Beyond the "right to die" and the "right to life" debate in Disorders of Consciousness: Reframing the ethical concerns through the writings of Paul Ricoeur

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Contents

Abstract

Much of the discussion of the ethical concerns involved in the care of those with Disorders of Consciousness (DOC) has been presented in terms of the dichotomous “right to die” / “right to life” (RTD/RTL) framework with nearly singular focus on (1) assessing whether the individual retains “consciousness,” and (2) making the “right” choices about the use of life sustaining treatments (LSTs). However, the lived experience of the family, friends and medical providers who have close contact with individuals with a DOC indicates that the ethical concerns involved cannot be reduced to the RTD/RTL framework, to proofs of consciousness, or to the right to make choices about treatment. Rather than advocate for a “right” choice in regards to use of LST in those with DOC, this essay utilizes the writings of Paul Ricoeur to illuminate the sources of our ethical confusion and to engage in deeper ethical reflection. I describe DOC from the perspective of neuroscience and review recent research. I then critique conceptions of autonomy and personhood within medical ethics, especially in so far as a model of consumer choice dominates conceptions of autonomy and cognitive capacity is considered a determinant of moral worth. I present Ricoeur’s understanding of autonomy as a relational project and his description of individuals as capable and fragile in varying degrees as an alternative. I proceed by examining the concepts of “sanctity of life” and “pain and suffering,” where I use Ricoeur’s description of all humans as acting and suffering, and his description of solicitude as the model for responding to suffering. I conclude with Ricoeur’s description of the ethical intention of “*aiming at the ‘good life,’ with and for others, in just institutions*” as an approach to analyzing ethical dilemmas and clarifying what it is at stake in various alternatives.

La majorité des débats portant sur les préoccupations éthiques quant au traitement des personnes atteintes de désordres de la conscience est présentée en fonction d’une classification dichotomique : « droit de mourir/droit de vivre », en se concentrant principalement sur (1) une évaluation pour savoir si l’individu demeure « conscient », et sur (2) la « bonne » prise de décision concernant l’utilisation de traitements de survie. Toutefois, les expériences vécues par la famille, les amis et le personnel médical, qui entretiennent un lien étroit avec l’individu atteint de désordres de la conscience, indiquent que les questions éthiques que cela comporte ne peuvent être réduites au schéma « droit de mourir/droit de vivre », ni à des preuves d’un état de conscience, ni au droit de faire des choix en ce qui concerne les soins administrés. Plutôt que de prôner un « bon » choix par rapport à l'utilisation des traitements de survie pour les personnes atteintes de désordres de la conscience, cette thèse se sert des écrits de Paul Ricœur pour éclairer les sources de notre imbroglio éthique et pour nous engager dans des réflexions éthiques plus profondes. Je décrirai les désordres de la conscience sous une approche neuroscientifique et par rapport à des résultats de recherches récentes. Je ferai ensuite la critique des conceptions de l'autonomie et de l'identité individuelle au sein de l'éthique médicale, en particulier dans la mesure où un modèle de choix de consommation prédomine dans les conceptions d'autonomie et de capacité cognitive, considéré comme étant un facteur déterminant de valeur morale. Je présenterai la conception de Ricœur sur l'autonomie en tant que projet relationnel ainsi que sa description des individus, tout aussi aptes que fragiles à différents niveaux, comme une solution. Je poursuivrai en examinant les concepts de « caractère sacré de la vie » et de « souffrance et douleur », où je me servirai de la description de Ricœur à propos de l'humain agissant et souffrant, tout comme sa description de la sollicitude en réponse à la souffrance. Je conclurai avec une description de Ricœur à propos de l'intention éthique sur « la visée de la vie bonne, avec et pour les autres, dans des institutions justes » comme approche pour analyser ces dilemmes éthiques et éclaircir ce qui est en jeu par rapport aux différentes solutions existantes.

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Introduction

As a hospital chaplain I sat with many family members and medical providers engaged in the task of making decisions about what medical care would best serve a severely injured or critically ill patient. Some of the most fraught situations I encountered involved patients who were severely brain-injured, in part because, in addition to evoking sadness, anger, grief, and fear, which are often felt by the family members of one who is critically ill or injured, sudden and severe brain injury also evoked profound bewilderment. Bewilderment involves an experience of losing one's bearings, a sense of disorientation. I witnessed families of severely brain injured individuals face an especially pronounced bewilderment because, not only were their everyday routines and sense of stability upended, their experience of the patient (to them, partner/spouse, child, sibling, parent or friend) as an integrated whole person was suddenly disrupted. Even specialists in neuroscience and neurology at times express bewilderment in response to Disorders of Consciousness (DOC)*. Robert T. Knight, writes:

> As clinicians we venture into the grey zone of the meaning and importance of consciousness when we are faced with diagnosis of the vegetative state (VS)* or the minimally conscious state (MCS)* . . . the key issue from the neurologist's perspective is whether the neurological insult . . . will leave any meaningful brain function. So, it is not clear if the key issue is 'consciousness' or the clinical experience with these patients per long-term recovery of 'meaningful' life. Of course, meaningful is as poorly defined as consciousness and herein lies the quandary (Knight, 2008, p. 1).

Going "into the grey zone" describes well the sense of bewilderment experienced by the families I encountered. William H. Colby, the lawyer who represented the Cruzan family in their legal battle to have the feeding tube removed from their daughter Nancy, diagnosed as being in a persistent vegetative state (PVS)*, later responded to the case of Terri Schiavo, a woman diagnosed as being in a PVS whose parents and husband disagreed about the removal of her feeding tube*: "From years of working on cases like *Schiavo*, I realize that at a very basic level it is impossible for us to understand – in any real way – what either the Schiavo [Terri's husband] or Schindler [Terri's parents] families have endured. Families I've talked with who *can* understand, like the Cruzans . . . watched the news coverage of this fractured family and picked no side. Their hearts went out to parents and husband alike" (Colby, 2006). But this "grey zone" experience is rarely expressed in the media or discussed in the public forum where the complexity is simplified and solidified into the black and white framework of the "right to die" and the "right to life" (RTD/RTL) debate; a debate which in the US in particular is highly politicized (Ball, 2012; CMAJ Editorial, 2005; Fins, 2006; J. Perry & Bishop, 2010a; J. E. Perry, 2006). At times this simplistic, politicized framework also pervades treatment decision-making as it occurs between families and medical providers (Racine, 2010; Spielman, 1995).

Our individual values, preferences and choices and our "right" to have our choices about medical care respected are important, and efforts aimed at helping individuals articulate in advance their medical treatment preferences in case of major illness or injury should continue to

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* throughout an asterisk (*) indicates a term can be found the list of Terms and Abbreviations. When a term is used multiple times, the asterisk will appear only next to the first usage of the term.

be pursued. However, we live our lives communally, and institutions whose values are communally (though not always intentionally) constructed, mediate individual preferences and choices about medical care. What medical treatments or supportive care will be offered to individuals is in part formed and controlled by the normative values of the institution of medicine: whether and what type of research is performed on particular illnesses, the impact specific research findings have on clinical medicine, and what treatments, interventions, or supportive care medical insurance (public or private) will cover, directs, limits and controls the choices that can be made by individuals about their own, or, if serving as surrogate decision-maker, another's care. Even evidence-based medicine*, which often presents itself as offering a empirically based approach to medical care that is normatively neutral, in fact, embodies certain values and serves a normative function (Rogers, 2005; Vos, Houtepen, & Horstman, 2002).

In an essay titled "Interpreting Situations: An Inquiry into the Nature of Practical Theology" the theologian Edward Farley argues that the interpretation of situations must be "self-conscious, self-critical and disciplined" as opposed to inattentive (Farley, 1987, p. 10). Accordingly, he describes four key tasks in the "hermeneutic task of interpreting situations" (Farley, 1987, p. 11). Though he describes his approach as theological and acknowledges he draws on modern approaches to biblical interpretation, the tasks of interpretation he describes prove useful far beyond the field of theology. I use Farley's four tasks as a guide for reframing the ethical questions involved in the care of those with DOC; these are: (1) identify the situation by describing its "distinctive and constituent features" (2) recover elements that have been "repressed" or "forgotten" in attempts to simplify the situation", (3) "correct the abstraction committed by the focus on a single situation" and reflect on the "larger and longer" context (termed "intersituational" by Farley), (4) discern what responses the situation demands (Farley, 1987, pp. 11-14). Farley cautions that this final task is the most difficult because "situations pose to human beings occasions for idolatry and redemption" (Farley, 1987, p. 14). To translate Farley's caution into non-theological language one might say that situations pose the occasion to cling to unanalyzed constructs or to embrace a more expansive and complex vision. In each of my first three chapters, I "interpret" different aspects of the situation of the care of those with DOC by proceeding through Farley's first three tasks; in the fourth chapter and conclusion I turn to discerning what the situation as whole demands. Ultimately, I argue that the construct of individual "rights" as the primary foundation for medical decision making in DOC encourages oversimplification and contains underlying normative assumptions that ought to be questioned; as an alternative I present Paul Ricoeur's description of "*aiming at the 'good life' with and for others, in just institutions"* as a more nuanced view.

In the first chapter I review the current neuroscience literature, attending especially to recent functional neuroimaging and electrophysiology studies that are challenging traditional understandings. I do so because DOC have often been misrepresented in public discussion and because an adequate understanding of the state of knowledge about these conditions is necessary to fully address the ethical issues involved in the care of these patients (Colby, 2006; Fins, 2009, 2013; Latronico, Manenti, Baini, & Rasulo, 2011; J. Perry & Bishop, 2010a; J. E. Perry, 2006; Racine, Amaram, Seidler, Karczewska, & Illes, 2008; Racine, Bar-Ilan, & Illes, 2005; Racine & Bell, 2008; Solarino, Bruno, Frati, Dell'erba, & Frati, 2011). I will describe differences of opinion amongst providers and between providers and loved ones regarding the level of awareness and the quality of life experienced by DOC patients, including assessment of the quality and degree of pleasure experienced (if any), the degree of pain and suffering experienced (if any), and the possibility for "meaningful" experience (if any), and I will address related disagreements regarding how to best care for these individuals. In particular I will describe the complex ways in which research on pain perception and beliefs about whether those in DOC consciously feel pain are tied to opinions about withholding/withdrawing[1] long-term provision of life sustaining treatments (LST)*[2], especially Artificial Nutrition and

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[1] In general in secular North American medical ethics, there is no ethical nor legal distinction made between withdrawing versus withholding medical treatments (American Medical Association, 1996; Canadian Medical Association, 2013). However, there is research showing that for families and for healthcare workers the acts of withholding and withdrawing are experienced differently and therefore should be treated differently (Levin & Sprung, 2005). Additionally, there are specialized branches of medical ethics, for example, Jewish medical ethics, in which an ethical distinction is clearly made between withholding and withdrawing treatments (Kinzbrunner, 2004).

[2] I use the term life-sustaining treatment (LST) as defined by the American Medical Association (AMA) to refer to "medical treatments that prolong life without reversing the underlying medical condition" (American Medical Association, 1992, p. 2229). Some professional medical organizations define LST differently, for example, the Canadian Medical Association (CMA) defines an LST as: "any medical procedure which utilizes mechanical or other artificial means to sustain, restore, or supplant a vital function for a condition that could be either reversible (the person will eventually recover to a point where the intervention will no longer be required in order to sustain life) or irreversible in nature (the person will never be able to survive without the life-sustaining intervention). [LST] can include, but are not limited to, mechanical ventilation and medically assisted nutrition and hydration" (Canadian Medical Association, 2013). There is no terminology for such interventions that is wholly unproblematic in that all such terms carry underlying normative assumptions and may be variably defined and understood (Rodriguez & Young, 2006). I do not use the term "life support" because it has often been associated more specifically with mechanical interventions such as ventilation, and because many prominent organizations,

Hydration (ANH)/Medically Assisted Nutrition and Hydration (MANH)*[3]. I focus on pain perception, because whether those in DOC can feel pain, and, if so, how their experience of pain can be accurately assessed, has directly clinical applications, and because, as I will describe in chapter three, I believe the complex nature of concepts of pain and suffering has not been adequately addressed in public discussion of DOC.

In the second chapter I analyze conceptions of autonomy as they are typically interpreted within the principle of "respect for autonomy" that is prevalent within North American Bioethics. I argue that the dominant conception of autonomy underlying respect for autonomy in medicine conceives of individuals as primarily isolated, rational, and self-interested, and as in the role of "consumers." I then present critiques from feminist ethics that present a more expansive conception of autonomy that some label, "relational autonomy." I conclude my analysis of autonomy by presenting Ricoeur's understanding of autonomy as a relational project and his description of humans as capable and fragile in varying degrees. Ricoeur draws the focus away from rational reflection and describes autonomy as exercised through the basic capacities to speak, act, and narrate our own stories; I propose this more nuanced reflection as an alternative to the overriding focus on decisional capacity and the right to make choices about medical treatments. In the second section of the chapter I address notions of personhood, critiquing those that describe cognitive capacity as the sole feature of personhood and as a determinant of moral worth. I conclude each section with reflections on how those with DOC and their family members are impacted by these conceptions and argue that the lived experience of these individuals must guide our approach to care.

As I describe in chapter one, the potential for those with DOC to experience pain and suffering concerns the family members of these patients as well as medical providers. In the public forum, the "right to life" is often associated with the notion of the "sanctity of life," and "the right to die" is often associated with the right to be free of unbearable pain and suffering.

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including the AMA and the CMA, use the term LST. I do not use the term "life-prolonging treatment" because I interpret the word "prolonging" to imply a more strongly value-negative assessment of the use of these treatments.

[3] Here I use the terms Artificial Nutrition and Hydration (ANH)/Medically Assisted Nutrition/Hydration (MANH) together to acknowledge that both terms are used. However, ANH is the most prominently used term within North American medical contexts; I will Use ANH through the rest of the essay. Families as well as healthcare workers often think and feel differently about ANH than other LST. The Roman Catholic Church in particular has argued that ANH constitutes the provision of "food and water," and is not a medical act. It is not my purpose to argue a particular stance on how ANH ought to be defined. Both the AMA and CMA consider it to be a type of LST; for further information about Roman Catholic perspectives on this issue see: (Bishop & Bedford, 2011; Brody et al., 2011; Tollefsen, 2008; Zientek, 2013).

In the third chapter I analyze the "sanctity of life" and "pain and suffering" as they find expression in clinical medicine and in Christian theology. I argue that for those who are close to individuals with DOC these concepts are particularly complex. This complexity can be seen in ambivalence about DOC patients' ontological status and confusion about whether they can experience pain and suffering. I place the lived experience of those close to someone with a DOC, including my own experience with a patient in MCS, as the central point of analysis.

In the fourth chapter I analyze more fully Ricoeur's description of selfhood. I focus on his understanding of "otherness" (the otherness of one's own body and that of other people) as constitutive of selfhood, his critique of reducing identity to "sameness," and his description of identity as a "dialectic of sameness and selfhood" (Ricoeur, 1992b, p. 18). I return to his view of human persons as "acting and suffering" (capable and vulnerable) and consider in depth his description of "solicitude" as essential to the ethical intention of "*aiming at the 'good life', with and for others, in just institutions,*" (Ricoeur, 1992b, p. 172). Finally, I apply his description of selfhood to DOC and argue that it is fruitful for understanding the roots of our ambivalence regarding the ontological status of those in DOC, and that it encourages us, despite our ambivalence, to relate to those with DOC as humans with moral status.

I conclude by arguing that we should not use lack of personhood or selfhood as ethical justifications for withholding/withdrawing LSTs in those with DOC. Attempts to diagnosis consciousness should be avoided, because the concept itself is too nebulous, and new evidence will continue to complicate our understanding of the relationship between brain function and behavior. Questions about how to best care for those with DOC are ethically, philosophically and theologically complex, in part, because such questions are inextricably tied to individuals' differing beliefs and convictions about life, death, love and suffering. Any attempts to "solve" the ethical dilemmas involved or declare a "correct" answer will feel right to some and not to others, and will hide rather than honestly attest to the complexities involved. I close by encouraging continued engagement with the questions involved and propose Ricoeur's ethics of argumentation in civil discourse as model for this engagement.

Chapter 1: Disorders of Consciousness (DOC) in Neuroscience: Past Understandings and Recent Research

DOC: Terminology, Diagnostic Criteria, and Prognosis

Progress in critical care medicine enables increasing numbers of individuals to be kept alive following severe traumatic and non-traumatic brain injuries. For a number of reasons clinically managing these individuals is particularly difficult: (1) brain injury usually happens suddenly, (2) it often occurs in the young and previously healthy who have not engaged in advanced healthcare planning or described to family and friends their preferences for medical treatment in the case of severe injury, (3) early aggressive treatment can save individuals lives and lead to significant recovery; it can also save their lives but leave them in states in which their physical, intellectual and relational capacities are severely limited, sometimes to the point of seemingly lacking even limited awareness of self and environment, (4) decisions regarding medical treatment must be made in a context of considerable prognostic uncertainty, especially soon after injury, and (5) withholding or withdrawing LSTs will typically result in death if withdrawn early post-injury, but decisions to pursue LSTs can lead to outcomes considered by many to be undesirable or even tragic (Bernat, 2004; Holloway, Gramling, & Kelly, 2013; J. Kitzinger & Kitzinger, 2013; Racine, 2010; Rubinstein, 2009; Smith, 2012; Turgeon et al., 2011).

Terminology

Often severe brain injury will initially result in coma, a state of eyes-closed unconsciousness in which the individual cannot be aroused to wakefulness by stimuli, even painful stimuli; coma is a temporary condition that rarely lasts beyond four weeks (comas lasting beyond four weeks usually involves metabolic dysfunction) (Bernat, 2008; Racine, 2010). Over time some individuals recover substantially, even eventually functioning at close to their pre-injury state, while others recover to states of chronic unawareness/unresponsiveness [4] or limited awareness/responsiveness; these states are described as disorders of consciousness (DOC). It is important to note that "consciousness" as a neurologic concept in the clinical care

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[4] I use the dual terms "unawareness/unresponsiveness" because in some localities "responsiveness" rather than "awareness" has been the preferred term, in part because many argue that responsiveness is less subjective. "Awareness" in DOC has traditionally been a word used to describe the capacity of the individual to behaviorally express *intentional responses*. As will be described below recent studies using functional neuroimaging has revealed a more complex picture in which a small percentage of those who cannot behaviorally express intentional responses, may be able to do so via functional imaging in a limited capacity.

of the brain injured differs from the discussion of the nature of consciousness as it occurs in philosophical and religious traditions; in clinical neurology and neurosurgery consciousness is considered a "two-fold concept defined by wakefulness and awareness" (Racine, 2010, p. 141). Niall Cartlidge explains:

> Consciousness is a state characterized by awareness of self and environment and an ability to respond to environmental factors. Normal consciousness can be regarded as having two separate but closely interrelated components. The first of these is the arousal component of wakefulness. It is this that keeps the patient awake and which relates to the physical manifestations of awakening from sleep—for example, eyes being open, motor activity. The second component is the content of consciousness or the awareness of self and environment. This consists of the sum of psychological functions of sensations, emotions, and thoughts (Cartlidge, 2001, p. i18).

The two primary diagnostic subcategories of chronic DOC are vegetative state (VS)/Unresponsive Wakefulness Syndrome (UWS) and minimally conscious state (MCS) (coma, though defined as a DOC, does not persist chronically). While VS/UWS and MCS in some cases become chronic syndromes, they also can be acute diagnostic stages that patients progress through in a process of recovery (Bernat, 2006).

Diagnostic Criteria

Chronic VS/UWS is often referred to as (Persistent) Vegetative State (PVS), a term first proposed by Bryan Jennett and Fred Plum in 1972. A VS is defined as "persistent" when it persists longer than four weeks and "permanent" (irreversible) when persisting for more than one year when resulting from traumatic injury or for more than three months when resulting from non-traumatic injury (such as anoxic injury sustained during cardiac arrest) (Bernat, 2008; J. T. Giacino & Malone, 2008; The Multi-Society Task Force on PVS, 1994a; Wijdicks et al., 2006). There are a few documented case reports of late recovery suggesting that prognostic indicators stated in guidelines should not be considered absolute (J. T. Giacino & Malone, 2008; Sara et al., 2007). The abbreviation PVS confusedly has been interpreted as both "persistent" and "permanent" vegetative state; thus, some experts recommend exclusive use of the term VS, accompanied by nuanced prognostic estimates based upon an individual patient's injuries and overall physiologic state (Bernat, 2008). VS is characterized by the presence of alternating periods of wakefulness and sleep (i.e. periodic eye-opening) accompanied by postural and reflex movements, but the absence of behavioral signs of awareness or purposeful/intentional movement; it has widely come to be defined as “wakefulness without awareness” (Bernat, 2006, 2008; Jennett & Plum, 1972; The Multi-Society Task Force on PVS, 1994a). Differentiating between reflexive and purposeful movements or behavior can be very difficult, and those in VS may exhibit reflexive behaviors easily interpreted as being stimuli-responsive such as crying and grimacing. Jennett and Plum chose the term “vegetative” to describe the preservation of the vegetative (autonomous) functions of the nervous system (respiration, digestion, regulation of sleep-wake cycles, etc.) in the “absence of function in the cerebral cortex as judged behaviorally” (Bruno, Vanhaudenhuyse, Thibaut, Moonen, & Laureys, 2011; Jennett & Plum, 1972). Due to confusion regarding the meaning of the term “vegetative” and the unintended pejorative connotation which has lead these individuals to in some instances be referred to as “vegetables,” the European Task Force on DOC recommends replacing the term VS with the term *Unresponsive Wakefulness Syndrome (UWS)* (Bruno et al., 2011; Laureys et al., 2010). In some locales other terms have been used to describe VS/UWS; for example, in Australia *Post-Coma Unresponsiveness(PCU)* has been utilized (Australian Government, 2008). In order to acknowledge the current state of disagreement regarding diagnostic terminology for this syndrome, I utilize the abbreviation VS/UWS[5].

Unlike those in VS/UWS, those in a minimally conscious state (MCS) do unequivocally and repeatedly (though often only intermittently) exhibit behavioral evidence of awareness of themselves and their environment (for example through brief, sustained visual pursuit, gesturing or verbalizing “yes/no” responses to simple questions, or by following some basic commands); however, their awareness/responsiveness remains severely impaired (Bernat, 2006, 2008; J. Giacino et al., 2002). The diagnostic criteria for MCS were not published until 2002 and prior to this time clinicians tended to lump those individuals who displayed limited consciousness together with those in VS/UWS (J. T. Giacino & Malone, 2008). Recently MCS has been subdivided into MCS(PLUS) and MCS(MINUS) to account for the wide range of behavioral expression of patients in this diagnostic category; MCS(PLUS) describes those who exhibit more complex behavioral responses (Bruno et al., 2011). Some have argued that “minimally responsive state” is a more accurate term for this syndrome since responsiveness can be

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[5] When describing and quoting from studies that utilize the term (Permanent Vegetative State)PVS, I will retain their utilization of PVS. When used it will always refer to “permanent” not “persistent” VS.

measured more objectively than "awareness"; indeed, this is the term used in Australia (ACRM, 1995; Australian Government, 2008; Bernat, 2006).

It should be noted that "recovery" when employed clinically does not indicate return to previous functioning or restoration of full health as typically described in the basic dictionary definition. For example, recovery from coma indicates that the individual now exhibits spontaneous or stimuli-responsive eye-opening (Bruno et al., 2011). Recovery from VS/UWS may merely indicate that the individual intermittently shows sustained visual pursuit, a behavior consistent with the diagnosis of MCS but not VS/UWS (Bernat, 2006; J. Giacino et al., 2002; Schnakers et al., 2009). Recovery from MCS indicates that the individual can functionally communicate and/or functionally use at least two different objects, meaning that those described as having emerged from MCS may still exhibit severe cognitive disability (Bekinschtein et al., 2005; Bernat, 2006; Cruse et al., 2011; J. Giacino et al., 2002; J. Kitzinger & Kitzinger, 2013; Luaute et al., 2010; Samuel, 2013; Smith, 2012).

At times other conditions are confused with VS/UWS and MCS, especially in the popular media (Racine et al., 2008; Racine & Bell, 2008). As stated previously, coma describes a temporary state that differs from both VS/UWS and MCS. Another confounding state, Locked-in syndrome (LiS), is a syndrome in which individuals possess awareness of self and environment, but suffer from near total paralysis, usually retaining only the ability to open, elevate and depress their eyes. LiS is not a DOC; the presence of preserved cortical functioning can be detected through electroencephalography (EEG)*, neuroimaging and careful clinical observation (Cartlidge, 2001; Racine, 2010). There have been a number of individuals in LiS who have overcome the profound barriers to communication in order to express themselves, most notably, the journalist Dominique Bauby, author of *Le scaphandre et le papillon.* Confounding LiS with DOC syndromes can lead to the misinterpretation that those in DOC retain complete awareness that we simply cannot access; this is not the case (Racine, 2010).

Prognosis

Establishing prognosis can be difficult especially in the acute post-injury period, and because prognosis informs treatment decisions, including withdrawal of LST, experts in neurology and neuroethics caution against the provision of either overly optimistic or overly pessimistic prognoses. For example, a multicentre Canadian study analyzing mortality associated with withdrawal of LST following severe traumatic brain injury (TBI) concludes that caution should be used regarding early withdrawal of LST in cases of severe TBI because study results showed that a high-portion of deaths due to LST withdrawal occur within the first 72 hours despite the limited accuracy of prognostic indicators that currently exist; given there are not sufficient prognostic criteria in place this may indicate that assessments of poor prognosis are being made too early (Turgeon et al., 2011).

Experts also describe the existence of a "self-fulfilling prophecy" in which notions about futility of care lead to withdrawal of LST thus biasing predictive models; some also cite as problematic the limitation or refusal of specialized neurorehabilitation by health insurers due to criteria for "medical necessity" which can require overt evidence of behavioral responses in order to be placed in a specialized facility or require behaviorally-demonstrated improvement in order to retain placement in such a facility (Becker et al., 2001; Bernat, 2008; Fins, 2009, 2013; Rubinstein, 2009). Conversely, a qualitative study describing experiences of family members who have a severely brain-injured relative develops the theme of a "window of opportunity" for death following brain injury in which withdrawing LST other than ANH (for example mechanical ventilation*) will enable death only in the first few days following injury (because reflexive functions like breathing will recover over time) and therefore is seen by some as an opportunity for allowing death. If the "window of opportunity" is missed the patient may be left in a state that some family members describe as a 'fate worse than death' and withdrawing ANH will be necessary to allow death (J. Kitzinger & Kitzinger, 2013).

Neuroimaging: New Questions, Little Clarity

Traditionally DOC diagnoses have been made based on clinical assessment of patients' behavioral repertoires. Research suggests that even experts sometimes fail to detect signs of awareness/responsiveness in patients, and the literature on DOC describes misdiagnosis of MCS patients as being in VS/UWS as a concern (Andrews, Murphy, Munday, & Littlewood, 1996; Bernat, 2008; Bruno et al., 2011; Gantner, 2013; Racine, 2010). Measurable signs of awareness/responsiveness can be very subtle and exhibited only intermittently, and recovery from brain injury often occurs in minute steps. Patients thus need to be assessed repeatedly and over time by experts using validated methods; this can be especially problematic if patients have been moved to nursing care facilities that do not have such specialists (ACRM Brain Injury-Interdisciplinary Special Interest Group DOC Task Force, 2010; Bernat, 2006; Fins, 2013; Schnakers et al., 2009). Some research indicates that use of validated neurobehavioral assessment scales such as the Coma Recovery Scale Revised (CRS-R)* can improve diagnostic accuracy (ACRM Brain Injury-Interdisciplinary Special Interest Group DOC Task Force, 2010; Doig & Lane-Brown, 2012; Schnakers et al., 2009). The behavioral signs marking the boundary between VS/UWS and MCS can be very subtle and some experts argue that the criterion for distinguishing between the syndromes can be somewhat arbitrary (Bernat, 2006; J. Giacino, 2002). However, since the 2002 publication of the diagnostic criteria for MCS, the category has come into wider use and research reveals important differences, most notably that those in MCS have improved recovery prognosis (Bruno et al., 2011; Fins, Schiff, & Foley, 2007; Gantner, 2013; Lammi, Smith, Tate, & Taylor, 2005; Luaute et al., 2010; Schnakers et al., 2009).

In recent years EEG, positron emission tomography (PET)* and functional magnetic resonance imaging (fMRI)* have been used to identify cortical activation patterns in patients with DOC[6]. In some cases these studies reveal differences in activation patterns between those in VS/UWS and those in MCS. For example, multiple studies indicate that those in VS/UWS exhibit more limited processing of auditory and noxious stimuli and/or a lack functional connectivity compared to those in MCS (Boly et al., 2005; Boly et al., 2004; Chatelle, Majerus, Whyte, Laureys, & Schnakers, 2012; Chatelle et al., 2014). However, fMRI, PET and EEG studies have also indicated there may be a subcategory of VS/UWS patients who have limited awareness of self and environment despite the absence of observable responsiveness to stimuli. In some studies small numbers of DOC patients, including some diagnosed in VS/UWS, have exhibited “willful modulation” of cortical functioning (brain activity within the cerebral cortex, the part of the brain associated with higher functions such as voluntary movement, coordination of sensory information, learning and memory etc.) leading some researchers to assert that these individuals retain a degree of consciousness (Bruno et al., 2011; Gantner, 2013; Monti et al., 2010; Owen et al., 2006; Schnakers et al., 2009). Imaging and electrophysiology studies reveal new possibilities but they also raise ethical concerns. Consciousness remains a contested and variably defined category, and a complex and not fully understood relationship exists between brain function and subjective experience (Fisher & Appelbaum, 2010; Wilkinson, Kahane, Horne, & Savulescu, 2009; Zeman, 2008).

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[6] It is important to note that increasing concern has been expressed regarding poor validity and over-interpretation of neuroimaging results. See: Logothetis, 2008; Poldrack, 2009).

In the popular media technologies such as fMRI have often been presented as a form of "mind-reading," and neuroimaging studies revealing residual brain function and possibly self-awareness in those in VS/UWS have been reported as "miraculous" (Racine et al., 2005; Racine & Bell, 2008; Samuel, 2013). Reports have at times sensationalized the implications of neuroimaging technologies by implying that everyone with DOC has latent awareness and can communicate directly through such technologies (Racine et al., 2005; Racine & Bell, 2008). Researchers themselves have generally cautioned against over-interpretation of results, but have differed in the degree to which they interpret such results as evidencing self-awareness or consciousness (Cruse et al., 2011; Monti et al., 2010; Nachev & Husain, 2007; Owen et al., 2006).

In encouraging an ethically focused research agenda for neuroimaging and DOC, Joseph Fins states:

> Emerging knowledge about brain states will heighten expectations for some families and bring tremendous disappointment to others. Investigators and clinicians need to be aware of the power of their words, impressions and their interlocutors' tolerance for ambiguity. Findings should be shared with caution and humility, in order to foster trust and reciprocity . . . This charge should also be part of the research agenda (Fins et al., 2008, p. 9).

Fins seems to imply in the above statement that in some instances investigators have not cited findings with humility or used caution in their words. Indeed, some family members of DOC patients have reported frustration with overly optimistic media reports about neuroimaging (some of which have been based on researchers' own highly optimistic press releases), reservations about the use of such technology, and/or ambivalence about learning that the patient may have more awareness than previously believed. One family member states:

> It's like a double edge sword because if we found that there was nothing there in a way that would've been easier … how do we handle it if there is something there but there's not a damn thing that we can do to get to her? If I knew that things were going on in Lavena I'd spend much more time with her…I'd talk to her a lot more and so on and of course then that would impact on us all'. She adds that also 'we'd feel so guilty that we haven't tried harder to get through to her but yet we know that everything has been done you know … so it's quite complicated to unravel (Samuel, 2013, p. 7).

Sensationalized reporting can saddle families with disappointed hopes. Responding to reports of fMRI studies with DOC patients that included newspaper articles with titles such as *Coma*

Victim 'Speaks' With His Thoughts, a family member responds:

> They [the newspaper articles] are really misleading because they give you hope and I suppose whilst all you cry for is a bit of hope I do understand why they [doctors] don't give you it because when you get given it …you make your own conclusions don't you? And you twist what's been said … that's what doctors don't want you to do, they don't want you to hear something different from what they're saying and that's what the media does. It changes everything and makes you think there's answers out there that just aren't (Samuel, 2013, p. 8).

Others have cautioned that increased awareness is not always a positive. For example, one family member states of her brother in a MCS:

> when he's asleep he looks peaceful. And when he wakes up he grimaces and roars and is so miserable – of course, because you're waking up into a nightmare. And it's always awful watching him wake up . . . He is very aware of his situation, and his situation isn't one you'd want to be aware of (J. Kitzinger & Kitzinger, 2013, p. 1105).

A family member of a patient with profound neurologic deficit (i.e. recovered from MCS) states, "I wish that mum was in a completely vegetative state and had no awareness at all really" (J. Kitzinger & Kitzinger, 2013). Upon being interviewed regarding media reports of awareness detected via neuroimaging, one family expressed reservation that increased awareness would result in improved quality of life, she spoke of witnessing a patient in the same facility who had more awareness/responsiveness than her loved one, "he had all this awareness, he had one of those machines that he could say 'I need some attention' and then press the button and in the end because he liked playing with it, they would switch his machine off, because he was doing it all the time;" a family member being interviewed with her quips: 'yeah, you've got a voice, now you haven't'" (Samuel, 2013). Neuroimaging may be a useful diagnostic tool, but it alone cannot improve the quality of life of DOC patients, even of those individuals in whom it reveals "latent awareness." J.J. Fins and others have argued vehemently for the "right" of DOC patients to have access to neuroimaging technologies (Fins, 2013; Fins et al., 2008). Providing access to various medical technologies is increasingly viewed as the goal of medicine, and those who seek medical care are increasingly identified not as "receivers" of care, but as "consumers" (Bishop, 2011; Chambre, Goldner, & Katz Rothman, 2008; Hauerwas, 1990) However, as the above quote indicates, access to technology is not the only ethical concern at hand. "Caring" for a patient is not done solely through offering them access to technology; human resources as well as technological ones are needed. We need not view the two as enemies, they can be integrated; a task which nursing and other medical providers have discussed at length (Musk, 2004). Supporting DOC patients' "right" to medical technologies, such as neuroimaging to assess awareness, must be combined with a demand for physical, emotional and spiritual care. If medical systems as whole (individuals clinicians, medical professional associations, medical facilities, and the government and private agencies that control funding) focus only on medical technology, DOC patients with limited awareness will be left in the state of the aforementioned patient: armed with expensive communication technologies, but no one to listen.

DOC, Nociception, Feeling Pain and Experiencing Pleasure

The study of DOC and pain perception further illuminates the challenges posed by the complexity and opacity of the relationship between brain function and subjective experience. A crucial concern regarding the experience of individuals with DOC is whether or not they experience pain, and if they do, how that pain can be treated in the context of severely limited (or totally absent) communication. Their capacity to experience pain and suffering[7] is cited by those who insist on a moral obligation to continue LST in DOC patients, often articulated as the "right to life;" it is also emphasized by those who endeavor to preserve the right to withhold/withdraw LST, often articulated as the "right to die" (Constable, 2012; A. Demertzi et al., 2013; A. Demertzi et al., 2009; Farisco, 2013; Kahane & Savulescu, 2009; Wilkinson et al., 2009). Pain is a subjective experience and is therefore typically assessed through direct questioning. With behaviorally unresponsive patients other means of assessment must necessarily be utilized. In individuals in DOC researchers highlight the distinction between "nociception" and "feeling pain," since the subjective experience of these individuals is difficult or impossible to access. Nociception refers to "the neural processes of encoding and processing noxious stimuli" and does not necessarily indicate a conscious experience of pain; for example peripheral nociception can occur without pain during certain types of anesthesia, and in the case of neuropathic pain and chronic pain, pain can be experienced without the activation of nociceptors ('sensory receptors capable of transducing and encode noxious stimuli") and without tissue damage, respectively (Loeser & Treede, 2008; Schaible & Richter, 2004). Pain is defined as "an unpleasant sensory and emotional experience associated with

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[7] "Suffering," as a philosophical and theological concept, including the relationship between pain and suffering is discussed and developed in chapter 3; here I limit my analysis to pain perception within neuroscience research.

actual or potential tissue damage or described in terms of such damage" (Loeser & Treede, 2008, p. 475). Pain is a complex phenomenon of which the conscious and unconscious aspects are not easily disentangled (Duffy, 2008; Gligorov, 2008).

Though our understanding of the neural correlates of pain remains incomplete, a substantial body of neuroimaging research has led many to propose the existence of a pain neuromatrix or "pain matrix' within the brain which includes the primary (S1), and secondary (S2) somatosensory cortices, the insula, and the anterior cingulate cortex (ACC)[8] (Pistoia, Sacco, Sara, & Carolei, 2013; Schnakers, Chatelle, Demertzi, Majerus, & Laureys, 2012; Schnakers et al., 2010; Schnakers & Zasler, 2007). Some subdivide the pain matrix into the lateral pain system "somato-sensory node" (including the S1 and S2) and the medial pain system "affective node" (including the ACC) correlating with the affective dimension of pain (Pistoia et al., 2013). For example, drawing on imaging studies of pain states, Schnakers et al. (2012) describe a difference between those areas of the brain thought to be involved in reflex responses to nociceptive stimuli and those areas involved in cognitive and affective aspects of pain processing. Put in more general terms, Schnakers et al. (2007) describe a distinction between "pain perception *per se*" and "suffering as related to the conscious perception of the pain in question" (Schnakers et al., 2012; Schnakers & Zasler, 2007).

However, it should be noted that despite significant steps taken towards identifying neural correlates of pain perception and isolating reflexive (nonconscious perception of nociceptive stimuli) versus cognitive-affective (conscious perception) processes of pain perception, our current understanding remains limited; some experts argue that we lack sufficient knowledge to identify a network specific to pain processing (Pistoia et al., 2013). Others raise concerns regarding the interpretation of neuroimaging data; for example, they cite the problem of *reverse inference* defined as, "reasoning backwards from the presence of brain activation to the engagement of that particular function," and exaggeration of the degree to which the brain region of interest is selectively activated (Poldrack, 2006, p. 59). One literature review of evidence used to support the concept of a pain matrix concludes that while the brain activation observed in imaging studies may indicate that specific areas are involved in the detection of "salient sensory events," it has not been unequivocally shown that these sensory

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[8] For an excellent scholarly online resource on brain structure and function that includes information written to beginner, intermediate and advanced levels (available in English and French): see http://thebrain.mcgill.ca/avance.php [Accessed November 23, 2014].

events are exclusive to nociception (Iannetti & Mouraux, 2010). Other researchers state the concern thus: “the presence of brain activation is insufficient evidence for the perception of pain unless it can be shown that the same activation cannot occur in the absence of pain” (Rees & Edwards, 2009, p. 77).

A lack of uniformity exists amongst treatment guidelines regarding the assessment and treatment of pain in patients with DOC, characterizing the differences of opinion regarding their capacity to feel pain (Farisco, 2013). For example, the Multi-Society Task Force (1994) report on PVS rules out the possibility that these patients can feel pain: “the perception of pain and suffering are conscious experiences: unconsciousness, by definition, precludes these experiences,” and the current American Academy of Neurology (AAN) practice parameters state that VS/UWS patients lack capacity to experience pain or suffering (American Academy of Neurology, 1989, p. 77; The Multi-Society Task Force on PVS, 1994b, p. 1756). A 1993 report by the American Neurological Association (ANA) Committee on Ethical Affairs offers a slightly less definitive statement:

> The question as to whether patients in vegetative state feel pain and undergo suffering may not be resolved scientifically to everyone’s complete satisfaction. Nevertheless, clinical observations of patients in a PVS and later postmortem examinations . . . do not give any indication that they experience the cognitive and emotional concomitants of pain and suffering (ANA Committee on Ethical Affairs, 1993, p. 387).

None of the aforementioned documents gives recommendations for treating pain in VS/UWS patients (American Academy of Neurology, 1989; ANA Committee on Ethical Affairs, 1993; Farisco, 2013; The Multi-Society Task Force on PVS, 1994b; Wijdicks et al., 2006). The Royal College of Physicians, in a newer document describing the withdrawal of ANH in VS/UWS patients states, “though it is extremely unlikely that the person can feel any pain, he or she will be given sedation . . . this will eliminate any possibility of suffering, however remote” (Royal College of Physicians, 2003). The Australian National Health and Medical Research Council guidelines declare that individuals in post-coma unresponsiveness (PCU)*/VS or in a minimally responsive state (MRS)*/MCS, “may be capable of suffering pain or discomfort though it may not be possible to establish this. Healthcare professionals therefore need to minimize any possible discomfort and respond to signs that may indicate distress” (Australian Government, 2008). Research also indicates that differing beliefs exist amongst individual medical providers, and that their opinions about, awareness, pain perception, and the use of LSTs, are interrelated.

In a 1996 survey of US nursing home Medical Directors (n=150) and Neurologists (n=169), 35% of medical director respondents and 25% of neurologist respondents indicated that patients in PVS experience feelings of pain, though only 12.7% and 13.7% respectively indicated that these patients have awareness of self and environment. 93.6% and 94% respectively indicated these patients would be "better off dead," 89% and 88% respectively that it is ethical to withdraw ANH for patients in PVS, and 54% and 44% respectively that those in PVS "should be considered dead" (Payne, Taylor, Stocking, & Sachs, 1996). Only 10.3% and 13% respectively indicated they themselves would want long-term ANH if they were in a PVS. The results present seemingly paradoxical beliefs in some respondents: if these patients lack "awareness of self and environment" how do they "experience feelings of pain"? What precisely about their existence leads to the assessment that they would "be better off dead"? The authors conclude that for those who indicate PVS/(UWS) patients can experience pain, it is unclear whether they lack knowledge of studies that "suggest that such patients are not capable of subjective experience," or whether they simply remain unconvinced (Payne et al., 1996, p. 108). The seeming paradox in beliefs may also be linked to concerns that patients with signs of awareness/responsiveness are misdiagnosed as being in PVS (Andrews et al., 1996; Payne et al., 1996).

In a more recent European survey, 68% (n=538) of paramedical professionals and 56% of medical doctors (n=1166) answered, "yes," to the question: "do you think that patients in vegetative state can feel pain?" Nearly all responded, "yes," to the question: "Do you think that patients in minimally conscious state can feel pain?" (97% of paramedical professionals and 96% of medical doctors) (A. Demertzi et al., 2009). In regards to the capacity of those in VS/UWS to feel pain, professional background followed by self-identification as religious (primarily Christian) were the highest predictors of caregivers' opinions. In a vignette-based online survey of German neurologists regarding diagnostic and ethical challenges in DOC and locked-in syndrome (LiS), 9% of the VS vignette group (n=132) indicated these patients have capability of "being aware of themselves," 6% of "being aware of surroundings," and 77% of "feeling pain;" these same capacities judged by the MCS group (n=148) were 54%, 57% and 96% respectively (Kuehlmeyer et al., 2012). In regards to opinions about LST the study allowed for nuanced responses by asking for agreement/disagreement on a five-point scale with limitation of LST in different circumstances. For most measures more readiness was shown in limiting LST in the VS/UWS group; in all groups respondents were more likely to consider withholding aggressive interventions such as Cardiopulmonary Resuscitation (CPR)* and less likely to consider withdrawing nutrition and hydration; only 34% who accurately diagnosed VS/UWS would withdraw nutrition and only 23% hydration. Why so many respondents indicate that those in VS/UWS lack awareness but feel pain is difficult to say. It may be these individuals have observed those in VS/UWS react to noxious stimuli (though many argue that such responses are reflexive/nonconscious) or may represent an acknowledgment of the complexity of pain and the difficulty of distinguishing in full its conscious and nonconscious components (Kuehlmeyer et al., 2012; Loeser & Treede, 2008; Schnakers & Zasler, 2007). The paradox could also be related to the fact that, though awareness lies on a continuum, questions usually describe awareness in an either/or dichotomy (i.e., as merely present or absent); in addition, there may be increasing concern that more VS/UWS patients than previously realized possess a limited degree of awareness/responsiveness despite lack of behavioral evidence.

Differing beliefs regarding awareness, pain and LST may be related to discrepancies amongst national and area practice standards (Asai et al., 1999; A. Demertzi et al., 2009; Payne et al., 1996). Provider beliefs regarding use of LST for DOC patients have also been correlated with profession, gender and religiosity (A. Demertzi et al., 2013; A. Demertzi et al., 2009; Kuehlmeyer et al., 2012; Payne et al., 1996; Rodrigue, 2013). As some authors note variability in beliefs about pain perception could have a negative impact by confusing family members of patients or causing distrust of providers' ability to offer accurate diagnostic and prognostic information (A. Demertzi et al., 2013). Differences in opinion about the provision of LST in patients with DOC could inappropriately be influenced by providers' personal convictions rather than evidence-based diagnostic and prognostic information and adherence to what is known of patients' treatment preferences. Difference of opinion and uncertainty could also reflect a need to revisit current guidelines and diagnostic categories since recent research on DOC seems to reveal the limitations of behavioral assessments of awareness/responsiveness that are the basis of many guidelines (Celesia & Sannita, 2013; Fins et al., 2008; Jox & Kuehlmeyer, 2013).

Currently, evidence of whether DOC patients experience pain is inconclusive and likely will remain so given the difficulty accessing these patients' subjective experience. In the neuroscience literature it is generally assumed that the higher a patient's cognitive level of awareness/responsiveness, the more likely they have the capacity to experience pain. Some clinicians clearly are concerned that DOC patients do experience pain and have developed and validated a scale, the Nociceptive Comma Scale Revised (NCS-R)*, to assess pain in these patients (Chatelle et al., 2012; Chatelle et al., 2014). Though guidelines on PVS, such as those of the Multi-Society Task Force on PVS, do not consider grimacing to be a sign of consciousness, in a study used to determine the sensitivity of the Nociception Comma Scale (the NCS-R prior to its revision), frequency of grimaces observed in response to nociceptive stimuli (pressure to fingernail) versus non-nociceptive stimuli (shoulder taps) showed grimaces were presented more frequently in response to the former in both the VS/UWS and MCS patient groups (Schnakers et al., 2010; The Multi-Society Task Force on PVS, 1994b). The clinicians who have done the most research on pain and DOC recommend that neurobehavioral assessments such as the CRS-R should be regularly used to assess awareness, coupled with the NCS-R to assess if relevant behavioral changes occur during pain-producing care interventions or new sequelae; they also advocate for treatment of pain if assessments indicate an individual could be experiencing pain (Schnakers et al., 2012; Schnakers et al., 2010). They caution, however, that there must be a balancing of the risks and benefits between over-treating pain and thereby masking behavioral signs of awareness or causing uncomfortable side effects, and under-treating pain and thus leaving individuals in pain who have no ability to express their distress.[9]

Even patients who are fully conscious and can articulate their distress sometimes describe an experience of feeling dehumanized through interactions with the medical system. Thus medical providers must strive to intentionally recognize the humanity of their patients, even those who clearly lack awareness of self and environment. James Duffy writes,

> the clinician faces the hardest question of all; i.e. how to provide compassionate care for patients whose experiences lie beyond the horizons of our own consciousness. In this regard, the principle of respect provides the ethical

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[9] Pharmaceutical treatments for pain such as opiates can have a dulling effect not only on pain but on general responsiveness, including voluntary movement, and some have uncomfortable side effects such as constipation; such side effects are especially concerning in individuals who cannot communicate their discomfort.

> bedrock that requires that we never fail to recognize the humanity of those who have slipped into a realm beyond our current understanding (Duffy, 2008).

Even if clinicians themselves experience distress in the presence of DOC patients, feel they would be better of dead, or believe that they would not want to be sustained in such a condition, the principle of respect demands engaged and gentle care of the patient as well as serious consideration of the perceptions of patients' family about whether the patient is experiencing pain or discomfort. In DOC, pain perception, questions and convictions about LST, and conceptions of consciousness, will continue to be intertwined, and uncertainty regarding awareness and pain perception may, at least for a time, be uncomfortably high. However, when navigating uncertainty and when employing new technologies into medical practice, caring for the individual patient as a person should always be the primary focus, perhaps most especially where curing remains impossible.

Finally, while unraveling the complexities of pain perception in this patient group is essential to addressing quality of life concerns and a crucial area of inquiry; the focus on pain betrays an underling assumption that avoidance of pain is the primary gauge of quality of life. While a PubMed search of, "pain" and "disorders of consciousness," performed on April 16, 2014 resulted in thirty-one articles, a search on "pleasure" and "disorders of consciousness" resulted in zero articles; a search on "noxious stimuli" and "vegetative state" resulted in ten articles, while "positive stimuli" and "vegetative state" resulted in zero articles. But providing care should not be limited to ANH and nursing interventions, such as regular turning. In addition to further research on pain and suffering, the possibility of providing patients who possess limited responsiveness/awareness with pleasurable experiences should also be investigated since most people would hope for more in life than being free of pain. One example of the use of positive stimuli is a study on music therapy with patients in low awareness states (Magee, 2005). Determining emotional response - its bare existence and its potential quality - in this patient population involves obvious complexities. However, researchers of DOC need to begin to consider methods for addressing the possibilities of pleasurable/positive experience. With the current neuroscience understanding of DOC established, I now proceed to conceptions of autonomy and personhood and their influence on the debate about how best to care for these patients.

Chapter 2: Conceptions of Autonomy and Personhood: Consumers and Contracts or Selves and Covenants?

Autonomy Within Principlism

Respect for autonomy is one of four major principles (alongside beneficence, nonmaleficence and justice) commonly promoted in biomedical ethics in North America. The emphasis on patient autonomy developed in response to a history of medical paternalism that led to instances of physicians making decisions for patients based on their own values or treating them in a condescending way that patients experienced as demeaning, the growth of life-sustaining technologies in medicine which led to individuals asserting their desire and right to "not die on machines," and perceived violations of patients' rights, most particularly in the area of medical research (Beauchamp & Childress, 2013; Bishop, 2011; Jonsen, Siegler, & Winslade, 2010; National Commission for the Protection of Human Subjects of Biomedical & Behavioral Research, 1978). Respect for patients' autonomy became a duty for medical providers and institutions that has been enshrined in laws upholding the right of individuals to refuse unwanted medical interventions, is exhibited in documents detailing patients' rights, guides informed consent practices, and pervades medical ethics literature (Beauchamp & Childress, 2013; Jonsen et al., 2010; J. Perry & Bishop, 2010b).

Autonomy is a normative concept; in conceiving of autonomy in a particular way one judges certain capacities or conditions as valuable and others as lacking value. As conceptions of autonomy have been adopted by the field of medicine, too often, they have been treated as merely descriptive and the field has failed to sufficiently analyze their underlying normative commitments (Ells, 2001; Mackenzie, 2001; Mackenzie & Stoljar, 2000; Sherwin, 1998). Particular conceptions of autonomy also implicitly influence opinions about how to best care for those with DOC. I will argue that the dominant conception of autonomy in medicine and in biomedical ethics misrepresents human beings as primarily individualistic and rationalistic, overemphasizes the political concept of individual rights, and is inappropriately influenced by a capitalist market mentality emphasizing "choice" as the most essential exercise of human power. This dominant view of autonomy encourages a simplistic view of the nature of those with DOC and reduces the complex ethical concerns in DOC to choices about LSTs thereby masking other crucial concerns. I will outline critiques of the dominant view of autonomy and then propose that concepts of relational autonomy, most particularly Ricoeur's description of the capacities associated with autonomy, better address the complexities of caring for those with DOC. I will then address conceptions of personhood that assume cognitive capacity is a determinate of moral worth, arguing that such views cannot account for the lived experiences of those who care for a severely brain injured individual.

Autonomy and Rational Choice

The concept of respect for autonomy as it has been enshrined in biomedical ethics focuses on one's capacity for rational reflection (Beauchamp & Childress, 2013; Jonsen et al., 2010). When an individual can competently, through rational reflection, make choices about his or her own medical care, duty demands that all involved respect those choices. The theory seems clear in principle, but in practice it is anything but; the principle itself does not tell us how to judge competency, how to assess the quality of rational reflection undertaken, how to describe the available treatment options to a patient, or how to assess when the pressure to make choices is overly burdensome to patients or surrogate decision makers.

The most influential conception of autonomy in North American bioethics arguably comes from Beauchamp and Childress' *Principles of Biomedical Ethics* now in its seventh edition. In their description of autonomy they explicitly assert a focus on decision-making:

> Some theories of autonomy feature the abilities, skills, or traits of the *autonomous person*, which include capacities of self-governance such as understanding, reasoning, deliberating, managing, and independent choosing. However, our focus in this chapter on decision making leads us to concentrate on *autonomous choice* rather than on general capacities for governance and self-management (*emphasis in original text*)(Beauchamp & Childress, 2013, p. 102).

Notably, even in their definition of the "autonomous personhood," they focus entirely on rational capacities. Beauchamp and Childress acknowledge that actions are rarely entirely autonomous, and they argue that a theory of autonomy would be unacceptable if it presents "an ideal beyond the reach of ordinary competent agents and choosers;" for this reason they reject those theories that insist individuals engage in higher-level reflection and identify with these "second-order" volitions above mere basic first-order desires, such as influentially presented by Harry Frankfurt (Beauchamp & Childress, 2013, p. 104; Frankfurt, 1971). Instead, they assert that the requirement ought to be for actions to be "substantially" autonomous in reflection of decision-making as engaged by "normal choosers" who act "(1) intentionally, (2) with understanding, and (3) without controlling influences that determine their action" (Beauchamp

& Childress, 2013, p. 104). They acknowledge that autonomous choice resides on a continuum in regards to individuals' understanding and independence, noting that the degree of understanding and independence required for "substantially autonomous" choices in medical decision-making is context dependent. As a reference, alongside "deciding about surgery," they give the examples "hiring a new employee, or choosing a university to attend" (Beauchamp & Childress, 2013, p. 105). These examples describe choices made by persons in privileged socio-economic contexts; this is particularly troubling considering their use of the phrase "normal choosers." These examples concern activities strongly governed by factors such as self-interest, independence, and future-orientation. The factors relevant to decision-making for an individual who is less privileged socio-economically may be quite different. For example, attending to immediate rather than long-term needs may be more relevant.

Echoing The Belmont Report, Albert Jonsen, Mark Siegler, and William Winslade, whose *Clinical Ethics* is now in its seventh edition, situate respect for autonomy within a broader principle of *respect for persons*, (which "affirms that each and every person has moral value and dignity in his or her own right"), but similar to Beauchamp and Childress they quickly narrow their focus to self-determination in the exercise of personal preferences and/or choices: "one implication of respect for persons is respect for personal autonomy, that is acknowledging the moral right of every individual to choose and follow his or her own plan of life and actions" (Jonsen et al., 2010, p. 47). Jonsen et al. limit their reflections on the demands of respect for autonomy to a discussion of "informed consent" and "decisional capacity." Though Jonsen et al. cover other related topics such as "truth in medical communication," and "cultural and religious beliefs," they consider these additional topics solely within the framework of informed consent and decisional capacity. Autonomy as described above primarily concerns an individual's capacity to make informed decisions, assumed to rest upon both the individual's capacity for rational thought and freedom from what Beauchamp and Childress term "controlling influences" (Beauchamp & Childress, 2013, p. 105). These two influential medical ethics texts reflect the dominant conception of autonomy in medicine, a view that roots autonomy in the action of rational choice concretized in informed consent practices.

Autonomy, Informed Consent, and Consumer Choice

Informed consent describes the medical provider's obligation to inform the patient of his or her diagnosis and prognosis and available treatment options; it also concerns the patient's understanding of the information disclosed and his or her consent to a particular course of treatment. Beauchamp and Childress explain, “the primary justification advanced for requirements of informed consent has been to protect autonomous choice” (Beauchamp & Childress, 2013, p. 121). As Beauchamp and Childress describe, much has been written regarding informed consent practices and what is necessary for consent, for example voluntariness, and what constitutes sufficient disclosure and understanding. Some have argued that while informed consent is necessary, it may not be sufficient to respecting the autonomy of patients. Onora O’Neill argues that informed consent practices suppose a minimal view of autonomy which amounts to “a right to choose or refuse treatments on offer, and the corresponding obligations of practitioners not to proceed without patients’ consent;” she acknowledges that this approach in some ways fits quite well with medical practice since an ill or injured person may find “robust” conceptions of autonomy burdensome (O'Neill, 2002). In other ways this minimal view of autonomy in medicine might be problematic. O’Neill cites the overarching dominance of consumer choice, an area in which informed consent is indeed seen as “not only *necessary* but also *sufficient”* as one of the reasons why the minimal view of autonomy contained in informed consent procedures in medicine are interpreted as not only necessary but also “*sufficient*” to “ethical justification” (O’Neill, 2002, p. 47). She expresses concern that too much may be demanded from informed consent practices if such practices are “to substitute for forms of trust that are no longer achievable” since personal and one-to-one relationships between physicians and patients have been in many instances replaced by “relationships between patients and complex organizations staffed by many professionals” (O’Neill, 2002, p. 29).

Influenced by Paul Wolpe and others, O’Neill expresses concern with autonomy in medical care being interpreted in the simple terms of consumer choice. If medical care is merely a product that is consumed in the way of other products, a minimal conception of autonomy may be sufficient. If medical care is interpreted to be rooted in a partnership or in as Ricoeur describes, a “pact of care,” ensuring that a patient independently makes a choice regarding his or her medical care might not sufficiently ensure his or her autonomy is respected (Ricoeur 2001). Beauchamp and Childress acknowledge O’Neill’s argument, but assert, “we hold that respect for autonomy does provide the primary justification of rules, policies, and practices of informed consent” (Beauchamp & Childress, 2013, p. 121) but they do not address her claim that the conception of autonomy assumed by informed consent practices is a minimal one, influenced by a model of consumer choice rather than one of a trusting relationship.

Catriona Mackenzie also critiques the emphasis on choice in medicine, and points out that the liberal commitment to maximizing choice is not normatively neutral and endorses certain values, namely of "individualism and negative liberty" (Ricoeur, 2001). She explains:

> One of the predicaments of our culture is that while we are steadily transforming the givens of human embodiment into choices, particularly in the areas of medicine and biotechnology, we have no clear idea what norms, other than the value of choice itself, should guide this process. Bioethics is a response to this normative vacuum, but to the extent that bioethics assumes without question maximal choice conceptions of autonomy, it provides little normative guidance (Mackenzie, 2001, p. 434).

Though other principles, such as beneficence and justice, might be appealed to as important guiding values, Mackenzie critiques the limitations of maximal choice as the value associated with autonomy.

Some argue that the field of bioethics itself has served to reinforce the interpretation of medical choice as a form of consumer choice, most particularly in the US. Jonathan Moreno for example, reflecting on the US context, argues that the principle of autonomy as adopted in a capitalist society needs to be reassessed:

> Empowering patients to determine the course of their medical care has not only turned them into consumers in a more overt sense than has traditionally been the case in healthcare; more to the point bioethics has provided a neat justification for this qualitative change . . . consumers who insist on exercising their 'autonomy' has dovetailed brilliantly with corporate interests (Moreno, 2007, p. 415).

Moreno highlights troubling outcomes from this dovetailing of patient autonomy and consumerism: "personal choice and interpersonal competition are two sides of the same coin." Most especially in the US the provision of medical care cannot be separated from the capitalist economic system. The treatments offered to patients often include material items such as pharmaceutical agents and medical devices that corporations advertise to physicians. In many instances these material items represent important advances in medicine that support individuals' health and healing. However, the extensive infiltration of consumerism, and most specifically consumer choice, into medical care, might also encourage viewing patients merely as consumers choosing one product over another with insufficient attention given to the importance of the development of a trusting relationship between medical providers and the patients they care for. From a justice standpoint this is particularly concerning since it could lead to a patient's ability to assert economic power as an arbiter of the type of care he or she receives. Alastair Campbell quotes a physician who works in an urban primary care setting in the United States:

> Private medicine is abandoning the poor . . . As a private physician I cannot even admit patients to the private hospital with which I am affiliated unless they have medical coverage or can pay the bulk of the expected fee in advance. What is available for the poor are long waits in emergency rooms and outpatient clinics of public hospitals . . . We physicians have not, I think deliberately chosen to abandon the poor; rather, we have been blinded to our calling by the materialism of our culture and the way medicine is structured . . . The realities of medical economics encourage doctors to do less and less listening . . . Instead the doctor is encouraged to act, to employ procedures . . . charges for procedures are universally higher than fees for talking with the patient (Campbell, 1995, p. 74).

While recent changes made to the U.S. medical system through the Affordable Care Act have created possibilities for more uninsured individuals to obtain medical insurance, the problems this physician attributes to materialism and medical economics will not necessarily be solved; patients may be refused care for having insufficient insurance, rather than no insurance; a problem commonly experienced by those insured through state Medicaid systems.

Autonomy and The Duty of Respect

The dominant conception of autonomy as expressed by Beauchamp and Childress asserts that individuals' capacity for rational choice creates the duty of respect; a duty conceived as having both positive and negative obligations. As a negative obligation respect for autonomy primarily concerns not subjecting others to "controlling constraints (Beauchamp & Childress, 2013, p. 107). As a positive obligation respect for autonomy demands specific action rather than merely requiring restraint from action. Beauchamp and Childress emphasize the obligation of medical providers to "disclose information, to probe for and ensure understanding and voluntariness, and to foster adequate decision making" (Beauchamp & Childress, 2013, p. 107). There are likely many types of action other than decision-making that are conducive to health and healing. Maintaining supportive relationships for example might serve to support a patient's autonomous action by giving them confidence and ensuring them of their value and importance to others, and therefore their responsibility to be an active participant in maintaining their health. By focusing solely on patients' cognitive capacities for decision-making and the obligations of individual medical providers in "building up or maintaining others' capacities for autonomous choice," and respecting patients autonomy by "acknowledging the value and decision-making rights of persons and enabling them to act autonomously," (2013, p. 107) Beauchamp and Childress ignore how providers might have other obligations in acknowledging and valuing patients as autonomous beings, for example, in respecting their privacy. Their focus on the cognitive capacities of individual patients also ignores larger contextual factors that might have a controlling influence on the options available to a patient, such as whether the patient is employed and whether he or she has medical insurance; they do not speak adequately to the ways that individuals reside in systems of power.

Implicit in the idea that rational choice is the primary representation of autonomy is the idea that rational thought is a capacity, but also a characteristic or quality of an individual: making rational choices renders one a rational being and therefore demands respect from others. Beauchamp and Childress state, "Our obligations to respect autonomy do not extend to persons who cannot act in a sufficiently autonomous manner - and who cannot be rendered autonomous - because they are immature, incapacitated, ignorant, coerced, or exploited. Infants, irrationally suicidal individuals, and drug-dependent patients are examples" (Beauchamp & Childress, 2013, p. 108). Implicitly, respect for autonomy as described by Beauchamp and Childress correlates human beings' value with their capacity to be rational choosers as interpreted by individuals with medical authority; it also restricts the duty of respect to individuals' choices while saying nothing of respecting individuals themselves or respecting individuals in other ways or on other grounds. Though they acknowledge such individual are owed "moral respect," but they delimit this to the obligation to "protect them from harm-causing conditions and to supply medical benefits" (Beauchamp & Childress, 2013, p. 108). Describing infants and drug-dependent individuals in the same category of inability to act in a sufficiently autonomous manner highlights this problem. Because those with DOC cannot render substantially autonomous choices, two crucial questions arise: "who are these individuals – that is, what is their nature?" and "what duty do we have to respect such individuals?"

Autonomy and "Surrogate Decision Makers"

Over time medical practice and bioethics have settled on two primary standards for surrogate[10] decision-making. The first, "substituted judgment" demands that the surrogate use

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[10] These include family members named as surrogates in legal documents such as advance directives and living wills, but also include family of patients who have no such document.

all he or she knows of the patient to decide *as the patient would decide* if he or she was capable (firstly in accordance with prior autonomously expressed treatment preferences or secondly in accordance with known values); the second, "best interest," demands that the surrogate make choices amongst various treatment options that "promotes and protects" the patient's best interest (Beauchamp & Childress, 2013, p. 105). Some also describe an additional standard labeled the "advance directive," "known wishes," or by Beauchamp and Childress the "pure autonomy" standard to represent decision-making in accordance with prior autonomously expressed treatment choices. Given the uncertainty that characterizes many medical situations, in some instances it might be difficult to assess when a previously expressed autonomous preference becomes relevant (Brock, 1994, p. S9; Dionne-Odom & Bakitas, 2012).

Dan Brock contends that there are two underlying ethical values in these standards: (1) "self-determination," conceived as the surrogate attempting to decide "in accord with the patient's values or conception of the good" (this value is qualified since the patient cannot make his or her own decisions); (2) the patient's "well-being." Brock concedes that these standards involve controversy, including in regards to the "range of discretion surrogates should have," in specific considerations such as "what weight we want to give in public policy to the family and to families' autonomy and responsibility in caring for their incompetent members" (Brock, 1994, p. S10). The degree of decision-making responsibility and authority given to surrogates is not universally normative. This in part stems from differing interpretations and emphases on the meaning of autonomy as it is applied to patients; this also, however, stems from ethical complexities more directly involved in the meaning of autonomy as it is applied to surrogates. Far more responsibility is given to surrogate decision-makers in the US then in some locals (Azoulay, et al., 1994); this might result from the strong link between autonomy and consumer rights.

Though it is the norm in North America for family members of incapacitated patients to participate in decision making, particularly regarding the introduction, refusal or withdrawal of life-prolonging interventions; this is not the case everywhere (Wendler & Rid, 2011). For example, a 2001 study in France of 357 patients in 78 ICUs revealed that only 15% of family members actually shared in decision making, and only half of those asked expressed a desire to be involved in decision making (Azoulay et al., 2004). However, in North America family members of incapacitated patients regularly act as surrogate decision makers and in this role assume (or are feel obligated or coerced to assume) high degrees of responsibility for treatment choices (Drought & Koenig, 2002; Russ & Kaufman, 2005; Wendler & Rid, 2011). When a narrow view of patient autonomy (particularly the emphasis on informed consent) is directly transferred onto surrogates, who often are close family members, these individuals are then viewed primarily as decision-makers; this can deny the complexity of their relationship with the patient and conflict with their identity as seen through the dominant role they have with the patient, such as mother, sister or spouse.

Embodiment and Relationship as Necessary Components of Autonomy

A primary challenge to the rational choice focused conceptions of autonomy comes from feminist ethics. In *Relational Autonomy* Catriona Mackenzie and Natalie Stoljar highlight five categories of feminist critiques of this dominant understanding of individual autonomy: symbolic, metaphysical, care, postmodernist and diversity. They emphasize that these critiques not only challenge the individualistic and rationalistic commitments inherent to the dominant conception of autonomy, but also establish and encourage new ways of conceiving individual autonomy from a feminist perspective; they do not seek to refute the importance of the concept of autonomy, but rather to present new ways of understanding the concept relationally (Mackenzie & Stoljar, 2000). They conclude by highlighting three concerns of relational approaches to autonomy. Firstly, describing a more complex understanding of agency that acknowledges agents as embodied, feeling and desiring as well as rational, that takes seriously the historical and social context of individuals' lives, including ways that individuals' capacity for autonomy is impeded or enhanced, and that addresses concepts such as self-respect, self-worth and self-trust (Mackenzie & Stoljar, 2000, pp. 21-22). Secondly, analyses must take oppressive social contexts seriously and address the ways in which the range of options for an agent to act autonomously can be impeded through oppressive socialization and social relationships by restricting the development of self-understanding and capacities necessary for autonomy or by restricting individuals' ability to act autonomously. Thirdly, "agents and their capacities should be conceived relationally" because agents' identities and self-concepts are themselves constituted within a social context in which others have a crucial role, and because individuals' natures cannot be considered independent of historical and social conditions in which those individuals are embedded (pp. 21-22).

As a whole, the collection of relational approaches critiques the following premises in the dominant view of autonomy: (1) conceiving of agents as isolated, self-developing and self-sustaining; a depiction which is both destructive and incompatible with the reality of human lives, (2) viewing agents as interchangeable rather than unique, (3) failing to recognize the importance of historical and social context, and (4) encouraging and idealizing self-sufficiency and independence at the expense of recognizing the value of interdependency and interconnection (Mackenzie & Stoljar, 2000).

Beauchamp and Childress briefly acknowledge feminist critiques but in a cursory and perfunctory manner. Carolyn Ells argues that Beauchamp and Childress fail to appreciate the nature of the criticism; they treat the critique as if feminists have failed to understand that they do not forward a stark individualistic concept of autonomy, and that the theory of autonomy they present can be logically consistent with feminist commitments (Ells, 2001). Nevertheless, some of the feminist criticism addresses the ideological commitments underlying the dominant concept of autonomy (for example commitments to impartiality and rationality as primarily moral goods) as well as the failure of Beauchamp and Childress to critically assess the ideologies underlying their theory (Ells, 2001). The ideological commitments of the dominant view of autonomy reinforce the false notion that all humans are equally situated self-interested individuals who voluntarily choose certain goods above others, but in fact contextual aspects of individuals' lives need to inform the theory of autonomy. Ells argues that Beauchamp and Childress' theory fails to understand people in ways consistent with their actual lives in such a way that incorporating such a re-understanding would require a dismantling of their whole approach (Ells, 2001).

Ricoeur: The Paradox of Autonomy and Vulnerability

Ricoeur describes autonomy as a project and insists that autonomy involves the capacity for particular actions all of which are developed and maintained through relationship with others. The capacities Ricoeur describes are the "the ability to speak, [the ability] to act on the course of things . . .and the ability to gather one's own life into an intelligent narrative;" to these three capacities he adds the capacity to "take oneself for the actual author of one's acts" which he links to "*imputability*," that is, the capacity to take responsibility for the consequences of one's actions (Ricoeur, 2007a, p. 75). Ricoeur refers to autonomy as a paradox because of the way it is coupled with fragility/vulnerability: "the autonomy in question is that of a fragile, vulnerable being," and is both the "prerogative of the subject of rights" and a "condition of possibility" (Ricoeur, 2007a, pp. 72-73). Ricoeur describes corresponding fragilities for each of the abilities he names (Ricoeur, 2007a, p. 75). For example, in regards to the ability to speak, Ricoeur states:

> If the basis of autonomy can be described in terms of the vocabulary of ability, it is in that of inability or lesser ability that human fragility first expresses itself. It is first as a speaking subject that our mastery appears to be threatened and always limited. This power is never complete, never fully transparent to itself (Ricoeur, 2007a, p. 76).

Though Ricoeur employs the term "ability," he does not speak merely of individual cognitive abilities; he emphasizes that the abilities associated with autonomy are developed and maintained through interpersonal relationships and within institutions. Abilities, he explains, must be affirmed and varying degrees of ability to speak and act often concern the distribution of power in society:

> Here the incapacities humans inflict on one another, on the occasion of multiple interactions, get added to those brought about by illness, old age, and infirmities, in short, by the way the world is. They imply a specific form of power, a power-over that consists in an initial dissymmetric relation between the agent and the receiver of the agent's action . . .. people do not simply lack power; they are deprived of it (Ricoeur, 2007a, p. 77).

Ricoeur asserts that autonomy develops through affirming relationships with others while also recognizing that interpersonal relationships occur within institutions. Ricoeur's conception of autonomy offers three important points: (1) autonomy concerns basic capacities of agency that include more than rational reflection, (2) autonomy is always connected to vulnerability and cannot be conceived of as a triumph over vulnerability or even over incapacity, (3) autonomy, though clearly a concept applied to individuals, always concerns interpersonal and institutional relationships and therefore is a matter of justice.

The principle of respect for autonomy carries with it particular convictions about human identity and personhood. Linked to autonomy are questions such as: What is essential to being human, to being a person, or to possessing selfhood? What renders one worthy of respect or demands particular duties or obligations from other individuals or from society? Am I "me" because of my brain, because of my body, because of my memories, or because of my relational and social experiences? If part or all of one of these components is lost am I still "me"? These questions cannot be separated from convictions about how individuals with DOC ought to be cared for because our appraisal of our duty and obligation to another being proceeds at least in part from our understanding of that being's nature. Too often we fail to accept that individuals can be ambivalent as well as express seemingly contradictory thoughts and behaviors – this likely proceeds from our long idealization of logic and rationality. But if we view the care of individuals with DOC solely in terms of individual rights this both undermines their humanity and traps us in two-choice construct: "the right to die" v. "the right to life." Sadly this also traps intimates of the cognitively impaired into roles as the decision-makers and undermines the complexity of their relationships they have with their loved ones who lack autonomy. In the following section I critique conceptions of personhood, which are also often linked to ideas about autonomy.

Personhood, Consciousness and Moral Status

In the collection of essays *Defining the Beginning and End of Life* John P. Lizza proposes seven categories of theories of persons: "persons as immaterial souls or minds, persons as ensouled bodies, persons as human organisms, persons as psychological qualities or functions, persons as psychological substances, persons as constituted by bodies, persons as relational beings, and persons as self-conscious beings" (Lizza, 2009). Modern conceptions of personhood tend to fall into one of two categories: (1) those that define personhood in terms of capacities that emphasize rational reflection (which some define in neuroscience parameters as cortex function), including those conceptions that concern self-awareness and/or self-reflection, psychological capacities or substances, or specific neural processing, and (2) those that claim personhood derives from other sources such as embodiment in human bodies, base biological functions, possession of an immaterial soul or spirit, or by virtue of being relationally connected to other humans. Philosophers make many detailed distinctions regarding the concept of personhood. In this two-category division I paint a complex philosophical debate in very broad strokes, but in the current context, philosophical concepts and neuroscience intermix in such a way that the primary distinction has become centered not just on rational capacity, but on "consciousness" as mediated by brain function. Theories assume that either a certain type or degree of brain function is essential to personhood or it is not.

Some contend that we do not have the same duty or obligation to human beings who lack consciousness or capacity for rational reflection that we have to those who possess these. For example, Peter Singer concludes:

> Only a person can *want* to go on living . . . this means that to end the lives of people against their will, is different from ending the lives of beings who are not people. Indeed, strictly speaking, in the case of those who are not people, we cannot talk of ending their lives against or in accordance with their will, because they are not capable of having a will on such a matter . . . killing a person against her or his will is a much more serious wrong than killing a being that is not a person. If we want to put this in the language of rights, then it is reasonable to say that only a person has a right to life" (Singer, 1994, pp. 197-198).

Singer here reflects Locke's description of a "person," but also the capacity for consciousness as understood by modern neuroscience. Singer and others make a clear distinction between human beings and persons, not all of the former category can claim the rights and duties of the latter category; for Singer, personhood depends upon rational capacity defined in terms of brain function. Regarding PVS Singer concludes it is ethically comparable to brain death, "the most significant ethically relevant characteristic of human beings whose brains have irreversibly ceased to function is not that they are members of our species, but they have no prospect of regaining consciousness. Without consciousness, continued life cannot benefit them" (Singer, 1994, p. 207). As detailed in the previous chapter, current understandings of DOC preclude a simplistic division of individuals into those who have (or can regain) consciousness and those who lack (or will not regain) it. Jeff McMahan expresses a similar view:

> To my mind, the most plausible general view is that there are certain properties and capacities that give their possessor an inherent worth that demands respect. It is the possession of these properties and capacities that makes an individual one's moral equal and thus brings him or her within the sphere of justice (McMahan, 1996, p. 30).

McMahan concludes of the cognitively impaired that, "their claims on us seem weaker than those of most other human beings" and that "the treatment of animals is governed by stronger constraints than we have traditionally supposed, while the treatment of the cognitively impaired is in some respects subject to weaker constraints than we have traditionally supposed" (McMahan, 1996, p. 33). He does concede that agents who are closely related to them may owe cognitively impaired humans some degree of priority.

In regards to how we think about those with DOC it is important to acknowledge that the advent of modern neuroscience has led to brain function and rational capacity being intertwined. Martha Farah argues that in cognitive neuroscience mental states and brain states (which we have a new type of observational access to via neuroimaging) are generally considered to be "non-contingently related" (Farah, 2008). Farah and Andrea Heberlein argue that in fact personhood is an illusory category because it "does not correspond with a category of objects in the world" (Farah & Heberlein, 2010, p. 321). They point out that the brain is genetically preprogrammed to represent persons as distinct from other kinds of objects in the world, but that this system is quite autonomous (as opposed to consciously mediated) and can be triggered quite easily by non-human stimuli (Farah & Heberlein, 2010, p. 329). They conclude that there are no "objective criteria" for personhood and that instead of trying to establish a criteria "we should ask how much capacity there is for enjoying . . . psychological traits" such as "(intelligence, self-awareness, and so forth) and what the consequent interests of that being are" (Farah & Heberlein, 2010, p. 332). In essence, however Farah concludes that it is cortical function that is essential, stating of those with "severe cortical damage," or in "vegetative state": "one might call them living nonpersons," (Farah, 2010). Farah places an extremely high degree of optimism in the ability of neuroimaging to provide sufficient information for assessing how those in DOC ought to be cared for, saying, "Given the appropriate research program, there is no reason why we could not identify the neural systems, and the states thereof, corresponding to the self-concept and the desire to continue living" (Farah, 2008, p. 17). Others are far more cautious regarding the possibility of neuroimaging to solve such problems (Iannetti & Mouraux, 2010; Poldrack, 2006, 2009).

Singer and McMahan describe the essence of being a person as possession of the capacity for rational reflection. They use neuroscience, however, not philosophy as the justification for their views: it is brain function that makes rational capacity possible, it is the capacity for consciousness as mediated by cortical function that makes one a person. This may be a widely held assumption amongst the general public as well. A study exploring perceptions about individuals in PVS found participants believed those in PVS have less mental capacity than the dead (seemingly an outgrowth in afterlife beliefs) and in sense view them as "more dead than dead" (Gray, Knickman, & Wegner, 2011). As described in chapter one, however, cortical function cannot be defined as either existing or not; the neural functions associated with consciousness exist on a continuum, neural processes are dynamic not static, and mental states involve complex physical and functional aspects (Bassett & Gazzaniga, 2011). In chapter four, I will return to conceptions of personhood and identity by analyzing Ricoeur's understanding of selfhood.

The lived experiences of those who live in close connection to individuals who are severely cognitively compromised emphasize the importance of embodiment, emotional experience and relationship, and indicate the nonautonomous can in fact transform the lives of others. In conclusion I present two experiences of such transformation.

Lived Experience: Relationship with the Severely Brain-Injured

The painter Tim Lowly often paints his daughter Temma who is severely brain injured; he writes of his experience with her:

> Temma, as far as we know – and this is highly speculative – likely experiences the world without a great deal of memory. She at least has little way of showing each day that she remembers me, for example – and for all I know, she may be experiencing me as a new person each time I see her. As a parent, this was once – and occasionally still is – a point of sadness and loss for me. But I've also come to see this possibility as granting my relationship with Temma something of a profound newness and freedom – our relationship, perhaps like more relationships than we know, is compromised utterly of the present" (Lowly, 2013, p. 153).

This is not a father insisting that his daughter has capacity for a level of self-awareness medical experts deny; his reflection is not a refutation of medical authority; rather it is an expression of acceptance of capacities his daughter lacks (memory as it functions in human beings who do not have severe brain injury) accompanied by a personal experience of relationship with his daughter despite, or perhaps even, because of that limitation. Of Lowly's painting *Carry Me*, in which six women hold Temma in their arms, Brian Volk comments:

> Lowly locates Temma at the center of a community lightly bearing her, depicting his daughter neither as an embarrassment to be hidden nor a problem to be solved through a series of technological fixes . . . Temma gathers those who hold her into a body. She is not autonomous (she is literally a burden, however light) but her presence - her body – transforms individuals into a people (Lowly, 2013, p. 9).

The 1988 Frontline documentary special "Let My Daughter Die" follows the legal efforts of the Cruzan family to discontinue the ANH keeping their daughter, Nancy, alive in a PVS. In the film a complicated picture of their relationship with their daughter emerges. As the family fights to discontinue her ANH and states repeatedly that they do not believe that she has awareness and would not want to be kept alive in PVS, they speak to her and touch her as if she is aware of their presence and able to understand their expressions of love. They even speak to her about the progression of the court case, giving her updates as if she can understand the complex details of the American juridical system (Frontline, 1988). To an outside observer this can appear irrational, even absurd. In observing this family's struggle, however, it seems clear that rather than assessing they have less obligation to their daughter because of her limited mental life, if anything they experience an increased obligation. Rather than being "decision makers," they are still mother, father and sister. In part their obligation proceeds from the assessment that Nancy would not want to be kept alive in a PVS, but their appeal to the desire to protect her dignity bespeaks a more complicated concern than representing the choices they believe she would make. The legal system itself demands that they frame their argument in the language of individual rights and personal choice, but in their actual interactions with their daughter they acknowledge a complex experience (Frontline, 1988). The insistence of the legal system and the medical system, which together insist on conceiving of the scenario as a battle between the 'right to die' and the "right to life' diminishes the complexity of experiences such as theirs.

Conceptions of autonomy that focus heavily on independent decisional capacity and views of personhood that link cognitive capacity with moral status, regard severely brain injured individuals solely in terms of incapacity; their inability to act autonomously essentially reduces them to objects who can be acted upon, whose autonomy must be replaced by another's. This view cannot incorporate the aforementioned experiences in which intimates of these individuals are transformed by their cognitively impaired loved ones. The dominant view of autonomy conceives of persons primarily as disembodied rational minds (or as brains which enable rational reflection). These stories of transformation through relationship with individuals who are severely brain-injured concern emotional attachment more than rational reflection. A relational autonomy that embraces a concept of persons as not only rational, but also embodied, emotional and relationally connected, can speak to these complex experiences of autonomy in which the intimates of cognitively impaired humans experience a unique type of mutuality in relationship with them. As I will describe in chapter four, Ricoeur, in his description of persons as "acting and suffering" asserts that vulnerability is an integral part of our humanity and that while dissymmetry does occur in relationships, solicitude rather than substituted autonomy more fully recognize the humanity of those made especially vulnerable.

Chapter 3: Sanctity of Life and Suffering: Sources of Tension in the Care of those with DOC

Medical decision-making in cases of chronic DOC has been brought to the attention of the public through high-profile cases of legal dispute. High-profile cases include the *Quinlan, Cruzan, Schiavo* cases in the US, the *Bland* case in the UK, the *Englaro case in* Italy and the *Rasouli* case in Canada[11]. Legal cases necessarily require a focus on the underlying "rights" involved; in the US cases have concerned the constitutional right of privacy, the common law right of personal autonomy/self-determination and the liberty interest in having the right to live (and die) according to one's own values; these have been weighted against the states' interest and responsibility in protecting and preserving the lives of its citizens (Ball, 2012; Colby, 2006; Ekland-Olson, 2013; Nelson & Cranford, 1999). Clarifying the scope of these rights in the context of medical decision-making has been important, but centering the conversation through the perspective of legal rights has come at the cost of erasing some of the complexities and tensions with which families struggle. Dichotomous frameworks, such as the RTD/RTL can lead us to ignore or disregard information that complicates the clear distinctions between the two sides; such frameworks also compel us to take sides. In *If That Ever Happens to Me: Making Life and Death Decisions after Terri Schiavo* Lois Shepherd writes:

> We fall along political lines, associating end-of-life law with other liberal and conservative issues. Unfortunately, media and political pressures have led us to too many easy answers, rallying around "right to die" and "right to life" as if these slogans could capture the real values that underpin our appreciation of health and life. If this way of looking at these issues becomes predominant, then we will trail further behind in rather than closer to improving our ethical and legal understanding of how best to make these decisions (Shepherd, 2009, p. 176).

Arguments for the "right to life" usually hinge on convictions about the "sanctity of life," while those for the "right to die" on the right to self-determination.

In my experience working as a hospital chaplain, the concerns of families and medical providers, including those with strong religious convictions, often did not fit neatly into to one or the other side of the dichotomy. The tensions involved for families making medical decisions for loved ones with chronic DOC do not solely concern beliefs; families experience

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[11] For information on the following: for *Quinlan, Cruzan* and *Schiavo* cases, see (Colby, 2006)*;* for *Bland* case, see (British Medical Journal, 1992)(ACRM Brain Injury-Interdisciplinary Special Interest Group DOC Task Force, 2010; Schnakers et al., 2009); for *Englaro* case see ; and for *Rasouli* case see: (Striano, Bifulco, & Servillo, 2009).

painful emotions and struggle with conflicting commitments. As with families facing other types of critical illness in a loved one, most families' decisions proceed neither solely from religious/philosophical beliefs nor from the medical information as given by a physician or other medical providers (Boyd et al., 2010; Long, Clark, & Cook, 2011; Schenker et al., 2012; Schenker et al., 2013). I supported families who decided to initiate and/or continue with LST, including long-term ANH, and those who decide to withhold or withdraw LST, including ANH; these families equally valued the life of their loved one and considered his/her life to be "sacred," in the sense of being worthy of unique respect and love. However, many felt ambivalence and uncertainty about whether or not the DOC patient was indeed still "alive;" and whether and to what degree he or she might be suffering. Families often agonized over decisions about LST, and ANH in particular, in part because they considered each choice about initiating or withdrawing LST in relation to whether and in what ways the decision might cause the individual to suffer. Over time some of those who experienced ambivalence and uncertainty clarified and solidified their beliefs, others continued to be deeply ambivalent. In this chapter I explore the concepts of sanctity of life and suffering and the unique tensions and complexities that lived experiences of those close to someone with DOC pose for these concepts. Since concepts have strong roots in religious traditions, I will address how Christian understandings of these concepts resonate with and diverge from medical ones; I focus on Christian understandings because it is the tradition with which I am most familiar and because Christian leaders have been heavily involved in the public conversation about the care of those with DOC.

The "Sanctity of Life": Religious Roots

In North America, right to life arguments proceed from the conviction that all human lives are sacred by virtue of being created by God. The use of the phrase "sanctity of life" is a fairly recent development; Fr. James Keenan points out that the phrase did not appear in any Catholic dictionary prior to year 1978 (Keenan, 2005). As Keenan claims, however, the phrase does have roots in prior Christian writings, for example in writings condemning suicide. Keenan describes a development in the Catholic understanding of the phrase; the focus, he explains, begins on the idea of human lives as created by God and therefore owned by God: "At its roots sanctity of life is about *God's* ownership; we do not own our lives; God does. Therefore we are not free to dispose of them" (Keenan, 2005, p. 53). Pope John Paul II, further developed the meaning of the phrase and drew the focus from the human being as an object owned by God to "a subject that bears the inviolable image of God" (Keenan, 2005, p. 54). The notion of the sanctity of life has intersected with bioethical issues primarily in the areas of the beginning of life (birth control, abortion and reproductive technology) and the end-of-life (withdrawal/withholding of LST, euthanasia and Physician Assisted Suicide - PAS). In 2004, John Paul II issued a statement on the care of those in PVS in which he stated that ANH should not be considered medical care but "comfort care," and in principle should be continued in those in PVS, because they are still persons in every sense of the word (O'Rourke, 2006). Other religious bodies express similar convictions regarding the sanctity of life. In relation to end-of-life care, withdrawal or withholding of ANH, the perspectives expressed within other monotheistic religions generally share the primary themes of the official Roman Catholic viewpoint: (1) the lives of human beings are sacred by virtue of being created by God and therefore are uniquely valuable, (2) all human lives, including those with DOC, are equally valuable and worthy of being preserved (these views tend to interpret DOC as severe disability rather than as a separate category) (3) the legalization of abortion, PAS, and euthanasia are dangerous and represent a trend towards devaluing human life, and religious people have an obligation to oppose them (Alibhai, 2008; Cameron, 1996; Cohen-Almagor & Shmueli, 2000; Lammers & Verhey, 1998; Maxon, 1982/1998; O'Rourke, 2006; Pellegrino, 1996). It is important to note that, within religious traditions, even those with centralized structures that publish official doctrinal opinions on biomedical issues, varying perspectives exist. For example, Fr. O'Rourke writes of the aforementioned papal allocution, "The statement was received with dismay by many people inside and outside the Catholic healthcare ministry;" he concludes that in regards to the long-term ANH in those with PVS the decision should be left to the patient (accessed through advance directives and/or statements made previous to becoming incapacitated), his or her proxies and those involved in the case (O'Rourke, 2006, p. 83).

DOC and Sanctity of Life: Ontological Status and Moral Status

In the United States in particular high-profile treatment withdrawal cases have been highly politicized, in part because they have been linked to the country's intense abortion debate (Colby, 2006; J. Perry & Bishop, 2010a; J. E. Perry, 2006). Joshua Perry points out that particular politicized Christian voices, which he refers to as, "politicized religious forces" and the "Religious Right," were instrumental in publicizing and politicizing the legal battle surrounding ANH withdrawal for Terri Schiavo; he refers to this type of involvement by religious leaders “Biblical Biopolitics” (J. E. Perry, 2006). Perry uses the word “Biblical” to refer to “a commitment to the advancement of societal transformation premised on a literal interpretation of the Bible and fervent allegiance to biblical authority, church doctrine and/or religious tradition,” adding that “these commitments are most frequently found among ‘fundamentalists and fundamentalistic evangelical’ Christians, but are also shared by their political allies, including Roman Catholics and some Jewish communities” (J. E. Perry, 2006). He employs the term “Biopolitics” to describe “the Religious Right’s legislative and public policy agenda in the realm of medical and health-related issues, including, for example abortion, emergency contraception, embryonic stem-cell research, and euthanasia, *inter alia*—subjects within the traditional purview of bioethics and health law” (J. E. Perry, 2006, pp. 555-556). Perry begins his article with quotations from prominent leaders of the Religious Right including James Dobson of the group *Focus on the Family*, Tony Perkins of the *Family Research Council* and Randall Terry of *The Society for Truth and Justice* and *Operation Rescue*. It is true that these leaders Perry admonishes used “irresponsible rhetoric in discussing Terri Schiavo;” for example James Dobson stated, “Is every mentally disabled human being now fair game . . . ? Apparently all they have to do is assert that starvation is what the victim wanted, and then find a wicked judge like George Greer who will order them subjected to slow execution. . . . It is eerily similar to what the Nazis did in the 1930s. They began by 'euthanizing' the mentally retarded, and from there, it was a small step to mass murder” (J. E. Perry, 2006, pp. 617-618). Such extreme views provide good scapegoats for decrying the involvement of religious viewpoints in bioethical issues, but they do not necessarily represent the viewpoints of most individuals who describe themselves as religious or even of most religious leaders.

Perry focuses on the involvement of anti-abortion activists in supporting the opposition of Terri’s parents to ANH withdrawal (J. E. Perry, 2006). Anti-abortion activists also publically opposed the Cruzan families attempts to seek ANH withdrawal for Nancy (Colby, 2006). However, not all see a link between abortion and withdrawal of LST for those in PVS. Joe Cruzan, Nancy’s father stated, “I think a lot of pro-lifers try to interweave our situation with the abortion law, but their mixing apples and oranges. The fetus has potential for a life, but our daughter hasn’t. I just can’t understand why they criticize us, and I don’t know why they see things in black and white. None of the questions in Nancy’s situation can be answered in black and white” (Colby, 2006, pp. 172-173). Cruzan’s statement that his daughter “does not have potential for life", highlights the ambivalence and uncertainty over the "ontological status"[12] of those in DOC, especially those in PVS.

James Dobson, leader of the evangelical Christian group, *Focus on the Family*, said after the death of Terri Schiavo, "We've all been diminished by this slow agonizing killing of a woman who had done absolutely nothing to deserve such cruelty;" sounding surprisingly similar, a family member of a chronic PVS patient speaks of the possibility if ANH withdrawal thus, "To starve somebody to death seems a particularly cruel thing to do" (Colby, 2006, p. 166; C. Kitzinger & Kitzinger, 2014, p. 3) This family member does not take the stance that long-term ANH must be provided; he objects to the method, not to taking action that will lead to the patients death: " I would view it [a lethal injection] as a kinder decision […] Because if you stop feeding them, they are going to die. If you've made that decision, you might as well do it as humanely as you possibly can. […]"(C. Kitzinger & Kitzinger, 2014, p. 3). Dobson and others who share his interpretation of the sanctity of life as applied to appropriate treatment and care of those with chronic DOC argue that ANH ought to be continued, but this family member of an individual in PVS argues that euthanasia would be a humane response; both refer to ANH withdrawal as cruel. One of the factors that seems to lead to such different conclusions is assessment of whether or not the individual in PVS is truly or completely "alive."

Those in PVS are biologically alive in the sense that the individual has not suffered "whole brain death" leading to the "permanent cessation of circulatory and respiratory functions" and the "ordinary function of the organism as a whole' (Bernat, 2009a; Holland, 2010; Holland, Kitzinger, & Kitzinger, 2014). However, some family members and medical providers who care for these patients express ambivalence about the patient's "ontological status," that is whether they are truly "alive;" similar ambivalence has been expressed in judicial responses to request for or conflicts about withdrawal of LST. Stephen Holland argues that, though our ordinary concept of death accommodates the biological definition, it also includes the "thought that for someone who has died, there will never again be anything it is like to be that person" (Holland, 2010, p. 113). Holland argues that this latter understanding of death is captured by the consciousness definition of death, which claims that death occurs at the irreversible loss of

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[12] I follow others in using the term "ontological status" to refer to the nature of the existence of these individual, not the value of their existence which is described by the phrase "moral status."

the capacity for consciousness.[13] As proof of his argument that the ordinary concept of death contains the concept of death as permanent loss of the capacity for consciousness Holland highlights death as presented in literature and he analyzes and critiques research studies which have queried individuals understanding of death in relation to borderline cases such as anencephaly and PVS (Bernat, 2009b; Holland et al., 2014). I addressed concepts of personhood and consciousness in chapter two; here I return to them not to analyze them as philosophical concepts, but to consider them in relation to the lived experience of those who are close to an individual with DOC, particularly those in PVS. In their interviews with family members of those with DOC, Celia and Jenny Kitzinger found that some family members expressed deep ambivalence about their loved one's ontological status. For example one family member of a woman in PVS stated, "What we are convinced about is that uhm, from everything that we can find out, it is not in Zoe's [the patient's] best interest to be still alive. 'Cause she's existing. She isn't living;" another relative of the same patient explained, "it's between life and death. You're in no man's land, basically" (Holland, 2010, p. 113). A family member of another patient vacillates in the interview and describes the patient (here called "Aaron") as both dead and alive:

> He's already dead. The only reason he's not dead is because his heart pumps […] And we're not sure whether he reasons because we don't know enough. But what we do know, or what information we have got at this present time, is he's effectively dead. . . Aaron hasn't got a life to lead. Or live. And I suppose that is the difference between Aaron and my friends that have died, right? They've died. Their life's ended, and it's gone. Aaron is alive but he hasn't got a life to live. I don't know if that makes sense (*emphasis in original text*) (Holland et al., 2014, p. 5).

Joe Cruzan expressed a similar ambivalence when, as quoted above, he describes Nancy as "not having a life to live." I too encountered family members who expressed ambivalence and would describe the PVS patient as both dead and alive, "here" and "gone," "existing but not living," or in an in-between state reflective neither of life nor death. Celia and Jenny Kitzinger acknowledge that some may assume that when these family members speak of the a PVS patient as being dead, they mean it only metaphorically. As evidence against this argument, they point to differences between how relatives of those in MCS describe the patient's status

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[13] For more information about definitions of death based upon loss of capacity for consciousness or cessation of higher-level brain function, see: (Machado & Shewmon, 2004)(Downar, Sibbald, Bailey, & Kavanagh, 2014).

compared to relatives of those in PVS; they conclude:

> Respondents' talk of the MCS patient being alive is literal; their acute sense that the person they knew before the injury having 'gone' leads them to speak metaphorically of their being dead. By contrast, the discourse illustrated in the previous section about PermVS patients is not metaphorical but, rather, expresses respondents' struggle to articulate the PermVS patients' ontological state (Holland et al., 2014, p. 7).

I do not claim that we ought to deduce from the ambivalence these family members experience that those in PVS should be labeled as dead, but merely to engender compassion for the degree of ambivalence and confusion that some family members experience. It is important to note that these family members are not making claims about whether the life of their loved one in PVS is worthy of being preserved, rather they are expressing ambivalence about whether they are truly alive or not; they are speaking of their ontological status, not to their moral status.

Judicial decision-making has mirrored to a degree the aforementioned distinction in which those in PVS are considered to have unclear ontological status, while those in MCS are considered to have clearer ontological status, even if the awareness they possess is seen by some as making their situation more difficult since they may suffer more. For distinctions regarding judicial decisions about those in MCS cases have contrasted to decisions about those in PVS, see: Nelson and Cranford 1999.

Are DOC a form of Disability?

As quoted above, James Dobson invoked Nazi euthanizing of the "mentally retarded" to argue that Terri Schiavo's ANH should be continued, because allowing ANH withdrawal in her case would threaten the lives of all people with cognitive disabilities (Holland et al., 2014, p. 5). The characterization of Terri Schiavo and other PVS patients as "disabled" is controversial, and whether those in PVS fit the category of "disabled" has serious implications. Joe Cruzan was also accused of being a "Hitler" and a "Nazi," and the Nursing Home Action Group (NHAG), a non-profit organization composed of members with physical and mental disabilities, filed a brief accusing him of "discriminating against the handicapped;" Mr. Cruzan responded by saying, "She is not disabled for Christ's sake . . . What do they think, with some wheelchair access ramps she'll be back in the marching band!" (Colby, 2006, p. 176). Neuroscience experts too have cautioned against inaccurate description of the neurologic condition of those in PVS including the use of the word "disabled," especially when employed by the media (Racine et al., 2008). The disability advocate group, Not Dead Yet (NDY)[14] was actively involved in opposing the removal of ANH for Terri Schiavo. Nick Drake a research analyst for NDY published an op-ed that first appeared in the L.A. Times; Drake begins the article by stating, "Bob and Mary Schindler consistently refer to their daughter, Terri, as a disabled person. They're right. Although most newspapers are covering this story as an "end of life" or "right to life" issue, what ultimately happens to Terri Schiavo will affect countless other people with disabilities in this country" (Drake 2003).[15]

The history of the treatment of persons with disabilities by medical and legal institutions understandably gives cause for concern. From State-ordered sterilization of individuals with intellectual disabilities (then called "mental defectives"), to decisions to withhold feeding from infants with Down Syndrome (Trisomy 21), to mistreatment of institutionalized children with cognitive disabilities such as in those housed at the Willowbrook State School[16], there are ample examples of mistreatment of individuals with intellectual disabilities (Colby, 2006; Pollack, 2011). The long history of maltreatment of persons with intellectual disabilities should be remembered and should remind us how readily societal institutions have devalued the lives of those with disabilities. The devaluation of the lives of those with intellectual disabilities, and failure to develop and maintain supportive care environments for those who need them, can lead to assessments that these individuals' lives are not worth living. Stanley Hauerwas describes, "When I was in the Association of Retarded Citizens, I would go into the Cardinal Nursing Home in South Bend, Indiana and see fifty people in the day room. Their clothes were stripped off, and they were often sitting in their own feces. The place was designed, I am afraid, to produce in visitors the reaction, 'These people would be better off dead;'" Hauerwas concludes by describing how the institutional environment and lack of the caring presence of others, not the capacity of these individuals, was the affecting factor, "If you took those same people in put them in a residential home with people who care about them, you might want to have a meal

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[14] The group describes itself thus on its website: "Not Dead Yet is a national, grassroots disability rights group that opposes legalization of assisted suicide and euthanasia as deadly forms of discrimination against old, ill and disabled people. Not Dead Yet helps organize and articulate opposition to these practices based on secular social justice arguments. Not Dead Yet demands the equal protection of the law for the targets of so called "mercy killing" whose lives are seen as worth-less"

[15] Other advocates of people living with disabilities have similar framed ANH withdrawal in those with DOC as a "disability rights" issue, see (Fadem, et al., 2003; Goodman, 2009; Johnson, 2006; Shildrick, 2008).

[16] The Willowbrook State School was an institution on Staten Island, NY for mentally ill or delayed children that was widely decried as inhumane; a research study on Hepatitis A performed there was later deemed by many to be unethical (Films for the Humanities and Sciences Group, 2012). For general information see: .

there" (Hauerwas & Vanier, 2008). Recognizing the wholeness of those with disabilities is essential, and likely will come only when those of us fit the societal and medical criteria necessary to carry the labels "normal" or "non-disabled," see that we too are vulnerable and dependent (Hauerwas, 1986; Hauerwas & Vanier, 2008; Reynolds, 2008).

I describe these concerns expressed by "disability rights" advocates and persons with disabilities, because their concerns demand a hearing, and because it is important to acknowledge that the publically voiced opposition to withdrawal of ANH from those with DOC has not come solely from the politically powerful nor from the religiously motivated. These concerns expressed by disability activists do not erase the fact that some individuals, including loving family members and experienced neuroscience researchers, view individuals in PVS as residing in a category essentially different from "disabled." Even if we argue that those in PVS are not accurately described by the term "disabled," it may be unclear exactly when the label becomes relevant, especially when considering those in MCS who manifest an array of intentional behaviors. Any attempt to categorize will to a degree be arbitrary, though this does not necessarily render such categories irrelevant or useless. Neuroscientist Joseph Fins encourages a balanced response that fully considers DOC as a spectrum and does not limit considerations to PVS:

> Instead of staking out ideological positions that do not meet the needs of patients or families, we should strive to both preserve the right to die for those who are beyond hope while affirming the right to care to those who might benefit from coming advances in neuroscience. If we can achieve that delicate balance, we will be able to transcend the partisan debate that shrouded the life and death of Theresa Marie Schiavo and begin to articulate a palliative neuroethics of care for those touched by severe brain injury and disorders of consciousness (Fins, 2006, p. 169).

Fins encourages carefully considering whether the patient "will regain the ability for functional and reliable communication" (Fins, 2006, p. 175). The term "Palliative Care" has multiple definitions; here Fins employs the phrase to advocate for articulating goals of care for those with DOC "that minimize the physical and bio-psycho-social burdens experienced by patients and their families" (Fins, 2006, p. 178).

The term sanctity of life is employed primarily to represent the religious conviction that human beings are uniquely sacred by virtue of being created by God and/or made in God's image. However, the ways in which this phrase is interpreted in relation to those with DOC varies and in part depends on assessment of individuals' ontological status; ambivalence regarding DOC patients' ontological status may be especially pronounced regarding those in PVS. The concerns expressed by some disability advocates should be carefully considered. However, the term "disabled" should be recognized as normative rather than strictly descriptive; it has meaning only in relation to a presumed notion of being "abled." Many terms associated with "quality of life" are similarly ambiguous. We have a tendency to attempt to resolve tensions with easy answers: ANH withdrawal in those with DOC is either "killing a disabled person," or an act of compassion to release someone from an existence in-between life and death; the difficult irony for those closest to an individual with DOC is that ANH withdrawal or even euthanasia may *feel* like both of these acts at once. The lived experiences of those close to someone with a DOC should always be met with understanding rather than accusations, and those who speak irresponsibly in the public forum should be held to account. To describe the ethical concerns involved as simply a battle between the liberal value of autonomous choice and the conservative value of respect for life does potential harm to the family members of DOC patients who daily struggle with these tensions.

Pain and Suffering

Becoming a Witness to Suffering

The relief of suffering has long been one of the goals of medicine (Cassell, 2004). Suffering has also been a primary concern of Christian theology. Jürgen Moltmann, describes "the open wound of life in this world" as the beginning of all theology (Moltmann, 1993, p. 49). Suffering, however, is not easily defined. Stanley Hauerwas, who has written extensively about suffering, explains:

> After trying to read all I could get my hands on concerning the meaning of suffering, I am convinced that never has there been a word used with such an uncritical assumption that everyone knows what they are talking about . . . Perhaps the absence of the kind of analysis about suffering we desire tells us something about the grammar of the word – namely that any use of the notion of suffering is context dependent. Our assumption that suffering is a universal phenomenon makes us forget that we can only talk intelligently about it through the use of paradigm instances (Hauerwas, 1986, p. 29)

Hauerwas, writes that we can only talk intelligently about suffering through the use of paradigm instances and that the notion of suffering is always context dependent; I begin therefore with the context that prompted this academic project. I remember many patients and families whom I met in my years of service as a hospital chaplain. There are some for whom the word "remember" does not seem adequate; I do not simply remember them, rather, I am haunted by the memories of their suffering. At times, however, it was difficult for me to know whether it was their suffering or my own that I sought to relieve, or even whether these two desires could be separated. One particular patient, who was in a MCS, stands out to me; "Robert,' as I shall call him, did not speak and the level of his awareness of self and environment was variable and difficult to assess. His expression, the look in his eyes, however, I can only describe as an expression of terror, and it was nearly unremitting; providing treatment for pain did not remove it and neither did any attempts made to connect with him, though he regularly maintained sustained eye-contact. Sitting at his bedside on a nearly daily basis, attempting to offer a supportive and caring presence left me with still lingering questions. How could I be sure that he was suffering? Was my presence supportive or an additional burden? What more could I and other clinicians possibly have done to relieve the suffering we seemed to perceive? Is it possible that there is suffering for which relief is achieved only in death? I proceed by analyzing the concept of suffering though medical paradigms and through the lens of Christian theology, yet my experience with this one particular patient will remain at the forefront of my thinking. I agree with Marsha Fowler, a nurse and bioethicists, that the issue that "underlies all clinical ethical dilemmas . . . is that of tragedy or suffering," not the clashing of philosophical principles (Fowler, 1996, p. 47). I do not present my experience with Robert to turn him into an object for analysis, but rather to assert that, though I consider suffering as a concept, ultimately I hope for my analysis to do justice to Robert and all who suffer in what Susan Sontag describes as "the kingdom of the sick;" a kingdom which, as she attests, we will all be citizens of, if only for a time (Sontag, 1978/1989, p. 3).

Witnessing the suffering of a patient can engender feelings of helplessness, shame and guilt in family members as well as medical providers. Deeming a patient's suffering to be caused by the medical treatments being provided has also been associated with "moral distress" in medical providers (Oberle & Hughes, 2001; Thorup, Rundqvist, Roberts, & Delmar, 2012). Research indicates that some medical providers who work specifically with patients with DOC experience depression or other types of emotional distress (Chiambretto, Moroni, Guarnerio, Bertolotti, & Prigerson, 2010; Chiambretto, Rossi Ferrario, & Zotti, 2001; Gries et al., 2010; Leonardi, Giovannetti, Pagani, Raggi, & Sattin, 2012).

Many families I supported expressed concerns about the suffering of their loved one; combined with uncertainty regarding hopes for his or her recovery, this often engendered anxiety and fear about “making the wrong decision;” indeed, research reveals serving as a surrogate decision maker can be stressful and even traumatizing (Anderson, Arnold, Angus, & Bryce, 2008; Tyrie & Mosenthal, 2012). Situations involving patients with chronic DOC who family members and/or medical providers perceived to be suffering (but were not by definition “terminally ill”), seemed to place some in a double-bind of emotionally-laden and provocative questions. In one moment they would ask, “how can we keep torturing him?” and in the next, “wouldn’t withdrawing ANH be starving him to death?” Part of the difficulty seemed to be that, when the sole LST being provided was ANH, suffering was attributed to the patients’ existence in his or her current state, and amelioration of these patients’ suffering was therefore interpreted to be achievable only by withdrawing ANH and allowing the patient to die; an act which some considered to itself be a form of cruelty. Some of the family members interviewed by Celia and Jenny Kitzinger speak to this tension (C. Kitzinger & Kitzinger, 2014; J. Kitzinger & Kitzinger, 2013). I turn now to an analysis of the concept of suffering in medicine and in Christian theology.

A Paradox: Relieving Suffering or Causing Suffering

In *The Nature of Suffering and the Goals of Medicine* Eric Cassell describes his purpose for addressing the topic thus:

> The obligation of physicians to relieve human suffering stretches back into antiquity. Despite this fact, little attention is explicitly given to the problem of suffering in medical education, research or practice. I will begin by focusing on a modern paradox: that even in the best settings and with the best physicians it is not uncommon for suffering to occur not only during the course of a disease but as a result of its treatment (Cassell, 2004, p. 29).

The paradox that the practice of medicine serves to alleviate suffering and yet also can causes suffering has existed from early in the history of modern medicine; for example, surgery without anesthesia was once the only option (Morrant, 2013). In his poem “Surgical Ward” W.H. Auden writes:

> They are and suffer; that is all they do; / A bandage hides the place where each is living. / His knowledge of the world restricted to / The treatment that the instruments are giving. / And lie apart like epochs from each other / - Truth in

> their sense is how much they can / bear; / It is not like ours, but groans they smother - / And are remote as planets; we stand elsewhere" (Auden, 1945/1998).

Concerns that some medical treatments caused too much suffering took on particular energy as medical technology increased, life support machines such as mechanical ventilators became standard, and the modern Intensive Care Unit (ICU) came into existence. Patients and their surrogates began to assert their "right" to free themselves from such technologies. Marsha Fowler examines the presence of medical technology in editorial cartoons over a 15 year period and contends that, over time, medical technologies progressed from being presented as positive or benign to being depicted as ominous; Fowler describes a cartoon by Pat Oliphant (1989) to illustrate this dark view of technology: "a moribund patient, whose head alone shows above the bed sheets, is surrounded by a morass of life-sustaining technology, dripping wires, and lines. The caption reads, 'Condemned to Life'" (Fowler, 1996). Lawyers representing patients and their surrogates began to characterize the use of medical technologies in some situations as a form of "bodily invasion" and even as acts of "battery" (Ball, 2012; Bishop, 2011; Colby, 2006; Ekland-Olson, 2013).

Some patients have also described the experience of medicine as a controlling institution to be a source of suffering. Arthur Frank analyzes the way patient-written illness narratives attribute suffering to medicine:

> Becoming a victim of medicine is a recurring theme in illness stories. The incompetence of individual physicians is sometimes an issue, but more often physicians are understood as fronting a bureaucratic administrative system that colonizes the body by making it into its 'case.' People feel victimized when decisions about them are made by strangers. The sick role is no longer understood as a release from normal obligations; instead it becomes a vulnerability to extended institutional colonization (Frank, 1995, p. 176).

Frank describes in particular the ways in which patients' experience of illness is increasingly dominated by the institutional and bureaucratic aspects of medicine. Medicine, though purposed with alleviating suffering, can, according to the above descriptions, become a source of suffering: it can isolate an individual from the rest of society, objectify and reify the individual as a "case," invade the privacy of an individual's body with its technologies, and exercise a controlling power.

Defining Suffering

Cassell precedes his analysis of the nature of suffering by considering the category of the *person*. Cassell points out that the idea of persons as characterized by individuality is a fairly modern concept; he writes, "political individualism is fundamental to our national heritage, yet its origins are in the seventeenth century and only in the last century has it come to stand for the unprecedented degree of personal freedom we enjoy" (Cassell, 2004, p. 33). Cassell also posits that medicine has often failed to understand the comprehensive nature of suffering, because in the underlying mind-body dichotomy, "person" has more readily been associated with "mind," while medicine has been assigned the body as its object of concern. When mind is associated with the spiritual and the subjective, "suffering is either subjective and thus not truly 'real' – not within medicine's domain – or identified exclusively with bodily pain;" thus, he warns, "Because of this division, physicians may, in concentrating on the cure of bodily disease, do things that cause the patient as a person to suffer" (Cassell, 2004, p. 33). Before considering the ways a person can suffer Cassell proposes the following factors as descriptive of persons: persons possess a lived past, a family, a cultural background, roles and relationship with others, and relationship with oneself; a person has a political being as a member of society, agency and the capacity to act, a body, a secret life, a perceived future and a transcendent dimension (Cassell, 2004, p. 33). Cassell cautions against attempts to reduce persons to their parts, but highlights these multiple factors to emphasize the complexity of persons.

Suffering, Cassell explains, is: (1) experienced by whole persons who cannot be divided into mind and body, (2) involves a state of severe distress in relation to events that are perceived to threaten the intactness of the person, and (3) can occur in relation to any aspect of the person (Cassell, 2004, pp. 39-40). He also emphasizes that suffering has temporal and relational components: "A sense of time is necessary for suffering; more than a future, there must also be an enduring past. I must have some sense of how I am constituted and what I can do to fear the loss of a piece of myself – and for that I must have a past. The person's idea of self must include others in order for the person to know what he or she can do or be" (Cassell, 2004, pp. 273-276). The importance of memory to the possibility of experiencing suffering has also been asserted by neuroscientists: Schnakers and Zasler (2007) write, "pain perception must be differentiated from suffering, as the latter involves a complex cognitive-affective phenomenon involving not only a negative emotional response to the pain experience but also the ability to remember that particular experience or set of experiences" (2007, p. 622). Cassell focuses on the loss of identity as the source of suffering, while Schnakers and Zasler focus on events (in this case one of pain experience) that can be remembered and presumably feared.

A 2001 case study that documents the recovery of a woman who developed a severe encephalomyelopathy and was in a VS/UWS or MCS (diagnosis somewhat uncertain) for 6 months includes the following written communications from the patient about her hospital stay:

> My stay there [in the initial hospital] was absolute hell they never told me anything. They used to suction me through my mouth and they never told me why . . . I can't tell you how frightening it was especially suction through my mouth. I tried to hold my breath to get away from the pain. . . you must tell them [patients] every thing especially if it hurts . . .if they had told me what they were doing and why it would have made it so much easier for me (Wilson, Gracey, & Bainbridge, 2001, p. 1098).

The patient's statement reflects both of these intersections of memory and suffering: a discrete pain experience is remembered in detail, and not being told what was happening is experienced as a loss of agency. The patient's initial statement, that the stay was, "absolute hell" illustrates the complexity of suffering. What exactly does "hell" represent for this particular patient? As Stanley Hauerwas contends, "the interpretive character of suffering will defy neat analysis" (Hauerwas, 1986, p. 28). Hauerwas argues that suffering "has at its root sense the idea of submitting or being forced to submit to and endure some particular set of circumstances," as he points out we often speak of an individual as suffering *from something* (Hauerwas, 1986). The notion of "suffering from" something is often articulated in laws allowing Physician Assisted Suicide (PAS) or other types of Physician Assisted Death (PAD)[17]. For example, Bill 52 in Quebec, utilizes the term "medical aid in dying," defined as: "a treatment consisting of the administration of drugs or substances by a physician to a person at the end of life, at that person's request, in order to relieve his suffering resulting in his death" ("An act respecting end-of-life care," 2014, p. 11). It requires that, in addition to being of full age, able to give consent, and be insured under the Quebec health system, a patient seeking aid in dying must:

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[17] Terminology used to describe medical practices at the end-of-life, especially in regards to causing death or giving another the means to cause her/his own death, have varied over time and can be quite confusing. PAD is generally an umbrella term. PAS generally refers to physicians giving patients means to end their own lives; "medical aid in dying" as stated involves physicians taking action themselves to end a patient's life, for example by lethal injection (in this past this has been termed "active, voluntary euthanasia"); this practice if used, for those in DOC would be "nonvoluntary" rather than voluntary since the individuals cannot consent (it is not "involuntary" since this would refer to acting against the will of the patient). The termination of treatment including withdrawal of ANH is not considered a type of PAD.

> (2) be at the end of life
> (3) suffer from an incurable serious illness;
> (4) be in an advanced state of irreversible decline in capability; and
> (5) experience constant and unbearable physical pain or psychological suffering which cannot be relieved in a manner the person deems tolerable (“An act respecting end-of-life care,” 2014, p. 11).

Some argue that while purporting to provide individuals with serious illness the opportunity to exercise greater choice and control over their lives, such laws in fact further subsume the personal and private under the authority of the State. Though the individual can contend that he or she suffers from intolerable pain, it is the bureaucracy of the State which holds the power to approve the claim (Bishop, 2011; Cameron, 1996).

Suffering, Hauerwas argues, does not always primarily concern passivity, but in the medical context, “the passive aspect of suffering seems to dominate” (Hauerwas, 1986, p. 28). Cassell describes the paradox of medicine that the physician though seeking to alleviate suffering may need to employ treatments that in fact cause suffering. This paradox, however, seems to proceed from a deeper paradox: we seek to eliminate suffering and yet recognize suffering as an inevitable part of life:

> I began to think that there is something odd about our sense that death is better than a life of suffering . . . the alleged obligation of doctors to eliminate suffering cannot be understood to be unqualified. This is so not only because we know that the therapy can require us to endure suffering, but also and more importantly because it seems odd that in the name of eliminating suffering, we eliminate the sufferer. . . the idea that a child might be allowed to die in order to spare it a life of suffering is inconsistent with our usual approach to the suffering we inevitably experience as a part of life. The only difference is in kind, degree and time (Hauerwas, 1986, pp. 23-34).

Hauerwas challenges the notion that the elimination of suffering can be an unqualified goal of medicine. He concludes that, “in the face of the constant temptation to try to eliminate suffering through the agency of medicine,” we must “let medicine be the way we care for each other in our suffering” (Hauerwas, 1986, p. 17). Attempting to replace the goal of eliminating suffering with the care of the sufferer involves a subtle, but crucial change in focus from the experience of suffering to the person who suffers. While a focus on caring for the suffering person may be commendable, the paradox remains. Certainly there are some instances in which eliminating the suffering is the care the sufferer desires. Who when experiencing pain would not articulate a hope for that pain to be eliminated?

The Pain is in My Soul: Can Suffering Be Distinguished from Pain?

The above section heading comes from an experience I had with a patient. He stated that he was in pain and repeatedly pointed to his chest area. Well-meaning hospital staff, including myself, attempted to assess the source of his pain: “Is it in your chest?” “Is it in your rib?” “Is it in your arm?” To every questioned, the patient shook his head “no.” Finally, in an outpouring of frustration, he yelled, “it’s in my soul!” Clifford Woolf contends that the biologic and mechanistic aspects of pain are distinct from psychological or spiritual interpretations:

> We are now finding ‘pain’ genes without having to consider the metaphysical aspects of pain. This is not to belittle suffering or spiritual unease, just to say that they are altogether different experiential categories, ones that happen to share through metaphorical allusion to the word ‘pain.’ When pain is used in a literary, religious, or symbolic context, it is infused with a meaning that is fundamentally different from that of neurobiological sensory pain, and there is no *mechanistic* commonality (Woolf, 2007, p. 27)

Yet, even if sensory pain can be reduced to its neurobiological processes, this does not necessarily indicate that the experiences of pain and suffering can be neatly separated. Arthur Kleinman responds to the notion that pain and suffering can ultimately be relegated to distinct categories by arguing, “we are going to continue to have human experiences that simply don't accommodate themselves to that sort of separation into suffering and pain as two distinctive things” (Kleinman, 2007, p. 123). Cassell expresses a similar conviction and emphasizes the inseparable cultural, relational, and emotional aspects of the experience of pain:

> Pain is not only a sensation; it is also an experience embedded in beliefs about causes and diseases and their consequences . . . It occurs in a setting (e.g., home, hospital, or hospice) and in a context that includes relationships with others . . . that make it perhaps lonely and estranged for one patient, or supported, cared about, or loved for another. Each of these features combines and coalesces over time to personalize the pain . . . Pain may also occur as a part of or as the sole expression of an emotional state (Cassell, 2004, pp. 267-273).

Cassell describes the distinction between pain and suffering as one of interpretation: the individual interprets the pain, or other symptoms or aspects of their illness in such a way “that involves all the aspects of the whole person in his or her individuality” (Cassell, 2004, p. 274). The elimination of pain is not always a goal, even from a medical perspective. Woolf describes an inherited neurologic condition in which the peripheral sensory apparatus for pain does not function: “the tips of the fingers of the affected individuals are typically lost through repeated trauma, their tongues and lips are usually mutilated by chewing, and their life spans are significantly shortened;" he concludes, "we need pain to survive" (Woolf, 2007, p. 29). Hauerwas comes to a similar conclusion about suffering, stating:

> To see the value of suffering we only have to ask what we would think of anyone who did not have the capacity to suffer (including God). Such a person could not bear grief or misfortune, and thus would in effect give up the capacity to be human (or divine). For it is our capacity to feel grief and identify with the misfortune of others which is the basis for our ability to recognize our fellow humanity (Hauerwas, 1986, p. 26).

While these reflections may convince us that a life devoid of pain and suffering, desirable though it may seem, would not ultimately be a "good life." They do not relieve us, however, of the need to sometimes distinguish pain from suffering. Perhaps more importantly, it is unclear how we might better identify the differences between the pain and suffering that will aid in our individual survival and communal thriving, and that which will be degrading rather than ennobling. Christian theology generally holds more firmly to the conviction that suffering has instrumentally positive value.

Suffering in Christian Theology: Evil, Theodicy and Redemption

Numerous interpretations of and reflections on suffering exist in the Christian Bible as well as within ancient and modern Christian theology. I will, therefore, merely touch on some of the major themes present in descriptions of the dimensions/types of suffering, the explanations/interpretations of the reasons why people suffer, and the conclusions about the appropriate response to suffering. In *A Pastoral Theology of Suffering: The Roots of Sorrow* Phil C. Zylla identifies four key dimensions of suffering: "physical pain, psychological anguish, social degradation, and spiritual desolation," though he adds a disclaimer: "even these descriptions fail to take on board the full weight of suffering. Suffering is immense. It is a difficult river" (Zylla, 2012, p. 6). Zylla states a primary purpose of his book is "learning to talk about God in our suffering;" he adds, "the intention of this volume is not simply to defend God in the face of unspeakable suffering but to articulate the dimensions of hope for those who suffer in extremis" (Zylla, 2012, pp.6-7). Zylla hereby articulates a primary distinction between medical or empirical investigations of suffering and explicitly Christian ones: the latter begin with the premise that suffering has something to do with God. Christian descriptions may propose quite different conclusions about what suffering has to do with God, but all contend that God is in some way intimately involved in the suffering of human beings. Zylla also hints that a major flaw in many Christian investigations into suffering is that they focus on defending God and fail to offer hope to suffering people.

Zylla describes five common explanations of suffering; (1) suffering is punishment for wrongdoing, (2) suffering has a deep meaning and purpose, but can only be understood from God's perspective, (3) suffering "is meant to educate, to purify our intentions, and to mold and shape our inner being", (4) suffering is a test of faith, (5) suffering can only be understood in relation to the afterlife: "the anguish, pain and hardship of the present life are not to be compared with the glory of the future that is yet to come" (Zylla, 2012, p. 30-37). Zylla analyzes and critiques the nuances within these five explanations, a task beyond the scope of my paper. In conclusion, he cautions against readily accepting any of these explanations:

> To take these explanations at face value is to disallow something that Scripture itself does not disallow: the ability to ask questions in the face of affliction. The biblical text, viewed with a wider lens, invites those who suffer to lament the realities of their suffering and to protest the anguishing situation (Zylla, 2012, p. 38).

Zylla's critique reflects other Christian and non-Christian descriptions of suffering which emphasize the relationship between suffering and the loss of one's voice (Soelle, 1975). Relatedly, some have also described torture as the humiliation of and forced silencing of another (Ricoeur, 1992a; Soelle, 1975). If being rendered voiceless, that is, being unable to communicate one's distress, lament one's losses, or protest against one's situation, causes suffering or deepens "the loneliness, the sense of abandonment, and the experience of forsakenness of those most afflicted," we ought to be particularly concerned for those with DOC, most particularly those in MCS, who may be aware but "suffering in silence."

Numerous Christian sources in various ways attempt to make distinctions between suffering and evil and also draw connections between them. Abigail Evans explains that some of these sources posit two types of suffering, "suffering which comes from disease rooted in evil and suffering which comes form opposing evil and its manifestations;" she points out however, that suffering "does not lend itself to a clear, systematic, and integrated treatment" (Evans, 2011, p. 226). Suffering is often interpreted by Christians through the symbol of the cross, and is therefore associated with redemptive power. Many theologians caution, however, that not all suffering should be seen as akin to the suffering of Jesus and that suffering for its own sake is not redemptive (Hauerwas, 1986; Soelle, 1975). Liberation and Feminist theologians have argued that Jesus' crucifixion should be interpreted "in liberationist terms as his refusal to back down in the face of oppression and evil, and his willingness to stand for healing, mercy, and justice for the least and the outcasts – even at the penalty of torture and death;" these interpretations describe Jesus as acting in opposition to the power of Empire (Cooper-White, 2012, p. 28). These various explanations of and interpretations of evil indicate that the way Christians remember the suffering and death of Jesus, and the interpretations such remembering leads them to make, impacts their responses to individuals who are suffering. More often than not, explanations of suffering, draw us away from rather than draw us closer to those who are suffering. In conclusion, I will transition from a focus on explanations of suffering to a focus on responses to suffering.

In "AIDS and the Church," Earl Shelp and Ronald Sunderland describe three levels of suffering in the Christian New Testament: (1) "suffering for Christ's sake," that is, the suffering of being a witness to the faith in the face of persecution, (2) "suffering as a result of oppression," and (3) "suffering due to disease or disability;" they also emphasize that Jesus as he appears in the New Testament "was concerned to show compassion to the afflicted rather than to establish the causes of disease and disability," and they lament that fact that "Western scholars have tended to be preoccupied with the latter concern, connecting their response to issues of morality" (Shelp & Sunderland, 1987/1998). Hauerwas similarly reflects on the difference between early Christians' response to suffering and modern preoccupation with questions about theodicy, evil, and questions about "why" suffering occurs:

> For the early Christians, suffering and evil . . . did not have to be 'explained'. . . Indeed it was crucial that such suffering or evil could not be 'explained' – that is, it was important not to provide a theoretical account of why such evil needed to be in order that certain good results occur, since such an explanation would undercut the necessity of the community capable of absorbing the suffering (Hauerwas, 1990, p. 49).

How can individuals show compassion to the afflicted and how can communities absorb the suffering of its members? Before hazarding a brief response to these complex questions, it is important to challenge the notion that compassionate response to suffering comes naturally and that our initial response to the suffering of others is always an empathic one. Phil Zylla writes:

> We like to think of ourselves as compassionate people who are basically caring, responsive to pain, and understanding in the situation of the afflicted. We more

> or less assume that compassion is a natural response to human suffering. We like to think that our natural instinct to the reality of affliction is one of care and concern. In fact, our first response is to move away in dread, to avoid suffering at all costs, and to withdraw from the situation of the afflicted. Dread, not compassion, is the natural response to the suffering of the afflicted (Zylla, 2012, p. 27).

Zylla's assertion is important for two reasons. Firstly, it brings out of the shadows a natural human response to suffering that we are often ashamed to admit that we have; if we fail to admit that at times we naturally respond to suffering with dread, we will likely react unintentionally out of that dread rather than responding to the suffering person intentionally. For medical providers this could result in avoiding or limiting time spent with patients and families under their care. Secondly, it offers a cautionary check on the idea that the best we can do for those who suffer from "intolerable" suffering is to give them the means to cause their death, or in the case of the incapacitated, to cause their death ourselves. We should ask ourselves whether it is relief of the others' suffering we seek, or escape from the dread we experience in the witnessing of it.

Conclusion: Being in Communion with the Afflicted

Suffering is a central part of human experience and is shared by all, but it is also deeply private and personal and the sharing of it is not equal. Every human being suffers, but the suffering of every human being is not the same. As many of the aforementioned authors argue, the total elimination of suffering is often not possible, and may not even be a desirable goal either from an individual perspective or from a communal one. How should we respond to individuals who are suffering? Both Martha Fowler and Stanley Hauerwas stress the importance of community response. Fowler encourages what she describes as communities of *Shalom*; she explains: "communities of *shalom* are communities of comfort, character, caring, conviction, refuge and welcome – communities in which one may be frail, or express suffering, or decline – and yet still find a place. It is to be present for the one who suffers, the ones who suffer' (Fowler, 1996, p.53). Hauerwas offers a similar vision, explaining, "It is the burden of those who care for the suffering to know how to teach the suffering they are not thereby excluded from the human community. In this sense medicine's primary role is to bind the suffering and the nonsuffering into the same community" (Hauerwas, 1986, p. 26). While both of these visions helpfully propose that the larger community, not just medical providers or medical institutions, are responsible for supporting those who suffer, they also maintain a clear dichotomy between the nonsuffering and the suffering, and emphasize the dissymmetry between the agents of compassion and the passive receivers of their care. Paul Ricoeur's description of human persons as both acting and suffering, as both an agents and a passive receivers of the actions of others provides a helpful rebalancing and reminder that vulnerability and fragility characterizes all of our lives (Ricoeur, 1992b).

I am no closer to having answers for how I or anyone else could have responded differently to the suffering of Robert, the patient who I described earlier in this chapter. What is clear is that no explanation of suffering can remove the pain of either experiencing suffering oneself or bearing witness to another's suffering. When an individual can speak we can become witnesses to his or her lament and supporters of his or her process of re-claiming wholeness in the face of whatever losses have been exacted by illness and its accompanying difficulties. Being allowed to make choices about one's medical care may in many ways be empowering, but human beings suffer not only from the loss of control that illness engenders, but also from the painful experiences that so often accompany it: loneliness, shame and fear, all of which are resolvable only through relationship with others. For those who are in DOC, the difficulties of how to respond are more pronounced. Listening to the experiences of those closest to individuals with chronic DOC, their family, friends and the medical providers who care for them, should be a first step. Those who traditionally identify themselves as advocates of "the right to die," will be made uncomfortable by those who decide to continue long-term ANH, while those who identify themselves of advocate of the "right to life" will be made uncomfortable by those who describe why they think withdrawing/withholding LST, including ANH or even euthanasia is the most loving response they could make to the suffering of their loved one. Responding to the *Schiavo* case, Prof. Abdulaziz, Islamic Bioethicist at the University of Virginia, stated, "These are the arguments of an advanced, free society. There are no such discussions in Egypt or Iran. There's no general public debate over death and dying. That's for the elite" (Colby, 2006, p. 186). As the discussion continues we would do well to move beyond the "right to die"/"right to life" framework and to address the ways we all share in the vulnerability and suffering from which we so often turn away in dread. Ricoeur describes suffering as integral to selfhood and relates our general aversion to our own vulnerability to practices whereby we exclude the most vulnerable from the bonds of community:

> In an individualistic society that emphasizes the capacity for autonomy, of being able to direct one's own life, any incapacity that reduces one to a state of tutelage in the double form of assistance and being controlled will be taken to be a handicap. Health, too, then is socially normed, as is sickness, as is the demand for care and the expectation that goes with this demand . . . Society would like to ignore, hide, or even eliminate its handicapped. But why? Because they constitute a menace, a disturbing reminder of our fragility, our precariousness, our mortality (Ricoeur, 2007b, p. 192)

I proceed with an in-depth analysis of Ricoeur's philosophy of selfhood.

Chapter 4: Ricoeur, Selfhood and Disorders of Consciousness

The core of many arguments for withdrawing LSTs allowing those with DOC to die[18] are rooted in descriptions of irreparable loss of identity epitomized in phrases such as “she is no longer herself” or “she is no longer *in there*;” likewise arguments for using medical interventions to sustain the lives of people with DOC mirror these: “she is still our daughter (mother, brother etc.)”; “she is still *in there*.” These statements concern more than the physical and biological mechanisms of cognition, they are rooted in questions more often dealt with in philosophy and theology such as, “what does it mean to be oneself?” “What does it mean to be in one’s body?” and “What does it mean to belong to others?”

These questions about consciousness and identity are not easily answered, and neurologists, those with direct experience of individuals with DOC, and philosophers who consider such questions may all struggle to articulate exactly what sort of state the individual is in, that is whether he or she is alive, dead, or in some in-between state and whether he or she is still him or herself in the sense of retaining personal identity (as described in chapter three, this is often referred to by the term “ontological status”)(Colby, 2006, p. 168). Our conclusions about the ontological status of these individuals proceed at least partly from preexisting beliefs about consciousness, personhood, personal identity and selfhood. Our beliefs about the nature of identity presuppose our beliefs about what constitutes a loss of identity; our beliefs about the nature of selfhood presuppose our beliefs about what constitutes a loss of selfhood. In *Oneself as Another,* Ricoeur presents selfhood as complex and dynamic and he resists simplistic categorizations; thus his understanding of selfhood provides a unique way to reflect on the identity questions that arise in cases of DOC and a useful avenue for more fully considering questions about how to best care for these individuals. For analyzing DOC I describe and use as frameworks the following aspects of Ricoeur’s conception of selfhood: the interaction between

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[18] In medical ethics and in law a distinction has been made by some between “killing” and “letting die” through withdrawal of LSTs since in the late case a natural death occurs because the process of dying proceeds as it would have had the LSTs not been initiated. Some argue that the principle of “double effect” is relevant in such situations because the primary goal in withdrawing is not death but relief of suffering. In the case of withdrawal of ANH in those with DOC, however, death is often the goal because it is interpreted as the only way to release the individual from suffering. I use to the phrase “allow death” here because in my experience this is representative of how medical providers and family members describe the reason for choosing ANH withdrawal. I acknowledge that many argue that the “killing”/”letting die” distinction is conceptually and morally ambiguous. For more analysis see (Beauchamp & Childress, 2013).

idem (sameness) and *ipse* (selfhood) and between self and other within his conception of *ipse*, and the self's rootedness in biological, historical and social realities of human life.

The Dialectic of Sameness(idem) and Selfhood(ipse)

For Ricoeur, the self is not one-dimensional but marked by plurivocity, and in using the term 'self," he does not refer simply to "an unchanging core of personality;" rather he describes identity as containing two aspects represented by the Latin terms *idem* and *ipse,* translated into English respectively as "sameness" and "selfhood" (Ricoeur, 1992b, p.2). He proposes that *idem* represents the sameness of character, or as he defines, "the set of lasting dispositions by which a person is recognized," and that it develops in part through relationship with others as an individual identifies with "values, norms, ideals, models and heroes;" a process Ricoeur terms, "acquired identifications;" he explains, "recognizing oneself *in* contributes to recognizing oneself *b*y" (Ricoeur, 1992b, p.121). These habits and identifications become signs of sameness that allow for the evaluation of actions as being "out of character" for an individual. As I will explain below, the "other" is even more prominent in the development of the *ipse* identity (Ricoeur, 1992b, p. 122).

To *ipse* identity Ricoeur attributes "a dialectic of *self* and the *other than self*;" the aspect of identity rooted in the question "who am I?" not the question "what am I?" (Ricoeur, 1992b, p. 121). Though he describes *idem* and *ipse* identity as overlapping, he asserts that it is important to uphold a distinction between the two forms of identity, he does so in part by contending that each is associated with a different type of permanence in time. He correlates *idem* identity with sameness of character, and *ipse* identity with "self-constancy,' described as "the keeping of one's word in faithfulness to the word that has been given." To further explain the self-constancy represented by *ipse* identity, Ricoeur states that the question, "who am I?" is being answered by the response, "I am the one who is fulfilling the promise I made (Ricoeur, 1992b, p. 122). *Ipse* identity assumes changes both internal (feelings, inclinations) and external (temporal realities); self-constancy concerns keeping one's word, choosing to "hold firm" despite such changes (Ricoeur, 1992b, p. 123). *Ipse* identity necessarily contains a dialectic of self and other; constancy in promising is constancy to the other, as Ricoeur describes, "The continuity of character is one thing, the constancy of friendship is quite another" (Ricoeur, 1992b, p. 123). In his descriptions of both *idem* and *ipse* identity Ricoeur holds relationship as essential. In *idem* identity relationship is important to character development and in *ipse* identity it is essential to self-constancy.

Personal Identity and Theories of "Sameness": Locke and Hume

Ricoeur raises concerns with the reduction of personal identity to sameness. The difference between identity conceived of solely as sameness and identity conceived of as a dialectic between sameness and selfhood is particularly relevant to DOC; if identity is described merely in terms of sameness, then a failure of sameness, a divergence from that sameness, can be described in simple terms as a total loss of identity as represented by statements such as "she is no longer herself." Ricoeur's description of selfhood resists an uncomplicated declaration of loss of selfhood, because he does not reduce selfhood to sameness.

Ricoeur establishes the problem with equating identity with sameness, by way of examining how John Locke and David Hume encountered "paralyzing paradoxes" in their analyses of the question of personal identity (1992b, p. 125). When considering Locke's description of personal identity Ricoeur focuses on the relationship Locke establishes between personal identity and memory; he cites Locke's example of the memory of a prince being transported into the body of a cobbler to which Locke decides the latter would become the prince he "remembers having been" (Ricoeur, 1992b, p. 126). Ricoeur argues that tradition has credited Locke with establishing the criterion of "mental identity," which is viewed as being in opposition to "corporeal identity," yet Ricoeur describes how this example that Locke used to provide clarity later came to be seen as an indeterminable troubling case:

> It is not in Locke but in his successors that the situation created by the hypothesis of transplanting one and the same soul into another body began to appear more undetermined rather than simply paradoxical, that is, contrary to common sense. For how could the prince's memory not affect the cobbler's body, his voice, his gestures, and his poses? And how could one situate the expression of the habitual character of the cobbler in relation to that of the prince's memory? What has become problematic after Locke, and which was not so for him, is the possibility of distinguishing between two criteria of identity: the identity termed mental and that termed corporeal, as though the expression of memory were not itself bodily phenomenon. In fact, the defect inherent in Locke's paradox, besides the possible circularity of the argument, is an imperfect description of the situation created by the imaginary transplant" (Ricoeur, 1992b, pp. 126-127, footnote).

Ricoeur points out in his analysis that the mental and the corporeal cannot be treated as if they exist in isolation from one another and are easily separable; experience and likewise memory of experience are sensorial and embodied (we remember how something appeared, felt, sounded, tasted). What Locke presents as simple, the act of severing memory from the body in which the remembered experiences occurred and placing them in some other body, cannot be taken as a matter-of-fact for it brings to the forefront the "collision between two opposing criteria of identity" (Ricoeur, 1992b, p. 126). Ricoeur argues that though Locke's concept of identity as "the identity of a thing with itself ('sameness with itself')," seen by comparing a thing with itself over time, seems to join the concepts of sameness and selfhood, his puzzling cases of memory in fact illustrated a "reversal in which selfhood was silently substituted for sameness" (Ricoeur, 1992b, p. 126). Ricoeur here points out that Locke ultimately assumes a self that is univocal, it is put simply, sameness over time.

The notion that memory, the method by which one can identify oneself as the same being over time, is the essential component of identity can be challenged from the perspectives on memory from within neuroscience and philosophy. Memory involves multiple processes, and the capacity for memory can be modified by various circumstances temporarily or permanently. If memory, and more specifically, remembering oneself in a unified manner, is the core of identity what do we say about one who is inebriated? Has the inebriated person temporarily lost his or her identity or merely his or her capacity to be aware of that identity? What do we say of someone with mild dementia or with advanced Alzheimer's? Is there an identifiable point where reduced capacity to remember renders one a different being than one was previously? Making clear classifications does not seem possible since capacity fluctuates and involves many types of remembering and likewise many types of possible deficits. Individuals with dementia may not remember what they did yesterday or be able to always recall the names of their children, yet they may recall formative incidents from childhood and may respond to their children as individuals with whom they have some special connection, and they may present a confusing mix of consistent and inconsistent preferences with their pre-dementia selves (Jaworska, 1999). Likewise such classifications fail to acknowledge that others experience an individual with dementia or with limited cognitive capacity as being the same self over time (Kittay, 1999; Zeiler, 2014). That others experience a person as the same self despite drastic changes, even major memory loss, indicates that selfhood cannot be reduced to sameness represented by the memory of one's experiences.

In analyzing David Hume's conception of identity, Ricoeur notes that Hume, following an empirical approach, finds the idea of the "self" to be an illusion since "when he 'enters most intimately into' himself he finds only a diversity of experiences" (Ricoeur, 1992b, p. 127). Ricoeur objects: Was not Hume seeking what he could not hope to find – a self which was but sameness? And was he not presupposing the self he was not seeking? . . . Here, then, is *someone* who claims to be unable to find anything but a datum stripped of selfhood; *someone* who penetrates within himself, seeks and declares to have found nothing;" an observation Ricoeur makes following Roderick Chisholm in *Person and Object: A Metaphysical Study (emphasis in original text*)(Ricoeur, 1992b, p. 128). Ricoeur maintains that neither a psychological nor a corporeal criterion for identity can be reduced to sameness; he explains, "character . . . is the self under the appearance of sameness" but it cannot be reduced to sameness entirely for character contains a "narrative dimension," it develops over time. Ricoeur may be too limiting in considering the category of sameness to be the main feature of character, as Gaëlle Fiasse points out in agreement with Jean Greisch: "It would be preferable as [Greisch] suggests, to understand character in the same manner as Rosenzweig, that is to say, as a challenge rather than as a destiny" (Fiasse, 2014, p. 46). Yet Ricoeur does point to selfhood being a project, a process, most particularly in its ethical dimension; he does not reduce it simply to self-awareness.

The corporeal criterion of identity, even if viewed as sameness of the body continuing to resemble itself proves more complex than simply sameness since it is most accurately considered as a dialectic between continuity and discontinuity depending on what level of structure one chooses to focus (genetic or molecular for example). In focusing on the body and its relation to sameness and selfhood Ricoeur does not consider simply the body as itself, rather he turns to his primary theme of *attestation,* the capacity to designate oneself as the acting agent; he explains, "it is not the sameness of my body that constitutes its selfhood but its belonging to someone capable of designating himself or herself as the one whose body this is" (Ricoeur, 1992b, p. 129). And while Ricoeur's focus on attestation may lead us to conclude that if those with DOC can be designated as non-agents since they seemingly lack the capacity for attestation (as described in chapter two, Ricoeur considers human agency through the principle actions of: speaking, acting, telling narrating one's own story, and imputing actions to oneself); his overarching consideration of individuals as acting and suffering beings, necessitates a more complex reflection. I will return to the theme of the relationship between acting and suffering at the conclusion of this chapter.

Personal Identity and the Neutralization of the Body

Ricoeur takes up Derek Parfit's conception of personal identity as presented in *Reasons and Persons* because he wishes to point out that it is conceiving of identity solely in terms of sameness that leads Parfit to conclude that "personal identity is not what matters" (Parfit, 1986, p. 255). As with his analysis of John Locke and David Hume's reflections on identity Ricoeur questions the presupposition that identity can signify only sameness; he proposes, "the question for us will be whether, as in the case of Hume, Parfit was not looking for something he could not find, namely firm status for personal identity defined in terms of sameness, and whether he does not presuppose the self he was not seeking" (Ricoeur, 1992b, p. 130). Ricoeur presents as the core of Parfit's argument (what Parfit calls the "reductionist thesis") as the belief that "a person's existence just consists in the existence of a brain and body, and the occurrence of a series of a interrelated physical and mental events" and that a *person* does not constitute "a separate further fact" (Parfit, 1986, p. 255; Ricoeur, 1992b). Ricoeur shows that Parfit's reductionist thesis attacks three basic beliefs about the nature of identity: (1) that it is "a separate existence of a core permanence," (2) that "a determined response can always be given concerning the existence of such permanence," and (3) that it is important to claiming status as a moral subject (Ricoeur, 1992b, p. 130).

Ricoeur argues that the reductionist thesis considers identity solely in terms of sameness, and that it neglects the experience of "mineness" of one's body that identity as a dialect of sameness and selfhood supports. Ricoeur further argues that the reductionist thesis differs from a non-reductionist thesis (Ricoeur's label for Parfit's "*Further Fact View*"), not because the former insists upon a dualistic notion of separate spiritual and corporeal substances as the reductionist thesis claims, but because it encompasses the reality that one "possesses her body and her experience" (Ricoeur, 1992b, p. 132). Ricoeur criticizes the assumption within the reductionist thesis that "*the* body is merely a neutral container for *my* brain" (*emphasis in original text*) (Ricoeur, 1992b, p. 135). Ricoeur emphasizes that the reductionist thesis assumes that the distinctness of the brain matters, but that any body will do; this is made clear by Parfit's choice of proposed puzzling cases which take the brain as equivalent to the person . Ricoeur finds this “neutralization” of the distinctness of one’s body concerning:

> “The true difference between the nonreductionist thesis and the reductionist thesis in no way coincides with the so-called dualism between spiritual substance and corporeal substance, but between my own possession and impersonal description. To the extent that the body as my own constitutes one of the components of mineness, the most radical confrontation must place face-to-face two perspectives on the body – the body as mine, and the body as a body among others. The reductionist thesis in this sense marks the reduction of one’s own body to the body as impersonal body. This neutralization, in all the thought experiments that will now appear, will facilitate focusing on the brain the entire discourse on the body” (Ricoeur, 1992b, p. 132).

Focusing solely on the brain (or on particular functions such as memory) divides the nervous system and denies its complexity and integration with the body through which it receives external input. Human beings exist in the world and experience the world as embodied beings, not as disembodied brains. Because DOC concerns the brain we naturally focus our discussion on the brain, but it may be that it is disruption of the normally observed integration of the brain and body that is most disturbing to us; acknowledging that it is the unity of being and the interaction of the unified being with the external environment that are disturbed checks us from equating a person with his or her brain and cautions us against assuming that knowledge about brain function as obtained through technologies such as *functional* MRI will be sufficient to solve questions about personal identity and selfhood.

Ricoeur analyzes selfhood within the context of our lived experience as rational, embodied, relational, and historically located beings, a condition he describes as our “corporeal and terrestrial condition,” rather than from the standpoint of an imagined world in which these constraints do not exist (Ricoeur, 1992b, pp. 134-135). He contends that, even if advances in neuroscience were to open the possibility of transplanted memories and transplantable brains, they would be ethically dubious to pursue because they would “violate the right of the person to his or her physical integrity;” indeed, research indicates that even tissue transfer can have a profound impact on the identities of both donor and receiver (Ricoeur, 1992b, p. 135; Waldby, 2002). Ricoeur’s understanding of selfhood thus challenges those theories of personhood or selfhood that reduce whole persons to their brains.

Selfhood and Otherness

Considering the brain as isolated and separable from the body does enable imagining challenges to identity, but only to identity understood as sameness. Ricoeur explores challenges to identity in which identity is understood as a dialectic between sameness and selfhood, with the latter comprised of three components of "otherness": (1) the otherness of one's own body for which Ricoeur utilizes the term, flesh, (2) the otherness of other people, and (3) the otherness of the moral conscience (Ricoeur, 1992b, pp. 317-356). I focus here on the otherness of one's flesh. Otherness for Ricoeur is integral to selfhood; "it is not added onto selfhood from outside" (Ricoeur, 1992b, p. 180). Ricoeur also describes the three aforementioned types of otherness as the "*triad of passivity;*" he uses the word "passivity" to describe the experience of being acted upon, the opposite experience of being an agent of action. Ricoeur views this as connected to the experience of suffering; he explains, "suffering is not defined solely by physical pain, nor even by mental pain, but by the reduction, even the destruction, of the capacity for acting, of being-able-to-act, experienced as a violation of self-integrity;" later he adds, "undergoing and enduring are, in a sense, revealed in their complete passive dimension when they become suffering" (Ricoeur, 1992b, p. 135). In this sense, Ricoeur describes passivity, as containing the possibility for suffering.

Ricoeur describes human beings as acting and suffering beings; when I turn to the otherness of other people, I will describe his understanding of solicitude as the response owed to another when he or she is a suffering "other." In order to understand the depth of what solicitude requires, we must first understand the more internal experience of otherness, that of one's own flesh. Ricoeur describes the passivity of being acted upon as being the "patient;" a term he uses in a general sense, not to describe those undergoing medical treatment. Using the term in this general sense helpfully reflects a difficulty inherent in being a medical patient that the medical establishment often fails to understand: in a subtle way, being in the role of the patient is the beginning of suffering, not because one is experiencing pain or being mistreated, but simply because one is being acted upon. Ricoeur points out that it is in suffering that the passivity of one's body and the passivity of other people can intersect to render one not only a suffering self, but a victim; in turn, the ethical danger inherent to being an agent, an acting self, is the ease with which one can enter into the role of the victimizer. Describing this intersection where the incapacity to act touches the edge of being a victim and the power of agency touches the edge of being a victimizer helps to elucidate how medical providers' and family members' can experience that they are in some way injuring the patient with a DOC by providing certain medical treatments or by using medical interventions to sustain them in a state in which they are primarily or solely in the passive state of being acted upon (Holland et al., 2014; C. Kitzinger & Kitzinger, 2014). As I will show below, however, Ricoeur does not conceive of passivity in solely negative terms.

The Otherness of One's Own Body

In describing the degrees of passivity that one can experience in relation to one's own body, Ricoeur writes that the body is "revealed to be the mediator between the intimacy of the self and the externality of the world" (Ricoeur, 1992b, p. 322). Ricoeur utilizes the term "flesh" to emphasize that the otherness of embodiment includes not only that "a body is my body, that is flesh" but along with that, "the flesh is also a body among bodies" (Ricoeur, 1992b, p. 326). Ricoeur follows Husserl in making this distinction between flesh and body, but argues that Husserl fails to answer the paradox of the question, "how am I to understand that my flesh is also a body?" because he thought of "the other than me only as another me, and never of the self as another" (Ricoeur, 1992b, p.326) To answer the aforementioned question Ricoeur turns to Martin Heidegger and Hannah Arendt to highlight a strangeness inherent in how we experience our existence: we experience being embodied and "being-in-the-world," but we do not have experience of placing ourselves here; we find ourselves in the task of "having-to-be," but do so having made no initial consent (Ricoeur, 1992b, pp. 326-327). Ricoeur utilizes Heidegger's term "*thrownness*, thrown-there," to represent the experience of the self as flesh in existential terms, by which he makes clear he does not intend to suggest a "fall from a higher place," but more simply to highlight the experience of having fallen in to being oneself; he concludes, "One could even say that the link, in the same existentiale of state-of-mine, of the burdensome character of existence and of the task of having-to-be, expresses what is most crucial in the paradox of otherness constitutive of the self and in this way reveals for the first time the full force of the expression 'oneself as another'" (Ricoeur, 1992b, p. 326). Ricoeur's emphasis here is that there is an otherness to us that is not "foreign" but "primary" (Ricoeur, 1992b, p. 327). Even for fully conscious adults who can easily acknowledge themselves as the author of their actions, there is **at least a slight experience of passivity, one's own body, or the flesh**, can be acted upon, and indeed one finds oneself to be an embodied being without having chosen to be so. For Ricoeur, agency and passivity reside on a spectrum and cannot be described by an either/or distinction; one is not simply an agent or a nonagent. Everyone experiences a degree of passivity, that those with DOC reside on the extreme end of the passivity side of this spectrum does not remove their selfhood even though it renders them profoundly vulnerable.

The Otherness of Other People

A major component of his philosophical system is the distinction Ricoeur makes between the terms "ethics" and "morality." He employs ethics to describe "the *aim* of an accomplished life," while he uses morality to indicate, "the articulation of this aim in *norms* characterized at once by the claim to universality and by an effect of constraint" (Ricoeur, 1992b, p. 170). The differentiation Ricoeur makes between these two terms is unique to his philosophical project; as he states himself, neither their etymological underpinnings nor their historical usage warrant this distinction (Ricoeur, 1992b, p. 170). Yet he uses this distinction to bring together and integrate two philosophical approaches: (1) the Aristotelian heritage with its *teleological* perspective, and (2) the Kantian heritage with its deontological perspective exemplified by the "obligation to respect the *norm,"* the norm here referring to the imperatives of universalization and the apprehension of persons as ends in themselves (Ricoeur, 1992b, pp. 170, 208).

Ricoeur presents the ethical aim as having individual, interpersonal and communal components: "Let us define 'ethical intention' as *aiming at the 'good life' with and for others, in just institutions"* (Ricoeur, 1992b, p. 170). Thus, interpersonal relationships and life within institutions are not add-ons to the ethical aim, but rather essential components of selfhood, part of aiming at the good life, and integral to individuals' developing an understanding of themselves as ethical beings whose actions have import. For Ricoeur, aiming at the 'good life' is contextually and temporally rooted, and aiming at the 'good life' contains reaching for an ideal as well as practical everyday choices made towards this end. His concept of the ethical aim thus overcomes some of the concerns raised by feminist critiques of autonomy: he considers individuals as embodied beings and he considers interpersonal relations and life lived within institutions[19] as ultimately intertwined in a way that resists separation; a self is not an

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[19] Ricoeur describes institutions as follows: "By 'institution' we are to understand here the structure of *living together* as this belongs to a historical community – people, nation, region, and so forth – a structure irreducible to interpersonal relations and yet bound up with these in a remarkable sense which the notion of distribution will

isolated, rational entity that enters into society fully formed, but rather a self is in part formed by interpersonal and communal life. He describes a self as a dialectic of "oneself and the other," a dialectic that finds its fullest development in ethics and morality, where "the *autonomy* of the self will appear then to be tightly bound up with *solicitude* for one's neighbor and with *justice* for each individual" (Ricoeur, 1992b, p. 18).

The second component of the ethical perspective, "with and for others," is designated by the term "solicitude; it is not added from the outside to the first component, aim for the 'good life,' but "unfolds the dialogical dimension of self-esteem" (Ricoeur, 1992b, p. 180). "Self-esteem and solicitude," writes Ricoeur "cannot be experienced or reflected upon one without the other" (Ricoeur, 1992b, p. 180). Individuals' participation in communal life is not "contingent and revocable," as Ricoeur argues is an assumption made by many theories of natural law, because rather than proposing a subject complete and self-realized, Ricoeur presumes a subject whose selfhood depends in part on others who serve a mediating role between "capacities and realization;" Ricoeur presents selfhood as a project more than a static state that can be lost or gained: "If one asks by what right the self is declared to be worthy of esteem, it must be answered that it is not principally by reason of its accomplishments but fundamentally by reason of its capacities" (Ricoeur, 1992b, p. 181). Capacity has an ethical dimension as "being-able-to-judge," being able to evaluate one's actions as good (Ricoeur, 1992b, p. 181). Others have an integral role in the transition from "capacity to realization;" in other words, I am a self in part because others support me in becoming a self. In order to articulate the meaning of solicitude, Ricoeur turns to Aristotle's treatise on friendship in *Nichomachean Ethics*.

Aristotle describes three kinds of friendship: for the sake of "pleasure," for the sake of "utility" and for the sake of the "good"; it is the latter type which is characterized by mutuality in which "each loves the other *as being the man he is"* and not in expectation of some other benefit, to which Ricoeur turns as the foundation of solicitude (Ricoeur, 1992b, p. 182). Thus from the outset solicitude incorporates reciprocity and cannot be interpreted solely as an individual with agency imposing solicitude on one who lacks agency. Ricoeur explains:

> The agent is invested with the responsibility of an action that is placed from the very outset under the rule of reciprocity, which the rule of justice will transform into a rule of equality. Since each protagonist holds two roles, being both agent

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permit us late to clarify. What fundamentally characterizes the idea of institutions is the bond of common mores and not that of constraining rules" (Ricoeur 1992b, 192).

> and patient, the categorical imperative requires the ‘matter’ of *plurality* of acting beings each affected by forces exerted reciprocally (Ricoeur, 1992b, p. 330).

Neither can reciprocity be interpreted in strict quantitative terms, even though the corollary of reciprocity in the realm of the moral norm will be equality (Ricoeur, 1992b, p. 188). Ricoeur also draws on Aristotle’s description of friendship as a process, an activity that supports the “realization of life;” friendship supports the aim of becoming good, of being happy (Ricoeur, 1992b, p. 186). In friendship, the two individuals are conscious of one another’s goodness and their friendship aids each in becoming conscious of his or her own goodness:

> for the good man, his own existence is desirable for him . . . the desirableness of what is one’s own – so to speak, is not foreign to the need for friends experienced by the happy man. This need has to do not only with what is active and incomplete in living together but also with the sort of shortage or lack belonging to the very relation of the self to its own existence (Ricoeur, 1992b, p. 186).

Ricoeur emphasizes the role of need, of lack, in friendship and thus in solicitude. Whereas some philosophical traditions set total independence as the ideal, Ricoeur, following Aristotle, considers friendship as essential for a happy life, that is, for a good life. The problem remains, however, of how mutuality or equality can be attained in a relationship that begins in dissymmetry, such as when one is made vulnerable by illness. Ricoeur contends that the other’s fragility, their suffering, elicits feelings of sympathy and solicitude from the agent, an equalizing occurs in which the suffering one, the receiver of the agent’s solicitude, becomes the giver when from weakness itself the suffering one reminds the agent of his or her own fragility; both share in the fundamental experience of acting and suffering, and ultimately of being mortal (Ricoeur, 1992b, pp. 190-192). As we have seen, for Ricoeur, capacity does not just mean the capacity to act, but the capacity to suffer; this is the essential point in distinguishing capacity from accomplishment. Ricoeur distinguishes solicitude from obligation or duty, by attributing to it a “benevolent spontaneity” which he posits as more fundamental than duty and of which he is not afraid to include a role for feelings (Ricoeur, 1992b, p. 190). The realization of one’s own fragility also invites a realization of oneself as a self among others (Ricoeur, 1992b, p. 190). Ricoeur describes three elements of the experience of symmetry or equality within this dynamic of solicitude: reversibility, nonsubstitutiblity, and similitude. Reversibility emphasizes the simultaneity of the roles of sender and receiver of discourse; each is capable of self-designation (Ricoeur, 1992b, p. 193). The persons who are in the reversible roles are also nonsubstitutable and irreplaceable to one another; it is in the experience of being irreplaceable to the other that each also recognizes the "irreplaceable character" of his or her own life (Ricoeur, 1992b, p.193). It is with the notion of similitude that Ricoeur describes most clearly the relationship between solicitude and self-esteem. Ricoeur explains: "I cannot myself have self-esteem unless I esteem others *as* myself. 'As myself' means that you too are capable of starting something in the world, of acting for a reason, of hierarchizing your priorities, of evaluating the ends of your actions, and having done this, of holding yourself in esteem as I hold myself in esteem . . . Becoming in this way fundamentally equivalent are the esteem of the *other as a oneself* and the esteem of *oneself as an other*" (Ricoeur, 1992b, 194).

Most crucial to DOC is the insistence that solicitude claims a more fundamental status than obedience to duty. Ricoeur explains:

> Our wager is that it is possible to dig down under the level of obligation and to discover an ethical sense not so completely buried under norms that it cannot be invoked when the norms themselves are silent, in the case of undecidable matters of conscience. This is why it is so important to us to give solicitude a more fundamental status than obedience to duty. Its status is that of *benevolent spontaneity,* intimately related to self-esteem within the framework of the aim of the 'good' life (Ricoeur, 1992b, p. 190).

Though he leans on Aristotle's treatise on friendship as the foundation for solicitude Ricoeur does not limit solicitude to circumstances of friendship, but rather to insist on the role of mutuality in solicitude and its relation to self-esteem; even in a situation in which an individual is in a professional care-taking role for another, by positing solicitude as the ethical component of the relationship, Ricoeur insists on a component of mutuality within the relationship. For example, in his writings on the doctor patient relationship, Ricoeur describes the physician and patient as united "in a sort of alliance sealed between two persons against a common enemy, the illness" (Ricoeur 2000 p. 17). A "Pact of Care" is established between the physician and the patient in response to suffering with the purpose of curing or at least caring for the one who is suffering. Ricoeur describes, "This is an act between two people, one of whom is suffering, who presents his complaint and requests help from an expert in matters of health" (Ricoeur 2007c p. 213-214). Trust binds the two parties together just as trust binds friends together; in this way solicitude expressed in a relationship that begins with significant dissymmetry shares the ethical foundation of friendship. It is the trust on the ethical plane which through the Golden Rule will find expression in the formal aspects of the pact. Ricoeur wants us to not overlook the importance of this foundation of trust. This dissymmetry renders the treatment pact precarious; it "is not unequivocally a pact of trust. Potentially, it harbors a component of suspicion" (Ricoeur 2001 p. 118). As Ricoeur explains, the patient may suspect the physician of abuse of power; the physician may suspect the patient of unreasonable expectations (for results rather than care) (Ricoeur 2007c p. 221). Solicitude assists in developing and maintaining trust. Situations of DOC in particular demand a considerable effort to esteem the other, since the physician does not hear directly from the patient about his or her needs, fears, suffering and hopes; in such situations solicitude becomes all the more important so that the care of the patient does retain the character of relationship rooted in trust, especially because the rules guiding the pact of care at the deontological level, for example informed consent, fail to function in the same way towards protecting the ethical demands of treating the patient as a irreplaceable and whole.

Applied to the actual troubling cases of DOC, Ricoeur’s concept of selfhood encourages considering an individual’s body as his or her possession and an aspect of his or her identity rather than a neutral vessel inhabited by a brain that contains the totality of his or her distinctness. It encourages taking seriously the fact that individuals live social embedded lives and it cautions against discounting the concept of personhood by imaginings that do away with terrestrial, historical, temporal location as if it is unimportant. This leads us to a few important decision-making parameters: the body cannot be considered as completely irrelevant, and thus the struggles that family members have with understanding to what degree the brain-injured individual’s identity is in their body should be honored and taken seriously since all their experience of the individual is through their bodies. More fully acknowledging our existence as beings that act and are acted upon, as acting beings and also suffering beings encourages us against conceiving of ourselves as subjects and those with DOC as objects. In his description of solicitude Ricoeur offers direction for how to respond to our own and others’ suffering. In the concluding section that follows, I will describe how Ricoeur’s concept of solicitude also finds voice in the realm of our institutional life where it gives us direction in managing societal conflicts respectfully.

Conclusion

Ricoeur maintains a balance between ethics and morality, defined respectively as the desire towards the 'good life' and the obligation to subject this primary ethical aim to the "test of the norm," interpreted in Kantian terms as the test of universalization and the treatment of persons as ends in themselves. He pairs each component of the ethical intention, "*aiming at the 'good life,' with and for others, in just institutions,"* with a corresponding one on the moral plane. "Solicitude," the action associated with the second component of the ethical aim, pairs with the "respect owed to persons" on the moral plane (Ricoeur, 1992b, p. 218). Ricoeur does not suppose, however, that an appeal to norms will solve conflicts, but that it will invite them: "A morality of obligation . . . produces conflictual situations where practical wisdom has no recourse . . . other than to return to the initial intuition of ethics, in the framework of moral judgment in situation; that is, to the vision or aim of the 'good life' with and for others in just institutions." He offers two cautions about circling back to the ethical aim:

> (1) "It is not a mater of adding a third agency to the ethical perspective," rather, it is "simply the reawakening of the resources of singularity inherent in the aim of the true life."
> (2) "This manner of referring morality back to ethics is not to be taken to mean that the morality of obligation has been disavowed . . . this morality continues to appear to us to be the means of testing our illusions about ourselves and the meaning of our inclinations that hide the aim of the good life," without which we would be "cast. . . defenseless into the realm of the arbitrary" (Ricoeur, 1992b, p. 240)

Ricoeur applies the term "*phronesis*" (practical wisdom) to this third and final ethical movement, which he enters into by reflecting on the play *Antigone*; he gives voice to tragedy in the midst of his philosophical analysis, he says, because "tragedy teaches us" (Ricoeur, 1992b, p. 242). Ricoeur observes that in the end Antigone is "left even without friends to morn her," adding, "The figure that walks away into the distance is not simply a person who suffers, but Suffering itself" (a phrase that closely resembles Auden's poem "The Surgical Ward": "They are and suffer; that is all they do") (Auden, 1945/1998).

In clinical medicine many situations arise when choices simply must be made: either the ANH will be withdrawn or not, the patient will be intubated* or not. I sat with many families and medical providers in the midst of this type of decision-making; more often than not, after a decision was made and a course of action chosen, even when all felt convinced the "right" decision had been reached, everyone walked away heavy with grief for the “good” in the choice that was not made. Poetry, Ricoeur explains, teaches not through didactic, but through a “conversion of the manner of looking.” In regards to the situation of DOC we need a conversion in the manner of looking. Both those who cling tightly to an RTL stance and those who cling to an RTD stance (perhaps more correctly described as the “right to choice” stance) fail to honestly acknowledge the tensions experienced by those closest to these patients.

I believe that values articulated by both sides are, in a sense, “right.” I remain ambivalent and therefore in the following advice I speak to both sides of myself. I begin with a reflection from the perspective of Christian theology. In Flannery O’Connor’s short story “Revelation” the protagonist, Mrs. Turpin, a woman who believes with fervor that she has “always had a little of everything and the God-given wit to use it right,” unexpectedly has a vision: a “swinging bridge extending upward from the earth through a field of living fire. Upon it a vast horde of souls were rumbling toward heaven.” Mrs. Turpin is seemingly shocked to see that among that vast horde are all *those* types of people who are not righteous like herself, they are “shouting and clapping and leaping like frogs.” Her people, the *right ones,* are bringing up the rear: “marching behind the others with great dignity, accountable as they had always been for good order and common sense and respectable behavior. They alone were on key. Yet she could see by their shocked and altered faces that *even their virtues were being burned away*” (*emphasis mine*) (O'Connor, 1956/1981). Scripture itself reminds that whatever we know of the “good” or the “right,” we know it only in part. Paul states this clearly in his first letter to the fledgling Christian community in Corinth: “For now we see in a mirror, dimly, but then we will see face to face. Now I know only in part; then I will know fully, even as I have been fully known” (1 Corinthians 13:12 NRSV). If we believe strongly in the sanctity of human lives, then we should treat those we disagree with as sacred. Defending the virtues we are so sure of should not come at the expense of seeing ourselves as *apart from* rather than *among* those with whom we disagree.

For those of us who are convinced of the rightness of freedom of choice, including the legitimacy of being able to choose death as a means to be freed from suffering incapacity, I offer Stanley Hauerwas’ caution: “too often [medicine] is tempted to increase its power by offering more than care, by offering in fact alleviation from the human condition” (Hauerwas, 1986, p. 86). We are, as Ricoeur repeatedly states, “acting and suffering” beings. I myself have an advance directive that stipulates refusal of long-term ANH if I am severely-brain injured and unable to speak for myself. However, I ask myself this question: “Is this because I am really convicted that such an existence would be meaningless or unrepresentative of my values,” or “Am I simply afraid that becoming totally dependent would render me worthless in the eyes of others?”

I conclude by offering one practical step forward. Astounding advances have been made in trauma care and in the fields of neurology and neurosurgery; we should applaud this progress. Yet, Severely brain-injured individuals with minimal capacity for communication are often placed in insufficiently staffed “custodial care” (nursing homes) that have no neurorehabilitation specialists (Fins, 2013). These facilities are often not structured to attend to bed-bound individuals’ needs for simple pleasures such as gentle touch, music, and human interaction; such needs have not even been considered worthy of research. Ricoeur adopts from Kurt Goldstein the idea that deficit or incapacity forces upon one the obligation to live in a “shrunken milieu” (Ricoeur, 2007b, p. 190). One question to ask ourselves is: “how can we expand the milieu of those who reside in extremely-dependent states?” One way to change our manner of looking is to turn our gaze away from those with DOC and onto ourselves and the institution of medicine, and to consider how we might, as Ricoeur describes, “make up for the deficiency of the other person, the patient, without denying or excluding him or her” (Ricoeur, 2007b, p. 194).

I have not solved the ethical concerns involved in the care of those with DOC; I do not believe they can be “solved.” Yet, I have utilized Paul Ricoeur’s unique philosophical system to illuminate limitations in the conceptions of “autonomy,” “personhood,” and “pain and suffering,” as they are commonly used in North American medical ethics. I have shown that Ricoeur’s description of human capacities (to speak, act, narrate and impute) more accurately reflect our lived experience of autonomy than a singular focus on “autonomous choices,” and that it offers clearer direction about how to ensure respect for patients as persons. Additionally, I have analyzed his understanding of humans as “acting and suffering” and offered his description of “solicitude” as a guiding value for caring for those with DOC. Finally, I have shown that Ricoeur’s approach of balancing a teleological and deontological approach and his ethical intention of “aiming at the good life, with and for others, in just institutions,” warrants more recognition from the biomedical ethics establishment in North America. Ricoeur’s approach is an alternative to the principlism approach for analyzing ethical dilemmas in medicine; especially those that are not limited to punctate clinical decisions, but concern whole areas of medical care such as the care of those with DOC. The principlism approach tends to neglect individuals' underlying desires and hopes for their lives and can easily lead to unsolvable binds between to competing principles. I have demonstrated that Ricoeur's approach can help to illuminate the sources of ethical confusion in a situation thereby clarifying what is at stake.

This critical exploration and personal reflection has taught me something else that is invaluable. My autonomously rendered treatment preference to refuse ANH if I should be severely brain injured is, at least in part, capitulation to the fact that medicine and society implicitly value success, strength, productivity, and ability. My true desire is to live in a circumstance in which should I be rendered totally dependent, I would not be abandoned and turned away from in dread. Instead, "patient" would be only one of my roles, the other would be "teacher," and I would teach my students - physicians and nurses and therapists and family members - by helping them to make peace with their own fragility and mine, their own mortality and mine, and the institution of medicine would value such care and be structured to support it.

Abbreviations

AAN - American Academy of Neurology

ACRM - American Congress of Rehabilitation Medicine

ANH - Artificial Nutrition and Hydration

CPR - Cardiopulmonary Resuscitation

CRS-R - Coma Recovery Scale Revised

DOC - Disorder(s) of Consciousness

EEG - Electroencephalography

fMRI - Functional Magnetic Resonance Imaging

LST - Life-Sustaining Treatment

MCS - Minimally Conscious State

NCS-R - Nociception Comma Scale (Revised)

PAS – Physician Assisted Suicide

PAD – Physician Assisted Death

PVS - Permanent Vegetative State

PET - Positron Emission Tomography

PCU - Post-coma unresponsiveness

UWS - Unresponsive Wakefulness Syndrome

VS - Vegetative State

Key Terms

Artificial Nutrition and Hydration (ANH) – (also termed “medically provided nutrition and hydration” - MANH) or sometimes simply referred to as a “feeding tube). ANH is the most prominent term utilized in North American medical contexts to describe receiving nutrition in a form other than by mouth. ANH can be delivered in various forms, as the Hastings Center describes: “These treatments may include total parenteral nutrition (TPN) delivered intravenously through a central-line catheter; percutaneous endoscopic gastrostomy (PEG), in which nutrients are delivered to the stomach through a tube sutured into the patient's abdomen; jejunostomy (J-tube), in which nutrients are delivered to the small intestine through a tube sutured into the abdomen; hypodermoclysis, in which nutrients are delivered through a subcutaneous needle or port; the use of a nasogastric (NG) tube to deliver nutrients into the digestive tract; and intravenous hydration" (Fins, 2013).

Cardiopulmonary Resuscitation (CPR) - An emergency procedure aimed at restoring flow of oxygenated blood to the brain and heart. The procedure includes chest compressions and in some cases rescue breathing.

Coma Recovery Scale Revised (CRS-R) - A standardized neurobehavioral assessment scale that assess auditory, visual, verbal and motor functions as well as communication and arousal level. There are various neurobehavioral assessment scales that have been developed for use with DOC patients. The CRS-R has shown superior performance in detecting MCS versus VS/UWS (Ricoeur, 2007b, p. 190)

Disorder(s) of Consciousness (DOC) - The umbrella term for a grouping of diagnostic categories of severe brain injury, including coma, unresponsive wakefulness syndrome/vegetative state, and minimally conscious state.

Electroencephalography (EEG) – A test of brain function that measure the electrical activity of groups of cortical neurons using electrodes temporary attached to the scalp.

Evidence-based Medicine – Described in a 1992 JAMA article as an emerging "NEW paradigm for medical practice" that "de-emphasizes intuition, unsystematic clinical experience, and pathophysiologic rationale as sufficient grounds for clinical decision making and stresses the examination of evidence from clinical research." (Ricoeur, 2007b, p. 194).

Feeding tube – see ANH

Functional Magnetic Resonance Imaging (fMRI) - ". . . a technique for measuring brain activity. It works by detecting the changes in blood oxygenation and flow that occur in response to neural activity – when a brain area is more active it consumes more oxygen and to meet this increased demand blood flow increases to the active area. fMRI can be used to produce activation maps showing which parts of the brain are involved in a particular mental process." Hannah Devlin, The Oxford Centre for Functional Magnetic Resonance Imaging. http://www.fmrib.ox.ac.uk/research/introduction-to-fmri [Accessed November 23, 2014]

Intubation – (Endotracheal Intubation) – A medical procedure that involves placing a tube into the windpipe through the mouth usually for the purposes of keeping the airway clear or accompanying use of mechanical ventilation.

Life Sustaining Treatment (LST) – I use this term as defined by the American Medical Association (AMA) "Any treatment that serves to prolong life without reversing the underlying medical condition. Life-sustaining treatment may include, but is not limited to, mechanical ventilation, renal dialysis, chemotherapy, antibiotics, and artificial nutrition and hydration" (Kuehlmeyer et al., 2012; Payne et al., 1996).

Minimally Conscious State (MCS) – State of limited consciousness in which individuals unequivocally (though often inconsistently) behaviorally show signs of cognitive awareness/responsiveness (such as visual pursuit or sustained eye contact) but cannot functionally communicate.

Mechanical ventilation – use of a tube and machine to get air in and out of the lungs.

Nociception Comma Scale-Revised (NCS-R) –- A scale developed to assess nociceptive pain in DOC patients. The scale has been tested and validated.

Persistent Vegetative State (PVS) – see Vegetative State

Physician Assisted Death (PAD) – see footnote 17, pg. 56

Physician Assisted Suicide (PAS) – see footnote 17, pg. 56

Positron Emission Tomography (PET) – In the most basic terms: "an imaging test that uses a radioactive substance called a tracer to look for disease in the body" (Holloway et al., 2013; Hukkelhoven et al., 2006; Turgeon et al., 2011). In Neurologic Disease: "Positron emission tomography (PET) is a powerful tool for in vivo imaging investigations of human brain function. It provides non-invasive quantification of brain metabolism, receptor binding of various neurotransmitter systems, and alterations in regional blood flow. The use of PET in a clinical setting is still limited due to the high costs of cyclotrons and radiochemical laboratories" (Ricoeur, 1992b, p. 179).

Post-coma unresponsiveness (PCU) — term used in Australia to describe the state termed Vegetative State (VS) or Unresponsive Wakefulness Syndrome (UWS) in North American and Western Europe.

Unresponsive Wakefulness Syndrome (UWS) – see Vegetative State

Vegetative State (VS) – (Also termed Unresponsive Wakefulness Syndrome – UWS and Post-coma unresponsiveness). A diagnostic category within the broader category of Disorders of Consciousness. The state is characterized by the presence of alternating periods of wakefulness and sleep (i.e. periodic eye-opening) accompanied by postural and reflex movements but absence of behavioral signs of awareness or purposeful movement and has widely come to be defined as "wakefulness without awareness" (Berlinger, Jennings, & Wolf, 2013). The terms "persistent" and "permanent" are now often discouraged from use due to confusion. However, for a description of the recommendation as to when a VS fits the criteria for "persistent/permanent," see chapter 1, pg. 11.

[References in footnotes: (Association, 2013; Bishop & Bedford, 2011; Brody et al., 2011; Kinzbrunner, 2004; Levin & Sprung, 2005; Logothetis, 2008; Poldrack, 2009; Rodriguez & Young, 2006; Tollefsen, 2008; Zientek, 2013)

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