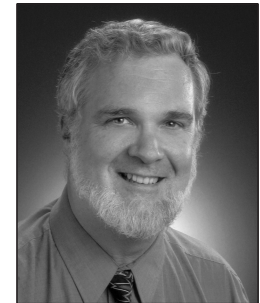


Current Concepts of Capacity and Autonomy in Medical Decision-Making: A Critique from a Christian's Perspective

James J. Rusthoven



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Determining a patient's capacity and protecting one's autonomy have become increasingly important in medical decision-making and bioethics. Capacity and autonomy usually connote the ability to make decisions (capacity) without necessary help or coercion from others (autonomy). Advances in neuroimaging have led to imaginative studies of the anatomic and physiologic basis of the different aspects of capacity. Similarly, clinical instruments have been created to capture clinical nuances of capacity among different patients. The worthiness as well as reductionistic pitfalls of both approaches are discussed. A major challenge for Christians is the pursuit of a biblically-grounded concept of capacity and autonomy that counters the rationalistic and individualist concepts of secular society. Such a concept could lead to more normative assessments of capacity and put added value on the communal and faith dimensions of autonomy in medical decision-making.

The concept of capacity to make informed decisions remains a major topic of discussion and debate in clinical bioethics.¹ Embedded in the premise that patients or clinical research subjects must give informed consent to participate in treatment or clinical research, capacity is not fully understood as a concept of medical decision-making. While the terms competence and capacity are often used interchangeably, the former tends to be used in legal contexts while the latter refers to decision-making capability in clinical situations. For example, when evaluating and designating a surrogate decision-maker, one looks for a person who is competent to make decisions in the best interest of the patient who is now incompetent to do so. One of the Oxford Dictionary's definitions of capacity is "the ability or power to do something." Competent, on the other hand, is defined as "having the skill or knowledge to do something successfully."² As such, competence implies the capability to act, to muster the communicative and/or technical know-how to act when called upon.

To understand what is known about both basic neuroscientific and clinical aspects of human capacity, I will begin with a recent example of how basic neuroscience information can be used to support one set of faith-based beliefs over another. In response to the claim that belief in the human capacity for reason and responsibility should supercede or replace "religious" belief as a moral guide to making decisions, I will explore the present concept of capacity. Some of the limitations inherent in reducing capacity to measurable and quantifiable functions both in neuroanatomical correlative studies and in the development of clinical tools to iden-

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tify clinical components of capacity will be discussed. Finally, I will suggest that our present societal concept of autonomy, as a fundamental bioethical principle of capacity, is a major stumbling block to developing a richer understanding of self, and thus a more normative appreciation for determining one's capacity to make medical decisions.

Does the Brain Have Serious Design Flaws?

In a May 2004 issue of our local Hamilton newspaper, Robert Buckman was quoted as saying that he "distrusts religious beliefs."³ An avowed atheist and president of the Humanist Association of Canada, Buckman "espouses a non-religious ethical philosophy of life that looks to human capacities for reason and responsibility rather than divine salvation." He believes, says the article, that "religious beliefs ... are a product of the right temporal lobe, a complex area of the brain associated with deep feelings of the mysterious or the divine when stimulated." He further raises concerns that, within the temporal lobe, religious feelings are linked to the limbic system which has been associated with aggressive behavior. Suggesting that this link is a design flaw in our brains, he urges that people should not trust their religious beliefs as moral guides out of fear that religious beliefs can generate violent behavior.

Buckman is no crackpot. He is an articulate and respected medical oncologist as well as an internationally recognized speaker who teaches health care professionals how to break bad news to patients in the terminal stages of disease.⁴ Brushing aside religious beliefs and expression as products of an evolutionary aberration of cerebral development, he tries to ignore the motives and presuppositional basis of actions on the Cartesian assumption that reason itself is a valid starting point for actions.

While several issues arise for us as Christians from Buckman's challenge, I would like to focus on his belief in the human capacities for reason and responsibility as a "non-religious" ethical philosophy of life. His narrow definition of "religious" tries to push aside the reality that such faith in reason is itself presuppositional, much like the Christian's faith in God. His faith in science

and reason is shared by many contemporary scientists. The concern is not that the scientific work is done. In *The God Gene*, Dean Hamer tries to make the case of a genetic basis of dispositions to religious belief.⁵ We may well be "hardwired" to seek God, though sin (an acquired trait!) interferes with our relationship with God. Rather, the concern is in the reductionistic interpretations that often result from scientific research and that can be used, as Buckman has done, to champion the cause of reason as the god in whom people should trust.

If we as Christians are to respond to such interpretive challenges, we must first understand human capacity (or incapacity) to reason, to act responsibly, and to make decisions requiring action. It is particularly in medicine where the lack of a patient's capacity to make decisions touches on major areas of bioethical concern, including the loss of that patient's free choice or autonomy. In addition, we must discern the differences in the perceptions of capacity between secular humanists such as Buckman and Christians and how one's world view impacts the framing of these perceptions for medical practice and for public engagement. In developing a Christian framework for understanding capacity, one must understand the present clinical and ethical paradigm and understand from where it has historically come. We then must decide, through reflective critique, if an alternative framework better captures the truth of how God would have us make decisions about our health.

Searching for a Neuroanatomic and Neurophysiologic Basis of Capacity

Bioethicists Ruth Faden and Tom Beauchamp have arguably claimed that decision-making requires three components: understanding, intentionality, and voluntariness.⁶ Understanding has been considered a fairly straightforward concept for which patient-friendly tools have been developed.⁷ Numerous decision-aids (perhaps more specifically called comprehension aids) have been shown to improve patient understanding of concepts related to the potential benefits and risks of treating diseases such as cancer.⁸ Intentionality and voluntariness, on the other hand,

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involve more abstract dimensions such as initiation, intention, motivations, and judgment, to name a few; these have been collectively referred to as executive functions. Early correlations of clinical syndromes of dysfunctional thought with brain anatomy suggested that normal initiation, planning, and problem solving are dependent on a normally functioning dorsolateral prefrontal cortex, lesions of which result in disorganized thinking, loss of abstract thinking, and difficulties with multistep tasks (so-called "dysexecutive syndrome"), attributes associated with reasoning capacity. Similarly, motivation was linked to the same region, with some anatomical disturbances associated with apathy, and in the extreme, loss of movement, speech, and indifference to pain (akinetic mutism).⁹

We should question whether reducing such complex functioning as capacity to variations in blood flow within specific parts of the brain will be helpful in understanding the implications of subtle clinical gradations of disorder among these components of capacity.

Utilizing the newer radiographic technologies such as magnetic resonance imaging (MRI) and positron-emission tomography (PET scanning), studies have shown anatomic variants consistent with losses of executive functions, as manifest by intentionality and voluntariness, in patients with overtly psychotic states such as schizophrenia.¹⁰ In less severe affective disorders such as depression or anxiety, PET neuroimaging has shown reductions in blood flow in depression states and increases in flow in anxiety states. While the number of studies is small, the internal validity of these results is supported by the return to normal blood flow following effective treatment.¹¹

These observations add to our understanding of the basic physical and physiological modalities of the cognitive and affective components of capacity. However, we should question whether reducing such complex functioning as capacity to variations in blood flow within specific parts of the brain will be helpful in understanding the implications of subtle clinical gradations of disorder among these components of capacity. Furthermore, the cost of performing such expensive tests may not ethically justify their use as practical components of clinical capacity determination.

Yet, less costly, clinical instruments designed to identify subtleties of executive dysfunction have often lacked reproducibility and are generally inadequate on their own.

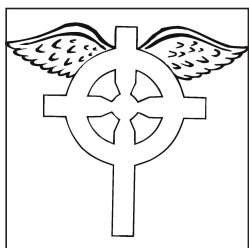
Attempts to Capture Capacity with Clinical Instruments

While comprehension aids seem to assist patients in translating information into terms and concepts that they better understand, such aids may not improve patient anxieties or even the ultimate choice in treatment options offered.¹² Moore has recently critiqued various clinical instruments designed to help determine capacity, including so-called executive dysfunctions. From his perspective, they tend to be brief, semi-structured, and narrow in scope, lacking in sensitivity and specificity, and often exhibiting heterogeneity of performance among subjects. Importantly, they fail to consider other dimensions including the effects of time, of beliefs and culture, of fears of abandonment or neglect if the patient does not enroll, and of the uniqueness of different clinical situations inherent to each case.¹³

In addition to testing with measurement tools, careful individual clinical interviews seem necessary to identify affective states that may distort decision-making capacity by suggesting reduced capacity through poor performance of the test.¹⁴ For example, apathy may result in decisions contrary to one's values and beliefs out of feelings of guilt deserving of punishment or a lack of caring. In anxiety disorders, tests may suggest patients are capable but they may be dependent on outside influence out of low self-esteem and fear; patients may fear that not following the physician's wishes could lead to retribution. Sensitivity to patients' vulnerabilities requires exceptional attention to expressiveness and responsiveness in the patient-physician dialogue, without which the clinician may unwittingly control the patients' choices through their powers of suggestion.

Suchman, et al. have recently constructed a thoughtful model for improving empathic communication, identifying empathic opportunities wherein patients express an emotion that creates an opportunity for a supportive, empathic response by the physician.¹⁵ Such aids to attentive interviewing involving nuanced interactions with patients or research subjects may be crucial in determining the emotions and "states of mind" that may affect a judgment of capacity, aspects that may not be captured by the sensitivity and specificity of present standard discernment tools.

This suggests that reducing capacity to its various components may be the easier part of the science. The challenge that comes to clinicians is to conceptualize and frame these multiple dimensions to gain a normative, working understanding of capacity to help guide patients to make decisions that are best for them. As newer, more complex, and more numerous treatment options have become available in medicine, decision-making has



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become increasingly complex. Models for developing patient-physician relationships have been proposed which, contrary to the paternalistic spirit of the Hippocratic tradition, attempt to derive decisions through negotiated trade-offs based heavily on the values and beliefs of each party.¹⁶ These models have been strongly influenced by liberal individualism and the care ethics developed largely by feminist leaders, with both traditions anchored in moral relativism and value-neutrality. In making care management decisions, a critical legal and ethical imperative is the expression of implicit or explicit consent to proceed with a mutually agreed upon course of action.

The Importance of Autonomy in Understanding Capacity

Such informed consent has been a major focus of therapeutic decision-making within the bioethics community. It involves a semi-formalized process through which patients should be empowered to make informed, uncoerced decisions about their care or about their willingness to serve as research subjects. A foundational principle of this process is the need for decisions to be made autonomously, usually defined as deciding on a course of action without external influence or coercion.¹⁷ This in turn has been tied to the belief that self-determination is an inalienable right to make one's own decisions, *even if they are not the wisest in the judgment of others*. Full capacity and autonomous choice are considered necessary, closely related requirements toward achieving meaningful decisions. Individuals who are judged less-than-fully capable to make decisions are often considered in law and in practice deprived of completely autonomous choice.

It is my contention that our current societal idea of autonomy is often inadequate, due in large part to (1) its place within the philosophical framework of liberal individualism and (2) a sequence of crises of abuse in human research that have occurred over the last seventy-five years. The reaction to the latter was a necessary focus on the individual subject. But in so doing, relational connections traditionally inherent in concep-

tions of self became detached under the prevailing philosophical and cultural influence of liberal individualism. Autonomy as conceived in modern secular terms is foreign to the biblical idea of individuality and the responsibility for one's own actions. Some have tried to understand what the Bible says to us about Christian ethics on the presumption that the isolated individual is the primary focus of such an endeavor. This in turn has led to the search to develop formalized methodologies using critical reason that all individuals can employ in making decisions.

Fowl and Jones contend that such a strong focus on the individual distorts one's interpretive reading of Scripture by failing to account for the ways that our predecessors in the faith have read the Scripture "in and through particular communities, particularly ecclesial ones, in the past."¹⁸ While the individual remains directly accountable to God, the central focus of the message to individuals is through communal structures. Janzen sees ethical teaching in Scripture through paradigms, understood as a personally and holistically conceived image of a model or theme. In the Old Testament, the individual is understood within the familial paradigm. God addresses individuals as his people through the family and through the peoplehood of Israel. In the New Testament, Jesus' message is to his followers while that message from Paul and the other apostles is often addressed to the Church at large or to specific church communities.¹⁹ Thus, contemporary ideas of autonomy are often stripped of the contextual and historical aspects that form part of the ontological essence of the individual. Seen through such lenses, the scriptural understanding is distorted.

In *After Virtue*, Alasdair MacIntyre has argued that the secularization of morality in the Enlightenment period resulted in the loss of the beliefs that moral judgments determine what human conduct would be teleologically appropriate and that such judgments reflected universal law as commanded by God.²⁰ The consequences have included "liberated" humans, with the resultant loss of traditional roles and relationships. Allied with this came the belief that autonomy as self-reliance is the best way to be free from the coercive influences that historically have plagued patients and

have made them subservient to paternalistic physicians for centuries. Unfortunately, such autonomy is largely devoid of the social and political dimensions that traditionally helped to define self. One result of this loss has been the necessity for legal protection for patients considered questionably or clearly incapable through an appointed surrogate decision maker. I propose that we need to revisit our historical concept of self. We need to reincorporate more integrally the relational support that helps to define us as individuals, the support which has historically been, and in many present-day non-Western cultures continues to be, an indispensable part of decision-making involving individuals in community.

The Necessary Complexity of Capacity Assessment

How should we discern between the capable and incapable? How does one's concept of decisional autonomy influence this distinction? Some have argued that creating dichotomous thresholds is too simplistic, not accounting for the continuum of capability within the population. Grisso and Appelbaum have suggested that competency assessments must consider not just the level of understanding and reasoning but also the level of cognitive demand associated with the decision.²¹ Furthermore, should the therapeutic ratio of any intervention be considered? If a patient is offered a treatment which is considered to offer a good chance of a major benefit with a low risk of toxicity, should a lower threshold be set when the patient accepts such an option but a higher threshold apply to patient refusal? In light of these multiple factors, Grisso and Appelbaum have argued that thresholds may need to vary from case to case, leaning toward a more casuistic, and perhaps more relativistic approach to capacity decision-making.²²

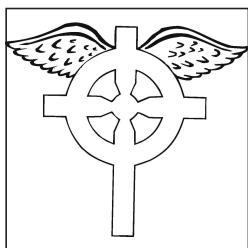
Note also that once such factors are added for consideration, patient autonomy becomes even more contingent on the value-laden judgment of the caregiver as to what defines "reasonable" and "sensible" decisions. Is this paternalism revisited? Is it coercion? In an attempt to move away from such caregiver influences, Moore feels that the caregiver's primary responsibility in capacity determination is to rule out both external and internal coercion, the latter connotating decisions "unduly motivated by a mental disorder."²³ The patient is left to determine his or her personal belief-driven choices, even if they seem unreasonable to the caregiver. Philosopher and bioethics scholar Robert Veatch seems to advocate the extreme of this position, moving aside physician beliefs and judgments in an effort to give complete autonomy and decision-making power to the patient.²⁴ But this creates a particular dilemma for those who are less-than-fully capable of making their own decisions. Is a legally designated surrogate the normative solution or just the only one in situations where supporting relationships are inadequate or non-existent?

Relational Autonomy: Secular and Christian Notions

The care ethics movement has provided insights into the relational void inherent in post-Enlightenment liberal individualism through its emphasis on the importance of human relationships in addressing ethical issues around patient decision-making. A product of feminist bioethical thought representing a family of moral reflections, ethics of care are devoid of a central moral principle. These reflections focus on the care for persons with whom one has a significant relationship, including an emotional commitment to and willingness to act on behalf of such persons. In an example from Beauchamp and Childress, a father is found to be histocompatible with his daughter who needs a kidney transplant.²⁵ After considering the situation, he declines to be the donor, citing various reasons including fear of surgery, a lack of courage, and the lack of guarantees that the transplant will be permanently successful. In addition, he asks the physician to tell his wife that he is not histocompatible, expressing fear that the truth would ruin his family. After considerable reservation, the physician tells the wife that her husband cannot donate because of medical reasons. A bioethicist from a care ethics perspective would emphasize not only what physicians do (for example, keeping confidentiality or not) but also how they act, what motivates them to act, and whether their actions support or disrupt positive relationships. From this moral perspective has come the idea of *relational autonomy*, a concept which denies the independence of self from other human relationships but seeks to understand the importance of those relationships for making medical decisions.²⁶

Christian character ethics also has developed in response to liberal individualism and the obsession with rationality. As with ethics of care, this framework focuses less on the rightness and wrongness of decisions and more on what factors shape the character of the agent of action and decisions. A movement akin to virtue ethics, character ethics recognizes the importance of relationships as an indispensable dimension for nurturing one's character. Character is not developed by self-made individuals but by the encouraging and correcting influence of community.²⁷ Within this ethical framework, discipleship through following Christ is essential in forming and molding human relationships. The life, death, and resurrection of Christ is the central moral focal point, in contrast to the anchor-less feminist idea of relationships for their own sake. Thus, while those using a care ethics framework recognize the moral deficiencies in liberal individualism, they cannot understand the full picture of their insights due to their ignorance of the meaning of Christ's redemption of human relationships as part of a redeemed creation order.

As Christians, we need to critically reassess the idea of capacity and autonomy in light of these historical and current realities. Our culture promotes self-determination



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and self-reliance as the true sign of maturity and adulthood, often leaving a vacuum for developing new and fulfilling relationships during adolescence. Yet, believers in Christ know that we are responsible for the welfare and care of our fellow human creatures as part of our creational mandate, especially those in our closest relationships of family and church. But should not this extend to meaningful discussions about what is important to the individual and the community at large for making later life and end-of-life decisions? Perhaps the legally designated surrogate could be replaced by advanced decision advisors who help individuals and families to understand and articulate preferences in advance of incapacity, in light of community-backed covenants based on common values and beliefs.

Conclusions

I think Moore and Raymont are on the right track in stressing the complexity of what constitutes decision-making; as Raymont suggests: "... the concept of capacity has now evolved into a sophisticated ethical and legal construct ..."²⁸ Not only must we be capable of making cognitive, logical, deductive associations of thought, we also need to be in the right frame of mind (e.g., minimal anxiety, fear of retribution if the wrong answer is given, etc.). We need to understand what level of capability is required of the circumstances, and how time may change either the level of capacity or the level of cognitive difficulty. But at a deeper level, perhaps we need to move beyond the past intense concern about coercive forces affecting patients and subjects, toward a more biblical understanding of autonomy in our culture.

In so doing, perhaps we need a greater focus on more formal communal support that incorporates mutually lived out communal values and beliefs in decision-making. For Christians, this could involve communal reflection among "moral friends"²⁹ on family and church community values and beliefs in anticipation of later medical decisions during times of future incapacity. Finally, I think it is our responsibility as Christian neuroscientists and health care workers to interact collaboratively toward a biblical and clinically meaningful concept of capacity and autonomy, and thus adding normative strength and validity to difficult health care decisions. ✱

¹Much of the content of this article was presented at the biomedical ethics symposium at the 2004 ASA annual meeting on "Neuroscience and the Image of God," at Trinity Western University, Langley, BC.

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Glossary of Defined Terms

- Autonomy** – freedom of action or self-government. In bioethics, one of the four basic principles conceived by William Ross and adapted by Tom Beauchamps and James Childress as the essence of a framework for bioethical engagement.
- Cartesian** – relating to the French philosopher Rene Decartes and his ideas, including his foundational faith in reason as the key to solving problems.
- Capacity** – the ability or power to do something. In bioethics, capacity often refers to the ability to think and make decisions for one's self.
- Christian character ethics** – a movement in Christian ethics responding to widespread moral decline, the need to recognize the historical consciousness of our time, a lack of recognition of the formative influences of friendship, discipleship to mentors, and emotions and desires. Central to this idea is incarnational discipleship which points to Christ as the embodiment of our ethical practices.

Competence – the quality of having the necessary skill or knowledge to do something successfully. In bioethics, competence is closely related to and sometimes considered synonymous with capacity, though it is often the term used in legal contexts. However, competence usually implies a similar degree of capacity but may also connote the actualizing of one's capacity.

Ethics of care – a framework for understanding ethical problems which emphasizes the empathetic and human relational aspects of ethics. Grounded in a feminist tradition, this family of ethical movements sees relationships for their own inherent value rather than in the context of a broken creation order in need of God's grace through Christ.

Hippocratic tradition – pertaining to the writings of Hippocrates, the Greek physician whose oath embodies much of the ethical basis for contemporary codes of medical ethics.

Histocompatible – referring to the presence of the same or similar proteins on cells of the immune system of an organ donor and of the recipient. This would predict for a low chance of an immune reaction against the graft's cells or against the recipient's cells after the transplant has occurred.

Limbic system – grouping of regions largely within the temporal lobe such as the hippocampus and amygdala associated with the neural organizations for emotional, motivational aspects of behavior. Abnormalities of this system can produce affective changes in personality including anxiety, aggression, and depression as well as memory loss.

MRI – acronym for magnetic resonance imaging, an imaging technique based on changes in the magnetic properties of living tissues.

Paternalism – the tendency to protect those over whom one has control by, at least in part, restricting their freedom. In bioethics, this usually refers to the disposition or policy to make decisions for patients rather than allowing them to make their own.

PET – acronym for positron emission tomography, a dynamic radiographic imaging technique used to distinguish parts of the brain according degrees of actively metabolizing glucose and blood flow. Also used in the management of cancer patients to visualize tumor deposits which are metabolically more active for glucose than surrounding tissues.

Relational autonomy – term used to connote a focus on the effect of relationships with other humans on the autonomy of individuals.

Temporal lobe – portion of the brain associated with a wide variety of functions including hearing, smell, the capacity to read, write, and to understand the meaning of spoken words. Disorders associated with this lobe include expressive or receptive dysphasias (inability to speak or understand words).