August,-2011\).pdf](https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/archive/Submission-on-Legal-Capacity-to-the-Oireachtas-Committee-on-Justice,-Defence--&-Equality-(August,-2011).pdf)> accessed 1 June 2019, 6.

³¹⁸ Veatch 2005 (n 51).

³¹⁹ *ibid.*

³²⁰ Naffine (n 256) 23 and 82-83.

³²¹ Engelhardt 1986 (n 316) at 107; Naffine (n 256) 23 and 82-83.

the capacity for sentience.³²² For a 'religionist', being human is necessary on the basis that humans are 'ensouled' beings with a 'spark of the divine'.³²³ Therefore, moral personhood theories delineate what having moral standing is, depending on its own standpoint of what is inherently valuable about a being, human or otherwise.

Likewise, personhood has historically been conferred on those who meet the standard of what human characteristic(s) society thought had moral value over and above other types of beings.³²⁴ The common law's history is fraught with discrimination based on age, sex, race, mental capacity or other character dependent notions.³²⁵ Despite this, legalists such as HLA Hart have attempted to 'expunge morality from the term person in law',³²⁶ where the example of corporations being accepted into the category of legal persons arguably supports this view of personhood. However, such a view is oversimplified because although personhood gives the corporation rights such as to sue others it believes are harming its interests, the attribution of personhood to corporations also attaches obligations such as social and environmental responsibility.³²⁷ In this sense, moral responsibility and freedoms are both attached to the recognition of corporations as legal persons and suggests that even for non-human persons, legalists have failed to create a purely abstract theory of personhood.

Such character specific instances demonstrate something further about personhood. It borrows from extra-legal sources and different moralities depending on what the proponent(s) believe(s) reflects the current moral standpoint of its jurisdiction.³²⁸ Examples of this practice include the legal battle for equality in same-sex marriages which fights against the legally adopted morality of religionists who view marriage as a sacred partnership that could only take place between a man and a woman. In the context of animal rights, the law has also taken a religionist view that humanity has a 'spark of the

³²² Naffine (n 256) 24.

³²³ *ibid* 23.

³²⁴ *ibid* 12.

³²⁵ *ibid* 12-13.

³²⁶ *ibid* 16. See for example, H L A Hart, *Definition and Theory in Jurisprudence* (Clarendon Press 1953).

³²⁷ See European Commission Statement, 'Disclosure of Non-Financial Information by Certain Large Companies: European Parliament and Council Reach Agreement on Commission Proposal to Improve Transparency' (Press Release Database, 26 February 2014) <http://europa.eu/rapid/press-release_STATEMENT-14-29_en.htm?locale=en> accessed 6 April 2019.

³²⁸ Naffine (n 256) 2-3.

divine' and non-human animals are subservient,³²⁹ hence why killing a non-human animal does not amount to murder and is more akin to a destruction of property offence.³³⁰

Naffine argues that the law has often failed to properly pay attention to the theories of standing and personhood that it is ascribing in a particular case.³³¹ For this reason, there seems to be no difference between legal or moral personhood: personhood is fundamentally a moral concept.

However, one obvious difference is that legal personhood is also context specific. For example, if a being does not have personhood it is rendered its theoretical opposite—property.³³² Therefore, to be a legal person ostensibly means one can own property however, the legal personality of ownership (seen as a cluster or bundle of rights³³³) is limited further by context, such as age or other legal restrictions. For example, it is legal for an adult to buy and own a knife but illegal to stab another with it.³³⁴ Likewise, it is legal to buy a house when a person is of age but illegal to use that property as a brothel regardless of age.³³⁵ Therefore, personhood unlike moral personhood, is even more exclusory, sometimes with good reason and at other times has been discriminatory or manipulative.³³⁶ However, I suggest that these are not examples of personhood at all but legal capacity in the sense of "freedoms recognised in law".³³⁷ Therefore, legal personhood

³²⁹ *ibid* 23.

³³⁰ Compare, for example, the prosecution difference of charging a person who "kills" an animal under the Criminal Damage Act 1971, which results in criminal court proceedings, versus an offence under the Animal Welfare Act 2006, where such an offence will appear in a Magistrates Court. The former will bring charges in a criminal court perhaps reflecting a severer punishment than the Animal Welfare Act 2006.

³³¹ Naffine (n 256) 2-3.

³³² *ibid* 47-49. See Feinberg (n 306) at pages 49-51, where he employs similar reasoning to argue that "things" cannot be harmed because they have no interests, morally or legally.

³³³ *ibid* 46-47. See also Wesley N Hohfeld, 'Some Fundamental Concepts as Applied in Judicial Reasoning' (1917) 23 *Yale Law Journal* 16; Anthony M Honoré, 'Ownership' in Anthony G Guests (ed) *Oxford Essays in Jurisprudence* (OUP 1961), for the 'Bundle of Rights' theory of property ownership.

³³⁴ Offences Against the Persons Act 1861, sections 18 and 20.

³³⁵ Sexual Offences Act 2003, section 53.

³³⁶ As evidenced by commonly known rights movements seeking equal treatment in law. This idea is further developed in Chapter Four, Subsection 4.2.2.

³³⁷ See John Coggon and José Miola, 'Autonomy, Liberty, and Medical Decision-Making' (2011) 70 (3) *Cambridge Law Journal* 523; Gerald Dworkin, *The Theory and Practice of Autonomy* (Cambridge University Press 1988). However, there is perhaps scope to suggest that a third agency-based capacity exists "to act on those freedoms" and is also being conflated with the other two. This possibility is further developed in Chapter Four, Subsection 4.2.2.

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is better reflected in the term "legal capacity", and its three identified instantiations in Chapter Four than personhood alone. Legal capacity should therefore be understood as a subset of freedoms (and restrictions on those freedoms) attaching to an individual who is recognised in law as having (moral) personhood.

Similarly to personhood, others have noted semantic conflation between two different meanings of the term "legal capacity".³³⁸ Specifically, they have noted the conflation of legal capacity as competence (the ability to 'weigh, retain, understand and communicate a decision'³³⁹) i.e. decision-making capacity, with legal capacity as liberty (legally recognised freedom).³⁴⁰ However, the findings of this thesis suggest that perhaps there is also a third conceptualisation of legal capacity that is also conflated with competence and better relates to liberty but is still distinct from (liberty as "freedom to"): legal capacity as the capacity to self-exercise agency. This is explained in more detail throughout Chapters Three and Four.³⁴¹

For current purposes, it is enough to say that personhood is a moral concept valuing a specific characteristic (its 'indicia'³⁴²) that gives that being a higher status of legal and moral protection.³⁴³ Personhood is consequently better understood as an amalgamation of at least competence and liberty, if not three types of legal capacity: liberty, decision-making competence and self-exercisable agency. Therefore, it is possible to be a legal person in law for holding "said" morally ascribed characteristic but also denied legal capacity (liberty) on the basis of a lack of self-exercisable agency or competence.³⁴⁴ For example, the blind are denied legal capacity (liberty) to drive because they cannot see

³³⁸ Coggon and Miola (n 338); Philip Bielby, 'The Conflation of Competence and Capacity in English and Welsh Law: A Philosophical Critique' (2005) 8 *Medicine, Health Care and Philosophy* 357; Dworkin 1988 (n 337).

³³⁹ Mental Capacity Act 2005 (MCA), subsection 3(1) (paraphrasing).

³⁴⁰ Coggon and Miola (n 338); Bielby (n 338); Dworkin 1988 (n 337).

³⁴¹ Specifically, Chapter Three, Section 3.2 and Chapter Four, Subsection 4.2.2.

³⁴² Quinn 2010 (n 317) 6.

³⁴³ *ibid.*

³⁴⁴ See John Dawson, 'A Realistic Approach to Assessing Mental Health Laws' Compliance with the UNCRPD' (2015) 40 *International Journal of Law and Psychiatry* 70, who at page 73 gives the example that it is not discriminatory to deny blind persons legal capacity to drive.

(self-exercisable agency) and are likely to harm themselves or other road users.³⁴⁵ They are still however, persons.³⁴⁶

Therefore, my suggested understanding is this: moral standing is the *indicia of personhood* (the morally valued characteristic); personhood is a philosophical status accruing to any being possessing that morally valued characteristic; and legal capacity (as liberty) is the bundle of legally protectable rights and interests that any individual with personhood status holds. These incidences of liberty include “freedoms to” and “freedoms from”, and possibly also the capacity to self-exercise those legally protected liberties to both ensure and protect against unwarranted interference from others.³⁴⁷ Additionally, legal capacity in the sense of liberty can be denied on any conceptualisation of legal capacity but the literature more often focuses on denials on the basis of lack of self-exercisable agency,³⁴⁸ or decision-making competence.³⁴⁹ Finally, Chapters Three and Four explore whether those who lack self-exercisable agency have in some circumstances had other mechanisms in law created to exercise some specific freedoms for them, such as the Mental Capacity Act’s best interests test.³⁵⁰

It is therefore important to question whether (from the preceding sections’ analysis) a specific moral characteristic has been delineated as the *indicia of personhood*. It was established in 2.3 that ‘the foot’³⁵¹ remaining in biology that determines and defines death is consciousness, or more accurately voluntary responsivity. This was found after exploring the consistency and factual accuracy of the official definition of death and its justificatory roots in the theory of somaticism.³⁵² Therefore, voluntary responsivity seems to be the *indicia of personhood* and in turn is what determines the permissibility of death behaviours, such as life support withdrawal (and possibly also organ donation).

³⁴⁵ *ibid.*

³⁴⁶ *ibid.* As discussed in Chapter Four, Subsection 4.2.2.

³⁴⁷ Quinn 2010 (n 317).

³⁴⁸ See Dawson (n 344).

³⁴⁹ For example, in *F v West Berkshire HA* [1990] 2 AC 1 (HL) (*re F*) the patient was held to lack decision-making competence to decide whether a sterilisation procedure should be undertaken because of her inability to understand the consequences and responsibility of sexual relationships, due to her learning disability.

³⁵⁰ MCA 2005 (n 339) section 4. As explored in Chapter Three, Sections 3.3 and 3.4.

³⁵¹ Younger and Arnold (n 129) 532.

³⁵² As discussed in Sections 2.2 and 2.3.

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Interestingly, it is not just brain death theorists who have argued that consciousness is the *indicia* for personhood. Philosophers such as Locke,³⁵³ Harris,³⁵⁴ Engelhardt,³⁵⁵ and Enlightenment philosophers,³⁵⁶ have all to varying extents prioritised higher brain function as the most valuable characteristic of life. However, it is unsurprising that such theories have often been treated with contempt. For example, they offend naturalists who see such theories as "speciesist" and religionists for excluding other human beings (cognitively disabled individuals, babies, foetuses etc³⁵⁷). The elitism of this characteristic would likely be shocking to many. Furthermore, as medicine is also defining death on the basis of responsiveness (consciousness) as the *indicia* for personhood, we should have even greater cause for concern because the neat divide between theoretical civil death and legally permissible medical killing is not so steadfastly safeguarded as perhaps thought.

In 3.2 I will explore the views of Locke and Harris that personhood is ascribed to those with consciousness and the legal implications that interpretation would cause for those with consciousness disorders.³⁵⁸ More specifically, I explore Harris' view that *Bland*³⁵⁹ can only be justified on the basis of personhood.³⁶⁰ Such a view intellectually makes much more sense than the adopted legal approach and I think should be looked at again in light of the disparity between how medicine defines and determines death in practice, and its official policy stance.³⁶¹ The fact that the determination of death has little to do with biology, as its only biological foothold is consciousness (specifically voluntary responsiveness), perhaps begins to indicate why the reasoning in *Bland* has failed to convince commentators that it is morally permissible to withdraw life support from a living person.³⁶²

³⁵³ John Locke, *An Essay Concerning Human Understanding* (first published 1690, E S Pringle-Paterson ed, Clarendon Press 1924) Ch 27, Book II.

³⁵⁴ John Harris, 'The Concept of the Person and the Value of Life' (1999) 9 (4) Kennedy Institute of Ethics Journal 293.

³⁵⁵ Engelhardt 1986 (n 316).

³⁵⁶ For example, René Descartes, *Discourse on the Method of Rightly Conducting the Reason, and Seeking Truth in the Sciences* (first published 1637, Donald A Cress tr, 3rd edn, Hackett Publishing Company 1998) in book IV discusses the superior importance of the mind over the body.

³⁵⁷ These are examples listed by Engelhardt 1986 (n 316) at page 107.

³⁵⁸ Locke (n 354) Ch 27, Book II; Harris 1999 (n 354).

³⁵⁹ *Bland* [1993] (n 161).

³⁶⁰ Harris 1999 (n 354).

³⁶¹ This assertion is defended in Chapter Three, Section 3.2.

³⁶² Referring to the moral inconsistency noted by: Andrew McGee, 'Defending the Sanctity of Life Principle: A Reply to John Keown' (2011) 18 (4) Journal of Law and Medicine 820; John Coggon,

To be clear, in agreement with Shewmon I think many healthcare practitioners would be shocked at the evidence that obliterates the idea that brain death is biologically evidenced by loss of somatic integration (presented in 2.2 and 2.3) and can only be justified by personhood theory (irrespective of vast remaining somatic functions in such patients).³⁶³ I therefore want to be clear that on the basis that death behaviours (such as life support withdrawal) are medically justified by a theory of personhood that prioritises voluntary responsivity, that in any assessment of medicine's defensibility I am not suggesting that doctors are maliciously killing cognitively disabled persons. Instead, I claim that there has been a dangerous conflation between what represents a contentious philosophical view on the value of life with what is thought to be biologically indicated "death".

I foresee a potential counter-response that seeks to undermine the view that life support withdrawal can be considered a death behaviour. For example, although loss of moral standing (as the loss of voluntary responsivity) better explains the permissibility of life support withdrawal than *Bland's* legal focused question on assault, it does not explain the "post-death" behaviours of palliative care or the prohibition of optimisation procedures such as elective ventilation.³⁶⁴ I suggest that instead of viewing the existence of such behaviours after life support withdrawal (death behaviour) as indicative that life support withdrawal is not a death behaviour, that palliative care and debates on optimisation procedures are indicative of a disparity between how death is assumed to be defined and determined officially, and how it is in practice.³⁶⁵

'Ignoring the Moral and Intellectual Shape of the Law After Bland: The Unintended Side-Effect of a Sorry Compromise' (2007) 27 (1) Legal Studies 110; John Keown, 'A Futile Defence of Bland: A Reply to Andrew McGee' (2005) 13 (3) Medical Law Review 393; Andrew McGee, 'Finding a Way through the Ethical and Legal Maze: Withdrawal of Medical Treatment and Euthanasia' (2005) 13 Medical Law Review 357; John Keown, 'Restoring Moral and Intellectual Shape to the Law After Bland' (1997) 113 LQR 481. As explored further in Chapter Three, Section 3.2.

³⁶³ See Shewmon 1997 (n 34) where Shewmon refers to these taught explanations of brain death as 'dogmas' to reflect the pervading attitude in medicine to not question taught evidence.

³⁶⁴ PDOC 2020 (n 1). Details of appropriate palliative care treatment are detailed at pages 151-165 of the 2020 guidance. See also John Coggon, 'Elective Ventilation for Organ Donation: Law, Policy and Public Ethics' (2013) 39 (3) Journal of Medical Ethics 130; Price 2011 (n 297); Coggon 2008 (n 297).

³⁶⁵ This disparity has been noted by Veatch 2005 (n 51); Fischer 1999 (n 299).

Finally, as “death” is medically defined and determined on the basis of loss of consciousness (responsivity), and because some personhood theories hold consciousness to be the *indicia* of personhood, two residual questions arise to be answered in Chapter Three. First, what legal capacity does a “loss of voluntary responsivity” amount to? And secondly, how effective is the best interests test at safeguarding the personhood status of those with responsivity disorders e.g. PDOC patients? This last question arises on the basis that the best interests test is how the law has been determining the permissibility of (dis)continuing life support from PDOC patients since *Bland*.

2.4.4 Section Conclusion

The most significant finding of this section is that the disparity between how death is defined and determined in practice and in biology, may better explain why personhood theories can better resolve the moral inconsistency often noted in *Bland*,³⁶⁶ after its legal constructs arguably failed to.³⁶⁷ It also established that medicine in the UK has adopted a mentalist view of death. That view cannot amount to embodied consciousness or even brainstem death (a somaticist theory) on the basis that vast somatic integrative functions remain. Therefore, the function key to delineating the line between life and death seems to be loss of consciousness, specifically the loss of voluntary responsivity.

This section has also explored the conceptual link between loss of moral standing and personhood. It found that moral standing is given to those holding the morally valuable characteristic(s) present in any being or entity capable of holding personhood status. The section also began to distinguish legal capacity from personhood and its three interpretations as decision-making competence, liberty (legally recognised freedom) and self-exercisable agency. Furthermore, in order to morally withdraw life-supporting treatment, loss of responsivity as consciousness is what amounts to having lost moral standing and personhood, and somatic integration is seemingly not vital to defining and determining death. Moreover, any residual care post-withdrawal, such as palliative care or optimisation procedures where organ donation is possible, are further indicators of the

³⁶⁶ Harris 1999 (n 353).

³⁶⁷ See for example, McGee 2011 (n 361); Coggon 2007 (n 361); Keown 2005 (n 361); McGee 2005 (n 361); Keown 1997 (n 361).

conceptual incongruity of death being defined on a moral or philosophical basis that has little to do with biology. Therefore, life support withdrawal likely indicates when an individual has lost moral standing and who would therefore be (like brain dead patients) defined as "dead".

2.5 Conclusion

This chapter has systematically broken the ties that defining and determining death is thought to have with the phenomenon of death and its biological indicators. It has demonstrated that a consensus exists among neurologists that brain death is a philosophical standpoint that argues that the irreversible loss of consciousness is enough to be classified as "dead". It has also highlighted the difficulty faced in accurately determining whether a PDOC patient has no inner awareness or whether they can feel pain.

The ramifications from the failure of somaticism to defend brain death on evidenced biological criteria is worrying. First, there is no difference viewed as morally significant in medical practice to distinguish brain death from other cognitive disabilities because both have lost that morally significant factor: loss of voluntary responsiveness. This is also demonstrated by the fact that brain death is merely the renaming of a permanent state of coma.³⁶⁸ Secondly, as the chapter progressed it became clearer that medicine's prioritisation of loss of consciousness as the morally valuable feature of human life, seemingly supports the theory that consciousness is the *indicia of personhood* and that PDOC patients may consequently also be "dead". The chapter's titular question--what's in a name? -- therefore refers to the fact that the categorisation and redefinition of "death" as "consciousness" is significant, as it represents the currently adopted 'theory of social justice'³⁶⁹ in medicine, which directly impacts cognitively impaired/ disabled persons. Voluntary responsiveness has consequently become the key biological indicator for the establishment of a continued duty of care where death is foreseen and categorises when a

³⁶⁸ Harvard Report 1968 (n 48); Shewmon 1997 (n 34).

³⁶⁹ Quinn 2011 (n 308) 59 (paraphrasing). This is an idea thematically explored throughout Chapter Four.

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patient is "dead". Such cases are categorised as futile where that duty of care no longer exists.

The findings of this chapter therefore point to alarming implications for the legal and moral protection of PDOC patients and their status as legal persons. Fundamentally, the findings question whether Harris' theory (that *Bland's* inconsistency is only morally resolvable by reference to PDOC patients having lost personhood³⁷⁰) may no longer be as far-fetched as it ostensibly seems. Moreover, if this is the case, the subsequent question to be explored in Chapter Three queries how the law is appropriately regulating and safeguarding the withdrawal of life support from PDOC patients and simultaneously guaranteeing their status as persons.

³⁷⁰ Harris 1999 (n 354).

Chapter 3 “Square Pegs in Round Holes”: Is “Best Interests” an Appropriate Standard for Delineating Personhood (Death)?

3.1 Chapter Introduction and Aims¹

The chapter’s central aim is to explore whether the way in which death is defined and determined in English and Welsh law (E&W) has impacted patients with prolonged disorders of consciousness (PDOC patients), due to the apparent link between personhood, responsivity and “death”. The Chapter examines whether the starting legal presumption in such cases (that continued treatment is not justified) should be re-examined in light of the medical evidence outlined in Chapter Two. Further still, it examines whether that crucial question’s framing as a starting presumption bars any means of challenging it. The results seem to suggest that those who are non-autonomous in practice do not have a right to life and that the law has possibly contradicted itself on the right to bodily integrity. Therefore, the chapter will examine the noted inconsistencies that have developed in and since the *Bland* judgment, to analyse whether personhood can better explain why life support can only be withdrawn from those who are “dead”, as the law on bodily integrity seemingly provides no means of permitting “killing” to prevent lesser (albeit still serious) assaults.² Note this contentious account was first proposed by Harris and I aim to strengthen it by demonstrating the relationship between responsivity, personhood, death and bodily integrity. This chapter also seeks to determine the particular type of legal capacity at issue in PDOC patients’ declaratory relief proceedings and its corresponding ethical basis, undertaking an assessment of whether a unique best interests test is occurring to justify life-supporting treatment withdrawal.

¹ Note this chapter’s sections do not have their own introductions, that structure was used in the preceding chapters for clarity and is not needed here.

² This account was first proposed by John Harris, ‘Consent and End of Life Decisions’ (2003) Journal of Medical Ethics 29.

3.2 Putting Morality Back into the 'Morally and Intellectually Misshapen' Law³

3.2.1 Overview of the Moral and Legal Inconsistency in *Bland*

Airedale NHS Trust v Bland [1993] (*Bland*) arose out of the Hillsborough Football disaster in 1989, where overcrowding in the stadium led to 96 persons being killed in a fatal crush.⁴ However, Anthony Bland, a seventeen-year-old boy who was caught up in the fatal crush, survived, but was left in a vegetative state (VS) as a result of his injuries.⁵ The question before the court was whether his doctors would be legally responsible for his death if they removed his feeding and hydration tube and withheld any antibiotics from him which would result in his foreseeable death.⁶ However, the crucial legal question was whether continued treatment was in his best interests.⁷

Whilst deciding *Bland*, Lord Mustill noted that despite the apparent success of its legal mastery, the judgment resulted in a law that was 'morally and intellectually misshapen'.⁸ As a result, their Lordships foresaw that the courts would revisit the issue and that possibly some VS patients would be found to have increased capacity for awareness, thereby adding further moral complexity to the crucial "continuation question".⁹ Since the case was decided their Lordships' prediction has been realised as demonstrated throughout this chapter.

Critiques of the *Bland* judgment and the subsequent line of cases can be divided into three groups:¹⁰ procedural, tortious and criminal issues. The least critiqued have been the procedural issues. They were assessed predominantly by Lord Browne-Wilkinson and Lord Mustill, who questioned whether a declaratory relief (civil law) proceeding was the

³ *Airedale NHS Trust v Bland* [1993] AC 789 (HL) (*Bland*).

⁴ *ibid*.

⁵ *ibid*.

⁶ *ibid* 879 (Lord Browne-Wilkinson), 887 and 889 (Lord Mustill).

⁷ *ibid*.

⁸ *ibid* 887 (Lord Mustill).

⁹ *ibid* 879 (Lord Browne-Wilkinson), 887 and 889 (Lord Mustill). Note Lord Mustill predicted and was concerned that the case would be extended to those with 'glimmerings of awareness' ie MCS patients at page 899 in the *Bland* judgment.

¹⁰ The key declaratory relief cases from *Bland* [1993] (n 3) up until *An NHS Trust v Y* [2018] UKSC 46, [2018] 3 WLR 751 (*NHS Trust v Y*) are specifically analysed in Sections 3.3 and 3.4.

correct legal process for a 'proleptic criminal trial',¹¹ and also whether the legal reasoning amounted to creating a new law on murder, thereby usurping the sovereignty of Parliament.¹²

Contrastingly, the criminal law issues are infamous. For instance, Keown¹³ and Finnis¹⁴ both criticise the *Bland* judgment for its inconsistent application of the law on 'intention'.¹⁵ The subsequent case of *R v Woollin* [1999] (*Woollin*) threw a spanner in the works by determining that, where virtual certainty of death is foreseen that foresight alone could amount to the necessary intent for full criminal responsibility.¹⁶ Those such as McGee however, argue that the 'causation' argument in *Bland* is the most problematic,¹⁷ he particularly questions whether the acts versus omissions distinction can sufficiently (morally) resolve why life support withdrawal from a living person does not amount to murder.¹⁸ The causation question also asks whether there is a sufficient legal distinction between "withdrawing" and "continuing" to legally permit "discontinuation" of life-supporting treatment,¹⁹ whether the withdrawal of life support in cases where death is foreseen can be brought within a doctor's duty of care,²⁰ and whether clinically assisted nutrition and hydration (CANH) is appropriately analogous to other more commonly recognised life-supporting treatment, such as mechanical ventilation.²¹

¹¹ *Bland* [1993] (n 3) 862 (Lord Goff), 888-890 (Lord Mustill).

¹² *ibid* 877-881 (Lord Browne-Wilkinson); Jo Bridgeman, 'Declared Innocent?' (1995) 3 Medical Law Review 117.

¹³ John Keown, 'Restoring Moral and Intellectual Shape to the Law After Bland' (1997) 113 Law Quarterly Review 481.

¹⁴ John M Finnis, 'Bland: Crossing the Rubicon?' (1993) 109 Law Quarterly Review 329.

¹⁵ *ibid*; Keown 1997 (n 13).

¹⁶ *R v Woollin* [1999] 1 AC 82 (HL); John Coggon, 'Ignoring the Moral and Intellectual Shape of the Law After Bland: The Unintended Side-Effect of a Sorry Compromise' (2007) 27 (1) Legal Studies 110. Note that Coggon comments that despite *Woollin*, the "doctrine of double effect" is still good law as affirmed in *Re A (Children) (Conjoined Twins: Medical Treatment)* [2001] Fam 147 (CA) by Walker LJ at page 251.

¹⁷ Andrew McGee, 'Finding a Way Through the Ethical and Legal Maze: Withdrawal of Medical Treatment and Euthanasia' (2005) 13 Medical Law Review 357, 384.

¹⁸ *ibid*. Note the legal and moral issues regarding life support withdrawal were first introduced in Chapter Two, Subsection 2.2.3. See also Subsection 3.2.3 for analysis on how brain death cases eg *R v Malcherek and Steel* [1981] 2 All ER 422 (CA) and *Re A (A Minor)* [1992] 3 Med LR 303 (Fam), do not treat life support withdrawal by a medical professional as a *novus actus interveniens*.

¹⁹ *Bland* [1993] (n 3) 884 (Lord Browne-Wilkinson); McGee 2005 (n 17).

²⁰ *ibid* 858-860 (Lord Keith), 866-868 (Lord Goff).

²¹ *ibid* 869-874 (Lord Goff). Note at the time *Bland* [1993] (n 3) was decided, CANH was known as ANH "assisted nutrition and hydration".

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Finally, the tortious issues arose due to the removal of the *parens patriae* power from the Mental Health Act 1959 which had given the courts power to consent or refuse treatment on behalf of patients who are unable to do so themselves.²² Consequently, a lacuna in law existed until the case of *F v West Berkshire HA* [1990] (re *F*) and the birth of the objective best interests test.²³ The case resolved the issue by providing an alternative justification for non-emergency medical interventions on the basis of necessity (duty of care) and best interests. Consequently, doctors could permissibly treat such patients in any way they saw fit as long as the proposed treatment held a consensus as proper practice by a 'responsible body of medical opinion'.²⁴ *Re F* can be characterised as a "welfare" case because it sought to shield doctors who acted in the best interests of their patients from criminal liability for assault.²⁵ After *Bland*, it seems that the best interests test became a mechanism for questioning the propriety of continued life-supporting treatment in non-capacitous patients, even where death was foreseen.²⁶

It is therefore necessary to distinguish the legal and moral argument. From a legal perspective *Bland* engaged a long-standing principle of E&W law, that to invade the bodily integrity of another person without justification amounts to an assault.²⁷ Consequently, even the most well-intended medical treatment that involves touching another's person (body) amounts to *prima facie* assault.²⁸ However, in the context of medical treatment there exists justifications which act as a defence against any civil or criminal charges brought against a medical professional for assault. These justifications are

²² *ibid* 862 (Lord Goff), 876 (Lord Lowry), 883 (Lord Browne-Wilkinson). Note Lord Browne-Wilkinson provides the most comprehensive analysis of *parens patriae*.

²³ *F v West Berkshire HA* [1990] 2 AC 1 (HL) (re *F*); *Bland* [1993] (n 3) 883 (Lord Browne-Wilkinson).

²⁴ *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582 (QB) (*Bolam*) 587 (McNair J). Note *Bolam* [1957] and the later judgment of *Bolitho v City and Hackney Health Authority* [1998] AC 232 (HL) were discussed in Chapter One, Subsection 1.3.3.

²⁵ Such cases are slightly easier to place within the natural meaning of 'best interests' because the patient has welfare interests. See Lord Goff's distinction in *Bland* [1993] (n 3) at page 869 as explained later in this subsection.

²⁶ *Bland* [1993] (n 3) 883 (Lord Browne-Wilkinson).

²⁷ For example, see *Collins v Wilcock* [1984] 1 WLR 1172 (QB) (*Collins*) at page 1177 where Goff LJ states that, '[t]he fundamental principle, plain and incontestable, is that every person's body is inviolate. It has long been established that the touching of another person, however slight, may amount to battery.'

²⁸ In *re F*'s Court of Appeal decision (n 23), Lord Donaldson at page 12 states that, '[P]rima facie, therefore, in the absence of consent all, or almost all, medical treatment and surgical treatment of an adult is unlawful, however beneficial such treatment might be. This is incontestable.'

informed consent,²⁹ emergency treatment,³⁰ 'physical contacts which are an inevitable ... feature of everyday life',³¹ and public interest (necessity/ duty of care owed to an adult patient³²). It is this final category (necessity/duty of care) that applies in cases of non-emergency medical treatment on non-capacitous adults,³³ and applies to not just the first instance of treatment but the continuation of it.³⁴ Therefore, the crucial legal question in *Bland* is not whether treatment can be withdrawn but whether continued treatment is justified. If it is not, continued treatment will amount to an assault (even if the first instance was justified).

However, as will be explored across 3.2 and 3.3 the legal standard for best interests has arguably changed quite dramatically, where medical decision-making is less important (medical necessity) than the questionably autonomous wishes of a non-autonomous patient, who has no advance decision or legal power of attorney to that effect.³⁵ I raise two concerns with this method of assessing whether continued treatment is in the best interests of a PDOC patient. The first relates to a conflation of bodily integrity with bodily autonomy (a legal argument) and the second (and consequential focus of this thesis) is how that conflation has impacted the personhood status of PDOC patients (moral argument). My argument is not that a new balance has been struck in favour of continued treatment but that on the basis of the law (traditionally interpreted), the starting presumption has not been established. The outcome of this analysis may bring law and medicine closer to resolving that moral (and possible legal) dilemma by better identifying what that dilemma is and how it has arisen.

²⁹ *re F*[1990] (n 23); *Montgomery v Lanarkshire Health Board* [2015] UKSC 11, [2015] AC 1430 (SC) (*Montgomery*).

³⁰ *re F*[1990] (n 23).

³¹ *ibid*. The Court of Appeal notes at pages 13-17 that within 'generally acceptable standards', jostling experienced by travellers on public transport, touching to engage another's attention and disciplining children are generally exempt from charges of assault.

³² *ibid*. The standard of medical decision-making set by McNair J in *Bolam* [1957] (n 24) at page 587 is that the proposed course of action/ treatment can be justified on the basis that it holds a consensus from a 'responsible body of medical opinion', as discussed in Chapter One, Subsection 1.3.3.

³³ *ibid*; *Bland* [1993] (n 3).

³⁴ Jonathan Herring and Jesse Wall, 'The Nature and Significance of the Right to Bodily Integrity' (2017) 76 (3) Cambridge Law Journal 566, 571.

³⁵ As explored in Sections 3.2 and 3.3. See also Subsection 3.4.2 for my noted concerns on reducing the role played by medical decision-making in favour of presumed patient wishes. Referring to the powers in s 4(6) and (7) Mental Capacity Act 2005 (MCA 2005).

Herring and Wall have explored the concept of bodily integrity and put forth a convincing argument that bodily integrity is different from bodily autonomy. The right to bodily integrity 'is the right to not have your body touched or interfered with without your consent'.³⁶ It has been exalted as 'the most important of civil rights'³⁷ and compared to a property right due to its negative nature preventing interference from others.³⁸ Alternatively, bodily autonomy is defined as 'any exercise of autonomy (choice or decision) that is to do with the body'.³⁹ Herring and Wall claim that the Courts in E&W have elided the two concepts and have pointed out why this is problematic for those who are considered non-autonomous.⁴⁰ They argue that cases where informed consent is at issue are rightly treated under negligence because of the infringement of the patient's consent (autonomous patients), as opposed to the law on trespass where no consent at all is given. Such cases (e.g. *Montgomery*⁴¹) are predominantly concerned with bodily autonomy, but where the patient is non-autonomous something else has to justify an infringement of their bodily integrity.

It is recognised in law that consent is not sufficient to justify an invasion of bodily integrity for assaults more serious than battery ('mere touching'⁴²).⁴³ Such situations according to *Re F, R v Brown* [1994]⁴⁴ and *Bland* prevent interference with the bodily integrity of another (irrespective of consent) on the basis of public interest. In such cases 'interference with bodily integrity requires a stronger justification than mere touching and therefore the consent of the victim is insufficient to justify that'.⁴⁵ Instead, a duty of care must be established; the proposed course of action must be in accordance

³⁶ Herring and Wall 2017 (n 34) 568.

³⁷ *R (on the application of Justin West) v The Parole Board* [2002] EWCA Civ 1641, [2003] 1 WLR 705 (CA) at [49] by Hale LJ (dissenting judgment); Herring and Wall (2017) (n 33) 566.

³⁸ Herring and Wall 2017 (n 34) 568.

³⁹ *ibid.*

⁴⁰ Herring and Wall 2017 (n 34) note the cases of *Montgomery* (n 29); *NHS Trust A v M and NHS Trust B v H* [2001] Fam 348 (Fam) (*A v M*); *Evans v Amicus Healthcare Ltd* [2004] EWCA Civ 727, [2005] Fam 1 (CA) (*Evans*).

⁴¹ *Montgomery* [2015] (n 29).

⁴² *R v Brown* [1994] 1 AC 212 (HL) (*Brown*); Herring and Wall (2017) (n 34) 572.

⁴³ *Re F* [1990] (n 23); *Brown* [1994] (n 42).

⁴⁴ *Brown* [1994] (n 42).

⁴⁵ Herring and Wall 2017 (n 34) 572.

with a responsible body of medical opinion that agrees such treatment is medically necessary.⁴⁶

From both a legal and moral perspective it is right that bodily integrity is not treated as 'a subset of bodily autonomy' because if it is, it begs the question of why either principle is relevant in cases where the patient lacks autonomy.⁴⁷ To over prioritise autonomy in cases that more accurately concern integrity raises alarms that those with cognitive or mental disabilities are not receiving the same legal and moral protection as those who are autonomous. Moreover, Herring and Wall go further and suggest that these concepts have been elided because 'we have learnt to think of ourselves as having two levels of existence': the first as mental (rational agency) and the second as physical (consisting of a set of physiological systems).⁴⁸ Such an explanation is strikingly similar to the moral argument advanced in 2.4 that the E&W definition of death (as the loss of voluntary responsiveness alone) is justified on the basis of loss of personhood rather than integrative somatic functioning. Consequently, from a disability perspective it is also understandable why the right to bodily integrity has achieved rights status whilst the right to autonomy does not exist as a self-standing right in E&W or international human rights law.⁴⁹ Ultimately, where the boundary between an individual's body and their environment is breached by another,⁵⁰ it is possible to also interfere with the autonomy of the patient (e.g. *Montgomery*) but it is not possible to only interfere with their bodily autonomy.⁵¹

Therefore, E&W law should be wary of arguments advanced that best interests can be decided predominantly on the basis of patients' wishes. This is not only due to the implications this has for the legal and moral protection of those with cognitive and mental disabilities, but because it also seems to be an incorrect interpretation of our long-established law on how interferences with the bodily integrity of non-autonomous adults

⁴⁶ *re F*[1990] (n 23); *Bolam* [1957] (n 24).

⁴⁷ Herring and Wall 2017 (n 34) 569.

⁴⁸ See Herring and Wall 2017 (n 34) at pages 576-581.

⁴⁹ Herring and Wall 2017 (n 34); Frédéric Mégret, 'The Disabilities Convention: Human Rights of Persons with Disabilities or Disability Rights?' (2008) 30 (3) Human Rights Quarterly 494. See Chapter Four, Subsection 4.2.3 for further analysis on why autonomy cannot achieve rights status.

⁵⁰ Note that Herring and Wall 2017 (n 34) have also grappled with the difficult question of what amounts to the boundaries of the body, such arguments are not necessary to advance here.

⁵¹ *ibid.*

(in a medical setting) are justifiable.⁵² Hence, why the question of medical necessity and establishing a duty of care are fundamental to the legal argument that continuation of treatment is or is not in the best interests of such a patient.⁵³ Therefore, the analysis on the parameters of the duty of care in 1.3 and medical evidence on PDOC patients' purported non-awareness in 2.3 were vital to challenge that crucial legal presumption. Moreover, that presumption must be challengeable rather than acting as an established fact from which to base the assessment on. Otherwise, that crucial legal question is legally problematic for being in direct conflict with *Bolitho* [1998] and morally for its crucial role in protecting the bodily integrity of (particularly) non-autonomous patients: 'if, in a rare case, it can be demonstrated that the professional opinion is not capable of withstanding logical analysis, the judge is entitled to hold that the body of opinion is not reasonable or responsible'.⁵⁴

The second noted concern to be addressed is how this possible conflation of bodily autonomy and integrity may also explain the moral inconsistency that has arisen since *Bland*. Herring and Wall argue that these concepts are conflated because our society has accepted a dualistic view of personhood and death.⁵⁵ Such a view prioritises the value of the mind (as the seat of rational agency) over the body and consequently fails to encapsulate the 'broader disrespect' caused by an infringement of bodily integrity than 'disrespect for the person's capacity to live life according to reasons and motivations that one takes as one's own (autonomy)'.⁵⁶ Instead, they argue that, 'our bodies are the "site" and "location" of where our subjectivity engages with the world'.⁵⁷ Accordingly, there are 'good moral reasons' for not interfering with another's bodily integrity 'that are broader than moral reasons that are grounded in respect for autonomy'.⁵⁸

⁵² Note that I do recognise that as the law is currently interpreted in such cases post- *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [2014] AC 591 (*Aintree*), that consent is sufficient (even if constructed by those who knew the patient) and is in fact encouraged. See for example, Alexander Charles Edward Ruck Keene and Annabel Lee, 'Withdrawing Life-Sustaining Treatment: A Stock-Take of the Legal and Ethical Position' (2019) 45 *Journal of Medical Ethics* 794.

⁵³ *re F* [1990] (n 23); *Bland* [1993] (n 3).

⁵⁴ *Bolitho* [1998] (n 24) 243 (Lord Browne-Wilkinson).

⁵⁵ Herring and Wall 2017 (n 34) 576.

⁵⁶ *ibid* 576-577.

⁵⁷ *ibid* 577.

⁵⁸ *ibid*.

Not only does this view again link personhood (death⁵⁹) with cognition but it may also explain why a dilemma has arisen in such cases: 'if they administer treatment which they believe to be in the patient's best interests ... they run the risk of being held guilty of trespass to the person, but if they withhold that treatment, they may be in breach of a duty of care owed to the patient.'⁶⁰ From a moral perspective, withdrawing life-supporting treatment with foresight of death amounts to killing a patient.⁶¹ Additionally for some, continuing to treat is an equally abhorrent assault where no justification can be provided. The dispute therefore boils down to different moral perspectives on which is the lesser of the two evils. Therefore, there is at least a possibility that *Bland* was more accurately weighing sanctity of life (arguably the highest form of protection of bodily integrity, e.g. right to life⁶²) against a conflicting view of bodily integrity itself (not autonomy, but less severe assault).⁶³ This may explain, from a moral perspective, why the judgment is 'intellectually misshapen'⁶⁴ and dilemmatic: how can the less severe (albeit still serious) assault be more legally justifiable than the more serious assault of murder? It may also explain why, the legal reasoning is still commented on and questioned.⁶⁵ Consequently, the rest of this section explores that dilemma from a moral perspective.

⁵⁹ Note that personhood and the E&W practice of determining death have been found in Chapter Two to be the same thing: the legal and medical definition of death is the loss of voluntary responsibility alone and indicates when a person loses "personhood". Further medical treatment is consequently deemed futile (no duty of care/ necessity to continue treatment).

⁶⁰ *re F* [1990] (n 23) 52 (Lord Bridge).

⁶¹ This assertion has been established on the basis of the debates on why the acts versus omissions distinction, causation and intention sit ill at ease with many commentators. See footnote 65 for a list of such papers.

⁶² UN, Convention on the Rights of Persons with Disabilities and Optional Protocol (adopted 13 December 2006, entered into force 3 May 2008) UNGA A/Res/61/106 (CRPD) Article 10; Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols 11 and 14, supplemented by Protocols 1, 4, 6, 7, 12 and 13, Nov. 4, 1950, Europ. T.S. No. 5, 213 U.N.T.S. 221 (ECHR), Article 2.

⁶³ This certainly seems to make more sense in light of the fact that the judges in *Bland* recognised him as a non-autonomous individual, building on the discussion in Chapter One, Section 1.3 on whether a rational calculus was undertaken in *Bland*.

⁶⁴ *Bland* [1993] (n 3) 887 (Lord Mustill) (*Bland*).

⁶⁵ Daniel Wei Liang Wang, 'Withdrawing Treatment from Patients with Prolonged Disorders of Consciousness: The Wrong Answer is What the Wrong Question Begets' (2020) 46 Journal of Medical Ethics 561; Charles Foster, 'Withdrawing Treatment from Patients with Prolonged Disorders of Consciousness: The Presumption in Favour of the Maintenance of Life is Legally Robust' (2020) 46 Journal of Medical Ethics 1; Ruck Keene and Lee 2019 (n 52); Charles Foster, 'It is Never Lawful or Ethical to Withdraw Life-Sustaining Treatment from Patients with Prolonged Disorders of Consciousness' (2019) 45 (4) Journal of Medical Ethics 265; John Coggon, 'Mental Capacity Law, Autonomy, and Best Interests: An Argument for Conceptual and Practical Clarity in the Court of

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To date and despite differing approaches, the moral inconsistency that arose in *Bland* has been notably addressed by Keown, Finnis, McGee, Coggon and Harris.⁶⁶ However, whilst I agree that PDOC patients' declaratory relief proceedings⁶⁷ remain morally inconsistent, perhaps the inconsistency remains because such academics largely, with the exception of Harris, resort to exploring it through legal constructs which are alone insufficient. Instead, perhaps the inconsistency is better explained by paying particular attention to the way in which death is currently (and has been since the 1960s⁶⁸) defined and determined by the moral concept of personhood.⁶⁹ There must be something more to the case to explain why it is thought "dilemmatic".⁷⁰ Otherwise, solely focussing on legal constructs suggests that what has been established in *Bland* is nothing more than the extension of the existing objective best interests test. Consequently, after the findings of Chapter Two, it is the question of death, or more specifically the overarching question of *Bland*'s status as a living, moral, legal and human person which elucidates the moral dilemma and gives rise to moral residue.⁷¹ The morality of withdrawing or "discontinuing" life support from a PDOC patient therefore perhaps relies on how death is morally, legally and biologically defined.

Protection' (2016) 24 (4) Medical Law Review 396; Coggon 2007 (n 16); John Keown, 'A Futile Defence of Bland: A Reply to Andrew McGee' (2005) 13 (3) Medical Law Review 393; McGee 2005 (n 17); John Harris, 'The Concept of the Person and the Value of Life' (1999) 9 (4) Kennedy Institute of Ethics Journal 293; Keown 1997 (n 13); Finnis 1993 (n 14).

⁶⁶ Coggon 2016 (n 65); Coggon 2007 (n 16); Keown 2005 (n 65); McGee 2005 (n 17); Harris 1999 (n 65); Keown 1997 (n 13); Finnis 1993 (n 14).

⁶⁷ Declaratory relief proceedings are the technical term for any case where the parties require clarification on a point of law, the procedure has therefore been consistently used to determine whether life support withdrawal from VS and later MCS patients is permissible. The term is therefore used synonymously with "life support withdrawal cases" throughout this thesis although I acknowledge that life support withdrawal is not the only issue brought via these proceedings.

⁶⁸ Harvard Medical School, 'Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, "A Definition of Irreversible Coma"' (1968) 205 (6) Journal of American Medical Association 337 (Harvard Ad Hoc Committee).

⁶⁹ Harris 1999 (n 65).

⁷⁰ *Bland* [1993] (n 3) 866 (Lord Mustill) and 877 (Lord Browne-Wilkinson); Coggon 2007 (n 16); Keown 2005 (n 65); McGee 2005 (n 17); Harris 1999 (n 65); Keown 1997 (n 13); Finnis 1993 (n 14).

⁷¹ This dilemmatic nature of *Bland* was first discussed in Chapter One, Section 1.4, including the concept of moral residue which refers to blameworthiness, or the feeling of wrongdoing and similar such emotions after facing a dilemmatic choice. See H E Mason, *Moral Dilemmas and Moral Theory* (OUP 1996).

3.2.2 How Death is Defined and Determined in *Bland* and its Ties to Personhood

As explored further in 3.4, the continuation of life support in living patients is currently determined under the best interests test (found under section 4 of the MCA) and should be read in light of the Supreme Court's guidance in *Aintree*.⁷² Best interests was first introduced as a concept of English and Welsh law in *re F* to endow clinically indicated but morally problematic treatment with legal authority.⁷³ However, in PDOC patients' cases and in practice, it can appear that the best interests test is doing the work of treatment consent or refusal if reference is not made to the criminal law's protection of bodily integrity. Therefore, it is important to query the ethical imperatives that underpin that best interests test and the legislation's role in such cases as predominantly legislation that protects bodily autonomy.⁷⁴

Gooding's brief history of the power of *parens patriae*⁷⁵ suggests that the roots of the best interests test's ethical justification lies in the principle of harm (prevention of harm to self or others i.e. bodily integrity).⁷⁶ Additionally, the 'Bolamised'⁷⁷ best interests test in *Re F* indicates its placement within a doctor's duty of care is appropriate and justifiable on the basis of prevention of harm as opposed to a consent-based

⁷² As outlined in *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [2014] AC 591 (*Aintree*) at [28]-[40] (Lady Hale). As far as I am aware, the cases analysed in Section 3.3 are those that directly impact the law on life support withdrawal from PDOC patients and are therefore the cases that are discussed.

⁷³ *re F*[1990] (n 23).

⁷⁴ This thesis coins this mechanism a 'constructed refusal' in recognition that although the best interests test's purpose is not officially to consent or refuse medical treatment on behalf of an incapacitated patient, for reasons explored in Section 3.4, there seems to be good reason to suggest that is how it is being implemented in these declaratory relief proceedings.

⁷⁵ *Parens patriae* is a legal doctrine granting the Sovereign power to "consent" to, or "refuse" medical treatment, and to have jurisdiction over the property of a mentally incapacitated person. It dates from Edward I's reign in the 13th Century. After the Mental Health Act 1959 and revocation of the Warrant under the Sign Manual, the power to consent or refuse medical treatment on behalf of incapacitated adults was removed leaving a lacuna in law. Only statutory jurisdiction over such patients property remained. For an explanation of the impact this had in medical law cases, see *Bland* [1993] (n 3) at page 883 (Lord Browne Wilkinson); Piers Gooding, 'Change and Continuity in Mental Health Law: The Long Road to the United Nations Convention on the Rights of Persons with Disabilities and its Implications for Mental Health and the Law Today' (2014) 20 (3) European Journal of Current Legal Issues <<http://webjcli.org/article/view/367>> accessed 26 June 2019.

⁷⁶ Gooding 2014 (n 75).

⁷⁷ *An NHS Trust v Y*[2018] (n 10) [115] (Lady Black) (paraphrasing). Lady Black is referring to *Bolam* [1957] (n 24). Its medical decision-making standard was discussed in Chapter One, Subsection 1.3.3.

justification.⁷⁸ However, the application of best interests in the post-MCA 2005 era has also introduced a best interests test that is justifiable on both consent and welfare bases, consequently its impact on PDO patients needs to be explored as it has perhaps added to the conflation of bodily autonomy and integrity.⁷⁹ It is therefore apparent that prevention of harm, welfare, and consent are different ethical bases for the best interests test depending on the type of legal capacity in question. The possible additional conflation and different interpretations of legal capacity have been importantly explored by Coggon and Miola.⁸⁰ It is therefore necessary to identify which of the two (possibly three⁸¹) legal capacity interpretations of autonomy underpin a given case.⁸²

Beyond mental capacity, the second noted legal capacity is liberty.⁸³ Keown argues that all medical decisions undergo a sort of "best interests" test to see whether treatment is clinically indicated before the issue of patient choice or consent arises, as is well established in law.⁸⁴ From a legal perspective this is correct: all medical treatment must be justified by medical necessity and a duty of care in order to protect the bodily integrity of the patient. From a moral perspective, identifying the type of legal capacity at issue in a best interests decision will help better identify whether the justificatory ethical principle underlying the decision is prevention of harm (welfare), consent, or as discussed below--futility, and thereby provides consistency to these cases.

⁷⁸ The standard of medical decision-making set by McNair J in *Bolam* [1957] (n 24) at page 587 is that the proposed course of action/ treatment can be justified on the basis that it holds a consensus from a 'responsible body of medical opinion'.

⁷⁹ Explored in Section 3.3.

⁸⁰ See John Coggon and José Miola, 'Autonomy, Liberty, and Medical Decision-Making' (2011) 70 (3) Cambridge Law Journal 523. Finally, the different interpretations of legal capacity that have given meaning to autonomy in law were outlined in Chapter Two, Subsection 2.4.3. The concept of legal capacity and its different interpretations will be further discussed in Chapter Four, Subsection 4.2.2.

⁸¹ The possibility of a third, as self-exercisable "agency" to realise a guaranteed legal capacity as liberty in law, is further discussed as a possibility in Section 3.4 and Chapter Four, Sections 4.2 and 4.3.

⁸² Coggon and Miola 2011 (n 80); Philip Bielby, 'The Conflation of Competence and Capacity in English and Welsh Law: A Philosophical Critique' (2005) 8 Medicine, Health Care and Philosophy 357; Gerald Dworkin, *The Theory and Practice of Autonomy* (Cambridge University Press 1988).

⁸³ Coggon and Miola 2011 (n 80). Note this article provides a good overview of points of concern in how the courts in England and Wales have been conflating liberty and informed consent. See the development of a possible discrimination concern in Section 3.4 and Chapter Four, Section 4.4.

⁸⁴ John Keown, 'Euthanasia in the Netherlands: Sliding Down the Slippery Slope' (1995) 9 Notre Dame Journal of Law, Ethics and Public Policy 407. Also noting the legally accepted standard of medical decision-making discussed in Chapter One, Subsection 1.3.3.

There are important differences between *Bland*-like (foreseeable life-ending) cases and those more similar to *re F*(welfare) that indicate the necessity of a different justificatory basis.⁸⁵ *Re F*-like cases, "welfare cases", can be supported with reference to patient autonomy (understood as a specific legal capacity at issue in any given case⁸⁶) because its interpretation as welfare protects the individual from harm and enhances their autonomous potential by enabling those charged with their care to ensure their interests.⁸⁷ In *re F*, the legal capacity at issue was mental capacity (or decision-making competence). For example, in *Re F* the sterilisation procedure can be defensibly rationalised on the basis that, 'concern for welfare complements autonomy in that it provides the conditions in which autonomy can flourish and our lives be given their own unique meaning'.⁸⁸ The rationalisation here is that although sterilisation is an irreversible 'harm', the benefits of the procedure and the surety it would bring her life outweighed the harm of sterilisation and in turn maximised her liberty to engage in sexual relationships.⁸⁹ This instantiation of autonomy is different from that of capacitous patients, it is therefore more accurately a holistic view of the patient's present and future welfare.

In cases considering the validity of continued treatment where its discontinuation results in the foreseeable death of the patient, welfare, as a basis for justifying 'proxy consents'⁹⁰ for incapacitated patients,⁹¹ is inappropriate.⁹² As Harris argues:

concern for welfare ceases to be legitimate at the point at which, so far from being productive of autonomy, so far from enabling the individual to create her own life, it operates to frustrate the individual's own attempts to create her own life for herself. Welfare thus conceived has a point, as does concern for the welfare of others; it is not simply a good in itself.⁹³

⁸⁵ By "justificatory basis" I intend to mean the moral or ethical basis underpinning the decision.

⁸⁶ Coggon and Miola 2011 (n 47); Bielby 2005 (n 47); Dworkin 1988 (n 47).

⁸⁷ Harris 2003 (n 2) 10.

⁸⁸ *ibid* 11.

⁸⁹ *re F*[1990] (n 23). The patient could not understand that a child could be born from intercourse or the care required to raise a child due to her learning disability. These facts are relayed at pages 8-11 of the judgment.

⁹⁰ Harris 2003 (n 2) 11.

⁹¹ Mental Capacity Act 2005 (MCA) subsections 4(6) and 4(7). Discussed further in Section 3.4.

⁹² Harris 2003 (n 2); Mary Donnelly, 'Best Interests in the Mental Capacity Act: Time to Say Goodbye?' (2016) 24 (3) Medical Law Review 318.

⁹³ Harris 2003 (n 2) 11.

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Harris argues that the decision in *Bland* was entirely different from welfare cases and based on 'fictional consent'.⁹⁴ However, Harris' fictional consent only explicitly identifies the mechanism used to facilitate the relevant legal capacity at issue in cases where the patient is non-responsive.⁹⁵

Returning to the idea of the underlying moral principle, Lord Lowry notes in *Bland* that *re F* was (unlike *Bland*) 'not concerned with matters of life or death at all'.⁹⁶ Lord Mustill adds that, 'the distressing truth which must not be shirked is that the proposed conduct is not in the best interests of Anthony Bland, for he has no best interests of any kind'.⁹⁷ Additionally, Lord Goff indicates that there exists a subtle but important distinction between cases concerning welfare and 'those where the patient has no interests'.⁹⁸ He adds that, quality of life and dignity are 'reasonable considerations' 'but in the end, in a case such as [*Bland*], it is the futility of treatment which justifies its termination'.⁹⁹ Therefore, futility has been identified as a further ethical principle that underpins these decisions. Furthermore, Lady Hale in *Aintree* (the current leading case on interpreting best interests¹⁰⁰) spends a notable portion of her judgment defining 'futility' and focussing on paragraph 5.31 of the MCA Code of Practice 2007 which also highlights the importance of 'futility'.¹⁰¹ There is therefore an indication that these cases assess something distinctly different from welfare as 'quality of life' or 'dignity' considerations, or even the prevention of harm principle.¹⁰² Instead, futility is the primary ethical "principle" under consideration.¹⁰³

⁹⁴ *ibid*. Discussed further in Subsection 3.4.3 under the analysis of subterfuges and whether the extension of such a "right to refuse on behalf of others" is in fact a misguided discrimination and equality consideration.

⁹⁵ This mechanism extends subsection 3(1) of the MCA 2005 (n 35) to those who cannot communicate. There is therefore a concern that informed consent and liberty are being conflated with communication, as a mechanism for others to exercise agency for them. The implications of this are discussed in Sections 3.3, 3.4 and Chapter Four, Section 4.3.

⁹⁶ *Bland* [1993] (n 3) 877 (Lord Lowry).

⁹⁷ *ibid* 897 (Lord Mustill).

⁹⁸ *ibid* 869 (Lord Goff).

⁹⁹ *ibid*.

¹⁰⁰ Factually accurate as of April 2020 (submission date).

¹⁰¹ See *Aintree* [2013] (n 72) at paragraphs [28]-[40] where futility's interpretation is determined by Lady Hale.

¹⁰² *Bland* [1993] (n 3) 869 (Lord Goff) (paraphrasing).

¹⁰³ Futility is placed in double-quotes because I doubt it is a self-standing ethical principle or moral value identified by moral philosophy, and instead seems to be a medically and legally created. See

Conversely, for patients who have all three legal capacity instantiations (mental capacity, liberty and self-exercisable agency-- to act on that legally enshrined liberty) informed consent is the underpinning ethical principle (bodily autonomy and integrity).¹⁰⁴ However, as Harris argues, in cases where consent or refusal for treatment is problematic (e.g. PDOC patients) the law has contrived what he coins 'fictional consents' such as 'substituted judgment', 'proxy consent' or 'presumed consent' constructs.¹⁰⁵ This analysis fits Herring and Wall's commentary that bodily autonomy has been conflated with bodily integrity in such cases.¹⁰⁶

However, it seems that Harris possibly confuses the underpinning ethical principle by identifying it as harm, or more specifically to 'do no harm'.¹⁰⁷ This is potentially problematic because prevention of harm has a close and proximate relationship to welfare and there seems to be no clear distinction between what is meant by welfare in law and prevention of harm in such cases. For example, in *re F*, consideration of her welfare involved weighing the harm from sterilisation against harm from becoming pregnant.¹⁰⁸ *Re F* is therefore appropriately identified as a welfare case. Instead, I suggest futility should not only be viewed as the basis for legally discharging medical necessity and a duty of care in such cases, but should also be seen as an entirely different ethical principle from prevention of harm or welfare because such patients are said to hold no welfare interests in accordance with *Bland*.¹⁰⁹ At the time *Bland* was decided futility was solely a medical determination and was measured under the *Bolam* standard of medical decision-making,

Chapter Two, Section 2.2, and seems to have been judicially adopted in *Bland* [1993] (n 3) where it is treated as an underpinning justificatory basis.

¹⁰⁴ See for example *R (on the application of Burke) v General Medical Council (Official Solicitor and others intervening)* [2005] EWCA Civ 1003, [2005] QB 273 (*Burke*) where at paragraph [31] refusals are considered one such legal capacity (as liberty) but not the capacity to request treatment. The legally enshrined liberty to refuse treatment was also affirmed in *re MB (Caesarean Section)* [1997] 2 WLK 313 (CA); and *Bland* [1993] (n 3) at pages 816 and 864.

¹⁰⁵ Harris 2003 (n 2) 11.

¹⁰⁶ The question of whether it is discriminatory that those who lack autonomy (in all of its capacity instantiations) should not be provided a proxy consent mechanism beyond advance decision instruments will be discussed in 3.4 and 4.4.

¹⁰⁷ *ibid*. More commonly referred to as the principle of non-maleficence. See for example, Tom L Beauchamp and James F Childress, *Principles of Biomedical Ethics* (7th edn, OUP 2013) where their theory of Principlism names non-maleficence as a key ethical principle in medical decision-making.

¹⁰⁸ *re F* [1990] (n 23). These facts are relayed at pages 8-11 of the judgment. Note *Bolam*'s standard was outlined and analysed in Chapter One, Subsection 1.3.3.

¹⁰⁹ *Bland* [1993] (n 3) 897 (Lord Mustill).

holding a direct relationship with bodily integrity considerations.¹¹⁰ That interpretation is consistent with the reasoning of Lord Goff, Lord Lowry and Lord Mustill in *Bland*.¹¹¹ To take the argument a step further, Lord Goff's words indicate that life support continuation decisions are no ordinary extension or application of *re F*'s best interests test and that the ethical principle underlying such cases is not based on 'quality of life' or 'dignity', even if such considerations are 'reasonable' (welfare considerations).¹¹² Therefore, when a question of life support continuation is raised and concerns a biologically and legally "living" patient, futility is not justified by harm (non-maleficence), consent or welfare (as dignity or any other such consideration). Such analysis suggests that futility is not just a different moral basis for justifying the discontinuation of life-supporting treatment from a living patient (personhood) but is also the legally accepted medical standard for establishing that both the duty of care and medical necessity to continue treatment no longer exist (bodily integrity). This view also accords with the evidence in Chapter Two that futility is also the medical standard for establishing a duty of care to treat.

Since then, the Supreme Court in *Aintree* has determined that futility is now a subjective standard and to be decided on the basis of what the now non or minimally responsive patient would deem as futile (welfare/liberty consideration).¹¹³ Moreover, in *W v M and S (A NHS Primary Care Trust) [2011] (W v M)*,¹¹⁴ Baker J conversely interprets Lord Goff's words (which I think were intended to distinguish welfare from futility cases) as creating a 'balance sheet' approach,¹¹⁵ which seems to have subsequently enabled the extension of life support withdrawal from those with 'glimmerings of awareness',¹¹⁶ i.e. minimally conscious patients (MCS).¹¹⁷

¹¹⁰ McNair J in *Bolam* [1957] (n 24) at page 587 stated that the proposed course of action can be justified on the basis that it holds a consensus from a 'responsible body of medical opinion'.

¹¹¹ *Bland* [1993] (n 3) 869 (Lord Goff), 877 (Lord Lowry) and 897 (Lord Mustill).

¹¹² *ibid* 869 (Lord Goff) (paraphrasing).

¹¹³ This conflation of autonomy and integrity is further explored in Section 3.4. Lady Hale's interpretation of futility in *Aintree* [2013] (n 72) at [28]-[40].

¹¹⁴ *W v M and S (A NHS Primary Care Trust) [2011] EWHC 2443 (Fam), [2012] 1 WLR 1653 (W v M).*

¹¹⁵ The balance sheet approach was first recognised in *Re A (Mental Patient: Sterilisation) [2000] 1 FLR 549 (CA)*. Note such a test had already been held to not apply to vegetative state patients' cases in *A Hospital v SW [2007] Med LR 273 (COP)*. The different approach taken in VS and MCS cases has since been questioned by academics and judges, see Subsection 3.3.1.

¹¹⁶ *Bland* [1993] (n 3) 889 (Lord Mustill).

¹¹⁷ *M v N [2015] EWCOP 76, [2015] 11 WLUK 514 (M v M)*. Note this further complexity and the particular issues it raises is discussed in Sections 3.3 and 3.4, and is further developed in Chapter Four, Section 4.3.

Consequently, the key moral question for current purposes is to identify why continued treatment is thought futile in *Bland*.¹¹⁸ From a legal perspective the question is framed in consideration of the fact that all medical treatment interfering with the bodily integrity of the patient is *prima facie* assault. Whilst this is legally correct on the basis of established precedent, *Bland* seemingly caused a moral and legal anomaly that the arguably lesser assault of continuing to invade the bodily integrity of the individual takes priority over the more severe assault of failing to continue to treat with foresight of their death.¹¹⁹

From a bodily integrity perspective, both Articles 3 and 2 of the European Convention on Human Rights (ECHR) are engaged as the identifiable and conflicting protections of bodily integrity, pitted against each other in such a claim.¹²⁰ Nevertheless, the European Court of Human Rights (ECtHR) in *Lambert* [2015] identified Article 8 and Article 2 ECHR as the conflicting Convention rights (i.e. that Lambert's bodily autonomy was in conflict with his right to bodily integrity, regardless of the fact that *Lambert* was deemed non-autonomous as a VS patient or the severity of the assaults being balanced).¹²¹ The majority held that Lambert's right to Article 8 held 'paramount' importance over Article 2 ECHR,¹²² 'even where the patient is unable to express his or her wishes'.¹²³ Consequently, it is possible that the ECtHR has also conflated bodily autonomy and integrity, prioritising a non-capacitous patient's bodily autonomy over their bodily integrity (Article 8 over Article 2 ECHR).

Before *Aintree* it was medical necessity and a duty of care that justified any medical treatment, particularly where consent is not available.¹²⁴ This is a better interpretation of

¹¹⁸ The question of what legal capacity is at issue (and therefore corresponds with futility) will be explored in Section 3.4.

¹¹⁹ Note that I am aware of the acts versus omissions distinction drawn in *Bland* to legally distinguish withdrawing life support as a lawful omission. However, this point is being made from the position of a moral argument. Note also that the severity of assault here is based on the law's own categorisation of assaults under the Offences Against the Person Act 1861.

¹²⁰ Article 3 ECHR (freedom from torture) and Article 2 ECHR (right to life) (n 62). Note the European Convention on Human Rights was not made an incorporated treaty until 1998.

¹²¹ *ibid* Article 8 ECHR (respect for private and family life) and Article 2 ECHR (right to life).

¹²² *Lambert and Others v France* App no 46043/14 (ECHR, 5 June 2015) (*Lambert v France*) [148].

¹²³ *ibid* [178]. See Chapter Four, Subsection 4.3.3 for commentary on the dissenting judgment in *Lambert*.

¹²⁴ Note that *Lambert* is a French case, however, their best interest laws for discontinuing life-supporting treatment are very similar and therefore I have assumed that it is likely that the UK

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the law on bodily integrity (assault) because to prioritise the patient's alleged wishes (accurate or not) over and above a cognitively impaired patient's right to life is not just alarming but deviates from the established law. Effectively this approach makes the consideration of assault on the basis of medical evidence less important, and the legal question more akin to a "right to die" on an implied right to refuse treatment basis. This analysis suggests that for those with cognitive disability, the right to bodily integrity is treated as a 'subset'¹²⁵ of bodily autonomy and therefore becomes a questionable legal and moral basis on which to justify continuation or discontinuation of treatment. Fundamentally, such patients are non-autonomous and their right to bodily integrity is much broader than autonomy,¹²⁶ covering not just assault from unjustified treatment but omissions to treat that have no 'logical' medical basis.¹²⁷

Having determined what is dilemmatic about *Bland* from a legal perspective, it remains unclear why such patients from a moral perspective are not also assaulted when life support is discontinued but are assaulted if it were to continue. Such analysis does not disregard the legal distinction of acts versus omissions but instead, on the basis of Chapter Two's findings, argues that a duty of care cannot currently be discharged under *Bolitho*. It is possible that it is the loss of personhood that justifies and underlies a medical determination of futility, for example, in the converging human rights debate, Quinn argues that the battle for equally recognised human rights for those with cognitive disability can be characterised as a 'proxy war over personhood'.¹²⁸ Furthermore, Chapter

would also adopt a similar response. Note also that the nature and purpose of ss 4(6) and 4(7) MCA 2005 (n 35) to facilitate non-capacious patients' presumed wishes will be assessed in Section 3.4.

¹²⁵ Herring and Wall 2017 (n 34) 569.

¹²⁶ Herring and Wall 2017 (n 34).

¹²⁷ See *Bolitho* [1998] (n 24) at 243 where Lord Browne-Wilkinson states that, 'if, in a rare case, it can be demonstrated that the professional opinion is not capable of withstanding logical analysis, the judge is entitled to hold that the body of opinion is not reasonable or responsible'. On the basis of the evidence in Chapter Two, Sections 2.2 and 2.3 the medical evidence to support the view that PDOC patients are non-aware and non-sentient was ill-supported. Note the question of whether this amounts to discrimination for failing to extend an equal right to refuse treatment to those who are non-autonomous will be addressed in Chapter Three, Section 3.4 and is the primary focus of Chapter Four.

¹²⁸ Gerard Quinn, 'Rethinking Personhood: New Directions in Legal Capacity Law and Policy' (University of British Columbia, 29 April 2011) <http://citizenship.sites.olt.ubc.ca/files/2014/07/Gerard_Quinn_s_Keynote_-_April_29__2011.pdf> accessed 1 June 2019. See also Harris 2003 (n 2) and Harris 1999 (n 31), for his argument that *Bland* is better explained by reference to his loss of personhood.

Two suggests that death is now defined and determined by loss of personhood and moral standing; a loss of moral (and possibly legal protection¹²⁹) that occurs when a patient loses voluntary responsivity (a type of cognitive disability). Therefore, Harris' argument that *Bland's* 'moral inconsistency'¹³⁰ could only be resolved by personhood theory,¹³¹ was particularly interesting because of Chapter Two's findings that "death" in medicine equates with futility, which is determined on the basis of a particular moral standpoint on personhood and holds a legal relationship with the right to bodily integrity.

Consequently, it is necessary to explore whether the futility of continuing life-supporting treatment for those who are "living" is determined on the basis of losing personhood. Whilst the analysis in *Bland* is deemed legally correct, the moral and possible legal dilemma arose on the basis of two conflicting bodily integrity considerations that determined that the lesser assault arising from continued treatment would be preferable to his death. Hence, PDOC patients are paradoxically considered both having and not having personhood status (thus both capable of being assaulted and not capable of being assaulted) in an attempt to reconcile this dilemma.¹³²

Personhood was first introduced in 2.4.3 as a predominantly moral concept, 'applied to those sorts of beings who have some special value or moral importance and where we need to prioritize the needs or claims of different sorts of individuals'.¹³³ Harris argues that it is 'a concept designating individuals like us in some important respects, but possibly including individuals who are very unlike us in other respects'.¹³⁴ Similarly to Harris, an aim of this thesis is to discover what those 'respects' (the 'indicia of personhood'¹³⁵) are. In Harris' paper, *The Concept of Person and the Value of Life*,¹³⁶ he uses several thought

¹²⁹ The rest of Section 3.2 questions whether it is the case that (legal) personhood (all legal capacities) have been lost.

¹³⁰ Lord Mustill's words in *Bland* [1993] (n 3) at 887 have been quoted by: Andrew McGee, 'Defending the Sanctity of Life Principle: A Reply to John Keown' (2011) 18 (4) *Journal of Law and Medicine* 820; Coggon 2007 (n 16); Keown 2005 (n 65); McGee 2005 (n 17); Keown 1997 (n 13).

¹³¹ Harris 1999 (n 65).

¹³² Additionally, the current law under *Aintree* [2013] (n 72) adds an additional complication of how bodily autonomy seemingly trumps bodily integrity in a patient who is non-autonomous. This latter problem will be addressed in Section 3.4.

¹³³ *ibid* 293 (paraphrasing). First introduced in Chapter Two, Subsection 2.4.3.

¹³⁴ *ibid*.

¹³⁵ Quinn 2011 (n 128).

¹³⁶ Harris 1999 (n 65).

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experiments and popular debates to explore what makes life valuable: 'speciesism';¹³⁷ 'potentialism';¹³⁸ the 'life begins at conception' debate;¹³⁹ 'brain birth',¹⁴⁰ and a thought-experiment on whether extra-terrestrial life would be recognised as "persons".¹⁴¹ He suggests that Locke's work, *Essay Concerning Human Understanding*, has 'attempted to answer this question in a way that has scarcely been surpassed':¹⁴²

we must consider what person stands for; which I think is a thinking intelligent being, that has reason and reflection, and can consider itself the same thinking thing, in different times and places; which it does only by that consciousness which is inseparable from thinking and seems to me essential to it; it being impossible for anyone to perceive without perceiving that he does perceive.¹⁴³

The indicia of personhood as 'intelligence, the ability to think and reason, the capacity for reflection, self-consciousness, memory and foresight'¹⁴⁴ are what medicine recognises as "consciousness" or the cognitive capacity for 'awareness of self and environment'.¹⁴⁵

However, consciousness as the indicia of personhood may not be sufficiently precise given the recent advancements in neuroscience noted in 2.3. Locke's quotation seems to indicate that others' perceptions of the individual's consciousness is more crucial, a factor more accurately known in medicine as responsivity. For example, consciousness as awareness is inaccurate because measuring inner awareness without responsivity is problematic.¹⁴⁶ This is reflected in the noted challenges to the nomenclature around

¹³⁷ ibid. "Speciesism" advocates a conceptualisation of personhood based on membership by nonmoral characteristics such as race, gender, nationality and religion.

¹³⁸ ibid. "Potentialism" explores whether embryos' potential to become adult human beings is sufficient for personhood status.

¹³⁹ ibid. Explores whether human beings become persons at the point of conception.

¹⁴⁰ ibid. Explores the idea that at the point when a foetus requires a brain and therefore can have brain activity is when personhood status should be granted.

¹⁴¹ Harris 1999 (n 65).

¹⁴² ibid 302.

¹⁴³ John Locke, *An Essay Concerning Human Understanding* (first published 1690, E S Pringle-Paterson ed, Clarendon Press 1924) Ch 27, Book II, 188.

¹⁴⁴ Harris 1999 (n 65) 303.

¹⁴⁵ Royal College of Physicians, *Prolonged Disorders of Consciousness Following Onset of Sudden Injury: National Clinical Guidelines* (2020) 23-25 (PDOC 2020 guidance). As discussed in Chapter Two, Section 2.3, wakefulness had less significance in determining whether to withdraw life support.

¹⁴⁶ As discussed in Chapter Two, Section 2.3. See also D Alan Shewmon, "'Recovery from Brain Death': A Neurologist's Apologia' (1997) 64 (1) The Linacre Quarterly 30, who at page 59 gives a particularly insightful account on the problems of diagnosing awareness in non-responsive

consciousness disorders as 'responsivity' disorders.¹⁴⁷ Awareness and responsivity are linked but are not always mutually inclusive and neurologists have been questioning the capacity for inner-awareness without recognisable signs of responsivity since the late 1990s.¹⁴⁸ Owens effectively summarises the problem of confounding awareness with responsivity by stating that, 'our ability to know unequivocally that another being is consciously aware is ultimately determined not by whether or not he or she is aware but instead by his or her ability to communicate that fact through recognised behavioural response'.¹⁴⁹ Consciousness alone is therefore insufficient and responsivity is more accurately the true marker of personhood. Those whose legal status would be particularly threatened by this are PDOC patients, as patients who have "disorders of responsivity".¹⁵⁰

Moreover, Harris draws a stark conclusion on the matter of PDOC patients' personhood and moral standing status with a conclusion that I have begun to draw myself on the basis of Chapter Two's findings, which indicated that those who have lost cognition have in the eyes of the law 'permanently lost personhood', placing them outside the legal protection of who can be wrongfully harmed or even killed.¹⁵¹ He argues:

I believe that the only way of making sense of their judgment [referring to *Bland*] is to conclude that they determined that individuals in a persistent vegetative state have permanently lost personhood. It was this fact that justified their eventual decision in the landmark *Bland* case to authorise cessation of life-sustaining food and hydration.¹⁵²

patients/ those with severe cortical damage, such as vegetative and minimally conscious state patients.

¹⁴⁷ See Royal College of Physicians, 'Prolonged Disorders of Consciousness: National Clinical Guidelines' (2013) at pages 2-3 and 19-22. See also that this policy approach is still adopted in the 2020 guidance, PDOC 2020 (n 145) at pages 23-24, and as discussed in Chapter Two, Subsection 2.3.3.

¹⁴⁸ These numerous sources are discussed in Chapter Two, Subsection 2.3.3.

¹⁴⁹ Adrian M Owen and others, 'Using Functional Magnetic Resonance Imaging to Detect Covert Awareness in the Vegetative State' (2007) 64 Archives of Neurology 1098, 1099 (paraphrasing).

¹⁵⁰ This is not merely a semantic objection; it can make all the difference to the moral and legal protection afforded to an individual. Compare, for example, locked-in syndrome (LIS) and PDOC patients, the propriety of continued treatment is not questioned from a bodily integrity (as opposed to autonomy) basis for LIS patients because of their ability to respond (via blinking). See PDOC 2020 (n 145) 24; Chapter Two, Section 2.3.

¹⁵¹ Harris 1999 (n 65) 305. Noting that cognition is measured by responsivity as explained in Chapter Two, Section 2.3 and by the PDOC guidance, PDOC 2020 (n 145) 23.

¹⁵² *ibid.*

He also notes the reluctance of their Lordships to 'change the definition of death, or to even address that issue',¹⁵³ even though their Lordships presumed that Bland's lack of awareness meant that the question of living or dying, 'must be a matter of indifference' to Bland himself.¹⁵⁴ Furthermore, Harris' account is possibly bolstered by Lord Mustill's assertion that he would not have 'reach[ed] the same conclusion in less extreme cases where the glimmerings of awareness may give the patient an interest which cannot be regarded as null'.¹⁵⁵ Whatever the case, the pains taken to distinguish Anthony Bland from conscious patients and simultaneously distinguish him from the brainstem dead indicates that legal constructs alone cannot morally justify withdrawal from a biologically living patient.

Consequently, such decisions seem to not strictly be "best interests" decisions at all and are more akin to what are now known as "Part 8 declarations" under the Civil Procedure Rules 1998, (similarly) overviewing whether the clinical guidelines have been met for disputed brain death declarations, such as in *Re M* [2020].¹⁵⁶ I acknowledge that in *Bland* their Lordships make repeated attempts to distinguish brain death from VS, particularly with reference to Bland's ability to breathe unaided in an attempt to highlight the significance of his somatic integrative function, allegedly signifying that Bland is undeniably "alive".¹⁵⁷ Nevertheless, his biological status as "living" is what causes the moral inconsistency: how is it that a biologically living person is not assaulted (killed) by the removal of his feeding tube but is by its continued presence?¹⁵⁸ Chapter Two's evidence also suggests that the definition of death (as it is implemented in practice) now extends to those with less severe cognitive disability than brainstem death. I will approach this question in two parts: first, by looking at inconsistency in the judges' interpretation of

¹⁵³ *ibid.*

¹⁵⁴ *Bland* [1993] (n 3) 826 (Lord Keith).

¹⁵⁵ *ibid* 889 (Lord Mustill).

¹⁵⁶ *Re M (Declaration of Death of A Child)* [2020] EWCA Civ 164 (CA).

¹⁵⁷ *Bland* [1993] (n 3) 856 (Lord Keith), 860 and 863 (Lord Goff), 878 (Lord Browne-Wilkinson).

¹⁵⁸ *ibid* 869-870 (Lord Goff). This is a point that has since been contested by neurologists and legal philosophers, for example, see Mohamed Y Rady and Joseph L Verheijde, 'Judicial Oversight of Life-Ending Withdrawal of Assisted Nutrition and Hydration in Disorders of Consciousness in the United Kingdom: A Matter of Life and Death' (2017) 85 (3) Medico-Legal Journal 148; and John Keown, 'Beyond *Bland*: A Critique of the BMA Guidance on Withholding and Withdrawing Medical Treatment' (2000) 20 (1) Legal Studies 66.

whether Bland is "alive" or "dead", and secondly, by looking at the causation and intention issues raised by their view that he is "alive".

3.2.3 Resolving *Bland*: Personhood, Causation or Intention?

Bland is interesting and problematic because of the judicial inconsistency and almost silence on the question of whether he is "dead", despite acknowledgment of his biological life. For example, Lord Browne-Wilkinson acknowledges Bland is alive under the brainstem definition of death but states that his life is being extended by skilled medical care,¹⁵⁹ and that death is not dictated by nature or "biology" but 'human decision' on what it is to be "dead" or "alive".¹⁶⁰ It may be a conceptual stretch to read his words as an explicit acknowledgment that "death" is currently a moral standpoint on whose lives are not worth living, but it is sufficiently clear that biology is no longer solely what determines death in law either.¹⁶¹ Nevertheless, Lord Goff still emphasises that determining and defining death is the domain of the medical profession as a science.¹⁶² And, in yet another conflicting approach, Lord Mustill senses *Bland*'s likeness to the brain dead and more specifically how death has truly been determined and defined since the 1960s:

even if *Bolam* is left aside I still believe the proposed conduct is ethically justified, since the continued treatment of Anthony Bland can no longer serve to maintain that combination of manifold characteristics which we call a personality.¹⁶³

He quickly reigns in his fundamentally essentialist¹⁶⁴ line of argument by adding:

¹⁵⁹ *ibid* 878 (Lord Browne-Wilkinson).

¹⁶⁰ *ibid* (even if he only implicitly or inadvertently acknowledges).

¹⁶¹ Robert M Veatch, 'The Death of Whole-Brain Death: The Plague of the Disaggregators, Somaticists, and Mentalists' (2005) 30 (4) *Journal of Medicine and Philosophy* 353. Noting that the role biology plays in determining and defining death is also minimal in medicine, based on the findings of Chapter Two, Sections 2.2 and 2.4.

¹⁶² *Bland* [1993] (n 3) 863 (Lord Goff).

¹⁶³ *ibid* 899 (Lord Mustill). Here I refer to the findings of Chapter Two, Section 2.2 on how death has been, and is, defined and determined since the advent of "brain death".

¹⁶⁴ Gerard Quinn, 'Personhood and Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD' (HPOD Conference at Harvard Law School, 20 February 2010) <[https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/archive/Submission-on-Legal-Capacity-to-the-Oireachtas-Committee-on-Justice,-Defence-&-Equality-\(August,-2011\).pdf](https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/archive/Submission-on-Legal-Capacity-to-the-Oireachtas-Committee-on-Justice,-Defence-&-Equality-(August,-2011).pdf)> accessed 1 June 2019, 6. An essentialist argument is one that seeks to define the characteristic(s) required for personhood status such as higher brain death theories.

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some ... maintain that this is too narrow a perspective ... I do not assert that the human condition necessarily consists of nothing except a personality, or deny that it may also comprise a spiritual essence distinct from both body and personality. But of this we can know nothing ... whether it perishes with death or transcends it.¹⁶⁵

It is perhaps no coincidence that concurrently to critiques on the questionable moral basis of *Bland* are similar criticisms of the somaticists' argument that "brain death is biological death".¹⁶⁶ Chapter Two's findings suggest that death has since the inception of "brain death" been an essentialist-based argument that loss of consciousness or "personality" indicates loss of moral standing.¹⁶⁷ Moreover, if the legal definition of death is the 'mere judicial application of the medical definition of death',¹⁶⁸ it is perhaps even more plausible to suggest that the law has adopted a personhood-based definition and process for determining death. If so, the ensuing problem would be how to safeguard a personhood-based determination of death to only those the law is willing to recognise as morally "dead"? This implication is at least implicitly acknowledged by both Lord Mustill and Lord Browne-Wilkinson, particularly where Lord Mustill doubted that *Bland* could be applied to those in future cases with 'glimmerings of awareness'.¹⁶⁹ Additionally, Lord Browne-Wilkinson also noted the difficulty of limiting the practice to only permanent VS patients.¹⁷⁰ The question of safeguards will be addressed in 3.3, for current purposes,

¹⁶⁵ *Bland* [1993] (n 3) 899 (Lord Mustill).

¹⁶⁶ Veatch 2005 (n 161). Discussed in Chapter Two, Section 2.4.

¹⁶⁷ This is what Veatch 2005 (n 161) at page 366 refers to as the 'mentalist' view of higher brain death theories. As discussed in Chapter Two, Subsection 2.4.2.

¹⁶⁸ Elizabeth Wicks, 'The Legal Definition of Death and the Right to Life' in Shane McCristine (ed), *Palgrave Historical Studies in the Criminal Corpse and Its Afterlife. Interdisciplinary Perspectives on Mortality and its Timings. When is Death?* (MacMillan Publishers 2017) 119 (paraphrasing).

¹⁶⁹ *Bland* [1993] (n 3) 899 (Lord Mustill).

¹⁷⁰ See *Bland* [1993] (n 3) at 879 where Lord Browne-Wilkinson states: 'if the withdrawal of life support is legitimate in the case of Anthony Bland, whose P.V.S. is very severe, what of others in this country also in P.V.S (whom we are told numbered between 1000 and 1,500) and others suffering from medical conditions having similar impact, e.g. the Guillain-Barré syndrome? Who is to decide, and according to what criteria, who is to live and who is to die? What rights have the relatives of the patient in taking that decision?'. Note in nursing homes alone in 2015, there was an estimated 4000-16000 VS patients and 'up to three times as many in MCS' according to the Parliamentary Office of Science and Technology, 'Vegetative and Minimally Conscious States' (POST notes POST-PN-489, 2015) <<http://researchbriefings.parliament.uk/ResearchBriefing/Summary/POST-PN-489>> accessed 15 January 2020 at page 1 (this number excludes coma and other individuals with cognitive/ responsivity disabilities, such as TDOCs).

Harris' argument needs to be tested to explore whether the personhood argument can better resolve the moral inconsistency in these cases than the legal causation or intention arguments that have been put forth by other academics.¹⁷¹

In *Bland*, Lord Mustill recognises that in *R v Malcherek and Steel* [1981] (*Malcherek*), the legal causation of death was the assault that placed the victims in a brainstem dead state, not the doctor's removal of the ventilator.¹⁷² In both *Malcherek and Steel* and *re A (A Minor)* [1992] (*re A (A Minor)*),¹⁷³ the behaviour of withdrawing life support from brainstem dead patients was justifiable because the patient was deemed "dead" at the point of the sustained "fatal" injury. Therefore, despite the factual cause of death as suffocation (after removal of the ventilator) the legal cause was asserted to be the illegal assault that resulted in their diagnoses as brainstem dead. Brainstem death was, and is, a legally accepted definition of death (despite the findings of 2.2 which questions its biological basis for equating brain death with death as a phenomenon). However, on the basis that it is thought to be the same as death (the phenomenon), no moral or legal disparity between the individual's legally and medically determined death occurs because they are dead on the basis of having lost personhood (irrespective of biological life).

Moreover, disputes on brainstem death determinations were arguably coronial until *Re A (A Child) (Medical Treatment: Removal of Artificial Ventilation)* [2015] (*Re A (A Child)*), where Hayden J doubted whether coronial powers extended over a ventilated body and placed brainstem death disputes under the ambit declaratory relief proceedings, and most significantly, under best interests decision-making.¹⁷⁴ Therefore, perhaps the recent acknowledgment that even disputes on brainstem death seek declaratory relief

¹⁷¹ Those further academic explanations on the moral inconsistency in *Bland* [1993] (n 3) are Coggon 2007 (n 16); Keown 2005 (n 65); McGee 2005 (n 17); Harris 1999 (n 65); Keown 1997 (n 13); Finnis 1993 (n 14).

¹⁷² *R v Malcherek and Steel* [1981] 2 All ER 422 (CA) (*Malcherek*). This case concerned withdrawal of mechanical ventilatory support from two "brain dead" murder victims.

¹⁷³ *Re A (A Minor)* [1992] 3 Med LR 303 (Fam) (*Re A (A Minor)*).

¹⁷⁴ *Re A (A Child) (Medical Treatment: Removal of Artificial Ventilation)* [2015] EWHC 443, [2015] 2 WLK 445. Note Hayden J comments that unlike the US, where coronial powers are used to remove or continue mechanical ventilation in cases of dispute, that in the England and Wales, the High Court (Court of Protection specifically) will determine such matters. He interestingly acknowledges that *Bland* [1993] (n 3) and *Mail Newspapers Plc v Express Newspapers plc* [1987] FSR 90 (HC) seem to be treating determinations of brain death under the jurisdiction of the coroner and yet decides they are appropriately decided by the High Court. Such a distinction fundamentally relies on whether the patient is deemed to hold welfare interests (is alive) or not.

demonstrates that determining and defining death is no longer a solely scientific matter. And more specifically, to not acknowledge that a different, non-welfare-based best interests assessment is happening under such decisions would lead to the paradoxical conclusion that even the brainstem dead have welfare interests. I suggest viewing *Re A (A Child)* as a case where welfare is possibly being conflated with futility because there has been no explicit acknowledgement of a different type of best interest test occurring in such cases, as evidenced in 3.3 and by the view of the High Court that life support continuation can be determined on a balance sheet approach like other welfare assessments.¹⁷⁵

Returning to the issue of their Lordships in *Bland*'s reliance on the somaticist distinction between brainstem death and the VS, the apparent consensus among neurologists is that the somaticists' argument has failed to defensibly prove that the brain dead are "dead".¹⁷⁶ Consequently, it seems that brainstem death (as it is recognised in law) is a concept justified by legal causation not biology. However, the assumed view ("that brainstem death is biological death") explains why Lord Mustill thought the extension of the legal causation argument to *Bland* (and VS patients more generally) would not be permissible:

the argument seems to me to require not manipulation of the law so much as its application in an entirely new and illogical way ... the argument asserts that for the purpose of both civil and criminal liability the cause of Anthony Bland's death, if and when it takes place, will be the Hillsborough disaster.¹⁷⁷

It was illogical because brain death was "death", whereas arguing that VS patients were also "dead" seemingly overstretched the argument as VS patients can independently breathe. There is no explicit acknowledgement of the fact that if death is a personhood-based determination that it now implicates VS patients also. However, 2.2 seems to have undermined this purportedly crucial and biologically-based distinction, obscuring the fact that a personhood-based definition and determination of death (on the basis of cognitive

¹⁷⁵ *W v M* [2011] (n 114); *M v N* [2015] (n 117); *Re Briggs (Incapacitated Person) (Medical Treatment: Best Interests Decision)* [2016] EWCOP 53, [2017] 4 WLR 37 (*Briggs (No.2)*); *Aintree* [2013] (n 72).

¹⁷⁶ This argument was explored in Chapter Two, Sections 2.2 and 2.4.

¹⁷⁷ *Bland* [1993] (n 3) 895 (Lord Mustill).

capacity alone) seems to have been adopted in medicine.¹⁷⁸ Biology cannot sufficiently maintain the distinction that one is alive (VS) and one is dead (brainstem dead).¹⁷⁹ Hence, *Bland* has plausibly brought to light the fact that the definition of death has been stretched beyond its logical parameters and is incongruous with common experiential knowledge of the phenomenon. If this conclusion is correct, the moral justification underlying the causation explanation can be resolved by personhood theory for brainstem death and its apparent extension to PDOC patients, further demonstrating why the AOMRC's official definition of death is defunct.¹⁸⁰

Consequently, such an understanding also explains how cognitively impaired individuals are having their personhood status questioned in more legal areas than just life support withdrawal.¹⁸¹ Harding notes the power of the courts to re-write and question the validity of the testamentary wishes of those who have cognitive impairment(s).¹⁸² Additional instances such as: the unwillingness of the media to call the sexual assault and subsequent pregnancy of a VS patient in the US, "rape",¹⁸³ and the United Nation's contempt for instances of "learning disability" being used as a justification on a *do not attempt cardiopulmonary resuscitation* order (DNACPR),¹⁸⁴ exemplify that without

¹⁷⁸ A key finding of Chapter Two, Section 2.4.

¹⁷⁹ As discussed in Chapter Two, Sections 2.2 and 2.4.

¹⁸⁰ I acknowledge that the AOMRC maintains a distinction between brainstem death and PDOC patients in their 2008 guidance on the definition of death (See Academy of Medical Royal Colleges, 'A Code of Practice for the Diagnosis and Confirmation of Death' (2008) (AOMRC) page 11). Nevertheless, as explained on the basis of the analysis in Chapter Two, Sections 2.2 and 2.3, such a distinction is difficult to logically justify on a biological or death behaviour (moral) basis.

¹⁸¹ Eilionóir Flynn and Anna Arstein-Kerslake, 'The Support Model of Legal Capacity: Fact, Fiction, or Fantasy?' (2014) 32 (1) *Berkeley Journal of International Law* 124.

¹⁸² Rosie Harding, 'The Rise of Statutory Wills and the Limits of Best Interests Decision-Making in Inheritance' (2015) 78 (6) *The Modern Law Review* 945. As discussed in Section 3.4.

¹⁸³ Jason Hanna and Keith Allen, 'A Nurse is Accused of Impregnating a Woman in a Vegetative State Who Later Gave Birth' (US, 24 January 2019) <<https://edition.cnn.com/2019/01/23/health/arizona-woman-birth-vegetative-state/index.html>> accessed 18 December 2019; BBC News, 'Nurse Arrested After Vulnerable Patient Gives Birth in US Clinic' (UK, 23 January 2019) <<https://www.bbc.co.uk/news/world-us-canada-46978297>> accessed 18 December 2019. Interestingly, perhaps it is their non-awareness and consequential lack of ability to give or refuse consent that means such cases are not classified as rape. In other words, the issue of consent is thought non-consequential. Yet, in cases of sexual assault against children, the offence where the child has "consented" and has awareness would still be labelled and prosecuted under "statutory rape".

¹⁸⁴ United Nations Committee on the Rights of Persons with Disabilities, 'List of Issues in Relation to the Initial Report of the United Kingdom of Great Britain and Northern Ireland', (20 April 2017) CRPD/C/GBR/Q/1<https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolid=10000000000000000000000000000000

voluntary responsiveness and “ordinary” cognitive and mental functioning, the law (and perhaps also society) views such patients as “dead” for having lost such capacities.

Regarding the ‘legal intention’ arguments, Harris argues that Lord Mustill recognises that the intention between withdrawal of life support and ‘mercy killing’,¹⁸⁵ is for all intents and purposes ‘indistinguishable’.¹⁸⁶ The arguments made in the debates between Keown and McGee on the difficulty of the law’s conflation of intention and foresight, and the strength of the acts versus omissions distinction have also been insightful.¹⁸⁷ Keown argues that moral consistency could have been maintained in *Bland* had their Lordships consistently upheld that the intention to withdraw life-supporting treatment was indistinguishable from euthanasia and justifiable on the basis of futility.¹⁸⁸ He argues that maintaining their indistinguishability would uphold a consistent approach in law to the sanctity of life ethic.¹⁸⁹ Whilst I agree with his point in principle, it unfortunately does not reflect parliamentary intention because voluntary euthanasia is still prohibited.¹⁹⁰ Therefore, it does not restore moral consistency to the *status quo* and could only do so if Parliament were to change its attitude towards voluntary euthanasia, which is unlikely as it remains a consistently contested point of law since the early 2000s.¹⁹¹ Moreover, his explanation would still have to implicitly acknowledge futility’s determination on the basis of loss of personhood in order to justify why life support withdrawal is morally justifiable.

From a moral perspective, the further causation (acts versus omissions) argument adopted in *Bland* (like intention) relies on the ‘[legal] distinction without (moral) difference’,¹⁹² and therefore arguably fails to answer the intention or causation issues that arise in the determination of criminal responsibility for a PDOC patient’s death after

mbolno=CRPD%2fC%2fGBR%2fQ%2f1&Lang=en> accessed 19 September 2019, Part A subparagraph 1 (f) and Part B subparagraph 19 (f).

¹⁸⁵ *Bland* [1993] (n 3) 887 (Lord Mustill).

¹⁸⁶ *ibid*; Harris 1999 (n 65) 306.

¹⁸⁷ McGee 2011 (n 130); Keown 2005 (n 65); McGee 2005 (n 17); Keown 1997 (n 13).

¹⁸⁸ Keown 1997 (n 13).

¹⁸⁹ Keown 2005 (n 65) 396 (paraphrasing).

¹⁹⁰ Suicide Act 1961, subsection 2(1).

¹⁹¹ For example, the most recent Supreme Court hearing was *R (on the application of Nicklinson) v Ministry of Justice, R (on the application of Lamb) v Ministry of Justice, R (on the application of AM v DPP* [2014] UKSC 38, [2015] AC 657 (Nicklinson). Likewise, the matter was quashed in Parliament in 2015 under the Assisted Dying (No.2) Bill (2015-16).

¹⁹² *Bland* [1993] (n 3) 877 (Lord Goff).

withdrawal.¹⁹³ For example, Foster demonstrates that the acts versus omissions distinction fails to resolve the causation issue by introducing a thought experiment where he questions the difference between a layperson removing a VS patient's CANH tube and a doctor under the acts versus omissions distinction.¹⁹⁴ He concludes that the difference is ultimately one of policy (a lay person would be found guilty of murder but a doctor would not if withdrawal was clinically indicated) as the intention is indistinguishable.¹⁹⁵ In a similar scenario where a patient is brainstem dead, a charge of murder would not be brought against either a lay person or doctor for withdrawal because the patient is dead by definition, following *Malcherek and Steel* and *Re A (A Minor)*. Perhaps, under public policy reasons, the defendant may be charged with some other offence, however its severity would seemingly only amount to any of the offences that can be brought for "harm" to a dead body.¹⁹⁶ This latter issue is outside the scope of this thought-experiment.

Returning to the circumstances where the patient is in a VS, intuitively, seeing an independently breathing and now starving patient would lead to the common-sense conclusion that his resulting death amounted to murder by withdrawing his CANH tube. Alternatively, if the VS patient has already had his CANH removed under a best interests determination and subsequently a family member injects enough morphine to kill him, i.e. a hybrid account of the facts in *R v Cox* [1992] (Cox) and *R v Inglis* [2010] (Inglis),¹⁹⁷ *Bland's* influence would be that the family member killed the VS patient, not the doctor. This is because of *Bland's* confirmation that VS patients are "alive" and are legal persons during and after withdrawal takes place. Therefore, the law is morally questionable as both are indistinguishably a form of mercy killing of those with cognitive impairments justified on the basis that the prevention of a less severe assault than killing trumps their right to life. Such findings suggest that not only is the moral rationale supporting this interpretation of bodily integrity incoherent, but that the legal rationale for permitting life support

¹⁹³ Harris 1999 (n 65) 306.

¹⁹⁴ See Charles Foster, 'Airedale NHS Trust v Bland' in Jonathan Herring and Jesse Wall (eds), *Landmark Cases in Medical Law* (Bloomsbury 2015) at page 101.

¹⁹⁵ *ibid.*

¹⁹⁶ Imogen Jones, 'A Grave Offence: Corpse Desecration and the Criminal Law' (2017) 37 (4) Legal Studies 599. Note these offences tend to be public policy or order offences rather than to the individual or any remaining interests they may have.

¹⁹⁷ *R v Inglis* [2010] 1 WLR 1110 (CA) (Inglis); *R v Cox* [1992] CLY 886 (unreported) (Cox).

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withdrawal from living but severely disabled persons is a form of mercy killing.¹⁹⁸ Yet the method itself is more drawn-out and possibly more painful than intravenous injections of lethal drugs.¹⁹⁹ It is therefore questionable whether the aim sought (for example, dignity) is in fact achievable with CANH withdrawal or amounts to a substandard compromise, let alone whether the aim reached is itself justifiable (killing to preserve dignity²⁰⁰).

Additionally, in *Inglis*, a mother injected her son (in a VS after falling out of an ambulance) with a lethal amount of Heroin for what she believed were benevolent reasons.²⁰¹ The Court of Appeal emphasises the legally recognised difference between mercy killing and lawful withdrawal of treatment and also reiterated that VS patients are "alive", thereby adopting *Bland*'s reasoning.²⁰² I would suggest, in agreement with Harris' analysis on *Bland*,²⁰³ that what the acts versus omissions distinction seems to have achieved is the temporary circumvention of the question of whether VS patients are persons at the point where withdrawal is legally permissible.²⁰⁴

Moreover, an often-overlooked consequence of this legal stance is the allocation of responsibility or culpability where a patient is placed in a VS due to unlawful assault or negligence, as occurred in *Bland*. For example, although the acts versus omissions distinction in *Bland* successfully removed any hint of legal liability from his doctors,²⁰⁵ the families of the victims of the Hillsborough Disaster are still awaiting justice in seeing anyone, or any public body, being held responsible for their loved ones' deaths.²⁰⁶ The

¹⁹⁸ *Bland* [1993] (n 3) 887 (Lord Mustill). See also Keown 2005 (n 65); Keown J, 'Beyond *Bland*: A Critique of the BMA Guidance on Withholding and Withdrawing Medical Treatment' (2000) 20 (1) Legal Studies 66; Keown 1997 (n 13); Keown 1995 (n 84).

¹⁹⁹ *ibid*.

²⁰⁰ Note the English and Welsh legal stance on euthanasia and assisted death suggests that it is not and raises a contradiction here unless loss of personhood is the justification for deemed futility of continuing life-supporting treatment ie withdrawal.

²⁰¹ *Inglis* [2010] (n 197). These facts are relayed at [1]-[3] of the judgment.

²⁰² *ibid* at [37]-[38].

²⁰³ Harris 1999 (n 65).

²⁰⁴ I suggest it is temporary because it is a continuously noted problem of *Bland* [1993] (n 3) and its subsequent declaratory relief cases (discussed later in this Chapter in Sections 3.3 and 3.4). Note by extension in later cases, I mean MCS patients also.

²⁰⁵ For example, Foster, 2015 (n 194) at page 101 notes that their Lordships succeeded in protecting *Bland*'s doctors from criminal liability for his death however, that does not mean all are immune to criminal responsibility for his death.

²⁰⁶ David Conn, 'Hillsborough Families Voice Outrage at Not Guilty Verdict' (UK, 28 November 2019) <<https://www.theguardian.com/uk-news/2019/nov/28/hillsborough-families-outraged-david-duckenfield-not-guilty-verdict>> accessed 15 January 2020.

issue of criminal responsibility is relevant because it indicates why legal causation for their death (as in brainstem death cases) needs to be applicable. To ignore this question leaves their personhood status even less legally protected than brainstem dead patients who are legally and medically accepted as "dead". Therefore, despite the moral incongruity of the argument, it is (purportedly²⁰⁷) legally sound on the basis of a legally accepted distinction. It has adopted legal causation to redirect liability away from the doctors but left unanswered who is responsible where an illegal assault arises that leads or even hastens their death post-withdrawal. *Bland* therefore overlooks personhood and its apparent relationship with defining and determining death,²⁰⁸ and further still, how legal causation can redirect liability away from one party but not all entirely.

Of course, from a legal perspective this is an accepted legal subtlety on the basis of intention arguments. However, from a causation perspective I have misgivings, on the basis of the medical evidence in 2.3, that the *Bolitho* standard for discharging a duty of care (a crucial element of the presumption in favour of not treating) has been met or that the right to bodily integrity is being appropriately protected in these cases post-*Aintree*. Consequently, the foundational importance for establishing that no duty of care still exists is also impacted by the question of a PDOC patient's personhood status: without personhood the patient has no right to bodily integrity. This is one of the most compelling moral reasons for supporting the personhood argument advanced by Harris,²⁰⁹ because it is the only existing and viable argument explaining why PDOC patients' life support withdrawal is morally inconsistent in English and Welsh law and why their legal protection is flawed. Moreover, if the personhood argument's extension to PDOC patients is morally abhorrent to the reader, I suggest it is because life support withdrawal from (living) PDOC patients' is incongruous with experiential knowledge of death.²¹⁰ The logical conclusion

²⁰⁷ I state "purportedly" sound because *Bland* has only partially adopted legal causation as it was understood in brainstem death cases (justified on the basis that patient was "dead" having lost personhood) through its acts versus omissions distinction, ie no question of assault/ bodily integrity arises for subsequent actions/ omissions of the doctor.

²⁰⁸ This was the key finding of Chapter Two, Section 2.4.

²⁰⁹ Harris 1999 (n 65).

²¹⁰ This was also explored in Chapter Two, Section 2.4, and has been noted by Josie Fischer, 'Re-Examining Death: Against a Higher Brain Criterion' (1999) 25 Journal of Medical Ethics 473, who at page 473 comments that the finding that defining and determining death is more of a legal and philosophical than biological determination has led to the concept's incongruity. As noted in Chapter Two, Subsection 2.4.2.

would therefore be that its practice is morally indefensible under factual accuracy assessments, where there is also good reason to question whether the law's own assessment on the right to bodily integrity has been correctly interpreted.

3.2.4 Section Conclusion

The personhood argument provided by Harris seems to be the closest legal academics have come to resolving the moral inconsistency in *Bland* (and by extension cases concerning withdrawal of PDOC patients' life support).²¹¹ However, it is the analysis on the right to bodily integrity that underlies the crucial legal presumption in favour of discontinuing treatment that has enabled further exploration of why *Bland* presents a moral and legal dilemma. There is scope to suggest that the dilemma is also legal in nature because of the difficulty of justifying a more serious invasion of bodily integrity on the basis of preventing a lesser assault and whether in more recent cases the crucial duty of care/ medical necessity element is being appropriately discharged under a conflated view of bodily autonomy and integrity (see 3.4). Additionally, the clash between Articles 3 and 2 ECHR was particularly interesting because the ECtHR has only recently passed judgment (in *Lambert*) on the justifiability of discontinuing CANH from a VS patient.

Furthermore, the criteria that support that starting presumption (that continued treatment is not in the patient's best interests) has radically changed post-*Aintree* and has seemingly been approved by the ECtHR in *Lambert*. In these cases, it seems that the patient's wishes are what ultimately discharges both the medical duty of care and determines the medical necessity of continued treatment. This is problematic because it treats bodily integrity as a 'subset of autonomy' and consequently begins to question why law and medicine should respect the bodily integrity of a non-autonomous patient at all: more than consent is often required to justify an invasion of the bodily integrity of a patient.²¹² That remaining legal question (of whether this has resulted due to a desire in law to achieve an equal right to refuse for those who are non-autonomous) will be explored in 3.4.

²¹¹ Harris 1999 (n 65).

²¹² Herring and Wall 2017 (n 34) 569.

This section then sought to explain how that legal analysis can better indicate why a dilemma arose in *Bland* and how the current legal *status quo* can only be explained by reference to personhood theory, which has been carried over from how life support discontinuation is justified for brainstem dead patients. The result is that PDOC patients have likely lost their personhood status at the point where the presumption in favour of discontinuing treatment applies (doctor's decision no duty of continued care exists), thus making them a 'human non-person' and such decisions more akin to a Part 8 declaration.²¹³ Nevertheless, the law is still incongruous because loss of personhood (as in the case of brainstem dead patients) would make any consideration of bodily integrity moot. Yet, the law maintains such patients hold a right to bodily integrity and are alive, hence the legal and moral dilemma. The question of VS patients' personhood raised by *Bland* is perhaps the single most important reason for reappraising the definition and determination of death. It is their loss of voluntary responsiveness that means they can also (like the brainstem dead) be considered "dead", irrespective of any other residual biological functioning.

Additionally, the circumvention of answering whether he is definitively "alive" or "dead" is not only the crux of the moral inconsistency in *Bland*, I also argue that it is the core legal, moral and biological question that so often goes unanswered in analysis of its legal reasoning,²¹⁴ and is a core conceptual point that is assumed to be irrefutable. Consequently, how can the law maintain the position argued in *R v Inglis* that all disabled lives (no matter how severe) and are worth the same as able-bodied (and minded) persons.²¹⁵ This sadly does not meet the experience of cognitively impaired persons in practice, where the law permissibly deems PDOC patients' lives to no longer be worth living. To continue to fail to reappraise death and thereby conclusively decide whether these patients are "living" or "dead" (are legal persons), means that the legal protection of their bodily integrity remains 'morally and intellectually'²¹⁶ dubious. But what of

²¹³ *ibid* 293 (paraphrasing); Civil Procedure Rules 1998.

²¹⁴ All of the legal philosophers mentioned come very close to this conclusion ie "the intention is the same" or "causation works on the basis of policy but there is a moral inconsistency". However, none go as far as Harris, as outlined in Subsection 3.2.1. See Coggon 2007 (n 16); Keown 2005 (n 65); McGee 2005 (n 17); Harris 1999 (n 65); Keown 1997 (n 13); Finnis 1993 (n 14).

²¹⁵ A policy position stated in *R v Inglis* [2010] (n 197) at [38] by Lord Judge CJ.

²¹⁶ Rephrasing Lord Mustill's often-noted proclamation about what the state of the law would be after *Bland* [1993] (n 3) at page 887.

subsequent legal developments, what safeguards exist and how accurately are the cases' moral and legal bases being interpreted?

3.3 Subsequent Cases and Noted Bodily Integrity Safeguarding Concerns

3.3.1 Developments of the Safeguard of Permanence

The two safeguards introduced in *Bland* to prevent the extension of (the loss of personhood and thereby) a determination of futility to other less cognitively disabled individuals were permanence²¹⁷ and judicial oversight.²¹⁸ The safeguard of permanence²¹⁹ sought to ensure that continuation decisions were only applicable to those who have a permanent VS prognosis.²²⁰ However, what is less clear in the case law is whether this safeguard also sought to secure certainty of diagnosis (i.e. VS, coma or MCS),²²¹ and whether permanence in both or either respect still exists as a safeguard today.

The safeguard of judicial oversight was intended to be a temporary measure until a reasonable 'body of practice had been built up'.²²² However in 2018, the Supreme Court queried the existence of such a duty in law that all life support continuation considerations must be overseen by the courts".²²³ Additionally, recent Court of Protection guidance seems to be in conflict with this Supreme Court's judgment for reasserting that cases

²¹⁷ Life support continuation was questioned in *Bland* because he was a living but nonetheless permanently non-responsive patient who gave no sign of an inner existing 'personality'. As discussed by Lord Mustill in *Bland* [1993] (n 3) at 899.

²¹⁸ *Bland* [1993] (n 3) 859, 873-5 and 899.

²¹⁹ 'Permanence' is diagnosed after 6 months regardless of aetiology or whether the patient is VS or MCS but can only be determined by a physician who meets the criteria of an 'Expert PDOC physician'. See PDOC 2020 (n 145) 37.

²²⁰ Recalling the concern noted by Lord Mustill and Lord Browne-Wilkinson in *Bland* of its extension to those with 'glimmerings of awareness' or 'Guillain-Barré Syndrome' at page 870 (Lord Browne-Wilkinson) and 899 (Lord Mustill) of the *Bland* [1993] (n 3) judgment. Note also that *An NHS Trust v Y* [2018] (n 10) at [117] notes the extension of the practice to those with Huntington's disease, multiple sclerosis and advanced stage dementia.

²²¹ *M v N* [2015] (n 117); *NHS Trust A v H* [2001] 3 WLUK 838 (Fam); *re G (Persistent Vegetative State)* [1995] 2 FCR 46 (Fam) (*re G*); *Frenchay Healthcare National Health Service Trust v S* [1994] 1 WLR 601 (CA) (*Frenchay*).

²²² *Bland* [1993] (n 3) 859, 873-5 and 899.

²²³ *An NHS Trust v Y* [2018] (n 10).

concerning continuation of life support 'must' be overseen by the courts.²²⁴ Finally, the safeguard of judicial oversight has opened up the question of whether those with increased awareness, such as MCS patients,²²⁵ could also have life-supporting treatment questioned, despite *Bland* warning against such an interpretation.²²⁶ Finally, there are good reasons that such safeguards should exist. Given the findings in 3.2, it is not just PDOC patients' right to life²²⁷ that is at stake,²²⁸ all of the legal protections preventing their abuse (more generally bodily integrity) are questioned by the defensibility of discontinuation because of its connection to loss of personhood and the way in which death is defined and determined in practice.

There is scope to suggest that permanence (as it existed in *Bland*) referred not only to prognosis but diagnosis. For example, Lord Mustill warns that he would not permit life support discontinuation from a patient with 'glimmerings of awareness'.²²⁹ Likewise, Lord Browne-Wilkinson's concerns about *Bland* having a wider-impact on other cognitive disabilities, such as Guillain-Barré Syndrome,²³⁰ suggests that the case's reasoning was limited to those with a permanent VS diagnosis only.²³¹ Moreover, the central focus on 'futility' must have some role in upholding permanence because as Lord Goff argues, 'treatment which is not futile because it is doing some good, is never to be withheld ... feeding a living patient is not futile'.²³² Lord Goff's words suggest that it is the "permanence" of prognosis that indicates the futility of continued treatment as those with

²²⁴ *Practice Guidance (CP: Serious Medical Treatment)* [2020] EWCOP 2, [2020] 1 WLR 641, [8] (Hayden J).

²²⁵ *W v M* [2011] (n 114); *M v N* [2015] (n 117); *Briggs (No.2)* [2016] (n 175); *Aintree* [2013] (n 72).

²²⁶ Lord Mustill and Lord Browne-Wilkinson in *Bland* [1993] (n 3) were concerned about an extension to those with 'glimmerings of awareness' or 'Guillain-Barré Syndrome', eg see pages 870 (Lord Browne-Wilkinson) and 899 (Lord Mustill)). Also note Lady Black in *An NHS Trust v Y* [2018] (n 10) at [117] mentions that the practice has been extended further than PDOC patients to those with Huntington's disease, multiple sclerosis and advanced stage dementia.

²²⁷ CRPD 2006 (n 62) Article 10; ECHR 1950 (n 62) Article 2.

²²⁸ Elizabeth Wicks, '*An NHS Trust and Others v Y and another* [2018] UKSC 46: Reducing the Role of the Courts in Treatment Withdrawal' (2019) 0 Medical Law Review 1, 1 (paraphrasing).

²²⁹ *Bland* [1993] (n 3) 899 (Lord Mustill).

²³⁰ Guillain-Barré Syndrome is a rare condition where the immune system attacks the nerves. In serious cases it can cause an inability to move, speak or swallow. See World Health Organisation, 'Guillain-Barré syndrome' (WHO, 31 October 2016) <<https://www.who.int/news-room/fact-sheets/detail/guillain-barr%C3%A9-syndrome>> accessed 20 March 2020.

²³¹ *Bland* [1993] (n 3) 870 (Lord Browne-Wilkinson) and 899 (Lord Mustill).

²³² *ibid* 869 (Lord Goff).

even a small chance of recovery could find 'some good' from continued support.²³³

Therefore, there is validity in suggesting that their Lordships in *Bland* sought to limit the applicability of the case and avoid the decision being used as a precedent in cases other than permanent VS. Finally, Lord Goff also emphasises that the question of futility is not a determination on quality of life,²³⁴ instead as argued in 3.2, cases concerning futility call into question a patient's personhood status. Therefore, it would seem that the safeguard of permanence requires a certain diagnosis and prognosis to ensure the practice is sufficiently safeguarded.

However, subsequent cases have seemingly eroded any indication that a certain diagnosis is needed to determine futility. In the subsequent case of *NHS Trust A v H* [2001] (*A v H*), the evidence presented suggests that the patient was in what is now recognised as the minimally conscious state (MCS).²³⁵ H's nursing staff and consultant deemed the patient to be in a MCS due to her demonstrable responses to 'visual menace'.²³⁶ Consequently, she was retested and the second neurologist deemed her to be in a vegetative state, as a result the declaratory relief application was approved and CANH withdrawn.²³⁷ However, the determination that she was in a VS seems particularly odd if not concerning. During the 8th November testing where she was determined to be in a VS, the neurologist noted that the patient showed no response to visual menace yet simultaneously acknowledged that the patient's eyes were shut.²³⁸ Therefore, the decision seems to have been made on the basis that her responsivity had not improved in 8 years,²³⁹ indicating that permanence of prognosis is more important than permanence (as certainty) of diagnosis.

Following *A v H*, the case of *W v M* seemed to at least temporarily reassert the importance of certain diagnoses as a core component of the permanence safeguard.²⁴⁰

²³³ *ibid.*

²³⁴ *ibid.*

²³⁵ *NHS Trust A v H* [2001] (n 221); J T Giacino and Others, 'The Minimally Conscious State: Definition and Diagnostic Criteria' (2002) 58 (3) *Neurology* 349.

²³⁶ *NHS Trust A v H* [2001] (n 221) [11]. Note that visual menace is described in the case as rapidly placing a hand close to her eye and moving it away again.

²³⁷ *NHS Trust A v H* [2001] (n 221).

²³⁸ *ibid* [11].

²³⁹ *ibid.*

²⁴⁰ *W v M* [2011] (n 114). I write 'temporarily' because it was reversed in *M v N* [2015] (n 117).

For example, Baker J in *W v M* held that the patient's CANH could not be withdrawn because her (albeit minimal) awareness meant that the patient could still 'derive some joy from life',²⁴¹ in other words she held welfare interests. Baker J highlighted the 'crucial role played by the formal assessment tools, SMART and WHIM', asserting that it was of the 'utmost importance that every step should be taken to diagnose the patient's true condition before any application is made to the court':²⁴² a position that was subsequently adopted into the revised medical guidance on diagnosing PDOC patients two years later.²⁴³ This interpretation seems to follow Lord Mustill, Lord Browne-Wilkinson and Lord Goff's reasoning in *Bland*.²⁴⁴ However, four years later in the previously mentioned case of *M v N* [2015] the decision was reversed,²⁴⁵ permitting CANH withdrawal from an MCS patient who had been in an MCS state several years less than the patient in *W v M*.²⁴⁶ Additionally, Hayden J corrected the 'crucial'²⁴⁷ role PDOC assessment guidelines played according to Baker J's judgment, stating that Baker J had not intended the guidelines to be 'determinative' by highlighting their crucial role.²⁴⁸ Therefore, *M v N*'s approach to certainty and permanence of diagnosis suggests that neither permanence in terms of prognosis or diagnosis are determinative.

Moreover, the "balance sheet" assessment applied in MCS declaratory relief proceedings seems to have been interpreted directly from Lord Goff's words in *Bland*.²⁴⁹ His words have been interpreted to mean that for cases where the patient retained some interests due to increased awareness, an entirely different assessment should be

²⁴¹ *W v M* [2011] (n 114) [250]-[252] (paraphrasing).

²⁴² *ibid* [258]-[259] (paraphrasing).

²⁴³ See PDOC Guidelines 2013 (n 147), where the guidance states at page 25 that, 'the Court of Protection for withdrawal of CANH has critical impact on a serious and irrevocable decision. The Court will rightly expect a high level of certainty with respect to diagnosis'). Note this has since been removed from the PDOC 2020 guidance (n 145) in line with subsequent case law developments as discussed below.

²⁴⁴ See *Bland* [1993] (n 3) at pages 869, 870 and 889 where it was only to apply to only permanent VS patients where continued treatment is futile.

²⁴⁵ *M v N* [2015] (n 117).

²⁴⁶ By January 2015 "N" was thought to be in an MCS state and the hearing in *M v N* (n 117) was in the same April; alternatively, in *W v M* [2011] (n 114) "M" had been in a VS/ MCS since 2003 and the hearing was in 2011.

²⁴⁷ *W v M* [2011] (n 114) [258] (paraphrasing Baker J).

²⁴⁸ *M v N* [2015] (n 117) [23] (Hayden J).

²⁴⁹ *W v M* [2011] (n 114) at paragraphs [250]-[252] argues her ability to have some joy means treatment is not futile; *M v N* [2015] (n 117); *Briggs (No.2)* [2016] (n 175); *Aintree* [2013] UKSC 67, [2014] (n 72).

undertaken because the patient would have welfare interests that need to be "balanced".²⁵⁰ However, in light of the moral analysis in 3.2, this reasoning is even harder to justify than for VS and therefore perhaps Lord Goff's words should more accurately be interpreted as an attempt to further distinguish the best interests test in life support continuation decisions (concerning futility) from best interests assessments based on welfare (quality of life). In other words, life support discontinuation is permissible from permanent VS patients only because "they have no interests" and are cases where any continued treatment can properly be regarded as futile, not that an alternative balance sheet approach could also permit withdrawal in those with higher awareness. Lord Lowry, distinguishes *re F* from *Bland* because the case 'did not concern matters of life or death at all'.²⁵¹ Moreover, Lord Mustill notes *Bland* 'has no best interests'²⁵² and Lord Goff adds that 'futility', not 'quality of life' or 'dignity' is what determines such cases.²⁵³

Of course, the subsequent difficulty is that the way in which personhood theory squares the legal dilemma (that their death is preferable to the lesser albeit still serious assault) means that it is implied that the patient both has, and does not have, personhood. They have personhood because their continued treatment in law without sufficient justification is deemed an assault, but they lose personhood in order to rationalise how omissions that cause their death do not amount to homicide. Consequently, it seems that the balance-sheet interpretation may have been misconstrued and instead Lord Goff's distinction should be read as highlighting the exceptionality of *Bland*, distinguishing the case from more ordinary best interests decisions concerning welfare considerations.

This alternative interpretation is also more consistent with the rest of the *Bland* judgment because to read Lord Goff's words as delineating a different legal test for those "with interests" (increased awareness) would be inconsistent with the rest of his reasoning, particularly his insistence that withdrawal is not a determination on 'quality of life' but futility.²⁵⁴ Moreover, if any interests remain the treatment will provide 'some good' and therefore cannot be described as futile.²⁵⁵ The current balance sheet approach as it has

²⁵⁰ *Bland* [1993] (n 3) 868-869 (Lord Goff).

²⁵¹ *ibid* 877 (Lord Lowry).

²⁵² *ibid* 897 (Lord Mustill) (paraphrasing).

²⁵³ *ibid* 869 (Lord Goff) (paraphrasing).

²⁵⁴ *ibid* 868-869 (Lord Goff) (paraphrasing).

²⁵⁵ *ibid*.

been adopted in MCS cases is also out of touch with the other judges in *Bland* who note concern of *Bland's* application to those with more awareness.²⁵⁶ To read Lord Goff's distinction as also deeming such considerations appropriate in patients who retain welfare interests and have more awareness in subsequent judgments, sits ill at ease with the moral tone of the judgment and further elucidates its legal contradiction.

For a different reason Baker J has since questioned the interpretation of the split-approach between VS and MCS proceedings in balance sheet assessments.²⁵⁷ He notes that 'a variety of commentators' have since seen such a distinction as impermissible because futility 'short-circuited any such analysis [of even a VS patient's interests] by labelling the patient's condition as futile'.²⁵⁸ For these proponents, a split approach is unjustifiable as all PDOC patients' interests must be considered.²⁵⁹ Furthermore, the developments in consciousness disorders have suggested that there is increasingly less of a significant difference between VS and MCS,²⁶⁰ and that such evidence possibly bolsters the argument that VS and MCS cases should both be assessed by balance sheet.²⁶¹ However, in recognition that a determination of permanence leads to a decision that continued treatment is futile and that permanence is therefore a safeguard for PDOC patients' personhood, perhaps what should be read from questions raised on their thought 'non-awareness' is that the law should err on the side of caution and prohibit withdrawal from both patient types (VS and MCS). This is because in such cases the duty of care, existence of medical necessity, and patients' best interests are currently unable to support the starting presumption that continued treatment is not justified under *Bolitho*, because bodily autonomy and integrity are conflated.²⁶² The only way of rectifying this is

²⁵⁶ *ibid* 870 (Lord Browne-Wilkinson) and 899 (Lord Mustill).

²⁵⁷ Justice Baker, 'A Matter of Life and Death' (2017) 43 *Journal of Medical Ethics* 427.

²⁵⁸ *ibid* 431 (paraphrasing).

²⁵⁹ *ibid*.

²⁶⁰ Baker J 2017 (n 257); Chapter Two, Section 2.3.

²⁶¹ Coggon 2016 (n 65).

²⁶² This is on the basis of the misgivings I outlined in Section 3.2 (that a duty of continued care seems to exist under the *Bolitho* standard; that bodily integrity seems to have been improperly interpreted on both its distinction from bodily autonomy and on the basis that prevention of a lesser infringement of bodily integrity can trump that of their right to life where no "right to die" even exists, even for those with autonomy). Consequently, the law on assault seems to be muddled in such cases. Its underlying moral basis to support the conclusion that life support discontinuation from a living patient with foresight of their death means that the patient has to have lost their personhood.

to categorise such patients as dead for having lost voluntary responsiveness and thus personhood. I therefore believe that Baker J's approach in *W v M* [2011] was correct not to extend withdrawal to MCS patients and that it is dangerous that his interpretation of Lord Goff's words led to the belief that a different test applies which can in fact extend the consideration of futility to those holding welfare interests.²⁶³

A further noted concern about the differential treatment approach in VS and MCS cases is that a diagnosis of VS automatically lead to a judgment in favour of discontinuation.²⁶⁴ The *Prolonged Disorders of Consciousness (Interim) Guidance* (2018) suggests that vegetative state proceedings have adopted a 'blanket approach' where permanence ultimately leads to an automatic judgment in favour of withdrawal.²⁶⁵ Additionally, Baker J in *W v M* [2011] commented that, 'in vegetative state cases the balance falls in one direction in every case—in favour of withdrawal.'²⁶⁶ Mr Justice Hayden comments in *M v N* (MCS case) that in cases of permanent VS, 'the balance sheet does not apply, the diagnosis itself establishing the futility of further intervention.'²⁶⁷ Finally, Kitzinger and Kitzinger have also commented that, 'no court in the UK has ever found in favour of continuing treatment for a patient with a confirmed PVS diagnosis.'²⁶⁸

However, Coggon has suggested that this assertion is erroneous and merely 'an observation of universal truth'²⁶⁹ using the permanent VS case of *Ahsan v University*

²⁶³ *W v M* [2011] (n 114) [65]. See also paragraph [74] where the case notes that the balance sheet approach has been carried over from a best interests case concerning welfare, not futility eg *Re A (Mental Patient: Sterilisation)* [2000] (n 115) and the previously mentioned earlier VS case, *A Hospital v SW* [2007] (n 115), where the court at paragraph 28 held that no balance sheet approach applies to VS patients, which arguably reinforces *Bland* rather than creates a new approach for MCS.

²⁶⁴ *M v N* [2015] (n 117) [47]; *W v M* [2011] (n 114) [34] (Baker J); *A Hospital v SW* [2007] (n 115); Royal College of Physicians, *Clinically-Assisted Nutrition and Hydration (CANH) and Adults Who Lack the Capacity to Consent. Guidance for Decision-Making in England and Wales* (2018) 34 ("PDOC Interim Guidance 2018").

²⁶⁵ PDOC Interim Guidance 2018 (n 264) 34.

²⁶⁶ *W v M* [2011] (n 114) [34]-[35] (Baker J).

²⁶⁷ *M v N* [2015] (n 117) [47]. Note Mr Justice Hayden refers to *A Hospital v SW* [2007] (n 115) and Sir Mark Potter's words at paragraph 28 for further authority on this point.

²⁶⁸ 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 (7) *Journal of Medical Ethics* 459, 459.

²⁶⁹ Coggon 2016 (n 65) 402.

Hospitals Leicester NHS Trust [2006] (*Ahsan*) as authority.²⁷⁰ Whilst I agree with Coggon's observation to the extent that sometimes these cases discuss more than continuation of life-supporting treatment, *Ahsan* does not ask that legal question at all. As such, that case by itself cannot evidence or undermine the assertion that as soon as a doctor determines continuation of CANH as no longer in the best interests of their patient that further treatment is deemed futile. Moreover, it seems that no further permanent VS declaratory relief proceedings have come to court since *NHS Trust A v M* [2001] (*A v M*),²⁷¹ (and even that case focused on human rights compatibility, not the specific issue of permissibility of continuation under domestic law). I therefore agree with Coggon that a qualification on the 'blanket approach'²⁷² comment would be helpful as not all permanent VS cases consider whether CANH should be withdrawn.²⁷³ However, when they do, it seems that withdrawal has and thereby will always been granted.²⁷⁴

Another issue relating to permanence of diagnosis concerns the almost dismissive nature of the courts' treatment of family members' and other healthcare staff's views on the patient's capacity for awareness (responsivity). For example, Huxtable and Birchley have noted in their qualitative analysis of patterns in MCS judgments that doctors' views are 'epistemically favoured' over other health professionals and family members.²⁷⁵ They also note its oddity because carers and nursing staff are likely to 'have more contact' with the patient and therefore hold a different view to doctors' on the patient's capacity for awareness.²⁷⁶ In VS cases such as *re G (Persistent Vegetative State)* [1995] (*re G*), the doctor's view was prioritised over the family's diverging view on the patient's capacity for awareness.²⁷⁷ For MCS, Huxtable and Birchley argue that Baker J held the 'most favourable account' of the family's opinion in *W v M* but still ultimately prioritised the opinion of the

²⁷⁰ *Ahsan v University Hospitals Leicester NHS Trust* [2006] EWHC 2624 (QB), [2006] 7 WLUK 821 (*Ahsan*).

²⁷¹ *A v M* [2001] (n 40).

²⁷² PDOC Interim Guidance 2018 (n 264) 34.

²⁷³ Coggon 2016 (n 65) 402.

²⁷⁴ PDOC Interim Guidance 2018 (n 264) 34; *M v N* [2015] (n 117) [47] (Hayden J); *W v M* [2011] (n 114) [34]-[35] (Baker J); *A Hospital v SW* [2007] (n 115) [28] (Mark Potter). Note further reasons why such concerns may represent truth are raised in Subsection 3.4.2 on the basis of how that starting presumption is framed.

²⁷⁵ Richard Huxtable and Giles Birchley, 'Seeking Certainty? Judicial Approaches to the (Non-) Treatment of Minimally Conscious Patients' (2017) 25 (3) Medical Law Review 428, 441.

²⁷⁶ *ibid* 442.

²⁷⁷ *re G (Persistent Vegetative State)* [1995] (n 221).

Chapter 3

doctors.²⁷⁸ Others in MCS cases have been more dismissive of familial views, in *M v N* Hayden J suggested that family members 'may sometimes interpret simple reflexive movements as more positive interactions.'²⁷⁹ Consequently, it seems that, 'expressions of dissent [from these other professionals] are often considered in a cursory manner' by the courts in MCS continuation decisions.²⁸⁰

However, the more recent case of *Briggs (No.2)* [2016] has suggested (in the slightly different concern of certainty of prognosis) that the court will favour familial representations over doctors', even where the patient's prognosis is not certain.²⁸¹ In *Re Briggs (Incapacitated Person) (Medical Treatment: Best Interests Decision)* [2016] (*Briggs (No.2)*) the doctors (in accordance with established medical guidance²⁸²) wished to analyse his progress for a further six months.²⁸³ His doctors did not think he would make a full recovery but nevertheless expected his awareness to further improve.²⁸⁴ However, perhaps this instance on prioritising the family's views is more likely to be a prioritisation of Briggs' 'wishes, values and beliefs'²⁸⁵ and is exceptional because the family's representation of his wishes were notably compelling.²⁸⁶ Consequently, the judgment ostensibly seems quite balanced in its attention to both the medical and familial opinions but is noticeably unbalanced in its consideration of a patient's right to bodily integrity under *Bolitho*. Moreover, a closer look reveals an uncomfortable treatment and almost harassment of the two doctors presenting evidence in what seems to be an attempt to undermine and question the level of prognostic and diagnostic certainty that can be guaranteed by the PDOC 2013 guidance on permanence, and yet the decision to discontinue treatment is still taken.²⁸⁷ Consequently, this case seems to suggest that

²⁷⁸ Huxtable and Birchley 2017 (n 275) 441.

²⁷⁹ *M v N* [2015] (n 117) [22]-[23] (Hayden J).

²⁸⁰ Huxtable and Birchley 2017 (n 275) 441- 442.

²⁸¹ *Briggs (No.2)* [2016] (n 175).

²⁸² PDOC 2013 (n 147) 23-25.

²⁸³ *Briggs (No.2)* [2016] (n 175) "The Overview" paragraph 43.

²⁸⁴ *ibid.*

²⁸⁵ MCA 2005 (n 35) subsection 4(6) (paraphrasing).

²⁸⁶ *Briggs (No.2)* [2016] (n 175). See British Medical Association, 'The Role of Family and Friends in Decisions about CANH' (BMA YouTube Channel, 29 November 2018)

<https://www.youtube.com/watch?time_continue=2&v=yw66KHs1g_0> accessed 21 January 2020, where this approach has been adopted by the British Medical Association (BMA) and is in line with *Aintree* [2013]'s (n 29) approach on the patient's subjective view of futility, see from 12 minutes onwards.

²⁸⁷ *Briggs (No.2)* [2016] (n 175) "The Overview" paragraphs 35-48.

prioritisation of families' representations of patients' wishes trumps certainty of diagnosis or prognosis (safeguard of permanence) and seemingly conflates bodily integrity with autonomy. Nevertheless, such an approach to determining the permissibility of continued treatment has been recently praised by practitioners.²⁸⁸ However, it seems at odds with the orthodox legal position on how treatment is legally justifiable on a patient who has no capacity to consent, where medical necessity and establishing a duty of care held greater weight (for good reason) than consent (constructed or explicitly given).²⁸⁹ To over prioritise subjective wishes side-steps the legal protection afforded to the patient's bodily integrity. Ultimately, if there is no logical reason to doubt a duty of care exists, a failure to treat is equally an interference with the patient's bodily integrity than a positive act.²⁹⁰

Drawing the analysis back to *Bland's* focus on futility in 3.2, Harris' personhood argument casts a particularly interesting perspective on the case of *Frenchay Healthcare National Health Service Trust v S* [1994] (*Frenchay*) and the safeguard of permanence.²⁹¹ So far, the analysis has demonstrated that permanence has increasingly become less significant in the courts' determinations, despite the fact that permanence was introduced to ensure that only where it had been established that medical necessity and a duty of care no longer existed should life support be discontinued. In *Frenchay*, a patient's feeding tube had become dislodged and as a result, a question arose on whether reinsertion would be in the best interests of the patient.²⁹² The doctor determined reinsertion would not be in the patient's interests,²⁹³ however, the Official Solicitor requested more time to assess the severity of the patient's consciousness disorder (permanence).²⁹⁴ As a result two

²⁸⁸ Ruck Keene and Lee 2019 (n 52).

²⁸⁹ As analysed in Section 3.2.

²⁹⁰ *re F* [1990] (n 23); *Bland* [1993] (n 3); *R v Stone; R v Dobinson* [1997] QB 354 (CA). This has also been affirmed in the ECtHR in the case of *Price v UK* App No 33394/96 (ECtHR, 10 July 2001) where depriving a detained disabled person who has no limbs from access to their wheelchair battery charger was held to be an interference with her bodily integrity and breached Article 3 (prohibition of degrading treatment per Judge Greve at [169]. Herring and Wall 2017 (n 34) have suggested that the right to bodily integrity for disabled persons seems to extend to interference with external objects which 'share a functional unity with the body' at 587.

²⁹¹ *Frenchay* [1994] (n 221).

²⁹² *ibid.*

²⁹³ *ibid.*

²⁹⁴ *ibid.*

issues arose: how necessary was a permanent diagnosis? And, would reinsertion amount to a 'battery, whilst the court decided whether to continue treatment or not'?²⁹⁵

The case decided that no further assessment was needed and that in such cases of emergency the doctor does not need to seek court approval if he or she deems withholding treatment to be in the best interests of the patient.²⁹⁶ Consequently, if it is accepted that withholding treatment from PDOC patients is deemed necessary on the basis of futility (as loss of personhood and no medical necessity/ duty of care), likewise reinsertion to review his condition could not amount to a battery because the patient would instead be deemed as living (a person), holding welfare interests, and establish a doctor's duty of care. If alternatively, reinsertion is in his best interests but later found not to be, again this follows because it is the consideration of personhood via the best interests test itself that determines whether the patient is "alive" and harmable, or "dead".²⁹⁷ Therefore, on this basis no emergency issue seemingly arises, in any case of doubt reinsertion would provide 'some good',²⁹⁸ and would therefore not be futile, would be within P's best interests and would not amount to assault.

There is therefore good reason to reinstate the safeguard of permanence because withdrawal should only occur in those extraordinary cases where continued treatment is deemed futile in living patients as their Lordships in *Bland* had intended. To morally practice life support withdrawal as "part and parcel" of ordinary medical practice under the guise of welfare considerations precariously balances the practice on a 'quality of life' assessment and is not a permissible legal or ethical basis for withdrawal, as their Lordships specifically warn in *Bland*.

3.3.2 Developments of the Safeguard of Judicial Oversight

The safeguard of judicial oversight arose in *Bland* after four out of the five judges determined that, 'until a body of experience and practice had built up' applications for

²⁹⁵ Lynne Turner-Stokes, 'A Matter of Life and Death: Controversy at the Interface Between Clinical and Legal Decision-Making in Prolonged Disorders of Consciousness' (2017) 43 Journal of Medical Ethics 469, 470 (paraphrasing).

²⁹⁶ *Frenchay* [1994] (n 221).

²⁹⁷ Here I build on the argument in 3.2 that the best interests test seems to be used in such cases to delineate personhood, and thereby, also decide if someone is "dead".

²⁹⁸ *Bland* [1993] (n 3) 868-869 (Lord Goff).

reviewing PDOC patients' life-supporting treatment should be made to the courts.²⁹⁹ The safeguards of judicial oversight and permanence were therefore written into the Court of Protection Rules 2007 under practice direction 9E (PD 9E).³⁰⁰ Subsequently, the safeguard of judicial oversight has also received high criticism from both academics and practitioners.³⁰¹

The first noted criticism focusses on what critics view as costly and unnecessary proceedings.³⁰² In 2015, Halliday, Formby and Cookson estimated that each declaratory relief proceeding costs the NHS £122,000 in combined legal fees and ongoing care costs.³⁰³ They also converted this cost using Quality of Life Adjusted Years (QALYs-- a health economics tool) to estimate that each proceeding costs 9 years of life to another patient in foregone treatment.³⁰⁴ However, QALYs are 'infamous' for their inherent bias against disabled persons because it measures life in an ableist manner where only able-minded and bodied persons can achieve a perfect score.³⁰⁵ The practicality of using QALYs makes it an attractive tool, for example, it is useful in providing a quick method of arriving at the desired end. However, the tool overlooks inherent limitations in arriving at a defensible decision;³⁰⁶ they enable moral agents to believe they have achieved defensible decision-making because utility has been maximised,³⁰⁷ but ultimately, the process

²⁹⁹ *ibid* 859 (Lord Keith), 873 (Lord Goff), 874 (Lord Lowry) and 885 (Lord Browne-Wilkinson) (paraphrasing).

³⁰⁰ Court of Protection Rules 2007, SI 2007/1744, PD 9E, paragraph 5a.

³⁰¹ Turner-Stokes 2017 (n 295); Alex Ruck Keene, 'Advance Decisions to Refuse Life-Sustaining Treatment and the Court of Protection' (*Mental Capacity Law and Policy*, 31 October 2016) <<https://www.mentalcapacitylawandpolicy.org.uk/advance-decisions-to-refuse-life-sustaining-treatment-and-the-court-of-protection/>> accessed 22 January 2020; Simon Halliday, Adam Formby and Richard Cookson, 'An Assessment of the Court's Role in the Withdrawal of Clinically Assisted Nutrition and Hydration from Patients in the Permanent Vegetative State' (2015) 23 (4) *Medical Law Review* 556. Note "practitioners" includes lawyers (judges) and doctors.

³⁰² Halliday, Formby and Cookson 2015 (n 301).

³⁰³ *ibid* 580-581 (paraphrasing).

³⁰⁴ *ibid*.

³⁰⁵ John Harris, 'It is Not NICE to Discriminate' (2005) 31 (7) *Journal of Medical Ethics* 373, 373; Ben Davies, 'Bursting Bubbles? QALYs and Discrimination' (2019) 31 (2) *Utilitas* 191; Josh Cohen and others, 'Will ICER's Response to Attacks on the QALY Quiet the Critics? A Reply from the Partnership to Improve Patient Care' (CEVR, 28 January 2019) <<https://cevr.tuftsmedicalcenter.org/news/2019/pipcreply>> accessed 19 December 2019; John Harris, 'QALYfying the Value of Life' (1987) 13 *Journal of Medical Ethics* 117.

³⁰⁶ Harris 1987 (n 305).

³⁰⁷ Guy Kahane, 'Sidetracked by Trolleys: Why Sacrificial Moral Dilemmas Tell Us Little (or Nothing) About Utilitarian Judgment' (2015) 10 (5) *Social Neuroscience* 551, 554. Note, this article provides a

overlooks the intrinsic and currently unsolvable problem of "commensurating" the value of human life.³⁰⁸

Moreover, given that PDOC patients' awareness is currently being contested by neurologists,³⁰⁹ perhaps there is still good reason for these cases to be overseen by the courts.³¹⁰ The Official Solicitor in *An NHS v Y* argues that, 'challenges of diagnosis have increased since the *Bland* case, rather than becoming clearer'.³¹¹ Nevertheless, Lady Black opines that the developments in medical science are adequately safeguarded without the need for judicial oversight.³¹² According to Lady Black, 'survival ... then so unprecedented, is now a well-established feature of medical practice' where specialist knowledge and the practice requirement of 'a second opinion from a senior independent clinician', provides adequate safeguards.³¹³

However, the evidence in 2.3 (that patients' survival rates have increased and that such patients have not lost the "awareness" that rendered continued treatment futile) means that the appropriateness of withdrawal is possibly more in question than ever. As Wicks comments, Lady Black's judgment seems to be deferential to the medical profession which 'stands in surprising contrast to post-MCA 2005 approaches' but 'would not have been out of place at the height of *Bolam*'s power and ubiquity'.³¹⁴ Interestingly, whilst I agree that such judgments seem in line with *Bolam*'s medical paternalism, this judgment seems to overlook the very basis of the *Bolam* and later *Bolitho* ruling. The review of medical evidence is not a peripheral issue, it is central to the established law on protecting bodily integrity for those who are unable to consent. Therefore, even if medical regulations have been met, if the practice itself holds no logical basis because the evidence is that such patients are aware (or at least cannot be proved unaware), the

comparative overview of benefits and pitfalls of deontology and utilitarianism in resolving moral dilemmas and the permissibility and prevention of harm.

³⁰⁸ Harris 1987 (n 305).

³⁰⁹ As discussed in depth in Chapter Two, Section 2.3.

³¹⁰ Baker J 2017 (n 257) 434.

³¹¹ *An NHS Trust v Y*[2018] (n 10) [122] (Lady Black).

³¹² *ibid* [122]-[124] (Lady Black).

³¹³ *ibid*.

³¹⁴ Wicks 2019 (n 228) 3.

practice is failing to discharge a duty of care and medical necessity under *Bolitho*.³¹⁵ Therefore, perhaps the judiciary should be doing more to investigate the medical evidence that allegedly supports discontinuation on the basis of loss of awareness rather than assuming that the starting presumption is still sufficiently supported.

A second criticism of the safeguard of judicial oversight relates to whether PD 9E of the Court of Protection Rules 2007 rendered the validity of Legal Power of Attorneys (LPAs)³¹⁶ and Advance Decisions (ADs)³¹⁷ that refused life-sustaining treatment ineffective, even if they were formulated in accordance with sections 24, 26 and subsection 11(8) of the MCA.³¹⁸ In Baker J's *Oxford Shrieval Lecture* he doubted whether LPAs or ADs were binding in the context of refusal of life-sustaining treatment due to paragraph 5a of PD 9E.³¹⁹ He also 'set a number of hares running in the public press'³²⁰ with the comment that, 'so far as I am aware, there is no instance in this country of a case in which ANH has been withheld or withdrawn from a [PDOC] patient ... without reference to the court.'³²¹ However, Baker J has since corrected these statements in a revised version of the lecture transcript,³²² and the COP Rules 2017 have since removed PD 9E entirely.³²³ Finally, the Supreme Court in *Aintree* reaffirmed that properly formulated LPAs and ADs that refuse life-supporting treatment will also be binding in such decisions.³²⁴

³¹⁵ Note that the analysis on how much patients' wishes weigh in the presumption that continued treatment is not in the patient's best interests after *Aintree* [2013] (n 72) and *Briggs (No.2)* [2016] (n 175) and will be assessed in Section 3.4.

³¹⁶ Under section 9 of the MCA 2005 (n 35), an LPA grants a nominated representative power to make decisions on an individual's behalf in case of their future incapacity. There are strict limitations on the scope of the power given to the nominated legal power of attorney under section 11 MCA 2005 (n 35), particularly in life support withdrawal decisions.

³¹⁷ An AD is a binding document that legally records an individual's wishes in the event of future incapacity under section 24 MCA 2005 (n 295).

³¹⁸ Turner-Stokes 2017 (n 295).

³¹⁹ Baker J 2017 (n 257) 429.

³²⁰ See Turner-Stokes 2017 (n 295) at page 471 where she refers to Steve Doughty, 'Don't Obey Orders in a Living Will, Judge Orders: Ruling Means Patients in Unconscious State Cannot Die Without the Case Going Before a Court' Daily Mail (London, 24 October 2016) <<https://www.dailymail.co.uk/news/article-3868762/Don-t-obey-orders-living-judge-orders-doctors-Ruling-means-patients-unconscious-state-die-without-case-going-court.html>> accessed 22 January 2020.

³²¹ Baker J 2017 (n 257) 429.

³²² This has been corrected in a footnote in Baker J 2017 (n 257) on page 429.

³²³ Information on this decision was outlined in *An NHS Trust v Y*[2018] (n 10) at [51]-[52] and [98] by Lady Black; *U v Liverpool City Council (Practice Note)* [2005] 1 WLR 2657 (CA) at [48] notes that PDs that create a legal obligation where none exists in law have gone beyond their proper scope.

³²⁴ *Aintree* [2013] (n 72) [19] (Lady Hale).

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Returning to the issue of whether these cases should continue to be overseen by the courts, Ruck-Keene notes that PD 9E in the COP Rules 2007 was silent on the issue.³²⁵ Likewise, the COP Rules 2017³²⁶ are still silent and have instead removed PD 9E in its entirety.³²⁷ Notably, *An NHS v Y* decided that no legal obligation ever existed that "such cases must be overseen by the courts" but advised in cases of conflict or uncertainty that such cases should be brought before the courts.³²⁸ Ostensibly, such a decision has not changed the law because doctors for some time have been deciding whether or not they should go to court, meaning that not all cases have or are being brought to court.³²⁹

However, Wicks argues that the judgment has removed the legal mechanism for State oversight (supranational obligation) to protect and oversee Article 2 'right to life' of the Human Rights Act 1998.³³⁰ Lady Black opines that the requirement for judicial oversight in *Bland* and later in the Mental Capacity Act Code of Practice 2007³³¹ was 'always advised but never an imperative'.³³² Her reasoning rests on an ambiguity between the Code of Practice 2007's paragraph 6.18 that, 'some treatment decisions are so serious that the court *has to make* them', and in paragraph 8.19 that they '*should* be put to the Court of Protection for approval'.³³³ As Wicks argues, 'despite apparent confirmation that there is a legal 'requirement' to bring such cases before the courts, the use of the word 'should' ... leads Lady Black to conclude that the Code of Practice is not consistent in its approach to involving the court', and consequently (and possibly illogically) that no requirement to do so exists.³³⁴ The judgment also potentially undermines the ability for future developments in medicine to shape the law in accordance with improving medical standards;³³⁵ a point of serious concern given the infamous misdiagnosis rates, the difficulty of accurate diagnoses and the increasing survival rates of PDOC patients.³³⁶ In

³²⁵ Ruck Keene 2016 (n 301).

³²⁶ Court of Protection Rules 2017, SI 2017/1035.

³²⁷ *An NHS Trust v Y*[2018] (n 10) [98] (Lady Black).

³²⁸ *ibid*.

³²⁹ Turner-Stokes 2017 (n 295) 472.

³³⁰ Wicks 2019 (n 228).

³³¹ Lord Chancellor, *Mental Capacity Act 2005: Code of Practice 2007* (Lord Falconer, 23 April 2007).

³³² *An NHS Trust v Y*[2018] (n 10) [48] (Lady Black) (paraphrasing).

³³³ *ibid* [46] (Lady Black).

³³⁴ Wicks 2019 (n 228) 4.

³³⁵ See the Official Solicitor's concerns raised on this point in *An NHS v Y*[2018] (n 10) at paragraphs [89] and [124].

³³⁶ *ibid*.

response to Lady Black's judgment the medical guidance has since been updated and has followed her interpretation.³³⁷

However, the Court of Protection has since issued guidance that possibly conflicts with *An NHS v Y*. For example, although it was decided that cases should (not must) go to court if the parties disagree or require clarification from the courts,³³⁸ in *Practice Guidance (CP: Serious Medical Treatment)* [2020], Hayden J asserts that, where a decision is 'finely balanced', involves a 'difference of medical opinion', or 'a lack of agreement' from relevant parties, or entails 'a potential conflict of interest', such cases must always consider whether court oversight is required.³³⁹ He further adds, 'where any of [those] matters ... arise and the decision relates to the provision of life-sustaining treatment an application to the Court of Protection *must* be made.'³⁴⁰ He states that this is required to be compliant with the UK's supranational obligations under the European Convention on Human Rights 1950 and that, 'for the avoidance of any doubt, this specifically includes withdrawal or withholding of clinically assisted nutrition and hydration.'³⁴¹ This last addition is particularly interesting because it seems to conflict with Lady Black's assessment in *An NHS v Y* that there is no reason to treat PDOC patients differently from other 'critically ill' patients or those with 'degenerative neurological conditions'.³⁴²

Wicks also argues that a further disappointing aspect of the *An NHS v Y* judgment is that it wasted an opportunity to grapple with the underlying ethical and procedural issues.³⁴³ Such issues certainly include safeguarding and the courts' role in upholding consistency and factual accuracy within their moral and legal reasoning which seems to have been lost in these cases.³⁴⁴ For example, due to the courts weakened ability to oversee medical practice in such cases, the law's potential to develop in line with medical advancements will consequently be more difficult and therefore has potentially created a

³³⁷ PDOC Interim Guidance 2018 (n 264) 40.

³³⁸ *An NHS Trust v Y* [2018] (n 10) [102] and [126].

³³⁹ *Practice Guidance (CP: Serious Medical Treatment)* [2020] (n 224) [8] (Hayden J).

³⁴⁰ *ibid* [8]-[9] (Hayden J).

³⁴¹ *ibid* [9] (Hayden J).

³⁴² *An NHS Trust v Y* [2018] (n 10) [119].

³⁴³ Wicks 2019 (n 228) 4.

³⁴⁴ This is a point being argued consistently throughout the analysis on safeguards in Subsections 3.3.1 and 3.3.2.

direct legal conflict with itself on the basis of *Bolitho*.³⁴⁵ This point supports Wicks' assertion that the judgment has arguably marked a reversion to an attitude of deference shown to the medical profession in determining these cases.³⁴⁶ This in turn suggests (in line with Harris' personhood theory and the findings of Chapter Two³⁴⁷) that the courts have deferred the definition and determination of death (and thereby futility and "who is a human non-person") back to doctors, despite the finding that death is no longer a predominantly medical or scientific issue. The effect of these key cases since *Bland* is that the safeguards of permanence and judicial oversight have been largely, if not entirely eroded. The subsequent question raised is how are these decisions currently being determined and safeguarded?

3.3.3 Section Conclusion

It seems that the safeguards of permanence and judicial oversight have been largely, if not entirely removed by the subsequent cases (after *Bland*) of *M v N*, *Briggs (no.2)* and *An NHS Trust v Y*.³⁴⁸ Moreover, the doctor's role has simultaneously been undermined (by the fact that diagnostic criteria no longer play a central role in such decisions³⁴⁹) but also affirmed by the courts (where the Supreme Court determined that the built up body of medical practice sufficiently safeguards the lives of PDOC patients, which consequently no longer requires judicial oversight³⁵⁰). Furthermore, the court maintained that in cases of dispute that resolution could still be sought from the courts,³⁵¹ indicating that the courts have not totally relinquished that power.

It seems that the courts are treating the starting presumption in such cases as an irrefutable and established fact that does not need to be reviewed. This in itself is problematic from a disability perspective. For example, noting how far the evidence on consciousness disorders has developed since *Bland*, that framing therefore blocks any

³⁴⁵ Wicks 2019 (n 228) 4.

³⁴⁶ *ibid* 3.

³⁴⁷ Harris 1999 (n 65); Chapter Two, Section 2.3 (loss of responsiveness is equated with death, even if inadvertently) and Section 2.4 (that death seems to be a personhood determination).

³⁴⁸ *M v N*[2015] (n 117); *Briggs (No.2)* [2016] (n 175); *An NHS Trust v Y*[2018] (n 10).

³⁴⁹ See *M v N*[2015] (n 117) at paragraph [23] where Hayden J downplays the role of the diagnostic tests to a non-determinative standing; *Briggs (No.2)* [2016] (n 175).

³⁵⁰ See *An NHS Trust v Y*[2018] (n 10) at paragraphs [122]-[124] (Lady Black).

³⁵¹ *An NHS Trust v Y*[2018] (n 10).

possibility of challenging the basis for presuming continued treatment would be an assault. Finally, given the particular responsibility of ensuring those with cognitive disability have an equally protected right to life, it is alarming that the judiciary have not invoked *Bolitho* to assess whether such a practice still holds a logical basis and is correctly protecting bodily integrity (and not autonomy) in line with established legal precedent on the matter. As a result, it seems that not only is the justificatory basis for life support withdrawal decisions unclear from a moral, medical and legal perspective (because it was the diagnosis of non-awareness which clinically indicated that withdrawal was necessary³⁵²) but that it is also unclear who has the final say as the clearly identifiable decision-making agent in such decisions.³⁵³

3.4 Identifying the Legal Capacity at Issue and its Safeguards

3.4.1 Mental Capacity, Liberty or Self-Exercisable Agency?

This chapter's sections have highlighted an inconsistent approach to safeguarding bodily integrity and the use of futility determinations to only those with permanent diagnoses. But it also builds on inaccuracy arguments by Coggon, Miola, Bielby and Dworkin that the best interests test conflates different types of legal capacities,³⁵⁴ by suggesting that it also conflates the moral principles justifying a particular legal capacity's use in a particular case.³⁵⁵ For example, 3.2 argues that the moral principle in these PDOC declaratory relief proceedings is not welfare (as a form of prevention of harm) or consent, and is instead futility which was found to be treated in law as a moral principle in its own right.

Moreover, and for the purpose of this thesis, it is necessary to identify what legal capacity is at issue in best interests tests that grapples with responsibility impairments to elucidate why life support withdrawal is thought necessary, how that is being implemented and justified, and who is formally making the decision. Consequently, it will answer the chapter's titular question on whether or not the best interests test is an appropriate mechanism to determine whether treatment is futile or not and safeguard

³⁵² *Bland* [1993] (n 3). As discussed in Section 3.2.

³⁵³ Discussed further in Section 3.4.

³⁵⁴ Coggon and Miola (n 80); Bielby (n 82); Dworkin (n 82).

³⁵⁵ It seems that entirely different tests are used under the umbrella term "best interests test".

bodily integrity. This section will therefore seek to identify what specific legal capacity is at issue in PDOC declaratory relief proceedings and highlight any further inaccuracy and safeguarding concerns that remain. The hypothesis is that PDOC declaratory relief claims seem to conflate bodily autonomy with integrity, disguise the decision-making agent, the justification for withdrawal (futility, welfare or consent) and the legal capacity at issue. A noted example evidenced throughout 3.3 is that such decisions do not follow or apply legal precedent.³⁵⁶ There is also little consistency found in the subsumption of judicially adopted moral values.³⁵⁷ I will therefore now turn to the Mental Capacity Act 2005 (MCA) itself to see if its key provisions can provide further guidance on the matter.

The Explanatory Notes of the MCA are territorially relevant for this thesis as its provisions specifically apply to E&W.³⁵⁸ Its key purpose is to clarify uncertainties that have arisen in the context of third parties making decisions on behalf of others who lack decision-making capacity to do so themselves.³⁵⁹ Additionally, its provisions aid those who, because of brain injury or illness, have lost decision-making capacity;³⁶⁰ adding that several 'European Convention of Human Rights (ECHR) issues arise in relation to a number of provisions'.³⁶¹ The Act also created the Court of Protection to oversee its implementation.³⁶² Importantly, its provisions specifically outline the nature of the best interests test and note that its overarching ethos is 'empowerment' of those who lack capacity, and therefore encourages patient 'participation'.³⁶³ The empowerment and participation ethos is most evidently held in subsection 4(4) MCA's 'participation' requirement. The Act does not include substituted decision-making powers for those who lack legal capacity entirely, instead the patient's past and present, wishes, values and beliefs (including those of their family or others' with proximate relationships) are

³⁵⁶ Camillia Kong and others, 'Judging Values and Participation in Mental Capacity Law' (2019) 8 Laws 3.

³⁵⁷ *ibid*.

³⁵⁸ MCA 2005 (n 35) Explanatory Notes para 17.

³⁵⁹ *ibid* para 4.

³⁶⁰ *ibid*.

³⁶¹ *ibid* para 9. Note paragraphs 10-16 outline the relevant parts and sections of the Act where European Convention on Human Rights 1950 (n 62) issues arise.

³⁶² MCA 2005 (n 35) Explanatory Notes para 8.

³⁶³ *ibid* section 4(4); House of Lords Select Committee on the Mental Capacity Act 2005, *The Mental Capacity Act 2005: Post-Legislative Scrutiny* (HL Paper 139, 2014) para 2. See also MCA Code of Practice 2007 (n 331) paragraph 5.23.

considered under subsections 4(6) and 4(7) MCA.³⁶⁴ However, it seems that there still remains some confusion on the purpose of the Act and what it seeks to achieve.³⁶⁵ The House of Lords Select Committee in 2014 criticised the courts' interpretation of section 4 MCA for failing to empower patients and include them in the decision-making process.³⁶⁶ Specifically, it was felt that the participation consideration in subsection 4(4) had been overlooked.³⁶⁷ The noted impact and criticism from independent mental capacity bodies was that the MCA's intended supported decision-making model had not been effectuated and substituted decision-making seems to be being practiced in its place.³⁶⁸

A recent paper by Kong and others has characterised the MCA as a 'values-based piece of legislation' where considerations of "autonomy" and its 'empowerment ethos' are present throughout the legislation.³⁶⁹ However, the Act may more accurately be described as a single value-based piece of legislation that instead encases different legal capacities,³⁷⁰ which are in turn supported by moral principles such as non-maleficence (prevention of harm), beneficence (welfare) and informed consent. All of these principles act as different aims of upholding an individual's autonomy. Consequently, autonomy as a moral value better translates into two distinct types of legal capacity: liberty as legally recognised freedom and mental or "decision-making" capacity.³⁷¹ This section will explore whether a third is also apparent. If correct, the view of the Act as a 'values-based piece of legislation'³⁷² obscures what the best interests test is doing, rather than ameliorates the noted confusion.

³⁶⁴ MCA 2005 (n 35) subsections 4(6) and 4(7). Note the updated PDOC 2020 guidance (n 145) at page 22 uses the term "family" inclusively, which is not 'restricted to those with legal ties or blood relations. Instead, "family" refers to 'anyone who has a sufficiently close relationship to be actively concerned with their management and well-being' for the purpose of best interests decision-making.

³⁶⁵ Select Committee 2014 (n 363); Kong and others (n 356).

³⁶⁶ *ibid.*

³⁶⁷ Kong and others (n 356).

³⁶⁸ Select Committee 2014 (n 363) paragraphs 2, 83 and 99.

³⁶⁹ Kong and others (n 356) 3 (paraphrasing).

³⁷⁰ This interpretation is supported by Coggon and Miola's (n 80) insight that autonomy in law is more than informed consent, representing two legal capacities (liberty and mental capacity). It is these different instances (capacities) of "autonomy" that are being identified by Kong and Others.

³⁷¹ Coggon and Miola (n 80); Bielby (n 82); Dworkin (n 82). Note decision-making capacity is also known as decision-making competence.

³⁷² Kong and Others (n 356) 3 (paraphrasing).

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Section 3.2 outlined that futility is the ethical basis underpinning such cases and that it is distinct from the other moral principles that underpin best interests decisions that can invariably be grouped together as welfare cases. It therefore began to elucidate that perhaps there is an entirely different best interests test occurring in PDOC patients' life support continuation decisions. However, it did not answer what type of legal capacity is at issue. For example, mental capacity in the sense of 'to weigh, retain and understand'³⁷³ is not explicitly at issue in these cases because the patient is thought non-aware not non-responsive. Decision-making capacity more often arises as an issue where a patient ostensibly has the liberty to choose between or refuse clinically indicated treatment options, but where welfare considerations have arisen that justify third-party intervention in overseeing that decision.

Forgiving the following generalisations to make the following point, the MCA covers a variety of welfare considerations that can be regarded as decision-making capacity issues, for example, anorexia,³⁷⁴ Jehovah's witnesses' refusals for blood transfusions,³⁷⁵ and sterilisation procedures (like those considered in *re F*). In such cases, liberty is not at issue, and in none of these aforementioned cases are the claimants arguing for the law to recognise a new freedom (unlike in *Burke* [2005] where it was at issue because Leslie Burke sought to enforce a right to "request" treatment and failed³⁷⁶). *Burke*-like cases consider legal capacity as liberty, whereas, in cases such as *re F*, decision-making capacity is at issue because doctors doubt the patient's ability to weigh, retain and understand the consequences of a decision.

It seems that the capacity to respond or 'communicate a decision' under paragraph 3(1) (d) is grouped together with the capacity to 'weigh, retain and understand' information pertinent to a decision, which is stipulated under paragraphs 3(1) (a)-(c) MCA. This is potentially problematic for PDOC patients because if it is the case that they are

³⁷³ MCA 2005 (n 35) paragraphs 3(1) (a)-(c).

³⁷⁴ *NHS Trust v L* [2012] EWHC 2741 (COP), [2012] WLUK 345 considered whether it was in the best interests of a patient with severe anorexia nervosa and in the closing stages of her life to be force-fed.

³⁷⁵ *Newcastle upon Tyne Hospitals Foundation Trust v LM* [2014] EWHC 454 (COP), [2014] 2 WLUK 846 considered whether a gravely ill Jehovah's witness had the decision-making capacity to refuse a life-saving blood transfusion if her condition deteriorated.

³⁷⁶ *Burke* [2005] (n 104).

inner-aware and able to form decisions but lack the ability to communicate, the MCA will automatically deny their decision-making capacity on the basis of their responsivity impairment, because a failure to demonstrate a single element of those listed under section 3(1) MCA will mean that the patient will be deemed to lack decision-making capacity.³⁷⁷ PDOC patients' particular impairment impacts their capacity to respond but not necessarily their capacity to weigh, retain and understand; as the findings of 2.3 suggest, neurologists believe PDOC patients to be generally inner-aware but non or minimally responsive. It would therefore be appropriate for PDOC patients' declaratory relief proceedings to discuss the implication of lacking the ability to communicate where such patients' hold the ability to form a decision on whether to continue life-supporting treatment. However, it is generally not considered because of the pervading view that PDOC patients are non or minimally aware. Ultimately, if a patient is found to lack any one of the abilities outlined in paragraphs 3(1) (a)-(d) then the presumption in subsection 1(2) MCA that, 'a person must be assumed to have capacity unless it is established that he lacks capacity', no longer stands. Therefore, PDOC patients' capacity to have inner awareness would largely be ignored without a legislative amendment, even if the erroneous view of their non-awareness is corrected in common law.

Moreover, there is an even more challenging bar to any assessment of what legal capacity is at issue in these declaratory relief proceedings presented by the MCA. The Essex Autonomy Project in 2014 surveyed the compliance of the MCA with the rights contained in the Convention on the Rights of Persons with Disability 2006 (CRPD).³⁷⁸ They argue that the MCA is, 'remediably non-compliant' and particularly noted subsection 2(1)'s potential for discrimination against PDOC patients.³⁷⁹ The subsection states that, 'a person lacks capacity in relation to a matter if at the material time he is unable to make a decision

³⁷⁷ Shewmon 1997 (n 146) 59-60. Note others have questioned the nomenclature of consciousness as opposed to responsivity disorders and is discussed throughout Chapter Two, Section 2.3.

³⁷⁸ Wayne Martin, Sabine Michalowski, Timo Jütten and Matthew Burch, *Achieving CRPD Compliance. Is the Mental Capacity Act of England and Wales Compatible with the UN Convention on the Rights of Persons with Disabilities? If Not, What Next?* (EAP, 22 September 2014) Essex Autonomy Project Paper <<https://autonomy.essex.ac.uk/resources/achieving-crpds-compliance/>> accessed 30 May 2019 (EAP 2014). Further discussed in Chapter Four, Sections 4.3 and 4.4.

³⁷⁹ ibid 1 and 5. Note after analysing, Law Commission, *Law Commission Paper 128: Mentally Incapacitated Adults and Decision-Making—A New Jurisdiction* (Paper 128, 1993) Part III, the EAP 2014 (n 337) claim the purposes listed for the diagnostic threshold's inclusion fail to pass the proportionality test for indirect discrimination.

for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain'.³⁸⁰ In the human rights literature this has been referred to as the 'diagnostic threshold':³⁸¹ the 'presence of the impairment is the basis for surmising lack of competence', where no further assessment of mental capacity is required.³⁸² It also has a sort of "chilling effect" by preventing any further assessment of what legal capacity is being considered in these particular best interests decisions. This is particularly problematic for the CRPD whose ethos is otherwise followed by the MCA's empowerment and participation approach, as evidenced by the CRPD's paradigmatic shift to remove substituted decision-making and roll out a policy of shared decision-making.³⁸³ These findings suggest that decision-making capacity (assessed under section 3 MCA) is not the legal capacity being assessed in such cases.

Further provisions in the Act suggest that liberty is not being assessed either as "freedom to" (i.e. legally enforceable rights³⁸⁴). Sections 4B and 21A outline the law on Deprivation of Liberty Orders (DOLs) necessary for life-sustaining treatment and which uphold a patient's welfare interests.³⁸⁵ These sections possibly uphold sanctity of life and prevention of harm (bodily integrity) more generally under their paternalistic approach to treatment. However, the DOL provisions that are underpinned by harm were deemed inapplicable to PDOC patients in *Re M (Withdrawal of Treatment: Need for Proceedings)* [2017] (*re M* [2017]), where Jackson J stated that, 'it is a fallacy to suggest that a patient without any real awareness could be deprived of their liberty by receiving life-sustaining treatment.'³⁸⁶ In both *re M* [2017] and *Director of Legal Aid Casework & Ors v Briggs* [2017] (*Director of Legal Aid v Briggs*),³⁸⁷ the claimants had sought to use the legal aid loophole available in DOL provisions to bring declaratory relief claims they otherwise

³⁸⁰ MCA 2005 (n 35) subsection 2(1).

³⁸¹ EAP 2014 (n 378) 1 and 5.

³⁸² Amita Dhanda, 'Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future' (2007) 34 Syracuse Journal of International Law and Commerce 429, 432.

³⁸³ This is discussed in Chapter Four, Section 4.3.

³⁸⁴ Liberty is more generally discussed later in this subsection (3.4.1).

³⁸⁵ Note that considerable changes have recently occurred to the regulation of DOLs which are now governed under the Mental Capacity (Amendment) Act 2019.

³⁸⁶ *Re M (Withdrawal of Treatment: Need for Proceedings)* [2017] EWCOP 19, [2018] 1 WLR 465 [39] (Jackson J) (*Re M* [2017]) (paraphrasing).

³⁸⁷ *Director of Legal Aid Casework & Ors v Briggs* [2017] EWCA Civ 1169, [2018] Fam 63 (*Director of Legal Aid v Briggs*).

could not afford.³⁸⁸ Therefore, Jackson J's *obiter* on DOLs and awareness seems common-sense at first sight. However, given the evidence in 2.3 that questioned the accuracy of viewing disorders of consciousness as consciousness, as opposed to responsibility disorders, his words, in a clear intent to show contempt for abuse of the legislation may have overstepped. If fMRIs continue to evidence not only communication but inner awareness in PDOC patients, there exists a real possibility that DOLs will also become applicable to such patients. For current purposes, it is enough to say that as the law stands even this different principle-based provision is deemed inapplicable to PDOC patients.

There is also scope to suggest that at the heart of these declaratory relief proceedings is freedom to "refuse" treatment (a recognised and "legally enshrined" freedom).³⁸⁹ The fact that the best interests test was created out of a lacuna left by the Mental Health Act 1959 meant that the courts could no longer, in effect, consent or refuse treatment on behalf of incapacitated adults.³⁹⁰ Consequently, *re F* extended its alternative justification for treating a patient who cannot consent to cases such as *Bland's*, to decide on the permissibility of continued life-supporting treatment. As discussed in 2.3, *Bland's* interpretation superficially seems to be a welfare test by placing the decision within a doctor's duty of care. Thereby, doctors were also identified as the moral (decision-making) agents. However, as 3.3 has demonstrated, subsequent cases have overlooked the bodily integrity element and seem to be treating such cases as liberty considerations necessitating proxy consent mechanisms (ss 4(6) and 4 (7) MCA 2005) and has left unanswered who the decision-making agent is.

However, on the basis of prior analysis doctors were not assessing welfare but futility which according to Lord Goff, could not be rationalised or justified on the basis of balancing harms; fundamentally, such patients "have no welfare interests" and cannot be harmed.³⁹¹ Consequently, it seems that no two separate moral values can be identified to suggest a moral value conflict is occurring in such cases, as first hypothesised in 1.3.2. Instead, and as identified in 3.2, there is a single value, futility, which is being assessed on the basis of losing a particular form of legal capacity. Therefore, the, in effect, constructed

³⁸⁸ *Re M* [2017] (n 386) [39] (Jackson J); *Director of Legal Aid v Briggs* [2017] (n 387).

³⁸⁹ As most recently reaffirmed in *Burke* [2005] (n 104) at paragraph [31].

³⁹⁰ As explained by Lord Browne-Wilkinson in *Bland* [1993] (n 3) at page 883; *Re F* [1990] (n 23).

³⁹¹ *Bland* [1993] (n 3) 869 (Lord Goff). As discussed in Subsection 3.2.2.

refusal (due to the conflation of bodily autonomy and integrity in such cases) needs to be explored, as well as to identify the legal capacity at issue.

The current test for futility is drastically different than *Bland's*. The Supreme Court in *Aintree*,³⁹² in line with the autonomy-based ethos of the MCA, sought to re-emphasise the importance of the patient's 'wishes and feelings' ... 'beliefs and values'.³⁹³ Fundamentally, the case interpreted 'futility' in line with the subjective views of the patient.³⁹⁴ There is a possibility that the purpose of rendering futility as a subjective test was to remove the controversial differential treatment between VS and MCS cases that the balance sheet distinction presented.³⁹⁵ Furthermore, the Mental Capacity Act Code of Practice 2007 indicated at paragraph 5.31, that 'futility' was still a key feature of such decisions, which, in light of the Act's empowerment ethos seems to make *Aintree's* interpretation of futility appropriate.³⁹⁶

Consequently, Lady Hale accepts Jackson J's interpretation of futility in the first instance hearing over the Court of Appeal's *Bland*-like interpretation.³⁹⁷ For Sir Alan Ward in the Court of Appeal, non-futile treatment is that which has a 'real prospect of curing or palliating the life-threatening disease or illness'.³⁹⁸ Instead, and post-*Aintree*, futile treatment is treatment which cannot 'resum[e]... a quality of life which [the patient] would regard as worthwhile'.³⁹⁹ Although the patient focussed interpretation of futility is more in line with the MCA's ethos, communication of the patient's subjective views is inherently problematic. Where no binding advance planning is in place,⁴⁰⁰ it opens up the question of how others' views of what the patient would regard as worthwhile can be safeguarded

³⁹² *Aintree* [2013] (n 72).

³⁹³ MCA 2005 (n 35) paragraphs 4(6) (a) and (b).

³⁹⁴ Discussed at paragraphs [27]-[41] in *Aintree* [2013] (n 72).

³⁹⁵ Discussed in Subsection 3.3.1.

³⁹⁶ MCA 2005 (n 35) subsection 4(4); Select Committee 2014 (n 363) at paragraph 2. See also MCA Code of Practice 2007 (n 331) paragraph 5.23.

³⁹⁷ See *Aintree* [2013] (n 72) at paragraph [30], where Lady Hale adopts Jackson J's wording and test for futility.

³⁹⁸ *Aintree* [2013] (n 72) [35] (Lady Hale quoting Sir Alan Ward in the Court of Appeal hearing).

³⁹⁹ See *Aintree* [2013] (n 72) at paragraph [30], where Lady Hale adopts Jackson J's wording and test from the first instance hearing.

⁴⁰⁰ 'Advance planning' is a collective term for an LPA, AD or advance statement. Advance statements are a relatively new form of advance planning and records the wishes of the patient to be considered by healthcare staff, note that for refusals of treatment an AD is more appropriate.

against.⁴⁰¹ Pre-empting the issue, Lady Hale recognises the 'strong element of substituted judgment' in the current best interests test but asserts that the test still holds an important, albeit subtle distinction from substituted judgment tests.⁴⁰² Lady Hale therefore highlights the central importance of the patient's views, wishes, values and beliefs,⁴⁰³ (which has since been praised by the House of Lords Select Committee⁴⁰⁴) but interestingly adds a qualification on the extent to which a patient's view of futility can be prioritised, stating that, their subjective view cannot 'prevail any more than those of a fully capacitous patient[s]'.⁴⁰⁵ It therefore seems that self-exercisable agency, as a form of legal capacity, is more accurately at issue in these proceedings than decision-making competence or liberty.

3.4.2 Fallout and Implications

Since *Aintree*'s interpretation of futility, the case has had three distinct impacts on the consistency and factual accuracy of judicial decision-making in such cases. First, that of safeguarding (What is the doctor's role in these decisions? How to prevent third parties wholly constructing a refusal without any means of assessing the legitimacy of their claims? How are these decisions being overseen in light of supranational duties to protect life after *An NHS v Y*?). Secondly, what is the legal capacity at issue in such cases under *Aintree*? And thirdly, how does this new test of align itself with how medical treatment is justified in patients who cannot consent?

Regarding the first concern of the doctor's role after *Aintree*, it seems that futility as an objective medical standard has become a quasi-substituted and subjective standard, particularly in light of the *M v N* and *Briggs (No.2)* judgments that seemingly, and increasingly, eroded the importance of medical decision-making from these decisions. The diagnostic criteria and tests are now non-determinative,⁴⁰⁶ and consequently withdrawal

⁴⁰¹ Mary Donnelly, 'Best Interests in the Mental Capacity Act: Time to Say Goodbye?' (2016) 24 (3) Medical Law Review 318, 322.

⁴⁰² *Aintree* [2013] (n 72) [24] (Lady Hale).

⁴⁰³ *ibid.*

⁴⁰⁴ See Select Committee 2014 (n 363) at paragraph 99.

⁴⁰⁵ *Aintree* [2013] (n 72) [39]-[40] and [45] (Lady Hale).

⁴⁰⁶ *M v N* [2015] (n 117) [23] (Hayden J). Discussed in Subsection 3.3.1.

does not seem to have to be clinically indicated;⁴⁰⁷ therefore, the erosion of the safeguard of permanence significantly seems to undermine the doctor's role and the law's protection of bodily integrity.

In relation to the additional concern of what safeguards exist to prevent others over-interpreting the patient's purported wishes, values and beliefs to construct a refusal, there is good reason to doubt that the courts have sufficiently provided a mechanism to fulfil a patient's wishes "with", as opposed to "for" them.⁴⁰⁸ As briefly mentioned in 3.2, subsection 1(5), section 18 and Schedule 2 paragraphs 1-4 MCA set out the powers of the Court of Protection to write a "statutory will" on behalf of a mentally or cognitively impaired individual, which can frustrate the previously "binding" wishes of a PDOC patient.⁴⁰⁹ Harding notes the discriminatory attitude that the practice has demonstrated towards mentally and cognitively impaired individuals on respecting their recorded wishes,⁴¹⁰ further noting that E&W 'is one of the few jurisdictions that allow a court (or anyone other than the testator) to execute a will'.⁴¹¹ The statutory will powers of the MCA grant the Court of Protection the power to write a will (and in effect re-write a will⁴¹²) on "behalf" of such individuals who have never executed a will, have now lost capacity and cannot do so, or for those whose will's validity and continuing relevance is in question.⁴¹³ In such circumstances, the Court seems to employ a process of just deserts to reallocate their property.⁴¹⁴ The question that arises is therefore, if legally binding and expressly formulated wishes are overruled by the court (albeit in the context of property), what evidence exists to suggest that the courts are willing to respect a non-refusal? In fact, this would fall under a request to be kept on life-supporting treatment as occurred in *Burke*.

⁴⁰⁷ *Briggs (No.2)* [2016] (n 175). Discussed in Subsection 3.3.1.

⁴⁰⁸ In line with the empowerment ethos of the MCA 2005 (n 35) subsection 4(4); Select Committee 2014 (n 363) paragraph 2. See also MCA Code of Practice 2007 (n 331) paragraph 5.23. As discussed further in Chapter Four, Section 4.3.

⁴⁰⁹ Harding (n 182).

⁴¹⁰ *ibid.*

⁴¹¹ *ibid* 947. See Harding's footnote 28 for her definition of a statutory will.

⁴¹² *Re D (Statutory Will)* [2010] EWHC 2159 (Ch), [2012] Ch 57. Note this case does not concern a PDOC patient but the lady in question had suffered a stroke leaving her unable to communicate properly and therefore has similarities with prolonged disorders of consciousness as "responsivity" disorders.

⁴¹³ Harding (n 182).

⁴¹⁴ *ibid* 962-964.

Moreover, if a doctor believes treatment to no longer be clinically indicated, neither the family, nor the patient, have a right to request continued treatment. Donnelly convincingly argues that a subterfuge⁴¹⁵ has occurred in subsections 4(6) and 4(7) of the MCA which relates to the moral and legal permissibility of third parties deciding such irrevocable decisions on behalf of a non- (or minimally) responsive patient.⁴¹⁶ For Donnelly, ignoring the epistemic limitations of accurately knowing what a non-responsive patient wants and values creates a scenario where the decision-making agency and rationale for the decision remains 'obscured'.⁴¹⁷ This idea is further developed below and in 4.3 which addresses how these epistemic limitations impact the defensibility of such judgments and whether they can be mitigated or alternatively indicate that indefensible decision-making has occurred.

An NHS v Y also raised some further problems post-*Aintree*. The safeguard of judicial oversight has been removed by the judgment because it was thought that enough of a practice had been established for doctors to safely oversee these decisions.⁴¹⁸ However, the cases of *M v N* and *Briggs (No.2)* suggest that the courts have been frustrating the key legal role (in protecting the patient's bodily integrity) that doctors hold in these decisions by either overruling their advice or subjecting them to a barrage of questioning that seems designed to undermine the role diagnostic testing plays.⁴¹⁹ Moreover, the Court of Protection's most recent guidance attempts to reassert the integral role that the courts have in overseeing these decisions by direct reference to the UK's supranational obligations to ensure the protection of the lives of all its citizens.⁴²⁰

⁴¹⁵ The definition and exploration of subterfuges occurs further below in this section.

⁴¹⁶ Donnelly 2016 (n 401). A subterfuge differs from a legal fiction as 'a device that accomplishes a socially desirable end without making clear the calculus that produces that end ... [and] are not used to justify the creation of new legal rules, but permit judges to say that the law requires one thing while they actually do something quite different,' as explained by Peter J Smith, 'New Legal Fictions' (2007) 95 *The Georgetown Law Journal* 1435 at pages 1470-1471. See also Guido Calabresi, *Ideals, Beliefs, Attitudes and the Law* (Syracuse University Press 1985), to whom the concept of legal subterfuges are often attributed and who notes that they often occur when a tragic choice has to be made at page 88.

⁴¹⁷ Donnelly 2016 (n 401) 327.

⁴¹⁸ *An NHS Trust v Y*[2018] (n 10) [122]-[124] (Lady Black); Wicks 2019 (n 228) 1. Discussed in Subsection 3.3.2.

⁴¹⁹ Discussed in Subsection 3.3.1

⁴²⁰ COP Practice Guidance [2020] (n 224) [8-9] (Hayden J).

Consequently, it seems that futility is being treated as a decision relating to the legally recognised capacity to refuse treatment (a form of legally enshrined liberty⁴²¹). However, due to PDOC patients' responsiveness (as opposed to consciousness) impairment, the legal capacity at issue is more accurately identified as self-exercisable agency than liberty (as occurred in *Burke*) or competence (like in *re A*). Moreover, this renders the current test of futility a subjective quality of life judgement and ignores Lord Goff's warning that such justifications are inappropriate.⁴²² Additionally, the emphasis in *Aintree* that the patients' wishes are restricted 'to the same extent as that of capacitous patients', further renders this test of futility analogous to a "right to refuse treatment".⁴²³

Perhaps such a finding is not surprising. In the leading judgment in *Bland*, Lord Goff argues that the extension of futility to VS patients was necessary because they had no way of refusing treatment, implicitly suggesting an inequality in law existed that, 'would lead to cruel and adverse effects'.⁴²⁴ Although in *Bland* this "right to refuse" was more appropriately formulated as part of doctors' objectively assessed duty of care,⁴²⁵ it is now justified on the subjective view of a non or minimally responsive patient, who cannot, nor is facilitated to communicate such a refusal.⁴²⁶ Consequently, in such cases the identity of the legal capacity at issue can only partially be liberty. Instead, it seems to suggest that these patients lack self-exercisable agency to fulfil a decision based on a recognised liberty as "freedom to refuse treatment". Perhaps it is for this reason that subsections 4(6) and 4(7) of the MCA 2005 incorporate such a mechanism for others to do so on their behalf, with the focus in such cases on fulfilling the patient's presumed wishes rather than substituting one's own in their place.⁴²⁷ However, the findings of this section have been that such third-party representations possess no safeguards, or method of testing and evidencing the legitimacy of such representations.⁴²⁸ Moreover, the findings of 3.2 suggest that the current best interests test elides bodily autonomy and integrity in decisions solely

⁴²¹ As most recently reaffirmed in *Burke* [2005] (n 104) at paragraph [31].

⁴²² See *Bland* [1993] (n 3) at pages 868 and 869 (Lord Goff).

⁴²³ *Aintree* [2013] (n 72) [45].

⁴²⁴ Originally argued in *Bland* [1993] (n 3) at page 849 by the respondent's legal team (led by Robert Francis QC and Michael R Taylor) and then again by Lord Goff at page 865.

⁴²⁵ Discussed in Section 3.2.

⁴²⁶ Discussed earlier in this section (3.4).

⁴²⁷ *Aintree* [2013] (n 72). See in particular paragraphs [38]-[41] for Lady Hale's opinion on this point.

⁴²⁸ Donnelly 2016 (n 401).

concerning bodily integrity. Consequently, the MCA's "liberty" based best interests test can therefore be characterised in PDOC patients' life support withdrawal cases as an attempt to fit "square pegs in round holes" and threatens their personhood.

As a result, there are some further notable implications. After the findings of 3.2, that futility decisions withdraw a patients' personhood status, a question arises: does this mean that PDOC patients can determine when they are no longer persons and consequently their own "death", albeit with the purported assistance of others to communicate such a decision? As shocking as this may seem it certainly fits the argument made that to not provide such patients with a mechanism to refuse life-sustaining treatment 'would lead to cruel and adverse effects'.⁴²⁹ It is therefore clear to see why Donnelly has characterised the current best interests test as a legal subterfuge, although not specifically in the context of futility.

Moreover, it is unclear who is formally making such decisions. *Aintree* suggests it is the patient albeit with assistance. *An NHS Trust v Yasserts* it is doctors and not the courts who at least safeguard the practice by determining whether withdrawal is clinically indicated. But what about *M v N* and *Briggs (No.2)*? In those decisions, the decision-making agent seems to be judges who have eroded the role of doctors by determining that such decisions no longer hinge on whether continuation is clinically indicated or not. And most deafeningly silent of all is whether futility (indicating loss of personhood) is therefore sufficiently safeguarded under *Aintree*'s subjective test. The answers seem to be it is not safeguarded at all.

Furthermore, the generalised observation in 3.3.1 (that this question is always answered by a decision to withdraw treatment) raises an important concern. It seems that the legal question starts with a presumption that itself seemingly does not need to be proved or established, making it exceptionally difficult to challenge and arguably blocking the *Bolitho* standard/ legal safeguard in the face of medical evidence that questions the very basis for believing continued treatment to be an assault. I therefore agree with Foster that the stronger starting presumption should be in favour of life and that the rebuttable

⁴²⁹ Originally argued in *Bland* [1993] (n 3) at page 849 by the respondent's legal team (led by Robert Francis QC and Michael R Taylor) and then again by Lord Goff at page 865.

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presumption should be to prove that continued care assaults the patient.⁴³⁰ To adopt the current interpretation that the starting presumption is correct overlooks that two invasions of bodily integrity are being weighed (not autonomy) and that Article 2 has greater weight than Article 3 ECHR unless shown otherwise. It also must be a presumption that has to be established rather than presumed because if not, patients with cognitive (and mental) impairments will never be protected legal persons on the basis of unsupported and outdated medical evidence. Consequently, my aim is not to replace one always with another (always preserve life) but to highlight that the current framing of that crucial legal question itself needs to be rebalanced to appropriately protect their right to bodily integrity in accordance with established law.

Moreover, *Aintree* emphasised that a PDOC patient's wishes cannot be given more weight than that of an autonomous patient; not that they hold the same rights, just that where they do they are to be given equal weight. Consequently, subsections 4(6) and 4(7) MCA seemingly amount to a courtesy to the family and patient, not confirmation of a presumption that does not need to be established by medical evidence first. It cannot be read or implemented as a power for the family to construct a refusal that can trump the need to establish no duty of care or medical necessity continues to exist (no matter how beneficent). To do so synonymises the presumption with a "right to die" even where the patient has no capacity to refuse (or consent) and where such a right does not exist in law. If such a right did exist, Lord Goff in *Bland* would not have taken the pains to explain that the right to refuse treatment is not akin to a suicide wish or a question of the doctors having aided or abetted a suicide.⁴³¹

The right to refuse is an exception in law where the patient has bodily autonomy (agency and decision-making capacity for this particular liberty). Where the patient lacks decision-making and agency capacity (and consequently lacks liberty to hold the right itself), an invasion of bodily integrity has to be justified by medical evidence (duty of care and necessity). Yet herein lies the problem, the starting presumption is never questioned

⁴³⁰ Foster 2019 and 2020 (n 65). This also seems to fit with the court's requirement for the safeguard of judicial oversight discussed in Subsection 3.3.2. Note however, that the Supreme Court in *An NHS Trust v Y*[2018] (n 10) has since cast further doubt on this requirement despite the Court of Protection more recently requiring that such decisions must be overseen by the court (*Practice Guidance (CP: Serious Medical Treatment)* [2020] (n 224)).

⁴³¹ *Bland* [1993] (n 3) 864.

or has to be proven by the *Bolam/ Bolitho* standard on which it has always been founded. Therefore, where *Bland* states that autonomy and sanctity of life were at odds, it would be more accurate to claim that two levels of an invasion of bodily integrity were in conflict: the right to life and protection from assaults other than killing. Fundamentally, even autonomous patients do not hold a right to die, their right to refuse is an exception in respect of their competing right to bodily autonomy. Those who lack autonomy can similarly achieve it through the limited use of LPAs and ADs if they so wish, fundamentally questioning the current approach to subsections 4(6) and 4(7) MCA in such cases. The key question in the fall out is whether the courts' attempt to extend a right to refuse life-supporting treatment (recognise a right to bodily autonomy) for those who are non or minimally responsive can attain the equality that it implicitly seeks to achieve? Chapter Four will therefore assess whether the use of subsections 4(6) and 4(7) MCA to determine futility achieve *de facto* equality or amount to a possible finding of indirect discrimination.

The core finding of this chapter is therefore that, PDOC patients may be legal persons in name only: a nominal status without any real legal or moral protection and in more than healthcare aspects of their lives; it extends to property,⁴³² sexual assault⁴³³ and also implications for the law on murder.⁴³⁴ *Bland* also demonstrates the consequences of translating across, and adjudicating on, an issue as important and politically wide-ranging as the definition of death in very particular and narrow circumstances.

To access the moral defence of *phronesis*, decision-makers in PDOC life support withdrawal cases will have to make a choice. They must either adopt a policy of candour⁴³⁵ (that some disabled lives (and their right to bodily integrity) are not equal to other disabled or able-bodied and minded persons' lives) or reappraise the definition of death on the basis that it is currently unsafeguarded and can immorally extend to PDOC patients and other cognitively impaired individuals as well. For example, it extends to the withdrawal of antibiotics from dementia patients and recorded instances of DNACPRs

⁴³² Harding (n 182) 962-964; *Re D (Statutory Will)* [2010] (n 412).

⁴³³ Hanna and Allen (n 183).

⁴³⁴ Explored in Section 3.2 and will be further assessed throughout Chapter Four.

⁴³⁵ Donnelly 2016 (n 401) at pages 326-328; Quinn 2010 (n 164) at pages 16-18 discusses candour as a needed policy change. The advantages and disadvantages of this approach for PDOC patients is discussed in Chapter Four, Subsection 4.3.3.

being justified on the basis of learning disability.⁴³⁶ The current acts versus omissions distinction does not create an exception, it has created a norm; the normalisation of treatment withdrawal (irrespective of its invasive or non-invasive nature or even inner awareness) to living, cognitively and even intellectually disabled “persons” on the basis that their right to life can be trumped by a lesser (albeit still serious) assault.⁴³⁷ I suggest, that in either case (whether PDOC patients’ personhood is reinstated or not) the definition and determination of death is desperately in need of reappraisal, not least for the practice to be appropriately regulated and safeguarded. The current presumption that death is determined by clear biological indicators enables a false sense of security that all biologically living and born individuals are protected persons.

The moral defence of *phronesis* is only applicable to those who have reflected on and drawn from, all sources of medical decision-making to make factually accurate and consistent choices.⁴³⁸ To continue the status quo with that knowledge and without an explicit choice being made on their personhood status, morally amounts to indefensible decision-making:⁴³⁹ the standard of medical decision-making after *Bland* was updated by *Bolitho*,⁴⁴⁰ therefore the intellectual and moral incongruity of these cases should have been questioned. It seems that the law assumes futility is an entirely different concept from how death is defined and determined.⁴⁴¹ If it had not, perhaps the definition and determination of death would have been reappraised sooner.

For futility, as the concept that defines death, Gurnham similarly notes this same tension (on whether patients’ “rights” or wishes should determine futility or the medical

⁴³⁶ See CRPD 2006 ‘List of Issues’ 2017 (n 184) Part A subparagraph 1 (f) and Part B subparagraph 19 (f). Note although this is noted case concerns withholding instead of withdrawing, there is little moral difference between withholding and withdrawing, as discussed in *Bland* [1993] (n 3). I also acknowledge that learning disability is an intellectual as opposed to cognitive disability but see their current treatment in medical practice as indistinguishable in terms of their personhood status.

⁴³⁷ *ibid*.

⁴³⁸ As discussed in Chapter One, Section 1.3 which explored the defensible standard of medical decision-making, however its principle can theoretically and perhaps morally extend to legal decision-making also. Note, this is an issue outside the ambit of this thesis ie if *Bolam* [1957] (n 24) and *Bolitho* [1998] (n 24) should also apply to legal decision-making.

⁴³⁹ The standard of factual accuracy and consistency, and its limitations and adoption in medicine and law were discussed respectively in Chapter One, Sections 1.2 and 1.3.

⁴⁴⁰ *Bolitho* [1998] (n 24). As discussed in Chapter One, Subsection 1.3.3.

⁴⁴¹ Note this was first hypothesised as a possibility in Chapter One, Subsection 1.4.4, where the evidence presented subsequently seems to clearly support it.

professional's judgement of what is clinically indicated) is at the heart of the *Burke* judgment that conversely determined that patients could not request life-supporting treatment.⁴⁴² The evidence from 3.3 and 3.4 suggests that the courts are more leniently interpreting what amounts to a request and what amounts to refusal in cases such as *Briggs (No.2)* and *M v N*, as the decision to discontinue treatment in either case was not clinically indicated by the standard of futility at the time they were decided. This in turn questions just how equal the courts' attempt to extend a refusal to non-responsive patients has been. However, the shift towards patients' wishes for those who are non-autonomous cannot itself support the conclusion that continued treatment amounts to an invasion of bodily integrity; explain or resolve the moral inconsistency;⁴⁴³ evidence the accuracy of any assumption of what a patient wishes;⁴⁴⁴ or who has the ability to exercise legal capacity on their behalf (decision-making agency).⁴⁴⁵ Therefore, I argue that the shift to patient wishes is not morally defensible, nor appropriate in such decisions whilst they are treated as non-persons presumed incapable of inner-awareness.

3.4.3 Section Conclusion

This section has evidenced that the decision-making agency and justificatory rationale supporting withdrawal is currently obscured in PDOC patients' best interests determinations concerning life support withdrawal.⁴⁴⁶ Both are obscured due to a purported dilemma having taken place in response to *Bland's cri de Coeur*.⁴⁴⁷ The subsequent developments in 3.3 have demonstrated that futility (as the process of delineating who is a legal person with moral standing and as the medical justification that continued treatment amounts to an assault) now exists or has possibly been replaced by the power given to third parties' representations of what the patient would deem futile under subsections 4(6) and 4(7) MCA.⁴⁴⁸ This process enables an unsafeguarded extension of the definition and determination of death and also obscures responsibility for the death

⁴⁴² David Gurnham, 'Losing the Wood for the Trees: *Burke* and The Court of Appeal' (2005) 14 Medical Law Review 253.

⁴⁴³ As discussed in Section 3.2.

⁴⁴⁴ Donnelly 2016 (n 401).

⁴⁴⁵ *ibid.*

⁴⁴⁶ Subsection 3.4.2.

⁴⁴⁷ Finnis 1993 (n 14) 329. As discussed in Chapter One, Section 1.4 and Chapter Three, Section 3.2.

⁴⁴⁸ *ibid*; *Aintree* [2013] (n 72).

of the patient if it arose from illegal assault.⁴⁴⁹ Moreover, the basis for third party representations is implicitly justified on a belief that to not extend an equal right to refuse would be discriminatory.⁴⁵⁰ Therefore, Chapter Four will assess this belief under equality and non-discrimination provisions to see whether such an assertion accurately interprets current non-discrimination law. In recognition of the epistemic limitations faced by judges,⁴⁵¹ and the fact that cognition, death and personhood are linked by a web of concurrent developments not easily traced in medicine, law and philosophy,⁴⁵² the defence of *phronesis* is only available to those who react accordingly and reappraise death.⁴⁵³

3.5 Conclusion

PDOC patients' declaratory proceedings' use of the best interests test are unique because they delineate a patient's personhood and seem more akin to a Part 8 declaration.⁴⁵⁴ Section 3.2 demonstrated that Harris' theory offers the most consistent interpretation of the moral and legal status of PDOC patients.⁴⁵⁵ Sections 3.3 and 3.4 subsequently highlighted the implications of holding on to the erroneous belief that *Bland* was, and can be justified on the basis of a quality of life assessment. The chapter's findings have ultimately demonstrated why best interests (as a legal tool for determining the permissibility of continued treatment) is ill-suited if not dangerous because of best interests predominant relationship with bodily autonomy. Other's views of a patient's stance on their quality of life cannot defensibly determine the futility of treatment and thereby the patient's personhood status on a moral or correct legal basis. The shift towards the prioritisation of autonomy in post-MCA 2005 case law has inconsistently and inaccurately interpreted the uniqueness of what *Bland's* judges sought to achieve and safeguard by conflating bodily integrity and autonomy. The result is paradoxical. By making futility (protection of bodily integrity) a subjective (to the patient) test in *Aintree* it

⁴⁴⁹ Discussed in Subsections 3.2.2 and 3.2.3.

⁴⁵⁰ *Bland* [1993] (n 3) 864-865 (Lord Goff).

⁴⁵¹ Discussed in Subsection 3.4.1.

⁴⁵² Discussed in Chapter Two, Sections 2.2 and 2.4.

⁴⁵³ As argued in Chapter One, Section 1.3.

⁴⁵⁴ Civil Procedure Rules 1998; Discussed in Section 3.2.

⁴⁵⁵ Harris 1999 (n 65). As discussed in Section 3.2.

seems that a non-responsive patient can now determine their own "death" by stripping themselves of personhood both morally and legally, despite no communication of such a refusal for life-supporting treatment, nor any attempt to facilitate such patients to communicate such a view.

The chapter challenges the perception that PDOC patients are unquestionably protected legal persons with moral standing. In 3.3, the subsequent legal developments indicate that this recognition is in name only and not just in the area of healthcare. Ultimately, PDOC patients are insufficiently protected against third-party interference to the extent that any assumed legal rights and protections are called into question.⁴⁵⁶ Additionally, these best interests decisions not only introduce a different and legally recognised moral principle—"futility" (how death is determined)—but also a further identified form of legal capacity as self-exercisable agency.

In response, this particular best interests test questions whether such patients hold a right to bodily integrity at all in the name of protecting their purported bodily autonomy, yet simultaneously provide instances where their alleged autonomy is also stripped away from them (statutory wills, questioning the binding power of LPAs and ADs etc). The current best interests test therefore not only perhaps overlooks the justificatory basis for continued treatment (clinical indication) but also treats that crucial point of law as a starting presumption that itself does not need to be evidenced, creating a direct conflict with the law on which it itself is established (*Bolitho*). This alarmingly makes that starting presumption unchallengeable and questions whether those who lack autonomy have a right to life at all. Therefore, the exploration of personhood has not only elucidated why life support discontinuation cannot be morally or legally justified from a living patient (personhood), but that the law holds a contradictory and conflated understanding on PDOC patients' right to bodily integrity and how withdrawal of treatment was traditionally justified on the basis of loss of personhood (brainstem dead patients).

To be clear, this chapter addresses why the law (as it currently stands) is confused and does not seek to answer how treatment can otherwise be positively justified. Such an endeavour is unnecessary if the law is correctly interpreted. I do not support the view that

⁴⁵⁶ Flynn and Arstein-Kerslake 2014 (n 181).

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PDOC patients should be regarded as 'human non-persons'.⁴⁵⁷ Instead, the point of this endeavour is to challenge the belief that they are currently recognised and sufficiently protected legal persons. Such assumptions have exacerbated their potential abuse by failing to explore how their personhood has been protected or undermined. *Bland*-like cases are no longer legal exceptions but the norm. Finally, *Bland* has wider-implications than for just PDOC patients as the case sadly marks legal approval of life support withdrawal (and withholding) from any patient with cognitive and now possibly intellectual disability as well. Fundamentally, if these cases are now predominantly about autonomy rather than bodily integrity, they amount to a form of assisted death/ euthanasia which is currently prohibited and raises concerns of discrimination and inequality in the law's treatment of impaired individuals (cognitively or otherwise). The battleground for their reinstatement as legal persons with moral standing is currently occurring within international human rights law debates,⁴⁵⁸ an area to which I will now turn.

⁴⁵⁷ Harris 1999 (n 65) 293 (paraphrasing).

⁴⁵⁸ Flynn and Arstein-Kerslake 2014 (n 181); Quinn 2011 (n 128); Quinn 2010 (n 164); Rosemary Kayess and Phillip French, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8 (1) *Human Rights Law Review* 1; Dhanda 2007 (n 382).

Chapter 4 Wars and Proxy Wars:¹ The Best Interests Test Under Heavy Fire in the Fight for Persons with Impairments' Equal Recognition in Law

4.1 Chapter Introduction and Aims²

Thematically, this Chapter will demonstrate that pivoting around the 'no-man's land'³ existence that patients with prolonged disorders of consciousness (PDOC patients) find themselves in are other battles that are all fundamentally focussed on a larger war.⁴ That war is fighting for 'persons with impairments'⁵ (disability) to hold equal recognition in law. As Chapter Three demonstrated, their personhood is in question due to the unsafeguarded powers of others to exercise legal capacity on their behalf (without consent), the starting legal presumption's treatment as a non-rebuttable standard and because bodily autonomy and integrity are conflated in such cases.⁶ The war's Western Front is found within the Convention on the Rights of Persons with Disabilities 2006

¹ An apt phrase borrowed from Gerard Quinn's speech presented to the University of British Columbia in April 2011, where he described the 'war over legal capacity' as a 'proxy war over personhood'. See Gerard Quinn, 'Rethinking Personhood: New Directions in Legal Capacity Law and Policy' (University of British Columbia, 29 April 2011)

<http://citizenship.sites.olt.ubc.ca/files/2014/07/Gerard_Quinn_s_Keynote_-_April_29_2011.pdf> accessed 1 June 2019. Note Gerard Quinn has two published papers in 2011 mentioned in this chapter. Therefore, this reference shall be shorthand referred to as "Quinn Conference Paper 2011 (n 1).

² Note this chapter's sections, like Chapter Three's, do not have their own introductions. That structure is not necessary here.

³ H A M J ten Have and J Welie, *Death and Medical Power* (OUP 2005) 8. The phrase 'no man's land paradox' has been borrowed from Have and Welie's book on euthanasia and assisted dying in the Netherlands.

⁴ Quinn 2011 Conference Paper (n 1).

⁵ Rosemary Kayess and Phillip French, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8 (1) *Human Rights Law Review* 1, 21. This terminology has been specifically used because it is how the CRPD 2006 itself refers to those with a disability. The CRPD's reasons for this are explained in Subsection 4.2.3.

⁶ Quinn 2011 Conference Paper (n 1). As discussed in Chapter Three, Section 3.4, these powers largely exist under the Mental Capacity Act 2005 (MCA), subsections 4(6) and 4(7).

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(CRPD), specifically Articles 12 and 5 which outline its interpretation of 'equality and non-discrimination' (Article 5) and 'equal recognition before the law' (Article 12).⁷

Therefore, the central aim of this chapter is to assess whether the current best interests test in such cases is compliant with the non-discrimination and equality provisions of the CRPD. Specifically, it examines whether subsections 4(6) and 4(7) MCA's attempt to, in effect, extend a "right to refuse treatment" may amount to a finding of indirect discrimination in an attempt to treat such patients equally.⁸ The chapter will also draw on European Court of Human Rights' (ECtHR) case law but ultimately focuses on the CRPD because of its potentially 'revolutionary'⁹ interpretation of equality and non-discrimination. The CRPD calls for a conceptualisation of legal capacity (mental capacity, liberty or agency) that is divorced from cognition by prohibiting status-based discrimination and equality mechanisms that fail to appropriately recognise "difference". Consequently, based on the findings of previous chapters that established a link between cognition as the 'indicia for personhood'¹⁰ and medically defined death (futility), the CRPD may hold the potential to appropriately restore the exercise of legal capacity to persons with impairments and thereby their status as legal persons.

⁷ UN, Convention on the Rights of Persons with Disabilities and Optional Protocol (adopted 13 December 2006, entered into force 3 May 2008) UNGA A/Res/61/106 (CRPD).

⁸ *Airedale NHS Trust v Bland* [1993] AC 789 (HL) (*Bland*) 864-865 (Lord Goff); *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [2014] AC 591 (*Aintree*). As argued in Chapter Three, Subsection 3.4.2.

⁹ Gerard Quinn, 'Legal Capacity Law Reform: The Revolution of the UN Convention on the Rights of Persons with Disability' (2011) 83 *Frontline* 26, 26. There are two Gerard Quinn papers referred to in this Chapter, therefore the shorthand of this paper will be referred to as "Quinn *Frontline* 2011 (n 9)".

¹⁰ Gerard Quinn, 'Personhood and Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD' (HPOD Conference at Harvard Law School, 20 February 2010) <[https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/archive/Submission-on-Legal-Capacity-to-the-Oireachtas-Committee-on-Justice,-Defence-&-Equality-\(August,-2011\).pdf](https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/archive/Submission-on-Legal-Capacity-to-the-Oireachtas-Committee-on-Justice,-Defence-&-Equality-(August,-2011).pdf)> accessed 1 June 2019, 6.

4.2 **Unlocking the 'Revolution':¹¹ Substantive to Universalist Equality**

4.2.1 **What is the CRPD 2006 Fighting Against?**

Mental health law shares the same tension at the heart of its legal and policy developments as the later established mental capacity law which can be described as an oscillating battle between law and medicine concerning who should have control over those of 'unsound mind'.¹² However, mental health law is traditionally more paternalistic than mental capacity law which purports to centralise the patient's autonomy.¹³ That paternalism was justified on the basis of a harmful political and philosophical attitude that saw these individuals as either a nuisance to be managed or as high-risk threats to the security of other persons and/or their property.¹⁴ For example, the *parens patriae* doctrine originated in 'Edward I's reign and from the powers of the Vagrancy Act 1744'.¹⁵ It later became 'the basis for non-consensual treatment and detention today' because of the 'risk of harm to self or others' that such patients posed.¹⁶ Both State sanctioned detainment measures and laws for non-consensual treatment were introduced to provide a justificatory basis to protect not only others' property but also to protect the property or person of individuals suffering from 'unsound mind' from themselves.¹⁷

However, the laws introduced in the 18th and 19th Centuries marked a shift towards an attitude of 'treatment and welfare' for such patients, and thus began the fight for increased regulation of the medical profession's detainment and treatment powers.¹⁸ It

¹¹ Quinn Frontline 2011 (n 8) 26.

¹² Piers Gooding, 'Change and Continuity in Mental Health Law: The Long Road to the United Nations Convention on the Rights of Persons with Disabilities and its Implications for Mental Health and the Law Today' (2014) 20 (3) European Journal of Current Legal Issues <<http://webjcli.org/article/view/367>> accessed 26 June 2019, sections 2 and 3.

¹³ Mental health law concerns the regulation of non-consensual treatment practices based on objective medical interests. Alternatively, mental capacity law focuses on issues such as informed consent standards and protection against undue influence. Gooding (n 12) has provided a detailed review of these historically oscillating tensions between paternalism and patient autonomy in the development of mental health and capacity law.

¹⁴ Gooding 2014 (n 12).

¹⁵ ibid section 2 (paraphrasing).

¹⁶ ibid.

¹⁷ ibid.

¹⁸ ibid section 3.

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was not until the 1970s that the rise of 'legalism', coupled with a policy of 'deinstitutionalisation', that the language of 'rights' was born with the intent to 'bolster the dignity and integrity of those who were dehumanised in psychiatric and medical institutions, and marginalised by discriminatory laws'.¹⁹ Despite this new wave of legalism and increased calls for rights, even the introduction of several human rights covenants in the 20th Century did not ameliorate the abuse persons with impairments were sometimes subjected to.²⁰ An often-noted criticism is that these instruments failed to specifically recognise disabled persons as a group particularly vulnerable to human rights violations.²¹ Consequently, 'disability has been an invisible element of international human rights law'.²² Therefore, the CRPD's adoption of concepts such as "personhood" and "rights" for "persons with impairments" are intentional and provocative linguistic tools to fight policy agendas and legislation that has historically abused and dehumanised them.²³

The specific dehumanisation and abuse faced by PDOC patients has already been outlined across Chapter Three. Specifically, 3.2's findings suggest that PDOC patients' cognitive impairment means that their personhood and moral standing status are brought into question because cognition is the likely 'indicia'²⁴ of personhood. Additionally, 3.2 noted specific instances of harm: the loss of their voice in decision-making;²⁵ the questionability of their right to bodily integrity in both life support²⁶ and sexual abuse

¹⁹ ibid.

²⁰ ibid section 5.

²¹ ibid. Gooding specifically refers to the International Bill of Rights, where none of its instruments specifically protect those with disability as a recognised vulnerable group, nor do any of the 'thematic conventions' either, except the UN, Convention on the Rights of the Child (adopted 20 November 1989, entered into force 2 September 1980) UNTS 1577, where Article 23 protects mentally and physically disabled children.

²² Kayess and French (n 5) 12.

²³ ibid. For example, the 'right to equal recognition in law' in Article 12 CRPD 2006 reasserts 'persons' with impairments' personhood in law and policy.

²⁴ Quinn 2010 (n 10) 6.

²⁵ As noted in Chapter Three, Section 3.4 PDOC patients' right to bodily integrity has been conflated with bodily autonomy. As a consequence, it seems that a non or minimally responsive patient who has no recorded wishes can have life support withdrawn on the basis of a constructed refusal by others, as opposed to medical necessity and a duty of care basis, and in a largely unsafeguarded manner.

²⁶ Noting the use of learning disability as a justification for placing a DNACPR on a patient's file. See United Nations Committee on the Rights of Persons with Disabilities, *List of Issues in Relation to the Initial Report of the United Kingdom of Great Britain and Northern Ireland* (20 April 2017) CRPD/C/GBR/Q/1 <https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fGBR%2fQ%2f1&Lang=en> accessed 19 September 2019, Part A

decisions;²⁷ the law's denial of their ability to be deprived of liberty;²⁸ the law's ability to overwrite testamentary wishes;²⁹ and the lack of criminal responsibility being brought for their wrongful "deaths".³⁰ Such instances align more easily with the historical and paternalistic attitude that saw those with mental and cognitive impairments as 'risks to be protected against'.³¹ This different attitudinal approach also supports the argument made in Sections 3.2 and 3.4, that the best interests assessment in PDOC patients' life support continuation cases is different to the autonomy-centralising ethos of the Mental Capacity Act 2005 (MCA) and thereby mental capacity law's ordinary purpose: welfare protection. Consequently, the relationship between cognitive (and mental) impairment, loss of moral personhood and the right to bodily integrity, need to be borne in mind because it questions if PDOC patients have a right to bodily integrity (and legal personhood) and if that right been elided with bodily autonomy in the fight for those with impairments to be centralised in the decision-making process. If so, PDOC patients require legislation that has the potential to reverse that second-class legal protection and appropriately restore the balance. The CRPD may hold that potential due to its ethos of 'equal recognition in law'³² which became its 'lodestar' for the revolutionary attitude shift that the CRPD calls for in the treatment of persons with (cognitive) disability.³³

subparagraph 1 (f) and Part B subparagraph 19 (f). As discussed in Chapter Three, Subsections 3.2.3 and 3.4.2.

²⁷ Jason Hanna and Keith Allen, 'A Nurse is Accused of Impregnating a Woman in a Vegetative State Who Later Gave Birth' (US, 24 January 2019) <<https://edition.cnn.com/2019/01/23/health/arizona-woman-birth-vegetative-state/index.html>> accessed 18 December 2019; BBC News, 'Nurse Arrested After Vulnerable Patient Gives Birth in US Clinic' (UK, 23 January 2019) <<https://www.bbc.co.uk/news/world-us-canada-46978297>> accessed 18 December 2019. As Discussed in Chapter Three, Subsections 3.2.3 and 3.4.2.

²⁸ *Re M (Withdrawal of Treatment: Need for Proceedings)* [2017] EWCOP 19, [2018] 1 WLR 465 (*Re M* [2017]); *Director of Legal Aid Casework & Ors v Briggs* [2017] EWCA Civ 1169, [2018] Fam 63 (*Director of Legal Aid v Briggs*). As discussed in Chapter Three, Subsection 3.4.1.

²⁹ Rosie Harding, 'The Rise of Statutory Wills and the Limits of Best Interests Decision-Making in Inheritance' (2015) 78 (6) The Modern Law Review 945. As first mentioned in Chapter Three, Subsections 3.2.3 and discussed in Section 3.4.2.

³⁰ Discussed in Chapter Three, Subsection 3.2.3 as a consequence of only the partial adoption of legal causation via the acts versus omissions distinction in *Bland*, which has been carried across into the later VS and MCS cases discussed in Chapter Three, Section 3.3.

³¹ Gooding 2014 (n 12) section 2 (paraphrasing).

³² CRPD 2006 (n 7) Article 12.

³³ Amita Dhanda, 'Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future' (2007) 34 Syracuse Journal of International Law and Commerce 429, 462.

4.2.2 What is 'Revolutionary'³⁴ About the CRPD 2006?

The CRPD is an exciting development in international human rights law. It is the first treaty to directly address the non-extension (in practice) of rights and legal protections to those with cognitive (and mental) impairments.³⁵ It is also 'the first United Nations human rights treaty of the 21st Century' and is 'reputed to be the most rapidly negotiated'.³⁶ The CRPD and its Optional Protocol have also signed by the European Union (EU) making it the first UN treaty the EU has signed.³⁷ It currently has 163 signatories with 92 States both signing and ratifying the Optional Protocol, allowing individuals to bring a claim before its overseeing body: the Committee on the Rights of Persons with Disabilities (Committee CRPD).³⁸ The UK has signed and ratified the Optional Protocol.³⁹

There are several reasons why the Treaty is surrounded by possibly 'hyperbolic' language praising its 'revolutionary character'.⁴⁰ The call for equal recognition of legal capacity in Article 12 promises that those with cognitive and mental impairments will be granted an equal and central role in decisions that directly impact them, and more importantly, will be granted equal legal 'agency' to exercise those decisions without discrimination.⁴¹ Additionally, the paradigm shift within Article 12 from the traditional 'welfare/medical model'⁴² (which left them voiceless), has been replaced by the 'social model'⁴³ which calls for each State and their respective societies to do more to facilitate self-exercisable legal capacity in the decision-making process, and to remove barriers which hinder that objective.⁴⁴ It has also challenged the unhelpful and exclusory interpretations of equality and discrimination that exacerbated the non-realisation of

³⁴ Quinn Frontline 2011 (n 8) 26.

³⁵ Kayess and French (n 5).

³⁶ *ibid* 2.

³⁷ *ibid* (see footnote 4 of this paper).

³⁸ CRPD 2006 (n 7) Optional Protocol Article 1 (statistics correct as of March 2020).

³⁹ The UK has both signed and ratified the Optional Protocol as of 7 August 2009.

⁴⁰ Kayess and French (n 5) 4 (paraphrasing); Dhanda (n 33).

⁴¹ CRPD 2006 (n 7) Article 12 (via its supported decision-making model); Eilionóir Flynn and Anna Arstein-Kerslake, 'Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity' (2014) 10 (1) International Journal of Law in Context 81, 83.

⁴² Kayess and French (n 5) 5-6.

⁴³ *ibid* 6.

⁴⁴ CRPD 2006 (n 7) Article 4 "General Obligations" and Article 8 "awareness-raising"; Kayess and French (n 5) 33.

equal legal capacity and agency.⁴⁵ The CRPD has also specifically challenged the use of decision-making assessment tests that deny legal capacity on the basis of held characteristics, i.e. cognitive impairment: the so-called 'diagnostic threshold' mentioned in 3.3.⁴⁶

Moreover, 'the little wars or skirmishes'⁴⁷ around Article 12 are in an important sense proxies for deeper tensions at the base of our political and legal systems'.⁴⁸ The CRPD is 'not primarily about disability ... it is about a theory of justice ... applied to disability'.⁴⁹ It is a theory of justice because the CRPD strives to ensure that all "disabled" persons are recognised as legal persons at all times. To do this, the CRPD has clarified how personhood can be ensured and how legal capacity can be denied as long as it is on an equal basis with others.⁵⁰ The CRPD therefore espouses 'a conception of personhood that is divorced from cognition',⁵¹ preventing direct discrimination and the outright denial of legal capacity, and historically personhood altogether.

However, one of the noted problems in the literature on the CRPD is the conflation of terminology.⁵² Specifically, there seems to be conflation of legal capacity and personhood.⁵³ It seems that the CRPD's view is that all "disabled" persons are legal persons (rights holders) due to their inherent status of being human, marking a shift away

⁴⁵ Note General Comment 6 argues that States are still not interpreting equality and non-discrimination properly. See United Nations Committee on the Rights of Persons with Disabilities, *General Comment No 6: Article 5 'Equality and Non-Discrimination* (26 April 2018) CRPD/C/GC/6 (GC 6).

⁴⁶ Wayne Martin, Sabine Michalowski, Timo Jütten and Matthew Burch, *Achieving CRPD Compliance. Is the Mental Capacity Act of England and Wales Compatible with the UN Convention on the Rights of Persons with Disabilities? If Not, What Next?* (Essex Autonomy Project Paper, 22 September 2014) (EAP 2014) 1 and 5.

⁴⁷ "Skirmishes" include shifts from substituted to shared decision-making models (discussed in Section 4.3); distinctions between personhood and legal capacity (discussed in Section 4.2); political rhetoric on shifting the labelling of "disability" to "impairment" and the inclusive interpretation of "universalist" equality (discussed in Section 4.2), all of which are smaller battles in the war for the affirmation of persons with impairments' personhood status.

⁴⁸ Quinn 2011 (n 1) 51.

⁴⁹ *ibid* 59.

⁵⁰ CRPD 2006 (n 7) Article 12(2).

⁵¹ Flynn and Arstein-Kerslake 2014 (n 41) 81.

⁵² John Dawson, 'A Realistic Approach to Assessing Mental Health Laws' Compliance with the UNCRPD' (2015) 40 International Journal of Law and Psychiatry 70.

⁵³ *ibid*.

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from a model that in practice has been based on cognition (responsivity).⁵⁴ Nevertheless, legal capacity can be denied as long as it is implemented on an equal basis with others:⁵⁵ there will be proportionate and legitimate reasons for denying legal capacity to persons with impairments. In response, the Committee CRPD has been criticised for misinterpreting that balance,⁵⁶ and it is the maintenance of this balance that has proven difficult in discussions on the topics analysed in 4.3 (shared or substituted decision-making) and 4.4 (non-discrimination).

Returning to the issue of conflation between legal capacity and personhood, Quinn has provided a starting point on distinguishing the two where legal capacity should be understood as:

a continuum that connects with everything needed to enable the person to flourish - a right to make decisions and have them respected, a place of one's own, a life in the community connected to friends, acquaintances and social capital, whether in public or private settings. Personhood is broader than just capacity - and these broader connections serve to augment capacity in a virtuous circle.⁵⁷

On the basis of the findings in 2.4 and 3.2, it seems that in law it is possible to deny personhood to some and attribute it to others on the basis of a physical characteristic.⁵⁸ The endowment of legal capacity in any form (i.e. decision-making competence, liberty or self-exercisable agency⁵⁹) is the recognition in law of personhood and its capacity to bear

⁵⁴ Discussed in Chapter One, Section 1.4; Chapter Two, Section 2.4 and Chapter Three, Section 3.2. The word "disabled" is placed in double quotation marks because the CRPD 2006 (n 7) defines disability in Article 1 as a social barrier for a person with impairment that needs to be eradicated by the State. This is explained further in Subsection 4.2.3.

⁵⁵ CRPD 2006 (n 7) Article 12(2).

⁵⁶ Dawson 2015 (n 52).

⁵⁷ Quinn Conference Paper 2011 (n 1) 4 "Introduction".

⁵⁸ This is the basis of Harris and Locke's argument that consciousness is the *indicia of personhood*, as discussed in Chapter Three, Subsection 3.2.2. See John Harris, 'The Concept of the Person and the Value of Life' (1999) 9 (4) Kennedy Institute of Ethics Journal 293; John Locke, *An Essay Concerning Human Understanding* (first published 1690, E S Pringle-Paterson ed, Clarendon Press 1924).

⁵⁹ Note this last legal capacity is a possible addition to those already recognised by Coggon and Miola, Bielby and Dworkin as a particular interpretation in law of "autonomy" because it is this legal capacity that seems to be at issue in PDOC patients' life support continuation decisions and in other cases where liberty is ostensibly granted but due to impairment is denied in law to individuals

rights, and therefore to an extent, that the individual has moral standing (value) that is deserving of legal protection from the unwarranted interference of others.⁶⁰ Legal capacity is the protections and freedoms (including restrictions on freedoms) granted in recognition of that personhood status. Consequently, it is therefore also possible to be recognised as a legal person and simultaneously be denied legal capacity.⁶¹ For example, it is possible to have legal capacity denied on the basis of mental incapacity and still be a legal person.⁶² And for this thesis, as explored in Chapter Three, it is possible to be granted legal capacity in such a way that it denies personhood and their right to bodily integrity.⁶³

Important work has been conducted on the conflation of "autonomy" as liberty (legal capacity) and mental capacity (competence) which will enable academics and judges to achieve and measure the defensibility of COP decisions by better identifying the legal capacity at issue.⁶⁴ Legal capacity is best understood as liberty (freedom) to the extent it is recognised in law. Moreover, some liberties (as a form of legal capacity) are so important

with that particular impairment, i.e. Dawson's (n 52) discussion on the blind being denied the "capacity" to drive. See John Coggon and José Miola, 'Autonomy, Liberty, and Medical Decision-Making' (2011) 70 (3) Cambridge Law Journal 523; Philip Bielby, 'The Conflation of Competence and Capacity in English and Welsh Law: A Philosophical Critique' (2005) 8 Medicine, Health Care and Philosophy 357; Gerald Dworkin, *The Theory and Practice of Autonomy* (Cambridge University Press 1988).

⁶⁰ Discussed in Chapter Two, Section 2.4. See also Ngaire Naffine, *Law's Meaning of Life: Philosophy, Religion, Darwin and the Legal Person* (Hart Publishing 2009).

⁶¹ Examples would include decision-making competence assessments under section 3 of the Mental Capacity Act 2005 or public policy "liberty" restrictions on behaviour proscribed in law as criminal or negligent.

⁶² For example, the patient in *F v West Berkshire HA* [1990] 2 AC 1 (HL) (*re F*) is a legal person, hence her welfare and rights are being considered even though she has been denied legal capacity to decide on sterilisation herself because of her lack of mental capacity.

⁶³ This chapter's core aim is to assess whether the constructed refusal mechanism of subsections 4(6) and 4(7) MCA 2005 (n 6), in an attempt to extend a quasi "right to refuse" life-supporting treatment to the non-responsive in *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [2014] AC 591, has misinterpreted "equal" treatment in law and is in fact a discriminatory as well as unsafeguarded practice. This is discussed in Section 4.4 and therefore builds on the arguments in Chapter Three, Section 3.4.

⁶⁴ Flynn and Arstein-Kerslake 2014 (n 41); Coggon and Miola (n 59); Bielby (n 59); Dworkin (n 59).

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that they have been conferred rights status, e.g. right to life,⁶⁵ right to an education,⁶⁶ freedom from torture⁶⁷. However, some freedoms are curtailed under public policy reasons (e.g. using one's property to harm others and prohibiting those who are blind from driving⁶⁸).⁶⁹ Consequently, the curtailment of legal capacity in certain contexts and circumstances is compatible with non-discrimination and equality law.⁷⁰ However, mental capacity tests can also act as a further threshold for a person which could be denied on discriminatory bases.⁷¹ Therefore, the relationship between a denial of personhood and a denial of legal capacity is that a denial of all legal capacities would amount to a denial of personhood, whereas a denial of legal capacity in a specific context does not necessarily amount to a denial of personhood. This is a fine but important distinction.

The conflation of denials of legal capacity with full denial of personhood (civil death⁷²) has received criticism from academics who note that, even *prima facie* discriminatory denials of legal capacity on the basis of impairment will not necessarily result in a finding of discrimination,⁷³ e.g. 'denying blind persons the legal capacity to drive'.⁷⁴ Such instances do not amount to a finding of discrimination on the basis of the

⁶⁵ CRPD 2006 (n 7) Article 10; Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols 11 and 14, supplemented by Protocols 1, 4, 6, 7, 12 and 13, Nov. 4, 1950, Europ. T.S. No. 5, 213 U.N.T.S. 221 (ECHR 1950), Article 2. Note the ECHR 1950 is an incorporated treaty in E&W under the Human Rights Act 1998, where the right to life is found under Schedule 1, Article 2 and is therefore more binding than the CRPD 2006 as an unincorporated treaty.

⁶⁶ CRPD 2006 (n 7) Article 24; ECHR 1950 (n 65) Protocol 1, Article 2.

⁶⁷ *ibid* Article 15; *ibid* Article 3.

⁶⁸ Dawson 2015 (n 52) 73.

⁶⁹ *ibid*.

⁷⁰ See Section 4.4 for the examination of whether third party decision-making to determine life support continuation amounts to a non-discriminatory denial of legal capacity.

⁷¹ Coggon and Miola (n 59); Dworkin (n 59).

⁷² See Flynn and Arstein-Kerslake 2014 (n 41); Gooding 2014 (n 12); Quinn Conference Paper 2011 (n 1); Quinn 2010 (n 10); Kayess and French (n 5); Dhanda (n 33) as examples of those who argue that a denial of personhood and resulting full civil death has historically occurred to those with cognitive and mental disability, and that persons with impairments are the last to enjoy the right to equal legal capacity despite being a right promised to all human beings since Article 16 ICCPR 1966.

⁷³ Dawson 2015 (n 52); EAP 2014 (n 46) 1 and 5.

⁷⁴ Dawson 2015 (n 52) 73.

'disproportionate impact test',⁷⁵ found under international legal conventions on equality.⁷⁶ This misinterpretation of discrimination has been exacerbated by the Committee CRPD in General Comment 1 (GC 1) which will be discussed in 4.3.1.

Nevertheless, the findings of Chapter Three suggest that the denial of legal capacity, in such a blanket manner, undermines any assertion in practice that PDOC patients are also legal persons.⁷⁷ Moreover, the additional diagnostic threshold in subsection 2(1) MCA and the use of third parties to decide whether the patient would want to remain on life-supporting treatment suggests that perhaps refusals for life-supporting treatment are being permitted in a discriminatory manner.⁷⁸ Finally, 3.4 began to explore the possibility that PDOC patients' declaratory relief proceedings are discriminatory for interpreting equality as "treating unalike, alike" by using subsection 4(6) and 4(7) MCA as a mechanism for a constructed refusal to continue life-supporting treatment. This was a result of deeming continued treatment impermissible, not on the basis of bodily integrity, but instead on an autonomy basis for those who are considered non-autonomous.

Finally, the revolutionary power of the CRPD and its Achilles' heel thus lies in its interpretation of equality and non-discrimination, and the balance to be struck between legitimate and discriminatory denials of legal capacity. Hence, the CRPD's relevance to social justice theories and this thesis.⁷⁹ The thesis' core strand has throughout argued that a particular level of cognition (responsivity) is required for an individual to be considered a legal person. Therefore, this chapter will assess whether PDOC patients' denials of legal capacity amount to discrimination, and if so, whether they are happening often enough and in enough areas of law that their status as legal persons becomes questionable (in effect rather than in name). Consequently, it is necessary to explore how the CRPD interprets "equality".

⁷⁵ The EAP 2014 (n 46) discusses the importance of the disproportionate impact test for assessing whether national legislation and policy is compliant with the CRPD 2006. See Section 4.4 for this thesis' assessment of subsections 4(6) and 4(7) MCA 2005 propriety in PDOC patients' life support continuation proceedings.

⁷⁶ Dawson 2015 (n 52).

⁷⁷ See footnotes 26-30 above for these specific instances and their cross-references for previous chapters' discussions on them.

⁷⁸ Discussed in Chapter Three, Subsection 3.4.1.

⁷⁹ This Chapter does not focus on ECHR 1950 (n 65) because the CRPD 2006 (n 7) (at least politically because the CRPD 2006 is less legally binding) has the most potential to galvanise change for PDOC patients.

4.2.3 Interpreting Equality

The CRPD has four key substantive principles: equality; non-discrimination; autonomy; and dignity, all of which add further “meat to the bones” of its rights and freedoms by providing further guidance on their intended implementation.⁸⁰ However, Donnelly and Westen deem equality and non-discrimination to be the least helpful in understanding how the CRPD is to be implemented; they argue that these principles are meaningless without ascribing a particular ‘moral standard’.⁸¹ Conversely, such an interpretation is misguided because, first, autonomy and dignity are no easier to define and also rely on the adoption of a particular moral standard to “hash out” their respective ambits.⁸² Secondly, unlike autonomy and dignity (and crucially for this thesis and the CRPD) equality and non-discrimination define when a denial of legal capacity is discriminatory or justified. Moreover, it seems that the States drafting the CRPD possibly agree because only equality and non-discrimination have been given the status of self-standing rights.⁸³ Additionally, Mégret argues that there are obvious difficulties with promoting autonomy to the status of a ‘right’ which problematically (for equality purposes) would exclude those who are described as non-autonomous.⁸⁴ Thirdly, the breach of any of its substantive rights will also breach Article 5 because the basis for the breach will be discrimination and inequality; the CRPD is fundamentally a non-discrimination convention which is further evidenced by the fact that no new rights have been created.⁸⁵ Consequently, to understand why the CRPD’s interpretation of equality is revolutionary it is necessary to seek out the moral standard upholding the CRPD’s interpretation of equality. Autonomy, as an identifiable

⁸⁰ CRPD 2006 (n 7) Article 3.

⁸¹ Peter Westen, ‘The Empty Idea of Equality’ (1982) 95 (3) Harvard Law Review 537, 547; Mary Donnelly, ‘Best Interests in the Mental Capacity Act: Time to Say Goodbye?’ (2016) 24 (3) Medical Law Review 318, 322.

⁸² See for example 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 404; Doris Schroeder, ‘Dignity: Two Riddles and Four Concepts’ (2008) 17 (2) Cambridge Quarterly of Healthcare Ethics 230; Matti Häyry, ‘Another Look at Dignity’ (2004) 13 (1) Cambridge Quarterly of Healthcare Ethics 118; Ruth Macklin, ‘Dignity is a Useless Concept’ (2003) 327 British Medical Journal; Coggon and Miola (n 59).

⁸³ CRPD 2006 (n 7) Article 5; GC 6 (n 45) paragraph 12.

⁸⁴ Frédéric Mégret, ‘The Disabilities Convention: Human Rights of Persons with Disabilities or Disability Rights?’ (2008) 30 (3) Human Rights Quarterly 494, 511. The debate on whether new rights were created will be addressed later in this section.

⁸⁵ GC 6 (n 45) paragraph 13; Mégret (n 84).

legal capacity in a given case will be discussed in subsequent sections (4.3 and 4.4), in relation to the extension of a "right to refuse treatment" to PDOC patients in life support continuation cases. Finally, the CRPD defines discrimination as:

any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including the denial of reasonable accommodation.⁸⁶

The key phrase 'on an equal basis with others', is indicative of equality's central role in determining whether *de facto* discrimination has occurred or not.⁸⁷ Therefore, I shall focus predominantly on equality because what amounts to discrimination is dependent on the adopted interpretation of equality, as demonstrated by the CRPD's simultaneous treatment of both under Article 5.

There have been three main interpretations of equality in the literature,⁸⁸ and problematically, the CRPD seems to have inadvertently adopted a conglomeration of the three within its rights and freedoms, instead of consistently applying the third which better achieves its ultimate aim and ethos. The adoption of the first two (formalist and substantive models) have arguably undermined the revolutionary potential of the CRPD to achieve equal recognition as persons in law for PDOC patients. It seems to be the latter (universalist) interpretation that holds the key to its revolutionary potential.

The formalist approach superficially requires all to be treated the same and consequently fails to account for difference.⁸⁹ Therefore, it is a particularly harmful moral standard for persons with impairments because achieving equal treatment 'will often require specific recognition and accommodation of their difference, i.e. 'different

⁸⁶ CRPD 2006 (n 7) Article 2.

⁸⁷ *ibid.*

⁸⁸ Kayess and French (n 5); Marcia H Rioux, 'Towards a concept of Equality of Well-Being: Overcoming the Social and Legal Construction of Inequality' in Marcia H Rioux and Michael Bach (eds) *Disability is not Measles: New Research Paradigms in Disability* (Roeher Institute 1994).

⁸⁹ Kayess and French (n 5) 8.

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treatment'.⁹⁰ The substantive equality model attempted to rectify this problem via a 'minority rights approach'⁹¹ which 'identifies a class of persons entitled to protection from discrimination and the adoption of special measures to compensate for disadvantage'.⁹² It has therefore been coined by Rioux as a model seeking 'equality of opportunity'.⁹³ However, this model is also problematic because it assumes that the class (disability) can be easily defined and identified, and 'pits the protected class against others in claims for scarce social resources' making it difficult to dismantle the existing inequalities.⁹⁴ As I argue below, both of these issues (with the substantive model of equality) are evident in the CRPD's adopted definition of "disability". Consequently, the CRPD's definition of disability may ironically be PDO patients' greatest barrier to unlocking the revolutionary potential of Article 12 because (and counterintuitively) not all would be defined as persons with impairments. The CRPD's attempt to define the (class) has demonstrably failed because the definition is founded on the problematic substantive model of equality.⁹⁵

The CRPD's definition of disability was intended to be 'non-exhaustive',⁹⁶ but has made the applicability of the CRPD's non-discrimination protection difficult for PDO patients due to linguistic errors that have resulted in the unintentional adoption of a substantive model of equality in parts of the text. Article 1, CRPD states that, 'persons with disability include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.' It is clear from this definition that the CRPD is calling for a wider attitude shift from viewing disabled persons as 'objects of charity, medical treatment and social protection, to subjects of rights able to claim those

⁹⁰ ibid.

⁹¹ Sandra Fredman, 'Disability Equality: A Challenge to the Existing Anti-Discrimination Paradigm?' in Anna Lawson and Caroline Gooding (eds), *Disability Rights in Europe: From Theory to Practice* (Hart Publishing 2005) 211.

⁹² Kayess and French 2008 (n 5) 9.

⁹³ Rioux 1994 (n 88).

⁹⁴ Kayess and French 2008 (n 5) 9.

⁹⁵ Fredman (n 91) 211. Note at page 206, Fredman notes the difficulty experienced in defining 'disability' during the CRPD's (n 7) drafting process.

⁹⁶ George Szmukler, Rowena Daw and Felicity Callard, 'Mental Health Law and the UN Convention on the Rights of Persons with Disabilities' (2014) 37 International Journal of Law and Psychiatry 245, 246; CRPD 2006 (n 7) 'Preamble' paragraph (e).

rights as active members of society'.⁹⁷ Therefore, the CRPD calls for a paradigm shift from the 'medical model' to the 'social model'.⁹⁸ The social model increases obligations on the State and (society generally⁹⁹) to facilitate persons with impairments' participation and guarantee their protected status as legal persons.¹⁰⁰ Additionally, the social model flips the notion of disability onto society; disability is understood to be a socially constructed barrier that must be removed and is distinct from the impairment itself.¹⁰¹ It therefore has the potential to be beneficial for PDOC patients by demanding a much needed attitude and public perception shift on disability.

However, the language of the CRPD has been unhelpfully unclear on emphasising this point because of its continued use of references to such persons as 'persons with disability' instead of 'persons with impairments'.¹⁰² This seems to have further limited the protection that the CRPD can provide. As Kayess and French argue, the unacknowledged implication of not being consistent with its linguistic shift to 'persons with impairments' as opposed to 'persons with disability' is that:

it logically means that the human rights protection provided by the CRPD is not triggered by impairment, but disability; that is, protection is post-facto -- only available to those with impairments who are already subject to discrimination and oppression, rather than those persons who may be at risk of it.¹⁰³

For PDOC patients this linguistic inconsistency has further concretised the discrimination they face (as being 'better off dead'¹⁰⁴) in the fight for equal recognition as legal persons. They are therefore less likely to be identified as those 'already subject to' or 'at risk of'

⁹⁷ Louise Arbour, 'Statement by Louise Arbour UN High Commissioner for Human Rights on the Ad Hoc Committee's Adoption of the Convention on the Rights of Persons with Disabilities' (5 December 2006) <<http://www.un.org/esa/socdev/enable/rights/ahc8hrcmsg.htm>> accessed 27 April 2019.

⁹⁸ Kayess and French 2008 (n 5) 5-6.

⁹⁹ For example, CRPD 2006 (n 7) Article 8(2) 'awareness-raising' calls for public re-education programmes and encouragement of 'the media to portray persons in a manner consistent with the purpose of the Convention'. Similarly, the Optional Protocol calls for NGOs and other stakeholders to also report on UK compliance directly to its Committee, the Committee on the Rights of Persons with Disabilities in accordance with CRPD 2006 (n 7) Optional Protocol, Article 33(3) and Article 1.

¹⁰⁰ Kayess and French (n 5) 3.

¹⁰¹ *ibid* 5 and 33; CRPD 2006 (n 7) Article 4 'general obligations' and Article 8 'awareness-raising'.

¹⁰² Kayess and French (n 5) 21.

¹⁰³ *ibid*.

¹⁰⁴ *ibid* 5.

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oppression.¹⁰⁵ Kayess and French have pointed this out more generally for persons with impairments where they argue that the traditional medical and welfare model saw disability as:

a 'personal tragedy'. [Where] persons with disability are victims of great misfortune who are variously perceived as socially dead or better off dead, as passively coming to terms with a condition that will forever limit their activities, or as bravely and triumphantly overcoming these limitations by great mental or physical effort.¹⁰⁶

The medical model therefore shifted the onus away from the State and onto the patient because the disability was the impairment itself and not their social exclusion.¹⁰⁷ This in turn justified the State's failure to ensure that (cognitively) impaired persons could also unlock equal recognition as persons in law through assimilation and facilitation in the legal decision-making process: a right that was purportedly intended for, and granted to all under Article 16 of the International Covenant on Civil and Political Rights in 1966 (ICCPR).¹⁰⁸ For PDOC patients, their thought non-existent or minimal awareness (responsivity) seems to have further justified the State's lack of attempt to facilitate their equal recognition as persons in law; possibly because suffering is thought to require awareness.¹⁰⁹ For example, in Chapter Three it was argued that there exists an assumption under E&W common law that PDOC patients cannot be deprived of their liberty because they lack of awareness,¹¹⁰ or raped for (seemingly) the very same reason,¹¹¹ an assumption

¹⁰⁵ ibid.

¹⁰⁶ ibid.

¹⁰⁷ GC 6 (n 45) paragraph 8.

¹⁰⁸ UN, International Covenant on Civil and Political Rights (adopted 16 December 1966, entered into force 23 March 1976) UNTS 999. An obligation the CRPD 2006 (n 7) now calls for under Article 12. As I will discussed in Subsections 4.3.2 and 4.3.3 under the shared decision-making model analysis.

¹⁰⁹ There is a separate and interesting legal-philosophical debate on whether awareness is required to be harmed (physically and mentally). See Robert M Veatch, 'The Dead Donor Rule: True by Definition' (2003) 3 (1) *The American Journal of Bioethics* 10; Elysa R Koppelman, 'The Dead Donor Rules and the Concept of Death: Severing the Ties that Bind Them' (2003) 3 (1) *American Journal of Bioethics* 1; Ronald Dworkin, *Life's Dominion: An Argument about Abortion, Euthanasia and Individual Freedom* (Harper Collins 1995); Thomas Nagel 'Death' in John Martin Fischer (ed), *The Metaphysics of Death* (Stanford University Press 1993).

¹¹⁰ *Director of Legal Aid v Briggs* [2017] (n 28); *Re M* [2017] (n 28). As discussed in Chapter Three, Subsection 3.4.1.

¹¹¹ Hanna and Allen (n 27).

that appears to be unsupported by the evidence presented in 2.3 on PDOC patients' inner awareness.¹¹²

To tackle the problematic medical model the Committee CRPD has provided guidance for States' interpretation of the CRPD's model of equality.¹¹³ For example, General Comment 6 (GC 6) argues that, the CRPD adopts an 'inclusive' model of equality which extends beyond 'substantive' equality' and is also known as the universalist model.¹¹⁴ For example, Article 5 CRPD's 'Equality and Non-Discrimination' and Article 3 CRPD's 'General Principles', evidently intend to adopt a universalist model of equality. These Articles simultaneously attempt to assimilate (include) and respect difference through support measures accessible to all persons, in recognition that all require support to exercise legal capacity and not just those with impairments.¹¹⁵

Returning to the CRPD's definition of disability and its unintentional adoption of substantive equality,¹¹⁶ the definition, although 'non-exhaustive', specifies that disability applies to those with long-term impairments.¹¹⁷ However, it provides no further explanation on how much time amounts to 'long-term'.¹¹⁸ This additional pre-requisite is problematic for PDOC patients because although the State could practically overcome the problem by employing the medical interpretation of 'permanent'¹¹⁹ as equivalent to 'long-term',¹²⁰ CANH withdrawal is no longer exclusively permissible for only those in a

¹¹² As discussed in Chapter Two, Subsection 2.3.2.

¹¹³ GC 6 (n 45); United Nations Committee on the Rights of Persons with Disabilities, *General Comment No 1: Article 12 'Equal Recognition Before the Law* (11 April 2014) CRPD/C/GC/1 (GC 1).

¹¹⁴ GC 6 (n 45) paragraph 11.

¹¹⁵ GC 1 (n 113). For example, GC 1 (n 113) paragraph 29 makes clear that the degree of support required cannot be a reason for denying legal capacity. See also Kayess and French (n 5) at page 10 where they argue that the CRPD 2006 (n 7) recognises able-minded and able-bodied persons will also require some form of support.

¹¹⁶ I argue it is unintentional because CRPD 2006 (n 7) Article 5 'Equality and Non-Discrimination' and Article 3 'General Principles' evidently intend to adopt a universalist model of equality in its simultaneous approaches to assimilate (include) and respect difference through facilitation of special measures, such as the support paradigm of Article 12(3) where necessary; GC 6 (n 45) also supports this view despite its conflicting argument in paragraph 11.

¹¹⁷ CRPD 2006 (n 7) Article 1 'Purpose'.

¹¹⁸ *ibid.*

¹¹⁹ Royal College of Physicians, *Prolonged Disorders of Consciousness Following Onset of Sudden Injury: National Clinical Guidelines* (2020) 37. As discussed in Chapter Two, Subsection 2.1.1 and Chapter Three, Subsection 3.3.1.

¹²⁰ CRPD 2006 (n 7) Article 1 "Purpose".

permanent vegetative state.¹²¹ This means that not all PDOC patients are necessarily covered by the CRPD, despite all being at risk of having their legal capacity denied and their right to life threatened.

It is also quite difficult to analyse and identify which PDOC patients are covered by the CRPD, which are not, and to what degree any are covered. Therefore, it is likely that judicial oversight and a broad purposive approach to interpreting 'equality' would need to be adopted by the courts in order to ensure compliance with the CRPD's 'object and purpose'¹²² in life support continuation decisions.¹²³ However, this is much less likely to happen after *An NHS Trust v Y*[2019],¹²⁴ which stated that such cases do not need to come to court, potentially undermining England and Wales' obligation to oversee its State actors' human rights compliance.¹²⁵ Moreover, because General Comments are non-binding and because substantive equality would inherently undermine the CRPD's central aim of achieving equal legal capacity for those with impairments, I suggest looking to the substantive rights themselves to evidence the equality model that the CRPD has adopted.

Returning to the three models of equality, the third approach has the most potential for revolution as evidenced by the rights and freedoms of the CRPD that reflect a universalist interpretation of equality, such as Articles 8, 12 and 16. The third model is the 'universalist'¹²⁶ or less coined 'equality of well-being'¹²⁷ model. The universalist model, unlike the formalist model, 'expects difference, instead of ignoring difference',¹²⁸ and accepts that all (including those without impairments) require assistance to overcome barriers which are non-existent for others due to different capabilities.¹²⁹ As previously

¹²¹ Discussed in Chapter Three, Subsection 3.3.1.

¹²² UN, Convention on the Law of Treaties (Signed at Vienna 23 May 1969, entered into force 27 January 1980) UNTS 1155, Article 31. This Treaty is more commonly known as the "Vienna Convention" and provides guidance on interpreting international treaties.

¹²³ *ibid.*

¹²⁴ *An NHS Trust v Y*[2018] UKSC 46, [2019] AC 978 (*NHS Trust v Y*).

¹²⁵ See Elizabeth Wicks, '*An NHS Trust and others v Y and another* [2018] UKSC 46: Reducing the Role of the Courts in Treatment Withdrawal' (2019) 0 Medical Law Review 1 at page 4. Notwithstanding the hope that the Court of Protection in *Practice Guidance (CP: Serious Medical Treatment)* [2020] EWCOP 2, [2020] 1 WLR 641, possibly brings as discussed in Chapter Three, Subsections 3.3.2 and 3.4.2.

¹²⁶ Kayess and French 2008 (n 5) 10.

¹²⁷ Rioux 1994 (n 88).

¹²⁸ Kayess and French 2008 (n 5) 11 (paraphrasing).

¹²⁹ *ibid* 10.

argued, the medical and welfare approach to disability has simultaneously used formalist and substantive interpretations of equality to justify different treatment by denying personhood on the basis of different cognitive capabilities.¹³⁰ It has been able to do this because different treatment for those with different capabilities matches the "treat like alike" known as the 'formalist' model of equality.¹³¹

Nevertheless, the way in which universalist equality is being interpreted in group specific treaties is revolutionary because it introduces rights and freedoms that are both 'assimilationist' (apply to all) and 'pluralistic' (equally apply to all through the acceptance of difference),¹³² by either 'extending', 'reformulating' and possibly 'innovating' existing rights contained in the International Bill of Rights' instruments.¹³³ Therefore, the universalist model in its attempts to eradicate inequality requires both participation and inclusion of persons with impairments via their assimilation as legal persons and simultaneously, the acceptance and accommodation of their difference within a pluralistic society.¹³⁴ Universalist equality is consequently vital to revolutionising the legal capacity of persons with cognitive (and mental) impairments.¹³⁵

The General Assembly mandate stated that the CRPD 'was not to create new rights' but to 'reaffirm and reformulate existing rights'.¹³⁶ Therefore, the CRPD has been called an 'implementation convention'¹³⁷ that merely provides guidance on how existing rights should apply to those with impairments, noting its 'integral' status in international human rights law.¹³⁸ In this respect, the CRPD is assimilationist and reaffirms the extension of all

¹³⁰ Rioux 1994 (n 88) 70.

¹³¹ *ibid.*

¹³² *ibid* 88-89.

¹³³ Mégret 2008 (n 84) 494-495. Note accommodation of difference and inclusion are key principles under CRPD 2006 (n 7) Article 3 'General Principles', an aspect of the CRPD that evidences an intention to adopt a universalist model of equality.

¹³⁴ *ibid.*

¹³⁵ Kayess and French 2008 (n 5) 11.

¹³⁶ *GA Resolution 56/168* (19th December 2001) A/56/583/Add.2 <<https://documents-dds-ny.un.org/DOC/undoc/gen/n01/488/76/pdf/N0148876.pdf?OpenElement>> accessed 29 August 2019 (paraphrasing); GC 1 (n 113) Part One, paragraph 1.

¹³⁷ UN Press Releases, 'Chairman Says Draft Convention Sets Out 'Detailed Code of Implementation and Spells Out How Individual Rights Should be Put into Practice' (UN, 15 August 2005) SOC/4680 <<http://www.un.org/News/Press/docs/2005/soc4680.doc.htm>> accessed 29 November 2019.

¹³⁸ *GA Resolution 56/168* (n 136); Kayess and French 2008 (n 5) 20.

existing Economic Social and Cultural Rights (ESCR) and Civil and Political Rights (CPRs) contained within the instruments of the International Bill of Rights for PDOC patients.¹³⁹

However, in some respects, if the CRPD has not created new rights it has come very close to doing so.¹⁴⁰ It has seemingly adopted a pluralistic approach by also accepting and accommodating difference. Moreover, if it were truly an 'implementation treaty' then it is questionable why it was not formulated as an anti-discrimination treaty, like the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW¹⁴¹) and the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD),¹⁴² both of which mention non-discrimination in their title, indicating that non-discrimination is their central object and purpose.¹⁴³ Instead, Mégret puts forth a convincing, albeit controversial account that, 'group specific treaties' demonstrate that international human rights law is becoming increasingly pluralised because 'the vision of human rights as being the same for all is both helpful and insufficient.'¹⁴⁴ Mégret's point is fitting and is also in line with Rioux's commentary on the need for disability rights to be both assimilationist and pluralistic in order to effectively fight the specific inequalities facing them.¹⁴⁵

However, there is a possible problem with Rioux's otherwise insightful account. She argues, for example, that sex equality requires pluralistic policies to fight the specific inequalities faced by women and that race equality requires assimilationist, unlike disability which requires both.¹⁴⁶ Instead, it seems that all group specific treaties require both assimilationist and pluralistic rights and that failure to recognise immutable differences among the human race is a glaring shortcoming of human rights efforts to date. For example, to suggest that women require only acceptance of difference (pluralistic policies) because assimilation has been unhelpful, whilst true for the current

¹³⁹ Kayess and French 2008 (n 5) 20; Mégret 2008 (n 84).

¹⁴⁰ Mégret 2008 (n 84) 498.

¹⁴¹ UN, Convention on the Elimination of all Forms of Discrimination Against Women (adopted 18 December 1979, entered into force 3 September 1981) UNTS 1249.

¹⁴² *ibid* 496; UN, International Convention on the Elimination of All Forms of Racial Discrimination (adopted 21 December 1965, entered into force 4 January 1969) UNTS 660.

¹⁴³ *ibid*.

¹⁴⁴ *ibid* 495-496.

¹⁴⁵ Rioux 1994 (n 88) 88-89.

¹⁴⁶ *ibid*.

fight for equal rights, forgets the struggles already made to be assimilated within the women's rights movement (such as to be recognised as full legal persons) and those that are still being fought. That is, it forgets the first battle on the road to equal rights for women: to be recognised in law as persons. Additionally, racial discrimination requires more than assimilationist policies. For example, the lack of acceptance of difference is a current battle being fought within the Beauty Industry which has notoriously failed to accommodate all skin tones and hair types.¹⁴⁷ These examples provide further evidence that back Mégret's claim that all group specific treaties need to be both assimilationist and pluralistic.¹⁴⁸ To be only assimilationist or only pluralistic in line with a formalist interpretation of equality is 'insufficient'.¹⁴⁹

There seems to be several rights contained within the CRPD that have evidently adopted this interpretation of universalist equality through demonstrable modifications or reformulations to existing rights, to the extent that they seem to create new disability-specific rights and new State obligations. It is therefore no surprise that these aforementioned points of interest are the rights, freedoms and State obligations which hold the key to revolution in the fight for equal recognition of legal capacity (universalist equality). Even those rights that superficially seem to have been solely reaffirmed such as: the 'right to life';¹⁵⁰ 'liberty and security of person';¹⁵¹ 'education';¹⁵² 'the highest standard of health';¹⁵³ and even 'recognition everywhere as persons before the law',¹⁵⁴ have been 'extended' and 'reformulated' to accommodate difference.¹⁵⁵

¹⁴⁷ A current example in the Beauty Industry is the lack of trained hairstylists familiar with Afro-Caribbean hair leaving black actors and actresses with higher costs to than their white counterparts. See Sabrina Barr, 'Black Actors Urge Hollywood to Hire Hairstylists Who Know How to Style Their Hair' (Independent, 12 March 2019) <<https://www.independent.co.uk/life-style/fashion/black-actors-hair-style-natural-ethnic-gabrielle-union-yvette-nicole-brown-a8818736.html>> accessed 30 August 2019.

¹⁴⁸ Mégret 2008 (n 84) 496.

¹⁴⁹ *ibid*.

¹⁵⁰ CRPD 2006 (n 7) Article 10. This right is originally found under Article 6 ICCPR 1966 (n 108).

¹⁵¹ *ibid* Article 14. This right is originally found under Article 9 ICCPR 1966 (n 108).

¹⁵² *ibid* Article 24. This right is originally found under UN, International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) UNTS 993, Article 13.

¹⁵³ *ibid* Article 25. This right is originally found under Article 12 ICESCR 1966 (n 152).

¹⁵⁴ Mégret 2008 (n 84) 499.

¹⁵⁵ *ibid* 496.

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Article 16 of the CRPD is a prime example of 'reformulation' and 'extension' of existing rights to almost create a new disability-specific right, demonstrating a shift towards the universalist model of equality.¹⁵⁶ In none of the International Bill of Rights instruments (Universal Declaration of Human Rights 1948 (UDHR),¹⁵⁷ ICCPR 1966 or International Covenant on Economic Social and Cultural Rights 1966 (ICESCR¹⁵⁸)) has there existed a 'freedom from exploitation, violence and abuse'.¹⁵⁹ Instead, the freedom can be described as 'somewhere between a compendium of existing rights and an almost entirely new right',¹⁶⁰ suggesting its creation was necessary because it 'must have been seen as adding something to the existing register of rights'¹⁶¹ that protects against different forms of abuse.¹⁶² In fact, a clear addition or 'extension' to Article 16 CRPD which goes further than previous rights that protect against exploitation, violence and abuse, is its recognition of familial abuse. Article 16(1) stipulates that, 'State Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.' The additional focus on abuse that occurs within the home is potentially revolutionary for PDOC patients because it demonstrates a shifting attitude that moves away from prioritising the family over the person with impairment(s).¹⁶³ The existing pattern 'in most societies'¹⁶⁴ is that:

family needs and rights tend to be privileged above those of persons with disability and, notwithstanding the enormous importance and contribution of families to the realisation of the rights and dignity of persons with disability it is sometimes family members who are principally responsible for, or collude in, human rights violations against them.¹⁶⁵

¹⁵⁶ *ibid* 499.

¹⁵⁷ UN, Universal Declaration of Human Rights (proclaimed 10 December 1948, entered into force 20 February 1967) UNTS 590.

¹⁵⁸ ICESCR 1966 (n 152).

¹⁵⁹ *ibid* 507. Note 'Freedom from Exploitation, Violence and Abuse' is the title of Article 16 CRPD 2006 (n 7).

¹⁶⁰ *ibid* 507.

¹⁶¹ *ibid*.

¹⁶² For example, 'Freedom from Torture, Cruel, Inhuman or Degrading Treatment or Punishment' under Article 7 ICCPR 1966 (n 108), or 'Freedom from Slavery' Article 8 ICCPR 1966 (n 108).

¹⁶³ Kayess and French 2008 (n 5) 25-26.

¹⁶⁴ *ibid*.

¹⁶⁵ *ibid*.

Prioritisation of the family was similarly pointed out by Wicks in relation to observed patterns in PDOC patients' life support continuation decisions in E&W, who argues that concerns for familial 'distress' and 'overstretched resources' left the patient and their rights completely out of the picture.¹⁶⁶ Therefore, the 'addition' that has been made to pre-existing rights in Article 16 is the explicit recognition that persons with impairment(s) have historically been given a 'passive' role and that their recentralisation in the decision-making process is required.¹⁶⁷ Moreover, failure to do so has enabled 'abuse within, as well as outside of the home'.¹⁶⁸ The CRPD therefore grants some protection to families but only where the effect is to further support the participation and realisation of the person with impairment's rights.¹⁶⁹

Article 8 is one such right which could prove instrumental to PDOC patients as it places obligations on States to 'raise awareness' throughout society and within 'the family' of the 'rights and dignity' and 'capabilities and contributions' of such individuals, to 'combat stereotypes, prejudices and harmful practices relating to persons with disability'.¹⁷⁰ Article 8 is therefore a useful and much needed weapon to help eradicate the conflation of bodily autonomy and integrity in post-MCA 2005 cases,¹⁷¹ and the prevailing attitude of treating PDOC patients as 'better off dead'.¹⁷² As Rioux aptly argues, 'if the right to participate is to be recognized, the notion would have to be jettisoned that people with intellectual disabilities are ... provided with goods and services because they are worthy of care rather than by right of citizenship.'¹⁷³

A further way in which the CRPD almost creates new rights is by adding 'extra semantic texture'¹⁷⁴ and safeguards which it has done most clearly in Article 12 and its adoption of the support model for exercising legal (decision-making) capacity.¹⁷⁵ The right to be recognised as a person was already contained in Article 16, ICCPR: 'everyone shall

¹⁶⁶ Wicks 2019 (n 125) 5.

¹⁶⁷ Kayess and French 2008 (n 5) 26.

¹⁶⁸ CRPD 2006 (n 7) Article 16 (paraphrasing); Kayess and French 2008 (n 5) 26.

¹⁶⁹ Kayess and French (n 5) 26.

¹⁷⁰ CRPD 2006 (n 7) Article 8 (1).

¹⁷¹ As explored throughout Chapter Three.

¹⁷² Kayess and French 2008 (n 5) 21. As discussed in Chapter Three, Section 3.4.

¹⁷³ Rioux 1994 (n 88) 88-89. I see no reason to view the particular mention of intellectual disability as not also applying to other disabilities, including cognitive impairment and disability.

¹⁷⁴ Mégret 2008 (n 84) 502.

¹⁷⁵ *ibid.*

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have the right to recognition everywhere as a person before the law'. Yet, as was noted in 4.2.1, the existing International Bill of Rights failed to highlight persons with impairments as those particularly at risk of having this right abused until the adoption of the CRPD in 2006.¹⁷⁶ These examples demonstrate that by recognising immutable differences and adding extra-semantic texture to facilitate their realisation, the rights, freedoms and State obligations within the CRPD have on the whole adopted a universalist interpretation of equality. It is no coincidence that these are the rights picked out in the academic sources analysed above for their revolutionary potential.¹⁷⁷ Moreover, the conclusion that the CRPD intends to uphold a universalist interpretation of equality is more compatible with its central purpose and aim.¹⁷⁸

4.2.4 Section Conclusion

Those with cognitive and mental impairments have historically been treated paternalistically and have been subjected to abuse due to their unequal recognition of personhood in law.¹⁷⁹ The universalist interpretation of equality has the most potential to revolutionise the exercise of legal capacity for PDOC patients and guarantee their status as persons in law. It seems to be the CRPD's unique interpretation of equality (and non-discrimination) that holds its key to much needed change and not necessarily Article 12 alone; without reading Article 12 in light of Article 5, Article 12 would be nothing more than a political statement that, "all hold equal legal capacity in law".¹⁸⁰ The universalist model of equality fights not only different treatment that is obviously discriminatory but also practices that seek to eradicate equality through disability-specific measures, but in doing so, amount to differential rather than same treatment.¹⁸¹ It therefore has direct

¹⁷⁶ Kayess and French 2008 (n 5) 12.

¹⁷⁷ Flynn and Arstein-Kerslake 2014 (n 41); Quinn Frontline 2011 (n 8); Mégret (n 84); Kayess and French (n 5); Dhanda (n 33); Rioux (n 88).

¹⁷⁸ CRPD 2006 (n 7) Articles 1, 4 and 12; GC 6 (n 45) paragraph 11.

¹⁷⁹ Gooding 2014 (n 12); Quinn 2011 (n 1); Quinn Frontline 2011 (n 8); Quinn 2010 (n 10).

¹⁸⁰ As argued in Subsection 4.2.3.

¹⁸¹ See Kayess and French 2008 (n 5) who argue this includes discrimination arising from same treatment, where, for example, the CRPD's 'Preamble' states the treaty prohibits, 'all forms of discrimination and failing of reasonable accommodation where there is a disproportionate burden' (paraphrasing), where Article 3 'General Principles' demands 'respect for difference' under paragraph (d), and their inclusion via 'full and effective participation and inclusion in society' under paragraph (c).

relevance for the discrimination analysis on subsections 4(6) and 4 (7) MCA in 4.4 and the apparent conflation of bodily integrity and autonomy.

However, the CRPD has in places undermined its potential for change by leaving some of its provisions still advocating older and discriminatory interpretations of "equality".¹⁸² This is due to linguistic ambiguity in the CRPD's text and General Comments which further undermine the legal protection promised, e.g. by casting doubt on whether the CRPD covers all PDOC patients in its definition of disability.¹⁸³ Finally, its problematic use of 'persons with disability' instead of 'persons with impairments' may undermine its potential to prevent abuse rather than merely provide remedy or redress retrospectively.¹⁸⁴ Nevertheless, in its defence, these limitations must be viewed in light of the fact that the CRPD is a politically 'negotiated text' and therefore will be far from perfect.¹⁸⁵ This does not mean the CRPD is impotent to galvanise the necessary changes as its provisions must be read in light of its adoption of universalist equality. The reformulation, extension and almost innovation of disability-specific rights, targets inequalities in the equal recognition of legal capacity by both assimilating persons with cognitive (and mental) impairments and accommodating their difference(s) (pluralism).¹⁸⁶

4.3 How Supported-Decision Making Could be Extended to PDOC patients

4.3.1 The "Impossibility" of Supported Decision-Making

Before assessing the defensibility of how death is defined and determined, or more specifically for this chapter, the defensibility of the mechanism by which death is defined and determined is examined,¹⁸⁷ the philosophical guidance suggests that a reasonable alternative must exist.¹⁸⁸ Therefore, this section will examine whether such an alternative can be identified. It will also demonstrate that within the academic literature, the drafting

¹⁸² As discussed in Subsection 4.2.3.

¹⁸³ *ibid.*

¹⁸⁴ Kayess and French 2008 (n 5). As argued in Subsection 4.2.3.

¹⁸⁵ *ibid* 33; Dhanda 2007 (n 33).

¹⁸⁶ Mégret 2008 (n 84); Rioux 1994 (n 88).

¹⁸⁷ MCA 2005 (n 6) subsections 4(6) and 4(7).

¹⁸⁸ Henry Sidgwick, *The Methods of Ethics* (6th edn, MacMillan & Co Ltd 1901).

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process,¹⁸⁹ and the Committee CRPD,¹⁹⁰ there exists a general consensus that extending the supported decision-making paradigm under Article 12(3) CRPD to PDOC patients will not always be possible. Article 12(3) calls for States to 'take appropriate measures to provide access to persons with impairments to the support they may require in exercising their legal capacity'. For PDOC patients, the support and facilitation required in life support continuation decisions will be support(s) to communicate either a refusal, or consent to continue with such treatment.

The conclusion of these aforementioned sources therefore rests on a belief that PDOC patients cannot be supported or facilitated to communicate a decision and that therefore some form of substituted decision-making will have to remain. For example, during the drafting process some State Parties and members of civil society circumvent this problem by effectively dividing traditionally understood personhood from legal capacity.¹⁹¹ The supposed benefit was that the central aim of the CRPD (to ensure recognition of persons with impairments as persons in law¹⁹²) could be met and substituted decision-making could also be permitted for those who could not communicate an autonomous choice or indicate their rights will and preferences.¹⁹³ In order to do this, some States sought to use a footnote in earlier drafts of the CRPD's text to reserve, in effect, a different meaning of legal capacity: one without agency (the ability to self-exercise other "legal capacities" i.e. decision-making competence or liberty).¹⁹⁴ I have found two problems with this approach, the first is theoretical and the second is procedural.

The theoretical argument is that splitting personhood from agency is not the crucial issue as they are (theoretically) already separate. The issue is whether such individuals are autonomous (or not), and consequently requires recognition that bodily integrity is not a subset of autonomy (in the sense of its mental and cognitive capacity instantiations). Instead, bodily integrity should be understood as the legal capacity of liberty or legal

¹⁸⁹ Dhanda (n 33).

¹⁹⁰ GC 1 (n 113) paragraph 21 introduces the "best interpretation approach" as the Committee CRPD's compromise model.

¹⁹¹ Dhanda (n 33).

¹⁹² *ibid.*

¹⁹³ *ibid.*

¹⁹⁴ *ibid.*

freedoms with rights status, not dependent on mental capacity or cognition.¹⁹⁵ Agency is an important component of being an autonomous person because it is the means by which legal capacity is exercised and thus personhood can be effectuated, but is not crucial to being recognised as a legal person (liberty) or autonomous individual (mental capacity).¹⁹⁶ In this sense, the split between legal capacity (agency) and personhood is being understood as: PDOC patients hold personhood status in name only because the exercise of legal capacity (agency) is removed from them,¹⁹⁷ further demonstrating how human rights law is also conflating the two concepts and overlooking the crucial component of bodily integrity.

This understanding of the relationship between autonomy, bodily integrity and personhood is therefore misguided because although moral personhood should not be based on cognitive capacity as voluntary responsivity (an agency instantiation of autonomy), legal personhood should also not be dependent on any mental or cognitive instantiation of autonomy (i.e. mental capacity or agency). Otherwise, it seriously questions non-autonomous patients' personhood and particularly their broader right to bodily integrity,¹⁹⁸ leaving the possibility of abuse via the unsafeguarded exercise of PDOC patients' legal capacity "for them", as opposed to "with them" (if deemed autonomous) and dangerously overlooking the alternative justification provided in *re F*[1990] from an E&W perspective (if not).¹⁹⁹

¹⁹⁵ With a particular emphasis in medical law on those liberties or rights that protect bodily integrity, as opposed to other non-medical legal liberties e.g., to drive.

¹⁹⁶ I say in theory because on the basis of the evidence in Chapter Three, Section 3.4 that identified cognition as closer to agency than mental capacity or liberty. It is cognition (on the basis of the findings in Chapter Two, Section 2.3 as the indicia of moral personhood) that seems to bar them from legal rights and protections (liberty) protecting their bodily integrity. As such, in practice, it is the conflation of agency, mental capacity and liberty (i.e. bodily autonomy and integrity) as well as the finding that cognition is the indicia of personhood, that questions their personhood.

¹⁹⁷ Flynn and Arstein-Kerslake 2014 (n 41).

¹⁹⁸ See Jonathan Herring and Jesse Wall, 'The Nature and Significance of the Right to Bodily Integrity' (2017) 76 (3) Cambridge Law Journal 566 at 569.

¹⁹⁹ As seems to be the case after the specific instances of abuse noted in the literature, which were outlined at footnotes 26-30 of this chapter. See also *re F*'s [1990] (n 62) outline in Chapter Three, Subsection 3.2.1. Note the key question for legislators and judges is therefore are these individuals autonomous or not and consequently, how to ensure their personhood status by preventing autonomy's conflation with bodily integrity.

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Thematically, Rose has identified that the assertion of rights in law is problematic because the language of rights is a political tool that circumvents the necessary process of agreeing on how those rights will be upheld and effectuated in the competition for scarce resources.²⁰⁰ The preparatory discussions on splitting personhood from legal capacity's agency component exemplify this problem,²⁰¹ whilst all understood that all instances of legal capacity, including agency, were required to give full effect to the aims and objective of the CRPD,²⁰² the disagreement largely rested on how agency could be ensured for those requiring the highest levels of support because they either could not, or had not communicated their 'rights, will and preferences'²⁰³ for any exercise of legal capacity as liberty or decision-making competence.²⁰⁴

Procedurally and customarily under international law, the CRPD is required to have the same meaning in all languages,²⁰⁵ linguistic differences were not to be used to 'substantively alter the meaning of the text' for a few.²⁰⁶ Therefore, using 'a footnote in the guise of providing linguistic clarification [to] alter the substantive commitment of the main text' and thereby maintaining substituted decision-making for some, severely undermined Article 12's purpose: to prohibit unequal and discriminatory denials of legal capacity.²⁰⁷ Moreover, the footnote also simultaneously broke UN protocol by circumventing the

²⁰⁰ Nikolas Rose, 'Unreasonable Rights: Mental Illness and the Limits of the Law' (1985) 12 (2) *Journal of Law and Society* 199.

²⁰¹ See Dhanda (n 33) at pages 441-453, where she notes the use of a footnote being included in the draft CRPD text to reserve a different meaning of legal capacity, separating 'legal capacity for rights' and 'legal capacity to act' (as self-exercisable agency) for those States who were unwilling to fully move to the shared decision-making model and thereby largely undermined its purpose.

²⁰² Bernadette McSherry, 'Legal Issues: Legal Capacity Under the Convention on the Rights of Persons with Disabilities' (2012) 20 (1) *Journal of Law and Medicine* 22, 23. Note legal capacity has been pluralised because this is grammatically correct on the basis, as others have explored, that there are different types of capacity being conflated in best interests decision-making i.e. liberty, decision-making competence and possibly self-exercisable agency. See Coggon and Miola (n 59); Bielby (n 59); Dworkin (n 59).

²⁰³ CRPD 2006 (n 7) Article 12(4).

²⁰⁴ Dhanda (n 33) 444-446; Clíona de Bhailís and Eilionóir Flynn, 'Recognising Legal Capacity: Commentary an Analysis of Article 12 CRPD' (2017) 13 (1) *International Journal of Law in Context* 6, 22-23; Flynn and Arstein-Kerslake 2014 (n 41) 98-9. This question is specifically addressed in Subsections 4.3.2 and 4.3.3.

²⁰⁵ Vienna Convention 1969 (n 122) Article 33(3) states that, 'all versions are equally authoritative, unless the treaty provides, or parties agree that where they do not, a particular version will be more authoritative under Article 33(1) Vienna Convention'. CRPD 2006 (n 7) Article 50 also asserts the equal authenticity of all its published languages' texts.

²⁰⁶ Dhanda (n 33) 453 (paraphrasing).

²⁰⁷ *ibid.*

correct procedure of entering individual State reservations for this purpose.²⁰⁸ Either legal capacity (i.e. personhood) is a universal human attribute or it is not.²⁰⁹ The unquestioned assumption that PDOC patients are equally recognised as legal persons is questionable because of the simultaneous denial of legal capacity in so many areas of law and in such an unsafeguarded manner.²¹⁰ However, as beneficent as this rhetoric intends to be substituted decision-making (e.g. the *Bolam/ Bolitho* standard of medical decision-making²¹¹) is only problematic if the patient is autonomous, retains some limited decision-making competency (i.e., can communicate general desires but not a decision) or where the medical decision-making standard is not being properly regulated and enforced.²¹² Additionally, there is no legal capacity which is a universal human attribute unless liberty (as bodily integrity/ personhood) holds a further limitation that "human being" applies only to born human beings.²¹³ Therefore, greater accuracy is needed in these debates.

The CRPD reasserts that all are legal persons and provides a model of support to facilitate that 'universal human attribute', rather than deny it on the basis of impairment.²¹⁴ As Dhanda has articulated, accepting that legal capacity is a universal human attribute does not mean asserting that all 'possess similar capacities',²¹⁵ amounting to a universalist understanding of equality. However, accepting that legal capacity is not a universal human attribute stipulates in law that some are automatically denied legal capacity on the basis of impairment, further legitimising unequal and potentially discriminatory treatment.²¹⁶

²⁰⁸ *ibid.*

²⁰⁹ *ibid* 457.

²¹⁰ These instances of denying legal capacity were reiterated in Subsection 4.2.1 in footnotes 26-30 and first explored in Chapter Three, Section 3.2 and 3.4, where the findings suggested the denial of legal capacity was occurring in many different areas of law and under different types of legal capacity that it calls PDOC patients' personhood status into question.

²¹¹ *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582 (QB); *Bolitho v City and Hackney Health Authority* [1998] AC 232 (HL). As discussed in Chapter One, Subsection 1.3.3.

²¹² As discussed in Chapter Three, Sections 3.3 and 3.4 in the context of PDOC patients' confused status.

²¹³ As discussed in Chapter One, Section 1.4.

²¹⁴ Eilionóir Flynn and Anna Arstein-Kerslake, 'The Support Model of Legal Capacity: Fact, Fiction, or Fantasy?' (2014) 32 (1) Berkeley Journal of International Law 124, 127 (paraphrasing). Flynn and Arstein-Kerslake have two articles published in 2014, therefore this article will subsequently be referred to as "Flynn and Arstein-Kerslake FFF 2014 (n 214)".

²¹⁵ Dhanda (n 33) 457.

²¹⁶ *ibid* 458.

The overarching question throughout the rest of this chapter therefore explores how the appropriate balance between legitimate and discriminatory denials of legal capacity (autonomy and bodily integrity instantiations) can be struck.²¹⁷ An example of where that balance has gone awry is the diagnostic threshold of subsection 2(1) MCA: a further status-based barrier within the Act which must be overcome before PDOC patients' decision-making capacity is assessed.²¹⁸ As explained previously, paragraph 3(1) (d) MCA treats and includes communication as a "competence" consideration instead of being recognised as a different legal capacity consideration (i.e., agency), providing another example of how the MCA has possibly 'conflated'²¹⁹ a different type of legal capacity with decision-making capacity.²²⁰ For example, subsection 3(1) MCA states that, 'a person is unable to make a decision for himself if he is unable to understand, weigh and retain that information, or to communicate his decision (whether by talking, using sign language or any other means)'. Yet, and as previously argued, the capacity to communicate seems to be overlooked in futility best interests assessments.²²¹ For example, the issue for PDOC patients is not the safety or appropriateness of the decision made (welfare of the patient and others affected by the decision): it is the capacity to communicate (exercise of agency) that is ultimately at issue (responsivity) suggesting they are autonomous persons (in the sense of having mental capacity but require assistance to exercise agency). By conflating decision-making competence with communication as a vital part of agency, their liberty is curtailed in the form of denials of their right to life²²² and freedom from abuse.²²³ The distinction may be subtle but again building on the findings of 3.4, there is arguably a different sort of capacity assessment underlying such cases.²²⁴

²¹⁷ First indicated in Subsection 4.2.2.

²¹⁸ Wayne Martin and others, *The Essex Autonomy Project Three Jurisdictions Report: Towards Compliance with CRPD Art. 12 in Capacity/ Incapacity Legislation Across the UK* (Essex Autonomy Project Paper, 6 June 2016) (EAP 2016).

²¹⁹ Coggon and Miola (n 59) 525.

²²⁰ Chapter Three, Subsections 3.4.1 and 3.4.2 discussed the possibility that self-exercisable agency is another type of legal capacity overlooked and conflated with decision-making competence by the MCA 2005 (n 6) under section 3 and consequently by the Court of Protection also.

²²¹ *ibid.*

²²² CRPD 2006 (n 7) Article 10; ECHR 1950 (n 65) Article 2; HRA 1998 (n 65) Schedule 1 Article 2.

²²³ CRPD 2006 (n 7) Articles 15 and 16; ECHR 1950 (n 65) Article 3; HRA 1998 (n 65) Schedule 1 Article 3.

²²⁴ Note in Chapter Three, Section 3.4 the capacity for decision-making competence and liberty were not found to be at issue. However, if it is accepted on the basis of Chapter Two, Section 2.3 that PDOC patients are inner-aware, it seems that communication equating to the capacity to self-

Moreover, the bracketed part of paragraph 3(1) (d) MCA,²²⁵ includes a further qualification which implies that all methods (including other non-conventional methods) should be exhausted before deciding the patient is non-aware and therefore non-communicative and non-autonomous. Additionally, and based on the findings in 2.3, it is debatable that the responses assumed to be reflex cannot hold some value in communication (legal capacity) assessments, at least to the extent of expressing comfort or distress. Additionally, recent neurological studies suggest that PDOC patients can communicate using fMRI's,²²⁶ and some with 'yes' and 'no' responses,²²⁷ therefore there is an argument that fMRIs should be used before ruling out that no communication can be made.²²⁸ Such assertions are also more compliant with subsection 3(1) MCA and the Act's participation and empowerment ethos,²²⁹ than the current assumption-based treatment that all PDOC patients cannot communicate by any means. Finally, the Essex Autonomy Project searched for and examined the reason for introducing subsection 2(1) into the MCA under a disproportionate impact assessment for indirect discrimination, and found that there exists no reasonable, objective or legitimate reason for its inclusion in the MCA.²³⁰ The inclusion of 'communication' in paragraph 3(1) (d) MCA is arguably sufficient (although I suggest still problematic as a conflation of decision-making and agency) without the need for subsection 2(1) MCA, which amounts to status-based discrimination. Therefore, perhaps the assumption that PDOC patients cannot be supported or facilitated to make a decision should be questioned. The question arising from Chapter Three's

exercise is. Hence, *Aintree's* subjective treatment of futility, in effect, renders subsections 4(6) and 4(7) MCA (n 187) a quasi "right to refuse mechanism" on another's behalf without being granted the power to do so by that individual. Note also, the principle or alleged moral value at issue was different, it was not welfare but futility, as discussed in Chapter Three, Section 3.2.

²²⁵ Referring to, 'or to communicate his decision (whether by talking, using sign language or any other means)' of paragraph 3(1) (d) MCA 2005 (n 6).

²²⁶ The scientific papers that argue that PDOC patients can communicate via wilfully modulating brain activity are noted in Chapter Two, Subsection 2.3.3 at footnotes 201-208.

²²⁷ *ibid.*

²²⁸ Quinn 2010 (n 10). See Subsection 4.3.2 for an outline of possible costs arguments and practical limitations against fMRIs widespread use.

²²⁹ The importance of the participation and empowerment approach of the MCA 2005 (n 6) was discussed in Chapter Three, Subsection 3.4.1.

²³⁰ EAP 2014 (n 46). Specifically, the EAP 2014 (after analysing the Law Commission, *Law Commission Paper 128: Mentally Incapacitated Adults and Decision-Making—A New Jurisdiction* (Paper 128, 1993, Part III)) claim at pages 32-36 that all the purposes listed for the diagnostic threshold's inclusion in the Law Commission Paper fail to pass the proportionality test (disproportionate impact) for indirect discrimination. This point has also been noted at footnote 379 in Chapter Three, Subsection 3.4.1.

findings would be whether such patients are being appropriately facilitated as deemed autonomous individuals to communicate (protecting both bodily integrity and autonomy).

4.3.2 How Can PDOC Patients' Legal Capacity Be Supported?

An obligation exists under Article 12(3) CRPD to facilitate supported decision-making through whatever means are necessary, with the limitation that those means do not place a 'disproportionate or undue burden on the duty bearer'.²³¹ A similar obligation also exists in the MCA under subsection 4(4)'s 'participation' provision.²³² However, the model of supported decision-making has possibly been overlooked in the context of PDOC patients by pervading negative views in the literature on their inability to communicate. As Kong and others argue, an often-overlooked part of the MCA is that support to participate must be ruled out before a determination that the patient lacks capacity can be made to ensure compliance with the subsection 4(4) MCA.²³³ Moreover, Huxtable and Birchley's research presents findings that carers and other support personnel's opinions on the awareness of the patient is often overlooked or ignored in favour of diagnostic tests.²³⁴ This is likely due to the pervading perception that PDOC patients can only communicate via reflexive levels of responsivity and suggests that beyond assessment of responsivity (to diagnose the PDOC state, i.e. level of severity) other modes of communication with, or by the patient are deemed less important in the overall diagnosis.²³⁵ Such attempts to understand and communicate with the patient must be ruled out under the MCA and in light of the CRPD's attempts to prevent and prohibit discriminatory denials of legal capacity on the basis of

²³¹ GC 6 (n 45) paragraph 25 (paraphrasing). Note GC 6 does not specify what would amount to a disproportionate and undue burden, making it difficult to analyse whether fMRIs would be considered as such.

²³² Camillia Kong and Others, 'Judging Values and Participation in Mental Capacity Law' (2019) 8 *Laws* 3, 1-3.

²³³ *ibid*; House of Lords Select Committee on the Mental Capacity Act 2005, *The Mental Capacity Act 2005: Post-Legislative Scrutiny* (HL Paper 139, 2014) was critical of the courts' approach which it considered had failed to implement the best interests test in light of the Act's central aims of participation and empowerment, under section 5 MCA 2005 (n 6).

²³⁴ Richard Huxtable and Giles Birchley, 'Seeking Certainty? Judicial Approaches to the (Non-) Treatment of Minimally Conscious Patients' (2017) 25 (3) *Medical Law Review* 428; Chapter Three, Subsection 3.3.1. Note that these diagnostic tests are now also treated as nearly irrelevant, further questioning the underlying basis for withdrawal in its entirety, as discussed in Chapter Three, Subsection 3.3.1.

²³⁵ *ibid* 441- 443.

the patient's impairment diagnosis.²³⁶ This exercise is important to determine whether such patients are autonomous and therefore that such decisions can appropriately be viewed as facilitation of a right to refuse treatment, as opposed to a consideration of their right to bodily integrity under E&W law.

Furthermore, recent advancements in medical technology such as fMRIs have 'put paid to the medical model',²³⁷ undermining the perception that such patients cannot voluntarily communicate via observable methods, which in turn support Shewmon's conclusion that such patients are in a super-locked-in state.²³⁸ There is therefore a compliance issue between the Court of Protection's (COP) interpretation of the MCA's participation and empowerment ethos,²³⁹ and a concern which questions why fMRIs are not routinely employed before withdrawing life support. The noted incompatibility of the COP's approach with the MCA was criticised by the House of Lords Select Committee in 2014.²⁴⁰ Fundamentally, without exhausting all support available the medical and legal profession will struggle to convince academics and wider society that the current best interests test sufficiently safeguards and upholds the patient's autonomy (and bodily integrity) under either the MCA's model of 'wishes, values and beliefs',²⁴¹ or the 'rights, will and preferences'²⁴² of the CRPD.

However, some resource arguments in the existing literature suggest that the use of fMRIs on a routine basis will not be achievable, listing, the specialist knowledge required, relative scarcity of the scanners and the high cost of installation (approximately £500,000 per scanner).²⁴³ For these reasons, it is predicted that responsivity tests will not be

²³⁶ MCA 2005 (n 6) section 4(4); CRPD 2006 (n 7) Article 12(3) and 12(4).

²³⁷ Quinn 2010 (n 10) 21.

²³⁸ See the list of ways in which this type of brain injury impacts communicative abilities in Chapter Two, Subsection 2.3.2, undermining the defensibility of currently employed responsivity tests to argue such patients are non-aware, where presumed non-awareness amounts to futility and is thus the key component justifying the extension of the moral permissibility and legal requirement of life support withdrawal for such patients in *Bland* [1993] (n 8), as discussed in Chapter Three, Section 3.2.

²³⁹ House of Lords SC 2014 (n 233).

²⁴⁰ *ibid.*

²⁴¹ MCA 2005 (n 6) subsection 4(6).

²⁴² CRPD 2006 (n 7) Article 12(4).

²⁴³ Johan Stender and Others, 'Diagnostic Precision of PET Imaging and Functional MRI in Disorders of Consciousness: A Clinical Validation Study' (2014) 384 (9942) *Lancet* 514; Steven Laureys, Adrian M Owen, Nicholas D Schiff, 'Brain Function in Coma, Vegetative State, and Related Disorders' (2004)

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replaced with routine scanning.²⁴⁴ However, 2.3 presents evidence that several VS patients could communicate and brings into question the justification of withdrawal itself: either all loss of responsiveness equates with death or worryingly only voluntary loss above a reflex level is sufficient to be classified as "dead".²⁴⁵

Legally, the original medical interpretation of futility (considering the non-autonomous patient's right to bodily integrity) in *Bland* (*Bolam* standard, now *Bolitho*) would not be met because some patients have inner awareness and therefore do not meet the standard for futility in non-autonomous patients' cases. But neither should they be deemed non-autonomous and lacking decision-making capacity due to the evidence in 2.3 on their capacity for awareness and Article 12 CRPD's requirement to facilitate communication.²⁴⁶ The current approach of the E&W Courts therefore places too much emphasis on the label of "PDOC" and not enough on challenging the starting presumption or the subsequent question of how the greater assault is preferable to the lesser, arguably misunderstanding the *Bland* judgment's implicit examination of personhood and its (albeit confused) interpretation of bodily integrity.²⁴⁷

The approach also (for deemed non-autonomous patients) ignores the central importance of clinical indication in protecting the right of bodily integrity and places more emphasis on subjective wishes, both failing to recognise such patients as autonomous persons requiring assistance to communicate, whilst paradoxically implying they have a right to bodily autonomy that trumps their bodily integrity. Moreover, under *Aintree*'s subjective standard,²⁴⁸ there is still a possible conflict with the CRPD if fMRIs are not

3 (9) *The Lancet Neurology* 537. See also PDOC 2020 (n 119) at page 54 for an overview of the limitations of fMRIs being routinely used.

²⁴⁴ Laureys, Owen and Schiff 2004 (n 243).

²⁴⁵ As discussed in Chapter Two, Sections 2.3 and 2.4.

²⁴⁶ *Bland* [1993] (n 8). As discussed in Chapter Three, Section 3.2. This assertion is made on the basis of the noted problems in Chapter Three, Subsection 3.4.1 that arise due to section 3 MCA 2005 grouping 'communication' with decision-making capacity assessments (understand, weigh and retain). I argue that such a capacity is better understood as agency rather than decision-making capacity. Separating these capacities would enable PDOC patients (on the basis of the evidence in Chapter Two, Section 2.3) to be recognised as "autonomous" in the sense of having decision-making capacity but require facilitation for agency (communication), and therefore appropriately rebalance *Aintree* [2013] (and PDOC continuation decisions more generally) as bodily autonomy focused.

²⁴⁷ *ibid.*

²⁴⁸ *Aintree* [2013] (n 8). Discussed in Chapter Three, Subsection 3.4.1 and 3.4.2.

undertaken because the balance rests on whether enforcing the use of this support method would amount to a 'disproportionate and undue burden on the accommodating party', which seems to not yet have been sufficiently explored.²⁴⁹ Therefore, I will now explore how supported decision-making could be extended to PDOC patients on the basis that they are autonomous persons (capable of decision-making) but requiring assistance to communicate.

There are certain available options that should be ruled out before permitting others to exercise legal capacity on behalf of PDOC patients.²⁵⁰ Where attempts to garner the patient's wishes via fMRI fail (which is likely in those with impacted capacity to hear, or perceive and understand language due to the fact that fMRI testing uses verbal commands²⁵¹) or if fMRIs cannot be used for resource reasons, attempts should be made to see whether the patient has used advanced planning instruments to record these wishes.²⁵²

The Committee CRPD in GC 1 argues that all persons with disabilities have a right to engage in equally protected and provided advance planning, such as legally binding advance decisions (ADs), legal power of attorneys (LPAs) and do not resuscitate orders (DNACPRs).²⁵³ However, evidence in the literature suggests that more needs to be done to protect PDOC patients' "right" to formulate advance planning instruments.²⁵⁴ Public

²⁴⁹ GC 6 (n 45).

²⁵⁰ As explained in Chapter Three, Section 3.4, the phrasing 'exercise on their behalf' is crude. However, it more accurately reflects the fact that others ultimately construct a narrative of whether they believe the PDOC patient would have deemed their life futile after *Aintree* [2013] (n 8) and therefore effectively exercise legal capacity for them because such decisions are no longer a predominantly medical decision.

²⁵¹ This was discussed in Chapter Two, Section 2.3.2.

²⁵² The legal obligation to rule out of advance planning instruments is covered under MCA 2005 (n 6) paragraph 4(6) (a), and where the formality requirements are found under paragraph 11(8) (a) and subsections 25(5) and 25(6). These were discussed briefly in Chapter Three, Subsections 3.2.3 and 3.3.2.

²⁵³ GC 1 (n 113) paragraph 17.

²⁵⁴ MacMillan notes procedural barriers at pages 16-20 on obtaining, recording and disseminating advance planning instruments across care medical teams. Baker J has noted the COP doubted the validity of advance planning in PDOC life support continuation decisions because of PD 9E Court of Protection Rules 2007. Also, the EAP 2016 (218) notes under "recommendation 7" and at footnote 43, that some Independent Mental Capacity Advocates (IMCAs) are reporting having their jobs threatened if they suggest a case needs to be referred to court. See Macmillan Cancer Support, Missed Opportunities: Advance Care Planning Report (2018); Baker J, 'A Matter of Life and Death' (2017) 43 Journal of Medical Ethics 427; EAP 2016 (n 218).

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awareness of these instruments needs to improve, as well as the recording of patients' wishes to ensure that they are made easily accessible across different medical teams.²⁵⁵ However, under current uses the MCA's provisions on advance planning may be non-compliant with the Committee CRPD's interpretation. GC 1 states that advance planning instruments come into effect not on the assessment that the person in question no longer has decision-making capacity,²⁵⁶ but when the person in question stipulates the date for entry into force and the date the instrument ceases to have effect.²⁵⁷ A further compliance issue raised is regarding recorded wishes in the context of wills and estate planning.²⁵⁸ As discussed in 3.3, Harding has noted that cognitively and mentally impaired persons still face unequal protection of their legally binding wishes in the form of testamentary wills, where the Court of Protection retains powers to rewrite these documents under the 'Statutory Wills'²⁵⁹ procedure of the MCA.²⁶⁰ In such circumstances, the court generally seems to employ a policy of "just deserts" to reallocate their property.²⁶¹ Therefore, a suggested additional safeguard under Article 12(4) CRPD should be that diagnosis of a mental or cognitive impairment is not the sole ground for justifying rewriting these instruments in favour of those who bring them to court to dispute them.

A final form of advance planning that is being abused and that the Committee CRPD has criticised the UK Government for, is the use of mental impairments (such as learning disabilities) being used to justify placing *do not resuscitate orders* (DNACPRs) on patients' files.²⁶² Although this last example does not specifically impact PDOC patients, each of the aforementioned denials of capacity (and ultimately status based discrimination) are prohibited under the CRPD and yet continue under UK medical practice.²⁶³ Most notably

²⁵⁵ *ibid.*

²⁵⁶ MCA 2005 (n 6) paragraphs 4(6) (a), 11(8) (a) and subsections 25(5) and 25(6).

²⁵⁷ GC 1 (n 113) paragraph 17. I do not intend to go into the practicalities of such a suggestion here, and instead intend to outline noted points of possible non-compliance in the literature.

²⁵⁸ Harding 2015 (n 29).

²⁵⁹ *ibid.* Note the meaning of "statutory will" here is adopted from Harding's definition as 'a will executed under the authority of the Court of Protection' and further adds that, 'England and Wales is one of a very few jurisdictions that allow a court (or anyone other than a testator) to execute a will' at page 947.

²⁶⁰ *ibid* 950; Mental Capacity Act 2005 (n 6) section 18 and schedule 2 paragraphs 1-4.

²⁶¹ Harding 2015 (n 29) 962-964.

²⁶² Committee CRPD List of Issues 2017 (n 26) part A subparagraph 1 (f) and part B subparagraph 19 (f). As mentioned in Chapter Three, Subsection 3.2.3.

²⁶³ United Nations Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Report of the United Kingdom of Great Britain and Northern Ireland* (3 October 2017)

for this thesis, in their Concluding Observations Report the Committee CRPD were critical of what it viewed as the UK's continued use of substituted decision-making in life support continuation considerations.²⁶⁴ The examples given fundamentally question what legal capacities or specifically "rights", if any, are ensured for those with mental and cognitive impairments. It seems that the right to life is particularly threatened and is a key point of continuing concern for the Committee CRPD, even after the UK Government's address and defence in the Committee's first Concluding Observations Report on the UK in 2017.²⁶⁵

This subsection has identified ways in which currently employed support methods for decision-making should be improved. It suggests that because PDOC patients cannot safely be deemed non-aware, they should be facilitated to exercise decisions where possible, by taking into account "reflexive" responses and that improvements to advance planning should be adopted before assuming the patient cannot communicate. The supported decision-making model therefore builds on several rights within the CRPD and not just the supported decision-making model under Article 12.²⁶⁶ For example, Article 5 CRPD is engaged because any failure to provide support²⁶⁷ on the basis of the impairment or diagnosis alone will amount to direct discrimination.²⁶⁸ Also Article 8 CRPD obligates States to raise awareness and tackle stereotypes which are crucial in order challenge the pervading view that they are non-aware or 'better off dead',²⁶⁹ and has prevented the provision of appropriate support to exercise legal capacity.²⁷⁰ Additionally, the "rights" of the family to exercise legal capacity on their behalf has been diminished under Article 16 CRPD, undermining the reliance the decision-maker can have on subsections 4(6) and 4(7) MCA's "third party representations" in best interests decision-making.²⁷¹ The

CRPD/C/GBR/CO/1, part B "Specific Rights" paragraph 12 (discriminatory attitude of impaired persons' life being worth less), paragraph 26 (critical of substituted decision-making in life support withdrawal decisions) and subparagraph 54 (d) and 55 (d) (no attempts to resuscitate persons with intellectual or psychosocial disability).

²⁶⁴ ibid part B "Specific Rights" paragraph 26.

²⁶⁵ Committee CRPD List of Issues 2017 (n 26); Committee CRPD Concluding Observations' 2017 (n 263).

²⁶⁶ Kayess and French 2008 (n 5).

²⁶⁷ Note the sole limitation is that the person with impairment has 'the right to refuse support and terminate or change the support or support relationship at any time' according to GC 1 (n 113) subparagraph 29(d).

²⁶⁸ CRPD 2006 (n 7) Article 5(2).

²⁶⁹ Kayess and French 2008 (n 5) 10.

²⁷⁰ CRPD 2006 (n 7) Article 8(1) (a) and (b).

²⁷¹ ibid Article 16; Kayess and French 2008 (n 5). As discussed in Subsection 4.2.3.

discontinuation of life-supporting treatment also engages Article 15, 'freedom from torture or cruel, inhuman or degrading treatment' and highlights E&W's confused interpretation of the right to bodily integrity, given the findings in 2.3 that no scientific evidence can definitively prove such patients cannot feel pain, and in fact that evidence exists to suggest that they can feel pain.²⁷²

However, more than any other right, what is at stake from failing to support their exercise of legal capacity on an equal basis with others is PDOC patients' right to life under Article 10.²⁷³ Therefore, if E&W seeks to treat such patients as autonomous persons in need of support (i.e. as in *Aintree* [2015]), the support paradigm of Article 12(3) and (4) CRPD requires a holistic reading of its text in order to fully understand what is required and what types of support are compatible with the aim and substantive 'right to equality and non-discrimination' under Article 5. However, it remains unclear what should be done where all support has been exhausted and no clear indication of their wishes exist.

4.3.3 Will Substituted Decision-Making Have to Remain Where all Supports Have Been Exhausted?

At the beginning of this section I outlined that the core contention in the CRPD's drafting process revolved around what should happen when all supports have been exhausted.²⁷⁴ Legal capacity is contentious because it is a 'fundamental issue at the core of our legal frameworks'²⁷⁵ and will widely impact the law.²⁷⁶ The responses in the academic

²⁷² See D Alan Shewmon, "'Recovery from Brain Death': A Neurologist's Apologia' (1997) 64 (1) The Linacre Quarterly 30, who presents this evidence at page 60. As discussed in Chapter Two, Subsection 2.3.2, where newer evidence is also presented that seems to further support, as opposed to counter, Shewmon's claim.

²⁷³ Explored in Chapter Three, Section 3.2. See also the same noted concern on persons with cognitive and mental impairments right to life in Committee CRPD Concluding Observations 2017 (n 263) at paragraph 26.

²⁷⁴ Dhanda 2007 (n 33).

²⁷⁵ Flynn and Arstein-Kerslake FFF 2014 (n 214) 137.

²⁷⁶ See Flynn and Arstein-Kerslake FFF 2014 (n 214) at page 137, where they give the examples of 'family, inheritance, property, marriage, consent to sex and medical treatment'; Piers Gooding, 'Navigating the 'Flashing Amber Lights' of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns' (2015) 15 Human Rights Law Review 45, who are page 65 has given the criminal law example of 'fitness to plead'; Harding 2015 (n 29) whose article notes the impact for statutory wills.

literature,²⁷⁷ the drafting process,²⁷⁸ and the Committee CRPD guidance in GC 1 have been split into several possible approaches that ultimately answer whether some form of substituted decision-making can remain or even subsist under the supported decision-making paradigm for PDOC patients.²⁷⁹

Aintree stated that the test for futility is whether the patient would view their life as futile.²⁸⁰ And, as discussed in 3.4, it seems that the 'wishes, values and beliefs' of the patient under subsection 4(6) MCA (read in light of proximate individuals' representations under subsection 4(7) of the MCA) ultimately form a mechanism for creating a refusal for life-supporting treatment on the non or minimally responsive patients' behalf.²⁸¹ Therefore, the chapters' remaining analysis will refer to the "mechanism" under subsections 4(6) and 4(7) as the "constructed right to refuse treatment". I do however acknowledge that the courts have sought to distinguish the best interests test from substituted decision-making, or even its characterisation as a right to refuse.²⁸² However, I view this as a distinction without difference for the reasons discussed below and in 3.4. To be consistent with E&W law on bodily integrity and autonomy, the courts will need to choose if they are autonomous on the basis of new evidence or not. If they are not, subjective wishes cannot be the basis of the judgment and the law will need to also answer how to resolve two conflicting instances of the right to bodily integrity (i.e. Article 3 ECHR and Article 2 ECHR).

²⁷⁷ de Bhailís and Flynn 2017 (n 204); Anna Arstein-Kerslake and Eilionóir Flynn, 'The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: A Roadmap for Equality Before the Law' (2016) 20 (4) *The International Journal of Human Rights* 471; Donnelly (n 81); Quinn 2010 (n 10).

²⁷⁸ The views in the drafting process were discussed in Subsection 4.3.1, this subsection will therefore focus on the views in the academic literature (see footnote 277), the Committee CRPD (n 113) and the ECtHR approach in *Lambert and Others v France* App no 46043/14 (ECHR, 5 June 2015) (*Lambert v France*).

²⁷⁹ See GC 1 (n 113) at paragraph 27, where it provides three characteristics of offending substituted judgment models: 'systems where legal capacity is removed from a person, even ... in respect of a single decision', where 'a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will', and 'any decision made by a substitute decision-maker is based on what is believed to be in the objective "best interests" of the person concerned, as opposed to being based on the person's own will and preferences'.

²⁸⁰ *Aintree* [2013] (n 8) [30] (Lady Hale quoting Jackson J).

²⁸¹ This was the conclusion of Chapter Three, Sections 3.3 and 3.4.

²⁸² *Aintree* [2013] (n 8).

The first and current approach under the MCA seems to be that both supported and substituted decision-making models can subsist. The MCA's approach seems compliant with the Committee CRPD in GC 1 which contradicts its hard-line stance to abolish all substituted decision-making models and offers a compromise under what is terms its coined 'best interpretation' approach, where both are deemed to be able to subsist.²⁸³ The second noted view in the literature argues that substituted decision-making can subsist but that decision-makers must be candid about when and how this is being undertaken.²⁸⁴ The third view argues substituted decision-making must be abolished and that the 'rights, will and preferences'²⁸⁵ of the individual must be determinative.²⁸⁶ After examining these options I will offer my own alternative.

In 3.3, I argue that the MCA's (current) best interests test amounts to a quasi-substituted decision-making model.²⁸⁷ Under this model, the objective medical interests of the patient are weighed in light of the patient's 'past and present wishes and feelings', any recorded wishes via advance planning instruments, 'the beliefs and values that would likely influence his decision if he had capacity', and 'other factors that he would be likely to consider if he were able to do so'.²⁸⁸ Where the patient cannot communicate their past or present wishes, values and beliefs, and has formulated no advance planning instruments, the decision-maker must consult next of kin and those closely associated with caring for the patient and their welfare according to subsection 4(7) MCA. Moreover, the Supreme Court in *Aintree* clarifies the extent to which the patient's interpretation of futility will be determinative by stating that their "wishes" cannot 'prevail any more than those of a fully capacitous patient['s']'.²⁸⁹ The Court adds that consideration has to be given to the patient's 'family life' and that the patient's wishes were important but no more determinative than a competent patient's.²⁹⁰

²⁸³ GC 1 (n 113) paragraphs 20-22.

²⁸⁴ Donnelly 2016 (n 81); Quinn 2010 (n 10).

²⁸⁵ CRPD 2006 (n 7) Article 12(4).

²⁸⁶ de Bhailís and Flynn 2017 (n 204); Arstein-Kerslake and Flynn 'GC 1 Roadmap 2016' (n 277).

²⁸⁷ Chapter Three, Section 3.4. See for example Select Committee 2014 (n 233) paragraphs 2, 83 and 99 for civil society organisations' criticisms of the implementation of the MCA's best interests test. Note however, that the evidence of current cases in 3.3 and 3.4 suggest that medical opinion seems to be treated as increasingly insignificant in such cases.

²⁸⁸ MCA 2005 (n 6) subsection 4(6); *Aintree* [2013] (n 8) [39]-[45] (Lady Hale).

²⁸⁹ *Aintree* [2013] (n 8) [39]-[40] and [45] (Lady Hale).

²⁹⁰ *ibid* [39]-[40].

Such an interpretation seems compliant with the Committee CRPD's best interpretation approach because it seems to correctly interpret equal recognition of legal capacity under Articles 12 and 5 CRPD. However, Wicks has expressed concern that after *Briggs (No.2)*,²⁹¹ patients' lives have been reduced to a burden and resource allocation issue, and that the interests of the family and NHS are prioritised over the patient's, who cannot rebut any presumption that continued treatment is not in their best interests.²⁹² If this is the case, the balance struck by the MCA between competing stakeholders' interests possibly infringes on Article 16 CRPD which sought to limit the family's prioritisation in the assessment of impaired persons' rights.²⁹³ Alternatively, it could be argued that Lady Hale's assessment that, a non-capacitous patient's legal capacity is equal to those with capacity, suggests an appropriate balance has been struck.²⁹⁴ Therefore, the Supreme Court is ostensibly compliant with Article 12 CRPD. However, whether the Supreme Court's adopted interpretation of equality matches the CRPD's (as analysed in 4.2) will be assessed in 4.4.

The Committee CRPD has been criticised for both adopting a stricter stance than the CRPD itself requires on the issue of abolishing substituted decision-making models and for not 'follow[ing] through entirely on its own position that all substituted decision-making must be entirely abolished'.²⁹⁵ GC1 suggests that substituted decision-making regimes must be abolished and that the simultaneous adoption of supported and substituted decision-making models will not be enough to comply with the CRPD.²⁹⁶ However, GC1 also recognises that situations arise 'where after significant efforts have been made [and] it has not been practicable to determine the will and preferences of an individual, the "best interpretation of will and preferences" must replace "best interests" determinations'.²⁹⁷ The best interpretation approach is seen as permissible by the

²⁹¹ *Re Briggs (Incapacitated Person) (Medical Treatment: Best Interests Decision)* [2016] EWCOP 53; [2017] 4 WLR 37 (*Briggs (No.2)*).

²⁹² Wicks 2019 (n 125).

²⁹³ Kayess and French (n 5) 25-26.

²⁹⁴ *Aintree* [2013] (n 8). Lady Hale notes that their legal capacity is equal at paragraph [40] of the judgment.

²⁹⁵ Donnelly 2016 (n 81) 321. See also Dhanda 2007 (n 33) at page 448 for similar comments; GC 1 (n 113) paragraph 17 for the characteristics of substituted decision-making, also noted at footnote 273 of this chapter and in the "Glossary of Terms" in the end matter of this thesis.

²⁹⁶ GC 1 (n 113) paragraph 28.

²⁹⁷ *ibid* paragraph 21 (paraphrasing).

Committee because it still prioritises the rights, will and preferences of the individual as stipulated by Article 12(4) CRPD.²⁹⁸ Therefore, the existence of the diagnostic threshold, the 'strong element of substituted decision-making',²⁹⁹ and silence on whether 'rights' trump 'will and preferences' or 'wishes, values and beliefs',³⁰⁰ suggests that the E&W approach is at least remediably non-compliant with the CRPD's shift to supported decision-making.³⁰¹ Therefore, it is necessary to assess in 4.4 whether the best interests assessment to discontinue PDOC patients' life support is compatible with the CRPD's interpretation of equality and non-discrimination.

This leads onto the second argument in the literature defending the coexistence of substituted and supported decision-making models. Donnelly and Quinn have both conceded that for PDOC patients, a substituted decision-making regime will need to remain as decisions will need to be made 'for' some people.³⁰² However, their model suggests that this can only be done as two entirely separate tests: supported for those who can communicate and thereby be supported, and substituted decision-making for those who cannot.³⁰³ There is no quasi-subjective or best interpretation-styled compromise in this model. Instead, they argue that honesty about the substituted nature of the decision for those who cannot be supported is the most defensible option.³⁰⁴ Donnelly adds that being candid about who is making the decision and on what grounds removes the legal subterfuge because pretence that any of the third parties permitted under subsection 4(7) MCA could construct an accurate view of what the patient wants ignores inherent 'epistemic limitations', where even employing unconventional support methods can only go so far (i.e. fMRIs).³⁰⁵ They consequently present a clear argument that separates the confusion on the legal propriety of adopting a bodily autonomy or

²⁹⁸ *ibid.*

²⁹⁹ *Aintree* [2013] (n 8) [24] (Lady Hale).

³⁰⁰ Dawson 2015 (n 52); Sergio Ramos Pozón, 'The Convention on the Rights of Persons with Disabilities and Mental Health Law: A Critical Review' (2016) 10 European Journal of Disability Research 301; George Szmukler, "'Capacity", "Best Interests", "Will and Preferences" and the UN Convention on the Rights of Persons with Disabilities' (2019) 18 (1) World Psychiatry 34.

³⁰¹ The Essex Autonomy Project 2014 (n 46) assesses the MCA 2005 in light of the CRPD 2006 and determined that it was remediably non-compliant for similar reasons, requiring slight amendments to be compatible with the CRPD 2006.

³⁰² Donnelly 2016 (n 81) 326-328; Quinn 2010 (n 10) 16-18.

³⁰³ *ibid.*

³⁰⁴ *ibid.*

³⁰⁵ Donnelly 2016 (n 81) 327 (paraphrasing). See also Quinn 2010 (n 10) 16-18.

integrity argument in a given case on the basis of established domestic law. Therefore, this is a more defensible model because if there is a question over the "equal" treatment of the non or minimally responsive patient's wishes and there are other competing considerations (propriety of treatment, resources, family life *inter alia*) that trump such decisions based on futility, there seems to be no reason to pretend anything more than a quality of life decision is occurring.³⁰⁶

However, it seems that Quinn's and Donnelly's model assumes all best interests decision-making is justifiable on the grounds of welfare, that there is no difference between the justification underlying life support discontinuation cases and those where the patient has interests.³⁰⁷ As argued in 3.2, *Bland* adopts a specific meaning of futility with particular safeguards of judicial oversight and permanence because of the irreversible nature of the decision. The findings also suggest that life support discontinuation could only be morally justifiable on the basis of having lost personhood.³⁰⁸ Therefore, as commendable, and arguably needed as Donnelly's and Quinn's policy of candour is, it only partially addresses the problem by improving, but not entirely resolving the defensibility of such decision-making. The judges in *Bland* were clear that quality of life considerations could not support a decision that continued treatment amounts to assault,³⁰⁹ and consequently the law must still answer how Article 2 can be trumped by Article 3 ECHR in cases concerning non-autonomous patients. Finally, their model does not examine whether equal refusals could genuinely be achieved by third-party decision-making and thus could be strengthened by doing so.

The third approach of de Bhailís and Flynn argues that substituted decision-making must be abolished in all cases and that supported decision-making can be extended to all (including PDOC patients) by centralising the wishes, values and beliefs of the patient.³¹⁰ In

³⁰⁶ Consistent with the Supreme Court in *Aintree* [2013] (n 8) over paragraphs [24]-[41].

³⁰⁷ I accept this is in fact the answer or official approach of the courts (ie that there is no difference). However, I believe the arguments I presented in Chapter Three, Section 3.2 and 3.3 at least begin to query whether that is entirely accurate in practice, particularly with reference to Lord Goff's misconstrued balance sheet distinction.

³⁰⁸ This is not just supported by Harris 1999 (n 58) and Locke's 1690 (n 58) arguments presented in Chapter Three, Section 3.2; those such as Flynn and Arstein-Kerslake 2014 (n 41), Quinn 2010 (n 10) and Rioux 1994 (n 88) all note a link between cognition as the indicia for personhood and the characteristic required to be treated equally in the law.

³⁰⁹ *Bland* [1993] (n 8) 869 (Lord Goff); Chapter Three, Subsection 3.2.2.

³¹⁰ de Bhailís and Flynn 2017 (n 204).

light of their arguments, their key criticism of the MCA's current interpretation in *Aintree* would be that 'the model ends with an outside decision-maker imposing a decision on an individual based on a labelling of incapacity, typically without the individual's input and based on an objective view of what is in their best interests', amounting to the hall-marks of substituted decision-making.³¹¹ In their paper, de Bhailís and Flynn opine that, 'it is almost always possible to come to some level of understanding of a person's values, beliefs and views ... underpin[ing] their will and preferences'.³¹² However, they suggest that, even in 'hard cases' where 'a person's will and preferences cannot be ascertained [by direct communication] i.e. comatose patients', 'the key to the support process ... is to arrive at a decision with the individual based on their will and preferences'.³¹³ They therefore demand more patient participation than the courts currently permit by removing objective-based judgments. Finally, their view would ensure the prioritisation of the patient's purported view over the interests of other stakeholders (family or NHS) to be compliant with Article 16 CRPD.

The view of de Bhailís and Flynn seems like an appropriate balance. It recentralises the patient and possibly more so than *Aintree* by realigning the patient's view as the key determinant in subsection 4(6) MCA, unless following those wishes cause harm to self or others. The problem with this model for PDO patients is that it does not answer the crucial domestic legal question concerning how the decision to continue to treat or not is decided. Instead, their model admirably seeks to centralise the patient (regardless of decision-making autonomy) but does not acknowledge the consequential issues arising from the apparent conflation of bodily autonomy and integrity. Moreover, their suggestion still allows others to construct a view of what those wishes are for a patient who cannot communicate and that 'this can happen without fear of contradiction'.³¹⁴ This

³¹¹ *ibid* 23. Note I write "would be" because they do not specifically discuss *Aintree* [2013] (n 8) as this assertion is inferred from their comments. See footnote 279 of this chapter for the characteristics of an offending substituted decision-making model according to GC 1 (n 113).

³¹² *ibid*.

³¹³ *ibid*. In a similar way that subsections 4(6) and 4(7) MCA (n 6) purport to.

³¹⁴ Using Donnelly's 2016 (n 81) words at page 327. I do recognise that such an observation may be unfair to de Bhailís and Flynn on the basis that my observations do not align with the purpose of their article or what they are seeking to assess. However, in the context of decision-making concerning the continuation of life-supporting treatment for those who are cognitively impaired, such considerations are central to the domestic legal question and therefore need to be accounted for.

is because under a strict interpretation, even where 'it is possible to come to [an understanding] of a person's [wishes]', how does one know if this view of what their assumed wishes are match their current non-communicated wishes?³¹⁵ Moreover, de Bhailís and Flynn's model does not provide guidance on what a decision-maker should do if a view cannot be ascertained because of contradicting options based on their rights, will or preferences.³¹⁶ Therefore, although their model seems to better prioritise the importance of interpreting equality correctly, it also (like Quinn's and Donnelly's) assumes that there is no difference between the nature of life support continuation best interests decisions and welfare-based best interests assessments on the basis of personhood.³¹⁷

Consequently, the next step is to first assess whether an "equal right to refuse" can be achieved by third party representations that seek to grant equal legal capacity and secondly, that even if *Aintree* is compliant in its approach to ordinary best interests assessments, its adopted justification (subjective futility) needs to be examined for its defensibility in life support continuation decisions.³¹⁸ Before, assessing this in 4.4, the European Court of Human Rights (ECtHR) has added further interesting developments.

The first time the ECtHR considered CANH withdrawal in light of Article 2 (right to life) European Convention on Human Rights 1950 (ECHR)³¹⁹ was in the case of *Lambert and Others v France* [2015],³²⁰ where the leading and dissenting judgment holds a diverging view on whether substituted decision-making occurs and is permissible in such cases. The ECtHR has largely not adopted Article 12 CRPD's approach to equal legal capacity.³²¹ This is likely to be because even though the European Union (EU) is a signatory of the CRPD not all signatories of the ECHR³²² are also signatories of the CRPD.³²³

³¹⁵ *ibid.*

³¹⁶ A possible and currently unresolved conflict between rights, will and preferences has been identified by Szmukler 2019 (n 300), Pozón 2016 (n 300) and Dawson 2015 (n 52).

³¹⁷ The argument that a different best interests assessment is occurring is specifically made in Chapter Three, Subsections 3.2 and 3.4.

³¹⁸ I have already begun to answer this second question in Chapter Three, Section 3.4.

³¹⁹ ECHR 1950 (n 65) as domestically incorporated in England and Wales under the HRA 1998 (n 65), Schedule 1.

³²⁰ *Lambert v France* [2015] (n 278).

³²¹ See Subsection 4.4.2 for some comparative analysis between the ECHR 1950 (n 65) and CRPD 2006 (n 7) where relevant.

³²² ECHR 1950 (n 65).

³²³ UN, 'CRPD Signatories' (UN, Live Updated weblink)
<https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-

However, as Flynn and Arstein-Kerslake argue, the ECtHR has 'been inching its way toward the protection of rights enumerated in Article 12 [CRPD]'.³²⁴

The judgment is important because, despite reiterating the 'wide margin of appreciation' that States have to determine whether life support continuation from cognitively impaired patients is permissible, it also indicated the correct balance to be struck between States' competing obligations to protect life under Article 2 ECHR and the person in question's autonomy under Article 8 ECHR.³²⁵ For example, the ECtHR reasserted the 'paramount importance of the patient's wishes in the decision-making process'.³²⁶ The ECtHR also added that the patient's wishes held the same level of importance 'even where the patient is unable to express his or her wishes'.³²⁷ More importantly for PDOC patients, the doctors' decision was deemed defensible not only because the Court was satisfied of the certainty of Mr Lambert's wishes but because it was also satisfied that the decision had not been made on the mere existence of a prolonged disorder of consciousness.³²⁸ This means that under the ECtHR's approach, life support continuation cannot be presumed to not be in their best interests solely on the basis of the patient having a prolonged consciousness (responsivity) disorder and neither could diagnosis or 'irreversible' prognosis itself 'be assumed to consist in a refusal to be kept alive'.³²⁹

The ECtHR's views seem to be progressive and compatible with the CRPD by prioritising the person with impairment and prohibiting status-based discrimination. However, it seems to suggest that PDOC patients are autonomous because (unlike in *Bland* where two rights protecting bodily integrity conflicted) their bodily integrity is said to be in conflict with their autonomy. This view is ostensibly in line with *Aintree*, yet there

15&chapter=4&clang=_en> accessed 25 October 2019; Council of Europe, 'ECHR 1950 Signatories' <https://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/005/signatures?p_auth=6IRcaVAz> accessed 25 October 2019. Note Lichtenstein has not signed or ratified the CRPD 2006 (n 7), Switzerland ratified on 15 December 2008 but has not ratified and the EU has neither signed or ratified the ECHR but had signed and ratified the CRPD 2006 by the 23 December 2010.

³²⁴ Flynn and Arstein-Kerslake FFF 2014 (n 214) 139.

³²⁵ ibid [148]; Wicks 2019 (n 125) 7.

³²⁶ ibid.

³²⁷ ibid [178]; Wicks 2019 (n 125) 7.

³²⁸ ibid [158]-[159]; ibid.

³²⁹ ibid [159]; ibid. As a traditionally key feature of these judgments, as explored in Chapter Three, Section 3.3.

is no emphasis on facilitating the patient to communicate leading to the contradiction that the patient is deemed autonomous but that others can speak for them and even trump their right to bodily integrity. For example, the majority judgment arguably undermined itself by allowing third-party constructed narratives³³⁰ as a permissible alternative where no advance planning had been formulated.³³¹ The decision therefore marks another judgment where there is a notable lack of clarity on whether the patient is autonomous or not. If they are not, clinical indication is what medically necessitates withdrawal and discharges the duty of care under domestic law; or in human rights terms, provides an objective, reasonable and legitimate basis for withdrawal.³³²

Therefore, even though this judgment seems to praise the removal of status-based discrimination, ostensibly no discrimination would have been found if continuation no longer holds a justifiable medical basis and the patient is non-autonomous. Of course, there are reasons to oppose the approach altogether on the basis of evidence that PDOC patients are inner-aware,³³³ however the objective interpretation of futility³³⁴ is certainly easier to justify in light of discrimination and domestic law. The majority's reasoning in *Lambert* therefore missed a crucial opportunity to safeguard the constructed refusal mechanism³³⁵ by failing to answer: how the existence of cognitive impairment can be prevented from being the reason for withdrawal (objective standard)?³³⁶ And alternatively, how certainty of what the patient wishes can be ascertained in light of evidence which suggests they are inner-aware (*Aintree*'s subjective standard of futility)?³³⁷ Both of which

³³⁰ Note it seems that the French model considers the views of those with a sufficiently proximate relationship like subsections 4(6) and 4(7) MCA 2005 (n 6) in England and Wales.

³³¹ *Lambert v France* [2015] (n 278) [158] and [179]-[181]. Note another permissible example is giving another permission to refuse on their behalf under an LPA.

³³² These words are directly taken from the various instantiations of the disproportionate impact test for discrimination in international law as discussed and specifically outlined in Section 4.4 below.

³³³ See Chapter Two, Section 2.3 for an analysis of the neurological evidence on PDOC patients capacity for awareness and the capacity to feel pain.

³³⁴ Referring to the interpretation of futility in *Bland* [1993] (n 8) as discussed in Chapter Three, Section 3.2.

³³⁵ Referring to subsection 4(6) and 4(7) MCA 2005 (n 6) as discussed in Chapter Three, Section 3.4.

³³⁶ Noting the EAP 2014 (n 46) and their reference to the status-based discrimination in subsection 2(1) MCA 2005 (n 6) and to my own analysis of the impact of communication (as a facet of self-exercisable agency) being treated simultaneously with decision-making competence under section 3 MCA 2005 (n 6), as discussed in Chapter Three, Section 3.4.

³³⁷ As a noted problem of de Bhailís and Flynn's 2017 (n 204) arguments earlier in this subsection.

cannot be answered without a clear judgment on whether the patient is autonomous or not.

On the basis of Kayess and French's indication of harmful stereotypical attitudes towards cognitive and mental impairment as being 'better off dead', it seems that it is possible that this proxy consent basis to discontinue treatment is based on a belief that the patient's reaction to being diagnosed as cognitively impaired would result in a refusal to continue treatment.³³⁸ Ascertaining such a purported and subjective belief relies heavily on third-parties' constructions of the patient's view, leaving the resulting question of when such a construction will become an impermissible assumption which is yet to be answered by the courts creating efficient safeguards.³³⁹ This construction approach under subsection 4(6) and 4(7) MCA is defensible in accordance with the majority in *Lambert* because of the consensus the approach holds in 'a number of countries' and that 'it was primarily for the domestic authorities to verify whether the decision to withdraw treatment was compatible with the domestic legislation The [ECHR], and to establish the patient's wishes in accordance with national law'.³⁴⁰ The Court adds that, its role is to 'ascertain whether the State had fulfilled its positive obligations under Article 2 of the Convention [ECHR]'.³⁴¹

However, this thesis' findings question the defensibility of the ECtHR's application of its wide margin of appreciation and its deference to States to protect persons with cognitive impairment's lives. On that basis, legal decision-making is informed by or follows medical decision-making and the ECtHR's satisfaction with "consensus" does not match the medical decision-making standard in the UK under *Bolitho*, because the justification for withdrawal would have to have a logical basis as well as consensus.³⁴² Nevertheless, Article 53 ECHR states that, 'nothing in this Convention shall be construed as limiting or derogating from any of the human rights and fundamental freedoms which may be ensured under the law of any High Contracting Party,' therefore suggesting that *Bolitho* should and would still be followed as the higher standard of protection.

³³⁸ Kayess and French 2008 (n 5) 5.

³³⁹ As discussed in Chapter Three, Section 4.3 and Chapter Four, Section 4.4.2.

³⁴⁰ *Lambert v France* [2015] (n 278) [181] (paraphrasing).

³⁴¹ *ibid.*

³⁴² *Bolitho* [1998] (n 211). As discussed in Chapter One, Subsection 1.3.3.

Alternatively, the dissenting judgment was much more critical of third-party construction, ultimately 'requiring an advance decision to that effect'.³⁴³ This judgment first analysed the engaged Articles 2 and 3 ECHR, arguing that neither 'involve any negative aspect' such as a "right to die" (Article 2) or within Article 3 "consent to be tortured".³⁴⁴ Moreover, they added that only in the circumstances where Lambert could communicate a refusal would 'two Convention rights' be 'pitted against each other' and only then on the grounds of dignity, could the State's obligation to preserve life under Article 2 ECHR be discharged.³⁴⁵ This interpretation is most compatible with the orthodox interpretation of E&W domestic law on how a decision to continue treatment is determined in those who are deemed autonomous. An autonomy-based right can only trump integrity where the domestic law grants such legal capacity as liberty (e.g., the right to refuse treatment). Interestingly, it also questions the reasoning that CANH amounts to medical treatment and the basis for viewing continuation as impermissible,³⁴⁶ which would justify the State discharging its duty to protect life under Article 2 ECHR.³⁴⁷

However, the final "nail in the coffin" of its scathing dissent was its attack on third-party constructed narratives where it argues only written wishes would suffice.³⁴⁸ They were of the view that the law correctly interpreted does not allow Article 2 to be disregarded on such uncertain and ultimately discriminatory grounds.³⁴⁹ The dissenting judgment therefore not only criticised the French approach of using familial or carer's representations of what they think the patient would want, it consequently also criticises the similar approach in current (post-MCA 2005) E&W law and medical practice.³⁵⁰ The dissenting judgment therefore has the most consistent understanding on whether bodily

³⁴³ Wicks 2019 (n 125) 7 (paraphrasing).

³⁴⁴ *Lambert v France* [2015] (n 278) (dissenting judgment) [2].

³⁴⁵ *ibid* [3].

³⁴⁶ *ibid*. See also John Keown, 'Beyond Bland: A Critique of the BMA Guidance on Withholding and Withdrawing Medical Treatment' (2000) 20 (1) Legal Studies 66. As discussed in Chapter Three, Section 3.2.

³⁴⁷ *Lambert v France* [2015] (n 278) (dissenting judgment) [4]. As discussed in Chapter Three, Section 3.4 and will be finally explored in the discrimination analysis in Section 4.4.

³⁴⁸ *ibid* [3].

³⁴⁹ Interestingly, ECHR 1950 (n 65) Article 8 was also advanced in this case but on the basis of protecting Lambert's bodily/ physical integrity and not his autonomy as it is normally invoked to protect. See *Lambert v France* [2015] (n 278) (dissenting judgment) [2].

³⁵⁰ Referring to subsections 4(6) and 4(7) MCA (n 6) that I have loosely coined the MCA's "constructed refusal" mechanism, as discussed in Chapter Three, Section 3.4.

integrity or autonomy is at issue and in what circumstances autonomy can trump integrity. It also seems to be more in tune with the idea that the medical evidence has moved on and therefore no longer supports the starting presumption that continued treatment is an assault.

Previously to *Lambert*,³⁵¹ no ECtHR guidance existed on Article 2 implications for life support discontinuations from PDOC patients. Oddly, Butler-Sloss LJ in *NHS Trust A v M; NHS Trust B v H* asserts that Article 2 is not violated in such cases because continuing treatment is no longer in the best interests of the patient.³⁵² Whilst this assertion seems to have been largely interpreted from the reasoning in *Bland*,³⁵³ *Bland* does not assess human rights compliance. In fact, Lord Mustill expressed regret that the Attorney-General did not appear to represent the State's interest in protecting life under Article 2 ECHR.³⁵⁴ Consequently, Wicks argues that Butler-Sloss LJ's reasoning therefore seems to be 'plucked from thin air given there is no precedent for reading the State's obligations under Article 2 [ECHR/ HRA] as subject to best interests determinations'.³⁵⁵ Butler-Sloss LJ's assertion possibly also lacks authority given that *Lambert* was the first case where the consideration of right to life in relation to decisions questioning life support continuation for PDOC patients was brought before the ECtHR.³⁵⁶ *A v M* therefore represents a missed opportunity for integrity-based cases to explore why Article 3 trumps Article 2 ECHR (lesser assault trumping the higher assault) and thereby resolve the legal dilemma discussed in 3.2.

Therefore, Donnelly, Quinn, and the dissenting judgment in *Lambert* have all (in some cases indirectly) criticised the 'fallback position' represented by the best interpretation approach in GC 1 and section 4 MCA's best interests test, arguing that it

³⁵¹ *Lambert v France* [2015] (n 278).

³⁵² *NHS Trust A v M; NHS Trust B v H* [2001] 1 All ER 801 (Fam) (*A v M*) at [30] (Butler-Sloss LJ).

³⁵³ *Bland* [1993] (n 8). Note Lord Goff at page 868 framed the legal question as 'whether it was in the best interests (objective medical) of the patient continue treatment' (paraphrasing).

³⁵⁴ *Bland* [1993] (n 8).

³⁵⁵ Elizabeth Wicks, 'The Legal Definition of Death and the Right to Life' in Shane McCristine, *Palgrave Historical Studies in the Criminal Corpse and Its Afterlife. Interdisciplinary Perspectives on Mortality and its Timings: When is Death?* (Macmillan Publishers Ltd 2017) 126.

³⁵⁶ Wicks 2019 (n 125); *NHS Trust A v M* [2001] (n 352). Note that at paragraph [30] Butler-Sloss LJ acknowledges no case had yet come before the ECtHR and that compliance with the ECHR 1950 (n 65) was having to be haphazardly deduced from similar cases.

amounts to a legal subterfuge and 'hidden exercise of power'.³⁵⁷ However, whilst Donnelly and Quinn argue that substituted decision-making can remain (as long as the courts are honest about when and how it is happening, and who is exercising the legal capacity 'to decide for them'³⁵⁸), this thesis' findings suggest that the third-party construction mechanism (subsections 4(6) and 4(7) MCA) needs to be assessed in light of the CRPD's interpretation of equality and non-discrimination as outlined in 4.2.3.

Nevertheless, if no advance planning is recorded in such cases (and in agreement with the dissenting judgment in *Lambert*) I advise that life support in the form of antibiotics or CANH cannot defensibly be withdrawn. The test in *Aintree* is now akin to a purported equal exercise of legal capacity to refuse life-supporting treatment on the subjective (patient's) view of what amounts to a futile life.³⁵⁹ This suggests that the courts in E&W and ECtHR are interpreting such cases as a battle between bodily autonomy and integrity and therefore implicitly believe but refuse to acknowledge the patient as autonomous. Therefore, if no refusal has been communicated by the patient there is no reason to discontinue, such cases are being made on the basis of wishes and not clinical indication.³⁶⁰ This view is not just in line with the dissenting judgment in *Lambert* it would also ironically be more in line with the judgment of the majority, who also question the basis of diagnosis and prognosis as the reason for withdrawal.³⁶¹

4.3.4 Section Conclusion

This section has analysed: the reasoning in the drafting process;³⁶² the Committee CRPD's 'best interpretation approach';³⁶³ the approach of the ECtHR in *Lambert* [2015];³⁶⁴ and those presented in the academic literature to present suggestions of how the supported

³⁵⁷ Donnelly 2016 (n 81) 362. See also Rose 1985 (n 200) where he argues that the language of rights is also employed to disguise a shift in power, as mentioned in Chapter Three, Section 3.4. Therefore, I suggest that GC 1's (n 113) "best interpretation approach" could be viewed in the same way.

³⁵⁸ Donnelly 2016 (n 81) 327 (paraphrasing); Quinn 2010 (n 10) 16-18.

³⁵⁹ The argument supporting this assertion was discussed in Chapter Three, Section 3.4.

³⁶⁰ Communicated via the means discussed in Subsection 4.3.2, such as advance planning instruments and where resources permit, fMRIs.

³⁶¹ *Lambert v France* [2015] (n 278) [159]; Wicks 2019 (n 125) 7.

³⁶² Dhanda 2007 (n 33).

³⁶³ GC 1 (n 113) paragraph 21.

³⁶⁴ *Lambert v France* [2015] (n 278).

decision-making model can and should be extended to PDOC patients in E&W. It argues that strengthening advance planning procedures; encouraging the use of fMRIs where possible and raising public awareness are necessary support methods that should be used before ruling out that a PDOC patient cannot be supported to exercise legal capacity under Article 12(3) CRPD.³⁶⁵ These support methods are essential in challenging the view that no PDOC patients can be supported to communicate and supports the implicit view in both current domestic cases and those of the ECtHR that PDOC patients are also autonomous.³⁶⁶

The section also sought to examine the views among the mentioned key sources on what to do where no wish can be communicated and where no advance planning has been recorded.³⁶⁷ The compromise approach ('best interpretation'³⁶⁸ or third-party construction³⁶⁹) has ultimately defended the view that in all scenarios a view of what the patient wants or would have wanted can be defensibly deciphered and is permissible to use because it is patient-centred.³⁷⁰ However, as Donnelly argues, there are inherent 'epistemic limitations' of knowing what the non or minimally responsive person wants.³⁷¹ I have added a few further epistemic limitations and criticised the ECtHR's majority approach in *Lambert* for its deference shown to States' wide margin of appreciation on protecting PDOC patients' right to life (bodily integrity), on the basis of those apparent epistemic limitations.³⁷² Deciphering or constructing a patient's wishes in life support continuation decisions is therefore questionable practice,³⁷³ particularly where the patient is autonomous (and not being facilitated to communicate) or deemed non-autonomous. And the compromise approach was arguably better safeguarded in E&W when futility was a medical determination.³⁷⁴ However, the basis for objectively interpreted futility seems to

³⁶⁵ Discussed in Subsection 4.3.2.

³⁶⁶ *ibid.*

³⁶⁷ Discussed in Subsection 4.3.3.

³⁶⁸ GC 1 (n 113) paragraph 21.

³⁶⁹ MCA 2005 (n 6) subsections 4(6) and 4(7).

³⁷⁰ de Bhailís and Flynn 2017 (n 204); GC 1 (n 113).

³⁷¹ Donnelly 2016 (n 81) 327 (paraphrasing).

³⁷² See *Lambert v France* [2015] (n 278) at paragraph [148].

³⁷³ Donnelly 2016 (n 81).

³⁷⁴ See the discussion on the gradual erosion of these safeguards in Chapter Three, Sections 3.3 and 3.4. Note that 3.2 also outlines my misgivings of this model, most notably how a lesser assault can trump their right to life and whether the *Bolitho* standard is still being met in these bodily integrity focused decisions.

no longer be clinically indicated after the findings of 2.3. Therefore, if the subjective view is to remain (as a minimum) safeguards need to demarcate how wide 'the wide margin of appreciation' is in such cases, and when the construction of a patient's wishes can be deemed certain and when they will amount to an impermissible assumption. Such analysis accounts for the view that not all would want to continue treatment. However, without explicit recognition that such patients are being facilitated to communicate a refusal because they are autonomous, valid concerns will remain that a questionable practice of non-voluntary euthanasia exists in E&W medical practice.

The best interpretation model is therefore very similar, if not the same as the third-party construction approach used under subsections 4(6) and 4(7) MCA. Both compromise models centralise the view of the patient and permit others to construct a refusal,³⁷⁵ therefore they both ultimately come under fire for the same epistemic limitations. The sole clear difference found between the CRPD and the MCA in such cases is the weight given to the family's views in subsection 4(7) MCA in comparison to Article 16 CRPD.³⁷⁶ Nevertheless, the section has found that the CRPD's interpretation of equality could positively influence the MCA's best interests test if support to communicate is exhausted first. However, it also found that the best interests test possibly espouses an outdated interpretation of equality. I therefore will assess the best interests test's third-party construction mechanism in 4.4 under international law's disproportionate impact test for indirect discrimination. The reason why I believe indirect, as opposed to direct discrimination is at issue in such cases is also explained in 4.4.

4.4 Is the Best Interests Test Used in Declaratory Relief Proceedings Discriminatory?

The suggestion that subsections 4(6) and 4(7) MCA amount to a mechanism allowing those who have lost capacity to refuse life-supporting treatment is not legally accurate.

³⁷⁵ I recognise that the construction mechanism of subsections 4(6) and 4(7) MCA (n 6) could also be used to construct a wish to continue. However, for the reasons provided and analysed in Chapter Three, Subsection 3.3.1, the consensus in the literature seems to be that this has never been brought before the courts and that there is good reason to doubt a family's wishes would trump a doctor's in those cases where the decision has not been brought to court.

³⁷⁶ Discussed in Subsection 4.2.3.

Likewise, there is no “right” to refuse treatment in the sense of a self-standing human right. However, in the case of non-autonomous PDOC patients the test for futility is no longer medical but based on the subjective view of what a non or minimally responsive patient would want.³⁷⁷ It seems that *Aintree* builds on subsections 4(6) and 4(7) MCA and particularly Lord Goff’s words in *Bland* that to provide no means for such patients to refuse (as those with the ability to exercise legal capacity can) would lead to the ‘most adverse and cruel [and possibly discriminatory] effects’.³⁷⁸ Consequently, I suggest that the efforts taken under the current best interests test to decipher PDOC patients’ views amounts to a mechanism to construct a refusal in an attempt to extend equal treatment and to treat them as facilitated autonomous persons.³⁷⁹ It could also be used to construct consent to continue treatment, however, there exists a consensus in the literature that it is more commonly employed or brought to court to construct a refusal.³⁸⁰ It is therefore important to understand what interpretation of “equality” underlies the presumed need for such a mechanism, and whether that interpretation of “equality” fosters *de facto* equality or potentially creates a disproportionate impact on the legal capacity (and possibly personhood) of PDOC patients.

4.4.1 What is the Best Interests Test’s Adopted Interpretation of Equality?

Articles 5 and 12 CRPD could be read to indicate that a decision to not create a mechanism for PDOC patients to refuse life-supporting treatment would be discriminatory; first, for failing to accommodate difference and secondly,³⁸¹ for failing to support the exercise of equal legal capacity.³⁸² Therefore, the use of the current test seems equitable.³⁸³ Additionally, Lady Hale’s clarification in *Aintree* that the patient’s wishes are

³⁷⁷ *Aintree* [2013] (n 8). See Chapter Three Section 3.3 and 3.4 for analysis on the domestic law that suggests such decisions are no longer medically determined.

³⁷⁸ *Bland* [1993] (n 8) 864-865 (Lord Goff). Note the hypothesis that it may have been discriminatory not to, is my own argument.

³⁷⁹ As argued in Chapter Three, Section 3.4.

³⁸⁰ As examined in Chapter Three, Subsection 3.3.1.

³⁸¹ CRPD 2006 (n 7) Article 5(3).

³⁸² *ibid* Article 12(3).

³⁸³ See *re F*[1990] (n 62) where the impact of the *parens patriae* power is discussed. See also *Bland* [1993] (n 8) at page 883, where Lord Browne-Wilkinson provides a comprehensive account of its impacts on medical decision-making for those who lack decision-making competence.

to be centralised to the same extent as a person's with decision-making capacity,³⁸⁴ suggests that the Supreme Court in both cases interpreted equality as treating unalike, alike through different means. The supposed fairness of such an approach is that it has accommodated difference,³⁸⁵ first, by *Bland* extending best interests assessments to life support continuation cases,³⁸⁶ and by its clarification in *Aintree* that the patient is central to the decision-making process.³⁸⁷ Additionally, discrimination is defined by the CRPD as:

any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms.³⁸⁸

Consequently, the exclusion of PDOC patients by failing to provide appropriate support or reasonable accommodation of difference (for their responsivity disorder) would seemingly amount to discrimination. Consequently, the use of subsections 4(6) and 4(7) MCA (and its advance planning provisions³⁸⁹) ostensibly amounts to support and accommodation of difference to enable an equal exercise of a right to refuse life-supporting treatment.³⁹⁰

However, to end the argument there leads to a threadbare interpretation of the CRPD's non-discrimination and equality provisions which could worsen rather than alleviate inequality.³⁹¹ For example, the exploration of the three models of equality in 4.2.3

³⁸⁴ See Lady Hale's discussion on this point in *Aintree* [2013] (n 8) at paragraph [40], and as discussed in Chapter Three, Section 3.4.

³⁸⁵ CRPD 2006 (n 7) Article 5(3) states that, 'in order to promote equality and eliminate discrimination, State Parties shall take all appropriate steps to ensure that reasonable accommodation is provided'.

³⁸⁶ This is the noted significance on the *Bland* [1993] (n 8) judgment noted in Chapter Three, Subsection 3.2.1.

³⁸⁷ See *Aintree* [2013] (n 8), specifically paragraphs [30]-[41] for the key part of the judgment. Also note the key judgments of *Re Briggs (Incapacitated Person) (Medical Treatment: Best Interests Decision)* [2016] EWCOP 53, [2017] 4 WLR 37 (*Briggs (No.2)*); *M v N* [2015] EWCOP 76, [2015] 11 WLUK 514 (*M v N*), where medical opinion and certainty has been increasingly eroded as discussed in Subsection 3.3.1.

³⁸⁸ CRPD 2006 (n 7) Article 2.

³⁸⁹ The legal obligation to rule out of advance planning instruments is covered under MCA 2005 (n 6) paragraph 4(6) (a), where the formality requirements of such instruments are found under paragraph 11(8) (a) and subsections 25(5) and 25(6). These were discussed briefly in Chapter Three, Subsections 3.2.3 and 3.3.2.

³⁹⁰ CRPD 2006 (n 7) Article 5(3) and 12(3).

³⁹¹ For example, Dawson (n 52) at page 73 has given the example that it is not discriminatory to deny legal capacity to blind persons to drive.

found that any attempt to assimilate such persons by creating a disability-specific mechanism (third-party construction) would exacerbate rather than ameliorate the inequality faced and amount to a 'substantive' interpretation of equality,³⁹² by 'pit[ting] the protected class against others in claims for scarce social resources' making it difficult to dismantle the existing inequalities.³⁹³ For example, Article 1 CRPD's 'non-exhaustive' definition of disability has (in its attempt to define the class) unintentionally excluded those with temporary consciousness disorders despite their inclusion in continuation decisions.³⁹⁴ Therefore, the assumption that a specific mechanism was, and is needed for PDO patients possibly misinterprets the meaning of equality under the CRPD. In fact, to not allow justifiable different treatment would make the CRPD's interpretation of equality unworkable because if differential treatment is not permitted at all, a State could not justify prohibiting, for example, a 'blind person from driving'.³⁹⁵ Therefore, the use of subsections 4(6) and 4(7) MCA to construct a refusal where none has explicitly been given ignores the noted epistemic limitations.³⁹⁶ Fundamentally, it is difficult to understand how a decision can be supported or accommodated if there is no evidence of a decision's existence or any clear recognition that such a patient is autonomous. Such actions can only amount to the creation of a refusal because no refusal evidently exists. Therefore, the 'reasonable[ness]' and 'appropriate[ness]' of such a mechanism is called into question.³⁹⁷

What the CRPD stipulates amounts to 'reasonable accommodation' or 'appropriate measures' of support is not specifically delineated, nor would they be in a politically negotiated text.³⁹⁸ Challengingly, the CRPD also does not delineate the circumstances in

³⁹² Note however this is another example of how the CRPD 2006 (n 7) has undermined its attempts to advocate universalist equality because under Article 5(4) it states, 'specific measures which are necessary to accelerate or achieve *de facto* equality of persons with disabilities shall not be considered discrimination under the terms of the present convention'. See the discussion on Kayess and French's 2008 (n 5) noted limitations of disability-specific mechanisms in Subsection 4.2.3.

³⁹³ Kayess and French 2008 (n 5) 9 (paraphrasing).

³⁹⁴ Subsection 4.2.3. Note that the PDO 2020 Guidelines (n 119) note that irrespective of the amount of time passed since the patient developed a PDO state, and irrespective of whether that is VS or MCS continuation of life-supporting treatment can be questioned. See Chapter Two, Subsection 2.1.1.

³⁹⁵ Dawson 2015 (n 52) 73 (paraphrasing).

³⁹⁶ Referring to the epistemic limitations Donnelly 2016 (n 81) notes and also those added in the discussion in Subsection 4.3.3.

³⁹⁷ Paraphrasing the key words of CRPD 2006 (n 7) Article 5(3).

³⁹⁸ Dhanda 2007 (n 33); Kayess and French 2008 (n 5) note that politically negotiated texts cannot be that specific due to social, political, cultural and financial differences between Sovereign States.

which 'differential treatment of persons with disability' may be justifiable.³⁹⁹ Instead, the provisions of the CRPD adopt a 'highly inclusive' interpretation of discrimination, encompassing 'all forms' and 'any distinction, exclusion or restriction'.⁴⁰⁰ However, the CRPD does stipulate its aims and purpose and is (like all international treaties) to be interpreted in line with international legal norms that provide further guidance on when a finding of discrimination will be made.⁴⁰¹

4.4.2 Assessing the Best Interests Test for a Disproportionate Impact on PDOC Patients

Proceeding on the basis that PDOC patients are legally deemed autonomous but need support to communicate a decision, the UN's Human Rights Committees have provided guidance on discriminatory practices.⁴⁰² To not be discriminatory, a practice must 'serve a legitimate aim' under the CRPD, use an 'objective basis' for its differential treatment and amount to 'reasonable means' to achieve that aim.⁴⁰³ A finding of discrimination will be found if the practice fails to meet all three of these tests.⁴⁰⁴ Notably for the UK, the ECHR also adopts this approach to analysing the discriminatory nature of differential and same treatment that fails to recognise and support difference appropriately.⁴⁰⁵ Therefore, whilst both indirect and direct discrimination are prohibited, a more thorough analysis is required to assess if a finding of either form of discrimination would be made.

The inadvertent removal of the *parens patriae* power⁴⁰⁶ did not stipulate that those such as PDOC patients could not have a "right to refuse", instead its removal left

³⁹⁹ EAP 2014 (n 46) 7.

⁴⁰⁰ *ibid.*

⁴⁰¹ CRPD 2006 (n 7) preamble, Article 1 'purpose' and Article 4 'general obligations'. Note this is key because failing to recognise difference is where inequality and discrimination arise from same treatment such as what possibly occurred in *Bland's* subterfuge, as argued in Subsection 4.4.2.

⁴⁰² United Nations Committee on Economic, Cultural and Social Rights, *General Comment 20 on Non-Discrimination in Economic Cultural and Social Rights* (2 July 2009) UN Doc E/C12/GC/20 (ESCR GC 20). As first adopted in the United Nations Human Rights Committee, *General Comment 18 on Non-Discrimination* (10 November 1989) UN Doc HRI/GEN/1/Rev6 (HRC GC 18).

⁴⁰³ ESCR GC 20 (n 402) paragraph 13 (paraphrasing); HRC GC 18 (n 402) paragraph 13 (paraphrasing).

⁴⁰⁴ *ibid.*; EAP 2014 (n 46).

⁴⁰⁵ See ECHR 1950 (n 65) Protocol 12, which notes 'the principle of non-discrimination does not prevent State Parties from taking measures in order to promote full and effective equality, provided there is an objective and reasonable justification for those measures'.

⁴⁰⁶ As discussed in Chapter Three, Subsection 3.2.1.

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unanswered how the question of continuing treatment could be justified.⁴⁰⁷ Therefore, the creation of the best interests test in *re F*,⁴⁰⁸ attempted to rectify the legal lacuna that amounted to indirect as opposed to direct discrimination, for seemingly failing to provide a means by which incapacitated patients could also discharge a doctor's duty of care to continue treatment through the exercise of doctors' decision-making judgement.⁴⁰⁹ Its subsequent extension to life support continuation decisions in *Bland* sought to mitigate the purported inequality,⁴¹⁰ and consequently under UN human rights law, a finding of indirect discrimination will only be made if it has a 'disproportionate impact'.⁴¹¹

The test is commonly interpreted to assess whether the practice serve[s] a legitimate aim under the CRPD, if its use holds an objective basis for its differential treatment, and, whether the use of that basis amounts to reasonable means for achieving the specified aim.⁴¹² Additionally, the disproportionate impact test cannot make a 'finding of discrimination' but 'constitute[s] grounds for an allegation of indirect discrimination'.⁴¹³ Therefore, subsections 4(6) and 4(7) MCA to construct a refusal for life-supporting treatment ("the practice") shall be assessed under the disproportionate impact test to see whether such an allegation could be brought.⁴¹⁴

For the first test ('legitimate aim'⁴¹⁵), Chapter Three found the current best interests test's aim is to uphold the autonomy (legal capacity) of the patient in order to protect their dignity (their own subjective view of the "futility" of their life).⁴¹⁶ The legitimate aims of the CRPD that match or are similar to the best interest justification are:

⁴⁰⁷ See *Bland* [1993] (n 8) at page 883 [A]-[F], where Lord Browne-Wilkinson concludes it was by 'mistake' or 'oversight' and Lord Lowry arrives at the same conclusion at page 875 [E]-[F].

⁴⁰⁸ *Re F* [1990] (n 62).

⁴⁰⁹ An explanation of the difference between direct and indirect discrimination has been provided by the EAP 2014 (n 46) 5-6.

⁴¹⁰ This is the hypothesis I reached in Chapter Three, Section 3.4. Specifically noting Lord Goff's view that to provide no means to refuse treatment in the case of incapacitated patients' would lead to 'adverse and cruel effects', see *Bland* [1993] (n 8) at pages 864-865 (Lord Goff).

⁴¹¹ EAP 2014 (n 46) 6.

⁴¹² ESCR GC 20 (n 402) paragraph 13 (paraphrasing); HRC GC 18 (n 402) paragraph 13 (paraphrasing); EAP 2014 (n 46) 6 (paraphrasing).

⁴¹³ ESCR GC 20 (n 402) paragraph 13 (paraphrasing); HRC GC 18 (n 402) paragraph 13 (paraphrasing); EAP 2014 (n 46) 6-7 (paraphrasing).

⁴¹⁴ *ibid.*

⁴¹⁵ *ibid*

⁴¹⁶ *Aintree* [2013] (n 8). As discussed in Chapter Three, Section 3.4.

- 1) To 'recogniz[e] the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices';⁴¹⁷
- 2) To '[e]nsure [the] effective enjoyment [of the right to life] by persons with disabilities on an equal basis with others';⁴¹⁸
- 3) To '[p]rotect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects';⁴¹⁹
- 4) To 'protect the physical and mental integrity of the person'.⁴²⁰

These four aims are all engaged in life support continuation considerations for those with cognitive disability. Consequently, the first aim (interpreted as both the legal capacity of liberty and decision-making capacity) is supported by the use of advance planning as an appropriate support measure because it is a legally binding statement permitting another to exercise legal capacity on their behalf (noting that the extent of the power differs in each instrument i.e., LPA or an AD).⁴²¹ On this understanding, the support measure of advance planning instruments passes the legitimate aim test.

Alternatively, the practice under subsections 4(6) and 4(7) MCA is more difficult to justify under autonomy as an extension of a right to refuse for patients who are deemed non-autonomous in law. In such circumstances, there exist no advance planning instruments, the patient is non or minimally responsive and is not being facilitated to communicate or recognised as being autonomous. There is therefore no genuine existence of a refusal or grounds to prioritise patients' wishes over clinical indication (autonomy vs integrity). The autonomy of the patient in the sense of "liberty to choose whether to continue life support or not" cannot be the aim that legitimises this practice. The best interests test under subsections 4(6) and 4(7) MCA purports to give effect to the individual they were known to be by constructing a view of what they would currently choose from their purported 'values, wishes and beliefs', and representations of those with proximate relationships.

⁴¹⁷ CRPD 2006 (n 7) preamble.

⁴¹⁸ ibid Article 10.

⁴¹⁹ ibid Article 16.

⁴²⁰ ibid Article 17. See EAP 2014 (n 46) at pages 16-17, where these aims were also chosen by the Essex Autonomy Project's analysis on MCA 2005's (n 6) compliance with the CRPD 2006.

⁴²¹ This was explained in Chapter Three, Subsection 3.3.2. Note this also applies to DNACPRs in the event that the patient is no longer breathing. However, this thesis focuses on CANH and antibiotic withdrawal from breathing patients with impaired responsiveness (PDOC patients).

Therefore, the current best interests test seems to have constructed a mechanism to extend as far as possible a "right to refuse" to such patients, moving away from clinical indication and its protection of bodily integrity, despite no acknowledgment that such patients are autonomous.⁴²² Furthermore, the safeguards of permanence and judicial oversight have been largely eroded in subsequent cases by the erroneous shift in its underpinning moral value from futility to welfare to facilitate a form of proxy consent.⁴²³ Hence, the mechanism has attempted at all stages (objective to subjective futility) to treat 'unlike, alike through different practices'. This substantive view of equality has enabled the unequal protection of PDOC patients' personhood and erosion of futility's safeguards:⁴²⁴ first, by failing to limit how others can, in effect, exercise legal capacity on their behalf without the patient's express permission to do so; secondly, because of the inherent limitations in the courts being able to know with certainty that the patient wishes to exercise legal capacity to refuse treatment; and thirdly, by eliding bodily autonomy and integrity in such decisions.⁴²⁵

Consequently, autonomy in the sense of liberty (legal capacity) ostensibly matches the aims of the CRPD, however, whether the practice can legitimately and accurately exercise legal capacity on their behalf is questionable.⁴²⁶ Furthermore, the fact that life support continuation cases seem to be no ordinary extension of the best interests test questions the practice's (construction mechanisms) propriety in such cases.⁴²⁷ Lord Goff's assertion that such treatment cannot be withdrawn on the basis of quality of life determinations evidences that this best interests test was intended to be distinctly

⁴²² This is the conclusion of Chapter Three, Section 3.2 and Subsection 3.4.2.

⁴²³ As discussed in Chapter Three, Sections 3.3 and 3.4. Note *Aintree* [2013] (n 8) still ostensibly discusses futility but treats it in a way where it is interpreted almost synonymously with welfare and the patient's subjective view of what is best for them ie facilitation of a "right to refuse" in a patient who is not considered autonomous. This is even more plausible given the conflation of bodily autonomy and integrity, as explored in Chapter Three, Section 3.2.

⁴²⁴ The different instantiations of equality and their respective benefits and limitations were discussed in Subsection 4.2.3.

⁴²⁵ These examples amount to an overview of the noted impact of adopting a substantive interpretation of equality for PDOC patients as discussed in Subsection 4.3.3.

⁴²⁶ As discussed in Subsection 4.3.3.

⁴²⁷ The key finding of Chapter Three, Section 3.2.

different from welfare considerations:⁴²⁸ life support continuation (and consequently defining and determining death) was to be a medical decision.

Therefore, the right to refuse is an authorised exception of legally granted liberty in law rather than reflecting ordinary practice; for those who cannot communicate a refusal (self-exercise agency) 'the source of the duty [lay and] lies elsewhere'.⁴²⁹ Ultimately, an autonomous patient needs to have agency to effectuate that right and advance planning mechanisms already provide a more balanced way of doing this for those who are non-autonomous. On the basis of this thesis' findings, I believe that futility should remain an objective test under *Bolitho*⁴³⁰ as the standard of medical decision-making for what amounts to futile treatment. It seems that the MCA's interpretation of equality in recognising equal legal capacity under ss 4(6) and 4(7)⁴³¹ cannot be the justificatory basis for a practice that attempts to rationalise a non-communicated and arguably non-existing choice that determines personhood (bodily integrity),⁴³² and has adopted a substantive model of equality.⁴³³

The second aim is to ensure the enjoyment of 'right to life' on an equal basis as those without disability.⁴³⁴ Throughout *Bland*, little attention was given to a right to life or the 'sanctity of life' other than to state that it is a 'non-absolute' right.⁴³⁵ Furthermore, the examples given in *Bland* to justify this assertion include State permitted exclusions only, e.g. execution or self-defence, which otherwise for all other purposes is a non-derogable right of the ECHR.⁴³⁶ Therefore, their Lordship's conclusion that sanctity of life was not absolute for the circumstances proposed in *Bland* arguably stretched those exceptions

⁴²⁸ See *Bland* [1993] (n 8) 868-869 (Lord Goff). As discussed in Chapter Three, Subsection 3.4.2. This is correct on the basis of how the law protects the bodily integrity of both autonomous and non-autonomous patients as some harms (ie intended death) are not left to personal choice.

⁴²⁹ *R (on the application of Burke) v General Medical Council (Official Solicitor and others intervening)* [2005] EWCA Civ 1003, [2005] QB 273 (*Burke*) [31]-[33] (Lord Phillips) (paraphrasing).

⁴³⁰ *Bolitho* [1998] (n 211). As discussed in Chapter One, Subsection 1.3.3.

⁴³¹ As discussed in Chapter Three, Section 3.4.

⁴³² As discussed in Subsection 4.3.3.

⁴³³ As discussed in Subsection 4.2.3.

⁴³⁴ CRPD 2006 (n 7) Article 10.

⁴³⁵ *Bland* [1993] (n 8) 859 (Lord Keith) 863-864 (Lord Goff).

⁴³⁶ *ibid*. The non-derogable right referred to is Article 2's right to life. Note as discussed in Chapter One, Subsection 1.4.4 the death penalty was abolished in the UK in Murder (Abolition of the Death Penalty) Act 1965 and therefore was not in force at the time of *Bland* [1993] (n 10).

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further than before by creating a new exception for when the right to life is derogable in the cases of severe cognitive disability.

Additionally, in 4.3.3, the further case of *A v M* determined that using the best interests test in such cases does not breach Article 2 ECHR, based on the reasoning in *Bland* rather than an ECtHR judgment.⁴³⁷ Therefore, the opposite is being argued in PDOC patients' declaratory relief proceedings; the right to life is derogable for severely cognitively impaired persons. Otherwise, if futility is the basis for necessitating discontinuation and is to be determined by the patient (*Aintree*), E&W seems to be moving closer to a recognised right to die. Yet, neither Article 2 ECHR or Article 10 CRPD currently encompass the right to die:⁴³⁸ an interpretation that was reasserted in *Lambert's* dissenting judgment and is evident in the Committee CRPD's criticism of the UK's protection of cognitively impaired persons' lives.⁴³⁹ As suggested in 3.2, the legal dilemma in such cases therefore seems to arise from two conflicting protections of bodily integrity (unjustified treatment under Article 3 and right to life Article 2 ECHR). Hence, the COP's interpretation and implementation of both the first and second aims (autonomy and right to life respectively) in such cases fails to meet the interpretation of a legitimate aim under the CRPD. Consequently, this failure also demonstrates that the aim of protecting impaired persons from abuse within and outside the home under Article 16 CRPD has not been met either.⁴⁴⁰

There may be a legitimate aim under dignity considerations as dignity would encompass the first (autonomy) and fourth (physical and mental integrity) noted aims to differing extents.⁴⁴¹ The CRPD's preamble states that an aim of the Convention is to

⁴³⁷ See *NHS Trust A v M* [2001] (n 352) at paragraph [30] (Butler-Sloss LJ). As discussed in Subsection 4.3.3.

⁴³⁸ *Lambert v France* [2015] (n 278) (dissenting judgment) [2]. Note the CRPD List of Issues 2017 (n 26) were critical of the unequal protection of disabled lives in health care practices: Part B "Specific Rights" Paragraph 12 notes the discriminatory attitude of disabled life being worth less; paragraph 26 is critical of substituted decision-making applied to life support withdrawal; and subparagraphs 54 (d) and 55 (d) denounces the use of intellectual or psychosocial disability as a justification on DNACPRs.

⁴³⁹ *ibid.* Noting the Committee CRPD Concluding Observations' 2017 (n 263).

⁴⁴⁰ CRPD 2006 (n 7) Article 16 (aim three above).

⁴⁴¹ *ibid* Preamble and Article 17. See EAP 2014 (n 46) at pages 16-17, where these aims were also chosen by the Essex Autonomy Project's analysis on MCA 2005 (n 6) compliance with the CRPD 2006 (n 7).

'recognise the inherent dignity, worth and the equal inalienable rights of all members of the human family'. Dignity is also mentioned in several parts of the Convention.⁴⁴² Article 1 states that the 'purpose' of the Convention is 'to promote respect for dignity'. Article 3 mentions 'inherent dignity' in the context of 'personal choice', including 'respect for difference' and 'non-discrimination'.⁴⁴³ Additionally, Article 17's 'right to respect the physical and mental integrity of the person with impairment on an equal basis with others' also includes aspects of protecting dignity. And finally, the Committee CRPD's GC 6 notes that the Convention mentions dignity more times than in any other UN human rights treaty.⁴⁴⁴ Therefore, there exists a strong argument that respect for dignity encompasses measures which respect difference and 'equality of opportunity' by promoting autonomous choice and independence of persons, as well as respecting their mental and physical integrity.⁴⁴⁵ Dignity could therefore be a legitimate aim of the best interests test and be seen to appropriately provide a different basis of refusal of treatment for high support persons (PDOC patients).

However, I am not entirely convinced by this possible counterargument. Dignity in the CRPD has a close relationship with autonomy, meaning that it is likely to falter under the first aim's objections (raised above): the propriety of autonomy-based justifications for discontinuation and difficulty overcoming epistemic limitations of the patient's view of dignity.⁴⁴⁶ *Aintree's* subjective view of what a patient would deem futile cannot be interpreted as dignity because, like autonomy, there are epistemic limitations in ascertaining what a dignified life amounts to for the patient in question.⁴⁴⁷ Additionally, it is unconvincing that the aim (at least originally in *Bland*) was to maintain PVS patients' dignity via protection of their mental and physical integrity because as Lord Goff argued, what morally permitted life support withdrawal was futility, not quality of life or dignity

⁴⁴² Notable examples include CRPD (n 7) Articles 1, 3, 17 and GC 6 (n 45).

⁴⁴³ CRPD 2006 (n 7) Article 3 'general principles'.

⁴⁴⁴ GC 6 (n 45) paragraph 6.

⁴⁴⁵ Loosely based and derived from Articles 3, 5, 12 and 17 CRPD 2006.

⁴⁴⁶ Charles Foster, *Choosing Life, Choosing Death: The Tyranny of Autonomy in Medical Ethics and Law* (Hart Publishing 2009); Macklin 2003 (n 82); Donnelly 2016 (n 81).

⁴⁴⁷ Donnelly 2016 (n 81). See *Aintree* [2013] (n 8) at paragraph [30], where Lady Hale adopts Jackson J's wording and test from the first instance hearing, and the noted impact for PDO patients in the discussion in 4.3.3 relating to epistemic limitations in knowing what non or minimally responsive patients want.

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considerations.⁴⁴⁸ Therefore, preservation of dignity (in the sense of the person they were or how others remember them pre-injury) will unlikely amount to a legitimate aim for those who are non-autonomous.

Moreover, the 'mental integrity'⁴⁴⁹ argument would be particularly weak given that Jackson J has suggested that no deprivation of liberty can occur in such cases because of the belief that PDOC patients are non-aware.⁴⁵⁰ Finally, dignity in the sense of protecting the physical integrity⁴⁵¹ of the patient would also be difficult to justify because of the pervading view that PDOC patients cannot feel pain or be assaulted in the same way that those with awareness can.⁴⁵² However, although dignity has also failed, for the purpose of academic analysis, it is useful to see whether the "legitimate" aim of dignity for PDOC patients' life support continuation decisions could pass both the other tests, that is, the objective basis for difference and reasonable means of achieving dignity.⁴⁵³

The Essex Autonomy Project 2014 interprets the second test of an objective basis for differential treatment to mean 'objectively assessed'.⁴⁵⁴ Additionally, the factor or concept being assessed in such cases is futility. There have been two different methods of assessing futility: objective futility (*Bland*- bodily integrity) and subjective futility (*Aintree*-bodily autonomy).⁴⁵⁵ On the assumption that patient dignity could be the legitimate aim, medically assessed futility (at the time of *Bland*) would more easily have passed as objective because it has an ostensibly scientific basis. Nevertheless, the test post-*Aintree* is determined from the perspective of the non or minimally responsive patient and is

⁴⁴⁸ See the discussion in Chapter Three, Subsection 3.2.2 on *Bland* [1993] (n 8) at page 869, where Lord Goff explains that quality of life and dignity were 'reasonable' considerations 'but in the end, in a case such as *[Bland]* it is the futility of treatment which justifies its termination'.

⁴⁴⁹ CRPD 2006 (n 7) Article 17 (of the possible compatible aims identified above).

⁴⁵⁰ Noting Jackson J's comment in *Re M* [2017] (n 28) at paragraph [39] (paraphrasing), as discussed in Chapter Three, Subsection 3.4.1.

⁴⁵¹ CRPD 2006 (n 7) Article 17 (of the possible compatible aims identified above).

⁴⁵² The specific instances of abuse and the differential legal treatment, which seems to be justified on the basis that PDOC patients have no awareness and therefore that the harm suffered is lesser than those with awareness are noted at footnotes 26-30 of this chapter. Note also that the challenge to PDOC patients' thought inability to feel pain is discussed in Chapter Two, Section 2.3.

⁴⁵³ EAP 2014 (n 46) 9. Note the EAP 2014 (n 46) authors have used the guidance in HRC GC 18 (n 402) paragraph 13.

⁴⁵⁴ *ibid* 18 (paraphrasing).

⁴⁵⁵ The interpretation of futility in *Bland* [1993] (n 8) is discussed in Chapter Three, Section 3.2 and futility's interpretation in *Aintree* [2013] (n 8) is discussed in Chapter Three, Section 3.4.

therefore inherently subjective by nature. The test for subjective futility could retain some element of objectivity if it could evidence the wishes of the patient and would therefore be the same right to refuse that patients with capacity have. However, due to the responsibility disorder that PDOC patients have, this is not possible and cannot currently be realised, particularly if appropriate support has not been used to rule out their inability to communicate.⁴⁵⁶ Therefore, to uphold dignity via the non-consensual and subjectively assessed exercise of legal capacity by others, to effectively construct a refusal, would likely not pass the objective basis for differential treatment.

The final test asks whether it would be reasonable to treat these two patients differently on the basis of their different capacity for agency:⁴⁵⁷ 'whether the differential treatment (the practice) employs a reasonable means to achieve dignity.'⁴⁵⁸ The question of reasonableness considers the relationship between the best interests test and its aim of upholding patient dignity in such cases. For example, if the aim of upholding patient autonomy was being assessed in relation to the functional test in section 3 MCA (to weigh, retain and communicate a decision) the test is reasonable because there is a direct relationship between decision-making capacity and being able to live an autonomous life.⁴⁵⁹ However, the link is much harder to pin down in the current question. Superficially, the patient's view of futility and thereby dignity do hold a mutual relationship. If the continuation of life-supporting treatment undermines the dignity of the patient it may be logical to assume that the patient would deem continued treatment futile. This is because *Aintree* interprets futility as a life worth living according to the patient,⁴⁶⁰ not, 'is the treatment doing some good'.⁴⁶¹ However, it has already been established that even if they were deemed autonomous, such a view cannot be objectively measured due to epistemic limitations in knowing what such a patient wishes or values and their (now likely capacity

⁴⁵⁶ Discussed in Subsection 4.3.2.

⁴⁵⁷ EAP 2014 (n 46) 18 (paraphrasing).

⁴⁵⁸ Employing the guidance of the EAP 2014 (n 46) at page 19 (paraphrasing) but inserting the key words for this particular test.

⁴⁵⁹ EAP 2014 (n 46) 18-19 (paraphrasing). This relationship is discussed by John Harris, 'Consent and End of Life Decisions' (2003) *Journal of Medical Ethics* 29 at page 11, see his discussion of welfare as the accurate legal interpretation of autonomy in cases concerning decision-making competence.

⁴⁶⁰ See *Aintree* [2013] (n 8) at paragraph [30], where Lady Hale adopts Jackson J's interpretation of futility in the first instance hearing.

⁴⁶¹ Recounting Lord Goff's words in *Bland* [1993] (n 8) 869 (Lord Goff).

for inner-awareness) means that the practice may no longer be clinically indicated,⁴⁶² leading to a further stalemate where no certainty can be achieved either way.

Another possible interpretation of 'reasonableness' under discrimination law equates to whether the practice is proportionate (and is fair to assume given that it is the third test of the "disproportionate impact" test⁴⁶³). The question would therefore ask whether there were other means of achieving the same aim that interfered less with the rights of the PDOC patient on the whole. In response, I have already assessed that advance planning provides an alternative and arguably safer method of upholding the dignity of the patient. Therefore, a subsequent question raised is whether the lengths needed to construct a refusal that overlook other legitimately competing rights of the patient (i.e., right to life), in light of those epistemic limitations, is necessary under subsections 4(6) and 4(7) MCA.

The failure to provide a further means of refusing treatment where no advance planning has been put in place may seem unfair and perhaps even discriminatory.⁴⁶⁴ However, the law's approach in using subsection 4(6) and 4(7) MCA to construct a refusal is seemingly unbalanced and disproportionate in its attempts to uphold the patient's dignity. This is because it significantly undermines the existing right of protecting PDOC patients' 'right to life' by failing to recognise that it is eliding bodily autonomy and integrity in such cases. Moreover, the subjective values of dignity and autonomy were thought unable to justify the arguably extraordinary circumstances that necessitate life support discontinuation from a living patient.⁴⁶⁵ This suggests that the law has over-compensated in its assessment of equality by creating a disability-specific mechanism that

⁴⁶² This is on the basis that *Bland* [1993] (n 8) remains the seminal authority on life support withdrawal from PDOC patients, where its justification was that withdrawal was only permissible where it was clinically indicated. Notwithstanding, *M v N* [2015] (n 387) and *Briggs (No.2)* [2016] (n 387), where this factor (known as the safeguard of permanence) has since been eroded. As discussed in Chapter Three, Subsection 3.3.1 and Section 3.4.

⁴⁶³ HRC GC 18 (n 402); EAP 2014 (n 46).

⁴⁶⁴ Note this is the hypothesis reached at the end of Chapter Three, Section 3.4, which may explain why subsections 4(6) and 4(7) MCA (n 6) are used to justify a subjective interpretation of futility and have nearly completely eroded the doctor's role in such decisions, as discussed in Chapter Three, Section 3.3.

⁴⁶⁵ *Bland* [1993] (n 8) 869 (Lord Goff). Also note the discussion in Section 4.3 and above, for the epistemic barriers dignity and autonomy are currently unable to overcome to make any such decision based on those values defensible, which are symptomatic of the fact that bodily autonomy cannot determine non-autonomous patients' cases. See Chapter Three, Section 3.2 for further explanation.

cannot defensibly evidence the patient's view. Advance planning already exists for this purpose and holds more certainty than can be achieved by third parties constructing a refusal.⁴⁶⁶ Therefore, the law has seemingly over-prioritised the permissibility of withdrawal over its obligations to protect persons with impairments' lives. This conclusion complements the conclusion in Chapter Three that the crucial starting presumption is problematically (from both a legal and moral perspective) non-rebuttable and that current cases are not only eliding autonomy and bodily integrity, but have left unanswered how autonomy can trump integrity where the patient is not recognised as being autonomous.

The practice is therefore imbalanced. The law holds a duty to protect the bodily integrity of non-autonomous patients which is being overlooked in cases of those who want treatment to continue. Ultimately, the law provides an appropriate balance without ss 4(6) and 4(7) MCA that does not conflate bodily autonomy and integrity and takes into account the values, wishes and beliefs of the patient through advance planning instruments. For such patients, the imbalance is possibly due to a stigma on disability which needs to be challenged by targeting the overwhelmingly negative social attitude towards disability.⁴⁶⁷ For some, a life with disability is thought to be unbearable, for others it is life.⁴⁶⁸ In a pluralistic society, both attitudes need to be equally valued. Therefore, if equal exercise of legal capacity to refuse life-supporting treatment is how the law achieves this, it can only be done for PDOC patients via advance planning in combination with medical futility (bodily integrity). Otherwise, what justifies the practice is an unsafeguarded "subjective" quality of life judgement that overlooks the law's duty to protect the bodily integrity of the patient under *Bolitho*.

⁴⁶⁶ See the discussion in Subsection 4.3.2 on existing alternatives to find a more appropriate balance than reliance on subsection 4(6) and 4(7) MCA (n 6).

⁴⁶⁷ Kayess and French 2008 (n 5) 5.

⁴⁶⁸ For example, the experience of locked-in syndrome patients' relays a narrative of the impact the negative attitude care staff have towards cognitive disability has had on the patient's view on whether to persevere or wish for death. See Nick Chisholm and Grant Gillett, 'The Patient's Journey: Living with Locked-In Syndrome', (2005) 331 (7508) British Medical Journal 94. See also the humorous quip made by Jean-Dominique Bauby noted in 'The Real Story Behind the Diving Bell and the Butterfly' (The Guardian, 30 November 2008), where his friend informs him of the horror his 'fashionable Parisian set' have when they hear he is a vegetable, to which he responds 'what kind of vegetable?'. See also Bauby's international best seller and memoir of living with locked-in syndrome—*The Diving Bell and the Butterfly* (first published in French 1997, Jeremy Leggatt tr, Vintage 1998).

In light of the universalist model of equality (which is the only version of equality that can achieve the CRPD's ethos and proclaimed rights⁴⁶⁹) there is scope to suggest an allegation of indirect discrimination could be brought for the use of subsections 4(6) and 4(7) MCA to justify life support discontinuation from cognitively impaired patients. The practice uses a disability-specific mechanism that 'pits' the value of disabled lives against others in the fight for scarce healthcare resources.⁴⁷⁰ Removing the use of subsections 4(6) and 4(7) MCA to construct a refusal in such cases would balance the law's protection of all lives, foster the encouragement of alternative methods of communication, and provide a safeguarded way of exercising capacity when it has been lost.⁴⁷¹ This interpretation of the MCA would be proportionate and compatible with the CRPD's universalist equality ethos.⁴⁷² Sadly, its current over-compensation via subsections 4(6) and 4(7) MCA is disproportionate. Therefore, no legitimate aim, objective basis or reasonable means have been found to justify the use of subsections 4(6) and 4(7) MCA to permit life support discontinuation from PDOC patients.⁴⁷³ This use of the best interests test therefore seems to fail the disproportionate impact test, adopting a substantive model of equality that is incompatible with the CRPD's ethos on equal legal capacity.

4.4.3 Section Conclusion

The use of the best interests test to construct a refusal for life-supporting treatment has adopted an outdated interpretation of equality and is potentially indirectly discriminatory in its attempt to achieve same treatment by failing to recognise and appropriately accommodate difference.⁴⁷⁴ This is because the legitimate aim it purports to uphold is patient autonomy (as the identified legal capacity of agency), by creating a mechanism for third parties to construct a refusal on the non or minimally responsive patient's behalf

⁴⁶⁹ Discussed in Subsection 4.2.3.

⁴⁷⁰ Kayess and French 2008 (n 5) 9 (Paraphrasing).

⁴⁷¹ These possible positive impacts of this alternative approach are discussed in Section 4.3.

⁴⁷² The argument that the CRPD 2006 (n 7) intends and needs to adopt a universalist interpretation of equality to give effect to its central aim of recognition of equal legal capacity for those with impairments is discussed in Subsection 4.2.3.

⁴⁷³ These are the elements of the disproportionate impact test that have been worked through in this subsection (4.4.2). See HRC GC 18 (n 402) and EAP 2014 (n 46) for the test.

⁴⁷⁴ This is an amalgamation of the conclusion in Sections 4.3 and 4.4.

without recognising such patients as being autonomous (but requiring facilitation).⁴⁷⁵ For the reasons outlined in 4.4.3 (conflation of bodily integrity and autonomy, epistemic limitations and lack of safeguards preventing over-interpretation) this aim does not achieve the equality it purports to.

Additionally, the second possible aim of dignity also fails because it is inextricably tied to autonomy.⁴⁷⁶ Beyond the provision of advance planning there is no proportionate or objective basis for providing further means for others to exercise legal capacity on their behalf.⁴⁷⁷ Moreover, there was no further compatible aim in the CRPD for using subsections 4(6) or 4(7) MCA to permit life support withdrawal.⁴⁷⁸ Consequently, the law must answer whether such patients are autonomous and if they are, how they are to be facilitated to make a decision. If they are not, the objective test protecting such patient's bodily integrity is correct but must reconcile how right to life is trumped by a lesser (albeit still serious) assault, i.e., re-examine whether this current practice meets the *Bolitho* standard. If *Bolitho* has been met, the decision is morally reconciled on the basis that the patient has lost personhood at the point of withdrawal and the definition of death will need to be officially reappraised: death will equate as the loss of voluntary responsibility only, as it arguably has always done since the introduction of brainstem death.

4.5 Conclusion

This chapter has approached the debates on the defensibility of using subsections 4(6) and 4(7) MCA in PDOC patients' continuation decisions from the different perspective of discrimination law. It seems that not only are the courts and MCA's use of the best interests test in such cases misguided by failing to appreciate that futility cannot defensibly be a welfare consideration,⁴⁷⁹ it also fosters indirect discrimination by attempting to create disability-specific measure to extend, in effect, an equal "right to

⁴⁷⁵ This is the legal capacity found to be at issue in PDOC patients' life support continuation decisions in Chapter Three, Section 3.4.

⁴⁷⁶ Macklin 2003 (n 82); Foster 2009 (n 446).

⁴⁷⁷ This is the conclusion of Section 4.3 and is based on the conclusion that the PDOC 2020 (n 119) guidelines is of the opinion that fMRIs cannot be routinely used for the practical and resource limitations outlined in Subsection 4.3.2.

⁴⁷⁸ This is the conclusion reached after assessing the first test of the disproportionate impact test for a legitimate aim, in Subsection 4.2.2.

⁴⁷⁹ This is the conclusions of Chapter Three, Sections 3.2 and 3.4.

refuse" life-supporting treatment.⁴⁸⁰ This has ultimately arisen because of the conflation of the basis on which continuation of treatment is decided in non-autonomous adults. Additionally, the CRPD's unique interpretation of equality has the potential to reinstate PDOC patients' personhood status by better catching "harder to spot", superficial equal treatment that is in fact discriminatory:⁴⁸¹ an interpretation of equality that is desperately needed after the finding of a dangerous attitude towards the enforcement and respect of PDOC patients' personhood.⁴⁸²

The combined findings of Chapters Three and Four is that PDOC patients are assumed legal persons in law but that in E&W that status is severely undermined by the weak protection against other's exercise of legal capacity for them (as opposed to with them) and in more areas than just end-of-life law.⁴⁸³ Consequently, the law's attempts to uphold its obligations to both protect life and equally recognise PDOC patients' legal capacity (as implied autonomous individuals) has over-interpreted the latter in a misguided attempt to achieve equality.⁴⁸⁴ The result is that PDOC patients' rights and legal capacity are so severely undermined that their status as legal persons is called into question.⁴⁸⁵ Furthermore, this chapter found that the CRPD also has the potential to revolutionise PDOC patients' treatment in law by divorcing personhood from cognition.⁴⁸⁶ Life-limiting treatment withdrawal practices can only morally continue on the basis that these patients are no longer legal persons.⁴⁸⁷ Finally, because the medical evidence that clinically indicated withdrawal has since been significantly undermined, withdrawal for

⁴⁸⁰ This is an amalgamation of the conclusions in Chapter Three, Section 3.4; Chapter Four, Sections 4.2 and 4.4.

⁴⁸¹ As discussed in Subsection 4.2.3.

⁴⁸² Noting the conclusion of Subsection 4.2.3. See footnotes 26-30 for specific instances noted in the literature.

⁴⁸³ Note in Subsection 4.2.2 I argue that the difference between a denial of legal capacity and a denial of (legal) personhood seems to be that a denial of personhood occurs when different legal capacities are abused on a frequent enough basis and in various different areas of law that the individual's personhood status in its entirety is called into question. Alternatively, a denial of legal capacity is a single or less frequent instance occurring in more limited areas of law.

⁴⁸⁴ Noting the conclusion of Section 4.4.

⁴⁸⁵ See footnote 483 for the distinction between denials of legal capacity and a denial of (legal) personhood, as argued in Subsection 4.2.2.

⁴⁸⁶ Noting the revolutionary potential of the CRPD 2006 (n 7), as discussed in Subsection 4.2.2.

⁴⁸⁷ Noting the conclusion of Chapter Three, Section 3.2.

PDOC patients is a questionable practice.⁴⁸⁸ Ultimately a choice needs to be made to determine if PDOC patients are legal persons or are not. If they are, their current treatment suggests it is a nominal status only.

⁴⁸⁸ See the discussion on the impact of *M v N*[2015] (n 467) and *Briggs (No.2)* [2016] (n 467) in Chapter Three, Subsections 3.3.1 and 3.3.2, and Section 3.4.

Chapter 5 Assessing the Defensibility of the Definition and Determination of Death in England and Wales

5.1 Introduction and Overview of Findings

This chapter will answer whether the definition and determination of death in England and Wales (E&W) is defensible given its implications for patients with prolonged disorders of consciousness (PDOC patients).¹ This thesis has outlined a methodology to assess its defensibility and has explored the literature for findings on how death is defined and determined,² its supporting rationales and justifications, and its implications for PDOC patients.³ These findings answer the first of the two fundamental philosophical questions that must be answered before defensible moral decision-making can be achieved: 'what is?'⁴

Chapter One delineated an applied ethics methodology that attempts to measure the defensibility of the definition and determination of death as it has been adopted in medicine and law. In doing so, it answered what the study of ethics is and that its purpose is to assess 'what is' in order to arrive at 'what ought to be', whilst minimising intuition-based judgements.⁵ It also established that a moral (decision-making) agent will face epistemic limitations in ascertaining what the definition and determination of death is.⁶ To address these limitations some further guidance from the philosophical literature was

¹ Note this is the central thesis question as outlined in the thesis introduction.

² The methodology for answering the question is developed in Chapter One.

³ Chapters Two, Three and Four note the findings of Chapter Two on how death is defined and determined in English and Welsh law and medical practice, and its impact on PDOC patients.

⁴ Henry Sidgwick, *The Methods of Ethics* (6th edn, MacMillan & Co Ltd 1901) 2. As discussed in Chapter One, Section 1.2.

⁵ *ibid.*

⁶ Chapter One, Section 1.2 outlines factual accuracy and consistency as the minimums of defensible moral decision-making and Section 1.3 discusses the unique way judges and doctors (moral agents) reason and why some leeway needs to be given to both disciplines in translating morality into law. Chapter One, Section 1.4 notes further epistemic limitations if the problem amounts to a genuine moral dilemma.

discussed on how to mitigate or overcome those limitations.⁷ Finally, the chapter began to explore the concept of a moral dilemma and what distinguishes a dilemma from a conflict, and a purported from a genuine dilemma.⁸ This last section therefore began to address the possible problem of ascertaining 'what ought to be'⁹ if the definition and determination of death amounts to a genuine moral dilemma.¹⁰ Therefore, 1.4 outlined the judges' belief in *Bland* that the case's moral inconsistency arose because of the existence of a moral dilemma at its heart.¹¹ Furthermore, it considered that the dilemma arose due to a change in how death is defined and determined in medicine (moral personhood),¹² which has impacted their status as legal persons (particularly their right to bodily integrity). Consequently, the moral and legal dilemma arises because PDOC patients are both considered and denied as persons. This explains how continued treatment amounts to assault but withdrawal does not amount to homicide.

The first step for this thesis was therefore to explore 'what is'¹³ using ordinary investigative questions such as: what is death and how is it defined and determined? How does medical practice's definition and determination of death differ from the phenomenon "death"? And what does this indicate about the defensibility of such a practice?¹⁴ Those investigatory questions from Chapter Two continued to be further developed in Chapter Three, which explored how E&W law regulates the definition and determination of death and life support withdrawal from severely impaired but nonetheless living persons.¹⁵

Chapter Three found that the moral inconsistency underlying current legal practice arises because life support withdrawal was traditionally justified by defining the patient as

⁷ Chapter One, Section 1.4 discussed the limitations of translating moral requirements into the law of a pluralistic society and the difficulties of resolving moral dilemmas.

⁸ Discussed in Chapter One, Subsection 1.4.2.

⁹ Sidgwick (n 4) 2.

¹⁰ As discussed in Chapter One, Section 1.4.

¹¹ *Airedale NHS Trust v Bland* [1993] AC 789 (HL) 877 (Lord Browne-Wilkinson) and 865-866 (Lord Mustill) (*Bland*). Discussed in Chapter One, Subsection 1.4.2.

¹² *ibid*. As discussed in Chapter One, Subsection 1.4.4.

¹³ Sidgwick (n 4) 2. As outlined in Chapter One, Section 1.2.

¹⁴ *ibid*. These questions were explored throughout Chapter Two.

¹⁵ Referring to the noted impact that death's definition and determination as a moral standpoint has on the personhood status of cognitively impaired individuals. Particularly in Chapter Two, Section 2.4 and Chapter Three, Section 3.2.

"dead" in accordance with medical practice on brainstem death.¹⁶ Moreover, where commentators agree that *Bland* is morally inconsistent but could not agree on what caused the inconsistency or how it could be resolved,¹⁷ this thesis suggests that perhaps the noted inconsistency arises because *Bland* demonstrates that the definition and determination of death has become far removed from experiential knowledge of death.¹⁸ The key biological feature lost in those defined as "dead" for the purpose of life support withdrawal is the loss of voluntary responsivity.¹⁹ Therefore, the certainty that the E&W definition of death purports to give, as a safeguard between those who are dead and those who are severely impaired, is in fact misguided. By exploring the moral and legal defensibility of life support discontinuation from both brainstem dead and VS patients it has become clear that the practice is indefensible on living persons under the law's own established practice of protecting bodily integrity.²⁰ Additionally, the case possibly highlights the ontological and phenomenological inconsistency of how death is currently defined:²¹ how can futility be the way in which death is defined and determined in practice?²² And, how does futility (as "death") translate to the loss of voluntary responsivity?²³ No justification other than, "living a life with cognitive disability is worse

¹⁶ Futility is how death is traditionally defined and determined in brainstem death cases. See *R v Malcherek and Steel* [1981] 2 All ER 422 (*Malcherek*); *Re A (A Minor)* [1992] 3 Med LR 303 (Fam) (*Re A (A Minor)*). As discussed in Chapter Three, Section 3.2.

¹⁷ Discussed in Chapter Three, Subsections 3.2.2 and 3.2.3.

¹⁸ Noting the finding that futility has a relationship with personhood and has stretched far beyond those who would traditionally be determined as dead. This conclusion was found in Chapter Two, Section 2.4 and Chapter Three, Section 3.2.

¹⁹ Futility no longer limited to the irreversible loss of capacity for consciousness and capacity to breathe (independently), as discussed in Chapter Two, Section 2.3. Moreover, Section 2.2 doubts whether the irreversible loss of capacity to breathe and for consciousness ever was its matching biological indicator, on the basis that brain death was found to have always been a moral standpoint on when continued treatment is considered futile.

²⁰ John Harris, 'The Concept of the Person and the Value of Life' (1999) 9 (4) Kennedy Institute of Ethics Journal 293. As discussed in Chapter Three, Section 3.2.

²¹ Note Josie Fischer's comment on how intellectually incongruous the higher brain death definition was to ontological and phenomenological knowledge of "death" as a phenomenon, yet in Chapter Two, Section 2.4, English and Welsh law was found to have adopted a higher-brain death definition of death to permit life support withdrawal from those who have purportedly lost consciousness but not the capacity to breathe. See Josie Fischer, 'Re-Examining Death: Against a Higher Brain Criterion' (1999) 25 Journal of Medical Ethics 473 at page 473.

²² As discussed in Chapter Two, Section 2.3 and 2.4; Chapter Three, Sections 3.2 and 3.3.

²³ *ibid.*

than death", was found to explain why life support withdrawal from living, severely impaired persons is thought to be morally and legally defensible.²⁴

In 2.2 and 2.4, objective futility was found to be the legal basis and requirement for withdrawal of life support in from brainstem dead patients, which amounts to loss of voluntary responsiveness (indicia of moral personhood). Moreover, it found that futility's corresponding biological functions have lessened even further than the official definition of death suggests to voluntary responsiveness post-*Bland*.²⁵ This explains why no dilemma between competing bodily integrity considerations arises in *Bland* on the basis that the patient is deemed "dead" for having lost the moral indicia of personhood and thus legal personhood (as the moral instantiation was adopted in law). Nevertheless, the judges in *Bland* (as have subsequent cases) maintained the position that such patients are living (legal persons) when treatment is discontinued. Consequently, the law protecting non-autonomous patients' right to bodily integrity in non-emergency cases is confused.

In a further twist of events, the law has since determined that futility is subjective (i.e. bodily autonomy) and that their right to bodily integrity can be determined by what other non-medical personnel (family members and those with a proximate relationship to the patient) believe the patient would have viewed as futile (bodily autonomy).²⁶ Additionally, Chapter Three found that futility's (bodily integrity/ legal personhood) safeguards have been gradually eroded.²⁷ Section 3.4 concluded that futility (and thereby the process of defining and determining death) has been subsumed within the best interests test, specifically subsections 4(6) and 4(7) MCA which attempt to extend a sort of "right to refuse treatment" mechanism on behalf of non-responsive patients.²⁸

²⁴ Referring to Harvard Medical School, 'Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, "A Definition of Irreversible Coma"' (1968) 205 (6) Journal of American Medical Association 337 (Harvard Report 1968); Rosemary Kayess and Phillip French, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8 (1) Human Rights Law Review 1. As discussed in Chapter Two, Sections 2.3 and 2.4; Chapter Three, Sections 3.2 and 3.3; Chapter Four, Section 4.2.

²⁵ As discussed in Chapter Two, Sections 2.3 and 2.4.

²⁶ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [2014] AC 591 (*Aintree*). As discussed in Chapter Three, Section 3.4.

²⁷ *An NHS Trust v Y* [2018] UKSC 46, [2018] 3 WLR 751 (*NHS Trust v Y*). As discussed in Chapter Three, Section 3.3.

²⁸ Noting the key finding of Chapter Three, Section 3.4.

Therefore, Chapter Four's investigatory question examines the defensibility of the legal mechanism by which futility (protection of bodily integrity) is now determined: subsections 4(6) and 4(7) Mental Capacity Act 2005 (MCA) under a conflated view of bodily autonomy in non-autonomous patients' cases.²⁹ The chapter assessed whether such a mechanism could defensibly and accurately interpret what a non-responsive patient would deem as futile, the consistency of such an approach and whether it is an appropriate basis to oversee their right to bodily integrity.³⁰ Consequently, it also explores the definition of equality and non-discrimination in light of the Convention on the Rights of Persons with Disabilities 2006 (CRPD),³¹ and concluded that the best interests test's determination of futility on the basis of bodily autonomy (for non-autonomous patients) potentially amounts to a finding of indirect discrimination, for improperly interpreting the right of "equal" recognition (treatment) in law.³²

Moreover, the courts seem to be treating the starting presumption as non-rebuttable on the belief that the supporting medical evidence has been long established and is defensible. Not only does this conflict with the *Bolitho* judgment on defensible medical decision-making in law, but it also highlights the flawed legal protection of those with cognitive (and mental) impairments' right to bodily integrity. To be clear, shifting the starting presumption to "continued treatment is favourable" (as it supports their right to life) is still challengeable by future medical evidence if needs be, and still fits the long-established law that all treatment is ostensibly an assault (both its provision and omission to treat). In fact, it seems such a model would actually be more in line with the law's own stance on the right to bodily integrity, as surely only rigorous scientific evidence should be able to rebut the presumption that all living and born human beings have an equally protected right to life? It therefore seems questionable why E&W law considers continued

²⁹ *Aintree* [2013] (n 26).

³⁰ As discussed in Chapter Four, Sections 4.3 and 4.4. Consistency focussed on the question of whether PDOC patients are treated as persons in more than a nominal status only. For factual accuracy the chapter not only examined the epistemic limitations of the current best interests test but also the compatibility of the MCA and CRPD's interpretations of equality and non-discrimination, for provisions and Articles impacting cognitively impaired individuals, specifically PDOC patients.

³¹ UN, Convention on the Rights of Persons with Disabilities and Optional Protocol (adopted 13 December 2006, entered into force 3 May 2008) UNGA A/Res/61/106 (CRPD). As explored in Chapter Four, Sections 4.2 and 4.4.

³² As discussed in Chapter Four, Section 4.4.

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treatment to automatically be an assault in such cases but not a failure to treat where no defensible justification for not providing treatment equally exists.

On the basis that the law now seems to support the view that continued treatment amounts to assault on the basis of bodily autonomy, Chapter Four's discrimination question examined what ought to be by exploring other existing options such as supported decision-making and the appropriate use of advance planning instruments.³³ The examination of other possible options is consistent with Sidgwick's advice that before any ought statement can be made, there is an implicit rule that, 'what the agent ought to do, is something they can do'.³⁴ Consequently, 4.3 is vital to assessing the defensibility of the current use of the best interests test to determine futility because it explores whether more defensible options exist. In doing so, the chapter begins to set the groundwork for answering moral philosophical enquiry's ultimate aim: 'what ought to be'.³⁵

To continue to answer the question of what ought to be, Chapter Five will therefore draw from the thesis' findings to answer whether futility (as the way in which death is defined and determined, and bodily integrity is protected) is defensible, and return to the question at the end of Chapter One concerning whether a genuine moral dilemma exists in such cases.³⁶ To do so, it uses the applied ethics methodology outlined in Chapter One for assessing defensibility. It will also consider resource and other justifications for changing the definition of death to futility that were outlined in Chapter Two.³⁷ Furthermore, if the definition and determination of death (as medical futility) in E&W medical practice and law is found to be indefensible on living persons, the possible defences available to the moral agents (judges and doctors) who have been determining and defining death on the basis of futility will also be explored.³⁸ Finally, the chapter will end by outlining the novelty and potential impact of this thesis and its findings.

³³ As analysed in Chapter Four, Section 4.3.

³⁴ Sidgwick (n 4) 3 (paraphrasing). As discussed in Chapter One, Section 1.2.

³⁵ *ibid* 2.

³⁶ As explored in Chapter One, Section 1.4.

³⁷ As discussed in Chapter Two, Section 2.2.

³⁸ As explored in Chapter One, Section 1.3.

5.2 Does the Definition and Determination of Death Meet the Minimums of Defensibility?

5.2.1 Assessing Factual Accuracy

A core problem with the factual accuracy of death's definition and determination on the basis of what amounts to futile treatment is its relationship with loss of the capacity to voluntarily respond and consequently, personhood.³⁹ Moreover, the link between futility and cognitive impairment is problematic because neurology's understanding of awareness as responsiveness is still in its infancy,⁴⁰ and fundamentally relies on the patient being able to physically demonstrate comprehension of an oral or physical command.⁴¹ Therefore, only voluntary responsiveness is equated with awareness (reflexes are dismissed and any possibility of inner awareness for those unable to move or speak is also excluded).⁴²

Additionally, loss of voluntary responsiveness is a radically different understanding of death than laypersons and even doctors would recognise as death.⁴³ For example, those who have lost voluntary responsiveness may breathe independently, be evidently awake, sleep, grimace in pain, laugh, and cry.⁴⁴ Therefore, for the purpose of assessing factual accuracy it becomes nearly impossible for law and medicine to reconcile such a radical view of death with common experiential knowledge of death as a phenomenon.⁴⁵

The findings in 2.3 evidenced that there exists 'no case or study'⁴⁶ that proves the commonly propounded "fact" that PDOC patients are non, or only minimally aware and

³⁹ As analysed in Chapter Two, Sections 2.3 and 2.4.

⁴⁰ As discussed in Chapter Two, Section 2.3.

⁴¹ Royal College of Physicians, *Prolonged Disorders of Consciousness Following Onset of Sudden Injury: National Clinical Guidelines* (2020) 23 (PDOC 2020 guidance). As explored in Chapter Two, Section 2.3. See also the discussion on the limitations of fMRIs in Chapter Four, Subsection 4.3.2.

⁴² *ibid.*

⁴³ D Alan Shewmon, "'Recovery from Brain Death': A Neurologist's Apologia' (1997) 64 (1) *The Linacre Quarterly* 30.

⁴⁴ PDOC 2020 (n 43) 28. As noted in Chapter Two, Subsection 2.1.1.

⁴⁵ Specifically, Chapter Two, Sections 2.2 and 2.4 discussed how death is a moral standpoint and that voluntary responsiveness, as its single foothold in biology, means that defining and determining death is morally and intellectually incongruous.

⁴⁶ Shewmon 1997 (n 43) 59.

unable to feel pain.⁴⁷ Shewmon argues that what the evidence does show is that such patients are more accurately described as being in a 'super locked-in state.'⁴⁸ Additionally, the area of the brain that produces awareness is still not known and assumed to be the cortex.⁴⁹ Instead, cortical damage has been shown to significantly impact an individual's ability to comprehend language, see and physically move.⁵⁰ PDOC patients' cortical damage therefore results in the inability to demonstrate a voluntary response to command i.e. to communicate.⁵¹ Therefore, testing for voluntary responsivity does not and cannot defensibly prove such patients lack awareness (partially or wholly).⁵² Moreover, functional magnetic resonance imaging (fMRI) has been able to demonstrate that at least some VS patients (thought non-aware) are in fact aware and able to follow commands, as evidenced by their brain activity.⁵³

Therefore, for all cognitive disorders (including PDOC patients) the ramifications arising from the inaccuracy of their supposed non-awareness is alarming. The presumption that CANH should not be continued is indefensible (in terms of its factual accuracy) because its medical justification is that the patient is so severely non-aware that their life is no longer worth living (futile).⁵⁴ Under this current medico-legal policy position, death is determined on the basis of futility of continued treatment due to the patient having lost awareness and is therefore difficult to reconcile under the objective (medical) accuracy assessment that *Bolitho* requires.⁵⁵ It is therefore a philosophical standpoint that ignores

⁴⁷ See *ibid* at pages 59-60 for challenges to the evidence that PDOC patients are incapable of a morally significant level of awareness and cannot feel pain. As explained in Chapter Two, Subsection 2.3.2.

⁴⁸ *ibid*.

⁴⁹ In Section 2.3, I explored more recent neurological evidence to see whether this had changed and found that it has not.

⁵⁰ See Shewmon 1997 (n 43). As discussed in Chapter Two, Section 2.3.

⁵¹ *ibid*.

⁵² *ibid*.

⁵³ Some notable examples of such studies include Adrian M Owen and others, 'Detecting Awareness in the Vegetative State' (2006) 313 (5792) *Science* 1402; W Staffen and others, 'Selective Brain Activity in Response to One's Own Name in the Persistent Vegetative State' (2006) 77 (12) *Journal of Neurology, Neurosurgery and Psychiatry* 1383. Recalling the fact that only some may be able to does not in fact undermine the argument that PDOC patients are inner-aware, as explained in Chapter Two, Subsection 2.3.3.

⁵⁴ At least this was the case in *Bland* [1993] (n 11), as discussed in Chapter Three, Section 3.2, is a rationale that began for brain dead patients only (Chapter Two, Section 2.2) and was subsequently extended to any patient who has lost the capacity to communicate (Chapter Three, Section 3.3).

⁵⁵ As discussed in Chapter Two, Section 2.4.

the other aspects of the official definition of death, such as the residual and vital capacities for wakefulness,⁵⁶ inner awareness,⁵⁷ and to breathe.⁵⁸

Incidentally, Chapter Two found that even brainstem death does not factually meet the official definition of death provided by the AOMRC because it does not amount to the 'irreversible loss of both the capacity for consciousness and to breathe'.⁵⁹ There is no way of proving whether someone is aware, and phrenic nerve surgery may reverse cardiopulmonary damage.⁶⁰ Therefore, despite the finding that death is a moral standpoint that equates to the loss of voluntary responsivity, the official definition of death neither accurately describes the loss of biological functioning experienced by PDOC patients or even those under either brain death variation (whole or brainstem).⁶¹ Death is therefore a philosophical standpoint on moral personhood that suggests its indicia is loss of voluntary responsivity.

However, Veatch has put forward an alternative account which prioritises consistency over factual accuracy in assessing the defensibility of the definition of death.⁶² Veatch contends that the moral standpoint was never intended to reflect biological death and instead provides a standpoint on what lives are worth living.⁶³ Therefore, the radical redefinition of death (on Veatch's account) also redefines the test for factual accuracy. For Veatch the current definition of death is still 'true by definition'⁶⁴ indicating what is so deceptive about the way in which death has been redefined. Instead, defining death wholly relies on consistency, irrespective of factual accuracy to be defensible, and therefore makes the rationale harder to detect.

⁵⁶ Chapter Two, Section 2.2 provided evidence which undermined the view that brainstem dead patients have irreversibly lost the capacity to breathe independently, and found that they also cannot be described as non-aware because medical science cannot test for inner awareness with a defensible level of accuracy, as discussed in Chapter Two, Section 2.3.

⁵⁷ Academy of Medical Royal Colleges, Academy of Medical Royal Colleges, *A Code of Practice for the Diagnosis and Confirmation of Death* (2008) 11 (AOMRC).

⁵⁸ As discussed in Chapter Two, Section 2.4.

⁵⁹ The neurological evidence for this assertion was discussed in Chapter Two, Sections 2.2 and 2.3.

⁶⁰ As discussed in Chapter Two, Section 2.3.

⁶¹ As explored in Chapter Two, Section 2.2.

⁶² Robert M Veatch, 'The Dead Donor Rule: True by Definition' (2003) 3 (1) *The American Journal of Bioethics* 10.

⁶³ Robert M Veatch, 'The Death of Whole-Brain Death: The Plague of the Disaggregators, Somaticists, and Mentalists' (2005) 30 (4) *Journal of Medicine and Philosophy* 353.

⁶⁴ Veatch 2003 (n 62) 10-11.

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Veatch contends that arguments calling for the removal of the dead donor rule are nonsensical because they are still 'dead by definition';⁶⁵ therefore, there is no need to remove the dead donor rule at all, even in the face of evidence proving the brain dead are not biologically dead.⁶⁶ It is the redefinition of death that justifies the application of these death behaviours (life support withdrawal and organ donation) and not the factual accuracy of their biological basis.⁶⁷ This explanation of how death is defined explains why he argues that, 'calling someone "dead" has little ... to do with the way we use the terms "living" and "dead" in biology ... [and] everything to do with moral (and legal) status'.⁶⁸ This is what the advent of brain death in the seminal Harvard Report in 1968 really achieved. However, Veatch's argument raises two further considerations, whether a consensus exists to support the view that this moral standpoint is defensible,⁶⁹ and secondly, what safeguards exist to prevent the definition of death's over extension to those with cognitive impairments.⁷⁰

Any attempt to accurately define death will encounter epistemic limitations.⁷¹ Where such epistemic limitations exist the adopted definition will instead represent a moral standpoint (as opposed to biological fact).⁷² Therefore, according to Engelhardt, that standpoint will at least need to hold a consensus to be defensible and prevent oppression of moral stranger communities.⁷³ Whilst some may disagree on the level of consensus needed in a democratic but nonetheless pluralistic society, to avoid the brink of nihilism I

⁶⁵ ibid (paraphrasing).

⁶⁶ ibid.

⁶⁷ ibid.

⁶⁸ Veatch 2005 (n 63) 360 (paraphrasing).

⁶⁹ As discussed in Chapter One, Subsection 1.4.3.

⁷⁰ The legal safeguards were discussed in Chapter Three, Section 3.3 and the moral safeguards of consistency and factual accuracy on medical decision-making were largely discussed in Chapter One, Sections 1.2 and 1.3 as the noted minimums of establishing "consistency". Note also that it voluntary responsibility/ communication also impacts those with mental impairments.

⁷¹ As discussed in Chapter One's introduction.

⁷² Note the epistemic limitation in knowing when death has occurred is apparent because doctors attempted to redefine death so that death behaviours were permissible on patients who were not obviously dead without some form of further testing. For example, there is no epistemic limitation in knowing when a body that has undergone rigor mortis and is thus obviously dead. See Chapter Two, Sections 2.2 and 2.4.

⁷³ H Tristram Engelhardt JR, *The Foundations of Bioethics* (2nd edn, OUP 1996). As discussed in Chapter One, Subsection 1.4.3.

suggest that at least its doctors and judges (as those currently regulating the practice) should agree on that moral standpoint.⁷⁴

Among all brain death theorists, loss of the capacity to voluntarily respond (consciousness) is a vital function of being alive.⁷⁵ And apart from mentalists, the embodied consciousness theorists and somaticists seemingly agree that some minimum somatic function should also remain.⁷⁶ However, Chapter Two concluded that it is still not clear what that minimum somatic function is, at least in the sense of what somatic function would need to be lost, and has been lost, in those from whom life support can be withdrawn or vital organs donated.⁷⁷ To an extent, it is therefore possible to argue that at least a partial consensus exists among these theorists; that the loss of the capacity to respond (consciousness) is the most important feature.⁷⁸ However, to implement a definition of death on that basis alone would still offend somaticists and embodied consciousness theorists for it is an essentially mentalist view of what singular (mental) characteristic alone is inherently valuable about human life.⁷⁹

Moreover, it seems likely that no such consensus on this moral standpoint (loss of consciousness alone) exists within the UK's medical profession. Chapter Two demonstrated that the medical body responsible for defining and determining death on behalf of all medical Royal Colleges and faculties across the UK and Ireland (the AOMRC⁸⁰), has adopted both the Somaticist view (officially) and the mentalist view of death (unofficially).⁸¹ For the AOMRC, to be defined as "dead" a patient must have 'irreversibly

⁷⁴ Discussed in Chapter One, Section 1.4.3.

⁷⁵ This conclusion was drawn on the basis of the combined findings of Chapter One, Section 1.3 and 1.4.

⁷⁶ Veatch 2005 (n 63).

⁷⁷ As discussed in Chapter Two, Subsection 2.4.

⁷⁸ This is the conclusion drawn in Chapter Two, Section 2.4 on the basis of the key findings throughout the chapter.

⁷⁹ Veatch 2005 (n 63).

⁸⁰ Academy of Medical Royal Colleges (AOMRC) was established in 1974 to provide clinical guidance across all the 24 UK and Irish medical bodies. See Academy of Medical Royal Colleges, 'About us' (Academy of Medical Royal Colleges, 14 March 2019) <<http://www.aomrc.org.uk/about-us/>> accessed 14 March 2019.

⁸¹ The somaticist (integrative unity) view is the AOMRC's official definition of death, and the embodied consciousness view is its adoption of brainstem death. However, given that the somaticists arguments failed to support the view that brain death in any form retains a link with somatic functioning, the definition and determination has been found to be a mentalist view of death. See Chapter Two, Section 2.4.

lost the capacity to breathe and for consciousness.⁸² Furthermore, given that defining and determining death is no longer a wholly biological determination,⁸³ there no longer exists any reason why doctors would be any more adept at assessing the defensibility of such a moral standpoint than philosophers, judges or medical ethicists. Hence, the legal capacity (as agency) question plays a paramount role in this thesis' investigations, particularly because agency is allegedly being exercised on behalf of those who are unable to communicate their own views on the futility of their continued treatment.⁸⁴

Additionally, Shewmon's paper demonstrated that in his personal attempts to reconcile the unease he felt about the rationales and justifications that supported the equation of brain death with death, he found that many of his colleagues were unquestioningly applying established practice: 'that brain death is death because that is official policy'.⁸⁵ Therefore, although it may merely be supposition, it would not be surprising if many neurologists in E&W also do not realise that brain death cannot be supported on a factually accurate biological basis and is instead a moral standpoint on which lives are futile.⁸⁶ Moreover, the official guidance on determining and defining death takes pains to reiterate that loss of consciousness alone is not death,⁸⁷ suggesting that medicine is unwilling to accept such a view, let alone support it by consensus.

But what about the law? And, can the adoption of this standpoint of death into English and Welsh law alternatively represent a consensus among legislators and judges? PDOC patient life support continuation cases suggest that they have accepted the official somaticist explanation of brainstem death and therefore seemingly do not believe that such cases are impacted by the definition or determination of death at all.⁸⁸ For example, in *Bland*, their Lordships reiterated that the common medical distinction between Bland and brainstem dead patients; that Bland was biologically alive because his brainstem was

⁸² AOMRC 2008 (n 57) 11.

⁸³ See Chapter Two, Section 2.2 for an in-depth analysis and defence of this point.

⁸⁴ As discussed in Chapter Three, Sections 3.3 and 3.4; Chapter Four, Sections 4.3 and 4.4.

⁸⁵ Shewmon 1997 (n 43) 40-45 (paraphrasing).

⁸⁶ Note that Shewmon's comment is limited to his experience as a neurologist in the US, for English and Welsh purposes.

⁸⁷ See eg AOMRC 2008 (n 57) at page 11, where the guidance notes the 'clear' distinction between brain death and VS patients (paraphrasing).

⁸⁸ As discussed in Chapter Three, Section 3.2.

intact.⁸⁹ Consequently, the result has been that because the professions regulating death largely rely on the justification that "death" is biologically accurate,⁹⁰ it is safe to say no consensus on the radical redefinition exists in law either.

Alarmingly, the Harvard Report 1968⁹¹ recognises that such a radical redefinition of death would require the need for a statutory definition of death (representing consensus) and yet asserts that medicine alone should define death, despite acknowledging that such a definition would be based on a moral standpoint more than biological science.⁹² Consequently, perhaps no subsequent reappraisal has occurred because of the somaticists tautological endeavour to ground a non-biological definition of death within biological evidence, creating many of the erroneous views that still pervade medical and legal knowledge on death today.⁹³ Therefore, although the definition of death is 'true by definition,'⁹⁴ the fallback position of consensus does not exist to support it. Accordingly, the moral standpoint on death has been found to be factually inaccurate not just for PDOC patients, but also for those defined as brainstem dead, on both its biological and "fact by consensus" bases: futility (death) as loss of voluntary responsibility does not equate with biological death and is instead the *indicia* of moral personhood, further explaining why death's definition needs to be reappraised.⁹⁵

However, if I am wrong that it lacks consensus in medicine and law; what safeguards exist to limit life support withdrawal from those with the severest cognitive disability (i.e., permanent VS and MCS cases)? The safeguards of permanent diagnosis and prognosis limited the withdrawal of life support to those in a permanent VS.⁹⁶ However, this

⁸⁹ See *Bland* [1993] (n 11) at pages 856 (Lord Keith), 860 and 863 (Lord Goff), 878 (Lord Browne-Wilkinson). As discussed in Chapter Three, Subsection 3.2.2.

⁹⁰ As discussed in Chapter Three, Section 3.2.

⁹¹ Harvard Report 1968 (n 24).

⁹² See Harvard Report 1968 (n 24) at page 339 for this acknowledgement and their response.

⁹³ For example, consciousness as awareness and the role of mechanical ventilators was discussed in Chapter Two, Section 2.2.

⁹⁴ Veatch 2003 (n 62) 10.

⁹⁵ As explored in Chapter Two, Sections 2.2 and 2.4. Note that as the law adopts the medical definition of death it is therefore apparent why Harris' 1999 (n 20) argument (that *Bland* (n 11) lost personhood) is supported by the conclusion of Chapter Two; that moral personhood (death) is loss of voluntary responsibility, and has subsequently been adopted into law as the *indicia* for legal personhood, further explaining why such patients do not hold a right to bodily integrity in futility judgments.

⁹⁶ Specifically, Chapter Three, Section 3.3.

safeguard was subsequently eroded in *M v N* [2015] when the courts permitted doctors to withdraw life support from a patient in a MCS and downgraded the PDOC Guidance's role from 'crucial'⁹⁷ to 'non-determinative'.⁹⁸ Additionally, *An NHS v Y* [2018] determined that the courts never required that continuation decisions must be overseen by the courts.⁹⁹ Moreover, there seems to be a divergence with the opinion of the Court of Protection which affirms such cases 'must'¹⁰⁰ be overseen, whilst *An NHS v Y* suggests it is discretionary. Moreover, although the Supreme Court reiterated that cases of dispute still could and should be overseen by the courts, the precedent set may mean that the courts' supranational duty to oversee how the lives of these severely disabled persons are protected is likely to be undermined.¹⁰¹ It is for this reason that the Court of Protection insists such cases must always be determined by the courts.¹⁰² Therefore, the evidence seems to suggest that the moral standpoint underpinning the definition and determination of death as, "continued treatment of non or minimally responsive patients is futile", is not appropriately safeguarded.

Consequently, the definition and determination of death is neither factually accurate by biological standards nor as a consensus-holding moral standpoint on when treatment is considered futile. The moral standpoint is both ontologically and phenomenologically incongruous with experiential knowledge on death,¹⁰³ and neither is it appropriately safeguarded.

⁹⁷ *W v M and S (A NHS Primary Care Trust)* [2011] EWHC 2443 (Fam) (*W v M*) [258] (paraphrasing). As analysed in Chapter Three, Subsection 3.3.1.

⁹⁸ *M v N* [2015] EWCOP 76, [2015] 11 WLUK 514 (*M v N*) [23] (Hayden J). This is assuming VS cases brought before the courts before were correctly diagnosing VS patients, where Chapter Three, Section 3.3 doubts this.

⁹⁹ *An NHS Trust v Y* [2018] UKSC 46, [2018] 3 WLR 751 (*NHS Trust v Y*) [48] (Lady Black).

¹⁰⁰ *Practice Guidance (CP: Serious Medical Treatment)* [2020] EWCOP 2, [2020] 1 WLR 641 [8] (Hayden J).

¹⁰¹ Elizabeth Wicks, '*An NHS Trust and others v Y and another*' [2018] UKSC 46: Reducing the Role of the Courts in Treatment Withdrawal' (2019) 0 Medical Law Review 1.

¹⁰² See *Practice Guidance* [2020] (n 101) at paragraphs [8]-[9].

¹⁰³ As discussed in Chapter Two, Section 2.4.

5.2.2 Assessing Consistency

Chapter One confirmed that the moral requirement that "to kill another living human being is morally wrong" is reflected in the law on murder.¹⁰⁴ Interestingly, further analysis found that the law has added qualifications on the face-value meaning of "human being."¹⁰⁵ For example, foetuses were deemed non-killable in the legal sense of the verb, "to unlawfully kill", because they are not regarded as legal persons.¹⁰⁶ Therefore, biological membership of the human race is not enough to be legally protected from morally questionable killing in law.¹⁰⁷ The individual needs to be endowed with legal personhood status. To be consistent, Kuhse, Schüklenk and Singer give the example that: 'if I say, "it is always wrong to kill another human being" and "abortion is not always wrong" then I am committed to denying that abortion kills a human being.'¹⁰⁸ Moreover, the findings of 1.4.4 demonstrated that such an assertion would be consistent in law because the term "human being" is more nuanced and is more commonly referred to as "person". Therefore, because foetuses are not persons, they are legally "killable".¹⁰⁹ Consequently, the specific question for this thesis is whether it is consistent to argue that PDOC patients are recognised as living persons (in medicine and law).¹¹⁰

Superficially, the answer found in previous chapters was that PDOC patients are presumed legal persons.¹¹¹ However, some have begun to doubt this previously assumed, unquestionable "fact".¹¹² The law in England and Wales asserts that it is wrong to kill

¹⁰⁴ As analysed in Chapter One, Subsection 1.4.4.

¹⁰⁵ *ibid.*

¹⁰⁶ *Rance v Mid-Downs Health Authority* (1991) 1 All ER 801 (QB) (*Rance*); *AG Ref No 3 of 1994* (1997) 3 All ER 936 (HL) (*AG Ref No 3* (1997)).

¹⁰⁷ As discussed in Chapter One, Subsection 1.4.4.

¹⁰⁸ Helga Kuhse, Udo Schüklenk and Peter Singer, *Bioethics: An Anthology* (3rd edn, Wiley Blackwell Publishing 2015) 1.

¹⁰⁹ *Rance* (1991) (n 106); *AG Ref No 3* (1997) (n 106). Note the law on abortion is more nuanced than this, for example abortion is not a legalised practice, instead a statutory defence is provided if certain factors are met such as the mother's own life would be at risk from having the child.

¹¹⁰ *Bland* [1993] (n 11); PDOC patients are at least officially recognised as 'persons' in law as discussed in Chapter Three, Section 3.2.

¹¹¹ *ibid* 877 (Lord Browne-Wilkinson) and 865-866 (Lord Mustill) both found that the dilemma existed because *Bland* was "alive", but that the definition of death had changed. As discussed in Chapter One, Section 1.4 and Chapter Three, Section 3.2.

¹¹² Jason Hanna and Keith Allen, 'A Nurse is Accused of Impregnating a Woman in a Vegetative State Who Later Gave Birth' (US, 24 January 2019)

<<https://edition.cnn.com/2019/01/23/health/arizona-woman-birth-vegetative-state/index.html>> accessed 18 December 2019; Rosie Harding, 'The Rise of Statutory Wills and the Limits of Best

another born (living) person and simultaneously that PDOC patients are living persons,¹¹³ or more specifically, that they retain that status as living persons even when their life support is removed.¹¹⁴ There is therefore an inherent inconsistency; either the law permits the killing of a certain class of impaired persons, or such persons are (similarly to foetuses) no longer "persons" and therefore, their deaths are lawful and morally defensible as no infringement on their right to bodily integrity arises.¹¹⁵

However, due to the established link between death's definition and determination as moral personhood and the law's unquestioned adoption of the medical definition of death,¹¹⁶ it is logical to assume that legal and moral personhood are both attributed and denied on the basis of moral personhood's indicia: the loss of voluntary responsivity. Consequently, legal personhood's legal capacities (bodily autonomy for choices and bodily integrity for liberty in a medical context) will be denied and attributed on the basis of whether an individual has moral personhood. Harris was the first to comment that the only way to reconcile the moral and legal inconsistency in *Bland* is to recognise that VS patients are not legal persons.¹¹⁷ Moreover, given that MCS patients now also face the same starting presumption,¹¹⁸ it follows that they allegedly have also lost their personhood status. This does not mean that they never were recognised as legal persons, just that the

Interests Decision-Making in Inheritance' (2015) 78 (6) *The Modern Law Review* 945; United Nations Committee on the Rights of Persons with Disabilities, *List of Issues in Relation to the Initial Report of the United Kingdom of Great Britain and Northern Ireland* (20 April 2017) CRPD/C/GBR/Q/1, Part A subparagraph 1(f) and Part B subparagraph 19 (f). Note also the consequences of only a partial adoption of legal causation to justify life support withdrawal, such as attributing responsibility for unlawful assault, as discussed in Chapter Three, Subsection 3.2.3.

¹¹³ The legal definition of murder derives from Edward Coke, *The Third Part of The Institutes of the Laws of England: Concerning High Treason and Other Pleas of the Crown and Criminal Causes* (E and R Brooke in 1797). As discussed in Chapter One, Subsection 1.4.4, the phrase 'reasonable creature' is more accurately interpreted as legal person.

¹¹⁴ See *Bland* [1993] (n 11) at pages 877 (Lord Browne-Wilkinson) and 865-866 (Lord Mustill), who both found that the dilemma existed because *Bland* was "alive" but that the definition of death had changed. Note also that Lord Mustill at page 895 rejects the legal causation argument that supports the loss of personhood theory on the basis it overstretches the definition of death beyond intellectual and moral credibility. However, this does not mean that this had not already occurred in medical practice, as discussed in Chapter Two, Section 2.4. See Chapter Three, Section 3.2 for the discussion on legal causation.

¹¹⁵ As discussed in Chapter Three, Section 3.2.

¹¹⁶ Elizabeth Wicks, 'The Legal Definition of Death and the Right to Life' in Shane McCorristine, *Palgrave Historical Studies in the Criminal Corpse and Its Afterlife. Interdisciplinary Perspectives on Mortality and its Timings: When is Death?* (Macmillan Publishers Ltd 2017).

¹¹⁷ Harris 1999 (n 20).

¹¹⁸ *M v N* [2015] (n 98). As discussed in Chapter Three, Subsection 3.3.1.

presumed legal requirement that their life-supporting treatment be withdrawn can only be made consistent by concluding that they have lost personhood when withdrawal is deemed permissible by doctors (or the courts).¹¹⁹

Harris' views on bioethical topics can be provocative,¹²⁰ however, nowhere in this paper does he suggest we should see VS patients as non-persons (at least not explicitly) but that it is the only way to reconcile the *Bland* judgment.¹²¹ Moreover, for those like myself who seek to better protect the lives of these severely disabled persons, this shocking suggestion should therefore be entertained for the alarming possibility that it accurately explains how such patients can be defined as "dead" (at least unofficially), and assaulted by continued treatment but not unlawfully killed by its withdrawal. If correct, there exists a worrying legal loophole concerning the practice of defining death which consequently enables the "medicalised murder" of those with severe cognitive impairment.

Furthermore, because the practice is unsafeguarded¹²² it seems that futility has been allowed to run amok in E&W medical law: how else could the withdrawal of antibiotics be permissible from dementia patients knowing they will succumb to deadly infection? Or the withdrawal of mechanical ventilation from patients in the later stages of motor neurone's disease,¹²³ and for the law to maintain a position that it is not murder to withdraw such treatment with foresight of their death but assault to continue it?¹²⁴ Additionally, the UK was found to be withdrawing medical treatment from those with 'learning disabilities' as a

¹¹⁹ As discussed in Chapter Three, Section 3.2.

¹²⁰ For example, see Margaret Brazier's response to Harris' opinions on organ donation conscription: Margaret Brazier, 'Retained Organs: Ethics and Humanity' (2006) 22 (4) Legal Studies 550; John Harris, 'Law and Regulation of Retained Organs: The Ethical Issues' (2002) 22 Legal Studies 527.

¹²¹ As analysed in Chapter Three, Section 3.2.

¹²² It is unsafeguarded because the definition is not anchored to a particular level of cognitive disability such as brainstem death.

¹²³ *Re AK (Medical Treatment: Consent)* [2001] 1 FLR 219 (Fam).

¹²⁴ Suicide Act 1961. Note *Bland* [1993] (n 11) acknowledges that some may view these sorts of actions as similar to euthanasia and assisted suicide but maintained that there was an important distinction. See also Chapter Three, Subsection 3.2.3 and John Keown, 'A Futile Defence of Bland: A Reply to Andrew McGee' (2005) 13 (3) Medical Law Review 393, for a discussion on the failing of the Keown's intention argument because Parliament is still unwilling to recognise that life support withdrawal is indistinguishable from euthanasia.

justification for not attempting cardiopulmonary resuscitation:¹²⁵ is it really possible to morally distinguish these practices from non-voluntary euthanasia without resorting to defining those for whom continued treatment is deemed futile as non-persons ("dead"), irrespective of their evident signs of life?¹²⁶

Additionally, Chapter Two mentioned that vital organs can be procured from patients categorised as brainstem dead and yet simultaneously demonstrated that these patients are not biologically dead.¹²⁷ Therefore, the law's first encounter with the concept of brainstem death accepted life support withdrawal as permissible from such patients because they are "dead", non-persons and consequently no question of assault from continued or discontinued treatment arises.¹²⁸ Their "non-personhood" meant that no legal issue arose in law like in *Bland* and subsequent VS/ MCS cases.¹²⁹ Therefore, even the more controversial behaviours of vital organ donation and life support withdrawal can also morally and legally occur when a patient is still biologically alive.¹³⁰

For PDOC patients, the fact that some life behaviours are also permissible after accepted death behaviours further demonstrates just how inconsistent their personhood status is in E&W law. For example, palliative care is appropriately defined as a life behaviour because it is carried out on living (albeit dying patients) who are categorically not biologically dead.¹³¹ Their recognition as living persons provides them with moral and legal respect from others. Alternatively, the life support withdrawal cases recognised brainstem dead patients as "dead."¹³² It is possible to argue that this is because they were thought biologically dead and therefore unquestionably non-persons, which in turn explains why those tested and determined to be brain dead are not palliated and why vital organ donation is permissible. Instead, it possibly amounts to a determination of

¹²⁵ See CRPD 2006 'List of Issues' 2017 (n 112) subparagraph 54 (d) and 55 (d).

¹²⁶ See Chapter Three, Subsection 3.2.3 for the discussion on why causation is a stronger argument than intention.

¹²⁷ Shewmon 1997 (n 43). Donation after Brainstem death (DBD) is commonly referred to as "heart-beating donation".

¹²⁸ *Re A (A Minor)* [1992] (n 16); *Malcherek* [1981] (n 16). As discussed in Chapter Three, Section 3.2.

¹²⁹ This was indirectly noted by Lord Mustill and Lord Browne-Wilkinson in *Bland* where they commented on why the case presented a dilemma, see *Bland* [1993] (n 11) at pages 877 (Lord Browne-Wilkinson) and 865-866 (Lord Mustill).

¹³⁰ As discussed in Chapter Two, Subsection 2.4.2.

¹³¹ See PDOC 2020 (n 41) for PDOC patients palliative care after life support withdrawal.

¹³² *Re A (A Minor)* [1992] (n 16); *Malcherek* [1981] (n 16). As discussed in Chapter Three, Section 3.2.

convenience; the oddity that brain "dead" patients' hearts still beat makes critics of the somaticist definition of death uncomfortable with the idea that they could accurately be described as biologically dead.¹³³ Therefore, it seems much more accurate to recognise that such patients were deemed "dead" not by biological but by moral criteria.¹³⁴ In law, this can only be defensibly explained by a loss of personhood.¹³⁵

Regarding PDOC patients, vital organ donation is prohibited and in any event is unlikely to be possible once such patients die several weeks later of 'supracritical multi-organ damage'.¹³⁶ However, after their life support is withdrawn, palliative care is permissible and is in fact encouraged.¹³⁷ Therefore, the inconsistent pattern (death behaviour, followed by life behaviour, followed by the prohibition of another death behaviour) demonstrates the inconsistent moral and legal status such patients hold. Despite the inaccuracy and lack of consensus, the argument that the brain dead are 'dead by definition'¹³⁸ on the basis of a moral standpoint on death is at least superficially consistent. However, for PDOC patients this is not the case. They are treated simultaneously as being living persons and paradoxically, as living non-persons (in other words "dead") like the brainstem dead.¹³⁹ Therefore, although it is consistent to state that the brain dead are "dead" because they meet the definition of death, it is inconsistent for PDOC patients to be described as living when death behaviours are permitted (and prohibited) on them. Their moral treatment in medical practice and law can therefore be described as an "in-between state" existence or a 'no man's land paradox'.¹⁴⁰ Consequently, these death behaviours therefore indicate the accurate definition and determination of death (loss of personhood) by indicating when a person loses that status (loss of voluntary responsibility).

¹³³ Shewmon 1997 (n 43).

¹³⁴ Veatch 2005 (n 63). See Chapter Two, Section 2.4.

¹³⁵ Harris 1999 (n 20). As I analyse and argue in Chapter Three, Section 3.2.

¹³⁶ PDOC 2020 (n 41) 157.

¹³⁷ *ibid.*

¹³⁸ Veatch 2003 (n 62) 10-11.

¹³⁹ This is also reflected in the moral inconsistency discussed in Chapter Three, Section 3.2.

¹⁴⁰ The phrase 'no man's land paradox' has been borrowed from Have and Welie's book on euthanasia and assisted dying in the Netherlands, see H A M J ten Have and J Welie, *Death and Medical Power* (OUP 2005) 8. As mentioned mentioned in Chapter Three, Subsection 3.4.3.

Chapter 5

Finally, Kuhse, Schüklenk and Singer, and Sidgwick,¹⁴¹ all argue that the law should be given a wider birth of discretion when assessing the consistency of its position due to its 'wider ramifications than the consequences of personal choice.'¹⁴² However, it is doubtful that this applies in the context of defining and determining death. It is commonly accepted that the law defers defining and determining death (and the process by which it is determined i.e. the establishment of medical necessity and a duty of care) to the medical profession.¹⁴³ Of course, in cases where a dispute arises on whether a patient is dead under brain death determinations, doctors and families can find resolution in court.¹⁴⁴

After *re A (A Child)* [2015], academics began to question the legitimacy of a 'secular construct' overriding the religious beliefs of the child's parents.¹⁴⁵ Nevertheless, in such disputes it seems likely that medical determination will be followed.¹⁴⁶ Alternatively, in cases concerning life support continuation for PDOC patients the courts have in recent years shown more willingness to allow the decision to be a 'personal choice'.¹⁴⁷ For example, this seemed to be the approach of the Supreme Court in *Aintree* which affirmed that the test for futility (whether they are dead or alive/ duty of continue treatment) was 'subjective'.¹⁴⁸ Additionally, in 2019 the parents of a child whose beliefs in Islam conflicted with the concept futility and life support withdrawal won their appeal to have their child

¹⁴¹ Note Sidgwick (n 4) at page 3 explores the difficulty for an individual moral agent to make an ought statement that requires a change in the law.

¹⁴² Kuhse, Schüklenk and Singer (n 108) 6.

¹⁴³ Wicks 2017 (n 116) 119. As mentioned in Chapter One, Subsection 1.2.2.

¹⁴⁴ *Re A (A Child) (Medical Treatment: Removal of Artificial Ventilation)* [2015] EWHC 443, [2015] 2 WLUK 445. Note Hayden J ruled that, unlike the US where coronial powers are used to remove or continue mechanical ventilation in cases of dispute, that in the UK the High Court (Court of Protection specifically) will determine such matters. Note also that the Court of Appeal in *Re M (Declaration of Death of a Child)* [2020] EWCA Civ 164 (CA) held that in such cases a best interests decision is not being undertaken. In such cases, a "Part 8 Declaration" under the Civil Procedural Rules oversees that the clinical guidelines for brainstem death have been met and consequently makes a declaration on the patient's status as living or dead.

¹⁴⁵ Katrina A Choong and Mohamed Y Rady, 'Re A (A Child) and the United Kingdom Code of Practice for the Diagnosis and Confirmation of Death: Should a Secular Construct of Death Override Religious Values in a Pluralistic Society?' (2018) 30 (1) HEC Forum 71.

¹⁴⁶ This supposition is based on the decision in *re A (A Child)* [2015] (n 144), where Hayden J ruled that life support should be withdrawn, despite objections raised from the child's parents on the basis of religious beliefs, where testing proved the child met the criteria for brainstem death.

¹⁴⁷ Kuhse, Schüklenk and Singer (n 108) 6 (paraphrasing their distinction between policy and personal choices).

¹⁴⁸ See *Aintree* [2013] (n 26) at paragraph [30] (Lady Hale). Discussed in Chapter Three, Section 3.4.

transferred to a children's hospital in Italy.¹⁴⁹ The child is thought to be minimally aware but also has severe brainstem damage meaning she could not breathe unassisted.¹⁵⁰ Recent newspaper articles have reported that the child is now out of intensive care and has been weaned off of ventilatory support.¹⁵¹ Therefore, *Raqueeb* is perhaps more in line with the currently and judicially adopted ethos of personal choice in defining futility in PDOC life support cases than the purportedly medically objective approach in the courts' treatment of brainstem death disputes.¹⁵² More importantly for assessing consistency, it suggests that the crucial exercise of discharging doctor's duty of care is now determined on the basis of a personal decision that does not require greater discretion.

Therefore, in the context of determining whether continued treatment is futile, the courts have gradually eroded the medical test for futility to a subjective test, where that test incidentally represents a personal (albeit non-communicated) choice of the PDOC patient.¹⁵³ On that basis, it seems that in the context of morally withdrawing life support on the basis of futility that the law does not require greater discretion. As demonstrated in 3.3, doing so has meant that the wider policy considerations (such as safeguarding) have been undermined by the courts themselves, as a result of that greater licence of unchecked discretion.¹⁵⁴ For example, note *M v N* downgraded the diagnostic criteria's importance in such determinations from 'crucial'¹⁵⁵ to non-determinative,¹⁵⁶ thereby largely removing the role doctors play in such decisions.¹⁵⁷

¹⁴⁹ *Raqueeb v Barts NHS Foundation Trust* [2019] EWHC 2531 (Admin) (QB), [2019] ACD 141.

¹⁵⁰ See paragraphs [21]-[22] of *Raqueeb* [2019] (n 149) for a description of her state of awareness and capacity to breathe.

¹⁵¹ BBC News, 'Tafida Raqueeb: Brain-Damaged Girl in High Court Case Out of Intensive Care' (London, 10 January 2020) <<https://www.bbc.co.uk/news/uk-england-london-51055153>> accessed 20 January 2020.

¹⁵² Note "purportedly" is in reference to the discussions in Chapter Two, Sections 2.2 and 2.4, which cast doubt on the view that even brainstem death is an objective medical assessment. Instead, the findings suggest it is, and always represented, a moral standpoint on when life and treatment is deemed futile by reference to the lost biological characteristic of voluntary responsiveness.

¹⁵³ As discussed in Chapter Three, Sections 3.3 and 3.4.

¹⁵⁴ *ibid.*

¹⁵⁵ *W v M* [2011] (n 97) [258]-[259] (Baker J).

¹⁵⁶ See *M v N* [2015] (n 98) at paragraph [23] (Hayden J). As discussed in Chapter Three, Subsection 3.3.1.

¹⁵⁷ As discussed in Chapter Three, Subsection 3.3.1.

5.2.3 Section Conclusion

This section has applied the minimums of defensibility to the thesis' findings on how death is defined and determined and its implications for PDOC patients. In 5.2.1 the factual accuracy of the way in which death is defined and determined was assessed. First, the basis for neurological death was found to be biologically (factually) inaccurate in 2.2. Moreover, that chapter found that the definition of death is in fact a question of personhood on when continued treatment is deemed futile, even where discontinuation will result in the patient's death.¹⁵⁸ Therefore, in order to be defensible as an officially emulated stance in medical policy and law, it should at least hold a consensus among those professions.¹⁵⁹

This subsection found that no such consensus could be found among doctors, legislators or judges, at least in part because futility is yet to be officially recognised as the accurate definition and determination of death in E&W medical practice and law, and consequently has also been shown to be a question of discharging a doctor's duty of care, not assessing biological death. Futility/ duty of care determinations (as the loss of personhood) is the most convincing account for how life support can morally be withdrawn from a biologically living patient without that omission amounting to murder.¹⁶⁰ This is a more accurate understanding of how the brain dead are defined as "dead" and how it implicates PDOC patients because both patients are biologically alive and both have their personhood status defined by a doctor's duty of care which is increasingly a subjective test in both brainstem death and PDOC patient's continuation decisions. Finally, this subsection found that due to the greater discretion given to judges in deciding such cases, no remaining appropriate safeguards exist to prevent death as futility (no continued duty of care) being extended to others who are less cognitively or intellectually impaired. The definition of death therefore needs to be reappraised and officially recognised as the loss of voluntary responsiveness (and consequently personhood)

¹⁵⁸ A finding of Chapter Two, Section 2.4.

¹⁵⁹ See the discussion in Chapter One, Subsection 1.4.3, that where epistemic limitations exist in "knowing" the factual accuracy of a concept, philosophy maintains that if the "facts" hold a consensus it holds some credibility, irrespective of whether the facts are ontologically accurate. This discussion is based on the work of Engelhardt 1996 (n 73).

¹⁶⁰ This assertion and finding is developed in Chapter Two, Section 2.4 and Chapter Three, Section 3.2.

and anchored to a particular level of responsiveness loss. Otherwise, continuation decisions will also be able to bring other cognitively and intellectually impaired individuals' treatment into question.

The last subsection assessed whether futility (as the definition and determination of death) is morally consistent. The subsection used the framework of consistency and found that law and medicine have adopted an inconsistent approach by maintaining that PDOC patients are living persons, and subsequently requiring life support withdrawal. This assertion was further supported by the analysis of death behaviours as indicators of the accurate definition. Finally, the section assessed whether greater discretion should be given to the moral agents in such determinations.¹⁶¹ In the case of PDOC patients' life support continuation, the Supreme Court's emphasis on futility being determined by the patient's personal choice,¹⁶² suggests that greater discretion in this context is not justified: such decisions are purportedly personal, not political, legal or medical. Ultimately, the section found that death (as futility of continued treatment/ no duty of care due to loss of voluntary responsiveness) is not defensible for PDOC patients because it is neither factually accurate or consistent in medical practice, nor upholds the law's assertion that PDOC patients are legally recognised and protected persons. Most importantly, it is also unsupported by medical science and therefore there is good reason to doubt it would meet the *Bolitho* standard for discharging a duty of care to continue treatment.

5.3 Defences and Dilemmas: Coping with the Fallout

5.3.1 Was the Redefinition of Death as Futility Necessary?

But what about the rationales and justifications that suggested that such a radical redefinition of death and life support withdrawal from living persons (no continued duty of care) was, and is necessary?¹⁶³ This thesis' question is limited to evaluating the existing rationales found in the literature that support the moral standing view of death (futility) and its extension to those whose PDOC is higher up the neuropathological spectrum than

¹⁶¹ Kuhse, Schüklenk and Singer (n 108); Sidgwick (n 4).

¹⁶² *Aintree* [2013] (n 26).

¹⁶³ Harvard Report 1968 (n 24). As later adopted in *Bland* [1993] (n 11) and discussed in Chapter Three, Section 3.2.

brain death.¹⁶⁴ Therefore, Chapter Two investigated, 'what is'¹⁶⁵ in relation to the historical development of life support withdrawal from brainstem dead patients and PDOC patients. It examined the origins of the concept of brain death;¹⁶⁶ what neuroscience has proven about PDOC patients' capacity for awareness,¹⁶⁷ and also, whether an important distinction exists between mechanical ventilation and CANH withdrawal that impacts how futility is interpreted.¹⁶⁸ These questions were key to ascertaining the rationales supporting the existence of brain death as they were later extended to PDOC patients.¹⁶⁹

The core rationales defending brain death originated from the seminal Harvard Report 1968.¹⁷⁰ That paper's authors argue that death (irreversible coma) needed to be redefined because of the emotional burden to patients and their families but also to protect the allocation of hospital resources and prevent the loss of opportunity that such patients present for vital organ donation.¹⁷¹ However, whilst it is possible that these rationales considered the emotional anguish of families, both Giacomini and Bishop provide convincing historical accounts that suggest it was more likely the opportunity life support removal provided for vital organ donation that convinced the medical profession to go as far as to redefine death.¹⁷²

Interestingly, in the context of PDOC patients there is little empirical literature specifically supporting a resource-based argument for necessitating legal change on withdrawal/ continuation practices. The only paper that specifically addresses this point

¹⁶⁴ Recalling the scope set by Sidgwick (n 4) at page 3 (paraphrasing); and discussed in Chapter One, Section 1.2, that what a moral agent 'ought to do must be something they can do', and that therefore alternative courses of action must already be in existence to maintain a fair assessment.

¹⁶⁵ Sidgwick (n 4) 2. As discussed in Chapter One, Section 1.2.

¹⁶⁶ As discussed in Chapter Two, Section 2.2.

¹⁶⁷ As analysed in Chapter Two, Section 2.3.

¹⁶⁸ Chapter Two, Sections 2.2 and 2.4. In other words, whether futility in brain death is distinctly different from futility assessments in PDOC patients life support withdrawal decisions.

¹⁶⁹ Harvard Report 1968 (n 24). As later adopted in *Bland* [1993] (n 11) and discussed in Chapter Three, Section 3.2.

¹⁷⁰ Harvard Report 1968 (n 24).

¹⁷¹ *ibid* 337.

¹⁷² See Jeffrey P Bishop, *The Anticipatory Corpse: Medicine, Power, and the Care of the Dying* (University of Notre Dame Press 2011) specifically Chapter 5; Mita Giacomini, 'A Change of Heart and A Change of Mind? Technology and the Redefinition of Death 1968' (1997) 44 (10) Social Science and Medicine 1465. The question of which rationale took more precedence in the decision to redefine death was explored in Chapter Two, Subsection 2.2.2.

seems to be Halliday and others' in 2015,¹⁷³ which specifically targets what its writers argue is the expensive and unnecessary legal costs of judicial oversight, estimated to be '£122,000 in ongoing care costs and legal fees'.¹⁷⁴ Interestingly, the authors themselves note how small this cost is in the NHS' annual budget of over £105 billion.¹⁷⁵ In the context of mounting pressure from different stakeholders,¹⁷⁶ the Supreme Court in 2018 determined that no legal duty existed for doctors to seek judicial oversight.¹⁷⁷

Halliday and others' use of Quality Adjusted Life Years (QALYs) to argue that this treatment costs '9 years of life [in] foregone care to other patients'¹⁷⁸ is problematic. QALYs are 'infamous' for their inherent bias against disabled persons because the presence of disability itself precludes those with disability obtaining a perfect score, unlike able-bodied and minded persons.¹⁷⁹ Additionally, such methods cannot defensibly arrive at such a decision because quality of life judgements are unmeasurable.¹⁸⁰ QALYs enable a disabled patient to be demoted to the status of non-persons without clear and defensible reasoning for doing so. Better put, the system enables moral agents to believe that they have achieved defensibility because resources are thought to be wasted on those who cannot attain perfect health.¹⁸¹ Therefore, the process overlooks the inherent and currently irresolvable problem of measuring and comparing the value of human life.¹⁸² Of course, in

¹⁷³ Simon Halliday, Adam Formby and Richard Cookson, 'An Assessment of the Court's Role in the Withdrawal of Clinically Assisted Nutrition and Hydration from Patients in the Permanent Vegetative State' (2015) 23 (4) *Medical Law Review* 556.

¹⁷⁴ *ibid* 580-581 (paraphrasing).

¹⁷⁵ These figures were correct as of 2015, it seems that the current NHS budget for 2020-2021 is approximately £178 billion. See HM Treasury UK Government, *Budget 2020: Policy Paper* (HM Treasury, 12 March 2020). The budget has been rising in recent years, in 2019-2020 the budget amounted to £140.4 billion. See also The King's Fund, 'The NHS Budget and How it Has Changed' (The King's Fund, 13 March 2020) <<https://www.kingsfund.org.uk/projects/nhs-in-a-nutshell/nhs-budget>> accessed 1 April 2020.

¹⁷⁶ These different stakeholders and their views were discussed in Chapter Three, Section 3.3.

¹⁷⁷ See *An NHS Trust v Y*[2018] (n 99) at paragraph [48]. Note that there currently is a conflict between recent guidance published by the Court of Protection in *Practice Guidance* [2020] (n 100), the Supreme Court's in *An NHS Trust v Y*[2018] (n 99) and new COP Rules 2017, which withdrew the old PD 9E from the COP Rules 2007. See this discussion in Chapter Three, Subsection 3.4.1, and Subsection 5.2.1 (Chapter Five).

¹⁷⁸ Halliday and others (n 173) 581 (paraphrasing).

¹⁷⁹ John Harris, 'It is Not NICE to Discriminate' (2005) 31 (7) *Journal of Medical Ethics* 373, 373; Ben Davies, 'Bursting Bubbles? QALYs and Discrimination' (2019) 31 (2) *Utilitas* 191; John Harris, 'QALYfying the Value of Life' (1987) 13 *Journal of Medical Ethics* 117.

¹⁸⁰ *ibid*.

¹⁸¹ *ibid*.

¹⁸² *ibid*.

a system of scarce health resources (e.g., the NHS) the need to use such tools is arguably necessary. However, health economists are still grappling with the task of achieving a non-biased means of commensurating life, particularly when one value involves a person with disability.¹⁸³ Currently however, the use of QALYS is therefore indefensible and as far as I am aware, no further resource justifications arising from continued care have been advanced.

For my own conclusion to be defensible the same limitations must be addressed; as Sidgwick suggests, in making any 'ought statement', 'what I ought to do, must be something I can do.'¹⁸⁴ In other words, if we are to recognise such patients as persons in need of facilitating communication, there must be an existing alternative option to the critiqued status quo (ss 4(6) and 4(7) MCA). In order to address this, Chapter Four's findings were vital. In 4.3, I challenged the view that PDOC patients cannot be supported to make decisions and that substituted decision-making regimes would need to be maintained for some impaired persons.

The first step to be compliant with Article 12(3) CRPD is to exhaust available methods of communication including non-conventional methods. Therefore, the evidence that at least some PDOC patients can communicate via fMRIs, suggests this non-conventional method of communication should also be exhausted.¹⁸⁵ There are however, resource arguments in the literature which suggest that this will not be practical.¹⁸⁶ For example, the scanner required to conduct fMRIs costs £500,000 to install and also requires highly trained staff to assess PDOC patients' awareness.¹⁸⁷ Moreover, Laureys and others argue that such technology 'will never replace responsivity tests'.¹⁸⁸ Yet, the evidence that some can respond and the fact that no response does not mean that patient is not inner aware,¹⁸⁹ surely begs the question of why life support is being removed: if the medical

¹⁸³ Josh Cohen and others, 'Will ICER's Response to Attacks on the QALY Quiet the Critics? A Reply from the Partnership to Improve Patient Care' (CEVR, 28 January 2019) <<https://cevr.tuftsmedicalcenter.org/news/2019/pipcreply>> accessed 19 December 2019.

¹⁸⁴ Sidgwick (n 4) 3 (paraphrasing). As discussed in Chapter One, Section 1.2.

¹⁸⁵ This evidence is discussed in Chapter Two, Subsection 2.3.3.

¹⁸⁶ As discussed in Chapter Four, Subsection 4.3.2.

¹⁸⁷ Johan Stender and others, 'Diagnostic Precision of PET Imaging and Functional MRI in Disorders of Consciousness: A Clinical Validation Study' (2014) 384 (9942) Lancet 514; PDOC 2020 (n 41).

¹⁸⁸ Steven Laureys, Adrian M Owen, Nicholas D Schiff, 'Brain Function in Coma, Vegetative State, and Related Disorders' (2004) 3 (9) The Lancet Neurology 537, 544 (paraphrasing).

¹⁸⁹ This evidence is discussed in Chapter Two, Subsection 2.3.3.

justification for withdrawal is non (or minimal) awareness,¹⁹⁰ why is withdrawal deemed necessary as fMRIs have demonstrated that PDOC patients cannot be safely diagnosed as non or minimally aware? Such tests can only measure responsivity, not awareness.¹⁹¹ Moreover, if they are capable of communicating, why is continued treatment being decided on a non-autonomous basis (duty of care/ medical necessity)? On that basis, failing to question the practice in its entirety is morally questionable (inaccurate and inconsistent) and is also legally indefensible because according to *Bolitho*, consensus itself is not enough to defend an inaccurate and 'illogical' practice.¹⁹² Either such patients are autonomous or they are not, ss 4(6) and 4(7) MCA are therefore unnecessary and at odds with the established law on bodily autonomy and integrity as a hybrid approach.

There is therefore real reason to doubt why the practice is not nullifying the MCA's section 5 defence for improper medical decision-making on such patients' capacity for decision-making. There is no justifiable resource or medical reason for discontinuing because the technology has proven such patients cannot be safely described as non-aware, and non-awareness is purportedly what makes continued treatment futile.¹⁹³ Moreover, if they have capacity, they are not appropriately being facilitated to communicate. In light of this, it is not clear how doctors can defensibly defend the view that the withdrawal is not to bring about the patient's death.¹⁹⁴ Regardless of clinicians' intentions, existing justifications and rationales fail to morally and legally support the practice. Consequently, PDOC patients' life support discontinuation on the basis of futility is in desperate need of reappraisal because the justifications that seek to distinguish this practice from non-voluntary euthanasia have gradually been eroded and no further distinguishing rationales have been offered. Ultimately, its practice in law has been shown to dangerously conflate bodily autonomy and integrity.

¹⁹⁰ Note if a patient retains the capacity to respond, life support withdrawal is not considered medically indicated. See the distinction with LIS patients in the PDOC 2020 (n 41) 24.

¹⁹¹ The evidence for this assertion can be found in Chapter Two, Section 2.3.

¹⁹² *Bolitho v City and Hackney Health Authority* [1998] AC 232 (HL) 241-242 (Lord Browne-Wilkinson). Referring to the discussion in Chapter One, Subsection 1.3.3.

¹⁹³ This is the key finding of in Chapter Two, Section 2.3.

¹⁹⁴ This intention is prohibited under Mental Capacity Act 2005 (MCA) subsection 4(5). See John Coggon, 'Ignoring the Moral and Intellectual Shape of the Law After Bland: The Unintended Side-Effect of a Sorry Compromise' (2007) 27 (1) Legal Studies 110, who comments that subsection 4(5) MCA is rendered ineffective because the intention to withdraw life support is difficult to distinguish from euthanasia, which was noted by Keown 2005 (n 127).

With that in mind, the next step would be to check for any existing and properly formulated advance planning instruments for non-autonomous patients.¹⁹⁵ As the dissenting judgment in *Lambert v France* [2015] interpreted the current basis of these decisions, if the practice of questioning continuation is still needed in the case of PDOC patients, it is not because of a medical need (bodily integrity) but a personal choice (autonomy), and consequently will require an explicit choice to be made via advance planning instruments.¹⁹⁶ These advance planning instruments are the only existing justifiable way of removing life support on the basis of personal choice, anything else will amount to conjecture.¹⁹⁷

This brings me to Donnelly's and Quinn's argument that candour could bring some level of ethical respectability back to these judgments.¹⁹⁸ However, I disagree that candour alone can resolve the problem.¹⁹⁹ Being honest that law and medicine hold what evidently seems to be a different value on the lives of those with severe cognitive impairment would not only fail to make the practice itself morally defensible, it would also be a shocking public statement to make in light of consistent rhetoric from the courts that disabled lives are equally protected and valued.²⁰⁰ Furthermore, to do so would fail to acknowledge the difficulty such moral agents face in making such decisions and would therefore result in an excessively harsh moral judgement on them. Instead, where no advance planning exists to

¹⁹⁵ Discussed in Chapter Three, Section 3.3 (how to formulate) and Chapter Four, Section 4.3 (noted examples of their lack of enforcement in practice).

¹⁹⁶ *Lambert and Others v France* App no 46043/14 (ECHR, 5 June 2015). As argued in Chapter Four, Section 4.3. Note after *Aintree* [2013] (n 26) the test for futility changed to personal choice but the Court of Protection, more leniently than *Lambert*'s dissenting judgment, allows subsections 4(6) and 4(7) MCA 2005 to be used to in effect construct a refusal to continue life-supporting treatment.

¹⁹⁷ This is the conclusion of Chapter Four, Section 4.3.

¹⁹⁸ Mary Donnelly, 'Best Interests in the Mental Capacity Act: Time to Say Goodbye?' (2016) 24 (3) Medical Law Review 318; Gerard Quinn, 'Personhood and Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD' (HPOD Conference at Harvard Law School, 20 February 2010) <[https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/archive/Submission-on-Legal-Capacity-to-the-Oireachtas-Committee-on-Justice,-Defence-&-Equality-\(August,-2011\).pdf](https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/archive/Submission-on-Legal-Capacity-to-the-Oireachtas-Committee-on-Justice,-Defence-&-Equality-(August,-2011).pdf)> accessed 1 June 2019.

¹⁹⁹ As argued in Chapter Four, Subsection 4.3.3.

²⁰⁰ *ibid*. That consistent rhetoric can be found in assisted suicide cases such as *R (on the application of Nicklinson) v Ministry of Justice*; *R (on the application of Lamb) v Ministry of Justice*; *R (on the application of AM) v DPP* [2014] UKSC 38, [2015] AC 657. And, murder cases such as, *R v Inglis* [2010] 1 WLR 1110 (CA). See the discussion in Chapter Three, Subsection 3.2.3 on these cases and their rhetoric that disabled lives are protected and equally valued.

indicate what the patient would want, the focus should be to treat their right to life with the care and respect they deserve as full legal persons (right to life trumps assault).

As I argued in 4.4, to continue to use the best interests test (subsections 4(6) and 4(7) MCA) to, in effect, construct a refusal to continue life-supporting treatment will likely be criticised for amounting to indirect discrimination.²⁰¹ The lack of resource justifications supporting the starting presumption and clinical indication supporting the view that such patients are non-aware suggests that using the best interests test in an attempt to morally justify life support withdrawal from PDOC patients is unnecessary and harmful.²⁰² Instead, the focus should be on raising 'public awareness'²⁰³ of these disorders to eradicate the perception of them as being 'better off dead'.²⁰⁴ Additionally, the recording and dissemination of advance planning instruments needs to be strengthened to raise awareness.²⁰⁵ There are therefore more defensible and existing methods of deciding whether life support should be continued on the basis of personal choice than the use of subsections 4(6) and 4(7) MCA.²⁰⁶

It seems that not only is the pervading view that PDOC patients lack awareness and cannot feel pain factually inaccurate,²⁰⁷ the practice is also inconsistent and has been found to hold no defensible resource or medical rationale supporting the continuation of its practice, which is integral for its doctrinal basis on the right to bodily integrity.²⁰⁸ Consequently, there is in fact a moral and legal requirement under existing law to continue treatment because the standard for discharging such a duty of care has not been met under *Bolitho* and the rationale offered is inconsistent and inaccurate. I therefore suggest that the law react accordingly with a public awareness campaign and reinstate PDOC patients as legal persons with moral standing by restricting withdrawal to those who have formulated advance planning instruments.²⁰⁹ Otherwise, no justification exists

²⁰¹ Argued in Chapter Four, Section 4.4.

²⁰² *ibid.*

²⁰³ CRPD 2006 (n 31) Article 8 'awareness-raising'.

²⁰⁴ Kayess and French (n 24) 5.

²⁰⁵ Argued in Chapter Four, Subsection 4.3.2.

²⁰⁶ As concluded in Chapter Four, Sections 4.3 and 4.4.

²⁰⁷ Discussed in Chapter Two, Section 2.3.

²⁰⁸ The conclusion that life support withdrawal from PDOC patients is an inconsistent practice is made in Subsection 5.2.2.

²⁰⁹ Building on the conclusions in Chapter Four on the demands of the CRPD 2006 to tackle discriminatory denials of personhood in cognitively disabled persons.

for palliation after withdrawal, nor the prohibition of vital organ donation, which would be a particularly abhorrent result. Moreover, without reappraisal death's definition and determination will implicitly be confirmed to be the loss of voluntary responsiveness only, meaning that PDOC patients would also be 'dead by definition'²¹⁰ for having lost that most valued characteristic of human life. The purpose of such analysis is not to replace one always with another (continued treatment is justified or not justified) instead it resets the balance on the basis of established domestic and international law that the current presumption should be rebuttable. Medical science is developmental but PDOC patients' status as persons should not be.

Finally, this thesis' findings touched on wider rights that are implicated by the treatment of PDOC patients as 'better off dead' individuals,²¹¹ presenting evidence that PDOC patients have been sexually abused and have had their testamentary wishes disproportionately interfered with.²¹² The thesis also (briefly) looked beyond PDOC patients to also those with mental impairments and their treatment.²¹³ There are therefore much wider considerations that spring from the idea that life support continuation is impermissible (both morally and legally) on those with cognitive impairments. It possibly has played a part in the wider mistreatment of those with other cognitive and mental impairments, which explains their treatment as equivalent to being 'human non-persons'.²¹⁴ I could not possibly also cover such instances in the same depth to concretise this apparent link for those with intellectual disability. However, as Quinn argues, the war on disability rights is in fact 'a proxy war on personhood', and consequently, the law's failure to provide 'equal recognition in law' to such persons indicates a wider pattern of behaviour that undermines their status as recognised and respected persons in law.²¹⁵ This

²¹⁰ Veatch 2003 (n 62) 10-11.

²¹¹ Kayess and French (n 24) 5.

²¹² Hanna and Allen (n 112); Harding (n 112).

²¹³ See the use of intellectual disability as a justification for placing DNACPRs on patients' files, CRPD 2006 'List of Issues' 2017 (n 117) Part A subparagraph 1(f) and Part B subparagraph 19 (f).

²¹⁴ Using Harris's phrasing. See Harris 1999 (n 20) at page 293 (paraphrasing). Note that the PDOC 2020 guidance (n 43) at page 20 now seeks to make a the distinction between PDOC patients and 'TDOC patients'—those who have awareness disorders and are not expected to live much longer because of multimorbidity or old age, which possibly suggests the PDOC guidance also recognises the apparent overspilling impact on wider cognitive disorders.

²¹⁵ Gerard Quinn, 'Rethinking Personhood: New Directions in Legal Capacity Law and Policy' (University of British Columbia, 29 April 2011)

noted wider abuse is a pattern of behaviour being observed and tackled by those in human rights discourse.²¹⁶

5.3.2 Dilemmas and Defences

The possibility that PDOC patients' continuation decisions are morally irresolvable because they present a moral dilemma was first introduced in 1.4, and raises an important question, not only to explore why these cases are described as 'morally misshapen,'²¹⁷ but also to appropriately decipher the moral defence available to the judges and doctors (moral agents) who at the time, and still regard the question before them as dilemmatic.²¹⁸

The findings of 1.4 established at least one purported universal moral precept is reflected in the criminal law as a moral requirement, "do not kill human beings". The further (non-universal) moral requirement in *Bland* is non-maleficence (protection from assault). That moral precept was found to be non-universal because the question of whether continued treatment amounts to harm is decided on the basis of medical judgement and not societal consensus. However, the section also discussed reasons why the term 'human being' is likely more qualified than a speciesist interpretation, i.e., "belonging to the human race".²¹⁹ Instead, the phrase 'reasonable being in *rerum natura*'²²⁰ in the definition of murder could mean 'beings who reason', which better fits the era's zeitgeist.²²¹ If accepted, the law's adopted moral requirement "not to kill" only protects to those who can "reason".²²²

<http://citizenship.sites.olt.ubc.ca/files/2014/07/Gerard_Quinn_s_Keynote_-_April_29_2011.pdf> (accessed 1 June 2019) 11.

²¹⁶ These academics and their relevant work for this thesis have been discussed throughout Chapter Four, specifically in Subsection 4.2.2.

²¹⁷ Lord Mustill's words have since been used in the titles of academic commentary on the moral incongruity in such cases, for example, Coggon 2007 (n 194); John Keown, 'Restoring Moral and Intellectual Shape to the Law After *Bland*' (1997) 113 Law Quarterly Review 481. The key debates on this central question were analysed in Chapter Three, Section 3.2.

²¹⁸ As first discussed in Chapter One, Subsection 1.4.2.

²¹⁹ See Chapter One, Subsection 1.4.4 for this discussion.

²²⁰ Coke (n 113) 47 (paraphrasing).

²²¹ See Chapter One, Subsection 1.4.4 for this discussion.

²²² This hypothesis from Chapter One, Subsection 1.4.4 seems to have been affirmed throughout the thesis' findings on the link between cognition, awareness/responsivity, death and personhood.

Furthermore, *Bland*'s judges imply that the (purported) dilemma arose due to a medicine's definition of death (how a duty of care is established).²²³ Chapter Two therefore examined medicine's definition of death to see if it diverged or complemented the law's. Throughout that chapter it became apparent that in jurisdictions where brain death is accepted it is based on a moral standpoint on what lives are worth living.²²⁴ More specifically, that its 'remaining foot in biology'²²⁵ is a mentalist (or higher brain death) view of death; where cognitive capacity is pedestalled as the most valuable characteristic of human life.²²⁶ Both disciplines have therefore adopted a personhood definition of death. Superficially at least, there is therefore agreement between the law's definition of murder and medicine's concept of "death", or more specifically when biologically living persons' treatment becomes futile. However, the law simultaneously maintains that PDOC patients are living human persons.²²⁷ Likewise, medicine continues to palliate them and prohibit vital organ donation,²²⁸ suggesting that medicine also recognises (to some extent) their morally and legally protectable worth. However, I do not think this negates the view that medicine and law have adopted a mentalist and consequently personhood view of death, and instead bolsters the view that their personhood status is confused.

Chapter Three also argued that a legal dilemma originally arose because of a conflict between two different instances of infringements with a PDOC patient's purported right to bodily integrity: assault from continued treatment but not murder (right to life) where their death follows, which can be resolved by answering whether they are persons or not. However, more recent judgments have seemingly departed from orthodox doctrinal precedent that these cases concern infringements of bodily integrity, instead focussing on the bodily autonomy of these deemed non-autonomous patients.²²⁹ For example, they

²²³ See *Bland* [1993] (n 11) at pages 865-866 (Lord Mustill) and 877-879 (Lord Browne-Wilkinson). As discussed in Chapter One, Subsection 1.4.2.

²²⁴ As concluded in Chapter Two, Section 2.4 on the basis of the rest of that chapter's findings.

²²⁵ Stuart J Younger and Robert M Arnold, 'Philosophical Debates About the Definition of Death: Who Cares?' (2001) 26 (5) *Journal of Medicine and Philosophy* 527, 532 (paraphrasing).

²²⁶ Discussed in Chapter Two, Section 2.4.

²²⁷ *Bland* [1993] (n 11); *Aintree* [2013] (n 26). As primarily discussed in Chapter Three, Section 3.2 and further developed in 3.4.

²²⁸ PDOC 2020 (n 41).

²²⁹ As discussed in Chapter Three, Section 3.4.2; notably *Re Briggs (Incapacitated Person) (Medical Treatment: Best Interests Decision)* [2016] EWCOP 53, [2017] 4 WLR 37 (*Briggs (No.2)* [2016]); *Lambert* [2015] (n 196); *M v N* [2015] (n 98); *Aintree* [2013] (n 26).

suggest that Article 8 trumps Article 2 European Convention on Human Rights 1950. This seems to have been confirmed by the majority in *Lambert*, where the patient has not been appropriately facilitated to communicate under the Convention on the Rights of Persons with Disabilities 2006, nor explicitly deemed autonomous. Such cases need to be clear on whether such patients are persons and whether they are autonomous or not. As Chapter Four demonstrated, it is not discriminatory to treat different people differently if it is on a reasonable, objective and proportionate basis.

Consequently, the dilemma in such cases is not a genuine dilemma because it is resolvable as long as a choice is made:²³⁰ are PDOC patients legal persons or not and are they autonomous or not? Answering these questions are key to providing moral and legal doctrinal clarity. Paradoxically, PDOC patients are currently recognised as both 'human persons' and as 'human non-persons'.²³¹ Consequently, the definition and determination of death in E&W is inconsistent and inaccurate. The starting presumption against continued treatment in PDOC patients' life support cases defines those who are biologically living as dead in order to morally and legally justify actions (legal omissions) that cause or hasten their death, whilst at the same time, maintaining that such persons are biologically alive and assaultable, and that non- and involuntary euthanasia are illegal.²³²

The findings of this conclusion may at first sight seem particularly critical of the doctors' and judges who deem discontinuation necessary. However, the presence of a purported dilemma demonstrates that the definition and determination of death has been largely inadvertent. The dilemma seems to arise from ontological limitations as the doctors and judges in *Bland* were likely to have been unaware that death (and consequently its death behaviours such as life support withdrawal on living patients) were being wholly justified on the basis of a moral standpoint.²³³ It was not until the late 1990s

²³⁰ Charles C Hinkley, *Moral Conflicts of Organ Retrieval: A Case for Constructive Pluralism* (Rodopi 2005); Terrance C McConnell, 'Moral Residue and Dilemmas' in H E Mason (ed), *Moral Dilemmas and Moral Theory* (OUP 1996).

²³¹ Harris 1999 (n 20) 293; Veatch 2005 (n 63) 367 (paraphrasing).

²³² As discussed in Chapter Two, Section 2.4 and Chapter Three, Section 2.3.

²³³ As discussed in Chapter One, Subsection 1.4.2; Chapter Two, Sections 2.2 and 2.4 and Chapter Three, Section 3.2.

and early 2000s that neurologists began to note this issue with increasing consensus.²³⁴ Moreover, *Bland's* case report is littered with examples of moral residue (feelings of guilt, regret and remorse²³⁵) that did not arise from what the moral agents felt was wrong action but right action (to prevent *Bland* suffering undignified treatment and torment arising from his continued care).²³⁶ Consequently, that moral residue is likely to be a mixture of both appropriately (blameworthy) and inappropriately (blamelessness) held moral residue, due to the extension of "death" as futility to PDOC patients.

However, the more recent and notable cases (extending the practice to minimally conscious patients on the inaccurate basis of a moral values assessment) has a slightly different result.²³⁷ Cases after *M v N* have gradually rendered futility a personal choice and consequently have failed to recognise that a different best interests test on the basis of bodily integrity (not autonomy) was undertaken in *Bland*.²³⁸ Additionally, the medical evidence of non or minimal awareness in such cases has subsequently been called into question by fMRI imaging,²³⁹ and suggests that the use of the best interests test as a dignity or welfare-based test in continuation cases should be reappraised to at least clarify if they are persons and autonomous or not.²⁴⁰ Consequently, the key question should have been: if such tests are more accurately measuring responsibility, is the inability to communicate enough to justify actions that ultimately kill them? In the end, the use of the best interests test to construct a view of what the PDOC patient would want therefore lacks medical indication (loss of voluntary communication cannot defensibly define an individual as dead) and lacks defensibility without societal debate and acknowledgement that the definition of death and criteria for personhood has been radically redefined.

²³⁴ Discussed in Chapter Two, Subsection 2.2.3.

²³⁵ See Hinkley (n 230) at pages 15-16 and McConnell (n 230) at page 36. As discussed in Chapter One, Subsection 1.4.2.

²³⁶ Moral residue was defined and analysed as a possible indicator of the existence of a moral dilemma in Chapter One, Subsection 1.4.2.

²³⁷ *An NHS Trust v Y*[2018] (n 27); *Aintree* [2013] (n 26); *Briggs (No.2)* [2016] (229); *M v N* [2015] (n 98); *W v M* [2011] (n 97).

²³⁸ *An NHS Trust v Y*[2018] (n 27); *Aintree* [2013] (n 26); *Briggs (No.2)* [2016] (n 229). As discussed throughout Chapter Three.

²³⁹ Owen and others 2006 (n 53); Staffen and others (n 53). Further papers were also discussed in Chapter Two, Section 2.3.

²⁴⁰ This assertion is reached on the basis of the findings in Chapter Three, Sections 2.3 and 2.4.

It is surprising that such cases have not yet been tested for their medical decision-making standards under *Bolitho* because if they had they would evidently not withstand logical analysis.²⁴¹ This is particularly so given that the courts and medical practice have been aware that new evidence exists to challenge their non-aware status, and yet has downgraded the evidence's relevance to non-determinative.²⁴² Moreover, when the Official Solicitor raised such concerns in *An NHS Trust v Y*, the response was that a sufficient body of practice had built up meaning that such concerns are no longer relevant.²⁴³ In other words, these cases prioritise a medical practice that is inconsistent with *Bolitho*'s decision-making standard (consensus itself is not enough, it must have a logical basis) and treat the starting presumption as non-rebuttable.²⁴⁴

Consequently, the definition and determination of death in law and medical practice in E&W has been found to be both inaccurate and inconsistent, and therefore that the presumption that continued treatment would amount to assault and withdrawal does not amount to murder is indefensible—a practice that has been carried over from brainstem death cases.²⁴⁵ Moreover, although a purported dilemma exists, it is resolvable by making a choice: are PDOC patients (living) autonomous persons or not?²⁴⁶ Moreover, it seems that the law is not accurately determining these cases on a correct doctrinal basis under *Bolitho*.²⁴⁷ Finally, failure to reappraise will mean the moral defence of *phronesis* will not be available either because that failure will amount to turning a blind eye to the evident moral and legal inconsistency in how PDOC patients are treated in law and medical practice.²⁴⁸

²⁴¹ *Bolitho* [1998] (n 192). As discussed in Chapter One, Subsection 1.3.3.

²⁴² See *M v N* [2015] (n 98) at paragraph [23] (Hayden J).

²⁴³ See *An NHS Trust v Y* [2018] (n 27) at paragraphs [122]-[124] (Lady Black). As discussed in Chapter Three, Subsection 3.3.2.

²⁴⁴ See *Bolitho* [1998] (n 192) at page 243 (Lord Browne-Wilkinson); Chapter One, Subsection 1.3.3.

²⁴⁵ As discussed in Section 5.2.

²⁴⁶ As discussed earlier in this subsection (5.3.2).

²⁴⁷ *ibid*. I do recognise that *Bolitho* sets a standard for medical decision-making, but it would seem biased from a moral perspective if judges were not also held to some similar account.

²⁴⁸ As discussed in Chapter One, Subsection 1.3.3 and based on the findings outlined in Section 5.2.

5.3.3 Section Conclusion

This section has explored the resource justifications necessitating the practice of life support withdrawal from PDOC patients and found the justifications wanting.²⁴⁹ The section returned to the question in 1.4 of whether a genuine dilemma exists in such cases and argued that the superficial dilemma is sufficiently resolvable because a choice on PDOC patients' status as persons (and autonomous persons) can and needs to be made. Consequently, this thesis calls for the definition and determination of death to be reappraised by medicine and law as the medical indicator at the heart of this duty of care/bodily integrity question. The section ended by also exploring their moral defensibility. It found that the later cases are harder to establish a moral defence for (i.e., *phronesis*) because they fail to meet the moral and legal standard of defensible decision-making and conflate bodily autonomy and integrity in a dangerous manner.²⁵⁰ There is even a possible conflict in the MCA if judges are in fact the decision-making agents in these cases because it would at least superficially suggest that section 5 and subsection 4(5) MCA applies to judges also,²⁵¹ leading to the constitutional quagmire of possible future judicial reviews of judicial decisions themselves.

5.4 Thesis Conclusion and Novelty

This Chapter has acted as a conclusion for this thesis's question of whether the way in which death is defined and determined in England and Wales is defensible. In short, it has found that it is currently indefensible because it fails the factual accuracy and consistency tests on both a moral and legal/doctrinal basis.²⁵² Moreover, the existence of advance planning instruments are themselves sufficient to justify withdrawal under the current test for futility as a personal choice, providing an alternative mechanism to defensibly account for patient's wishes where they are no longer deemed autonomous.²⁵³ Admittedly, the

²⁴⁹ Halliday and others 2015 (n 173); *Bland* [1993] (n 11); Harvard Report 1968 (n 24).

²⁵⁰ *An NHS Trust v Y*[2018] (n 27); *Aintree* [2013] (n 26); *Briggs (No.2)* [2016] (n 229); *M v N* [2015] (n 98). *Phronesis* is introduced and discussed as a partial moral defence for moral decision-making in Chapter One, Subsection 1.3.3.

²⁵¹ At least theoretically, as discussed in Section 5.3 and Chapter Three, Section 3.4.

²⁵² As discussed in Section 5.2.

²⁵³ This conclusion is reached on the basis of the discussions in Chapter Four, Sections 4.3 and 4.4.

process for recording and disseminating such instruments requires improvements.²⁵⁴ However, the use of subsections 4(6) and 4(7) MCA to determine continuation decisions is indefensible because the practice is no longer clinically indicated on the basis that such patients are likely inner-aware (bodily integrity), and that it fails to answer whether such patients are persons and if they are autonomous (conflation issue).²⁵⁵ Continuing to do so not only ignores inherent epistemic limitations of “knowing” patients’ wishes, it paradoxically implies that patients are autonomous, yet denies their capacity for inner awareness/ responsiveness (autonomy) and overlooks that bodily integrity is the proper doctrinal basis for such decisions.²⁵⁶ Additionally, the fact that disorders of consciousness are more accurately described as responsiveness (communication) disorders, begs the question of why withdrawal is clinically indicated:²⁵⁷ lack of awareness is what made the practice seem clinically indicated yet such patients are not accurately “non or minimally aware”.²⁵⁸ Finally, the practice supports the view that such patients can permissibly be treated as non-persons, as evidenced by the noted various instances of abuse in Chapters Three and Four.

Ultimately, PDOC patients’ treatment as non-persons likely arises due to an implicit extension of the definition and determination of death as the loss of voluntary responsiveness, where such treatment is considered futile. Moreover, this definition and determination of death has no appropriate legal or medical safeguarding, which explains why other cognitively, and even mentally impaired patients can also have other less invasive forms of life-supporting treatment “justifiably” withdrawn on the presumption that continued treatment amounts to assault. It also possibly explains why life support withdrawal is thought distinguishable from non-voluntary forms of euthanasia;²⁵⁹ as the common adage goes, “how can one kill that which is already “dead”?

²⁵⁴ The evidence supporting this assertion is discussed in Chapter Four, Subsection 4.3.2.

²⁵⁵ In the sense of being sentient and “conscious”, as drawn from the collective findings of Chapter Two, Section 2.3; Chapter Three, Section 3.4 and Chapter Four, Sections 4.3 and 4.4.

²⁵⁶ As discussed in Chapter Four, Sections 4.3 and 4.4.

²⁵⁷ As explored in Chapter Two, Section 2.3.

²⁵⁸ *Bland* [1993] (n 11).

²⁵⁹ As discussed by Lord Goff in *Bland* [1993] (n 11) at page 865, and explored in Chapter Three, Subsection 3.2.3.

Finally, the current legal and medical standard of decision-making does not meet the requirements of section 4 MCA's decision-making requirements or *Bolitho*'s medical decision-making standard. Consequently, as there is no medical reason for questioning continuation, how can a doctor's duty of care be appropriately discharged to enable discontinuation?²⁶⁰ The evidence in Chapter Two demonstrated a positive balance in favour of continuing on the basis that these bodily integrity cases cannot demonstrate such patients are non-aware, and thus cannot be defined as futile/ dead without explicit recognition that death has been redefined and such patients are morally and legally "dead". Consequently, how can doctors distinguish the practice from subsection 4(5) MCA (to prove withdrawal is not 'motivated by a desire to bring about the patient's death'). Likewise, if doctors fail to change their practice in light of the fact that such patients cannot be accurately described as non-aware and that such a justification is also morally questionable as a definition of death, how can they be meeting the requirements for the section 5 MCA defence or *Bolitho*'s standard of decision-making?²⁶¹ Moreover, there is scope to suggest that the use of the current best interests test to determine continuation is indefensible because it is based on a misguided interpretation of "equality" which does not meet the CRPD's interpretation of the concept.²⁶² Consequently, it is possible that a *prima facie* finding of indirect discrimination will in future be brought against the best interests test's use in such cases.²⁶³

This thesis has demonstrated that it is possible that the often-noted moral inconsistency²⁶⁴ in such cases derives from an unacknowledged and implicit extension of how death is defined and determined to those with severe cognitive disability. The findings have also shown that it possibly extends further beyond PDOC patients and into other cognitively and mentally impaired persons' medical treatment.²⁶⁵ The definition and determination of death and its basis as the concept of futility/ discharging a duty of care is

²⁶⁰ As rationalised in *Bland* [1993] (n 11).

²⁶¹ The *Bolitho* [1998] (n 192) standard of medical decision-making was discussed in Chapter One, Subsection 1.3.3.

²⁶² As discussed in Chapter Four, Sections 4.2 and 4.4.

²⁶³ A key finding of Chapter Four, Section 4.4.

²⁶⁴ Coggon 2007 (n 194); Andrew McGee, 'Finding a Way Through the Ethical and Legal Maze: Withdrawal of Medical Treatment and Euthanasia' (2005) 13 Medical Law Review 357; Keown 1997 (n 227); John M Finnis, 'Bland: Crossing the Rubicon?' (1993) 109 Law Quarterly Review 329.

²⁶⁵ As discussed in Chapter Four, Section 4.2 and Section 5.3 (of Chapter Five).

therefore in desperate need of reappraisal if medicine and law choose to maintain the position that cognitively (and mentally impaired) individuals are legal persons.

Consequently, E&W's current medical and legal interpretation of futility (death) is precariously tied to cognitive (and possibly mental) impairment and the unmeasurable concept of awareness.

This thesis has attempted to further several aspects of the debates around PDOC patients' continuation decisions. From a philosophical perspective it has acknowledged the often-noted moral inconsistency²⁶⁶ at the heart of such cases and has attempted to resolve the inconsistency from a different perspective. Instead of focussing on whether the moral inconsistency can be better explained by reference to acts versus omissions, intention or causation, it has focused on the philosophical distinction between moral conflicts and dilemmas.²⁶⁷ In doing so, it has brought the moral inconsistency debate at least a step closer to answering how such cases could be resolved, steering away from fundamentally incommensurable moral values and by looking at cognitive disability's underlying ties to futility, personhood and consequently how death is defined and determined.²⁶⁸ In that sense, it has possibly pushed the literature further still, and consequently Harris' argument that *Bland* can only be resolved by reference to personhood theory seems more plausible than the attention it has received in the literature.²⁶⁹

This thesis has demonstrated that death's personhood-based definition and determination deserves greater attention if E&W law are to appropriately protect PDOC patients' deserving status as persons. Consequently, those developments led to the exploration of the debates on disability rights which demonstrated that although the CRPD is limited as a 'politically negotiated text',²⁷⁰ further analysis suggests that its interpretation of equality has the potential to reinstate cognitively impaired persons'

²⁶⁶ Coggon 2007 (n 194); McGee 2005 (n 264); Keown (1997) (n 264); Finnis (n 264).

²⁶⁷ Discussed in Chapter One, Section 1.4 and Section 5.3 (Chapter Five).

²⁶⁸ As discussed in Chapter Three, Section 3.2.

²⁶⁹ Harris 1999 (n 20).

²⁷⁰ Kayess and French (n 24) 33; Amita Dhanda, 'Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future' (2007) 34 Syracuse Journal of International Law and Commerce 429.

Chapter 5

personhood status in law.²⁷¹ This is because its universalist interpretation of equality has the potential to challenge the law's interpretation of "human being" as "only those with the capacity to reason (voluntarily respond) are legal persons",²⁷² by divorcing cognition from legal capacity,²⁷³ and consequently personhood entirely.²⁷⁴ Finally, it has suggested a possible way to create an appropriate balance via existing legal instruments and processes.²⁷⁵ That balance should permit discontinuation from those who would rather have life support withdrawn (even with knowledge that they may be inner-aware) and better protect the lives of those PDOC patients who would want treatment to continue.²⁷⁶

The thesis therefore unpicks the currently adopted 'theory of social justice'²⁷⁷ to present other options and briefly outline the foreseeable consequences of not making a choice. I argue that the choice is clear, loss of personhood is no longer an option even if it was previously thought defensible. The facts seem to be that the medical evidence has moved on and the impact has been too far reaching.²⁷⁸ The starting legal presumption needs to be challenged and this thesis's evidence does just that by demonstrating that the presumption has not been established on *Bolitho*'s doctrinal basis for protecting patients' bodily integrity, because such patients' inner awareness means continued treatment cannot be questioned on the basis of thought non or minimal awareness. Consequently, the current definition and determination of death is in desperate need of reappraisal. Whatever the choice, a choice must be made: are patients with prolonged disorders of consciousness to be respected as human beings, let alone legal persons, or not?

END

²⁷¹ As discussed in Chapter Four, Section 4.2.

²⁷² As discussed in Chapter One, Subsection 1.4.4.

²⁷³ Eilionóir Flynn and Anna Arstein-Kerslake, 'Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity' (2014) 10 (1) International Journal of Law in Context 81, 81.

²⁷⁴ See Chapter Four, Subsection 4.2.2, where an outright denial of personhood is defined as frequent denials of different if not all forms of legal capacity.

²⁷⁵ As explored in Chapter Four, Section 4.3.

²⁷⁶ *ibid* and reiterated above in Subsection 5.3.1.

²⁷⁷ Quinn 2011 (n 215) 59 (paraphrasing).

²⁷⁸ This conclusion is based on the collective findings of Chapter Two, Sections 2.3 and 2.4; Chapter Three, Sections 3.2 and 3.4; Chapter Four, Sections 4.2 and 4.3. And is reiterated in Section 5.3.

Glossary of Terms

Advance Decision (AD) or an advance decision to refuse treatment (ADHRT), is a legal instrument that allows an individual to prospectively refuse a specific type of treatment that they may medically require in the future. If specific formalities are followed under the Mental Capacity Act 2005, these can also be used to refuse life-supporting treatment.

Advance planning is a collective term for a legal power of attorney, advance decision (to refuse treatment) and advance statement.

Advance statement is a relatively new form of advance planning and records the broader wishes of the patient to be considered by healthcare and care staff, note that for refusals of treatment an AD is more appropriate.

Aetiology is spelt etiology in the US, and is the cause of origin of the disease, disorder, illness or condition.

Autonomy is a moral value that is heavily qualified in PDOC patients' declaratory relief cases and is likened to welfare interests, as opposed to self-determination or even informed consent.

Apnea is the US spelling of apnoea, and is the medical terminology for short-term interruption of breathing, especially during sleep as occurs in sleep apnoea.

Apraxia is an inability to make voluntary motor movements.

Brain herniation occurs when severe pressure within the skull pushes or squeezes the brain across other structures within the skull.

Causation is a legal concept which traces the harm sustained to the guilty or negligent party. A break in the chain of causation caused by an intervening event (see *novus actus interveniens*) will mean that responsibility for the harm sustained cannot be established for the accused party.

Cerebrospinal fluid is a clear body fluid found in the brain and spinal cord. The fluid protects the brain from injury, supplies nutrients to nerve tissue and removes waste.

Glossary of Terms

Circulatory stasis is a slowing or stoppage of blood flow.

Constructive Manslaughter is where the defendant lacks the specific intent for murder but has killed as a result of an unlawful and dangerous act. It differs from gross negligence manslaughter where there is no specific intent to kill but killing has occurred as a result of a lawful act.

Cortical blindness is caused by a lesion in the visual cortex. It can be temporary or permanent, and some patients are unaware of their blindness due to neurological miscommunication.

Death behaviours are practices and procedures that are undertaken just before, during, or after a human being dies, or is defined as dead. In this thesis, I restrict death behaviours to those practices and procedures that occur only after the patient is deemed to have lost significant moral standing, such as vital organ donation and life support withdrawal, among others.

Dementia is an umbrella term for different diseases that cause problems with thinking, memory, reasoning, perception and language. For example, Alzheimer's disease and dementia with Lewy bodies are categorised under the umbrella term dementia.

Doctor is used loosely to refer to the relevant healthcare practitioner in a specific context. Where specificity is required that particular healthcare practitioner is mentioned i.e., neurologist or nurse.

Decerebrate spasms are caused by brainstem damage which induces muscle rigidity and unnatural posture in the patient.

Declaratory relief proceedings are a particular type of legal judgment that seeks to resolve uncertainties for the litigants as opposed to determining fault.

Disaggregator theory or "disaggregators" propound(s) the view that certain death behaviours can be stripped away from the moment of death, and thereby are morally permissible before biological death occurs.

Do not attempt cardiopulmonary resuscitation (DNACPR) is a non-legally binding document placed on a patient's file to guide medical professionals on whether to attempt

resuscitation or not, should the patient suffer from cardiac arrest. This is necessary because resuscitation can cause significant harm to the patient and should therefore not always be attempted. The request is made in advance by the patient and their doctor, or with other healthcare team members.

Electroencephalography (EEG) is a test that monitors electrical activity of the brain.

Epinephrine is more commonly known as adrenaline and is a hormone and medication which narrows blood vessels.

Euthanasia is the deliberate act of killing another. It differs from assisted suicide where the individual takes their own life with assistance. There are three types of euthanasia. Voluntary euthanasia occurs where the victim consents and requests to be killed. Involuntary euthanasia occurs where the individual does not consent and is therefore conducted directly against their will. Non-voluntary euthanasia occurs where explicit consent is unavailable i.e., comatose, vegetative state patients or minors.

Essentialism is the study of the fundamental properties a being or thing must possess to be that being or thing. To do so, the investigation discriminates between essential (vital properties) and accidental (additional but non-defining) properties.

fMRI (functional magnetic resonance imaging) is a type of medical scan that can map brain activity by demonstrating where blood supply increases around areas of neural activity, thus creating a map or the ability to see patients' inner awareness.

Gestate is a biological term referring to the development of the foetus in the womb from conception to birth.

Global aphasia is the most serious form of aphasia and is where the patient has difficulty speaking and understanding words. It also affects the ability to read and write.

Guillain-Barré is a rare condition where the immune system attacks the nerves. In serious cases it can cause an inability to move, speak or swallow.

Independent Mental Capacity Advocate (IMCA) is a specially trained individual who supports another who is unable to make decisions for themselves and where that individual does not have family or friends who are able to speak for them.

Glossary of Terms

Infarction is where blood clots or other obstructions to the blood supply limit oxygen intake, leading to the death of local tissue.

Intracranial means within the skull.

Ischemia is a condition where blood supply is restricted to a particular part of the body.

Lazarus sign is movement seen in brain or brainstem dead patients where the patient briefly, and reflexively, raises and drops their arms crossed over their chest.

Le coma dépassé is a permanent coma and the original name for brain death.

Legal capacity is context specific meaning that its exercise can be restricted in law. Two conceptualisations of legal capacity have been found to be conflated in the literature: legally recognised liberty (freedom to and freedom from) and competence, also known as mental capacity. I assert the existence of a third, self-exercisable agency.

Legalists are theorists who argue that personhood is a status that has removed any hint of morality.

Legal Power of Attorney (LPA) is an instrument that permits a nominated representative (Legal Power of Attorney) to execute specified decisions on behalf of an individual who has now lost the capacity to do so themselves.

Locus standi is the capacity to bring a claim or action in court because the individual(s) or company are said to hold a sufficiently proximate connection to the harm sustained.

Mechanical ventilation is a medical technology that assists and replaces the function of spontaneous breathing.

Moral agent(s) are decision-makers and actors employing moral philosophical concepts and processes to ultimately decide on a course of action. The term is simultaneously used with moral reasoners or decision-making agents.

Moral conflict(s) occur where two moral values conflict with each other. They are, unlike genuine dilemmas, resolvable.

Moral dilemma(s) occur only where two ought requirements are conflicting. For example, the agent must but cannot complete both demands, and in the case of a negative dilemma, cannot perform the two forbidden actions demanded of them.

Moral precept is a moral rule from a larger moral code such as Christian morality, that guides a moral agent on what to do in a particular situation. It is also conceptually similar to a moral value such as sanctity of life e.g., the Christian precept of "do not kill". The difference between a value and a precept is therefore that a precept is identifiable as being from a specific code.

Moral requirement is a philosophical concept indicating, in a strong binding sense, that a moral agent act on it. It is used synonymously with Henry Sidgwick's phrasing of "ought statement".

Moral standing means to hold moral interests and therefore that the being in question should not be harmed.

Moral Strangers is a term borrowed from H Tristram Engelhardt and is used to denote members of different moral communities who do not share the same view on morality.

Moral Values is a concept used in this thesis to describe an umbrella term of precepts that can be grouped together. For example, moral precepts such as "do not kill" and more generally "do not steal" would come under "do no harm" or the commonly recognised moral value of non-maleficence.

Mores are customs or conventions of a society or community.

Naturalists believe that personhood should be given to any living being with sentience.

Necrosed tissue is the premature death of cells and cell tissue due to an interruption of their oxygen supply.

Neural correlates (of consciousness) are the minimum number of neural events that have to occur to manifest consciousness, or conscious experience.

Neuropathology is the study of diseases (or disorders) of the nervous system.

Nihilism a philosophical theory that rejects all moral and religious values or precepts, a belief that nothing has meaning or significance.

Glossary of Terms

Non-universal morality is a set of norms or code of ethics particular to a moral community such as a professional ethics codes.

Novus actus interveniens is a Latin term used in law to describe an intervening act or event that occurs after the defendant's act, which exacerbates the loss or harm suffered by the victim. Such an act breaks the chain of causation between the act committed by the defendant and the harm suffered by the victim.

Ontology is essentially the study of, or search for objective existence outside of consciousness or perception, and how these "things" in existence relate to each other, a conventional example of an ontological question in philosophy is: "is there a God?"

Personhood is a status held by those holding the valued characteristic of human life and are therefore deemed worthy of legal and moral respect and protection. Such individuals are consequently endowed with legal capacity.

Phenomenology is the study of or search for knowledge derived from conscious experience and awareness of the world around us. This study of existence and knowing what exists and how therefore relies on perception.

Pseudobulbar palsy results in impairment of voluntary movements of tongue and facial muscles, and rapid or exaggerated emotional reactions.

Rational calculus is employed in moral philosophy to weigh competing moral values against each other to arrive at an ought statement on the most defensible course of action. The calculus will normally have a defined end or "good" that it is seeking to achieve in any given assessment.

Religionists are those who believe that personhood is endowed on humans because they are ensouled beings.

Shared decision-making is where a person is supported to make a decision based on their will and preferences rather than objective interests based on what another thinks is best for them. The possible forms of support are non-exhaustive, and the person is also free to reject any offered support if they so wish.

Somaticism is a brain death theory that propounds that the brain is the central integrating organ of the human body, connecting the mind and body (soma) together. To its proponents, the death of the brain is the same as traditionally diagnosed cardiopulmonary death because of the brainstem's connection to the phrenic nerve which plays an integral role in the capacity to breathe.

Spastic quadriplegia can occur as a result of brain damage where all four limbs, and the trunk and face are affected. It results in abnormal posture and impaired motor movement.

Substituted decision-making is where legal capacity is removed from a person by someone not appointed by the individual to make that decision and where the decision is made on the basis of what the substituted decision-maker believes is in the objective best interests of the person, and not on the basis of their own will and preferences. It can also occur in respect of a single decision.

Supraccritical damage means damage above a critical threshold and is therefore life-threatening.

Trauma is a severe or life-threatening injury caused by sudden impact.

Universal morality is a set of norms on right or wrong conduct that is so widely shared that they form a stable social pact.

Vasopressin is a hormone and medication which regulates the solute to water ratio of body fluids by causing the kidneys to reabsorb excess water lost from around cells.

Glossary of Terms

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