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Assessing Decision-Making Capacity After Severe Brain Injury

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Abstract

Severe brain injury is a leading cause of death and disability. Following severe brain injury diagnosis is difficult and errors frequently occur. Recent findings in clinical neuroscience may offer a solution. Neuroimaging has been used to detect preserved cognitive function and awareness in some patients clinically diagnosed as being in a vegetative state. Remarkably, neuroimaging has also been used to communicate with some vegetative patients through a series of yes/no questions. Some have speculated that, one day, this method may allow severely brain-injured patients to make medical decisions. Yet, skepticism is rife, due in part to the inherent difficulty of assessing decision-making capacity through neuroimaging communication. In this thesis, I provide the first systematic analysis of this problem. I present and defend a strategy for assessing decision-making capacity in brain-injured patients who can only communicate through neuroimaging.

Keywords

Vegetative state, minimally conscious state, disorders of consciousness, brain injury, neurology, functional neuroimaging, decision-making capacity, medical ethics, neuroethics

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Preface

I. The Case of Mr. R.

Mr. R. was involved in a motor vehicle accident in December, 1999, which resulted in severe brain injury. Upon admission to the hospital, Mr. R. was unable to open his eyes or produce sound, and showed little reaction to painful stimuli. Neuroimaging showed herniation, bleeding, and contusions in his left parietal and temporal lobes. Mr. R. stayed in the intensive care unit for 1 month, and was then transferred to a specialized, long-term care facility. A year after his injury, Mr. R. was discharged into the care of his family.

Mr. R. was diagnosed as being in a vegetative state. He had regular periods of wakefulness, yet showed no behavioral evidence of awareness. Between 1999 and 2011, Mr. R. was assessed regularly by neurologists. Between 2012 and 2013, 20 bedside assessments were performed by clinical staff. All examinations consistently failed to reveal evidence of awareness. Mr. R.'s diagnosis did not improve throughout this time and it was believed his condition was permanent.

In February 2012, Mr. R. was enrolled in a study at the University of Western Ontario, in which functional neuroimaging was used to assess preserved cognition and awareness. Neuroimaging demonstrated that, despite satisfying all of the behavioral criteria of the vegetative state, Mr. R. was aware of his surroundings. Investigators adapted neuroimaging to allow Mr. R. to respond to a series of yes/no questions. Mr. R. was able to correctly identify his own name, the name of his support worker (whom he had met *following* injury), and the date. Additionally, Mr. R. was asked whether he was in physical pain, to which he answered no.

Mr. R.'s case touches on a number of important issues in philosophy of science, philosophy of mind, and medical ethics. Perhaps the most provocative philosophical issue raised is how this method of communication relates to medical decision-making. If we can communicate with Mr. R., is it ethically permissible to allow him to participate in medical decisions?

To date, medical ethicists have responded to this problem with skepticism. Communication limitations make it difficult to evaluate a patient's state of mind, which can lead to misinterpretation and even harm. Yet, there has been no systematic analysis of this problem in the medical ethics literature and no one has persuasively argued why patients like Mr. R. should—or should not—be allowed to participate in medical decisions.

In this thesis, I aim to resolve this problem by determining whether patients like Mr. R. have decision-making capacity. Working within the received framework, I present a strategy for assessing decision-making capacity in such patients. I argue that successful completion of the tasks involved in this strategy warrants the attribution of decision-making capacity to patients like Mr. R. for some low- to medium-stakes medical decisions. My argument is as follows:

A) In order to provide informed consent to medical treatment, a patient must have decision-making capacity.

B) Due to extensive brain injury, decision-making capacity in patients like Mr. R. cannot be presumed; it must be assessed.

C) Standard methods for assessing decision-making capacity cannot be applied to patients like Mr. R. because of limitations in communication.

D) If standard methods cannot be applied, it is permissible to modify the rules of assessment.

E) The rules of assessment can be modified by adopting a 3-step strategy:

Step 1: Evaluate cognitive functions and their relation to capacity.

Step 2: Deploy a vignette approach tailored to neuroimaging communication.

Step 3: Adopt a supported decision-making model.

F) The 3-step strategy does not produce evidence as strong as the standard method. Thus, only low- to medium-stakes decision-making should be permitted.

Conclusion A): Provided the rules of assessment are modified, decision-making capacity for some low- to medium-stakes medical decisions is demonstrable through neuroimaging.

Conclusion B): Provided a patient satisfies this strategy, it is permissible, in principle, to allow her to participate in some low- to medium-stakes decisions through neuroimaging.

II. Chapter Outlines

This is an interdisciplinary thesis, yet, the central problem and arguments explored herein are primarily philosophical. Communication with patients like Mr. R., while remarkable, is not an end in itself. Rather, communication is a *means* to an end, namely, improving the life of a patient. Future scientific advancements will help realize this end, yet, philosophy can help explain why this end matters and how we can achieve it in an ethically responsible manner. A prescriptive account of how the science should evolve requires such philosophical insight.This thesis contains 6 chapters. Chapters 1 and 3 are predominantly scientific. Chapters 2 and 6 are predominantly philosophical. Chapters 4 and 5 are a combination of the two.

Chapter 1: Neuroimaging after severe brain injury

In chapter 1, I review current clinical and scientific approaches to assessment, diagnosis, and neuroimaging after severe brain injury. I briefly review and respond to criticism of this research. I provide a comprehensive overview of neuroimaging communication. I document relevant information about the patients that have been involved in research, including patient histories, methods of communication, and the questions that have been posed. This chapter is intended to serve as the scientific backdrop for analysis of decision-making capacity.

Chapter 2: Decision-making capacity

In chapter 2, I provide an exegesis of the doctrine of informed consent, the received theory of decision-making capacity, and the standard method for evaluating decision-making capacity in clinical populations. I explain why this method of assessment cannot be applied in neuroimaging communication and review arguments that suggest it is ethically problematic to allow severely brain-injured patients to participate in medical decisions. I respond to these arguments to motivate the assessment strategy proposed in the following chapters.

Chapter 3: What cognitive functions are preserved following severe brain injury?

In chapter 3, I provide a systematic task analysis of the various neuroimaging methods used in the Owen Lab at the University of Western Ontario. I argue that satisfaction of each task recruits a number of cognitive functions. I specify which cognitive functions are required to execute which tasks. I argue that such information can shed light on the preserved cognitive profile of a patient before she is eligible for neuroimaging communication.

Chapter 4: Cognitive functions and decision-making capacity

In chapter 4, I provide a functional analysis of decision-making capacity and review recent findings that demonstrate that particular cognitive functions are differentially important to decision-making capacity. I argue that, from a coarse-grained perspective, certain cognitive functions are conceptually related to decision-making capacity and that these functions are recruited in tasks deployed in the Owen Lab. I also argue that, from a fine-grained perspective, neuropsychological research suggests a predictive relationship between cognitive functions and decision-making capacity. These relationships give reason to believe that the cognitive functions involved in decision-making capacity may be intact if a patient satisfies the neuroimaging tasks deployed by the Owen Lab. I argue that investigation of cognitive functions is a heuristic for informing practical judgments as to which patients may retain decision-making capacity, but that further evaluation is needed.

Chapter 5: The vignette approach

In chapter 5, I describe the vignette approach. The vignette approach is a practical test of decision-making capacity tailored to neuroimaging communication. A practical test is required because decision-making capacity is decision-specific, and cannot be attributed to patients by the mere evaluation of cognitive functions. The vignette approach discloses medical information to patients in a highly refined snap-shot, or vignette. A series of questions are posed to probe decision-making capacity. I argue that this approach is ideal for neuroimaging communication because it takes into account the technical limitations of neuroimaging, as well as the cognitive limitations of this patient population.

Chapter 6: Supported decision-making and severe brain injury

In chapter 6, I propose a model of supported decision-making. I revisit criticisms raised against the use of neuroimaging communication in medical decision-making. I then introduce the supported decision-making model, medical trusteeship, as a way to respond to these worries. I argue that medical trusteeship is a useful framework for thinking about how severely brain-injured patients can reasonably participate in decision-making.

III. A Note on Terminology

This thesis contains technical terms that cut across disciplinary boundaries. I have taken care to ensure consistency in terminology. Two key terms are identified here.

Capacity and *competence:* Capacity is an ethical condition of medical decision-making, while competence is a legal condition. The medical ethics and legal literatures sometimes use these terms interchangeably. Yet, their distinction is important for this thesis. This thesis provides an *ethical argument*, not a legal argument. The term, “decision-making capacity” has been used throughout, yet the term “competence” appears in some block quotations.

Cognition: The term “cognition”, and related terms, including “cognitive function” and “cognitive profile”, are used throughout this thesis. I do not defend a particular theory of cognition. I employ these term as they are commonly used in the scientific literature.

IV. The Owen Lab and The Neuroethics Research Group

This thesis is the product of a unique collaboration between the Rotman Institute of Philosophy and The Owen Lab. In 2011, Adrian M. Owen relocated his lab from Cambridge University to Western to take up the Canada Excellence Research Chair in Neuroscience and Imaging. In 2012, Charles Weijer, Canada Research Chair in Bioethics, and Professor Owen began discussions on collaborative projects. A working group was formed and CIHR funding was secured (2014-2018). The research program is entitled, “The Ethics of Neuroimaging After Serious Brain Injury”. Central contributors to the program include, Tommaso Bruni (Western), Damian Cruse (Birmingham), Davinia Fernández-Espejo (Birmingham), Teneille Gofton (London Health Science Centre), Laura Gonzalez-Lara (Western), Mackenzie Graham (Western), Andrea Lazosky (London Health Science Centre), Adrian M. Owen (Western), Lorina Naci (Western), Loretta Norton (Western), Andrew Peterson (Western), Kathy Speechly (Western), Fiona Webster (Toronto), Charles Weijer (Western), and Bryan Young (Western).

Chapter 1

1 Neuroimaging after severe brain injury

In this chapter, I review current clinical and scientific approaches in the assessment, diagnosis, and neuroimaging of severely brain-injured patients. I briefly review and respond to objections raised against this research. I provide a comprehensive overview of neuroimaging techniques used to communicate with severely brain-injured patients. I document relevant information about the patients that have been involved in research, including patient histories, methods of communication, and the questions that have been posed. This chapter is intended to serve as the scientific backdrop for philosophical analysis of decision-making capacity.

1.1 Acquired brain injury

Acquired brain injury is a leading cause of death and disability (Greenwald et al., 2003; Thurman et al., 1999). There are approximately 50,000 cases of brain injury per year in Canada and 1.4 million in the United States. Conservative estimates suggest an acquired brain injury rate of 250-300 per 100,000 inhabitants in developed Western nations (Campbell, 2000).

Acquired brain injury has both traumatic and non-traumatic etiologies. Traumatic brain injury can result from motor vehicle accidents, falls, or assaults. Non-traumatic brain injury can result from stroke, encephalitis, anoxia, or brain tumors (Tokutomi et al., 2008; Mosenthal et al., 2002; Rapoport and Feinstein, 2000). Epidemiological data indicate that age is an important distinguishing factor. In 2003-2004, the Canadian Institutes of Health estimated that 50% of all traumatic brain injury in Canadians aged 39 and younger was caused by motor vehicle accidents while more than 68% of traumatic brain injuries in Canadians aged 60 and older was due to falls. Brain injury is particularly high in males aged 15 to 24 and is often associated with risk-taking behaviors (Greenwald et al., 2003). Non-traumatic brain injury, meanwhile, appears to be most prevalent in individuals aged 40 and older.

Traumatic brain injury is classified as mild, moderate, or severe. Sports-related head trauma is a common source of mild to moderate brain injury. These injuries result in disorientation, confusion, or a state of transient unconsciousness lasting no longer than 1 hour (Multi-Society Task Force, 1994). By contrast, severe brain injury is life altering and may result in protracted unconsciousness. Severe brain injury requires immediate and intensive medical intervention and may lead to significant cognitive or physical disability.

Improvements in critical care have prolonged the lives of individuals who sustain severe brain injury, including those who are comatose (see table 1). Coma is characterized by unarousable unawareness with median duration of approximately two weeks (Young, 2009). The pathophysiology of coma is damage to the cortex, underlying white matter, or bilateral thalamus (Giacino et al., 2014). Damage to the ascending reticular activating system prevents comatose patients from breathing on their own (Young, 2009). Artificial hydration, nutrition, and ventilation are required. Intensive care for severely brain-injured patients can include therapeutic hypothermia to slow or prevent neuronal damage (Nikolov et al., 2003).

Predicting outcome in comatose patients is extremely difficult. Clinical exams, structural neuroimaging, biomarkers, and electrophysiological testing are the main source of prognostic information. In non-traumatic etiologies, poor outcome is indicated by absent brainstem reflexes, prolonged and recurrent epileptic seizures, specific biomarkers, or lack of response to electrical stimulation of the somatosensory nerves (Wijdicks et al., 2006). In traumatic etiologies, poor outcome is predicted by herniation in regions associated with the brainstem and particular abnormalities of the brain structure (Lingsma et al., 2010).

Following a period of coma some patients may enter into a vegetative state (also known as unresponsive wakefulness syndrome). Clinically, this transition coincides with recovery of spontaneous respiration (Demertzi et al., 2013). Mechanical ventilation can be safely removed; however, artificial hydration and nutrition are still required.

Table 1: Stages of recovery following severe brain injury

Condition	Clinical features	Clinical care	General prognosis
Coma	No sleep/wake cycles No awareness	Intensive care unit. Artificial ventilation, hydration and nutrition.	Recovery or death within 2 to 4 weeks. Outcome dependent on etiology.
Vegetative state	Semi-regular sleep/wake cycles Absence of awareness	Long-term care or family home. Artificial hydration and nutrition.	Outcome dependent on etiology.
Minimally conscious state	Regular sleep/wake cycles. Intermittent awareness	Long-term care or family home. May require artificial hydration and nutrition.	Outcome dependent on etiology.

Behaviorally, the vegetative state is characterized by dissociation between wakefulness and awareness. Vegetative patients will exhibit sleep/wake cycles yet evidence no concomitant awareness of visual, auditory, or tactile stimuli. The vegetative state is often referred to as "wakeful unresponsiveness" (Multi-Society Task Force, 1994; Plum and Posner, 1982).

It is difficult to predict recovery from the vegetative state (Beaumont and Kenealy, 2005). However, epidemiological data strongly suggest that patients with non-traumatic brain injury are unlikely to recover if they remain vegetative for longer than 3 months, while patients with traumatic brain injury are unlikely to recover if they remain vegetative for more than 12 months (Multi-Society Task Force, 1994).

A number of vegetative patients may enter into a minimally conscious state (Giacino et al., 2002). The minimally conscious state is characterized by sleep/wake cycles and intermittent behavioral evidence of awareness. Distinguishing features of the minimally conscious state include inconsistent command following, purposeful yet minimal language use, visual pursuit, object recognition, and localization of painful stimuli. The pathophysiology of the minimally conscious state is diffuse axonal injury with variable thalamic involvement. The severity of damage to the thalamus and specific cortico-thalamic connections is usually greater in vegetative than minimally conscious patients. This may explain why vegetative and minimally conscious patients differ in cognitive processing and behavior (Giacino et al., 2014).

1.1.1 Clinical assessment of severe brain injury

Patients with severe brain injury are assessed using clinical exams, structural neuroimaging, and electrophysiology. Clinical exams administered at the bedside evaluate a patient's wakefulness and awareness. Wakefulness is operationalized by behavioral or electrophysiological evidence of arousal, including periodic eye-opening and sleep/wake rhythms. Awareness is operationalized by sustained, reproducible, purposeful and voluntary behaviors, evidence of language comprehension or expression (Giacino et al., 2014; 2002; Owen, 2013; Young, 2009; Laureys, Owen, Schiff, 2004; Multi-Society Task Force, 1994).

A variety of neurobehavioral scales are available to assess wakefulness and awareness. A recent comprehensive review by the Brain-Injury Interdisciplinary Special Interest Group and The Disorders of Consciousness Task Force describes 13 different scales (Seel et al., 2010). Each scale is based on the premise that awareness can be inferred from behavior. These scales are designed to elicit agent directed behaviors, such as command following, response to painful stimuli, or functional communication. These behaviors, it is reasoned, require awareness (Owen, 2013; Laureys, Owen, Schiff, 2004). The attribution of awareness to such patients thus makes an "evidentiary detour" through behaviors that could not be performed without awareness (Bayne and Hohwy, 2014).

Three commonly used scales are the Glasgow Coma Scale (Teasdale and Jennett, 1974), the JFK Coma Recovery Scale (Giacino et al., 2004), and the Wessex Head Injury Matrix (Shiel et al., 2000) (See table 2). The Glasgow Coma Scale is applied to patients upon admission to a hospital and is divided into three subscales: eye response, verbal response, and motor response. Each subscale is scored individually. Eye response scores range from 1 to 4 (from no eye opening to spontaneous or stimulus-driven eye opening). Verbal response scores range from 1 to 5 (from no verbalization to subject-oriented conversation). Motor response scores range from 1 to 6 (from no spontaneous movement to reproducible command following). A maximum aggregate score of 15 indicates normal

Table 2: Behavioral scales used to assess severe brain injury

Scale	Behaviors assessed	Time to complete	Common application
Glasgow Coma Scale	Eye, verbal, motor/brain stem reflexes	5 min.	Admission to hospital
JFK Coma Recovery Scale	Auditory, visual, motor, oromotor, communication, arousal	25 min.	Assess emergence from coma Research
Wessex Head Injury Matrix	Basic behaviors, communication, attention, orientation, memory	30-120 min.	Patients at referral facilities Research

wakefulness and awareness. Aggregate scores less than or equal to 8 indicate significant neurological impairment (Teasdale and Jennett, 1974).

More detailed scales are used as a patient becomes medically stable. The JFK Coma Recovery Scale consists of six subscales: auditory function, visual function, motor function, oromotor function, functional communication, and arousal (Giacino et al., 2004). Each subscale is tested through three to five unique behavioral interventions. An aggregate score of 23 is consistent with normal wakefulness and awareness. An aggregate score less than or equal to 7, with no evidence of functional communication or object use, is consistent with coma or the vegetative state. Relatively high scores in any one of four subscales, or minimal yet reproducible communication are consistent with the minimally conscious state. The JFK Coma Recovery Scale is broadly considered the most sensitive and reliable scale for assessing awareness following severe brain injury (Stender et al., 2014).

More comprehensive scales, such as the Wessex Head Injury Matrix, are used to assess patients at specialized rehabilitation centers (Shiel et al., 2000). The Wessex Head Injury Matrix was developed through extensive clinical observation of patients recovering from severe brain injury. Initial development of the scale identified 145 behaviors characteristic of functional recovery. The Wessex Head Injury Matrix is not widely used in clinical practice due to the time needed to complete the exam—between 30 and 120 minutes—and the special training required.

Neurobehavioral scales are the standard method for assessing preserved awareness following severe brain injury. Yet, scale implementation and interpretation depend on the subjective appraisal of individual examiners and utilization is highly variable across medical facilities. As a result, a recurring trend of inconsistent diagnoses is observed and documented in the literature.[1]

In 1993, Childs and colleagues studied 49 patients admitted to a rehabilitation facility over a 5-year period. All 49 patients were classified as comatose or vegetative yet the diagnostic methods varied widely, employed different terminologies and different observation times. Childs and colleagues applied a standard reassessment method to this group of patients and found that 18 (37%) of them demonstrated behavioral evidence of awareness (Childs et al., 1993).

In 1996, Andrews and colleagues conducted a similar study of 40 patients diagnosed as vegetative upon admission to a rehabilitation facility. Andrews and colleagues discovered that 17 (43%) of these patients demonstrated evidence of awareness through volitional eye movement or a touch sensitive buzzer. They concluded that bedside examinations that rely on eye blinking as the primary indication of awareness are poor for assessing severe brain injury (Andrews et al., 1996). They note that:

> Many patients who are misdiagnosed as being in the vegetative state are blind or have a severe visual [disability]; thus lack of eye blinking to threat or lack of visual tracking are not reliable signs for diagnosing the vegetative state. (Andrews et al., 1996:13)

Importantly, the forgoing studies were conducted prior to development of standardized neurobehavioral scales *and* the introduction of the "minimally conscious state" as a diagnostic category. The JFK Coma Recovery Scale and Wessex Head Injury Matrix were developed in the early 2000's, while the "minimally conscious state" was

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[1] These findings are often referred to as "misdiagnosis rates". Yet, there is confusion in the literature regarding what "misdiagnosis" *means* and what a misdiagnosis *is relative to*. There are at least two kinds of misdiagnoses in this context. First, a misdiagnosis can occur because behavior is misinterpreted. Second, a misdiagnosis can occur because the scale used is insensitive, in principle, to the relevant kinds of evidence of awareness.

introduced in 2002 (Giacino et al., 2002). This may explain some of the diagnostic inconsistency observed. Nonetheless, a recent multi-center validation study of the JFK Coma Recovery Scale revealed similar results. In this study, investigators followed 103 severely brain-injured patients at multiple rehabilitation centers. Diagnoses made by consensus among medical staff were compared with the results of the JFK Coma Recovery Scale. Of 44 patients diagnosed as vegetative by medical staff, 18 (41%) were reclassified as minimally conscious when assessed with the JFK Coma Recovery Scale (Schnakers et al., 2009).

These findings demonstrate a number of important facts. First, the use of multiple neurobehavioral scales can engender heterogeneity of diagnosis between clinicians or medical facilities. Standardizing neurobehavioral scales would therefore reduce inconsistency. Second, reliance on particular behaviors, such as eye blinking, may be inappropriate in patients with motor disabilities secondary to brain injury. Indeed, a patient may be aware even if she is unable to demonstrate these behaviors. Finally, recent data suggest that clinical consensus likely underestimates awareness in some severely brain-injured patients. Consensus diagnoses must therefore be interpreted with caution.

1.2 fMRI and EEG assessment of severe brain injury

Technical advances in neuroscience have provided new avenues for exploring residual cognitive function and awareness in severely brain-injured patients. These methods reveal information that may be diagnostically and prognostically relevant when neurobehavioral evaluation is uncertain. Two modalities used are functional magnetic resonance imaging (fMRI) and electroencephalography (EEG).

fMRI is a non-invasive brain imaging technique that measures changes in blood flow and oxygenation in the brain (Belliveau et al., 1990; Ogawa et al., 1990). fMRI scanners expose participants to a magnetic field that alters the properties of hemoglobin, the primary oxygen-carrying molecule in blood. Hemoglobin contains iron atoms that express different magnetic properties when blood is oxygenated or deoxygenated (Aguirre, 2014). fMRI scanners detect these changes and identify where, and to what extent, hemoglobin is deoxygenating in the brain.[2] fMRI data are organized in 3-dimensional coordinate maps individuated into small units called voxels. Analytic methods are applied to data to compare estimations of hemoglobin de-oxygenation for statistical significance. fMRI generates brain images with high spatial but low temporal resolution. The method is relatively expensive and non-portable. fMRI units with high spatial resolution are found primarily in research institutes.

A second instrument is EEG. EEG is a non-invasive technique that records electrical activity on the surface of the brain (Luck and Kappenman, 2011). This activity has characteristic changes in amplitude and latency that are represented in EEG waveforms. A waveform often investigated in severely brain-injured patients is the P-300 wave (cf. Chennu et al., 2013; Faugeras et al., 2011). The P-300 wave has a positive deflection and occurs approximately 250 to 500 milliseconds after a stimulus is introduced. Research in healthy participants demonstrates the P-300 wave is elicited through odd-ball tasks. An odd-ball task exposes participants to a standard visual or auditory stimulus with short, random exposures to a distinct stimulus (e.g., a different auditory tone). Investigators hypothesize the P-300 wave is associated with alterations in attention (Chennu et al., 2013). Similarly, EEG may also be used to estimate diffuse polarization or depolarization of electrical fields on the brain's surface. This may reveal activation of broad cortical structures, such as the motor cortices. EEG has high temporal but low spatial resolution, particularly for sub-cortical brain structures (Luck and Kappenman, 2011). EEG is relatively inexpensive, portable, and widely used in neuro-critical care (Young, 2009).

A subset of fMRI and EEG-based techniques, called active paradigms (Laureys and Schiff, 2012), has been used to demonstrate awareness in patients clinically diagnosed as being in a vegetative state. An active paradigm requires the participant to perform a mental action (e.g., visualize an object, count, or sing to oneself). These paradigms, like neurobehavioral scales, are motivated by the view that agent directed behavior provides evidence of awareness. Yet, unlike neurobehavioral scales, overt behavioral response to a

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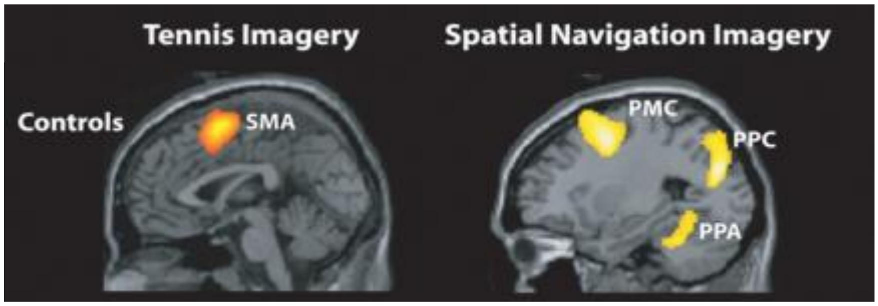
[2] Called a Blood Oxygenation Level Dependent (BOLD) signal.

Figure 1: Mental imagery activation patterns



Legend: SMA=Supplementary Motor Area; PMC= Pre-Motor Cortex; PPC= Posterior Parietal Cortex; PPA=Parahippocampal Gyrus. Image from Owen and colleagues (2006).

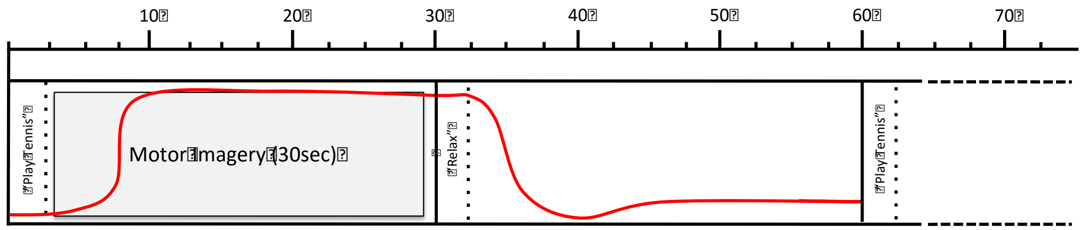
command is replaced with willful modulation of brain activity.

In the first-ever demonstration of this technique with fMRI, investigators assessed 36 healthy volunteers to determine if they could reliably follow commands with mental imagery (Boly et al., 2007). First, investigators assessed what type of mental imagery induced the greatest change in brain activity at the single subject level. While lying in the scanner, two participant subgroups were instructed to imagine two different tasks. The first group (n=12) was instructed to imagine either moving from room to room in their home or singing “jingle bells”. The second group (n=12) was instructed to imagine either playing tennis or visualizing familiar faces.

Participants were instructed to engage in mental imagery for 30-second intervals, repeated 7 times, and to relax on command. Standardized auditory stimuli, such as “play tennis” and “relax”, were used for task presentation. Analysis revealed spatial navigation imagery (imagining moving from room to room in one’s home) and motor imagery (imagining playing tennis) produced the strongest BOLD signal at the single subject level. Imagining moving from room to room in one’s home (e.g., spatial navigation) reliably produced activity in the pre-motor cortex, the posterior parietal cortex, and the parahippocampal gyrus. Imagining playing tennis (e.g., motor imagery) reliably produced activity in the supplementary motor area (see figure 1).

Investigators then tested a second group of healthy participants (n=12) to determine if neuroimaging evidence of spatial navigation or motor imagery could be distinguished

Figure 1: Mental imagery task design

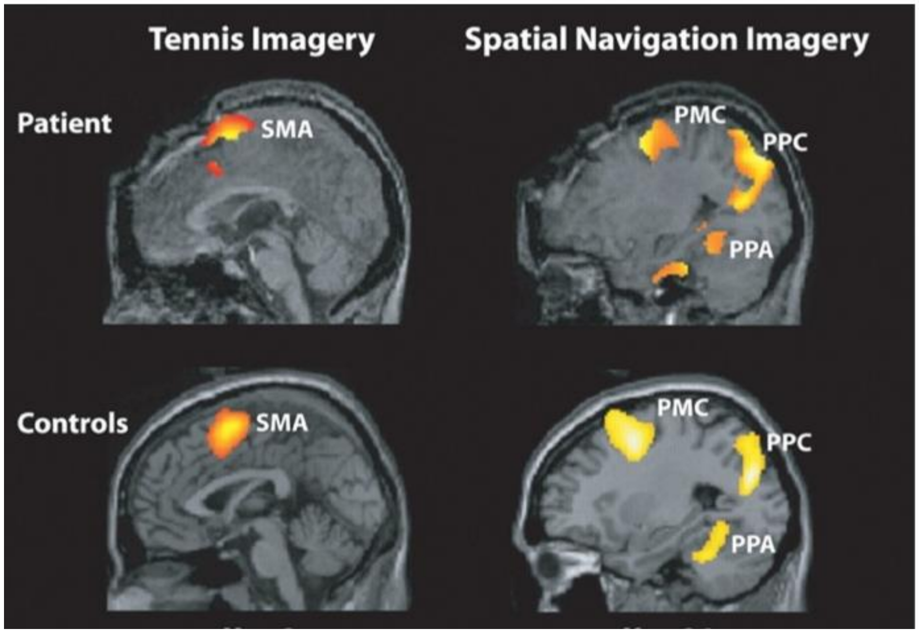


Legend: Mental imagery task design (motor imagery trial). X-axis is in seconds. Red line represents characteristic BOLD signal during task performance.

through blinded discrimination. While lying in the scanner, participants were instructed to imagine spatial navigation or motor imagery tasks for 30-second blocks, repeated 7 times (see figure 2). The sequence of task presentation was randomly selected by the neuroimaging computer system. This resulted in a distinct mental imagery sequence for each participant. A team of blinded experts assessed the post-scan data. In each and every case, the team accurately discriminated between rest, spatial navigation, and motor imagery tasks (Boly et al., 2007). According to the study authors, these findings suggest that fMRI mental imagery could be used as "a supplementary tool in clinical situations to diagnose some patients who are aware but unable to produce an overt motor output…" (Boly et al., 2007:989).

Investigators applied this technique to a severely brain-injured patient who was consistently diagnosed as vegetative over a 5-month period (Owen et al., 2006). Despite the patient's inability to demonstrate voluntary behavioral responses, investigators discovered that the patient could willfully follow commands by modulating her brain activity. fMRI signals were statistically robust, task-appropriate, reproducible, and sustained for discrete 30-second periods (see figure 3). In the five days of assessment leading up to fMRI scan, the Wessex Head Injury Matrix was administered to the patient at different times of the day and in different postures. Each assessment was consistent with the vegetative state. 11.5 months after injury (6 months post-scanning), the patient remained behaviorally unresponsive. Painful stimuli only elicited minimal and transient dilation of the left pupil, and no behavioral response to command following was observed (Owen et al., 2006: supplement).

Figure 2: Patient brain activation during mental imagery



Legend: SMA=Supplementary Motor Area; PMC= Pre-Motor Cortex; PPC= Posterior Parietal Cortex; PPA=Parahippocampal Gyrus. Image from Owen and colleagues (2006)

remained behaviorally unresponsive. Painful stimuli only elicited minimal and transient dilation of the left pupil, and no behavioral response to command following was observed (Owen et al., 2006: supplement).

Following publication of these findings, additional studies confirmed the efficacy of mental imagery in large, heterogeneous patient cohorts (Stender et al., 2014, Monti et al., 2010), and extended it to EEG (Cruse et al., 2012). These findings make a compelling case for the inclusion of functional neuroimaging and EEG in standard diagnostic protocols (Owen, 2013; Coleman et al., 2009). As previously noted, neurobehavioral scales may lead to inconsistencies in diagnosis (Schnakers et al., 2009, Andrews et al., 1996, Childs et al., 1993). fMRI and EEG can therefore complement neurobehavioral evaluation when diagnosis is unclear.

1.2.1 Criticisms of mental imagery

The mental imagery task has numerous critics (Klein, 2015; Nachev and Hacker, 2010; Nachev and Husain, 2007; Greenberg, 2007). Broadly, these critics maintain that positive results in vegetative patients do not provide persuasive evidence of awareness and are better explained by automatic brain activity. The supplementary motor area can automatically activate if participants are subliminally exposed to stimuli incidentally related to action (Nachev and Hacker, 2010; Nachev et al., 2008). Both epileptic patients and healthy participants have shown evidence of unconscious emotional or semantic processing during subliminal exposure to emotionally charged words or task descriptions (Naccache et al., 2005). Thus, the words contained in auditory instructions may elicit automatic brain activity that could be mistaken for voluntary mental imagery.

Proponents of the mental imagery task have responded to this criticism by systematically ruling out factors that might contribute to automatic responses. For example, the mental imagery task is organized in repeating 30-second blocks of mental imagery and rest. While it is possible that automatic brain activity could occur in response to task presentation, it is likely to be transient (Monti et al., 2010: supplement; Owen et al., 2007). In one study, healthy participants were tested to determine if relevant brain activity could be elicited automatically for 30-second intervals. Participants were presented with sentences containing the words “tennis” or “house” without receiving prior task instructions. fMRI results were modeled for 30-second response intervals. Owen and colleagues had hypothesized that significant and sustained activation would be observed if brain activity was merely automatic. However, no such activity in the supplementary motor area, the parahippocampal gyrus, or any other relevant brain region was observed (Owen et al., 2007:1221c).

A second, related, criticism is that, while it may be apparent that patients are capable of following commands through mental imagery, the associated brain activity is not due to an endogenous intention (Klein, 2015). An endogenous intention is formed as a result of the agent’s own volition, while exogenously driven behavior is believed to result from stimuli independent of this volition. Proponents of this view claim that neural modulation elicited by the mental imagery task is exogenously driven. They argue further that certain conditions that inhibit the formation of endogenous intentions, such as akinetic mutism, explain the clinical presentation of these patients better than a presumption of covert awareness.

One response to this brand of criticism hinges on an anatomical model that explains the dissociation between imagined and performed movements. Proponents of this critique presume a condition like akinetic mutism best explains the observed phenomena. Yet, a recent study by Fernández-Espejo and colleagues (2015) proposes, and subsequently confirms, a neural model that explains the clinical presentation of these patients without raising worries about endogenous intention formation. White matter tracts that project from the thalamus to the motor cortex are uniquely damaged in patients that appear vegetative but are covertly aware. This accounts for the clinical presentation of these patients and their ability to perform mental imagery without invoking a distinction between endogenous intention formation and exogenously driven brain activity.

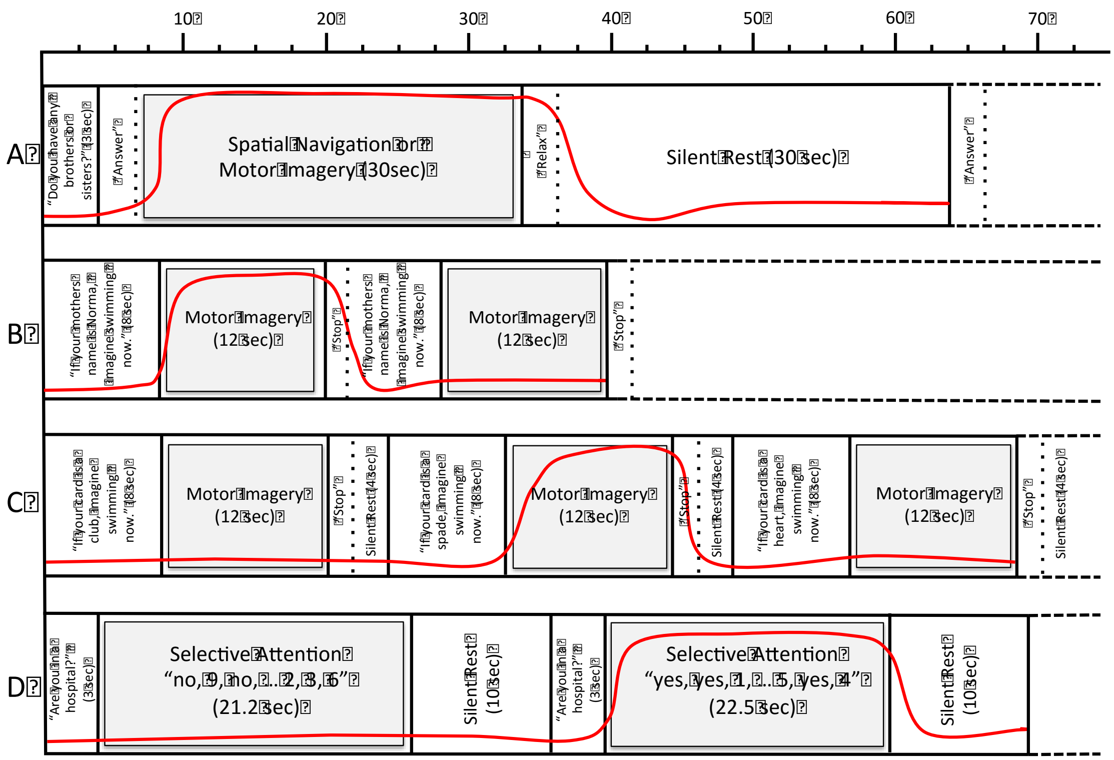
The mental imagery task design combined with a neural model that explains the clinical presentation of these patients suggests that the probability of an automatic, exogenously driven response to the task is low. In order for brain activity to be automatic and still satisfy the mental imagery task, the activity would have to occur in the correct brain region, at precisely the right time in the experiment, and be sustained for repeated 30-second intervals (Owen, 2013; Owen et al., 2006). The fact that patients can perform this task on command, and likely have focal lesions that dissociate imagined from performed movement, provides reason to believe that these patients, despite their clinical presentation are, in fact, aware.

1.3 Communication through neuroimaging

The reliability of fMRI and EEG-based active paradigms has paved the way for attempts to communicate with severely brain-injured patients. To date, several fMRI studies have identified a minority of patients capable of functional communication.

In the first reported demonstration of neuroimaging communication (Owen and Coleman, 2008), investigators sought to determine whether a single healthy participant could accurately convey responses to yes/no questions. Prior to scanning, the participant provided a team of blinded investigators with a set of names (e.g., Terry, Chris, Steve) and familial relations (e.g., father, brother, brother-in-law). The participant was asked a series of yes/no questions, such as “Is your father’s name Terry?” and “Is your brother’s

Figure 3: Communication task designs



Legend: A=Monti et al., 2010; Fernández-Espejo and Owen, 2013. B,C= Bardin et al., 2011. D= Naci and Owen, 2013. X-axis is in seconds. Red line represents characteristic BOLD signal during task performance.

name Chris?" To answer "yes", the participant was instructed to imagine playing tennis for 30-second blocks. To answer "no", the participant was instructed to relax. Activity in the supplementary motor area, the brain region associated with motor imagery, was observed in real-time with fMRI. Decoded answers were compared to participant reports to assess accuracy. All answers were subsequently confirmed as correct (Owen and Coleman, 2008).

In 2010, this technique was refined in an experiment involving 16 healthy participants (Monti et al., 2010). The study involved a localizer scan and a communication scan. In the localizer scan, participants were instructed to perform mental imagery. The data obtained allowed investigators to create brain activity maps that indicate where, and to what degree, BOLD changes occur during communication. In the communication scan, participants were instructed to answer yes/no questions through mental imagery. Prior to the neuroimaging session, participants were asked a yes/no question, such as "Do you have any brothers?" While lying in the scanner, participants were prompted with the neutral word "answer" to begin mental imagery and "relax" to cue rest (see figure 4, A).

Blinded investigators assessed the neuroimaging data. Answers decoded from the communication scans were compared with participant reports. Real-time fMRI data for all trials were decoded with 100% accuracy. To rigorously quantify these findings, investigators used a Relative Similarity Metric, which estimates the geometric distance between activated brain regions observed in the localizer scan versus the communication scan (Monti et al., 2010: supplement). Scans with high similarity suggest the activation of near identical brain regions. Using this method, participant answers were again decoded with 100% accuracy. This approach outlined a rigorous method for quantifying the communication scans at the single-subject level.

This task design (see figure 4, A) has subsequently been applied to two severely brain-injured patients. In 2010, Monti and colleagues reported communication with a patient who had been consistently diagnosed as vegetative for 5 years (see table 3, patient 1) (Monti et al., 2010). While lying in the scanner, the patient was asked 6 yes/no autobiographical questions. Questions ranged from "Do you have any brothers?" to "Is your father's name Alexander?" The neutral words "answer" and "relax" were used to cue repeated 30-second blocks of mental imagery for each question. The total scanning session lasted approximately 1 hour.

Blinded investigators decoded the neuroimaging data. Visual inspection identified answers to 5 of 6 questions. Calculation of relative similarity confirmed these findings. Post-scan analysis of answer 6 revealed insufficient data to confirm a "yes" or "no" response with high confidence. Investigators hypothesized this was due to patient fatigue (Naci et al., 2012). Of the initial 5 answers, all were successfully decoded and subsequently verified by the patient's family.

In 2013, Fernández-Espejo and Owen (2013) applied this task design (see figure 4, A) to a patient who had been consistently diagnosed as vegetative for more than 12 years (see table 3, patient 3). This patient was assessed on several occasions and underwent multiple communication scans. In total, this patient responded correctly to 12 yes/no questions. These ranged from simple autobiographical to complex questions, including "Is the year 1999?" and "Are you in a hospital?" Investigators also posed several questions regarding clinical well-being, including "Are you in pain?", to which the patient responded "No".

In 2011, Bardin and colleagues reported an alternative task design (see figure 4, B, C). This design was divided into increasingly complex steps. The first step involved mental imagery. 7 healthy participants and 6 severely brain-injured patients (5=MCS, 1=LIS) were instructed to imagine swimming for 30-second blocks. As with the tennis imagery task, swimming imagery was hypothesized to produce activity in the supplementary motor area. Relevant brain activity was observed in all healthy participants and 3 of 6 brain-injured patients (2=MCS, 1=LIS).

In the second step, swimming imagery was adapted for communication. Participants were presented with an auditory question, such as "Do you prefer preparing dinner yourself or dinning out?" Participants were instructed to imagine swimming when presented with their preference. The auditory cues, "preparing dinner yourself" and "dinning out", were presented in 12-second blocks. Brain activity time-locked to a specific option was interpreted as communication of that preference. Of the 7 healthy participants tested, all produced brain activity that was subsequently decoded correctly.

A similar task design (see figure 4, B) was then tested in a sample of 4 brain-injured patients (3=MCS, 1=LIS). Patients were asked their mothers' name. Bardin and colleagues phrased these questions as conditional propositions, for example, "If your mother's name is Norma, imagine swimming." Bardin and colleagues argued this phrasing decreased cognitive demand on patients; the task instructions were embedded in the task presentation and the task itself only required patients to engage in motor imagery. Post-scan analysis, however, revealed no statistically significant brain activity in any of the 4 patients. These findings were unexpected, as 2 of the 4 patients demonstrated "the ability to communicate fluently [through head movement or verbally], and were able to indicate *post hoc* that they attempted to perform the task" (Bardin et al., 2011:778).

The final step applied a multiple-choice task design (see figure 4, C), the reliability of which was previously demonstrated in healthy participants with mean decoding accuracy of 94.9% (Sorger et al., 2009). Prior to the scan, healthy participants and 4 brain-injured patients (3=MCS; 1=LIS) were presented with a playing card from a deck containing all face cards (ace, king, queen, jack) in all four suits (spade, heart, club, diamond). Healthy participants were instructed to record the face and suit of the card on a questionnaire before and after the scanning session. Patients were visually presented with the card on multiple occasions in the days leading up to their scans. While lying in the scanner, each participant was presented with a series of four auditory prompts regarding possible card faces or suits. These prompts were phrased as conditional propositions, for example, “If your card is a diamond, imagine swimming now”. Brain activity consistent with motor imagery time-locked to a 12-second response block was interpreted as a positive response to one of the 4 choices.

The answers provided by all of the healthy participants were correctly decoded, yet none of the patient responses were correct. Bardin and colleagues reported that these results were unexpected. On the day of the multiple-choice scan, one patient correctly identified her card (the ace of spades) with downward eye movements. Bardin and colleagues hypothesized that, given the patient’s ability to perform the task outside the scanner, the fMRI task design may have contributed to incorrect responses. Indeed, the short, 12-second response intervals could have exacerbated a delayed reaction to task presentation.

In 2013, Naci and colleagues reported a novel communication design that utilizes selective attention (Naci et al., 2013). Previous studies have demonstrated that selective attention can significantly enhance the neural representation of sounds (Bidet-Caulet et al., 2007). Thus, it is possible that modulation of attention may serve as a proxy for spatial navigation or motor imagery in patients that have difficulty performing the mental imagery task. To test this hypothesis, Naci and colleagues assessed 15 healthy participants with fMRI while they performed a counting task. Participants were instructed to count the number of times they heard the term “yes” or “no” in a stream of numerical auditory distraction stimuli (e.g., “Yes, 1, 7, Yes, 5, 3, 0, 1, Yes, 9, Yes…”). Response sets were organized in 22-second blocks with 10-second relaxation periods. Post-scan analysis revealed significant activation in the attention network—incorporating the bilateral inferior parietal, superior temporal, pre-motor, and inferior prefrontal gyri. Using these data, Naci and colleagues calculated brain activity maps to determine where, and to what extent, the attention network would activate during selective attention at the single subject level.

This design was then adapted for communication (see figure 4, D). Participants were asked such questions as "Do you have any brothers or sisters?" or "Are you over 21 years old?" Following the question, a series of "no" terms was presented interspersed with auditory distraction stimuli for a 21.5-second block with a 10-second rest period. The question was then repeated. A similar series of "yes" terms interspersed with auditory distraction stimuli was presented for a 22.5-second block with a 10-second rest period. Each question set required 69.7 seconds to complete and was repeated on average 5 times, for an approximate total scanning time of 6 minutes per question.[3] Of all responses to yes/no questions conveyed through selective attention, 90% were decoded with high confidence. 5.6 minutes of scanning time per question was sufficient to accurately decode answers in 92% of participants (Naci et al., 2013: 9390).

This method was then tested in a sample of 3 severely brain-injured patients (2=MCS; 1=VS) (Naci and Owen, 2013). All patients successfully completed the counting task, suggesting they were aware of the auditory stimulus and instructions. 2 of the patients (1=MCS; 1=VS) were then tested for communication. The two patients (table 3, patients 2 and 3) each underwent 4 communication scans. The first patient—a 25-year-old male whose clinical diagnosis had fluctuated between vegetative and minimally conscious for 5.5 years—correctly responded to the questions "Is your name Steven?" and "Are you in a super market?" The second patient—a 38-year-old male who had been clinically diagnosed as vegetative for 12 years—correctly answered 4 questions in two independent scanning sessions.

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[3] This time interval is important for determining how many questions can be asked of a patient in a single scanning session. I return to this in chapter 5.

Table 3: Patient characteristics

	Age/ sex	Diagnosis	Time since injury	Task	Correctly answered questions
1	29 M	CRS-R and SMART confirmed VS	60.8 m	Mental imagery	Is your father's name Thomas? Is your father's name Alexander? Do you have any brothers? Do you have any sisters?
2	25 M	CRS-R confirmed VS	67 m	Selective attention	Is your name John?* Is your name Mike? Are you in a supermarket? Are you in a hospital?
3	38 M	CRS-R confirmed VS	146 m	Mental imagery	Is a banana yellow? Is your name John?* Is your name Mike? Is the year 1999? Is the year 2012? Is your support worker's name Bob? Is your support worker's name Sarah? Is your support worker's name Julia? Do you like watching ice hockey on TV? Are you in pain?
			Scan 1: 147 m Scan 2: 152 m	Selective attention	Is your name John?* Is your name Mike? Are you in a supermarket? Are you in a hospital?

Legend: CRS-R= JFK Coma Recovery Scale-Revised. SMART= Sensory Modality Assessment Technique. VS= Vegetative State. Time intervals are in months. *=Name has been changed for confidentiality.

1.3.1 Patient characteristics

A review of the literature indicates that communication through neuroimaging has been attempted with at least 7 severely brain-injured patients (Monti et al., 2010= 1 VS; Bardin et al., 2011= 3 MCS, 1 LIS; Fernández-Espejo and Owen, 2013 = 1 VS*; Naci and Owen, 2013 = 1 MCS, 1 VS*; *same patient). 3 of these patients have correctly responded to at least 2 yes/no questions. The most successful task designs have used longer response intervals, ranging from 22 to 30 seconds, and longer rest periods, ranging from 10 to 30 seconds (see figure 4, A, D).

All patients who successfully completed a communication scan sustained a traumatic brain injury due to a motor vehicle accident. The average time between injury and communication scan for these patients was approximately 93 months (7.7 years) with a range of 60.8m to 152m. No patient showed signs of awareness or functional communication during repeated bedside examinations prior to scans (Naci and Owen, 2013: supplement; Fernández-Espejo and Owen, 2013: supplement; Monti et al., 2010: supplement). The most extensive evidence of neuroimaging communication was demonstrated by patient 3. This patient correctly responded to more than 10 questions, across 3 distinct scanning sessions, using two different task designs. Only a subset of questions was posed during any particular scanning session. The patient did not respond to questions on every occasion and, in some cases, did not produce any significant brain activity. Investigators hypothesized this may have been due to a "lack of attention or motivation on that particular day" (Fernández-Espejo and Owen, 2013: 804). However, there is no evidence the patient ever responded with a factually incorrect answer.

1.4 Conclusion

In this chapter, I have reviewed the relevant scientific literature related to fMRI and EEG-based active paradigms used to assess awareness in severely brain injured patients. Such techniques provide information ancillary to neurobehavioral scales, which can enhance diagnostic accuracy in patients whose clinical presentation is unclear. Further, fMRI-based active paradigms have been adapted for communication in a minority of severely brain-injured patients. To date, there is no study that determines the proportion of severely brain-injured patients who are capable of neuroimaging communication. Nonetheless, the frequency of patients reported in the literature is nontrivial. These patients raise difficult ethical questions regarding the appropriate application of neuroimaging communication following severe brain injury.

In the following chapters, I focus on one such ethical problem, namely, whether it is permissible to allow these patients to participate in medical decision-making. I present and defend a strategy for assessing decision-making capacity through neuroimaging communication, which in turn, provides the ethical grounds for allowing some severely brain-injured patients to make some low- to medium-stakes medical decisions.

Chapter 2

2 Decision-making capacity

A key component of informed consent is decision-making capacity. Given that some severely brain-injured patients cannot verbally consent to treatment, might clinicians be justified in using neuroimaging communication to elicit consent? In this chapter, I outline the standard view that decision-making capacity is required for informed consent, and describe the most broadly used instrument for assessing decision-making capacity in clinical practice. In outlining the features of decision-making capacity, I refer to the foundational texts in the literature.[4] I identify three concerns raised in the medical ethics literature regarding the use of neuroimaging communication as an alternative means of assessing decision-making capacity and obtaining informed consent. I address these concerns and argue that it is not impossible, merely difficult, to assess decision-making capacity through neuroimaging communication. The purpose of this chapter is to motivate the strategy proposed in chapters 3 through 6.

2.1 The doctrine of informed consent

Patients have the right to exercise self-determination in medical decision making (President's Commission, 1982: 44). This right derives from the principle of autonomy and is intimately associated with liberal notions of self-governance (Francis, 2009:201). In defining autonomy, Beauchamp and Childress assert that patients "have unconditional worth…the capacity to determine [their] own moral destiny…the right to choose…[and] the right to accept or decline information" (Beauchamp and Childress, 2012: 63). The President's Commission on Bioethics adopts a similar stance, stating that patients have the intrinsic ability to "form, revise, and pursue personal plans in life" (President's Commission, 1982: 44).

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[4] I acknowledge that, in the current literature, there is disagreement over this foundational account. Nonetheless, the purpose of this thesis is not to develop an alternative theory of decision-making capacity. Rather, I ask whether decision-making capacity—as traditionally construed—can be assessed in severely brain-injured patients who can only communicate through neuroimaging. For a detailed account of decision-making capacity, see Charland (2015).

Self-determination is central to the doctrine of informed consent (Faden and Beauchamp, 1986; President's Commission, 1982). This doctrine derives from both English and U.S. common law relating to battery and negligence. Battery includes "harmful or offensive non-consensual touching" in contexts such as surgery (President's Commission, 1982: 18-19), while negligence results from a failure to perform a dutiful action, or the careless performance of an action that leads to harm (Faden and Beauchamp, 1986: 27). Laws preventing battery and negligence reflect the view that health care providers have a fiduciary relationship with patients, which entails a range of duties, including a duty to respect self-determination.

Fiduciary relationships are characterized by structural inequality. One party in the relationship has more power or control than the other. This inequality engenders dependence and vulnerability (Miller and Weijer, 2006). Clinicians, by virtue of their knowledge, expertise and authority to prescribe, have power over sick and vulnerable patients. Patients therefore place their trust in clinicians to treat them competently. Violation of trust, whether through battery, negligence or failure to respect patient self-determination, undermines the fiduciary relationship.

Informed consent consists of three components: disclosure, voluntariness and decision-making capacity (cf. Faden and Beauchamp, 1986). Disclosure requires that clinicians reveal all relevant information to the patient, including treatment options, the risks and benefits of those options, and alternative therapies (cf. President's Commission, 1982: 42). Voluntariness requires that the patient be free from coercion, external manipulation, or interference (cf. President's Commission, 1982: 45). Decision-making capacity requires that the patient be capable of understanding the medical information presented to her, and rationally deliberating upon it to come to a decision. Each of these components must be satisfied for informed consent to be valid.

The doctrine of informed consent is also intended to balance the interests of patients with the duties of clinicians (Glass, 1997: 7). Clinicians have fiduciary duties to protect patients and obtain their consent. Patients, meanwhile, have interests in their own liberty and welfare. Clinician duties and patient interests will often align. However, in certain instances a patient's decision to ignore medical advice may challenge the clinician's duty to protect. When the patient chooses to ignore the clinician's advice her decision-making capacity may be called into question. If the patient ignores the clinician's advice but possesses decision-making capacity the clinician must respect the patient's choice. If the patient does not possess decision-making capacity, she must be protected through the appointment of a surrogate decision maker.

2.2 What is decision-making capacity?

Decision-making capacity is the ability of a specific individual to make a specific medical decision, at a specific point in time, and under specific conditions. This view is widely expressed in the philosophical, legal, and neuropsychological literatures (Dunn et al., 2006; Grisso and Appelbaum, 1998; Buchanan and Brock 1990; President's Commission, 1982; Freedman, 1981).

Decision-making capacity is mediated by a number of psychological abilities (Berg et al., 1996). These include: understanding, appreciation, reasoning, values, and communication.[5] In what follows I review the philosophical discussion of these abilities in the work of Buchanan and Brock (1990) and in the President's Commission Report (1982). I then review an operationalized model deployed in the MacArthur Competency Assessment Tool for Treatment (MacCAT-T) (Grisso and Appelbaum, 1998).

2.2.1 Understanding

Understanding is the ability to receive and retain relevant medical information (President's Commission, 1982: 58) and is based on a range of cognitive attributes. One must be able to comprehend language, grasp sophisticated concepts related to disease and treatment options, and recall information for application in future medical decisions (Buchanan and Brock, 1990: 23-24).

[5] I introduce these as "psychological abilities" here. However, throughout the rest of this thesis, I refer them as "subcomponents of decision-making capacity".

There are differing views on how much understanding is needed in order to provide consent. One view is that the patient must be *fully* informed. Being fully informed means the patient has exhaustive understanding of the medical information provided to her. But this suggests that the patient would need to know just as much as her clinician in order to provide consent. This requirement is unfeasible for patients lacking medical training. Moreover, patients often fail to comprehend medical terms (Chapman et al., 2003) and are unable to accurately recall the content of a consent interview (Robinson and Merav, 1976).

An alternative view considers what sort of information is truly essential for consent (Freedman, 1975). Ultimately, it is desired that patients make *responsible* medical decisions. How much medical information is imparted to the patient, and the extent of her understanding, are thus a function of the ability to make decisions responsibly (Freedman, 1975: 34-35). For example, the extent of information provided, and the understanding required to consent to a novel chemotherapy treatment for stage-4 breast cancer will be considerably greater than the information provided and the understanding required for the use of a routinely prescribed antibiotic. This difference is due to the extent of understanding required to hold a patient responsible for her consent or refusal of therapy. Understanding need only extend to information relevant to responsible medical decision-making. Understanding does not require a "mini-course in medical science" nor a "lengthy polysyllabic discourse on all possible complications" (Cobbs v. Grant, 1972: 502 P. 2d 1, 11).

2.2.2 Appreciation

Appreciation is the ability to imagine what future states will be like based on consent or refusal of treatment (Buchanan and Brock, 1990:24). If a patient is faced with a medical decision, she should be able to reasonably foresee the consequences of her medical decision.

A defining feature of appreciation is the ability to recognize how medical information relates to one's own situation. This is referred to as clinical insight (Owen et al., 2009:92). A variety of circumstances may diminish clinical insight. A patient may remain unaware of her illness due to a causal connection between illness and lack of awareness (Owen et al., 2009:95). Some stroke survivors, for example, suffer from a unique monothematic delusion called somatoparaphrenia, which results in denial of ownership of bodily limbs (Feinberg et al., 2010; Feinberg, 2010). Remarkably, this delusion cannot be corrected through proof or explanation. The deficiency of appreciation in these patients is a *false belief*.

Discussions of understanding and appreciation often overlap (Buchanan and Brock, 1990: 23-24; President's Commission, 1982: 56-57). However, appreciation differs from understanding in important ways. While both abilities involve general retention of medical information, appreciation requires the patient to recognize that the information relates to her own situation and to imagine what future states will be like given her treatment options (Glass, 1997: 12). Indeed, it is possible for a patient to fully understand the medical information while, at the same time, failing to appreciate that she is the subject of the medical decision. Understanding, therefore, does not entail appreciation. Appreciation must be demonstrated independently.

2.2.3 Reasoning

Reasoning is the ability to consider the potential outcomes of a medical decision and to assess how those decisions will affect goals and life plans. This ability requires one to consider probabilities, assign those probabilities to various outcomes, and weigh the importance of outcomes based on personal values (Buchanan and Brock, 1990: 24-25; President's Commission, 1982: 59-60).

Reasoning is distinguished from understanding and appreciation in that it captures the *process* by which a patient comes to make a medical decision. Deficiencies in appreciation may generate false beliefs, yet a patient can still reason appropriately with this information. Likewise, a patient may hold true beliefs about her medical situation but fail to reason appropriately. Reasoning is thus a function of the way a patient uses information. Failure to use information in a way that promotes one's goals and life plans will call a patient's reasoning into question.

It is often assumed that medical decisions are irrational if they contradict recommendations of clinical staff (Ganzini et al., 2004: 264). Evaluation of reasoning allows clinicians to determine if a patient has arrived at the decision through a logical process or through delusion. If the patient can explain her decision in a way that is consistent with her own goals and life plans, even if that explanation is inconsistent with medical recommendations, then the patient retains decision-making capacity. This reinforces the view that the possession of decision-making capacity is a function of the *process* by which a patient comes to her decision (Grisso and Appelbaum, 1998:53; President's Commission, 1982:55).

2.2.4 Values

A fourth component of decision-making capacity is the possession of a reasonably stable set of values. A set of values identifies the patient's conception of the good (Buchanan and Brock, 1990: 25) and provides a framework according to which subjective weight may be assigned to particular treatment outcomes (President's Commission, 1982: 57). Such values needn't be entirely consistent. It is not expected that a patient will have her entire life plan and goals determined in detail. All that is required is a set of values that is sufficiently stable to allow the patient to make a decision, follow through with it, and accept responsibility for it (President's Commission, 1982: 58).

Discussion of patient values is often folded into analysis of reasoning. One explanation for this is that patient values are not, strictly speaking, psychological abilities. As we shall see, standard neuropsychological instruments designed to assess decision-making capacity do not contain explicit probes for values (cf. Dunn et al., 2006). Instead, assessment of patient values is subsumed under the evaluation of reasoning. This is done under the assumption that patient values are operationalized through an explanation of the medical decision. In order for a patient to reason adequately, she must explain why the decision is best for her. Tacit or explicit reference to one's own values typically occurs in such explanations.

Some, however, have questioned this approach, motivated by the concern that standard methods of assessment do not account for harmful shifts in patient values. On this view, it is plausible that an individual may satisfy all of the conditions of decision-making capacity yet still be incapable because her values are unreasonable. In a study conducted by Tan and colleagues (2006), it was demonstrated that a group of anorexia nervosa patients could describe their condition with considerable insight and clarity. On standard assessment, these patients had decision-making capacity. Yet, closer examination demonstrated their decisions were ultimately motivated by distorted values, depression, and beliefs about the role of anorexic behaviors in alleviating mood alterations. This suggests that values can play a pivotal, yet often unseen role in a patient's decision-making process. There is a need to more accurately assess the how values, particularly "pathological values", contribute to medical decision-making (Charland, 2001). Such an approach would highlight the *rationale* behind a patient's decision more accurately than standard methods of assessment.

2.2.5 Communication

Communication is the ability to indicate, verbally or otherwise, that one has made a decision (Buchanan and Brock, 1990:23-24). If a patient lacks the ability to communicate, due to a neurodegenerative disease, for example, she will most likely be deemed incapable. A surrogate decision maker will be appointed in such cases.

2.3 Determining decision-making capacity

Clinically, decision-making capacity is determined by three factors: the patient's medical condition; the patient's process of deliberation; and, the demands placed on the patient by her medical situation (Grisso and Appelbaum, 1998: 31). Various neuropsychological instruments have been developed to assess the second of these factors. The MacAuthur Competence Assessment Tool for Treatment (MacCAT-T) is considered the most authoritative and rigorous instrument for assessing decision-making capacity in medical practice (Dunn et al., 2006).

The MacCAT-T is a structured interview, lasting between 15 and 20 minutes, which evaluates a patient's deliberation against an operational model of decision-making capacity (see table 4) (Grisso and Appelbaum, 1998: 103). This model includes four subcomponents: understanding, appreciation, reasoning, and expressing a choice (Grisso

Table 4: Operational model of decision-making capacity

Subcomponent	Operational features	Question probes
Understanding	Ability to describe the disorder, treatments, and risks and benefits in one's own words.	"Explain in your own words…" "Tell me what will happen if we don't treat the problem…"
Appreciation	Ability to acknowledge the disclosed disorder, symptoms, and treatment outcomes are about one's own medical situation.	"Do you believe you have these symptoms?" "Do you believe the treatment will be of benefit to you?"
Reasoning	Ability to foresee the consequences of treatment, compare consequences, acknowledge their influence on daily life, and provide a choice that is consistent with one's own values.	"Why do you think this treatment is better than others?" "What are some ways that this treatment might influence your activities at home?"
Expressing a choice	Ability to express a medical choice, verbally or non-verbally.	"What is your decision?"

and Appelbaum, 1998: 31). The operationalization of these subcomponents is broadly consistent with the theory of capacity advanced by Buchanan and Brock (1990) and the President's Commission Report (1982). Moreover, the model is also consonant with legal competence (Appelbaum, 2007).

The MacCAT-T begins with a structured disclosure of the patient's medical condition and treatment options. This follows the first component of the doctrine of informed consent. Disclosure includes identifying the patient's disorder, its expected course and potential outcome, different therapies, and the risks and benefits of these therapies (Grisso and Appelbaum, 1998: 103).

A series of questions probing the patient's understanding are posed during disclosure. Understanding is operationalized as the patient's ability to describe, in her own words, the medical disorder, proffered treatment, and risks and benefits of treatment (Grisso and

Appelbaum, 1998: 105). The patient's understanding is rated across three domains: understanding the disorder; understanding the treatment; and understanding the risks and benefits (see table 5). High ratings indicate the patient can paraphrase the medical information and provide a reasonably accurate indication of the potential risks and benefits of each treatment (Grisso and Appelbaum, 1989:183). Low ratings indicate the patient is unable to recollect or accurately describe the treatment options and their consequences (Grisso and Appelbaum, 1989:183-184). If there is a perceived deficiency in the patient's understanding, the clinician is encouraged to repeat the evaluation.

The clinician will also ask questions that probe the patient's appreciation. Appreciation is operationalized as the patient's ability to acknowledge that the disclosed disorder, symptoms, and treatment options relate to her. Evaluation of appreciation is based on the patient's explanation of her beliefs. Appreciation is rated across two scoring domains: appreciation of the disorder and appreciation of the treatments (see table 5). High ratings indicate the patient acknowledges all described symptoms and the potential benefits of treatment, or disagrees with the proffered diagnosis or treatment for non-delusional reasons, such as, "another doctor told me something else" (Grisso and Appelbaum, 1989:184-185). Low ratings indicate that the patient holds false, distorted, or delusional beliefs about her condition and treatment options (Grisso and Appelbaum, 1998: 106).

Following disclosure, the patient is asked to express a preliminary choice. The patient's reasoning is evaluated with respect to this choice. Reasoning is operationalized as the ability to compare treatments and explain why the choice made is the right one (Grisso and Appelbaum, 1998: 106). Reasoning is rated across four subdomains: consequential reasoning; comparative reasoning; generating consequences reasoning; and logical consistency (see table 5). High ratings indicate the patient sufficiently compares the proffered treatments, reasonably foresees their consequences, and offers reasons for her decision that are logically consistent (Grisso and Appelbaum, 1998: 189-190). Low ratings indicate the patient is unable to compare treatments, unable to foresee consequences, and provides reasons that are logically inconsistent (Grisso and Appelbaum, 1998: 189-190).

Table 5: Rating guidelines for MacCAT-T

Element	Scoring domains	Rating
Understanding	Understanding of disorder	2- Recalls and offers clear description of disorder 1- Recalls some features of disorder 0- Does not recall, provides inaccurate description, or distorts meaning
	Understanding of treatment	2- Recalls and offers clear description of treatment 1- Recalls some features of treatment 0- Does not recall, provides inaccurate description, or distorts meaning
	Understanding of risks/benefits	2- Recalls and offers clear description of risks/benefits 1- Recalls some features of risks/benefits 0- Does not recall, provides inaccurate description, or distorts meaning
Appreciation	Appreciation of disorder	2- Acknowledges being subject of disorder/symptoms 1- Acknowledges being subject of disorder but not all symptoms 0- Does not acknowledge being subject of disorder or believes symptoms are not related to disorder
	Appreciation of treatment	2- Acknowledges, with sufficient explanation, that treatment may or may not have benefit 1- Acknowledges, with no explanation, that treatment may or may not have benefit 0- Acknowledges that treatment may or may not have benefit based on false beliefs
Reasoning	Consequential reasoning	2- Identifies at least two consequences 1- Identifies no more than one consequence 0- Identifies no consequences
	Comparative reasoning	2- Identifies at least one difference in consequences 1- Identifies at least one difference between treatments 0- No comparison between treatments
	Generating consequences reasoning	2- Identifies at least two everyday consequences of treatment 1- Identifies one everyday consequence of treatment 0- No everyday consequences identified
	Logical consistency	2- Choice follows logically from reasons 1- Not clear whether choice follows logically 0- Choice does not follow from reasons
Communication	Expressing a choice	2- States one choice 1- States more than one choice/ambivalent 0- No choice stated

Finally, the patient is instructed to express a choice. Expressing a choice is operationalized as the ability to communicate a decision, verbally or otherwise, or to communicate the preference that a surrogate or clinician should choose instead. Expressing a choice is rated in one scoring domain (see table 5). High ratings indicate the patient expresses exactly one choice. Low ratings indicate the patient expresses more than one choice, does not make a choice, or vacillates (Grisso and Appelbaum, 1998: 190).

Aggregate scores are compared against normative data from both healthy and clinical populations (Grisso and Appelbaum, 1998: 122, 124). The MacCAT-T provides no cutoff score for any of the four subcomponents (Grisso and Appelbaum, 1998: 120-121). Rather, these scores are subjected to the clinician's judgment to determine whether the patient's performance justifies the attribution of decision-making capacity for the medical decision in question (Grisso and Appelbaum, 1998: 190). Nevertheless, decision-making capacity cannot be reduced to these subcomponents. Instead, it is the function of these subcomponents balanced with the patient's medical situation and the stakes of the clinical decision that determines whether it is permissible to attribute decision-making capacity to the patient. I return to this point in greater detail several times throughout this thesis.

2.4 Decision-making capacity as a threshold concept

Descriptive claims about decision-making capacity differ from claims about whether decision-making capacity *ought* to be attributed to a particular patient. Questions over decision-making authority may elicit conflict between the duties of clinical staff and the liberty interests of patients. Resolving such conflicts cannot be achieved merely through administration of the MacCAT-T (Grisso and Appelbaum, 1989: 33). Rather, it requires a normative judgment regarding who possesses decision-making authority for particular medical decisions (Buchanan and Brock, 1990:47).

Decision-making capacity has three normative features. First, it is decision-specific. This means the evaluation of decision-making capacity is restricted to one and only one decision. Second, it is a threshold concept. This means that the attribution of decision-making capacity does not admit of degrees. From a normative perspective, one either has or does not have decision-making capacity—there is no grey area.[6] Finally, the threshold of decision-making capacity required for each medical decision will vary.

There are at least three views regarding how to set the threshold of decision-making capacity for any medical decision. First, the threshold can be fixed and minimal (Buchanan and Brock, 1990: 49, 59). On this view, a patient has decision-making authority if she is simply aware of her medical situation and can either follow a health care provider's recommendation (Drane, 1985: 18) or freely make a choice regarding treatment (Buchanan and Brock, 1990: 59). This view maximally ensures patient self-determination but fails to discriminate between capable and incapable patients. It may remain unclear whether patient decisions are based on reasoned deliberation or not. A fixed minimal threshold of decision-making capacity may expose patients to harm.

Second, the threshold of decision-making capacity can be set according to the outcome of a medical decision. This view holds that patients ought to be respected if they demonstrate decision-making capacity and their decisions are not *seriously* irrational (Culver and Gert, 1990; Buchanan and Brock, 1990: 65). A decision is seriously irrational if the patient "knows or should know that its foreseeable results are that she will suffer…death, pain, disabilities, or loss of freedom, or loss of pleasure, or be at increased risk of suffering any of these, and she has no adequate reason for her action or decision" (Culver and Gert, 1990: 630).

There are both benefits and drawbacks to this view. On one hand, a patient is maximally protected if health care providers are allowed to intervene in cases in which otherwise capable patients refuse safe and effective treatment for life-threatening conditions (Culver and Gert, 1990:624). Yet, removal of decision-making authority from a capable patient on the basis of *apparent* irrationality violates autonomy. If this view were adopted, then "the principle that the voluntary and informed treatment decisions of a [capable] patient must be respected [would be rejected] in favor of the principle that… treatment choices can be set aside on paternalistic grounds if sufficiently irrational" (Buchanan and Brock,

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[6] Note, however, that this view is critiqued in chapter 6.

1990: 69). Determination of *serious* irrationality is highly subjective. Foreseeable negative outcomes are indeed important for evaluating patient decisions. But revoking decision-making authority on subjective grounds of irrationality is, in turn, a violation of the doctrine of informed consent.

A third alternative is to set the threshold of decision-making capacity according to the stakes of a medical decision (Buchanan and Brock, 1990:50-52; Drane, 1985: 18). Some medical decisions may lead to significant harm if there is deficient understanding or appreciation. Moreover, the importance a patient places on self-determination may vary with the decision being made. If a decision outcome poses substantial risk, where risk is "a function of the severity of expected harm and the probability of its occurrence", then the threshold of required decision-making capacity will be high (Buchanan and Brock, 1990:55). If the decision outcome poses risks that are roughly comparable to alternatives, then the threshold for that decision will be moderate. Finally, if the decision outcome poses less risk than alternatives, the threshold of required decision-making capacity will be low (Buchanan and Brock, 1990:53).

This view is attractive for a number of reasons. First, it is the standard approach for evaluating thresholds of decision-making capacity in much of North America and Western Europe (Buchanan and Brock, 1990:61). Second, this view is endorsed by research groups responsible for policy development, such as the President's Commission (Appelbaum, 2007:1836). Third, this view restricts the threshold of decision-making capacity to one and only one medical decision. It is not required that a patient satisfy a high threshold of decision-making capacity for all medical decisions (Buchanan and Brock, 1990: 63). Finally, this approach is consistent with the doctrine of informed consent. Rather than allocating decision-making authority entirely to patients or clinicians, this approach aims to balance the competing interests of both parties (Buchanan and Brock, 1990: 61).

One complication of this approach is how it deals with cases involving asymmetrical treatment outcomes. Treatment outcomes are asymmetrical in a minority of medical decisions when consent carries different risks than refusal of therapy. In some cases, consent may carry low risk while refusal carries high risk. This may result from the recommendation of an otherwise routine and harmless therapy for a life-threatening condition. In other cases, consent may carry higher risk than refusal. For example, in an oncology study investigating multiple interventions for advanced breast cancer, the internal review board judged that consent to research participation posed greater risk than refusal (Skrutkowski et al., 1998). This suggests that each medical decision may require multiple thresholds of decision-making capacity. The number of thresholds will depend on the extent of possible outcomes and the difference in risk that each outcome poses (Buchanan and Brock, 1990: 56-57).

The problem with this approach is that it may lead to interpreting decision-making capacity as a feature of the treatment choice rather than as a dispositional property of the patient (Freedman, 1975). If medical decisions have asymmetrical outcomes, and differing thresholds of capacity are needed to consent to or refuse therapy, it may be argued that patient decisions are open to review and revision.

One way to reconcile this problem is to interpret asymmetry of risk as a practical mechanism for triggering formal capacity assessment (Buchanan and Brock, 1990: 56). Legally, patients are presumed to have decision-making capacity until they demonstrate otherwise. Refusal of routine and harmless treatment for a life-threatening condition is a type of behavior that calls decision-making capacity into question. This does not mean the patient lacks decision-making capacity. Rather, it suggests the clinician needs more information about the patient’s rationale. Additionally, it should also be noted that not all medical decisions lead to asymmetrical outcomes. For example, many daily medical decisions do not lead to significant asymmetries in risk. Indeed, in some cases, a clinician may provide a variety of treatment choices that carry the same risk. In these cases, multiple thresholds are not required and the problem of asymmetrical outcomes is resolved. As we shall see (in chapter 5) this approach will be instrumental for allowing severely brain-injured patients to participate in medical decisions.

2.5 Decision-making capacity and neuroimaging

The principle of autonomy requires clinicians to respect patient self-determination if a patient has decision-making capacity. Efforts must be made to assess decision-making capacity before removing decision-making authority from the patient. The decision-making capacity of individuals with cognitive or communicative impairment is difficult to determine. Yet, national law (ADA, 1990; Canadian Charter, 1982) and international policy (United Nations, 2007) suggest that individuals with cognitive or communication impairments should not be stripped of access to goods and services, including decision-making authority, merely by virtue of their disability.[7]

To date, the medical ethics literature has demonstrated a great degree of skepticism regarding the possibility of evaluating decision-making capacity and eliciting informed consent using neuroimaging communication (cf. Glannon, 2014; Jox, 2013; Hardcastle and Stewart, 2013; Mackenzie, 2013; Rich, 2013; Fisher and Appelbaum, 2010; Fins and Schiff, 2010). Three objections are commonly made: first, that severely brain-injured patients lack decision-making capacity by virtue of their injury; second, that decision-making capacity cannot be adequately evaluated through neuroimaging communication; and third, that the validity of consent elicited through neuroimaging communication is questionable due to possible misinterpretation of patient responses. Each of these criticisms is addressed in the following section. I revisit these criticisms at several points throughout this thesis.

2.5.1 Do all severely brain-injured patients lack decision-making capacity?

In a recent review by an influential research group at Weill Cornell Medical School, it was claimed that "research and treatment in patients [with severe brain injury] is complicated by the lack of decision-making capacity" (Giacino et al., 2014: 109). This presumption is not surprising. After all, severe brain injury likely diminishes cognitive function. But does it follow that all severely brain-injured patients lack decision-making

[7] I return to the issue in Chapter 6.

capacity? Or that severely brain-injured patients lack decision-making capacity for all medical decisions?

There is a long history of treating certain patient populations as though they lack decision-making capacity for all medical decisions without formal evaluation. Persons with dementia or psychosis, for example, are commonly believed to lack decision-making capacity globally (Ganzini et al., 2004: 266). This presumption is based on the view that the nature of these conditions entails an inability to make rational decisions. But this view is false for a number of reasons.

Assumptions regarding a patient's decision-making capacity should not be made without appropriate evidence. The principle of autonomy holds that efforts must be made to respect patient self-determination when it is believed decision-making capacity may be present. When such efforts are made, some patient populations historically treated as incapable of making decisions (e.g., patients with dementia or schizophrenia) have been found to be capable of doing so (cf. Etchells et al., 1999).

By the same token, severely brain-injured patients should not be assumed to be globally incapable. During recovery, such patients may become capable of making certain decisions (cf. Ganzini et al., 2004:265). Two recent longitudinal studies investigating the recovery of decision-making capacity after traumatic brain injury found that recovery can occur 6 months or more post-injury (Triebel et al., 2014; 2012). In one study, approximately 50% of participants with severe traumatic brain injury showed marked improvement across all domains of decision-making capacity relative to assessment in the acute stage of injury (Triebel et al., 2014: 2299). This suggests that, while not all patients fully recover decision-making capacity after brain injury, some do. Lack of decision-making capacity, thus, is only contingently related to a patient's condition. Regular evaluation during recovery can help clinicians uphold their duty to respect patient self-determination.

2.5.2 Can decision-making capacity be assessed through neuroimaging?

A second objection is that it is impossible to assess decision-making capacity through neuroimaging communication (Glannon, 2014; Jox, 2013; Hardcastle and Stewart, 2013; Rich, 2013; Mackenzie, 2013; Fisher and Appelbaum, 2010). This concern is motivated by three technical obstacles associated with neuroimaging communication, namely, limits on communication, limits on the number of questions posed, and limits on accessibility. I briefly review these technical obstacles below and I return to them in greater detail in chapter 5.

2.5.2.1 Limits on communication

One obstacle associated with neuroimaging communication is that it only permits participants to answer yes/no or multiple-choice questions.[8] This raises concerns about the inability to communicate complex information in capacity assessments. For example, Glannon argues that, while "emotionally laden decisions about [medical treatment] reflect a person's values and attitudes…It is questionable whether these values and attitudes can be expressed by simple 'Yes' or 'No' responses" (Glannon, 2014: 2).

The limited communication inherent in neuroimaging is a relevant concern. Yet, this is based on the presumption that communication beyond "yes" or "no" responses is necessary to evaluate decision-making capacity. The MacCAT-T interview and similar instruments are indeed the most authoritative tools for assessing decision-making capacity (Dunn et al., 2006). However, there is no stipulation in the legal or philosophical literature that obligates clinicians to conduct a semi-structured interview in order to make such a determination. Indeed, in their guidelines for conducting the MacCAT-T, Grisso and Appelbuam admit the permissibility of deviating from standard rules of assessment. They state that:

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[8] Note that, to date, no patient has successfully responded to multiple-choice questions through neuroimaging communication.

> Patients who are on respirators or impaired by strokes may still be able to communicate using hand signals, letter boards, eye blinks, and the like. When evaluators are dealing with such patients, the evaluators usually will need to frame their questions in a "yes-no" or multiple-choice format. This is relatively easy for assessment of ability to express a choice itself. Determining how well patients understand information can also be successfully addressed by multiple-choice questions. Assessing appreciation and reasoning, however, are more difficult in this context. When results of such an evaluation are significantly incomplete, the usual rules for determining whether a patient has [decision-making capacity] may have to be slightly modified. (Grisso and Appelbaum, 1998: 86)

Generally speaking, assessment techniques need to be adapted to accommodate patients with communication impairments. A greater degree of flexibility in the rules for determining decision-making capacity would allow for assessment of such patients. Yet, there is little empirical literature on this topic and only a handful of case studies have reported strategies for overcoming communication impairments (Jayes and Palmer, 2014; Neumann and Kotchoubey, 2004; McMillan, 1997). These strategies use a combination of yes/no questions, multiple-choice questions, and communication aids, including pictures and spelling boards. In one of the most dramatic case studies to date, McMillan (1997) reported the assessment of decision-making capacity in a severely brain-injured patient with the aid of a hand-held buzzer (McMillan and Herbert, 2004; 2000; Shiel and Wilson, 1998).

Certain subcomponents of decision-making capacity, such as communication and understanding, might reasonably be assessed through neuroimaging communication. However, more sophisticated subcomponents of decision-making capacity are more elusive. Reasoning, for example, requires the patient to explain why a particular medical decision is right for her (Grisso and Appelbaum, 1998:187-190), but the limitations of neuroimaging communication prevent a patient from providing such explanations.

In such cases, it may be feasible to appeal to alternative evidence. In a recent study investigating logical processing skills, a patient clinically diagnosed as vegetative successfully completed a 3-minute grammatical transformation task through fMRI (Hampshire et al., 2013). This suggests that specific cognitive functions related to logical processing remained intact. Ancillary information of this kind can be brought to bear on the evaluation of decision-making capacity and, in certain circumstances, may help build a case for attributing decision-making authority to a patient for some medical decisions.[9]

2.5.2.2 Limits on the number of questions

A second technical obstacle related to task design is the number of questions that can be asked in any scanning session. To date, a single patient has correctly answered 5 questions in one hour (Monti et al., 2010). New task designs have, in principle, increased the number of questions that can be asked, but this quantity is still quite limited (Naci et al., 2013; Naci and Owen, 2013) and patient fatigue may be a limiting factor. Frontal lobe damage characteristic of traumatic brain injury may cause deficits in sustained attention (Coughlan et al., 2005: 252), which may leave a patient unable to answer more than 5 questions regardless of task design.

Intuition suggests that a large number of questions is needed to assess decision-making capacity. However, there is no consensus as to how many questions are sufficient (cf. Dunn et al., 2006). In borderline cases, the number of questions will not necessarily affect the determination of decision-making capacity. Rather, clinicians will assess the content of patient answers (Coughlan et al., 2005: 252). This suggests that the number of questions is not central to the determination of decision-making capacity. Provided that questions elicit *the right* information, it is possible that the number of questions could be relatively small.

[9] I return to this topic in chapters 3 and 4.

2.5.2.3 Limits to accessibility

A third technical obstacle is the logistical difficulty of using neuroimaging communication on an ongoing basis. Neuroimaging communication is technically complicated, expensive, and time-consuming. It requires transport to an imaging unit, which may be unfeasible if patients are not located in adjacent facilities. These logistical features, according to Fisher and Appelbaum, make "the determination of proxy answers…time consuming; and opportunities for follow up questions [are] limited" (Fisher and Appelbaum, 2010: 380).

Limits on accessibility may also be problematic for patients with ongoing changes in decision-making capacity. Mackenzie argues that, "during neurorehabilitation and recovery…patients' states of consciousness are likely to alter and fluctuate" (Mackenzie, 2013). In one recent study examining recovery of consciousness following severe brain injury, investigators observed that patient arousal fluctuated significantly over a 6.5-hour period (Candelieri et al., 2011). Similarly, Hardcastle and Stewart argue that "depression, anxiety, fear, euphoria, even sleep disturbances" can change on a daily basis (Hardcastle and Stewart, 2013). These changes may cause alterations in decision-making capacity. It may be argued that capacity should be assessed on an ongoing basis to account for these changes (Appelbaum, 2007). However, the logistical difficulties associated with neuroimaging communication prohibit ongoing evaluation.

The logistics of neuroimaging raise broader concerns regarding accessibility, yet they do not affect the plausibility of assessing decision-making capacity. Ongoing assessment is ideal but it is not necessary in order to evaluate decision-making capacity *for a specific decision*. We can imagine, for example, a healthy, capable individual expressing a medical decision and subsequently suffering an incapacitating brain injury. The individual's decision-making capacity has surely fluctuated, but it does not follow that clinicians are no longer obligated to respect the medical decision made before this fluctuation occurred.

It may be argued that some medical decisions have long-term consequences that need to be processed by the patient on an ongoing basis. For example, consent to cancer treatment may require a series of ongoing medical decisions, including surgery, chemotherapy, radiation therapy, and recurrent invasive diagnostics. In these situations, consent is distributed across the entire treatment regime. If a capable patient expresses the decision to no longer participate in treatment, her decision must be respected. Fluctuating capacity creates obstacles for such long-term treatment regimes. Safeguards must be put in place to protect patients with fluctuating capacity when participating in long-term treatments. As neuroimaging technology evolves, there may be opportunity for more accessible communication strategies that enable long-term capacity assessment (Fisher and Appelbaum, 2010: 380). Yet, for *routine medical decisions*, limited access is not a clear reason to exclude assessment of decision-making capacity through neuroimaging communication or other assistive technologies.

2.5.3 Misinterpretation of patient answers

A final criticism is the potential danger of misinterpreting a patient's answers. In their discussion of the use of neuroimaging communication to specify a "Do Not Resuscitate" status for a brain-injured patient, Fins and Schiff argue that:

> [t]here is a risk of reading too much into these one sided interviews…Whether the yes/no box is a primitive one or a sophisticated fMRI, the response seems unlikely to meet the 'clear and convincing' evidentiary standard for informed consent (Fins and Schiff, 2010: 22).

At best, they argue, neuroimaging communication can only be used for decision-making by *assent* (Fins and Schiff, 2010: 23).

While Fins and Schiff raise a difficult obstacle for neuroimaging communication, it is important to note that the *clear and convincing* evidentiary standard is only used for end-of-life decisions in some states. It is therefore misleading to presume that patients must satisfy this evidentiary standard in *all* states and for *all* medical decisions. Indeed, some medical decisions with significantly lower stakes will have a more lenient evidentiary standard. This is consistent with the view that the threshold of capacity required to make a medical decision is contingent on the risks and benefits of the treatment outcome.

Nonetheless, all assistive communication technologies are vulnerable to misinterpretation. But this does not mean that their use is necessarily problematic. Indeed, the same concerns apply to forms of communication that do not require assistive technologies. For example, patients who require an interpreter because they do not speak the same language as their health care provider may be subject to misinterpretation. Like assistive communication technologies, it does not follow that informed consent provided through an interpreter is necessarily invalid due to the possibility of misinterpretation. It merely means that precautions must be taken in order to ensure answers are interpreted correctly.

2.6 Conclusion

In this chapter, I have outlined the standard view that decision-making capacity is essential to valid informed consent. Decision-making capacity assists health care providers in mediating cases in which their duty to protect patients conflicts with a patient's liberty interests. In cases of uncertainty, neuropsychological tests may be used to probe decision-making capacity. The judgment of the clinician ultimately determines whether decision-making capacity is attributed to the patient.

Neuroimaging communication raises difficult challenges for informed consent. A patient's self-determination must be respected, but this can only be done if it is demonstrated that she has decision-making capacity. This is problematic for patients who can only communicate through neuroimaging, and raises a good deal of skepticism in the medical ethics literature. Yet, detailed analysis of the skeptics' arguments reveals that, in principle, they are resolvable. Modifications in the rules of assessment of decision-making capacity may allow for evaluation with neuroimaging communication.

Provided that the rules of assessment are modified to accommodate this patient population, what exactly would the procedure look like? In what follows (chapters 3 through 6), I respond to this question by presenting and defending a strategy for assessing decision-making capacity through neuroimaging communication. If successful, this strategy would allow some severely brain-injured patients to participate in the decision-making process for some medical decisions.

Chapter 3

3 What cognitive functions are preserved following severe brain injury?

Valid informed consent requires decision-making capacity. Neuroimaging communication poses several obstacles to assessing decision-making capacity in severely brain-injured patients. These obstacles do not, in principle, preclude the possibility of assessing decision-making capacity in this patient population but they do make it very difficult.

Whether patients recover decision-making capacity after severe brain injury is difficult to determine. However, during recovery, a patient may show signs of decision-making capacity in the form of preserved cognitive function. The duty to respect patient self-determination requires clinicians to seek out decision-making capacity where it exists. Exploration of cognitive function is therefore motivated by this duty.

A first step in determining whether a severely brain-injured patient retains decision-making capacity is to examine his or her preserved cognitive profile. Systematically reviewing the cognitive functions required for successful neuroimaging and electroencephalographic task performance, and assessing how these functions bear on decision-making capacity more generally, may allow investigators to determine if a patient has the requisite cognitive machinery.

In this chapter, I review the cognitive functions required for successful completion of the paradigms deployed by the Owen Lab. This chapter prepares readers for chapter 4, in which I draw connections between these cognitive functions and decision-making capacity. I provide practical details to highlight the extensive testing that occurs before neuroimaging communication. The overarching goal of chapters 3 and 4 is to develop a heuristic for the assessment of decision-making capacity in this patient population. As we shall see, a great deal of information about preserved cognition is revealed prior to neuroimaging communication. This information gives reason to believe that elements of

Table 6: Typical Owen Lab Schedule

Day	Imaging modality	Imaging paradigm
Monday	No imaging	• Arrival at testing facility • Rest day
Tuesday	EEG	• Hierarchical speech processing paradigm
Wednesday	fMRI, structural MRI, DTI	• Mental imagery paradigm • Hi-resolution structural scan • Resting state scan
Thursday	fMRI	• Rich stimuli paradigm • Selective attention paradigm
Friday	EEG	• Mental imagery paradigm
Saturday	No Imaging	• Return to long-term care facility

Legend: Electroencephalography = EEG; Functional magnetic resonance imaging = fMRI; Diffusion tensor imaging = DTI. Shading represents paradigms that are more cognitively taxing and require transport to neuroimaging unit.

decision-making capacity may be intact in brain-injured patients, and that further evaluation of high-functioning patients is warranted.

3.1 Owen lab evaluation schedule

Patients referred to the Owen Lab undergo a variety of experimental paradigms. A paradigm is a combination of different experimental features, including imaging modality and task design. Neuroimaging and electroencephalography based paradigms are administered over the course of five days (see table 6). During this period, patients are housed at the specialized neuro-rehabilitation facility, Parkwood Hospital, in London, Ontario. Paradigms that involve portable imaging modalities, such as electroencephalography, are administered at Parkwood Hospital, while structural and functional neuroimaging is conducted at the Robarts Research Institute at Western University.

Some paradigms involve tasks that are cognitively demanding or require transportation to an imaging unit. To ensure that the administration of these paradigms is productive, they are performed when the patient is known to be most alert. Paradigms conducted at the bedside, or those that involve tasks that do not require significant cognitive effort, are performed at other times.

All paradigms are intended to probe preserved cognitive function or awareness. Previous studies suggest that preserved cognitive function, such as speech perception, can predict functional recovery (Coleman et al., 2009). Investigators begin by probing basic cognitive functions before patients are subjected to more cognitively demanding tasks. If a patient demonstrates positive performance on a majority of paradigms, particularly mental imagery, she will return to the Owen Lab for further evaluation, including neuroimaging communication.

3.2 What cognitive functions are revealed in neuroimaging and EEG tasks?

Positive findings on different paradigms give reason to believe that some cognitive functions are retained or recovered following severe brain-injury. The paradigms developed by the Owen Lab are designed to recruit a variety of cognitive functions during task performance. A cognitive function is, loosely, a cognitive operation that allows one to perform a particular task.[10] Evaluation of cognitive functions is the focus of neuropsychology. Tasks deployed in neuropsychology often take the form of a written test or structured interview. A task called the WAIS-Digit Span, for example, requires a participant to recall a sequence of numbers in a specified order. A participant's ability to recall the sequence suggests that certain cognitive operations are recruited in task performance. Inferences about the participant's cognitive functions, such as memory, auditory processing, or abstract thinking, are made on the basis of the participant's speed and accuracy in completing the task (cf. Carroll, 1993).

The cognitive functions revealed by the neuroimaging and EEG-based paradigms deployed in the Owen Lab can be clustered into four domains (see table 7). A cognitive domain is a clustering of functions that contributes to the performance of a particular task or type of task. Philosophically rigorous definitions and classifications of cognitive functions are difficult to articulate and, in some cases, can lead to disagreement across disciplinary boundaries (for example, see Anderson, 2015). To avoid confusion, focus is

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[10] This is not intended to be a philosophically rigorous definition. See preface for notes on terminology.

Table 7: Cognitive functions organized by cognitive domain

Cognitive domain	Cognitive function	Description	Key paradigms
Language functions	Auditory processing	Reaction to sound versus silence	**Hierarchical speech processing paradigm** (Coleman et al., 2009; Davis et al., 2007)
	Speech processing	Reaction to speech versus signal correlated noise	
	Speech comprehension	Reaction to highly ambiguous versus non-ambiguous sentences	
Memory functions	Semantic memory	Capacity to remember concepts (e.g., tennis, house, numbers, etc.)	**Mental imagery paradigm** (Monti et al., 2010; Owen et al., 2006) **Selective attention paradigm** (Naci et al., 2013; Naci and Owen 2013)
	Working memory	Capacity to encode and retrieve task instructions	
	Episodic memory	Capacity to retrieve memories related to one's self	
Executive functions	Decision-making	Task compliance	**Mental imagery paradigm** (Monti et al., 2010; Owen et al., 2006) **Selective attention paradigm** (Naci et al., 2013; Naci and Owen 2013) **Rich stimuli paradigm** (Naci et al., 2014)
	Planning	Visualization and planning of movements	
	Selective attention	Sustaining attention to a specific stimulus	
	Theory of mind	Attribution of mental states to others	
	Information processing	Monitoring and encoding information and updating beliefs	
Basic reasoning functions	Abstract thinking	Recognition of logical/spatial relations between concepts/objects	**Grammatical transformation paradigm** (Kirschner et al., 2015; Hampshire et al., 2013)
	Reasoning	Reasoning according to a set of rules	

paid to how cognitive functions are operationalized by *specific task designs*. This analysis is coarse-grained and is merely intended to serve as a heuristic for evaluating decision-making capacity in a population with significant cognitive and communication impairments.

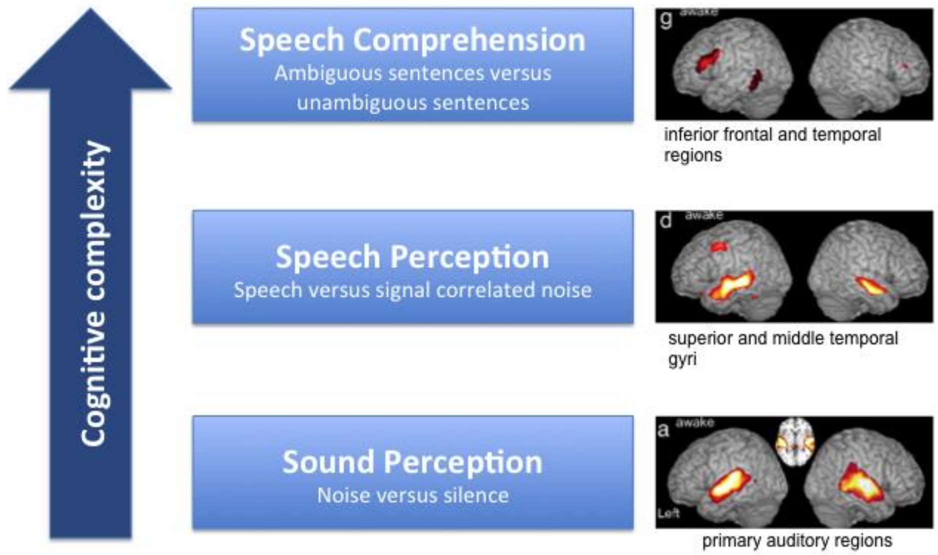
3.2.1 Language functions

Language functions are a cluster of cognitive functions that allow one to distinguish sound from silence or speech, and to comprehend speech. Preserved language functions are essential to positive performance on many cognitively demanding neuroimaging tasks (cf. Owen and Coleman, 2008: 132). Mental imagery, for example, requires understanding of task instructions. Task-appropriate brain activity in paradigms in which participants are passively exposed to speech requires the capacity to distinguish sound from speech. Basic language functions thus form a foundation for more cognitively demanding tasks. If a patient's language functions are limited, it will be difficult for her to perform cognitively demanding tasks.

It is well known that some patients clinically diagnosed as vegetative remain sensitive to auditory stimuli. Laureys and colleagues (2000) demonstrated that some vegetative patients show activation in primary auditory cortices in response to auditory clicks. Perrin and colleagues (2006) and Staffen and colleagues (2006) also demonstrated that some vegetative patients show characteristic brain activity in response to hearing their own name. Finally, Fernández-Espejo and colleagues (2008) have shown that some vegetative and minimally conscious patients react differently to auditory narratives played forward and backward. These findings suggest that, in some patients, auditory processing can remain intact following severe brain injury. However, further information is needed to determine how auditory processing is related to speech processing and comprehension.

In 2007, Davis and colleagues developed the first neuroimaging paradigm to show the hierarchical relation of brain regions associated with language. While lying in the scanner, 12 healthy participants were presented with auditory stimulus sets of increasing cognitive complexity. The first set contained trials of silence versus noise to test for auditory processing. The second set contained trials of spoken sentences versus speech-spectrum signal correlated noise to test for speech processing. The third set contained trials of sentences with low-ambiguity words (e.g., "there was beer and cider on the kitchen shelf") versus matched sentences with high-ambiguity words (e.g., "there were *dates* and *pears* in the fruit bowl") to test for speech comprehension.

Figure 5: Hierarchical speech processing paradigm



Healthy participants were exposed to these stimulus sets under light, moderate or no sedation. Light sedation was achieved by administering an anesthetic until the participant's response to conversation was relaxed and slowed, with slurring or impairment. Moderate sedation was reached when participants demonstrated no spontaneous engagement in conversation and responded in a slurred or impaired voice when their name was shouted. Participants received a post-scan interview once the sedation had metabolized. The post-scan interview tested the participants' recollection of the auditory stimulus.

Results demonstrated that brain activity associated with auditory perception, speech perception, and speech comprehension was elicited with particular stimuli (see figure 5). Sound versus silence contrasts elicited reliable activation of brain regions associated with auditory perception, including primary auditory regions. Speech versus signal-correlated noise contrasts elicited reliable activation of regions associated with speech perception, including anterior and posterior regions in the superior and middle temporal gyri, and inferior frontal and premotor regions. Finally, sentences containing ambiguous terms contrasted with sentences containing unambiguous terms activated regions associated with speech comprehension, including the inferior frontal and inferior temporal regions.

The increase in complexity of the cognitive task also recruited a broader range of activity throughout the brain.

Language functions were also dissociated under different levels of sedation. Auditory and speech perception were both preserved under light and moderate sedation. Characteristic activity in primary auditory regions, and superior and middle temporal gyri was observed. However, speech comprehension was inhibited under light and moderate sedation and no characteristic activity was observed in the inferior frontal and temporal regions. Likewise, post-scan interviews revealed that participants' recollection of the stimulus was diminished following light and moderate sedation. These findings suggest that evidence of passive speech comprehension can only be elicited if a participant is aware, or is not sedated.

In 2009, Coleman and colleagues reported the use of this paradigm in 14 severely brain-injured patients. Two patients had entered into a minimally conscious state, yet remained profoundly disabled. These two patients showed characteristic activation in appropriate brain regions to each stimulus contrast. Another 5 patients (3=VS; 2=MCS) showed characteristic activation when presented with silence versus noise contrasts, and noise versus speech contrasts. Finally, 3 of the 5 (2=VS; 1=MCS) patients that demonstrated auditory and speech perception also demonstrated some evidence of speech comprehension (Coleman et al., 2009).

These findings suggest that some severely brain-injured patients may retain or recover language functions following injury. Indeed, 2 patients that appeared to be entirely unresponsive at the bedside showed brain activity consistent with speech comprehension. Conversely, those patients who did not show evidence of language processing were also unlikely to perform well on cognitively demanding tasks involving language functions.[11] If it is known that a patient is unable to perceive or comprehend spoken instructions, then she is, by definition, unable to follow spoken commands. Preserved language functions

[11] Note that this presumes confounding factors, such as deafness, did not undermine performance.

thus serve as a threshold for further evaluation of a patient's cognitive profile, including the ability to communicate.

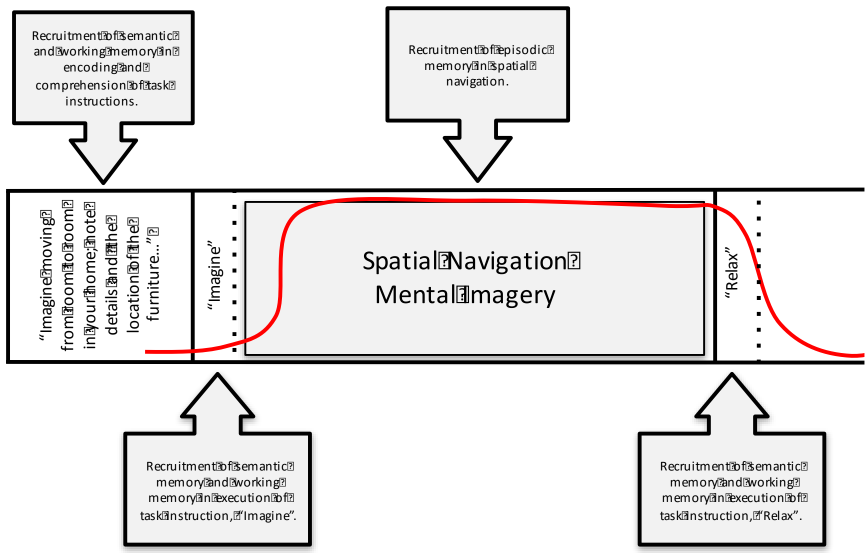
3.2.2 Memory functions

Memory functions are a cluster of cognitive functions that allow one to encode new information, deploy concepts, and recall autobiographical facts. Individual memory is broken into procedural and declarative types. Procedural memory involves the application of previous knowledge in the execution of tasks, such as riding a bicycle. Declarative memory, on the other hand, involves consciously accessing concepts or autobiographical facts, such as remembering what happened at your college graduation. Two types of declarative memory are semantic memory and episodic memory. These types are reviewed below. Readers should note that, while semantic and episodic memory are presented here as distinct memory functions, declarative memories often have *both* semantic and episodic aspects. It is therefore difficult to determine experimentally if a declarative memory is purely semantic or episodic. As we shall see, this is important for determining which cognitive functions may be preserved following brain injury.

Much can be inferred about preserved memory functions in severely brain-injured patients based on performance in task-driven paradigms (see figure 6). One memory function recruited in mental imagery, working memory, is the capacity to process information and make it readily available for immediate application in complex cognitive operations (Baddeley, 1992). Working memory is generally understood as a feature of executive processing (or attention) and a gateway to the consolidation of information in long-term memory (Engle, 2002). Working memory is involved in mental imagery task performance through the encoding and retrieval of the task instructions. Participants must encode the task and auditory cue for later task execution. They may be told, for example: "When you hear the word 'imagine', imagine moving from room to room in your home making note of details and the location of furniture." Participants must then recall the content of the task instructions over the course of five 30-second task intervals.

This design is unique in that it requires the participant to associate the task instructions with the cue word "imagine". If the participant is unable to initially encode the task

Figure 6: Memory functions recruited in mental imagery



instructions, or is unable to retrieve the content of the task instructions upon presentation of the cue word, she is unlikely to complete the task.

Another memory function recruited by mental imagery is semantic memory. Semantic memory is a highly structured internal lexicon that is essential for understanding language or concepts (Tulving, 1972: 386). Semantic memory is involved in mental imagery task performance through a participant's ability to understand the content of the task instructions. For example, a participant must understand what it *means* to "imagine playing tennis". This likely involves understanding the meaning of a set of associated concepts, including *racket*, *ball*, and *tennis court*. Aside from the concepts associated with the task instructions, participants must also understand the imperative statement "imagine" and associate its meaning with the task-appropriate mental imagery—either motor or spatial navigation. Failure to recruit semantic memory will likely inhibit a participant's ability to understand the task-instructions, or inhibit a participant's task-appropriate response to the command "imagine" when cued.

A third memory function recruited in mental imagery is episodic memory. Episodic memory is knowledge of events, places, or periods of time that are specific to one's own history (Conway and Pleydell-Pearce, 2000). Episodic memory is involved in mental imagery through performing a task that incorporates autobiographical facts. For example, the instructions for spatial navigation mental imagery ask participants to “imagine moving through *your* home.” Likewise, execution of the motor imagery task, which requires participants to “imagine playing tennis” requires some previous experience with tennis.

It may be argued that episodic memory is not necessary to perform spatial navigation mental imagery. According to this view, the spatial navigation task does not require one to imagine a particular *episode* of walking through one’s home. Indeed, one could perform this task by imagining navigating through *any hypothetical home* or walking through one’s home on any *hypothetical day*. Semantic memory alone could allow for this. Yet, this objection also depends on some structural independence between semantic and episodic memory. As indicated above, this can be difficult to determine because declarative memories often contain both semantic and episodic aspects. Given this uncertainty, inferences about preserved episodic memory following severe brain injury may require patients to communicate details about a particular episode in their lives. As we shall see, this may be important for assessing a patient’s reasoning in the medical decision-making.

3.2.3 Executive functions: Response selection, planning, and selective attention

Executive functions are a cluster of cognitive functions that allow one to make decisions, plan tasks, and attend to stimuli. Executive functions are essential for completing cognitively demanding tasks and will often recruit more basic cognitive functions, such as language and memory, in task execution (Elliot, 2003).

One executive function recruited in mental imagery and selective attention tasks is response selection. Response selection is the ability to choose between one or more alternative options. In the mental imagery task, participants are instructed to engage in motor or spatial navigation imagery for discrete and repeated 30-second intervals (Monti et al., 2010; Owen et al., 2006). Likewise, in selective attention tasks, a participant must respond to the instructions by sustaining attention to an auditory stimulus until instructed otherwise (Naci et al., 2013). In each case, a participant must actively respond to complete the task.

Another executive function recruited in cognitively demanding tasks is planning. Planning is the organization and implementation of thoughts to achieve a desired goal. The mental imagery task involves planning in the execution of imagined movements. When instructed to navigate through one's home, one must decide a point of entry, which rooms to navigate through, and the general direction or end-point of navigation. Likewise, when imagining playing tennis, one must plan a series of complex movements to achieve the imagined goal. The supplementary motor area—the region activated during motor imagery—has been shown to be involved in the organization and planning of movement prior to action (Nachev et al., 2008). This suggests that the process of imagining itself is associated with the ability to plan.

A further executive function recruited in cognitively demanding tasks is selective attention. Selective attention is the ability to attend to a single stimulus when it is presented in the context of a variety of competing stimuli, and to sustain attention beyond the period of reflex response. Novel stimuli are known to elicit attention, but this is often transitory and a function of "bottom-up" processing. Sustained attention, by contrast, recruits "top-down" processing of an attention system that detects and selects a stimulus based on relevance (Sarter and Bruno, 2001; Woldorff et al., 1993: 8722).

The selective attention task developed by Naci and colleagues leverages activation of a known attention system as evidence of awareness (Naci et al., 2013; Naci and Owen, 2013). Selective attention, Naci and colleagues argue, is known to "significantly enhance the neural representation of sounds" (Naci et al., 2013: 9385). The selective attention task not only demonstrates that the participant is able to volitionally recruit this attention system upon instruction, but also serves to elicit robust neural activity during fMRI scanning. This latter feature is important, as many brain-injured patients lack the cognitive resources necessary to produce robust neural activity in neuroimaging and EEG-based paradigms.

Figure 7: Scenes from Hitchcock's "Bang, bang, you're dead" (1961)

3.2.4 Executive functions: Theory of mind and belief updating

Task-driven paradigms require participants to perform a task. Such tasks recruit particular executive functions, such as response selection, planning, and selective attention. Yet, some patients may sustain injuries that degrade the ability to regulate brain systems involved in task-driven paradigms (Chung *et al.*, 2013; McDowell *et al.*, 1997). For these patients, an alternative strategy is needed to identify the integrity of executive functions.

One approach to assessing executive functions in patients who lack the ability to respond, plan, or selectively attend is a naturalistic stimuli paradigm (Naci et al., 2014). This paradigm measures brain activity as participants are passively exposed to a rich, naturally occurring stimulus, such as a film or story. Synchronization in brain activity across participants can be time-locked to specific features of the stimulus. For example, it has been demonstrated that synchronized brain activity associated with natural vision is elicited across study participants upon exposure to a highly engaging film (Hasson et al., 2008a; 2008b).

In 2014, Naci and colleagues extended this technique to determine if synchronized brain activity associated with particular executive functions could be elicited in severely brain-injured patients when exposed to Alfred Hitchcock's "Bang, bang, you're dead" (1961) (see figure 7). The film's plot involves a young boy, pretending to be a cowboy, who discovers his uncle's loaded revolver and mistakes it for a toy. Audience members become helpless bystanders as the boy ventures forth and pretends to shoot other characters. At several points the boy spins the cylinder—as in a game of Russian-roulette—takes aim, and pulls the trigger. A series of experiments sought to determine which features of the film drove brain synchronization across healthy participants, as well as the extent of synchronization between healthy participants and patients.

The study produced a number of important findings. First, brain regions associated with executive processing, including fronto-parietal regions, were highly synchronized across healthy participants while viewing the film. This was contrasted with both resting-state brain activity and brain activity elicited from a scrambled version of the film. In the two latter cases, no synchronization was observed, suggesting that the content and structure of the film's plot was, in some way, driving brain activity.

Second, synchronization of brain activity in healthy participants was predicted by two behavioral studies tracking the film's plot. In the first study, the executive demands of the film were measured with a go-no-go task in an independent group of healthy participants. Participants were instructed to push a button each time they heard a number, except for the number "8", while viewing the film. In the second study, another independent group of healthy participants was instructed to rate the "suspense" of the film every 2 seconds on a scale from "least" to "most suspenseful". Performance on the go-no-go task was delayed during executively demanding scenes, such as when the boy aims the loaded revolver at another character. Likewise, subjective ratings of suspense were highest during scenes that were executively demanding. Remarkably, these behavioral findings predicted synchronization of brain activity associated with executive processing.

This synchronization model was then compared against the brain activity of a severely brain-injured patient viewing the film. This patient satisfied all clinical criteria of the vegetative state for 134 months, yet his brain activity was highly synchronized with that of healthy participants when viewing the film. Brain systems associated with executive processing were active when the film's protagonist was aiming at another character or pulling the trigger. By contrast, these brain systems were relaxed during scenes of mundane plot development. This strong correlation in brain activity suggests that the patient's executive functions remained intact (Naci et al., 2014).

Positive performance on this paradigm requires a number of executive functions distinct from response selection, planning, and selective attention. These functions are recruited in the processing and interpretation of the film's plot and the manifestation of plot-driven affective states, such as suspense. One executive function recruited is a theory of mind, which is generally understood as the ability to attribute, interpret, and predict others' mental states (cf. Gopnik and Wellman, 1992).

A theory of mind is crucial for understanding the film's plot. First, many of the executively demanding and suspenseful scenes are driven by discordance between what the viewer knows and what the characters in the film are believed to know. For example, while viewers know the revolver is real, the fact that characters do not is central to generating suspense. Indeed, the qualitative distinction between suspense and surprise hinges on the fact that viewers are aware that they know more about the revolver than the film's characters. If the viewers had the same beliefs about the revolver as the characters, they would merely be surprised when it fires at the end of the film. By contrast, because the true nature of the revolver is revealed to viewers at the outset, viewers must reconcile this knowledge with the characters' actions as the plot unfolds. Film psychologists contend that this "initiating event" facilitates discordance between the viewers' knowledge and the characters' knowledge (Brewer 1996: 113). Viewers are able to anticipate counterfactual situations that the film's characters are unaware of, such as the revolver firing. This leads to feelings of suspense every time the boy pulls the trigger.

A second way a theory of mind is involved is in the willing suspension of belief (Brewer, 1996: 109). Witnessing Hitchcock's story as it might unfold in real life would surely generate suspense. But Hitchcock's corpus is, of course, fictional. Generating suspense thus requires the viewer to be an active participant in becoming engrossed in the film's plot. Cinematic features—such as the how the story is told, how shots are framed, and how characters are developed—serve to draw viewers in. Viewers must also be capable of genuinely taking the point of view of characters as the plot unfolds. This allows viewers to sympathize with the characters (Zillman, 1994). A good film elicits happiness when good things happen to the protagonist, and sadness when bad things happen. This involvement, like an "initiating event", creates further affective tension; the viewer must reconcile her third person knowledge of the plot's facts with what could happen to the characters. If one is unable to willingly suspend the belief that Hitchcock's story is fictional, it is unclear how the plot would motivate sympathy for the characters, which ultimately leads to suspense.

A third way a theory of mind is involved is in the viewer's ability to appreciate the morally relevant consequences of the boy's actions. For example, ratings of suspense were greatest during scenes in which the boy aims at a person (Naci et al., 2014: 14279). The suspense of these scenes is likely driven by two factors. First, viewers are able to distinguish between persons and objects. When the boy points the revolver at an object, there is little consequence if the revolver fires. Persons, on the other hand, can die. A second factor is that viewers likely appreciate the boy's relationship with other characters. For example, the suspense ratings recorded in healthy participants when the boy is aiming at his mother are greater than when he aims at a stranger. This suggests that, together with the ability to sympathize with characters' roles and interpret their belief states, appreciating the identity of characters, and how they are related to one another may modulate feelings of suspense and executive demand.

A final executive function recruited is the ability to process and update beliefs based on an ongoing flow of information. This involves incorporating new information with background knowledge—particularly semantic memory—to form an initial understanding of the film's plot, and to update this knowledge when new information is disclosed. The Hitchcock film draws on a variety of important concepts from semantic memory to drive the plot. Among others, one must know what a *gun* is, how a *revolver* works, what *make-believe* is, and the different types of relationships characters can have with each other, including being a *stranger*, *friend*, or *family member*.

Elements of semantic memory must then be synthesized with new information contained in the plot to create narrative tension. The dissonance between a toy and real gun, and how this bears on the characters' false beliefs, is central to the suspenseful elements of Hitchcock's story. Tracking the beliefs of characters over time and updating one's own beliefs about them once the true nature of the revolver is revealed is dependent on one's ability to process an ongoing flow of information. If one is unable to update beliefs in this way, it is unlikely one will be sensitive to the contextual features of Hitchcock's story.

3.2.5 Basic reasoning functions

Basic reasoning functions are a cluster of cognitive functions that allow one to think abstractly and solve problems. Basic reasoning functions are closely related to executive functions, but can, in certain circumstances, be dissociated. A brain-injured patient, for example, may be able to perform tasks that recruit executive functions, but be unable to solve basic problems. Indeed, the dissociation of basic reasoning from other cognitive functions is well documented in both mild traumatic brain injury (McDonald et al., 2002) and early stage neurodegenerative diseases, such as dementia (Perneczky et al., 2006). These cases present ethical challenges, as it is difficult to determine to what extent reasoning functions are inhibited and how this bears on a patient's decision-making capacity.

Mental imagery and selective attention tasks have been modified in recent years for assessment of basic reasoning functions in severely brain-injured patients. Hampshire and colleagues (2013) adapted a 3-minute grammatical transformation task for application in neuroimaging. While lying in the scanner, participants were presented with a series of auditory propositions specifying a spatial relationship between two objects (e.g., "the face is preceded by the house" or "the house is not preceded by the face"). Participants were instructed to "imagine the object that comes in front" for each proposition. Selectively attending to faces or houses modulates anatomically distinct visual processing areas (Epstein and Kanwisher, 1998). This allowed investigators to determine which object a participant was likely imagining despite her inability to provide a self-report. Remarkably, when applied to a patient previously diagnosed as being in the vegetative state for over 4 years, nearly all of her responses were correct.

Positive performance on the grammatical transformation task recruits a number of cognitive functions. As in other task-driven paradigms, grammatical transformation involves selective attention and response selection. Additionally, one must also be able to manipulate information in order to solve a problem. This involves encoding new information from the stimulus, synthesizing that information with previous knowledge, and applying rules to derive a solution. This process is no easy feat. Indeed, it recruits a broad range of cognitive functions, and is dependent upon the ability to manipulate information in logical space.

Hampshire and colleagues (2012) and Kirschner and colleagues (2015) have developed several neuroimaging and EEG-based paradigms to probe residual reasoning functions following brain injury. These paradigms target memory, grammatical reasoning, deductive reasoning, spatial rotation, and spatial planning (Hampshire et al., 2012). While these have not yet been applied in severely brain-injured patients, their reliability has been validated in in healthy participants. Most recently Kirschner and colleagues demonstrated that it is possible to implement a variety of memory and grammatical transformation tasks through portable EEG (Kirschner et al., 2015). This gives promise for future application of complex reasoning tasks in some severely brain-injured patients, even if transfer to a neuroimaging unit is unfeasible.

3.3 Conclusion

In this chapter, I have provided a systematic task analysis of the central neuroimaging- and EEG-based paradigms deployed in the Owen Lab. The purpose of this analysis is to demonstrate that a variety of cognitive functions are recruited in task performance, and that evidence of these cognitive functions is revealed prior to neuroimaging communication.

The evaluation of patients at the Owen Lab is hierarchical. Basic cognitive functions are assessed prior to attempting more cognitively demanding tasks. Because of this hierarchical assessment, much is known about a patient's preserved cognitive profile by the time she is eligible for neuroimaging communication. The evidence born out of this evaluation can inform practical judgments regarding the evaluation of decision-making capacity. Likewise, it may also reduce the evidentiary burden of any practical test of decision-making capacity applied in neuroimaging communication (this practical test is developed in chapter 5).

Chapter 4

4 Cognitive functions and decision-making capacity

In chapter 3, I provided a systematic task analysis of neuroimaging and EEG-based paradigms deployed in the Owen Lab. This analysis demonstrates that a variety of cognitive functions are recruited in task performance. As noted, planning, selective attention, response selection, and ongoing information processing are key to performing neuroimaging and EEG-based tasks. These functions serve as a foundation for more cognitively demanding tasks, such as neuroimaging communication.

In this chapter, I map the relationship between cognitive functions and decision-making capacity. First, I show there is a *conceptual relationship* between certain cognitive functions and decision-making capacity. This relationship is derived from a functional analysis of the four subcomponents of decision-making capacity. A functional analysis is the process of breaking down a cognitive phenomenon into more basic, functional parts by analysis of its operational definition. For example, the clinical operationalization of understanding suggests that memory functions are involved in encoding new medical information. These cognitive functions are thus embedded in the *meaning* of understanding.

Second, I argue that there is a *predictive relationship* between cognitive functions and decision-making capacity. As we shall see, particular cognitive functions, such as working memory and attention, are predictive of decision-making capacity in patients with psychiatric illness, brain metastases, and traumatic brain injury. Indeed, in these patients, deficits in cognitive function, as measured through validated psychometrics, are strongly associated with deficits in decision-making capacity. The presence of certain cognitive functions may therefore give reason to believe that one or more of the subcomponents of decision-making capacity—or decision-making capacity, broadly—remains intact.

The conceptual relationship between cognitive functions and decision-making capacity outlined in the first half of this chapter is intended to serve as a framework for interpreting the empirical literature in the second half. The conceptual relationship is intended to be *coarse-grained* in the sense that, *broadly speaking*, cognitive functions are embedded in the meaning of the subcomponents of decision-making capacity. By contrast, the predictive relationship is *fine-grained* in the sense that it identifies particular associations between *specific* psychometric scales and decision-making capacity. The overarching purpose of this chapter is to specify a conceptual relationship that elucidates the predictive relationship between cognitive functions and decision-making capacity[12], and to modestly show that the cognitive functions involved in the tasks used by the Owen Lab provide at least provisional evidence that decision-making capacity may be preserved. As indicated in the previous chapter, this analysis is merely intended to serve as a heuristic for informing practical judgments about which patients require further evaluation. The attribution of decision-making capacity will ultimately be determined by a clinician's judgment and performance on the practical test introduced in chapter 5.

4.1 Cautionary notes

Before proceeding, readers should be alerted to several important facts. First, the conceptual relationship developed here is non-standard. It is non-standard in the sense that entailments from cognitive function *to* decision-making capacity do not operate in the standard way. According to a standard view, decision-making capacity might be entailed from cognitive functions in two ways. First, the *presence* of certain cognitive functions might entail the *presence* of decision-making capacity. Second, the *absence* of certain cognitive functions might entail the *absence* of decision-making capacity.

The former entailment relationship cannot be developed with respect to decision-making capacity. Certain cognitive functions may be embedded in the operationalization of the subcomponents of decision-making capacity, but the mere presence of these cognitive functions does not entail a subcomponent, nor decision-making capacity broadly. This is because cognitive functions underlying decision-making capacity are normatively

[12] Drawing out this conceptual relationship has implications beyond assessment of severely brain-injured patients. For example, this can be useful for thinking about decision-making capacity in legal minors, elderly, and persons with mild cognitive and communicative impairments.

constrained (cf. Grisso and Appelbaum, 1998). They are normatively constrained in the sense that the attribution of decision-making capacity is ultimately determined by how cognitive functions bear on a patient's *decision-making process* in a *particular* medical context, balanced with the *stakes* of the medical decision. As reviewed in chapter 2, the clinician seeks to determine the appropriate balance between these normative features of decision-making capacity. By contrast, if there is a lack of essential cognitive functions, such as language processing, then—at least from a coarse-grained perspective—the patient will also lack decision-making capacity.

A second important fact to note is that any functional analysis of decision-making capacity is vulnerable to equivocacy. Ultimately what is desired is a clear inferential link from performance on a neuroimaging task, to cognitive functions, and finally to decision-making capacity. But this line of reasoning may be tenuous due to vagueness in the description of cognitive functions associated with decision-making capacity. It is well known that terms used in the psychological literature, such as working memory, have various working definitions (cf. Poldrack et al., 2011). Moreover, the referents of these terms may not be identical to those picked out by the subcomponents of decision-making capacity. This raises the worry that a functional analysis of decision-making capacity, or any attempt to operationally define cognitive functions underlying decision-making capacity, will be inaccurate.

I return to these concerns in greater detail below. However, in order to motivate this chapter, it is important to stress the pragmatic benefit to sketching relationships between cognitive functions and decision-making capacity. By the time a patient is eligible for neuroimaging communication, much is already known about her cognitive profile; a patient who is capable of satisfying cognitively demanding tasks likely retains decision-making capacity while a patient who is unable to satisfy such tasks likely does not. Focus on cognitive functions allows investigators to leverage this information when determining who is eligible for further evaluation. Additionally, it accounts for some degree of urgency in attempting to enroll such patients in research. For some brain-injured patients, neuroimaging communication presents the best possible opportunity to participate in

Table 8: Key cognitive functions associated with decision-making capacity

Subcomponent	Key cognitive functions	Neuroimaging tasks that recruit these cognitive functions
Understanding	Memory functions	Mental imagery Selective attention task
Appreciation	Executive functions	Rich stimuli paradigm
Reasoning	Memory functions Abstract thinking	Mental imagery Grammatical transformation task
Communication	Language functions	Hierarchical speech processing assessment Mental imagery

medical decision-making. Building the strongest possible case for participation thus requires exhausting all possible avenues of evidence.

4.2 Cognitive functions are conceptually related to decision-making capacity

To sing, one must be able to perform a number of basic tasks. For example, one must be able to verbalize language in order to sing lyrics. Additionally, one must also be able to carry a rhythm and melody, however offbeat and out of tune one's singing may be. These claims are not derived from observation. Rather, they are derived from what it means to sing. Singing is therefore conceptually related to a number of basic tasks.[13]

The same may be said of decision-making capacity. The standard model of decision-making capacity is broken down into four subcomponents: understanding, appreciation, reasoning, and communication. Each of these subcomponents is conceptually related to more basic cognitive functions. Functional analyses of the four subcomponents may therefore determine which more basic cognitive functions form the cognitive building blocks of decision-making capacity.

[13] Singing is not the same as having decision-making capacity. This example is merely used to illustrate the argument developed in this chapter.

In what follows, I provide coarse-grained functional analyses of the four subcomponents of decision-making capacity. I show that they are related to *key* cognitive functions recruited in tasks deployed by the Owen Lab (see table 8). I do not intend for these functional analyses to be exhaustive, as that would be beyond the scope of this thesis. Rather, I aim to show that the cognitive functions recruited in tasks deployed by the Owen Lab provide good reason to believe that decision-making capacity may be intact and that further evaluation of high-functioning patients is warranted.

4.2.1 Understanding, working memory, and semantic memory

In the medical setting, understanding includes the ability to describe the disclosed diagnosis, treatments, risks and benefits in one's own words. The ability to perform this task recruits a number of basic cognitive functions. Two cognitive functions that are essential to understanding are working memory and semantic memory. These functions are involved in the performance of cognitively demanding tasks used by the Owen Lab.

Memory functions are involved in understanding in at least two ways. First, understanding involves the ability to learn and recall new information related to diagnoses, treatments, risks and benefits. Working memory—the capacity to encode and store information such that it is readily available for more complex cognitive operations (Baddeley, 1992)—is crucial to this process. Working memory is recruited when a patient listens to the disclosed information and recalls it when instructed to do so.

Now, suppose working memory was not involved in understanding. If this were true, a patient would not be required to encode and store novel medical information when making autonomous medical decisions. But this is a counterintuitive view of understanding. Indeed, if working memory was not involved in understanding, then it is unclear that patient consent could ever truly be *informed*. A patient could freely consent to a medical procedure with deficient knowledge of her own medical condition. This, however, is inconsistent with standard accounts of understanding.

Another memory function essential to understanding is semantic memory. Roughly speaking, semantic memory is an internalized conceptual lexicon (Tulving, 1972: 386).

Medical information is disclosed as a series of facts, and includes such familiar concepts as *hospital*, *rehabilitation*, and *injury*. Semantic memory allows patients to make sense of these concepts. Additionally, it also allows patients to interpret concepts and recapitulate them in *their own words*.

Now, suppose semantic memory was not involved in understanding. In this case, a patient would understand even if she didn't have the ability to process familiar concepts. For example, a patient would understand even if she lacked the ability to process the concepts contained in the disclosure "you are at risk of cardiac arrest." This, however, is highly counterintuitive. Additionally, even if the patient was able to process these concepts, it is unclear whether she would be able to recapitulate them *in her own words*. Recall that semantic memory is related to one's ability to process the content of language. Without semantic memory, how would the patient incorporate new medical information, relate it to her existing knowledge base, or express it in her own words?

As noted in the previous chapter, memory functions are recruited in a number of cognitively demanding tasks deployed by the Owen Lab. Memory functions are involved in the encoding and retrieval of task instructions, and in the processing and execution of instructions. These cognitive functions are also embedded in the operational definition of understanding. To be sure, it is likely that the extent and kind of memory function varies between tasks used in the Owen Lab and the ability to understanding medical information. It would be false to presume that *identical* memory functions are recruited. Yet, from a coarse-grained perspective, the memory functions recruited in neuroimaging and EEG-based tasks give reason to believe that the cognitive machinery essential for understanding may be preserved.

4.2.2 Appreciation and executive function

Appreciation is the ability to acknowledge that the diagnosis, symptoms, and treatment options relate to one's own medical situation, and to acknowledge the consequences of choosing one treatment over another, or refusing treatment altogether. Like understanding, appreciation involves working memory and semantic memory. To appreciate how medical information applies to oneself, one must first encode and recall the information disclosed. Appreciation also involves the ability to revise beliefs: one must process a continuous flow of information, and update beliefs over time.

The ability to monitor and update beliefs over time is essential to appreciation in at least two ways. First, a patient must appreciate that the symptoms associated with the described medical disorder are those manifest in her own body. Generally, this might involve the ability to track interoceptive information—such as pain, fatigue, or changes in mentation—and update that information as one recovers or deteriorates. Additionally, one must be able to process counterfactual situations in which one treatment is chosen over another, or treatment is refused. This requires the ability to anticipate consequences of particular treatments, or refusal of treatment, and incorporate that information into one's knowledge base.

Suppose, now, that appreciation did not involve these executive functions. On this view, processing a continuous flow of information—whether in recognizing symptoms or foreseeing consequences—would not be involved in a patient's appreciation of her medical situation and could result in holding incompatible beliefs. Indeed, in the notable case of *Northern v. Tennessee Department of Health and Human Services* (1972), the patient, Mary Northern, was unable to process information related to her symptoms and treatment options. Her leg became gangrenous as a result of a diabetic condition, yet she was unable to appreciate that she, in fact, had gangrene and, as a consequence, would die without amputation. This led her to refuse amputation even though she clearly did not want to die. Her inability to process and update beliefs inhibited her appreciation of what *would* happen if she refused treatment.

As noted in the previous chapter, executive functions are recruited in rich stimuli paradigms. The Hitchcock film stimulus used by Naci and colleagues (2014) demonstrates the ability to track information, update beliefs, and anticipate counterfactuals. While tracking a film's plot is certainly different than appreciating a medical situation, it is reasonable to presume that similar executive functions underpin the ability to do both. Indeed, appreciating how disorders and symptoms are related to oneself or how accepting or refusing treatment could lead to different outcomes requires the ability to follow one's own *medical narrative*. Like the presence of memory functions, evidence of executive functions gives reason to believe that features of decision-making capacity may be preserved.

4.2.3 Reasoning, episodic memory, and abstract thinking

In the medical context, reasoning is the ability to foresee the consequences of a treatment, compare its consequences to those of other treatments, acknowledge their influence on daily life, and provide a choice that is consistent with one's own values. Like understanding and appreciation, reasoning involves working memory, semantic memory, and executive functions. To compare the consequences of different medical therapies, one must first be able to encode and recall information. Likewise, one must be able to process counterfactuals to acknowledge how a treatment will influence daily life. Apart from these cognitive functions, reasoning also involves abstract thinking and episodic memory.

Abstract thinking is the ability to manipulate information in order to solve a problem. Patients must weigh the relative benefits and harms of various treatments, and choose the option that best realizes their values. The ability to abstractly manipulate information is essential to this process. Without abstract thinking, one could not compare possible treatment outcomes, nor reasonably calculate the probabilities of outcomes that best realize one's own values.

Reasoning may also involve aspects of declarative memory, including semantic and episodic memory. On a strong interpretation of the relationship between declarative memory and reasoning, episodic and semantic memory would be involved in the process of making choices that are consistent with one's own values. One's values drive medical choices and are often derived from personal history. For example, Jehovah's Witnesses forgo blood transfusions—a common and otherwise safe medical intervention—on the grounds that these are inconsistent with *their beliefs* of biblical teachings. Likewise, when faced with stage-4 breast cancer, some individuals may choose a less aggressive therapy because *they value* quality rather than quantity of life. The values that drive these decisions are rooted in personal history. The determination of decision-making capacity often hinges on the ability to make these values explicit. Indeed, when a patient is asked to justify her medical decision, a clinician will evaluate the source and consistency of the values that are applied to the decision-making process. Episodic memory may allow an individual to recall episodes that led to her to adopt particular values that motivate the medical decision.

A weaker interpretation of the relationship between declarative memory and reasoning would emphasize semantic rather than episodic aspects. According to this view semantic memory could play a compensatory role in expressing values if episodic memory is diminished. Explanations of the values that motivate a medical decision would hinge on an internalized conceptual framework. The Jehovah's Witness, for example, would merely rehearse the rules for refusal of blood transfusions rather than also recognizing that such rules are derivative from episodes that *occurred in her own life*. This scenario is further complicated by the fact that it may be difficult to determine which aspect of declarative memory—semantic or episodic—is motivating the patient's explanations of values. Indeed, from an external vantage point, it is likely that both explanations would appear the same.

One potential way to identify how semantic and episodic aspects of declarative memory are involved in reasoning is to distinguish the *application* of values in decision-making from the *justification* of these values. For example, it is possible that a dementia patient with diminished episodic memory may apply certain values in decision-making in spite of her disease. Yet, if asked to justify those values, the she is unlikely to be able to appeal to episodes in personal history. Thus, while a patient may apply values consistently with the aid of semantic memory, lack of episodic memory may prevent her from adequately justifying these values. This tension between episodic and semantic memory, and how they are involved in decision-making capacity, speaks to the importance of identifying the source and authenticity of a patient's values.

As noted in the previous chapter, aspects of declarative memory and abstract thinking are recruited in tasks deployed by the Owen Lab. The mental imagery task itself is a form of abstract thinking; the tennis match and house are not actually there. Additionally, mental imagery can recruit declarative memory. When instructed to imagine moving through one's *own* home, one presumably remembers the layout, position of furniture, or décor. These memories can have both semantic and episodic features. Other tasks also recruit abstract thinking. The grammatical transformation task, for example, requires abstract manipulation of information to solve a problem.

The extent of involvement of these cognitive functions surely varies between tasks deployed in the Owen Lab and the ability to reason in medical decision-making. Indeed, the simple satisfaction of tasks in the Owen Lab does not suggest that one can also reason in medical decisions. Even if episodic memory is recruited in the mental imagery task, recalling details about one's own home is different from recalling one's own values and using these to justify medical decisions. Nevertheless, without these cognitive functions, it is arguable that one would *neither* be able to satisfy tasks deployed by the Owen Lab *nor* reason in the medical context. This suggests that patients who do satisfy neuroimaging or EEG-based tasks that recruit these cognitive functions may also retain certain elements of decision-making capacity.

4.2.4 Communication and language functions

Communication, in the context of medical decision-making, is the ability to express, verbally or otherwise, that one has made a choice regarding treatment. This view of communication is *expressive*, yet it is important to note that communication may also be *receptive*. The receptive qualities of communication are not highlighted in standard assessment techniques of decision-making capacity because it is presumed that a patient is able to comprehend language by virtue of her participation in a semi-structured interview. However, in patients with profound communication impairments, the receptive qualities of communication cannot be overlooked. Communication, in this case, involves basic cognitive functions related to receptive and expressive language processing. If one cannot process language, then one can neither *receive* relevant medical information nor *express* a medical choice.

Language processing and comprehension are demonstrated in hierarchical speech processing assessment (Coleman et al., 2009; Davis et al., 2007) and task-driven paradigms that contain verbal instructions (Naci and Owen, 2013; Monti et al., 2010). Sensitivity to speech versus signal-correlated noise indicates language processing, while sensitivity to high- versus low-ambiguity sentences, or the ability to follow instructions, indicates language comprehension.

It should be stressed that the language functions revealed in hierarchical speech processing assessment or task-driven paradigms that contain verbal instructions do not indicate global language comprehension. The mere fact that a patient reacts differently to sentences containing semantically ambiguous words, or can follow the instructions for mental imagery, does not imply she will understand the nuances of complex medical information. Nevertheless, if a patient satisfies hierarchical speech processing assessments and task-driven paradigms, and is then subsequently able to communicate with neuroimaging, then surely she understands language to the extent that she is capable of expressing a choice. Simply put, if a patient is eligible for neuroimaging communication, then her ability to *communicate* a medical choice is unlikely to be called into question.

4.3 Cognitive functions are predictive of decision-making capacity

Functional analyses of the subcomponents of decision-making capacity demonstrate a conceptual relationship with certain cognitive functions. These include, but are not limited to, working memory, semantic memory, episodic memory, executive functions, language processing, and language comprehension. Further reflection also shows that these cognitive functions, *at least on a coarse-grained view*, are recruited in many tasks deployed by the Owen Lab. This gives provisional evidence that the cognitive functions involved in decision-making capacity may be preserved in patients who successfully complete these tasks.

Apart from the conceptual relationship between cognitive functions and decision-making capacity, neuropsychological research also identifies a *predictive relationship*. This

Table 9: Psychometric scales correlated with decision-making capacity

Cognitive domain	Psychometric scale	Key studies
Vocabulary	Vocabulary Subset of WAIS Hopkins Verbal Learning Test-Revised Phonemic verbal fluency test	Gerstenecker et al. (2015) Dreer et al. (2008) Taub and Baker (1983) Taub et al. (1981)
Memory	Logical Memory I Subset of WAIS Hopkins Verbal Learning Test-Revised Arithmetic Working Memory Subset of WAIS Rey Auditory Verbal Learning Test	Gerstenecker et al. (2015) Dreer et al. (2008) Stroup et al. (2005) Palmer et al. (2004) Carpenter et al. (2000)
Executive function	Digit Span Subset of WAIS Digit Symbol Subset of WAIS Token Test	Gerstenecker et al. (2015) Okonkwo et al. (2007)

predictive relationship is founded on correlations between performance on psychometric scales and one or more of the subcomponents of decision-making capacity (see table 9). Performance on psychometric scales may therefore be important compensatory information if standard methods of assessing decision-making capacity cannot be applied.

As noted above, the conceptual relationship developed in the first half of this chapter is non-standard and coarse grained. It is merely intended to serve as a heuristic to motivate closer examination of patients whose decision-making capacity may be intact. The neuropsychological literature reviewed in the second half of this chapter specifies a fine-grained relationship. The relationship is fine-grained in the sense that specific cognitive functions are related to decision-making capacity by virtue of performance on *particular* psychometric scales. An important connection between the two halves is that the conceptual relationship provides a helpful vantage point for interpreting the empirical literature. Interestingly, while the neuropsychological literature identifies correlations between certain cognitive functions and decision-making capacity, it does not specify why these cognitive functions should be targets of investigation in the first place. The coarse-grained analysis therefore helps elucidate why these cognitive functions should be considered relevant in empirical research.

In what follows, I review key findings in the neuropsychological literature. These finding demonstrate an empirical link between particular, operationally defined cognitive functions and decision-making capacity.

4.3.1 Vocabulary and decision-making capacity

Vocabulary comprehension is positively associated with decision-making capacity. Vocabulary comprehension is understood as "semantic knowledge" or the ability to pair concepts with words (cf. Okonkwo et al., 2007:305). Taub and Baker (1983) and Taub and colleagues (1981) found that understanding varied in correspondence with the vocabulary subset of the Wechsler Adult Intelligence Scale in elderly populations. In the vocabulary subset, individuals are presented with either pictures or words and asked to identify or define them. The vocabulary subset is indented to assess vocabulary knowledge and verbal concept formation. Gerstenecker and colleagues (2015) and Dreer and colleagues (2008) also found that verbal memory and fluency were highly associated with understanding in patients with diagnosed brain metastases. Verbal memory was assessed with the Hopkins Verbal Learning Test-Revised. Patients were presented with 12 words over 3 learning trials. After a 25-munite delay, patients were instructed to recall the words. Phonemic verbal fluency was assessed by instructing patients to name as many words as possible that begin with the letters "C," "F," or "L" in a one-minute period. Semantic verbal fluency was assessed by instructing patients to name as many animals as possible in a one-minute period. In all cases, scores were highly associated with patients' ability to understand medical diagnoses, treatment options, and the risks and benefits of treatment.

4.3.2 Memory and decision-making capacity

Dreer and colleagues (2008) reported that short-term verbal memory, as assessed by the Wechsler Memory Scale-R Logical Memory I, was associated with understanding and reasoning during acute impairment following traumatic brain injury. The Wechsler

Memory Scale-R Logical Memory I assesses a patient's ability to recall a short story. Participants are read two short stories and are instructed to retell one of the stories through free recall immediately afterward.

At six-month follow-up, a patient's ability to reason was associated with auditory working memory, as assessed with the Wechsler Adult Intelligence Scale Arithmetic Working Memory Subset (Dreer et al., 2008). This subset requires participants to solve a series of verbally disclosed arithmetic problems in a specified period of time. Using the Rey Auditory Verbal Learning Test, meanwhile, Dreer and colleagues observed that reasoning was also highly associated with verbal learning and memory. In this test, participants are given a set of 15 words, repeated over 5 trials, and then instructed to repeat them. A second, independent set of 15 words is then disclosed. Participants are instructed to immediately repeat the original set and to do so again after 30 minutes.

In their systematic review of the literature, Palmer and Salva (2007) reported that appreciation and reasoning were highly associated with memory functions in schizophrenic patients. They observed that:

> Relative to neuropsychological tests of other cognitive abilities, working memory scores had the highest bivariate correlations with appreciation in three of the five schizophrenia studies (Stroup et al., 2005; Palmer et al., 2004; Carpenter et al., 2000), and the highest bivariate correlations with reasoning in two of the five studies (Stroup et al., 2005; Palmer et al., 2004). (Palmer and Salva 2007:1050)

Based on these and similar findings, it is hypothesized that impaired working memory—particularly verbal working memory—is a "red flag" for diminished decision-making capacity following traumatic brain injury (Triebel et al., 2014) and in psychiatric populations (cf. Palmer and Salva, 2007).

4.3.3 Executive functions and decision-making capacity

Psychometric scales of executive function are also highly correlated with decision-making capacity. This is unsurprising because, as noted above, particular subcomponents of decision-making require synthesis and processing of an ongoing flow of information.

Indeed, Palmar and Salva observed that, of the non-psychiatric patient studies included in their systematic review, "measures sensitive to executive functions were frequently among the strongest correlates of understanding, appreciation, or reasoning." (Palmer and Salva, 2007:1050) A similar observation was made by Okonkwo and colleagues (2008). They also found that:

> The convergent evidence from our neurocognitive models, across consent standards and study groups, suggest that treatment consent capacity…is primarily subserved by two broad domains of cognitive abilities—memory and executive function. (Okonkwo et al., 2008: 305)

The specific features of executive function correlated with decision-making capacity in these studies are attention, concentration, processing speed, and the ability to perform a task with divided attention. In a study including patients with diagnosed brain metastasis, Gerstenecker and colleagues (2015) applied the digit span and digit symbol subsets of the Wechsler Adult Intelligence Scale. The digit span subset requires participants to repeat a set of verbally disclosed numbers forward and backward. The digit symbol subset requires participants to match a set of number-to-symbol pairs based on a symbol key. Performance on these scales was highly correlated with a participants' understanding of medical information during consent procedures.

In a more sophisticated assessment of executive function, Dreer and colleagues (2008) applied the Token Test (Renzi and Vignolo, 1962) to a group of traumatic brain injury patients with varying levels of preserved decision-making capacity. The Token Test evaluates preserved semantic processing. A series of 20 cards are set out in a grid pattern on a table in front of the patient; 5 large rectangles; 5 small rectangles; 5 large circles; and 5 small circles. Each subset of cards is colored white, red, green, yellow, and blue. In a series of increasingly difficult trials, participants are instructed to turn over cards of a particular size and color, to place cards of differing size and color *on top of* or *under* each other, and to respond to counterfactual instructions, such as "if there is a black circle, touch the small green rectangle." Dreer and colleagues found that "at baseline assessment, poorer performance on the…token test…was related to poorer… performance on appreciation." (Dreer et al., 2008: 492)

4.3.4 Demographics and decision-making capacity

Finally, certain demographic factors have been shown to be highly predictive of decision-making capacity. In their systematic review, Dunn and Jeste (2001:599) found that 6 studies reported significant correlations between diminished understanding and age in heterogeneous populations, including routine surgical patients, healthy participants, and patients in long-term care facilities. Older adults tended to perform worse than younger adults, with a progressive inverse correlation between decision-making capacity and age. This could be explained by diminished cognition, which naturally accompanies aging. Additionally, as hypothesized by the authors, changes in decision-making capacity related to age may also be influenced by education. Dunn and Jeste note that, "despite the negative association of age with understanding, even older patients derived significant benefits from education interventions in a number of studies." (Dunn and Jeste, 2001:599)

4.4 Cognitive functions and judgments of decision-making capacity

The relationships outlined above give reason to believe that certain cognitive functions bear a strong relationship to decision-making capacity and, in certain circumstances, may provide compensatory evidence that decision-making capacity is preserved when standard methods of evaluation cannot be applied. Nevertheless, the move from cognitive functions to decision-making capacity faces at least two inferential gaps. A first gap is the difficulty of moving from cognitive functions *to* decision-making capacity. As argued several times throughout this thesis, the mere presence of certain cognitive functions does not warrant the attribution of decision-making capacity. This is because these cognitive functions are normatively constrained by a clinician's judgment. It is the clinician's judgment, not the simple presence of relevant cognitive functions that determines whether a patient is capable of making the decision in question. Yet, even if the presence of cognitive functions *did warrant* the attribution of decision-making capacity, there is second inferential gap regarding the patient population in question. How do we know that performance on tasks deployed by the Owen Lab is good evidence of the cognitive functions relevant to decision-making capacity?

Part of the problem with the second of these inferential gaps is possible vagueness in the definition of cognitive functions deployed in this thesis. The definitions deployed are sufficiently vague to allow for coarse-grained associations between neuroimaging and EEG-based tasks, cognitive functions, and decision-making capacity. Yet, with this vagueness also comes the risk of equivocacy. Indeed, on a fine-grained analysis, it is possible that neuroimaging and EEG-based tasks *do not* recruit the same cognitive functions measured by psychometric scales.

Consider episodic memory. Suppose that episodic memory is highly associated with decision-making capacity as measured by a hypothetical episodic memory test. This test operationalizes episodic memory according to a particular recall task, say, the number of times a participant uses visceral terms to describe a memory during free recall. On a coarse-grained analysis, aspects of declarative memory—including semantic and episodic—appear to be involved in neuroimaging tasks deployed in the Owen Lab. Yet, a fine-grained analysis teases them apart. Indeed, the recall task described above *is not* deployed in neuroimaging tasks used by the Owen Lab, nor do the task designs used in the Owen Lab resemble, in any way, the features of this test. In fact, as previously noted, it is unlikely a recall task *could be* deployed in neuroimaging given the current state of communication techniques since the task requires the participant to *freely recall* her memory. Coarse grained analysis suggests that the episodic memory recruited in both cases is sufficiently similar to warrant further investigation of decision-making capacity. Yet, fine-grained analysis demonstrates that these two methods of assessment simply measure different things.

A straightforward response to this problem is to claim that a coarse-grained analysis of the relationship between cognitive functions and decision-making capacity is all that is needed for the overarching argument of this thesis. The purpose of identifying relationships between cognitive functions and decision-making capacity is to merely create a heuristic that motivates further evaluation of high-functioning patients, nothing more. A coarse-grained analysis does this job successfully while simultaneously avoiding worries concerning equivocacy.

Another, more sophisticated solution to this problem is to evaluate relevant cognitive functions *directly* through neuroimaging. This approach would close the second inferential gap outlined above by resolving the problem at a *fine-grained level*. Many of the tests outlined above require the participant to engage in fluid communication, and thus are inappropriate for the neuroimaging methods used in the Owen Lab. Yet, there are several validated psychometric scales that could be deployed in neuroimaging and may indeed be highly associated with one or more subcomponents of decision-making capacity. These scales are briefly reviewed at the end of the previous chapter in the discussion of basic reasoning abilities.

It may be argued that deploying these scales in neuroimaging adds yet another layer of complexity to assessing decision-making capacity after severe brain injury. After all, if a patient is capable of engaging in neuroimaging sessions used for extensive testing of cognitive functions, why not use this time more efficiently by simply communicating with the patient? This is a reasonable proposition, and ultimately calls for sensible judgment when determining which patients require sophisticated neuropsychological assessment. However, as we shall see in chapter 5, there may be a lingering concern that the evidence of decision-making capacity produced by the strategy developed in this thesis is incomplete (in the sense that not all subcomponents of decision-making capacity are represented in the evidence). The application of psychometric scales in neuroimaging may compensate for incomplete evidence *even if* it makes evaluation more complicated.

Another concern—as captured by the first inferential gap outlined above—is that the attribution of decision-making capacity requires a clinician's judgment of the patient's ability to make a *specific medical decision*, not a decontextualized evaluation of cognitive functions. Indeed, as Dreer and colleagues argue:

> the present findings illuminate contributions of several neurocognitive domains to decisional capacity in traumatic brain injury. At the same time, judgments of

> capacity should not be founded solely, or even primarily, on neuropsychological test results. Neuropsychological test data by itself cannot be determinative of capacity questions, which involve issues of individual autonomy. A capacity judgment is ultimately a clinical judgment that draws upon a wide variety of evidence, including the clinician's interview of the patient and others, formal capacity measure results…cognitive test results, and the clinician's experience. (Dreer et al., 2008: 495)

Thus, even if the second inferential gap is closed by directly measuring relevant cognitive functions through neuroimaging, this still would not necessarily warrant the attribution of decision-making capacity.

A solution to this problem will inevitably require a method of assessment that resembles standard decision-making capacity evaluation. This line of argument will be developed in chapter 5. In part, this is a concession to the first inferential gap outlined above. According to all received views of decision-making capacity, there is no way to dispense with clinician judgment in capacity determinations. Nonetheless, evaluation of cognitive functions is essential, particularly for the patient population under consideration in this thesis. The cognition of these patients is currently a black-box. Thus all information about their cognition can help to build a case about the preservation or recovery of decision-making capacity.

4.5 Conclusion

In this chapter, I have argued that particular cognitive functions, including memory and executive functions, bear conceptual and predictive relationships to one or more of the subcomponents of decision-making capacity. Further, I have argued that these cognitive functions, at least from a coarse-grained view, are recruited in tasks deployed by the Owen Lab. This does not provide definitive evidence that the cognitive functions involved in decision-making capacity are preserved in severely brain-injured patients. Yet, it is suggestive that the cognitive machinery involved in decision-making capacity may remain intact in high-functioning patients and that further evaluation is warranted.

Chapter 5

5 The vignette approach

In chapters 3 and 4, I argued that preservation of particular cognitive functions gives reason to believe that decision-making capacity, or some aspect thereof, may remain intact. In patients in whom cognitive functions are apparent, this can inform practical judgments about further evaluation. In patients in whom cognitive functions are not apparent, this can inform judgments regarding exclusion from further evaluation.

Investigating cognitive functions is a fruitful strategy for assessing decision-making capacity in severely brain-injured patients.[14] As a heuristic, it motivates the search for decision-making capacity in populations that may be falsely presumed to be incapable merely by virtue of disability. Nonetheless, evaluation of cognitive functions is ultimately insufficient for the attribution of decision-making capacity. A practical test is needed that evaluates decision-making capacity according to a *particular* medical decision. In this chapter, I propose such a practical test adapted to neuroimaging communication. This test is intended to follow the assessment of cognitive functions.

Standard methods for evaluating decision-making capacity use a semi-structured interview (see Dunn et al., 2006 for extensive review). Yet, for reasons outlined in chapters 1 and 2, an interview cannot be used in neuroimaging communication. In response, I propose a vignette approach. A vignette approach evaluates decision-making capacity by disclosing medical information in a highly refined snap-shot—or vignette. A series of questions are asked about the content of the vignette, in order to probe decision-making capacity. The vignette approach is attractive because it is efficient. Additionally, questions coupled with the vignette can be phrased for "yes" or "no" responses. Finally, this approach intertwines the disclosure of medical information with the evaluation of

[14] There are also benefits to this approach beyond evaluating decision-making capacity, such as specifying a fine-grained analysis of the kind of consciousness that is preserved following severe brain injury.

capacity. This has been shown to increase uptake of medical information in individuals with cognitive deficits.

In what follows, I revisit limitations posed by neuroimaging. I then sketch the conceptual features of the vignette approach and describe how it may be used to transcend those limitations. Finally, I raise two problems associated with the vignette approach and respond to each. I conclude by identifying avenues of empirical research to further refine the vignette approach for application in neuroimaging communication.

5.1 What are the relevant limitations?

It is instructive to understand the relevant limitations associated with neuroimaging communication before presenting the vignette approach. These limitations are due both to the condition of the patient and to the technical constraints of neuroimaging technology. Outlining these limitations can determine the practical boundaries one must work within when conceiving a strategy for evaluating decision-making capacity through neuroimaging communication. Outlining these limitations can also assist in identifying those that can be resolved through technical innovations and those that cannot.

5.1.1 What kinds of questions can be asked?

The kinds of questions that can be asked are, in part, delimited by the answers that can be expressed through neuroimaging communication. To date, the most successful instances of neuroimaging communication have deployed questions with yes/no responses (Fernández-Espejo and Owen, 2013; Monti et al., 2010). Questions with yes/no responses are binary questions. A binary question is a question with exactly two responses and a forced choice. A forced choice means the question must be answered in order to yield an interpretable response. There are at least three kinds of questions that can be deployed in neuroimaging communication: factual questions, counterfactual questions, and decision questions.

A factual question, such as, “are you in a hospital?”, probes a patient’s ability to understand relevant facts about her medical situation. These questions are important as they can situate the patient in a medical context. For example, if a patient has a shoulder injury that requires physiotherapy, factual questions can probe contingent features of the patient's condition (e.g., "do you have a shoulder injury?") and recommended treatment (e.g., "does your injury require physiotherapy?"). Both questions can reveal understanding of the medical situation.

A counterfactual question, meanwhile, contains a counterfactual statement (or conditional proposition). Counterfactual questions relate to situations that have not yet transpired but could occur in the future (e.g., "If you do not seek the recommended therapy, will your injury heal without complication?"). Like factual questions, counterfactual questions reveal information relevant to decision-making capacity. In particular, they reveal a patient's ability to anticipate reasonably foreseeable consequences of a medical decision. This is essential to appreciation.

Finally, a decision question probes the patient's preference regarding a particular medical decision. Unlike factual or counterfactual questions, a decision question is not independently verifiable; it derives from the patient's preferences. As such, decision questions do not shed light on understanding, appreciation, or reasoning. However, they do satisfy the condition of expressing a choice, which is essential to decision-making capacity.

One drawback to the kinds of questions (and responses) that can be used in neuroimaging communication is that they are forced choice questions. Forced choice questions can inadvertently drive patients to answer questions in a way they do not intend. For example, patients *have to* answer "yes" or "no" in order to produce an interpretable response; there is no option for the patient not to answer. This is due to the inability to verify whether a patient chooses not to respond, or if the patient became fatigued or did not understand the question. The fact that the patient must answer in order to provide an interpretable response leaves no room to maneuver and, in some cases, could inadvertently suppress the true preferences of the patient.

A second drawback is that binary questions do not allow for nuanced responses. For example, a nuanced response could involve taking an epistemic attitude toward a question, such as "I'm inclined to choose option A, but I have some further questions."

Additionally, a nuanced response could be the conjunction of two options, such as "I want treatment A *and* B, rather than just A, or just B." Such a response may occur when the treatment options presented are mutually exclusive, but the patient believes they are consistent. Questions that yield nuanced responses like these are crucial to determining if a patient appreciates the consequences of her medical situation or is capable of reasoning with a consistent set of values. If a patient insists on receiving both treatment options, yet cannot appreciate they are mutually exclusive, then the patient lacks decision-making capacity.[15]

5.1.2 How many questions can be asked?

The number of questions that can be asked in any given communication session is, in part, delimited by accessibility to the fMRI unit and the scanning time required to elicit reliable data. On average, scanning sessions last approximately 2 hours, with 1 hour devoted to scanning, and 1 hour devoted to logistics, such as situating the patient in the scanner. Patients can become progressively fatigued, which may render them unable to regulate brain systems involved in neuroimaging communication (I return to this point below). This can affect the reliability of patient responses and raise reasonable doubts regarding the accuracy of communication.

To date, two fMRI-based methods have allowed for successful communication with patients. The first is an adaptation of the mental imagery task (Fernández-Espejo and Owen, 2013; Monti et al., 2010). In this method, patients are instructed to engage in motor or spatial navigation imagery to respond to yes/no questions. The second method is a novel communication task that leverages selective attention (Naci and Owen, 2013). In this method, patients are instructed to respond to questions by counting the number of times they hear the word "yes" or "no" as it is presented in a stream of auditory distraction stimuli.[16]

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[15] For example, Mary Northern refused treatment of a life-threatening condition, yet she also wanted to live (see chapter 4).

[16] See chapter 1 for detailed review.

The former method has allowed investigators to pose the greatest number of questions in a single scanning session, i.e., 6 questions in 1 hour (Monti et al., 2010). Yet, there is reason to believe that more questions could be posed. Naci and colleagues (2013) reported that the selective attention method requires, roughly, 6 minutes of scanning time to accurately decode an answer to one question in 92% of participants. Based on these data, one can predict that a participant could answer 10 questions in a 1-hour session with a high degree of decoding accuracy.

Of course, it is important to note that this prediction derives from studies of healthy participants. Whether a patient could produce brain activity sufficiently robust in this time-frame, or remain reasonably lucid, has yet to be demonstrated empirically. Nonetheless, the theoretical possibility that 10 questions could be posed in a 1-hour scanning session provides clear boundaries to work within when conceiving a strategy for assessing decision-making capacity. With refinement, it is likely that the number of questions a patient can answer in a single scanning session will eventually exceed 10. Future innovations may also lead to reliable multiple-choice or other question formats that increase the extent of communication.[17]

5.1.3 How long does it take to analyze neuroimaging data?

Neuroimaging data requires analysis to ensure that patient responses are interpreted correctly. Analysis is not instantaneous. Ideally, it could take as little as 24 hours, but this assumes the data are relatively clean (e.g., containing no artifacts due to patient movement). If the data are not clean, analysis is protracted and may require review by expert consultants. This is important to highlight, as it shows that neuroimaging communication—at least, currently—is not *real-time* communication. Patients are asked questions, they respond, the fMRI unit records brain activity, and the data are analyzed *after* the scanning session is complete.

[17] For example, the multiple-choice method developed by Bardin and colleagues (2011) or the spelling technique developed by Sorger and colleagues (2012).

It is possible to estimate answers by gross visualization of neural responses represented on the fMRI control screens. The spatial distinctness of activity generated by motor and spatial navigation imagery allows for this without necessarily requiring formal data analysis. Indeed, in previous studies involving healthy participants, blinded experts accomplished this with ease (Coleman and Owen, 2008). Nonetheless, the fact that neuroimaging communication could potentially be used to facilitate clinical decision-making in severely brain-injured patients suggests that misinterpretation of data could have harmful consequences. It is therefore prudent to formally analyze data to prevent misinterpretation, even if this means that communication does not occur in real-time.

The fact that neuroimaging communication does not unfold in real-time also makes it difficult to customize a line of questioning for a particular patient based on prior responses. Customization would allow for real-time feedback. For example, if a clinician were to ask a patient, “what do you think about treatment X?” and the patient responds, “actually, I’m not sure what treatment X is, could you explain it again?” the clinician could adjust her line of questioning to account for this unanticipated turn in the interview. This sort of flexibility—what some have called “fluid” communication—would allow clinicians to identify mistakes and return to certain questions to probe them more deeply.

5.1.4 What limitations does the patient’s condition pose?

Unlike technical limitations, limitations that result from the patient’s condition cannot be resolved by future innovations. These limitations include the patient’s ability to focus, to store information in working memory, and to engage in cognitively taxing tasks before becoming fatigued. Fluctuations in arousal may also inhibit communication. A patient might be lucid at certain times during the day, but not at others. Such limitations are highly variable. They may change throughout a patient’s recovery, and may vary according to the nature of the patient’s injury.

The limitations that result from the patient’s condition speak to the importance of adjusting our interaction to enhance their performance on neuroimaging tasks. For example, sensitivity to sleep/wake cycles can allow for more effective scheduling of scanning sessions.[18] Likewise, reflecting on more effective means of disclosure of medical information may help enhance uptake, understanding and appreciation. As we shall see, the vignette approach can help achieve these goals by interweaving questions that probe decision-making capacity with disclosure of medical information.

5.2 Bandwidth

A useful metaphor for describing the limitations identified in the preceding is "bandwidth" (cf. Fins and Schiff, 2010). Very loosely, bandwidth is the rate at which information is available or consumed. In neuroimaging communication, bandwidth takes at least five forms. First, bandwidth can refer to the number of questions that one can ask (e.g., 10). Second, bandwidth can refer to the content of possible responses (e.g., binary or forced choice). Third, bandwidth can refer to the directional flow of information. In neuroimaging communication, we can only ask questions of the patient, and information flow *from* the patient is narrow. Fourth, bandwidth can refer to the accessibility of neuroimaging technologies. As noted above, neuroimaging requires the patient to be transported to a research-grade imaging unit, which is time consuming and costly. Finally, bandwidth can refer to the extent to which information is readily available. As noted above, this may be reduced as a result of diminished attention or working memory and may prevent a patient from providing meaningful responses even if technical limitations are resolved.

5.3 The vignette approach

The vignette approach is a strategy that may be employed to meet the challenges described above. The vignette approach presents medical information in a highly refined snap-shot, or vignette, can be coupled with yes/no questions, and has been shown to be effective at assessing decision-making capacity in a variety of clinical populations. Velligna and colleagues (2004) compared the use of a vignette method with standard clinician assessment of capacity in 80 geriatric patients. Disagreement between findings

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[18] The Owen Lab schedule accounts for potential changes in patient arousal. See chapter 3.

revealed by the vignette method and standard assessment occurred in a minority of cases. When disagreement did occur, standard assessment by clinicians tended to be *more* lenient than that provided by the vignette method. This suggests that the vignette method required a higher burden of proof. Similar vignette methods have also been used to assess elderly patients (Schmand et al., 1999; Fitten and Waite, 1990), patients with dementia (Sachs et al., 1984), and early stage Alzheimer's disease patients (Marson et al., 1995). Additionally, vignette methods have been used to assess children (Weithorn and Campbell, 1982) and individuals with congenital cognitive disabilities (Cea and Fisher, 2003). Finally, Grisso and Appelbaum (1991) have used vignette methods to assess patients with schizophrenia and major depressive disorder. In the two latter cases, assessment by vignette accurately identified deficiencies in decision-making capacity, particularly in schizophrenic patients' ability to understand medical information.

If applied to neuroimaging communication, this approach would require a systematic method for vignette and question set construction. A set of vignettes could be constructed prior to interaction with any patient by reflecting on medical decisions commonly faced by severely brain-injured patients, such as decisions regarding physiotherapy. Constructing a repository of vignettes and question sets in advance addresses, in part, the inability to customize questions in real-time. However, in cases in which a vignette is not yet available, a construction formula can provide guidance. Such a formula should address at least three components: the content of the vignette; the structure of the vignette; and the formulation of the question set. I review each of these components below.

5.3.1 The content of the vignette

The content of the vignette is the specific clinical scenario in which the patient is forced to choose between two medical options.[19] This can be the choice between two alternative medical therapies, or the choice between accepting rather than refusing a proposed therapy. In general, the content of vignettes constructed for a repository should

[19] It is possible to offer more than two medical options, yet this would require a greater number of decision questions. This issue is clarified with the presentation of sample vignettes below.

incorporate the views of those with first-hand experience of the patient population, including patients' families, neurologists, and neuro-rehabilitation specialists.

The content of the vignette should be limited to low- to medium-stakes medical decisions. A low-stakes clinical decision is a choice with a risk-benefit ratio *substantially better* than alternatives, while a medium-stakes clinical decision is a choice with a risk-benefit ratio *on par* with alternatives (Buchanan and Brock, 1990:53). The purpose of restricting the content of vignettes to low- or medium-stakes decisions is to avoid concerns that the vignette approach offers weak evidence of decision-making capacity. I return to this issue in detail below.

5.3.2 The structure of the vignette

The structure of the vignette specifies which content is considered relevant, how information is arranged, and how information is effectively and efficiently disclosed to the patient.

The Measuring Understanding of Disclosure (MUD) form, developed by Grisso and Appelbaum (1991), provides an ideal template for vignette structure. The MUD is a research instrument used to assess informed consent and employs a vignette composed of five paragraphs. The content of each paragraph is determined by the ethical requirement of adequately informing the patient. The first paragraph describes the medical disorder; the second describes a treatment; the third describes benefits of the treatment; the fourth describes risks; and the fifth describes an alternative treatment and its respective benefits and risks (Grisso and Appelbaum, 1991: 379).

The structure of the vignette determines the way in which medical information is disclosed. A beneficial feature of the MUD is that it is designed for *single unit disclosure* (Grisso and Appelbaum, 1991), which divides the vignette into units, and couples each with specific questions related to the content of the paragraph included in the unit. The first unit contains information and questions regarding the medical disorder, the second contains information and questions regarding treatment, and so forth. At the beginning of disclosure, the entire vignette is presented. The examiner then returns to each unit, reads the paragraph aloud, and asks questions relevant to it. Each unit is presented sequentially until the vignette is complete.

Structuring the vignette according to the MUD template is ideal for neuroimaging communication in severely brain-injured patients. This allows clinicians to meet technical limitations posed by neuroimaging communication without significant loss of content. Moreover, the method is ideal for eliciting evidence of decision-making capacity in patients with cognitive deficits. The fact that the questions are *interwoven* in the disclosure document allows for increased comprehension of medical information. This is particularly useful for assessing patients that may have problems with memory or attention (Chung et al., 2013; McDowell et al., 1997).

5.3.3 The questions coupled with the vignette

A series of 10 “yes” or “no” questions can be posed with the vignette. The set of questions can be divided and coupled with each paragraph during disclosure. 8 questions can be distributed across all paragraphs to probe understanding and appreciation, and 2 questions can be reserved for the medical choice at the conclusion of the vignette. The target and formulation of each question will depend on the content of each unit. Flexibility in question distribution may be required for units that contain important information. For example, clinicians may choose to allot more questions to a unit containing substantive information about risks and benefits.

As noted above, factual, counterfactual, and decision questions can be used in neuroimaging communication. Factual questions probe information relevant to understanding and abstract thought. These questions can be coupled with units that disclose information about the medical disorder and treatments. Understanding the medical disorder and potential treatments involves comprehending medical facts, and this is essential to decision-making capacity. Counterfactual questions probe information relevant to consequential reasoning. These questions can be coupled with units that disclose information about the risks and benefits of treatments, or the consequences of refusing treatment. These questions generate information relevant to appreciation. Finally, upon completion of the vignette, the patient will be given a medical choice.

Decision questions are posed at this stage. Ideally, question sets should be randomized to prevent all correct answers being “yes” or “no”. This prevents patients with cognitive deficits that bias responses toward “yes” or “no” from answering all questions correctly.

As with all capacity assessments, the number of questions that must be answered correctly in order to attribute decision-making capacity to the patient is contingent on clinician judgment. However, it may be argued that, even if all questions are correctly answered, a set of 10 is insufficient. After all, very little information can be obtained from such a small set of questions. A review of the vignette literature, however, suggests that investigators are divided on this point. Vignette-based studies utilize between 6 (Vellinga et al., 2004) and 13 (Cea and Fisher, 2003) questions to assess decision-making capacity. Investigators report that the number of questions required is, in part, associated with the open-endedness of the questions (e.g., fewer questions are asked if they are more open-ended) or the length of the vignette (e.g., more questions were asked in longer vignettes). This suggests that the relevant factor is not necessarily *how many* questions are asked, but *what kind* of questions are asked. Provided the right kind of questions are asked, it is plausible that a high degree of information about decision-making capacity can be garnered from a small set of questions.

5.3.4 Preparation of the vignette for neuroimaging

Vignettes developed for neuroimaging communication will be shorter than the MUD template for logistical purposes, but will use the same five-unit structure. The vignette and questions should be assessed for ease of comprehension. Grundner’s “reading ease” formula for medical research consent forms (Grundner, 1978; 1986) should be used to ensure that language is relatively jargon free, and that sentences are short and terse. The vignette and question set should be calibrated to a 6^{th} - 8^{th} grade comprehension level (a standard used in previous construction of vignettes for clinical populations) (Grisso and Appelbaum, 1991). The vignette should be recorded in the native language of the patient. Ideally, the rate of spoken language in the recording should be between slow (approx. 2.2 syllables /sec.) and normal (approx. 4.4 syllables/sec.) (Weismer and Hesketh, 1996). Adjusting the rate of spoken language can facilitate comprehension in patients with memory deficits.

5.4 Two sample vignettes

Two sample vignettes have been provided below. These are intended to illustrate what the content and questions of a vignette might look like. Ideally, vignettes delivered to patients will pertain to their *specific* medical situation. Construction of such vignettes can follow the general formula developed above.

The first vignette involves choosing between two physiotherapy regimes. In one regime, the patient has physiotherapy twice weekly for two hour sessions with a physiotherapist named David. In the second regime, the patient has physiotherapy four times weekly for one-hour sessions with a physiotherapist named Sue. Both therapeutic options are beneficial and pose little or no potential for harm. Refusal of physiotherapy carries the risk of pain and stiffness. This medical decision is considered to be low-stakes.

The second vignette involves the decision to participate in research involving the drug amantadine.[20] Amantadine is a drug commonly used to treat patients with traumatic brain injury. Although the mechanism of action is unclear, several trials (Maythaler et al., 2002; Schneider et al., 1999), including a placebo-controlled trial (Giacino et al., 2012), suggest amantadine aids functional recovery. Because little is known about amantadine, consenting to study participation involves risks and benefits on par with refusal to consent. This decision is considered to be medium-stakes.

5.4.1 Sample vignette 1: physiotherapy regimes (low-stakes)

Disclosure

> Your condition has made it difficult for you to stretch and flex your arms and legs. You can benefit from physiotherapy. Physiotherapy can help maintain normal motion and decrease pain. If you do not receive physiotherapy, this may result in loss of mobility and ongoing pain. There are two physiotherapy options:

[20] There are relevant ethical differences between medical therapy and research. The presentation of both therapeutic and research decisions is meant to illustrate the kinds of decisions that could plausibly be made through neuroimaging communication.

The first involves appointments two days per week, for 2 hours, with David. The second involves appointments four days per week, for 1 hour, with Sue. David and Sue can come to your home. Receiving physiotherapy twice a week means fewer appointments, but potential stiffness in between appointments. Receiving physiotherapy four times a week means more appointments, but potentially less stiffness. All physiotherapy sessions will likely involve mild to moderate discomfort and pain. Advil can relieve the pain. Both physiotherapy options will result in a positive outcome. (12 lines)

Unit 1 (The Disorder)

Your condition has made it difficult for you to stretch and flex your arms and legs.

1. Is it difficult to stretch your arms? (Understanding)
2. Have you injured your foot? (Understanding)

Unit 2 (Treatment)

You can benefit from physiotherapy. Physiotherapy can help maintain normal motion and decrease pain. If you do not receive physiotherapy, this may result in loss of mobility and ongoing pain.

3. Is physiotherapy recommended? (Understanding)
4. If you do not have physiotherapy, will the pain go away? (Appreciation)

Unit 3 (Treatment)

There are two physiotherapy options: the first involves appointments two days per week, for 2 hours, with David. The second involves appointments four days per week, for 1 hour, with Sue. David and Sue can come to your home.

5. If you have physiotherapy twice weekly, will it be with David? (Appreciation)
6. Do you have to travel to see the physiotherapist? (Understanding)

Unit 4 (Risks and benefits)

Receiving physiotherapy twice a week means fewer appointments, but potential stiffness in between appointments. Receiving physiotherapy four times a week means more appointments, but potentially less stiffness. All physiotherapy sessions will likely involve mild to moderate discomfort and pain. Advil can relieve the pain.

7. If you have physiotherapy more often, will you be more stiff? (Appreciation)
8. Will physiotherapy involve discomfort and pain? (Understanding)

Unit 5 (Summary)

Both physiotherapy options will result in a positive outcome.

9. Would you like physiotherapy twice a week by David? (Choice)
10. Would you like physiotherapy four times a week by Sue? (Choice)

5.4.2 Sample vignette 2: amantadine research (medium-stakes)

Disclosure

Your condition has resulted in disabilities, which makes it difficult for you to move your arms and legs. Your condition may improve with the drug, amantadine. The benefits of this drug are currently unknown, but it may help speed your recovery. We would like you to participate in an amantadine study. The study involves regular neuro-rehabilitation combined with administration of amantadine, or a pill with no drug, called a placebo. In rare cases, amantadine can cause nausea, constipation, and nervousness. The placebo has no negative side effects. If you choose not to participate, or receive a placebo instead of amantadine, there are no known risks. There may be benefits to amantadine, but they are unknown. This study can inform future rehabilitation for patients like yourself. (10 lines)

Unit 1 (The Disorder)

Your condition has resulted in disabilities, which makes it difficult for you to move your arms and legs.

1. Do you have difficulty moving your arms and legs? (Understanding)
2. Do you have a head injury? (Understanding)

Unit 2 (Treatment)

Your condition may improve with the drug, amantadine. The benefits of this drug are currently unknown, but it may help speed your recovery.

3. If you take amantadine, is it likely your condition will worsen? (Appreciation)
4. Could amantadine improve you condition? (Understanding)

Unit 3 (Treatment)

We would like you to participate in an amantadine study. The study involves regular neuro-rehabilitation combined with administration of amantadine, or a pill with no drug, called a placebo.

5. Are you being asked to enroll in a study? (Understanding)
6. If you participate in the study, could you receive a placebo? (Appreciation)

Unit 4 (Risks and benefits)

In rare cases, amantadine can cause nausea, constipation, and nervousness. The placebo has no negative side effects. If you choose not to participate, or to receive a placebo instead of amantadine, there are no known risks.

7. Does amantadine have no side effects? (Appreciation)
8. If you participate, might you experience nausea? (Appreciation)

Unit 5 (Summary)

There may be benefits to amantadine, but they are unknown. This study can inform future rehabilitation for patients like yourself.

9. Would you like to participate in the study? (Choice)
10. Would you like to refrain from participation? (Choice)

5.5 Challenges to the vignette approach

The purpose of the vignette approach is to provide a practical test for evaluating decision-making capacity that transcends the limitations of neuroimaging communication. In principle, this approach can reveal some evidence of decision-making capacity. Yet, it is reasonable to criticize this approach on the grounds that it produces *weak* and *incomplete* evidence. I respond to these criticisms below.

5.5.1 The vignette approach produces weak evidence

It may be argued that the evidence produced by the vignette approach is too weak for the attribution of decision-making capacity. It is true that the information elicited from neuroimaging communication provides a very narrow view of the patient's decision-making process, including understanding and appreciation of the medical disorder and treatment options. The weakness of evidence is due to at least three factors. First, the patient can only answer "yes" or "no" questions. Second, we can ask only ask 10 questions. Finally, the number or kind of questions a patient answers correctly may influence the quality of the evidence.

Strength of evidence is a perpetual challenge in the assessment of decision-making capacity in all clinical scenarios. At stake is a trade-off between patients' liberty interests and a clinician's duty to protect patients. The attribution of decision-making capacity is ultimately dependent on clinician judgment. In setting the "threshold" of evidence required, the clinician can make two types of errors. A higher threshold will protect patients but infringe on self-determination. A lower threshold will respect patient self-determination but may negatively affect patient welfare.

A common strategy for resolving this tension is to appeal to the stakes of medical decisions (see also, chapter 2). The stakes of a medical decision are derived from the

Table 10: Stakes of medical decisions

Stakes	Risk/Benefit Ratio	Example	Relevant features
High	Substantially worse than alternatives	Participation in deep brain stimulation research	Invasive Requires general anesthesia Long-term benefits unclear
Medium	On par with alternatives	Participation in randomized trial of amantadine	Non-invasive Little to no known side-effects Benefits unclear but may speed recovery
Low	Substantially better than alternatives	Choice of different physiotherapy options	Therapeutic No long-term difference between options

potential risks and benefits of treatment options. Low-stakes medical decisions involve a choice with a risk-benefit ratio *substantially better* than alternatives. Medium-stakes decisions involve a choice with a risk-benefit ratio *on par* with alternatives. High-stakes decisions involve a choice with a risk-benefit ratio *substantially worse* than alternatives (Buchanan and Brock, 1990: 53) (see table 10).

The threshold of evidence required for the attribution of decision-making capacity is a function of these stakes. For high-stakes decisions, the potential for harm is high and the requisite evidence must also be high. Requiring robust evidence ensures that the clinician is adequately protecting the welfare of the patient, even if this infringes on patient self-determination. By contrast, low-stakes decisions carry a substantially lower probability of harm and the evidence required may permissibly be lower. The fact that low-stakes decisions will likely benefit the patient, no matter what choice she makes, allows for greater decision-making freedom, even if evidence of capacity is not robust. This balancing act is intended to harmonize the liberty interests of patients with protection of patient welfare (Brock, 1993: 42).

Compared to other methods of assessment, such as the MacCAT-T, the vignette approach produces weak evidence of decision-making capacity. Nonetheless, this evidence may suffice for some low to medium-stakes decisions. Combined with systematic assessment of cognitive functions, the vignette approach arguably produces evidence that satisfies the threshold for low- to medium-stakes medical decisions.

5.5.2 The vignette approach produces incomplete evidence

A second problem with the vignette approach is that it produces incomplete evidence of decision-making capacity in the sense that some features of capacity captured by the MacCAT-T cannot, in principle, be evaluated through the vignette approach. This is particularly true of reasoning. The design of the MacCAT-T allows a patient to demonstrate reasoning by explaining why a decision is right for her. The technical limitations of neuroimaging communication do not allow for this. Thus, the vignette approach is deficient—at least, currently—due to its inability to produce evidence of this subcomponent.

Reasoning is a core feature of decision-making capacity. Without evidence of reasoning, the motivations for a patient's decisions may be misinterpreted (cf. Fins and Schiff, 2010). Yet, the authors of the MacCAT-T acknowledge that:

> Patients who are on respirators or impaired by strokes may still be able to communicate using hand signals, letter boards, eye blinks, and the like. When evaluators are dealing with such patients, the evaluators usually will need to frame their questions in a "yes-no" or multiple-choice format. (Grisso and Appelbaum, 1998: 86)

They argue further that, in cases in which evaluation is *incomplete*:

> the usual rules for determining whether a patient has [decision-making capacity] may have to be slightly modified. (Grisso and Appelbaum, 1998: 86)

The argument developed in this thesis hinges on the meaning of "slightly modified". Does the vignette approach fall within or outside the scope of slight modification? I maintain that it falls *within the scope* of slight modifications. The structure of assessment and evidence produced is, admittedly, different than that produced by instruments like the

MacCAT-T. Yet, every effort has been made to preserve the theoretical features of decision-making capacity that characterize standard methods of assessment (cf. Dunn et al., 2006). The vignette approach seeks to investigate the subcomponents of capacity identified in the MacCAT-T, it follows the general definition of subcomponents laid out therein, and structures the disclosure of medical information according to the ethical requirement of adequately informing the patient.

Skeptics, however, may argue that the vignette approach falls *outside the scope* of slight modification. After all, reasoning is a subcomponent of decision-making capacity that the vignette approach cannot evaluate given current technical limitations. On this view, the modifications inherent in the vignette approach are simply too radical to produce persuasive evidence of decision-making capacity. The vignette approach is sufficiently different from the MacCAT-T to justify this skepticism even if assessment is restricted to low- to medium-stakes medical decisions.

Like the problem of weak evidence, the problem of incomplete evidence might be resolved by harmonizing patients' liberty and welfare interests. Harmonizing these interests may be achieved by determining the required strength of evidence as a function of the stakes of the medical decision. High-stakes decisions will require robust evidence of decision-making capacity, and robust evidence will inevitably be *complete* evidence in the sense that all subcomponents of decision-making capacity are represented. Low-stakes decisions, by contrast, do not require robust evidence of decision-making capacity.

Additionally, as previously noted, basic reasoning functions can also be evaluated *prior* to neuroimaging communication. In chapter 3, I described assessments of basic reasoning functions amongst healthy participants (Kirschner et al., 2015) and one brain-injured patient (Hampshire et al., 2013). These tests can provide compensatory information when the assessment of decision-making capacity is *substantially* incomplete. I chapter 6, I propose a model of supported decision-making that will allow an individual with knowledge of the patient's background to support her through the decision-making process by providing explanations on the patient's behalf. Combined with assessment of basic reasoning functions, this may assuage concerns of incomplete evidence in certain cases.

5.6 Conclusion

In this chapter, I have presented and defended the conceptual features of the vignette approach—a practical test for decision-making capacity tailored to neuroimaging communication. Coupled with evaluation of preserved cognitive functions, this approach can, in principle, demonstrate evidence that warrants the attribution of decision-making capacity for low- to medium-stakes medical decisions.

Full development of the vignette approach requires a number of empirical steps. These steps are beyond the scope of this thesis, yet warrant brief acknowledgment here. First, the vignette approach must be validated to ensure that it accurately picks out relevant features of decision-making capacity. Validation of the vignette approach will be challenging, as it is distinct from standard methods of assessment. An alternative method of validation could incorporate the judgment of an expert panel, including clinicians, clinical bioethicists, philosophers, and health lawyers, who could assist in the formulation of vignette content and questions. The validity of the vignette approach would rest upon consensus among such experts.

Second, the vignette approach must be piloted in neuroimaging. In principle, it is possible to deploy the vignette approach in neuroimaging communication. Yet, in practice, it may turn out that this approach raises unforeseen complications, including significant patient fatigue, the burden of transporting the patient to an imaging unit, or other logistical problems in the scanning procedure. Such practical complications suggest that allotting limited scanning time to assessing decision-making capacity may have little benefit. Alternative uses of neuroimaging communication, including allowing patients to interact with family or assessing quality-of-life (Graham et al. 2015) may be important avenues to explore.

Chapter 6

6 Supported decision-making and severe brain injury

Evaluation of cognitive functions and the vignette approach can, in principle, shed light on decision-making capacity in some severely brain-injured patients. This can warrant the attribution of decision-making capacity for some low- to medium-stakes decisions. The picture of decision-making capacity presented here differs from the rigorous model set out in the MacCAT-T. This is due to modifications in the rules of assessment, which, as I have argued, are permissible in cases of limited communication.

As noted above, however, there are several skeptical arguments that could be raised against the vignette approach. It could be argued that the approach provides insufficient evidence of decision-making capacity. Additionally, some could be concerned about how this strategy unfolds *in practice*. In response to these concerns, I propose a supported decision-making model involving medical trusteeship. The concept of medical trusteeship has its origins in the philosophy of disability. A medical trustee is an individual—often a close family member—who supports a cognitively or communicatively impaired person by interpreting and relaying her wishes (Silvers and Francis 2009; Francis 2009). In the following chapter, I adapt this model to neuroimaging communication with severely brain-injured patients.

6.1 Criticisms revisited

As noted in the preceding chapters, efforts to use neuroimaging communication to assess decision-making capacity in severely brain-injured patients are subject to a variety of criticisms.

Critics contend that the proposed strategy does not adequately evaluate reasoning. Autonomous decision-making requires a patient to *explain* why a particular medical decision is right for her (Grisso and Appelbaun, 1998). The inability of brain-injured patients to communicate on their own, coupled with the restriction of neuroimaging communication to yes/no responses, makes it extremely difficult to evaluate reasoning within such a “narrow bandwidth” (Glannon, 2014: 2).

Critics further contend that the decision-making capacity of a severely brain-injured patient is subject to fluctuation. This is a reasonable concern, as many aspects of cognition are known to change throughout recovery. As Hardcastle and Stewart argue, “depression, anxiety, fear, euphoria, even sleep disturbances” can change in brain-injured patients on a daily basis (Hardcastle and Stewart, 2013: 22). Thus, while the vignette approach demonstrates decision-making capacity in principle, practical limitations will not permit longitudinal evaluation to account for fluctuations in capacity.

A third worry is that the limits of neuroimaging communication can both engender misinterpretation and also prevent us from realizing that such misinterpretation has occurred. There are two kinds of misinterpretation that can occur in neuroimaging communication. As Fins and Schiff point out, they can occur in the interpretation of a patient’s preference (Fins & Schiff, 2010: 22). Second, a misinterpretation can occur in the analysis of neuroimaging data. For example, artifacts may bias the data toward “yes” or “no” answers. So, even if the patient’s preferences are interpreted correctly, misinterpretation at the data level can still suggest a “preference” that is inconsistent with the patient’s wishes. Misinterpretations of both kinds can lead to potential harm.

I have responded to these criticisms throughout this thesis. However, I acknowledge that some may be unconvinced by my arguments. To account for this, I propose a supported decision-making model. Supported decision-making for severely brain-injured patients can speak to these criticisms. In what follows, I expand upon the conceptual foundations of supported decision-making, what this decision-making model would look like in practice, and respond to several criticisms of this approach.

6.2 Medical trusteeship

Supported decision-making allows a patient with cognitive or communicative impairments to make medical decisions in collaboration with a family member or trusted individual. An ideal model of supported decision-making for severely brain-injured patients is that of medical trusteeship. Medical trusteeship appeals to ethical, rather than legal, principles to determine who has decision-making authority and allows for a degree of flexibility in decision-making roles. This flexibility of medical trusteeship can also help accommodate the fluctuations in decision-making capacity that may occur throughout the recovery process.

The medical trustee's role is to *assist* the patient in the decision-making process. "Assistance" means participation in the medical decision-making process, broadly construed. This assistance can take the form of helping the patient interpret complex medical information, identifying medical decisions that best realize the patient's values, or explaining on behalf of the patient why a particular medical decision is right for her.

The role of a medical trustee differs from other *legally defined roles* in medical decision-making. Unlike a surrogate decision maker or legally appointed guardian, the medical trustee is meant to support the patient in making decisions for herself, not to make medical decisions for her. In this sense, the concept of medical trusteeship may be in conflict with the legally defined threshold of competence.[21] According to the law a patient either is or is not legally competent and the appointment of a surrogate decision maker or guardian hinges upon this determination. Medical trusteeship, on the other hand, involves the recognition that cognitive impairment is highly variable, particularly in patients recovering from brain injury. Medical trusteeship allows for flexibility in these situations and aims to empower patients with cognitive or communicative impairment.

6.2.1 Medical trusteeship and autonomy

Medical trusteeship originates from philosophical reflection on the role of cognitively disabled persons in political life (cf. Silvers and Francis 2009; Francis and Silvers, 2007). Cognitively disabled persons are often marginalized in political discourse because they are believed to lack autonomy. The concept of autonomy is central to both political

[21] Note that, on standard interpretations of decision-making capacity as a "threshold concept", medical trusteeship may also be in tension with the way capacity is attributed to patients in the clinical context. See chapter 2 for detailed discussion.

liberalism (cf. Rawls, 2009) and the doctrine of informed consent (Beauchamp and Childress, 2012; Faden and Beauchamp, 1986). According to one definition, autonomous decision-making involves,

> [b]eing able to value, being able to reason, being able to resist impulses, being able to imagine an ordered life, being able to order one's life, being able to put one's plans into practice, being able to participate in moral deliberation of an idealized kind, and being politically free. (Francis, 2009:202).

This definition may be challenged on a number of grounds. In the first place, individuals seldom deliberate and choose purely as autonomous agents (cf. Francis, 2009). Most individuals make decisions—whether political or medical—in consultation with experts or a trusted network of family and friends. Patients ask others for advice, defer to the expertise of clinicians, and trust that, if they are unable to choose for themselves, their family will make decisions that respect their values and beliefs. Some patients will require more support than others and dependence may increase in tandem with the complexity of the patient's situation. From an ethical standpoint, this suggests that autonomy, like capacity, is not all or nothing, but comes in degrees (Francis, 2009:207).

The abrogation of some or all decision-making authority does not deprive patients of autonomy. Kukla (2005), for instance, argues that deferring to others during medical decisions may constitute a conscientious affirmation of autonomy. More broadly, Francis and Silvers (2007:319) speak of "wide agency" in medical decision-making. A patient's autonomy is instantiated in representatives or technologies that support self-determination throughout the decision-making process. On these views, medical decisions are embedded in complex relationships between the patient, family, and clinical staff.

The above analysis gives reason to believe that a liberal notion of autonomy does not accurately capture how medical decisions unfold in practice. Indeed, all individuals—disabled or not—are dependent on others to some degree when making medical decisions. Patients with profound disabilities, such as those in acute coma, are maximally dependent on others. Even otherwise healthy adults may be dependent on others when seeking advice or asking for clarification of medical information. These varying degrees of dependence give reason to believe that providing assistance to disabled persons in decision-making does not violate the norms of autonomy.

To be sure, there is a relevant distinction between *degrees* and *kinds* of dependence. Otherwise healthy individuals may depend on others when making medical decisions, but this kind of dependence does not undermine autonomy. By contrast, some severely brain-injured patients will clearly lack autonomy to make decisions for themselves. The kind of dependence required by these patients is altogether different. The difference between kinds and degrees of dependence elucidates how such patients can reasonably participate in medical decision-making. The medical trusteeship model is thus intended to facilitate an alternative *kind* of participation in medical decision-making that acknowledges the autonomy one may have, or recover, in the face of disability.[22]

6.2.2 Ethical and legal support for medical trusteeship

From an ethical perspective, the duty to respect patient self-determination obligates clinicians to involve patients in medical decision-making to whatever extent possible. Children, for instance, are generally believed to lack the mental maturity needed to participate in most medical decisions. Very young children have not yet achieved key developmental milestones and may lack certain rational capacities associated with autonomy. Nevertheless, some children, particularly those on the cusp of legal adulthood, may have the mental maturity to participate in some medical decisions. The duty to respect self-determination suggests these children should have some say in decisions that affect *their* bodies and *their* medical care (cf. Leikin, 1993:1). Allowing children to have a say in their medical care—with parental oversight—respects their nascent autonomy.

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[22] A key challenge is determining what kinds of dependence trigger medical trusteeship. It is plausible that, as in the case of varying thresholds of decision-making capacity, kinds of dependence will covary with the stakes of a medical decision. High-stakes decisions will require a kind of dependence that maximally protects the patient, such as the appointment of a surrogate decision maker. By contrast, low-stakes decisions may require a different kind of dependence that gives the patient more voice in the decision-making process, such as the appointment of a medical trustee.

Arguably, there is a clear distinction between decision-making by assent and medical trusteeship. In the assent model a child's preference can be overruled by a parent, while, in the trusteeship model, the role of the trustee is to support the patient in making a decision.[23] Apart from these structural differences, the general spirit is the same. Children and disabled persons do not possess the same kind of autonomy as otherwise healthy adults. Yet, it does not follow that they lack autonomy. Both models recognize this fact and seek to allow children and disabled persons to participate in the decision-making process to whatever extent possible.

From a legal perspective, there is also precedent to involve disabled persons in medical decision making. Article 15 of the Canadian Charter of Rights and Freedoms states that "Every individual…has the right to equal protection and equal benefit of the law without discrimination" (Canadian Charter, 1982). This stipulation suggests that disabled persons should be afforded every opportunity to participate in medical decision-making. Section 12132 of The Americans with Disabilities Act (1990), meanwhile, states that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of services, programs, or activities of a public entity, or be subjected to discrimination by any such entity" (ADA, 1990). Finally, article 12.1 of the United Nations Convention of the Rights of Persons with Disabilities states that "persons with disabilities have the right to recognition everywhere as persons before the law" (United Nations, 2007). This final assertion carries moral weight, and grounds the duties to respect self-determination, and to seriously consider the welfare of disabled persons if they are unable to advocate for themselves (cf. Graham et al., 2015).

The forgoing consensus documents motivate a legal duty of reasonable accommodation. An accommodation is a mechanism that facilitates equal access to public goods or services where access would otherwise be precluded due to disability. An accommodation is reasonable if it does not cause undue hardship to the agent that provides the accommodation (cf. ADA, 1990; Canadian Charter, 1982). Reasonable

[23] Whether a trustee can step in to overrule the decision of a capable patient is a matter of debate. Strictly speaking, this is not the role of a medical trustee.

accommodations are applicable to disabled persons seeking goods or services from health care institutions. Reasonable accommodations extend to equal access, as well as the ability to make medical decisions. Mobility aids, technological devices, or use of a medical trustee are different forms of reasonable accommodation in the health care setting (cf. Silvers and Francis, 2009).[24]

The legal and ethical views outlined above provide context for medical trusteeship. On these views, medical decision-making is not a bargaining process between rational agents. Rather, it is a trust-building exercise between the patient, family, and health care team (Francis, 2009: 209-10). The medical trustee can paly a communicative role by helping the patient interpret her notion of the good—including wishes, hopes, fears, and life plans—and communicating this to other parties. The trustee can also play a deliberative role by helping the patient reflect on her notion of the good. The trustee is distinct from a surrogate in that she represents the current wishes of the patient to the extent to which she can *faithfully* interpret them.[25]

6.2.3 Hypothetical examples of medical trusteeship

How would medical trusteeship unfold in the context of severely brain-injured patients who can only communicate through neuroimaging? In what follows, I provide three scenarios to outline the different ways a trustee might support a patient in this context, namely, as an explainer, as an interpreter, and as a decision maker.

6.2.3.1 Scenario 1: Medical trustee as explainer

Consider the following example:

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[24] See also, the British Columbia Representation Agreement Act (1996), for further legal analysis.

[25] The term "faithfully" is used to distinguish medical trusteeship from facilitated communication. Facilitated communication is a method of communicating (speaking, writing, inter alia) for another based on a subjective interpretation of the individual's wishes. By contrast, a medical trustee is required to faithfully express the patients wish according to objective features of the individual's communicated preferences (or attempts at communication).

> A brain-injured patient visits the Owen Lab and the strategy proposed in chapters 3 through 5 is applied. The patient performs well on all neuroimaging tasks, which reveal relevant cognitive functions underlying decision-making capacity. The patient additionally satisfies a vignette assessment.
>
> The vignette applied involves the following decision: of two long-term care facilities, which would you like to move to? The first is a secular facility with a good reputation among clinical staff, while the other is a religious facility with a less favorable reputation. Clinical staff may intuit that the secular facility is a better choice because of its reputation, yet the patient chooses the opposite.

Should the patient's decision be respected? The patient satisfied the proposed assessment strategy, and is deemed to possess decision-making capacity for a low-stakes decision of this kind. Yet some clinical staff worry that the decision is incompetent, as it is inconsistent with the decision *they would have made*. If the patient could easily communicate, a clinician could ask her why she has chosen the religious facility. Yet the limitations of neuroimaging communication preclude this.

A medical trustee can assist in this context by helping the patient express the reasons for her decision. Suppose the medical trustee is the patient's mother. Having known the patient intimately before her injury, she will be well acquainted with the patient's values. The trustee is thus in the best position to generate trustworthy explanations of the patient's decision. The trustee may know, for example, that the patient is deeply religious, and while moving to the secular facility is a better decision from a medical perspective, moving to the religious facility reflects the patient's values. The medical trustee's explanation can therefore help medical staff understand the patient's choice in the absence of standard methods of assessing decision-making capacity.

It may be argued that the medical trustee can misinterpret the patient's wishes. After all, a patient's values may change after injury or the medical trustee may have a distorted understanding of the patient's wishes (I return to these concerns below). Nonetheless, the medical trustee's explanations can guide follow-up questioning if clinical staff are not confident with the assessment. For example, in a follow-up session, the patient could be asked "did you choose the religious long-term care facility because of your religious values?" An affirmative response could instill confidence in the patient's capacity to make this particular decision. The limitations of neuroimaging communication engender reasonable skepticism about incomplete evidence. Yet, in this case, the medical trustee can fill gaps in evidence with trustworthy explanations of the patient's rationale.

6.2.3.2 Scenario 2: Medical trustee as interpreter

Suppose, now, that the same patient successfully answered a majority of questions in the medical vignette, yet did not correctly answer *a sufficient number* or the *right kind* of questions to satisfy the clinical staff. As it turns out, the decision between long-term care facilities is not urgent, and the clinical staff agree the patient can be re-evaluated the following week.

During this time, the medical trustee can serve as an interpreter. In this role, the medical trustee can arrange information in a way that enhances patient understanding. For example, it may be that the patient did not fully understand or appreciate the medical decision in question, which led to difficulty in answering. During the interval between evaluations, the medical trustee could speak with patient about the medical decision, help the patient interpret the nuances of the decision, and identify which decision might best realize the patient's values. The trustee is likely to have continued access to the patient during this time (e.g., if the trustee is a family member). This continued access could help to improve the patient's performance on the second evaluation.

6.2.3.3 Scenario 3: Medical trustee as decision maker

Suppose, now, that the patient does not answer any questions, or does not provide a response to the final decision questions of the vignette. Suppose further that the decision is urgent and that there is no opportunity to re-evaluate the patient before a decision needs to be made.

In this scenario, the medical trustee can function as a decision maker. The medical trustee can step in and make a decision for the patient based on her previously expressed wishes or best interests. This is not generally the role of a medical trustee. On the contrary, it is properly the role of a surrogate decision maker. Yet, as this scenario suggests, the trustee may, in certain circumstances, be entrusted with making decisions that normally lie within the purview of the surrogate decision maker. I return to this in greater detail below.

To be sure, this scenario is unique in that the patient *has not communicated* a decision. The medical trustee is thus not overriding the patient's decision. Yet, in other cases it is conceivable that a trustee could feel compelled to step in because she believes the patient *made the wrong* decision. Is the medical trustee warranted in overriding the decision of the patient in such situations? Strictly speaking, this is impermissible if it has been established that the patient has decision-making capacity. To prevent this from happening, it is important for clinical staff and the medical trustee to have clear expectations about decision-making authority *before* the patient is evaluated. Likewise, the clinical staff and medical trustee must work together to identify which medical decisions are appropriate for the patient to make.

Medical trusteeship adds yet another layer of complexity to caring for severely brain-injured patients and, as the scenarios described above demonstrate, there are ways in which medical trustees can go astray: the trustee's explanations might not be corroborated; the trustee might bias the patient's preferences; or the trustee may be inclined to override the patient's decision. Ideally, a medical trustee should enrich the clinical staff's understanding of the patient's decision-making process. In certain circumstances, the trustee can help allay worries regarding misinterpretation of information or questions of capacity. In cases of conflict, however, family and clinical staff may be required to revert to a legally defined decision-making model. While this is not ideal for respecting patient self-determination, it may be necessary to protect the patient if it is believed the decision could result in harm.

6.3 Medical trusteeship is beneficial due to its flexibility

A patient's dependence during medical decision-making is contingent on a number of factors. Patients with different kinds of impairment will require different kinds of support or protection, including surrogate or supported decision-making. Likewise, patients will require different degrees of support or protection at different times throughout the course of their disease. Patients with neurodegenerative diseases may require gradually increasing protection as their condition worsens, while brain-injured patients may need progressively less support as they recover.

Medical trusteeship is ideal for these situations because of its flexibility. Medical trusteeship is an ethically motivated model of supported decision-making, and thus is not hindered by strict, regulatory guidelines. By contrast, legally defined roles, such as that of surrogate decision maker, hinge on a clear distinction between competence and incompetence. This distinction allows legal mechanisms inherent in medical decision-making to operate efficiently. Yet, such mechanisms do not always accurately track the complex ways in which patients can be deficient in decision-making capacity, nor how a surrogate decision maker should comport herself toward a patient as she recovers.

The relationship between trustee and beneficiary can manifest itself in various ways. This is because the focus of medical trusteeship is the *trusting bond* between trustee and beneficiary. Medical trusteeship, as discussed in the philosophy of disability, focuses on supporting decision-making by individuals with congenital cognitive or communicative impairments. In these cases, the role of the medical trustee is largely static (cf. Francis, 2009; Silvers and Francis, 2009). However, the role of the medical trustee for a patient *recovering* from severe brain injury could be quite different. At first, a severely brain-injured patient will require the protection of a surrogate decision maker. Yet, over time, the patient may regain the capacity to make some low- to medium-stakes medical decisions. The role of the surrogate may therefore evolve into that of medical trustee.

The role of a medical trustee may also shift according to the stakes of the decision. If a patient requires protection from the harmful outcomes of high-stakes decisions, the medical trustee could become a surrogate decision-maker. If a low- to medium-stakes decision calls for a more supportive role, the medical trustee can yield decision-making authority to the patient, provided that the patient has already demonstrated decision-making capacity for the decision in question. The fluidity of the medical trustee's role thus complements the dynamic nature of brain recovery. The medical trustee can support decision-making when the patient is highly lucid, yet step in to protect the patient when she is not. This can help resolve concerns regarding changes in decision-making capacity over time.

Despite this beneficial feature of medical trusteeship, flexibility can be problematic. From a legal point of view, a patient either has or does not have decision-making authority. Models of supported decision-making—especially those that allow fluid transition between protective and supportive roles—can obscure decision-making authority. Nonetheless, medical trusteeship—from an ethical perspective, at least—is useful in the initial stages of recovery from severe brain injury. Thereafter, examination of the patient's decision-making capacity will be required to determine whether her interests are better served by continued use of a medical trustee or the appointment of a surrogate decision maker.

6.4 Problems with medical trusteeship

6.4.1 Who is the medical trustee supporting?

I have argued that one role of the medical trustee is to provide trustworthy explanations of the patient's rationale for medical decisions. This can be helpful in filling in the inferential gaps caused by the limitations of neuroimaging communication, particularly with respect to assessing patient values. Yet medical trusteeship raises a difficult question, namely, whose values does the trustee represent? The person that emerges from severe brain injury is likely to be different than the person she was before; and her values are also likely to be different (Albrecht and Devlieger, 1999; Cantor, 1993). This could complicate efforts to explain the patient's decision. If the trustee relies on values held by the patient *before* injury the trustee may fail to accurately represent decisions motivated by values formed *after* injury. Further, limitations in neuroimaging communication may prevent family and clinical staff from accurately detecting this value shift.

Ideally, clinical staff and family should attend to the patient's current values. This is consistent with the view that decision-making capacity is the ability to make a particular decision at a *particular time*. As neuroimaging technology evolves, communication may become more fluid. This may allow clinical staff and family to adequately identify transformations in values, and to attend to them. In the meanwhile, clinical staff and medical trustees should consider whether a shift in values is a plausible explanation when the patient's response is unanticipated.

6.4.2 The mistaken medical trustee

A second, related criticism is that a medical trustee may not faithfully represent a patient's authentic wishes. For example, a patient may express a wish for *X*, while the trustee recommends *not X*. The trustee's recommendation may be due to misinterpretation of the patient's wishes or bias (Silvers and Francis, 2009: 492). Unfortunately, it is difficult to check the accuracy of the trustee's recommendation. In patients for whom communication is already limited, it is difficult to find an objective vantage point from which inauthentic recommendations can be reliably identified.

Proponents of medical trusteeship offer several rebuttals. First, it is possible that the interests of the trustee are "encapsulated" within the interests of the patient (Francis and Silvers, 2009: 327). For example, it is reasonable to assume that a patient's interest in living pain-free likely encapsulates the interest of her trustee who does not wish her loved one to live in pain. To the extent that the trustee's interests are encapsulated within the interests of the patient, errors in interpretation are unlikely.

Second, an individual fills the role of a trustee on the basis of having "the deepest caring relationship with the beneficiar[y] and thus may be expected to know them well and care about them…" (Francis and Silvers, 2009: 327). The presumption of intimate knowledge suggests the trustee is in the *best position* to interpret the patient's wishes and is likely to continue caring for her throughout recovery. An analogy is the caring relationship between a mother and child. A mother and child share a caring bond that evolves and strengthens throughout their lives. Indeed, in many cases, it is a mother (or parent) who knows her child best and will continue caring for him or her regardless of the child's state in life. The same can be said for the individual fulfilling the role of medical trustee. The inertia of the relationship between trustee and beneficiary gives strong reason to believe that care and trust between the two will continue in spite of the patient's disabilities.

It is, of course, still possible that the trustee could fail to accurately represent the patient's wishes. When a trustee's judgment is questioned, family and clinical staff have recourse to legal intervention. The trustee's views can be assessed according to various legal standards (Francis and Silvers, 2009: 327). For example, if there is conflict between a patient's medical choice and the trustee's account, evidence of the patient's previously expressed wishes may be used to verify whether the trustee's representation is faithful. If the trustee's representation fails this evidentiary standard, her interpretation of the patient's wishes can be overridden.

6.4.3 Medical Trusteeship and The Law

A third criticism of medical trusteeship is that it is inconsistent with the law. Medical trusteeship is highly flexible and complements the dynamic nature of brain recovery. Yet, because of its flexibility, medical trusteeship can conflict with legally defined roles. As Fins and Pohl argue:

> Guardianships, by their nature as a product of the law, have the virtue of stability, what is described as *stare decisis*, which stresses the precedence of stasis. This is necessary for the enduring and efficient practice of guardianship. After all, we can't have shifting guardians with differing decisions all attempting to stabilize the shattered world of a patient with brain injury. (Fins and Pohl, 2016: 250)

Additionally, a clear attribution of decision-making authority is grounded in liberal notions of autonomy. On this view, an individual is autonomous if she can be held solely responsible for her medical decisions. Responsibility, just like decision-making authority, cannot be divided between patient and medical trustee (but see Francis, 2007, for rebuttal).

The ethical notion of capacity and the legal notion of competence, while generally consistent, come into conflict in such circumstances. Patients who are recovering from severe brain injury may have their wishes interpreted and cultivated within the *ethical* framework of decision-making capacity (as done in this thesis), but this may be insufficient for the attribution of legal competence. Although patients recovering from severe brain injury "may make 'authentic choices,' their deviation from global legal norms can render them wholly incompetent in the eyes of civil society and the law." (Banja and Fins, 2013: 1376; Fins and Pohl, 2016: 251)

Despite this conflict, some argue that there is a need to reconsider how supported decision-making can be integrated into legal frameworks. Fins and Pohl argue that:

> In directing care, guardians should not only respect the patient's prior voice but also be responsive to his re-emerging one. This approach is sensitive to the injured brain's potential to recover, encouraging guardians to uncover means to functionally communicate and to continually assess decision-making capacity. When patients are able to communicate…guardians should weigh their present preferences against those expressed in the past and current safety concerns and best interests. (Fins and Pohl 2016: 255-6)

So, while medical trusteeship can conflict with the law, the role of a legally appointed guardian may come to resemble that of a medical trustee when considering how supported decision-making can be used to empower the voice of severely brain-injured patients. More broadly, medical trusteeship provides a framework for thinking about medical decision-making *before* the law is invoked. Conflicts will inevitably arise and require recourse to legally defined roles. Yet, in most cases, family and clinical staff can reasonably work together to enhance the self-determination of a brain-injured patient in day-to-day health care decisions. Medical trusteeship is thus an ideal framework for guiding *practical judgments* about how to incorporate brain-injured patients in the decision-making process.

6.5 Conclusion

In this chapter, I have proposed using medical trusteeship to address concerns raised by the strategy developed in chapters 3 through 5, and to explain how this strategy would unfold in practice. By virtue of her relationship with the patient, the medical trustee can generate trustworthy explanations of a patient's medical decisions, help the patient interpret medical information, or make decisions for the patient if the patient fails to communicate a preference. Additionally, the flexibility of the medical trustee's role allows her to be both protective and supportive. This prevents incapable patients from making harmful decisions, yet creates avenues to efficiently yield decision-making authority to the patient as she recovers.

The use of a medical trustee thus rounds out the strategy proposed in this thesis. First, as a heuristic, we start with evaluation of cognitive functions to determine if the cognitive machinery underlying decision-making capacity is intact. Once this is determined, we move on to an application of the vignette approach to evaluate decision-making capacity. Finally, we integrate the medical trustee to ensure the patient is protected in the event that the evidence produced by the vignette approach is weak or incomplete. If applied in practice, this strategy would empower severely brain-injured patients to express their wishes, yet ensure that their welfare interests are protected as the decision-making process unfolds.

Conclusion

7 Conclusion

In this thesis, I have presented a strategy for assessing decision-making capacity in severely brain-injured patients who can only communicate through neuroimaging. In chapter 1, I reviewed the relevant scientific literature. In chapter 2, I outlined the conceptual foundations of decision-making capacity and responded to criticism of efforts to evaluate decision-making capacity through neuroimaging communication. In chapters 3 and 4, I provided a systematic task analysis of key neuroimaging and EEG-based paradigms deployed in the Owen Lab and mapped the relationships between cognitive functions recruited by these paradigms and decision-making capacity. In chapter 5, I presented a practical test for decision-making capacity tailored to neuroimaging communication, namely, the vignette approach. In chapter 6, I proposed a model of supported decision-making for severely brain-injured patients, namely, medical trusteeship.

The strategy proposed in this thesis was motivated by the following question: is it permissible to allow severely brain-injured patients, who can only communicate through neuroimaging, to participate in making medical decisions? I have argued that the strategy proposed in this thesis offers the ethical grounds for the attribution of decision-making capacity to some severely brain-injured patients for low- to medium-stakes medical decisions. It follows that patients to whom such decision-making capacity has been attributed should be allowed to participate in making low- to medium-stakes medical decisions.

7.1 Recommendations and future directions

Beyond the argument outlined above, this thesis sheds light on several other conceptual and empirical issues, including the nature of decision-making capacity, our obligations to other patient populations, and the nature of consciousness itself. Attending to these questions can help elucidate our obligations to severely brain injured patients. Further philosophical and scientific research offers hope to these patients, their families, and the clinicians who care for them. Below, I briefly outline three recommendations and three avenues of future research.

7.1.1 Recommendation 1: Increase communication bandwidth

Technical innovation can help resolve the problem of assessing decision-making capacity through neuroimaging communication. Such innovations involve an increase in communication bandwidth. As indicated in chapter 5, increasing bandwidth can help to increase the number of questions that can be posed in a single scanning session, the accessibility of neuroimaging communication itself, and the possibility of communicating in real-time. It is recommended that future efforts to refine neuroimaging communication should focus on increasing communication bandwidth.

7.1.2 Recommendation 2: Explore quality-of-life

Medical decision-making is only one of the potential uses of neuroimaging communication. Patients have welfare interests, clinicians have a duty to attend to these welfare interests and a theory of welfare that helps protect severely brain-injured patients should be developed. Ideally, a theory of welfare designed to protect this patient population would involve the development of a quality-of-life instrument that can be deployed through neuroimaging communication.

7.1.3 Recommendation 3: Modify autonomy to accommodate disabled persons

The standard view of autonomy does not extend to disabled persons. However, it is clear that some disabled persons are capable of participating in making some medical decisions provided they are supported in appropriate ways. In chapter 6, I described alternative forms of autonomy. Further efforts should be made to clarify these forms of autonomy to accommodate individuals with cognitive or communicative impairments.

7.1.4 Future direction 1: Decision-making capacity in other populations

How might this research bear on the assessment of decision-making capacity in *other* patient populations? Severely aphasic patients, for example, also have great difficulty communicating. The inability of both brain-injured and aphasic patients to communicate may compromise their individual autonomy. Assessment of decision-making capacity in severely brain-injured patients through neuroimaging communication may therefore have profound implications for other patient populations with similar communication impairments.

7.1.5 Future direction 2: Decision-making capacity and cognitive functions

What is the relationship between cognitive functions and decision-making capacity? Standard methods of assessment do not attend to cognitive functions. Yet, as demonstrated in this thesis, particular cognitive functions are differentially important to decision-making capacity, particularly understanding and appreciation. Attending to cognitive functions may be beneficial for a number of reasons. First, cognitive functions may provide a more objective means of attributing decision-making capacity. Second, attending to cognitive functions may allow for the development of more sensitive instruments for assessing decision-making capacity. Finally, focusing on cognitive functions may help identify mechanisms that allow us to repair or enhance decision-making capacity. This may be particularly beneficial in aging populations or those with mild to moderate brain injury.

7.1.6 Future direction 3: Consciousness

How does this research bear on the science of consciousness? In this thesis, I have focused on assessment of decision-making capacity. Yet, neuroimaging in severely brain-injured patients raises a host of conceptual problems related to the attribution of consciousness in general. As noted above, assessment of cognitive functions can provide nonstandard evidence of decision-making capacity in individuals with cognitive and communicative impairments. Increased focus on cognitive functions could allow for useful revisions of diagnostic categories as well as the identification of signposts indicative of functional recovery.

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