

# JOURNAL OF HOSPITAL ETHICS

VOLUME 4

NUMBER 2

WINTER 2017

THE JOHN J. LYNCH MD CENTER FOR ETHICS AT MEDSTAR WASHINGTON HOSPITAL CENTER

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**Impairments in Moral Decision Making due to Neurodegenerative Disease: Ethical and Practical Considerations for Clinicians**

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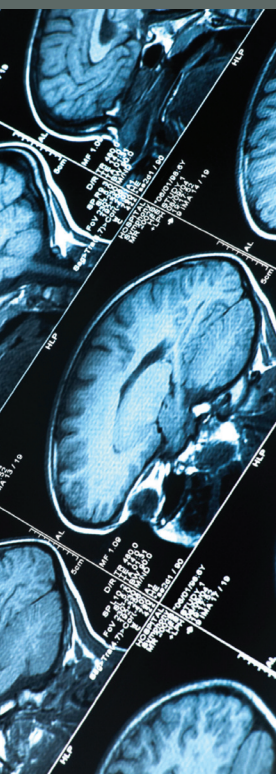
The Editorial Group of the John J. Lynch MD Center for Ethics

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**John J. "Jack" Lynch, 1929-2016**

Evan G. DeRenzo, PhD



NEUROETHICS

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**The mission of the *Journal of Hospital Ethics*** is to enhance bioethical discussion and to assist in the development of skills associated with recognizing, understanding, and managing moral uncertainties and ethical complexities in hospital practice.

**The mission of the John J. Lynch MD Center for Ethics at MedStar Washington Hospital Center** is to help clinicians and other hospital professionals meet a standard of excellence in the care of our patients through education, training, consultation, policy development, and research in clinical ethics. Additionally, when appropriate, we address the ethical concerns of our patients and families directly. The MedStar Washington Hospital Center's bioethics program began in 1982. The John J. Lynch MD Center for Ethics, subsequently established, is involved in over 300 clinical ethics consultations a year, as well as the development of internationally recognized bioethics conferences and education programming.

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# As Only Makes Sense, We Are Evolving

Dear Reader,

Welcome to the *Journal of Hospital Ethics (JOHE)* 4.2 on Neuroethics. This issue, developed from beginning to end by Christian Carrozzo, is the first issue in which he and I are running the journal remotely. In addition to his assignment with the John J. Lynch MD Center for Ethics at MedStar Washington Hospital Center (hereafter referred to as “the Center”), Christian is now with the Department of Philosophy at SUNY Albany, where he is working on his doctorate. I shall leave the proper introduction to this issue to him.

Here, I would like to comment a bit about how amazing (and amazingly simple) it is to work remotely. Whether an academic or clinician, working with colleagues across the country or around the globe, one notices little difference than simply having them in another building on the far side of a sprawling campus like ours. Today, we often make central to our work whatever communication exists through the now standard use of email and teleconferencing, while supplementing the ways in which we can work effectively while distanced with text messaging, Facetime, Skype, and a seemingly infinite array of similar applications. These technologies vastly improve communication for a wonderfully rich, far-flung community of mutually interested others.

The vastness of our global clinical bioethics community was in plain view most recently at the International Conference on Clinical Ethics Consultation (ICCEC) 2016, which we at the Center had the pleasure and privilege to host. Twenty-six countries were represented. The richness of the interactions among colleagues who spoke so many different languages was spectacular.

Many presentations included persons from different states and countries focused on the same or similar issues. During a session that included only persons from Colorado, ICCEC 2016 became the public announcement event for Colorado state legislation that finally passed just a few days before the ICCEC meeting. This legislation was the result of years of work by a statewide coalition and allows a hospital physician, not caring for a patient, to serve as surrogate decision-maker in situations where no one else (ie, no family, friends, or guardian) can be found or appointed.

The issue of hospital care and discharge of homeless patients arose repeatedly throughout the meeting. Of course, dependent upon where around the world, or which region of the United States (US) was represented, the numbers of homeless patients, and thus severity of the issue, varied. Nonetheless, the contours of the problems were

comparable everywhere. As a result of so many similarly focused sessions, on the last day of the meeting a new idea emerged that holds out the promise for (at least a partial) solution in various US states and countries around the world.

The notion involves working with, at minimum, local social service agencies, departments of housing and health, local hospital associations, realtors and undoubtedly others to establish a network of residential buildings willing to subsidize small apartments and the employment of

As the national and international work of the Center evolves, it only makes sense that *JOHE* is evolving also. This is especially true following our most recent Editorial Advisory Board meeting, held March 14, 2016. The best news out of the meeting is that our Board is very happy with the continual improvements in the quality of content. Quality of content is always our first order of business and we were greatly pleased to hear such comments on this point. On the other hand, our ability to produce *JOHE* on schedule has been

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nurses and social workers, to house capacitated, previously homeless patients. The tenants would be capacitated person discharged from a hospital who would be able to live independently in a small apartment with a little supervision and assistance. Staffing such a building, including only a very few such residents, with a nurse and/or social worker, could allow those patients who don't want to be discharged to homelessness and have no other option to be sheltered more satisfactorily and safely upon discharge.

The idea took shape in talking about creating a coalition among clinical bioethicists and others starting with Washington, DC, and New York. However, the beauty of being able to work remotely is exemplified by what happened as part of this open discussion with the remaining meeting participants. A physicist from India who works in cancer research came over to me when the meeting was breaking up and the discussion was over (we at the Center have volunteered to begin convening the coalition) and said he would like to be included. He explained that he has received funding to construct a small building in which his laboratory and clinical research is to be housed and he thought, perhaps, he might be able to configure a few rooms in this building to house homeless cancer patients. A fabulous idea almost immediately layered on top of the original one. As this coalition takes shape and makes progress, we will be certain to keep our *JOHE* readers posted.

a continued challenge. To assist us in doing so I am very happy to report that production of the completed manuscript will now be in the able and steady hands of the University Publishing Group and its President, Leslie LeBlanc. This issue will have been the first to be produced by UPG and we look forward to our new collaboration.

Now that the post-manuscript preparation production functions of *JOHE* are moving to a professional publisher, we would like to thank Catherine Avery for her many years of devoted service. Once she taught Christian everything she could, she turned to being focused exclusively on the management and production aspects of the journal and continued to be the glue that held this project together. I want to thank Catherine sincerely. During *JOHE's* incipency, she and I slogged through the vertical learning curve together. There would be no *JOHE* without her.

Jean Wilhelmsen-Exter, our graphic designer, will also be departing *JOHE's* Editorial Group as we begin our collaboration with UPG. Jean was often invisible to the rest of us because it was she and Catherine who worked out all the design issues from the start. I have known Jean for a long time and we thank her for everything she has done for *JOHE* throughout these years.

Next, I would like to welcome Kahlia Kéita, the Center's newest Ethics Educator, taking over the management and further development of education programming once directed and/or developed

by Christian prior to his move. Kahlia, who holds a master's in bioethics from Loyola, Chicago and is presently attending law school at the University of the District of Columbia (UDC), is our newly titled journal Administrator. She has the big job of keeping track of everything from editorial timelines to fulfillment.

We would also like to say thank you and goodbye to Nneka Sederstrom, whose idea it was for the Center to produce a MedStar focused bioethics publication. As *JOHE*'s Executive Director, she supported the production and funding of this journal from the outset. Nneka has now taken on the important job of building a clinical ethics program at Children's Hospitals and Clinics of Minnesota Hospital. We wish her much success.

I am pleased to report that Norine McGrath, MD, has become the third Director of the Center. She is a physician with MWHC's Emergency Department group. She has been the Chairperson of the hospital's ethics committee since 2012, when Jack Lynch, MD, our beloved and now deceased Medical Director, retired from that position. Jack

As to *JOHE* content evolution, the original strategy was been to create issues tightly designed around specific conceptual topics (issue 1 of a volume), a therapeutic area (issue 2 of a volume) and a policy or departmental focus (issue 3 of a volume). We all have decided, under Christian's leadership on working through these editorial changes, that these constraints limit our ability to identify excellent thinkers and writers about hospital clinical bioethics whose work is, of its own original development, both intellectually appropriate and timely, whether or not it can be accommodated into our concurrent, working "theme," or not. That is, we believe that *JOHE* ought to yield its content decisions to the work of those who propose the most pressing, relevant, and normative considerations about hospital clinical ethics.

My thanks go to Richard Benson, MD, Associate Medical Director of the Comprehensive Stroke Center here at MWHC, for being so helpful in the development of the In Practice section of this issue. Richard and I work together all the time; our clinical ethics consultation service often assists him

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established the ethics committee in 1982 and was chairperson himself intermittently for all those years.

Norine, as Center Director, now also becomes *JOHE*'s Executive Director. Some have asked why an academic journal such as *JOHE* needs an Executive Director, but we feel strongly that *JOHE* does. The Executive Director is the last person to read the manuscript before it goes into production. Given the number of potentially controversial issues addressed by *JOHE*'s authors, it is critically important that we have someone else's eyes on our work. As Editor-in-Chief, it is good to know that someone who is a step away from our work and the journal itself has had the opportunity to raise any red flags that might only be seen with fresh eyes.

untangling the care of some of our most ethically complicated and vulnerable patients. He's a great neurologist, technically excellent, and ethically sensitive.

Also, I want to thank Christian Carrozzo for his special devotion to this issue. In general, there would be no *JOHE* without him. But because of his own intellectual interest in neuroethics, this issue has been a special one for him and for us. For some, neuroethics does not immediately conjure up images of clinical hospital care. But Christian has a special gift (among many) for seeing what is relevant in even the most profoundly theoretical and often seemingly distant from clinical bioethical issues and he has elegantly connected this highly complex work to the everyday business of the hospital.

Finally, and just as we go to press, the Center is being named the John J. Lynch MD Center for Ethics at MedStar Washington Hospital Center. For this, I want to thank Gregory Argyros, MD, Senior Vice President of Medical Affairs and Chief Medical Officer, MedStar Washington Hospital Center. This name change has been a long time coming. Thankfully, Jack knew about the dedication before he suddenly died earlier this year. That Dr. Argyros finally shepherded this through all the leadership levels at MedStar Corporate to the final signature of Ken Sammett, FACHE, President and CEO of MedStar, is a testament to Greg's respect for Jack and everyone's recognition of Jack being the champion of ethics at MWHC for all of his 52 years with the hospital.

Let us now turn to *JOHE*: Neuroethics and a special introduction by Christian Carrozzo. We hope you enjoy this special issue.



Evan  
Evan G. DeRenzo, PhD  
Editor-in-Chief



## *Neuroethics, Moral Agency, and the Hard Problem: A Special Introduction to the Neuroethics Edition of the Journal of Hospital Ethics*

Christian Carrozzo, MA

Neuroethics is often given a two-sided definition.<sup>1-3</sup> On the one hand, it is described as the subfield of bioethics that more narrowly focuses on complexities arising from the moral evaluation of the use of neurologic technologies intended to diagnose, treat, ‘enhance,’ or sustain neurologic function. Moral relevance here often takes the form of individual or communal value positions within a relevant complex leading to legitimate normative debate over courses of action in social and political realms, as well as at the bedside. On the other hand, its sufficient distinctness from bioethics has been attributed to what neuroscientific advances may be able to tell us in a very privileged and direct way about the moral nature of ourselves as minded beings. With this latter distinction we might also ask the question of whether neuroethics, as a field distinctly positioned and equipped to interpret the moral significance of neuroscientific advances, carries itself the moral task of assisting the ethical subject in accommodating new belief systems that oppose those grounded in religion or folk psychology.<sup>4,5</sup>

Indeed, what has resulted in the academic distinction between neuroethics and bioethics, at least, has been the former’s intimate relationship with properly philosophic questions that relate to our self-apprehension as minded *as well as* moral beings in light of actual or hypothetical advances in neuroscience. In particular, notions

involving moral responsibility and determinism, moral worth and personhood, and even what some have argued are the metaphysical (essential) properties necessary to be considered human. The latter comes into question in bioethics and the philosophy of science in debates over ‘humans’ as a biological class of organisms and what happens when the ‘essential’ biological functions of the class are altered by the introduction of some biotechnology. Relatedly, is it appropriate to claim that such alterations specific to neurologic function can affect human moral judgment, or ought they be understood as merely changes in biological function whose associated changes in behavior are then to be evaluated independently and contextually for moral relevance?<sup>6</sup>

All physicalist theories of mind contend as a matter of metaphysical commitment that whatever the mind is, and whether or not we can theoretically reduce it to a description of micro-physiologic processes, nevertheless *supervenes* on the physical. The assumption in effect here is an appeal to the generality of physics; an underlying notion that commits to a physical ontology in relation to the mind. Some theorists take this to suggest that questions surrounding the mind-body relation, rest assured, can and will be *explained* by a scientific theory grounded in physical law. Others are content with the mere metaphysical claim that whatever the mind is (and, sometimes,

whether we should be using ‘mental’ concepts and language to understand consciousness, at all), it shares physical identity with the brain. That is, in a very real and physical sense, the mind is an *aspect* of the brain. One way of understanding this notion is the following:

Think of a flock of birds viewed from a fair distance (see figure 1). Together, they form a pattern or figure (supervening higher-level property/mental state). Each and every instance of a bird (token lower-level property/neurologic event), however, is not evident as part of the figure. The figure thus appears while not able to be defined by its lower level properties (instances of birds).

From this, we can see how a *supervening figure* or pattern undergoing sufficient alteration from its lower level property activity could appear itself to *cause* another figure or pattern to emerge when apprehended from a particular perspective. I have used this example to argue against mental causation in a non-reductive model of consciousness; that is, against the notion that mental states (higher level properties) themselves play a causal role in our everyday conscious actions. If the mind is thusly a higher level supervening aspect of the brain, multiply realized from lower level property activity although irreducible to it, then much like the emerging figure in relation to the flock, mental states themselves can be understood as non-causal while causation is sufficiently provided by lower level neurologic activity. The mind emerges from that activity in what we experience as irreducible, phenomenal states. For our purposes here, the figure illustrates the *supervening* relationship between consciousness (mental states and properties) and the brain (neurologic events and properties).

Although by way of this example we arrive at a conclusion that renders higher level properties non-causal, there are those who argue for the causal properties of mental states by understanding the relation of supervenience to be between higher level abstract computational structures which are functionally distinguished and realized by lower level neurologic events and properties. In this picture of supervenience, the higher level

abstract structure is presupposed a causal system, as mental states are defined, functionally. Like other non-reductive models, such structures have physical identity (mental states are identified with functional roles played out by neurophysiological structures), multiple realizability (such systems come to be by way of many different neurophysiological states or events), and irreducibility (they cannot be defined at the neurological level).

Beyond abstract models, particular relations of supervenience can be found and similarly described between many previously known levels of biological property organization with which we already have some scientific familiarity. Although neurologically specific examples might enlighten us to the ways we can locate and experience the otherwise abstract concept of supervenience in relevant biological systems,

in these cases, just as in the functionalist model, such examples make room for higher level causation often due to the relational analysis of supervenience taking place between what are two already known-to-be causal levels of organization. In terms of the actual supervenience relation presupposed by physicalist theory between mind and its neurological identity, we neither know what the describable systems fully responsible are for phenomenal states, nor are phenomenal states themselves something that will likely ever be described in the same way we do a neurological system or biological level of organization. A supervenience relation between one level of objectively accessible properties and another level of objectively accessible properties may do well at offering an instance of supervenience between two describable systems already known to be causal, but does little to suggest that the subjective, phenomenal properties of conscious experience are necessarily causal, any more than the abstract example depicted (figure 1) demonstrates how they could very well not be.

Neuroethics involves these sorts of concerns when in its academic form it attempts to understand how mental states and mental causation relate to the understanding of ourselves as willful moral agents and the psychological significance of our ‘mental’ lives. Even a complete ontological and causal account of the mind as a supervening aspect



Figure 1.

of the brain that exhausts all scientifically acquired knowledge of our neurologic apparatus, cannot account for what having a mind and a conscious experience *is like* for humans; that is, an account of the subjective phenomena of consciousness. What it is like to desire, to feel pain, to see green, to taste sweet, to hate, to wish, to love. This is not as much a charge against a physicalist account as it merely points to the irreducibly subjective character of experience.<sup>7</sup> Physicalist theories of mind that accept (and expect) this irreducibility may continue to commit to a physical ontology, while for others, not having cognitive access to conscious experience across subjects for the purpose of scientific generalization presents a troublesome incongruity. This latter concern is a way of understanding the “hard problem” in the philosophy of mind.<sup>8</sup>

Although some have offered empirical methods of obtaining useful information from introspective reports about subjective experience,<sup>9,10</sup> the hard problem does not refer to one for neuroscience to specifically overcome. The hard problem is a notion that intends to convey precisely the opposite: the intractable quality of capturing the nature of the subjective aspect of our phenomenal states, the properties of conscious experience, in physically reductive (scientific) terms. Perhaps the most telling feature of this intractability is that we insist on an inquiry that makes the object of scientific investigation the very thing by virtue of which we have the capacity to investigate, viz, consciousness. For some, this feature presents an unattainable objectivity, for others, a view of introspection that posits the act as epistemically privileged, returning us to the question of subjective reliability. These are only some of the derivative concerns of the irreducible subjectivity associated with the hard problem, and they are long-standing in the philosophy of science and the philosophy of mind.

Solutions to the hard problem are not anticipated in what neuroscience can yield. To think this is the case (as some who have attempted to characterize the problem as a defining feature of neuroethics) is to miss the point. This is not to say that neuroscience will fall short in its relevant work, but that it is simply not equipped to provide an explanation of subjective phenomena satisfactory to its own empirical standards and therefore consistent with its own method. Even the kinds of explanations that could arise from a complete neuroscience addressing all functional and structural aspects of the brain will not likely explain the qualitative aspects of subjective conscious phe-

nomena. In my view, this extends to the qualitative aspects of our subjective sense of morality.

The phenomenology of consciousness is precisely where our moral lives take form, where the individual experiences moral agency. What it feels like to value something is indeed a supremely subjective thing. To feel in control of one’s moral decision making or to recognize the relationship of responsibility to one’s actions for some are inalienable features of our mental lives. Even our moral worth is most often understood as both an external evaluation by way of the judgment of others in balance with the internal evaluation we make about ourselves because of what moral qualities *feel like* in our private, mental lives. The ontology and experience of having ‘moral knowledge’ is also tied to this notion. Taking on the stance of moral realism for illustrative purposes here, this can be articulated in the following way: Should there exist moral facts in the world about which I can come to have knowledge, how can the subjective conscious experience of having such knowledge ever be explained through a purely descriptive account? If subjective phenomenal consciousness is the realm in which our sense of moral agency resides (ie, moral language and concepts as referring to mental states and dispositions), then it seems clear why questioning its nature fails the test of clinical relevance.

Even the most ‘philosophically grounded’ bioethics departments of the kind embedded in academic hospitals and that practice a solid and edifying dialectical process with healthcare providers and staff (I am privileged to work in association with one such program), neither in light of immediate ethical uncertainties or for the greater purpose of educating, find there to be any use in addressing such questions. This may point to precisely why, as a *clinical ethics*, neuroethics has comparably less legitimacy. However, this is not only due to a pragmatic collapse of its two-sided definition in a clinical context. What should also be considered is that philosophy of mind, a field whose standard set of influential inquiry is largely responsible for providing the moral questions of neuroethics a sufficiently distinct character, might obtain the problem of objectifying moral agency itself as a derivative symptom of the hard problem, ie, the inability to objectify mental states and the irreducibility of subjective, *including moral*, experience.

In short, academic neuroethics cannot lend its intended clinical counterpart its most fundamental morally relevant inquiry to any good use. In prac-

tice, clinical bioethics must admit the language of mental states and moral agency, including the acceptance of free will and mental causation at face value in a similar way to psychiatry; while what questions provide neuroethics a distinct character, make central the ontological and causal inquiry of those very states and concepts. This might be reason to believe that neuroethics can perhaps practically serve to identify a neurologic clinical case *specialty*, but what theoretical import can be argued to be sufficiently different from that

best second order. Klein completed medical school and a PhD in philosophy at Georgetown University under the mentorship of Edmund Pellegrino. His article entitled “Who Invited the Clinical Neuroethicist?” explores the history and pragmatic dimensions of the preceding consideration of clinical legitimacy, questioning even the notion of a neuroethics clinical specialty as perhaps too homogenous to standard clinical bioethics to be required or even recognized as a distinct practice in the hospital setting. His exploration of three

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of bioethics and thus legitimizing neuroethics as a *justifiably distinct realm of moral inquiry* is effectively impotent in helping establish it as a distinctive *clinical ethics practice*.

**JOURNAL OF HOSPITAL ETHICS: NEUROETHICS**

In a way, this issue was an experiment with the following question in mind: Given the above argument, does neuroethics have a place at all in the clinical sphere? The answer is yes, but perhaps only when understood as a specialty. As the presence of bioethics emerges increasingly stronger in clinical and hospital organizations, functionally embedded and treated within many systems as simply another department, clinical ethics consultants, like healthcare providers and other staff, also find themselves beginning to specialize. How distinct will the questions and concerns of the clinical neuroethicist be from those of the bioethicist? Not very. However, this does not mean that practical and very direct benefits might not emerge from applying the specialized knowledge that comes from immersing as a clinical bioethicist in a particular medical subfield or department. This is the natural way; and it is already evident in the most sophisticated of hospital bioethics programs.

In constructing this issue, my relevant exchanges with Eran Klein revealed his position to be that a clinical neuroethics may inherit some of the legitimacy of its academic self, but this is at

complex and telling clinical cases related to decisional capacity is a timely and important one that delves directly into the question of whether or not a ‘clinical neuroethicist’ can be said to bring forth a special set of relevant expertise to the work of clinical ethics consultation.

The pursuit of understanding moral norms and practices as rooted in our microphysical structure occupies a significant portion of the core questions of neuroethics seen as an interdisciplinary field involving neuroscience, evolutionary biology, anthropology, psychology, and even the social and political sciences.<sup>11</sup> Whether one philosophically recognizes the extent of the scientific inquiry as eventually limited in light of the hard problem as previously discussed, depends on whether one sees knowledge about moral *experience* as critical to the full epistemic picture. If, on the other hand, the goal is to obtain knowledge of what physical facts may underlie morally significant behavior, including decision-making processes, then one need not feel burdened by the irreducibility of subjective moral agency and may confidently move forward with the ‘science of morality’ in pursuit of a descriptive account. The danger here lies in the assumptive view of morality as reducible to particular types of behavior that can then be themselves causally reduced to physiology. What we need in these ever-increasing scientific accounts is the removal of the assumption and the replace-

ment of it with a static definition of the kind of behavior being theoretically described as morally significant. Alternatively, as Chalmers suggests, if the pre-experimental goal is to attempt to ascribe consciousness to some neuroanatomical process, then the bridging principles involved (by which we make inferences from neurologic processing facts to facts about consciousness) should be made explicit in our reports.<sup>12</sup>

A look at how neuroscience continues to improve our understanding of such behaviors in relation to neurodegenerative disease and therefore directly informing the ethics of clinical practice was a perspective I felt ought to be included in this issue. When Sam Horng and I discussed the importance of including a static definition when making inferences about the “neuroanatomical substrates of moral behavior,” it took no convincing at all. Horng received his MD from Harvard Medical School and PhD in neuroscience at the Massachusetts Institute of Technology’s Department of Brain and Cognitive Sciences. Although he is a scientist first, the meta-ethical point was not lost here. Responsibly, Horng restricts his use of “impaired moral-decision making” to a definition of *practical behaviors that potentially cause harm to others*. In this way, he was able to construct an evidence-based practical framework for clinicians and hospital systems that suggests ways to better understand, predict, and manage the behavioral manifestations, including decisional impairments, of patients who suffer from neurodegenerative disease while addressing the problematic aspects of the behaviors themselves without claims about their ‘intrinsic moral nature.’ In an impressively broad but accessible review, Horng covers the current data in relation to several common forms of relevant dementia and then builds his guidelines with a focus on education, detection and assessment, treatment and resource referral, protection of others, and prevention of harm.

Finally, several different possible topics arose in conversation with Thomas Cochrane regarding his contribution to this issue. Cochrane is Director of Neuroethics at the Center for Bioethics and Assistant Professor of Neurology at Harvard Medical School, although as a practicing neurologist, he spends a good deal of his time on the hospital floor doing the challenging work of neuro-intensive care. What he told me motivated him most was a 2006 study that revealed through a novel fMRI technique an increase in brain activity (elevated blood flow and inferentially, neuronal activity) in a young patient who was considered by definition

of her disorder (vegetative state) to be unconscious, but was nevertheless asked to perform certain cognitive tasks. What is of significance here is that this activity was measured in the same regions of the brain that showed increased activity in healthy control subjects when asked to perform the same task, including regions associated with visual-spatial processing. Cochrane covers many subsequent studies that have used various techniques to attempt to determine signs of clinical consciousness in patients with disorders of consciousness by way of imaging (DOC-I), showing promising results. He argues that despite the popular notion that such techniques represent a “revolution in our understanding of consciousness” and therefore will have a significant impact on the ethics of decision making for patients with DOC, that this transfer of utility might be misguided, as the *prognostic* value of such techniques has yet to be scientifically established.

Despite a few high-profile cases that have shifted our perception of patients with DOC and the controversial protraction of life-sustaining therapies (LST) as typical, Cochrane notes that such disorders are common, and in most cases surrogates and clinicians are quite clear on a course of action that would be in the patient’s overall best interest. When decision making about withdrawing LST becomes uncertain, the relevant factors for surrogates are not often about the particular DOC *diagnosis*, but about *prognosis*, and in these cases it seems DOC-I does not provide us with added certainty. The question then becomes in what clinical scenarios will DOC-I be helpful to the decision-making process? That is, how do we make best use of an inference of consciousness through the fMRI studies mentioned? Cochrane attempts to answer this question for clinicians through an exploration of scenarios in which DOC-I would indeed be helpful, focusing largely on a carefully structured analysis of when the ethical complexities relate to possible signs of consciousness.

As I mentioned in the beginning of this section, whether neuroethics can transfer its sufficiently distinct self from academia to the academic hospital and remain fully relevant is perhaps a question best answered by doing the work. The recognition of its most fundamental questions as perhaps limited in certain contexts by their philosophical nature is one possible conclusion, although its relevance and import in other areas should be explored through actual attempts to extend its reach, as our authors have done here, and see what happens. The experiment may very well take place

in the intellectual and practical work of testing its boundaries and subsequently refining its theoretical objectives. As good pragmatists, we should engage in these experiments with a hefty dose of fallibilism and adjust our explorations (and expectations) accordingly.<sup>13</sup> Waving the neuroethics flag (*argumentum ad populum*) or proclaiming against all reasonable circumscription that “neuroethics is here to stay” gets us nowhere. Providing exciting avenues for professional development while upholding the promise of 21st century neuroscience are questionable as the only reasons why neuroethics should persist in all forms. Indeed, it also reminds us that narrow attention and investment into the prospects of any single science (eg, genetics, evolutionary psychology) as that which will finally uncover the fundamental nature of ‘morality’ might itself be conceptually misguided.

#### Acknowledgments

Special thanks to Ron McClamrock for his critical comments and suggestions on an earlier draft of this article.

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# *Neuroimaging and Inferring Consciousness: Implications for Life-Sustaining Therapies?*

Thomas Cochrane, MD, MBA

## INTRODUCTION

### **Decision Making for Patients with Disorders of Consciousness.**

Some disorders of consciousness (DOC) are associated with an extremely poor perceived quality of life.<sup>1-4</sup> When clinicians and surrogates care for patients with a prolonged DOC that could be permanent, they are often faced with having to make explicit decisions about life-sustaining therapies (LST). These situations pose a number of ethical difficulties: making decisions for someone who has lost capacity, decisions to withhold or withdraw LST, and decision making under prognostic uncertainty.

These disorders are common, and the associated ethical difficulties are nothing new. Decisions about LST typically involve the substituted judgment standard and what can be known about a patient's values and preferences, given her current diagnosis and prognosis. When a surrogate and clinician agree that the patient would not want to continue LST, then clinicians are permitted to withdraw any LST, including tube feedings, ventilators, intravenous fluids, and medications. Notwithstanding a few contentious cases that have received intense public attention, this process of deciding whether to continue or discontinue LST in patients with DOC is usually quite uncontroversial.

In what follows, I will use the term DOC to encompass coma, the vegetative state (VS), and the minimally conscious state (MCS). LST can refer to any life-sustaining therapy, but unless otherwise specified, the reader can infer the discussion to be about a patient whose LST consists only of artificial hydration and nutrition. Accordingly, when discussing withholding or withdrawing of LST, I will not be discussing patients diagnosed as brain-dead or locked-in. When referring to novel neuroimaging techniques to detect consciousness, I will use the term disorders-of-consciousness—Imaging (DOC-I).

### **New Radiographic Techniques**

In 2006, Owen and colleagues described a patient in VS with radiographic evidence that suggested some level of conscious awareness.<sup>5</sup> She was 23 years old, and underwent the study five months after experiencing a traumatic brain injury (TBI) from a motor vehicle accident. The study involved a novel fMRI technique whereby she was asked to imagine herself playing tennis, and then to imagine herself navigating through the rooms of her home. One would ordinarily not expect a vegetative patient to respond to verbal instructions, as patients in VS are by definition unconscious, but this patient was found to have increased blood flow (and by inference, neuronal activity) in the same brain regions that showed increased activ-

ity in healthy control subjects who were asked to perform the same task.<sup>5</sup>

Some have suggested that inferring consciousness from this type of study is problematic, because there is not yet an agreement about which types of neural activity are necessary and sufficient to support consciousness.<sup>6,7</sup> However, most observers agree that the level of coordinated cerebral activity seen in this subject (and others like her) is high enough that we should infer from this some degree of consciousness.<sup>8</sup> This is partly because (presently, at least) *all* of our judgments about the

Published literature contains little about whether subjects in VS or MCS who demonstrated greater-than-expected awareness were more likely to recover from these states. In 2014 Stender et al reported using fMRI and PET techniques on 41 subjects in PVS and 81 subjects in MCS.<sup>12</sup> The main finding of importance in this study was the following: 13 of 41 subjects in VS showed imaging evidence suggesting awareness. Of these, five were TBI patients, five had ischemic injury, and three had other conditions (two had infection and one had subarachnoid hemorrhage).<sup>12</sup> Research-

*Presently, at least, all of our judgments  
about the consciousness of others are based on  
inferences drawn from observations of behavior.*

consciousness of others are based on inferences drawn from observations of behavior, and often with particular attention to the complexity of the behavior that is observed. In response to the verbal instruction regarding tennis imagery, the subject's brain did what healthy brains do when planning motor activity. Moreover, in response to the verbal instruction regarding navigation, the subject's brain appeared to activate regions devoted to visuospatial processing.

In 2010, Monti et al studied 54 patients using techniques similar to Owen's protocol. Of these, 23 subjects were in VS and 31 in MCS. Out of five subjects who demonstrated greater-than-expected signs of awareness, four were in VS and one in MCS.<sup>9</sup> Lastly, one of these could consistently answer yes-no questions.

While this was an impressive demonstration of the power of DOC-I techniques to detect awareness, the results were not terribly surprising to clinicians. All of the responsive subjects had suffered a TBI—no subjects with ischemic brain injury showed DOC-I evidence of awareness. Four of the five were in their 20s, and the fifth was in his 40s. The study looked at three of these five participants within the first six months after their injury.<sup>9</sup> Many patients in VS after TBI have a reasonably high likelihood of regaining consciousness within the first year after injury.<sup>10,11</sup>

ers saw the following outcomes among the 13 VS subjects who responded on DOC-I: three died due to complications of their illness; one remained in VS; six emerged into the MCS; two were severely disabled, and one had a good (full) recovery.<sup>12</sup>

Was there a difference among these subjects when it came to the mechanism of injury (TBI, ischemic, or other)? It does not seem so, though the numbers are small. Among the five TBI patients, one did experience a good recovery 12 months after the study—a 58-year-old man who was initially evaluated one month and one week after his TBI. Another patient was slightly better than MCS, and so received a rating of “severe disability.” The remaining three were in MCS<sup>2</sup> or dead.<sup>12</sup> Among the five ischemic patients, the best recovery at 12 months was to “severe disability.” The others were in MCS<sup>3</sup> or dead.<sup>1</sup> Among the patients with other conditions, one died, one was in VS, and one was in MCS.<sup>12</sup>

The authors of this paper assert that PET “correctly predicted” outcomes in 74% of subjects, which turned out to have agreement between their PET at the time of study and their one-year clinical outcome.<sup>12</sup> However, the agreement in imaging studies between consciousness at the time of study and eventual outcome was only 56% when using fMRI. Note that fMRI only “predicted” the one-year outcome with the accuracy of a coin flip, and that



PET only did slightly better.<sup>12</sup> In short, the prognostic value of DOC-I is not yet established, and it may never be better than other clinical indicators.<sup>13</sup>

#### IMPLICATIONS FOR DECISION MAKING

It is often implied in the popular press that DOC-I findings represent a revolution in our understanding of consciousness, and that DOC-I findings will have a major practical impact on decision making for all patients with DOC. Both claims are heavily overstated, and only partly true. It is certainly humbling to learn that some patients who appear to be unconscious may not be. On the other hand, we know that clinicians' ability to detect consciousness at the bedside is less than ideal, so the idea that modern tools would improve our ability to detect consciousness is hardly a revolution.<sup>14,15</sup> The second claim—that DOC-I will have a major practical impact on decision making—has two problems. First, it is premature, because there has been so little research done on the prognostic value of DOC-I. Second, it is overly broad, because only some patients with DOC would find DOC-I

“no” to LST in one, you would likely say “no” in the other. Based on my clinical experience (and for what it is worth, my related intuitions), for most people, the question that matters is not, “Precisely which severe DOC am I in?” but rather, “What are the odds that I will recover?” In addition, for most people the difference between VS and MCS is not important—most people find both unacceptably poor states in which to continue LST once it is reasonably certain that the condition will be permanent or significantly prolonged. On the other hand, for the minority who would want to continue LST in one state, it seems likely that they would want to continue LST in the other.

When it comes to making decisions about LST, the most important question to answer is always, “What are the odds that the patient will recover to a state that he or she would find acceptable?” Since most of us would find permanent VS and permanent MCS equally unacceptable (or acceptable), this question is a question of prognosis rather than diagnosis.

*It is impossible to know what the subjective experience of the MCS patient is, but there is good reason to believe (or presume) that the MCS patient is capable of some physical or emotional suffering.*

findings useful. In what follows, I will attempt to help the clinician by exploring the situations in which DOC-I would be useful, and those in which it would not.

#### **When Prognosis Is the Issue—and It Very Often Is—DOC-I Is Not Likely To Be Helpful**

Would you want to continue LST if you were in a VS and extremely unlikely to recover? For argument's sake, let us say all the experts agree that the odds are less than one in a hundred. Now imagine that you are in MCS, with exactly the same odds of recovery. Would you want to continue LST now? I would not try to guess your answers, but I do feel confident in making this prediction: if you said “yes” to LST in the VS, you would likely also say “yes” to LST in the MCS. Likewise, if you said

#### **When Detection of Consciousness Is the Issue—and It Only Occasionally Is—DOC-I May Be Helpful**

Surely, one might think, making the most precise diagnosis possible would be essential before deciding whether to continue LST. As I argued in the previous section, when deciding about LST what matters to most patients is not the precise diagnosis, but the *prognosis*. In these patients, DOC-I in its current stage of development is not particularly helpful. There are, however, some patients for whom a precise diagnosis is a primary ethical consideration. Generally, the following types of patients may have a deep interest in making sure their diagnosis is clear.

- **Patients in chronic VS who would continue LST in any case.** Some patients would consider even a permanently unconscious life to

be a life worth living. For these patients, the decision about whether to continue life support often does not depend on whether they are comatose, vegetative, minimally conscious, or in some other neurological state.

One might initially think that DOC-I would hold no particular importance in this context, because the decision about continuing LST does not depend on the precise diagnosis. However, for these patients—who may live a long life in what looks at the bedside like VS—detecting consciousness may be of paramount importance in order to avoid the error of treating a conscious patient as if she is unconscious. This may have implications for simple bedside interactions with patients (talking to the patient, treating her gently and with respect) or it could have implications for the type of rehabilitation efforts that are attempted.<sup>16</sup>

- **The chronic VS patient who would continue LST if there were evidence of awareness, but not otherwise.** One could perhaps imagine a patient who would want to continue LST if he were in a permanent MCS, but not in VS. For such a patient, a “positive” fMRI study would mean the difference between continuing LST and not.

Note, however, that this would be an unusual instance. It is impossible to know what the subjective experience of the MCS patient is, but there is good reason to believe (or presume) that the MCS patient is capable of some physical or emotional suffering. Subjectively, therefore, it seems likely that chronic MCS is a *worse* experience than chronic VS, because the VS patient is unconscious and incapable of experiencing suffering. This is why most people would consider both VS and MCS unacceptably poor neurological outcomes.

Patients for whom detection of consciousness is *not* the main issue would include the following.

- **Patients (in MCS or better) who already demonstrate clinical evidence of awareness.** The MCS patient, by definition, shows bedside evidence of awareness. For such a patient, one does not need DOC-I in order to avoid the mistake of treating a conscious patient as unconscious.
- **Patients in acute coma or VS and a high probability of recovering consciousness based on already-known prognostic factors.** Patients who have recently suffered a traumatic brain

injury, and who have no imaging evidence of major/widespread structural damage (such as hemorrhaging or other evidence of severe axonal injury) have a very high likelihood of recovering some consciousness, and some will have a good neurological outcome.<sup>11</sup> Unless and until the prognostic value of DOC-I is established, DOC-I can have little role in decision making for a patient in this phase of care.

- **Patients with little to no chance of a recovery they would consider meaningful.** In some patients, it is already possible to prognosticate with a high degree of confidence that a recovery *the patient would consider sufficient* will not occur. For instance, some patients with severe hypoxic-ischemic insult (eg, a large stroke or prolonged asphyxia) will demonstrate widespread irreversible brain damage in MRI. For these patients, one might not be willing to predict whether the patient will regain any consciousness, but could confidently predict that the patient will have severe cognitive and functional limitations. For a patient whose decisions about LST will depend on cognitive or functional outcomes, the fact that they have a “positive” DOC-I study will not alter the prognosis or the decision about LST.

#### Patients with DOC in Long-Term Care Should Have Diagnosis Revisited Frequently

It is well known that there is an uncomfortably high misdiagnosis rate for DOC—as high as 43%.<sup>16</sup> A large percentage of patients diagnosed as in VS, based on clinical consensus, when studied very carefully, are found to have behavioral responses to the environment—meaning that their real diagnosis is at least MCS, and possibly even higher.

Sometimes a misdiagnosis of VS occurs because a patient’s brain injuries impair her mobility or language, thus preventing clinicians from detecting subtle behaviors that serve as evidence of improved awareness. Sometimes brain injuries impair sensation (vision, hearing, and relatedly, language comprehension), preventing the patient from perceiving an environmental stimulus that is meant to elicit a behavioral response. Sometimes, surely, a misdiagnosis occurs because of clinical confirmation bias—ie, clinicians who already *believe* a patient is unconscious are likely to interpret subtle behaviors as reflexive, or coincidental, simply because that is what they expect to see.

The development of the JFK Coma Rating Scale-Revised (CRS-R) represented an improvement over

clinical consensus diagnosis.<sup>17</sup> This evaluation tool for patients with DOC is an important tool in systematically searching for behavioral evidence of awareness, and reducing the odds of missing that evidence when it exists.<sup>17</sup>

However, DOC-I findings make the misdiagnosis concern even more serious. DOC-I reveals that even the CRS-R is not perfect at detecting awareness when it exists. In fact, the study by Stender et al suggests the possibility of a persistent 32% misdiagnosis rate *even using the CRS-R*.

#### **Patients with Chronic DOC Must Have the Opportunity to Forego LST, Including Oral Hydration and Nutrition**

Although it may seem counterintuitive, I argue that we should be *more* willing to let patients with *chronic* DOC forego LST. I reach this conclusion precisely because DOC-I research is eventually likely to further undermine our certainty about prognosis in the *early* stages of DOC. DOC-I findings introduce further uncertainty about our ability to examine the brain at the bedside, which makes it even more important to be certain about prognosis before withdrawing or withholding LST. However, our current system of caring for patients with

this “window of opportunity.”<sup>18</sup> This sometimes happens in spite of serious prognostic uncertainty, which means that, inevitably, some patients who would have had an acceptable outcome will forego LST.

As I have argued elsewhere, this fear of being stuck, and this perceived “opportunity to die,” exists mainly because of the difficulty in withdrawing LST from a patient in a chronic DOC. If we were to make it *easier* to withdraw LST from a patient in chronic DOC whose prognosis is reasonably certain, then we might make it *harder* to withdraw in the acute phase when prognosis is uncertain. If we reduce that time pressure in the acute phase, we would be less likely to withdraw LST from a patient with a reasonable (or unknown) chance of an acceptable recovery.<sup>17</sup>

The difficulty in withdrawing LST in the chronic phase is partly a practical reality, though it is one that we should change. For example, in some states there is little explicit support for withdrawing LST from patients in MCS from a legal perspective.<sup>19</sup> This in turn makes some providers nervous about the legality of withdrawing LST in the MCS. However, this difficulty could be

*As it is sometimes expressed, patients fear missing the “opportunity to die” in the first days or weeks after their injury.*

DOC puts pressure on surrogates and providers to withdraw LST in the first weeks after injury, when prognosis is extremely uncertain. Surrogates and providers caring for patients in the first days and weeks after brain injury fear that, if they accept LST in the acute/subacute phase of the injury, the patient might be “stuck” in a chronic and unacceptably poor neurological state. As it is sometimes expressed, they fear missing the “opportunity to die” in the first days or weeks after their injury.<sup>18</sup>

Approximately two weeks after an acute brain injury, the comatose/vegetative/minimally conscious patient will need to have his endotracheal tube replaced by a tracheostomy, and his nasogastric or orogastric tube by something like a gastrostomy tube (G-tube). Providers and surrogates often feel that these procedures should not be performed, and the patient should be allowed to die during

overcome by educating providers about the ethical and legal arguments that support patients’ right to refuse LST, or by amending applicable laws where necessary. Another barrier to withdrawing LST is the feeling experienced by clinicians that somehow they are acting in an ethically inappropriate way when withdrawing oral hydration and nutrition in the rare patient with DOC who is able to eat and drink by mouth. However, if the patient in VS or MCS has the right to withdraw LST, then one need not fear being “stuck,” and the time pressure that comes from fear of missing an “opportunity to die” will be relieved. Once the time pressure is relieved, patients can afford to wait and see whether they will recover to an acceptable state.

As contradictory as it might seem, making sure that patients with chronic DOC can withdraw LST might well have the effect of *saving* lives of

patients with DOC. For this reason, we should try to ensure that patients with chronic DOC have the legal right to withdraw LST (eg, by clarifying laws that fail to support the right of the MCS patient to withdraw LST). In addition, ensure that the institutions where patients with chronic DOC typically live (eg, nursing homes, rehabilitation hospitals) have policies and procedures that protect this right and ensure that LST can be withdrawn.

## DISCUSSION

Novel imaging techniques for detecting consciousness are likely to alter practice when it comes to caring for patients with DOC, but the ways in which they will alter practice are still limited and unclear. Until DOC-I techniques can provide useful prognostic information about who will and will not recover consciousness, the clinical usefulness of such techniques will be very limited.

At this point, DOC-I can only provide diagnostic information, and no prognostic information that is reliable. As long as this remains the case, the implications of DOC-I for clinical care are limited. I believe the following are the major implications of the current state of the art:

1. Patients in the acute phase after injury (weeks to months) gain no useful additional information from DOC-I unless and until the prognostic value of DOC-I is established.
2. DOC-I might be helpful for patients in chronic VS who will continue LST whether or not they are conscious, because if such a patient were actually aware, then it would be a grave mistake to treat as unconscious.
3. It might rarely be deemed that a patient in chronic VS would continue LST if there were imaging evidence of awareness but would stop it otherwise. For such a patient, DOC-I might make the difference between continuing and discontinuing LST.
4. For patients diagnosed as MCS or better based on the clinical exam, DOC-I has little or no utility, as these patients' responsiveness can be detected at the bedside without DOC-I.
5. Patients whose prognosis can be established with a high degree of certainty are unlikely to benefit from DOC-I.
6. Because DOC-I findings further undermine the certainty with which we assess consciousness at the bedside, great care must be taken to examine and re-examine patients with chronic DOC.
7. Because DOC-I findings further undermine the confidence with which we prognosticate

in the early phases of brain injury, we must take care not to make decisions under a false sense of time pressure. If prognosis is uncertain (or completely unknown), then decisions about discontinuing LST should generally be postponed.

8. In order to make waiting a viable strategy, we must ensure that patients who do not go on to have an acceptable recovery have the option to discontinue LST later on. For example, institutions and legal structures must support the right of the patient in MCS to forego LST once an unacceptably poor prognosis (from the patient's perspective) is sufficiently certain.

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# Who Invited the Clinical Neuroethicist?

Eran Klein, MD, PhD

## INTRODUCTION

Ronald Cranford proposed the term *neuroethicist* in 1989,<sup>1</sup> more than a decade before the emergence of neuroethics as a distinct area of bioethics.<sup>2</sup> He used the term to refer to clinical ethics consultants trained in diseases of the brain and spinal cord, principally neurologists like himself. The term gained little traction. Clinical ethics in the 1980s and 1990s was itself coming of age.<sup>3</sup> The young field showed little interest in singling out individuals with narrow organ-specific expertise. As such, the term neuroethicist instead came to be associated with people engaged in ethical reflection on neuroscience *research*.<sup>4</sup> More than 25 years later, a desire has arisen to set apart and affix a special name to the clinical ethicist who possesses brain-related expertise. Before doing so, it is worth asking: Is the clinical neuroethicist necessary?

The term *clinical neuroethicist* has had something of a circuitous birth.<sup>4</sup> Neuroethics in general describes research into the nonscientific—ethical, legal, sociological, historical, theological—implications of neuroscientific advances. What should be done about incidental findings in neuro-imaging research? Is forensic lie detection a proper (or conceptually coherent) use of neurotechnology? Can a line be drawn between medical treatment and enhancement of mental life? Can neural correlates of moral judgment be identified? These and

related questions are now the subject of dedicated journals (*Neuroethics*, *AJOB Neuroscience*), neuroethics centers and institutes (Stanford University, University of Pennsylvania, University of Oxford, University of British Columbia, and University of Montreal<sup>4</sup>), and a neuroethics society (International Neuroethics Society, or the INS<sup>5</sup>). In the formative years of neuroethics, clinical issues largely resided at the periphery, important but perhaps too downstream from cutting-edge neuroscience research to warrant pressing concern.

The rapid expansion of information and interventions in neuroscience have increasingly shown this view to be anachronistic. Prescription drugs that enhance academic performance are a problem for pediatricians *now*.<sup>6</sup> The threat of depression and suicide from modulating deep brain stimulator (DBS) settings in Parkinson's disease is a problem for neurologists *now*.<sup>7</sup> Diagnostic uncertainty in disorders of consciousness raised by recent functional imaging studies is a problem for families and critical care intensivists *now*.<sup>8</sup> Developments in neuroscience and neurotechnology are rapidly converging on clinical care and along with this convergence arise dilemmas in clinical ethics. It is not surprising that expertise relevant to addressing such dilemmas is sought. Nor is it surprising that "clinical neuroethicist" has come to connote this desired expertise.

The term “clinical neuroethicist” is both catchy and broad. Clinical neuroethics problems are “neuro” in that they relate to the brain, “ethical” in that they raise moral questions and require the use of moral concepts, and “clinical” in that healthcare professionals do or may conceivably encounter them in their care of patients. The term covers not only the emerging ethical challenges of applying neuroscientific advances to medicine but encompasses the scope of expertise originally envisioned by Cranford, such as care of patients with diagnoses of coma, amyotrophic lateral scler-

of 20 years that he will no longer be coming into work, and arranges a meeting with an estate attorney to put his financial affairs in order. However, he also begins to behave in ways his family finds worrisome. He volunteers at a home for juvenile offenders, despite having no previous interest or experience. He takes up rock climbing, though he has never been much of an athlete. He adopts six new dogs from the local humane society, stating that he wants to “make amends with the animals of the world.” He informs his family that he will be traveling to a foreign country to participate in

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osis (ALS), or stroke. While sometimes cleaved of its “clinical” modifier in medical contexts (eg, the journal *Neurology Today* has a recurring column entitled “Ask the neuroethicist”<sup>9</sup>), *clinical neuroethics* and its practitioners—*clinical neuroethicists*—are emerging as terms of art.<sup>10,11</sup>

The emergence of clinical neuroethics may be understandable, but whether this is a useful development is a separate question. In this article, I begin to explore this further question through presentation of three hypothetical clinical ethics cases. I argue that the purported “need” for clinical neuroethics often rests on a misunderstanding of the kind of expertise involved in clinical ethics consultation and, as such, reserving a place for the clinical neuroethicist may not be necessary.

**THREE HYPOTHETICAL CLINICAL ETHICS CASES AND THE BRAIN**

**Case 1**

Van is a 51-year-old government economist diagnosed with invasive but non-metastatic pancreatic cancer. After a rapid but thorough diagnostic workup, his prognosis is found to be grim with limited therapeutic options. A rather serious and introverted person by nature, he initially takes the diagnosis in stride. He discusses his condition with his wife and parents, informs his employer

an experimental treatment for pancreatic cancer for which his family, after painstaking research, can find little scientific evidence. He seems to express little concern that this treatment will exhaust the family’s resources and geographically separate him from his family. The change to Van has been so dramatic, claims his family, that they question his decision-making capacity and request that his physicians consider medical and psychiatric evaluation.

The experience of disease can be transformative. It can lead to radical changes in beliefs, values, preferences, commitments, and so on. Sometimes these changes are so out of character as to raise concerns about decisional capacity, as in this case. It may be the case that Van has lost decision-making capacity, perhaps due to yet undiscovered metastatic or metabolic changes, or due to a psychological schism leading to beliefs and commitments that no longer hold together in a rational, coherent whole. On the other hand, it is possible that these changes do not ultimately impugn his rationality. His diagnosis may have sparked him to reconfigure his values and interests, to push forward, in what limited time he has left, down an uncharted, but explicable, path. In any case, his experience of illness has changed him in important ways. The appropriate clinical response to the changes noted in Van—deference

or intervention—involves a recognition that the change in him is, at some level, a change *in his brain*.

### Case 2

Shireen is a 54-year-old former bus driver with liver failure and associated fluctuating mentation. She has gone back and forth during recent lucid intervals about whether she wants a liver transplant and the requisite monitoring and behavioral “policing” she feels this will invite. Her three adult children desperately want her put on the transplant list. She takes medications, though not always consistently, for comorbid conditions. To the consternation of her three children, as her mentation has deteriorated, so has her medication adherence. Effective medical management of her comorbidities is a prerequisite for being maintained on the transplant list. As her periods of confusion have become more frequent, her family members admit to tricking her into taking her daily medications. They want to preserve her opportunity for a liver transplant if she ultimately decides to pursue one.

Decision-making capacity is a centerpiece of biomedical ethics. Does a patient possess the capacity to make a particular healthcare decision? Capacity determination is not always easy, but is typically a critical early step in a clinical ethics evaluation. In starkest terms, an affirmative response ushers in considerations of respect for autonomy, while a negative response considerations of beneficence. Pathological conditions of the nervous system, whether primary (eg, brain tumor, schizophrenia, Parkinson’s disease) or secondary (eg, from toxic buildup of metabolites in the brain, as is likely in this case), commonly affect decision-making capacity. A patient with a poorly functioning nervous system is at significant risk of compromised decision making. In the case of Shireen, addressing ethical questions about her decision making must start with recognizing a potential problem *in her brain*.

### Case 3

Dominic is a 62-year-old former construction worker recently implanted with a deep brain stimulator (DBS) for Parkinson’s disease. Soon after implantation, his family notes a change in his personality. He is no longer the conservative, religious man they have always known, but has become outgoing and, at times, abrasive. He is overly flirtatious with women and shows little regard for the feelings of both family and strangers.

His DBS neurologist offers to adjust his stimulation parameters in hopes of reversing these personality changes, though perhaps at a cost of worsening his Parkinson’s disease symptoms. He refuses, telling both the clinician and his family, “I like the way I am now. I feel like I am finally free to be the real me.”

DBS is a highly effective treatment for Parkinson’s disease. An increasingly recognized side-effect of DBS in a minority of patients is a change in personality. Patients have been noted to experience poor impulse control, aggression, laughter, hypersexuality, apathy, depression, suicide, marital problems, occupational disinterest, and impaired sociomoral judgment.<sup>12</sup> Changes in personality are at times so profound as to lead some in bioethics to question whether individuals have undergone a change in personal identity. In the case of Dominic, it is clear that addressing the “question of identity” starts with recognizing that DBS has led to changes *in his brain*.

The three cases—all centered on facets of decisional capacity—highlight that most ethical dilemmas arising in medicine *can* be viewed through the lens of changes in brain structure or function. Given this, it is reasonable to ask whether clinicians with expertise in brain structure or function are needed because they can bring a brain-centric expertise to clinical ethics consultation.

### A PLACE SETTING FOR THE CLINICAL NEUROETHICIST

The question whether the clinical neuroethicist deserves a spot at the clinical ethics table only makes sense against a background understanding of the purpose and practice of clinical ethics. Fletcher defines clinical ethics as “an interdisciplinary activity to identify, analyze, and resolve ethical problems that arise in the care of particular patients.”<sup>13</sup> La Puma defines it as “the process of identifying, analyzing and resolving moral problems of a particular patient’s care.”<sup>14</sup> And Jonsen et al define the goal of ethics consultation as “identifying, analyzing, and working to resolve ethical problems encountered in individual cases.”<sup>15</sup> Set against this understanding of clinical ethics, a clinical neuroethicist must both fit into this professional framework but also add some nonredundant value to clinical ethics. Is that the case?

The cases highlight the sense in which many, if not most, clinical ethics cases involve the brain. Patients’ values and preferences, personalities, and decision-making capacities, emotions, and sense of self all intimately involve and depend upon the function of the brain. That being said, clinical



ethics hardly needs a specialist *in the ethics of* neurology or neuroscience to evaluate and work through such cases. Clinical ethics has gotten along for decades without a special class of experts called clinical neuroethicists. The principal reason for this is that the expertise that matters in most clinical ethics cases, even cases that primarily involve pathology of the brain, is *general* ethical expertise. The ability to discern the morally appropriate choice within a given set of practical circumstances is what Aristotle in Book 6 of the *Nicomachean Ethics* calls *phronesis*.<sup>16</sup> While *phronesis* may depend on a working knowledge of the brain insofar as how it supports complex and varied forms of mental life, it does not depend on an organ-specific ethical expertise.

This should not be read as denying the importance, particularly in certain cases, of specialized knowledge of neuroscience, neurology, or psychiatry. Relevant facts about neurological disease or brain function certainly frame normative questions, but they do not decide them. It is no mistake that the first “box” in the Jonsen et al eth-

hammer, everything looks like a nail. There may be important perspectives that are lost or devalued by affording epistemic or methodological priority to brain-centric viewpoints. While recognizing the special status of the brain in terms of moral agency, nevertheless, pragmatic concerns remain that a clinical neuroethics designation opens the door to a silo-ing of clinical ethics, perhaps inviting hepato-ethicists, ophthalmo-ethicists, and the like. One imagines that this would create more problems for clinical ethics than it would solve.

Clinical ethics may not *need* clinical neuroethicists, but one might still ask whether there are benefits to leaving the door open to them. There are two reasons to think that it might be. First, by current accident of history, neurologists, psychiatrists, neuropsychologists, neurosurgeons, and similar clinicians currently find themselves wedged between traditional medical practice on one side and a rapid expansion in knowledge about brain function and pathology on the other. This positions them as *de facto* translators of neuroscience to the clinical world, even if this does not

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ics consultation method is “medical indications.” The descriptive facts of a case make certain ethical questions relevant and others less so. It may be crucial to know, for instance, whether and in what ways Dominic’s personality has changed since receiving the DBS, but even with such knowledge further normative questions remain. What do these changes mean for Dominic or his family? Are they good? What is the appropriate role of the clinician in persuading or intervening? Addressing *these* kinds of questions is well within the domain of clinical ethics.

There would seem good reasons to resist carving out a special place for clinical neuroethics. I have argued elsewhere that skepticism of clinical neuroethics, at least in its uncritical and overly ambitious forms, is warranted.<sup>17</sup> For one, filtering all clinical ethics problems *first* through a neurological lens can be distorting; to the proverbial

confer special ethical expertise. Calling some subset of these individuals “clinical neuroethicists” might have pragmatic value. The second reason to leave the door open is that it is not clear yet how developments in neuroscience may change the practice and organization of medicine. The future of medicine, for instance, might one day include a medical specialty specifically focused on how changes in brain structure and function influence patients’ values and preferences. One can imagine that specialists in such an area might develop, over time, not just technical expertise, but some limited degree of ethical expertise. Whether medicine would, or should, ever move in that direction is unclear, but if it did, reserving the term “clinical neuroethicist” could be useful.

Whether it is unnecessary or just premature to welcome the clinical neuroethicist is unclear. Cranford’s proposal for a new kind of clinical

ethicist—the neuroethicist—should garner no warmer a reception now, on the other side of the birth of neuroethics, than it did nearly three decades ago. For now, clinical ethics does not need a special class of brain-centric ethicists. That said, the neuroscience revolution is only just beginning, and its effects on the practice of medicine are only beginning to come into view. It may be wise to leave a seat open just in case.

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# *Impairments in Moral Decision Making due to Neurodegenerative Disease: Ethical and Practical Considerations for Clinicians*

Sam Horng, MD, PhD

## **INTRODUCTION**

Over the last two decades, the field of human social neuroscience has accelerated our understanding of the neuroanatomical substrates of decision making, particularly in domains of moral behavior.<sup>1-3</sup> Behavioral neurology, in turn, has advanced its characterization of specific decision-making impairments in various neurodegenerative diseases.<sup>4,5</sup> These conditions provide the opportunity to learn how a loss of function or dysregulation of previously normal pathways may influence many behaviors of moral significance. A rapidly aging population and the growing recognition of these cognitive impairments<sup>6</sup> require a practical and ethical framework for clinicians, including internists, geriatricians, neurologists, and psychiatrists.

In this paper, I provide a working framework for the clinician confronting impairments in moral decision making in patients with neurodegenerative disease. I will start by defining my terms and outlining the scope of my discussion. I will then discuss the bioethical principles at stake in scenarios of moral decision-making impairment and provide a broad but succinct review of the current data describing distinctive moral decision-making deficits in the most common and relevant forms of dementia: behavioral variant frontotemporal dementia (bvFTD), Alzheimer's disease (AD), Parkinson's disease (PD), and Huntington's disease (HD). Finally, I will proffer guidelines on ethical

considerations for clinicians caring for such patients, focusing on the following issues: education, detection and assessment, treatment and resource referral, and finally protection of others and prevention of harm.

I will restrict my use of the term *impaired moral decision making* to practical behaviors that potentially cause harm to others. These behaviors carry the widest consensus for moral concern and are the most pertinent in their outcomes to everyday interactions with clinicians, caregivers, loved ones, and strangers.<sup>2</sup> This restricted range of behaviors, nonetheless, involves a diversity and heterogeneity of neural pathways, differentially affected in different neurodegenerative conditions.<sup>7,4</sup> I will also limit my discussion to the effects of neurodegenerative disease, although impaired moral decision making, as defined above, is present in other psychiatric and neurodevelopmental disorders.

As our understanding of moral decision making continues to advance, this framework will guide clinicians in the context of a rapidly evolving field. Integrating basic discoveries on the cognitive mechanisms of moral decision making with clinical studies that demonstrate selective impairments in practical moral tasks should ideally result in compassionate and preventative strategies against harmful behaviors by patients, and is a dynamic and challenging frontier in neuroethics.<sup>8</sup>

## MORAL DECISION MAKING AND DEMENTIA: DEFINITIONS AND SCOPE

A biological basis for moral decision making has been argued by philosophers and supported empirically by cognitive neuroscientists, neurologists, and psychiatrists alike.<sup>9-15</sup> Within the clinical neurosciences, however, *morality* is defined as a collection of values that guide social behaviors, and it is assumed to be normative, or universal.<sup>16-18</sup> Neural networks are hypothesized to drive cognitive and affective strategies that promote various moral dispositions and manifest as practical prin-

strategic approach for the clinician in preventing these behaviors.

## RESPECT FOR AUTONOMY IN THE SETTING OF CHANGING VALUES AND BEHAVIORS

Much of the previous bioethics literature on neurodegenerative disease has focused on ethical conflicts related to decision making for medical treatments, participation in clinical research, and more recently, financial management risk, particularly when the perceived wishes of the demented patient appear to diverge from those expressed when previously healthy.<sup>33-38</sup> Ethical

*A biological basis for moral decision making has been argued by philosophers and supported empirically by cognitive neuroscientists, neurologists, and psychiatrists alike.*

ciples, including the avoidance of harm, fairness, community, authority, and purity.<sup>18</sup> From an evolutionary perspective, these pathways may have evolved to optimize parent-offspring bonds as well as the fitness of individuals living in communities and social hierarchies.<sup>19-21</sup>

Whatever the neuro-anatomical substrates of moral decision making might be, what we can say is that they do not represent a monolithic process. Multiple parallel and hierarchical neural networks engage in a variety of subprocesses that theoretically contribute to what we recognize as moral deliberation and behavior.<sup>22,23,13</sup> Conceptual aspects of moral decision making that are most heavily emphasized and investigated in the literature include emotional processing, empathy, and theory of mind (ToM), that is, the ability to understand and interpret another's beliefs, emotions, and behaviors.<sup>24-26</sup> Abnormalities in emotional processing, empathy, and ToM are most notably described in autism spectrum disorders, Williams syndrome, schizophrenia, and antisocial personality disorder.<sup>27-32</sup> Neurodegenerative diseases have well-defined neuro-anatomical substrates,<sup>5</sup> and generally seem to affect narrower and more specific aspects of moral decision making. Furthermore, they occur in individuals who previously exercised normal function, and subsequent loss of these faculties is incremental. Therefore, anticipatory planning is a

analysis in these contexts often grapples with the well-established bioethical principle of respect for autonomy.<sup>39-41,33,42,36</sup> In settings where loss of cognitive capabilities alters or degrades the ability to formulate values and pursue them without assistance, one must first determine whether there are values still espoused and, if so, whether to accord the patient the same decision-making autonomy as before.

Two different types of values were identified by Dworkin to inform whether someone possesses a "capacity for autonomy": the first are "experiential interests," which represent a state of mind, or how an experience feels; the second are "critical interests," which represent a more reflective and integrative set of values, and are deemed to be good in a more abstract sense, even if they sometimes provide for unpleasant experiences.<sup>39</sup>

Jaworska argues that demented patients with Alzheimer's disease often still possess critical interests, which may be identifiable in conversation or meaningful behavioral interactions during what she calls "the twilight of agency."<sup>33</sup> These residual interests, though likely to be limited or less complicated than those earlier in life, are still worthy of respect and facilitation, and may even demand precedence over those previously held.

Impairments in moral decision making raise additional ethical considerations regarding au-

tonomy. To what extent do changes in moral behaviors in dementia reflect changes in critical interests, or, more broadly, the personal identity of a patient? Interviews with family members of dementia patients reveal that changes in character traits associated with moral decision making, such as generosity, honesty, and loyalty, were more strongly associated with perceived changes in identity than changes in other features, such as curiosity, creativity, intelligence, and humor.<sup>43</sup>

As will be explored below, some degenerative conditions do seem to alter critical interests, such as in cases of apathy and loss of empathy noted in bvFTD.<sup>44,45</sup> In other conditions, such as PD treated with dopamine agonists, it seems more likely that the same critical interests persist, but that cognitive impairments in risk assessment and impulse control alter aspects of moral decision making, which may lead to harmful outcomes that undermine otherwise unchanged interests.<sup>46</sup>

Finally, what restrictions should be placed on the patient in moral consideration for potential victims? Range of harm may vary across a spectrum, from physical assault by an agitated AD patient, and petty theft in bvFTD, to homicidal ideation and planning in HD.<sup>47</sup> The specific clinical strategy employed is likely to depend on the specific neurodegenerative disorder and stage of disease, the deficit in moral decision making, and the individual patient. Though the approach would be highly case dependent, the psychiatric ethics literature offers guidance in negotiating the conflict between respect for autonomy, the right to privacy in healthcare, and the safety of potential victims.<sup>48-50</sup> Typically, protection of potential victims is prioritized over the patient's autonomy, though in accordance with the bioethical principle of nonmaleficence, preventative strategies protecting potential victims must also carefully consider potential harms to the patient.<sup>51,42,50</sup>

A retrospective medical record review revealed that 37% of bvFTD and 20% of HD patients developed a history of criminal behavior during their illness, while the rate for AD patients was much lower at 7.7%.<sup>52</sup> There currently exist no legal statutes requiring clinicians to monitor or report moral decision-making deficits in dementia to law enforcement agencies. Unlike the public safety hazard posed by potential automobile drivers with epilepsy, which has led to mandatory legal reporting requirements in a handful of states in the United States,<sup>53,54</sup> the causal relationship between impairments of moral decision making and criminal behavior are not known. As the ag-

ing population grows, and more empirical data become available on predictive factors for criminal behavior in these groups, developing consensus guidelines among behavioral neurologists for the elective reporting of a dementia patient's potentially harmful behavioral tendencies may be warranted to optimize public safety.

#### MORAL RESPONSIBILITY IN DEMENTIA

The potential for criminal behavior raises the broader question of whether patients with dementia should be held responsible for harms resulting from behavioral extensions of their disease. Debate continues among philosophers and cognitive neuroscientists on the existence, extent, and operation of free will, even in healthy individuals.<sup>55-60</sup> Since such arguments carry implications for moral responsibility in the context of both moral theory and criminal justice, and will not be addressed within the scope of the present discussion.

Nonetheless, for the clinician, it is helpful to consider the legal standards of criminal responsibility, which include three required conditions:

1. The act is deemed voluntary or intentional
2. The person possesses a mental state in which awareness of harm or of risk of harm is present, termed *mens rea*
3. The person demonstrates an "appreciation" that the "nature and quality" of the act is harmful, as used in the so-called "insanity" defense by the U.S. federal M'Naughton rule.<sup>61,62,60</sup>

Defining and ascribing these features to patients in a given situation is complex, case-dependent, and certainly beyond my scope here. Nevertheless, it is evident that this determination can and should be empirically driven to the best extent possible, though available data are often incomplete. Yaffe argues that cognitive neuroscientists and criminal psychologists must collaborate, moving forward, to design empirical studies that yield relevant data on these three conditions in relation to neurodegenerative disease.<sup>60</sup>

In so far as dementia represents a pathogenic process modulating decision-making pathways in a degenerative or progressive fashion, it may be practically assumed for the clinician's purposes that this process is beyond the patient's control. The acting patient, even if attempting to modulate aberrant decision-making pathways in line with pre-existing critical interests, likely exercises less control over these harmful acts. Therefore, a preventive (rather than punitive or remedial) strategy is likely to prove more clinically efficient

and compassionate in our attempts to minimize harm from these behaviors.

#### **EMPIRICAL DATA ON MORAL DECISION-MAKING IMPAIRMENTS IN DEMENTIA**

Case studies have described harmful behaviors arising during the course of various neurodegenerative diseases.<sup>47</sup> A growing body of studies has further characterized deficits in cognitive tasks of moral relevance, including those measuring emotion recognition, ToM, and impulsivity.<sup>7,46,63,64</sup> Deficits in the performance of established decision-making paradigms that have been designed to weigh unknown and known risks against monetary benefits have also been investigated, and these changes may contribute in additional ways to moral behavior.<sup>5</sup>

#### **Behavioral Variant Frontotemporal Dementia**

FTD encompasses a group of dementias that are defined by common pathologic features underlying temporal and frontal cortical degeneration.<sup>65,66</sup> Behavioral variant FTD leads, at its core phenotype, to the transgression of social norms.<sup>67</sup> Patients exhibit a seeming loss of empathy, insight, and impulse control, and criminal behaviors in this population may include theft, physical aggression, violence, public urination, and inappropriate sexual advances.<sup>68,69,52</sup> Early degeneration of the ventromedial prefrontal cortex (VMPFC) occurs and has been behaviorally correlated to emotionally absent and purely logical responses to moral dilemmas.<sup>70</sup> Deficits in ToM tasks, including first-order false belief and *faux pas* tests, are more frequently impaired in bvFTD compared to AD patients, and these impairments correlate to decreases in VMPFC volume.<sup>7</sup> Decreased empathy is associated with atrophy of the right orbitofrontal/ventrolateral (OFC/VL) cortex and anterior temporal areas.<sup>24</sup> Finally, bvFTD patients exhibit impairment in decision making under conditions of unknown risk, as assessed by the Iowa Gambling Task, a test in which subjects select cards of monetary value from four piles, two of which have predominantly low value cards.<sup>71</sup> This deficit does not correlate with ToM performance, suggesting that independent deficits occur in separate decision-making pathways.

#### **Alzheimer's Dementia**

Alzheimer's dementia is characterized by degeneration of the basal forebrain, causing decreased acetylcholinergic input into the lateral temporal, frontal, and parietal cortices, leading to progressive

deficits in memory, language, visuospatial skills, and executive functioning.<sup>72</sup> Early involvement of the medial temporal lobes, particularly the hippocampus and entorhinal cortex, mediates impairments in memory encoding. Deficits in social behavior stem largely from complications of memory loss, which include disorientation to place and to other persons, which may lead to agitation and possibly aggressive behaviors.<sup>46</sup> ToM and empathy are largely spared, particularly in comparison to bvFTD patients.<sup>7</sup> Deficits in the Iowa Gambling Task in AD reveal a lack of strategic thinking, without apparent increases in risky behavior consistent with the inability to learn or apply probabilities of risk to decision-making strategy.<sup>5</sup>

#### **Parkinson's Disease**

Idiopathic PD involves the degeneration of dopaminergic projections from the substantia nigra (midbrain) to the dorsal striatum (basal ganglia), causing motor abnormalities, such as tremor, rigidity, and bradykinesia.<sup>73</sup> Mesostriatal (dorsal) and mesolimbic (ventral) projections modulate activity in the dorsolateral and orbitofrontal prefrontal cortices, respectively; dopaminergic tone and bursts into this system are believed to mediate reward signaling for corresponding motor and cognitive tasks.<sup>74-76</sup> PD patients on dopamine agonists have been noted to exhibit pathologic gambling, hypersexuality, pathologic eating, compulsive shopping, and kleptomania.<sup>77</sup> An "overdose theory" proposes that exogenous dopamine agonist affects both the pathologic dorsal and intact ventral mesostriatal pathways, leading to overstimulation of cognitive/emotional decision-making pathways and potentially promoting novelty seeking and impulse dysregulated behaviors.<sup>78</sup> This process may also account for deficits in weighing gains and losses, set shifting, and decision making under unknown risk, as assessed with the Iowa Gambling Task.<sup>5</sup> Finally, emerging work has identified progressive deficits in ToM tasks in PD patients, particularly *faux pas* and emotional recognition tests.<sup>64</sup> The anatomical substrates of these deficits are unclear.

#### **Huntington's Disease**

Huntington's disease is caused by a CAG-repeat expansion mutation in the Huntington gene, which causes progressive medium spinal neuron degeneration in the striatum and manifests clinically by choreiform movement abnormalities, cognitive deficits, and psychiatric disturbances, most commonly depression, and changes in personality.<sup>79</sup> Neurodegeneration progresses in a stereotyped,

topographic manner, involving dorsal to ventral, anterior to posterior, and medial to lateral striatum, and thereby corresponding to sequential involvement of the dorsolateral to orbitofrontal cortices.<sup>80</sup> Studies demonstrate deficits of ToM, as well as facial and vocal emotion recognition in HD patients, particularly with negative emotions, including anger, disgust, and fear.<sup>63</sup> Deficits in the Iowa Gambling Task, accompanied by absence of autonomic skin conductance changes during losses, points to an aberrant negative feedback response.<sup>81</sup> HD patients have been reported to demonstrate violent outbursts, homicidal planning, and a schizophrenia-like psychosis has been reported in 6-25% of patients.<sup>82</sup>

In summary, neural circuits affecting moral behaviors in dementia include: frontal cortical areas affecting intuitive and emotional responses (right VMPFC) and empathy and perspective-taking (OFC/VL, anterior temporal cortex) in bvFTD; medial temporal, frontal; and parietal cortices subserving spatial and social memory and orientation in AD; ventral mesolimbic-cortical pathways mediating reward feedback and impulse control

independence, and resource referral. Additional considerations unique to moral decision-making impairments involve the protection of others and prevention of harm.

#### **Education**

Educating patients, families, and caregivers about the potential for harmful behaviors and the typical deficits associated with neurodegenerative disease can provide reassurance and, importantly, encourage preventive measures throughout the course of illness. From the patient's perspective, early education provides the opportunity to establish a healthcare proxy and express one's own preferred management of potential harmful behaviors. Explicit statements of current values and critical interests may be useful. For family and caregivers, recognizing that apparent changes in identity may be due to pathologically mediated deficits in particular tasks (such as emotional processing and perspective taking, visuospatial and social memory, or the assessment of risk) may demystify these behaviors and attenuate offense or harm. Environmental strategies to minimize the opportunity for such decision making can be pro-actively

### *The potential for criminal behavior raises the broader question of whether patients with dementia should be held responsible for harms resulting from behavioral extensions of their disease.*

in PD; and striatal-prefrontal cortical networks mediating emotional recognition and ToM in HD.

#### **A PRACTICAL FRAMEWORK FOR CLINICIANS**

Clinicians caring for a patient with neurodegenerative disease must anticipate that the patient is at risk for decision-making behaviors with the potential to cause harm to others, including family, caregivers, medical personnel, and strangers in the community. I propose the following framework to address the ethical responsibilities clinicians face in such cases. The first few features are adapted and extended from a framework provided by Marson in the management of financial capacity in dementia, as many of the same considerations apply, particularly with regard to autonomy.<sup>38</sup> These areas are education, detection and assessment of impairment, strategies to treat and support

explored, such as enforcing explicit social rules with bvFTD patients, providing orienting stimuli to AD patients, or avoiding risk-laden options for PD patients.

#### **Detection and Assessment**

The clinician may assist in the early detection of moral decision-making impairments with the use of screening questions focused on common behavioral deficits described in the different dementias. Early warning signs may include apathy, impulse dysregulation, agitation, and social withdrawal. An assessment of early behavioral markers may be helpful. While cognitive studies have identified certain early deficits, such as with the Iowa Gaming Task in PD or negative emotional recognition tasks in HD, clinical tools to sensitively identify specific moral decision making impairments in dementia

have not yet been standardized. Further research will help to identify and clinically validate more sensitive cognitive assessment tools. Professional consensus guidelines may be helpful in developing more effective and efficient screening algorithms for this purpose. Recognizing specific impairments, as discussed previously, can help tailor the approach, particularly with regard to protecting others and preventing harm.

### **Treating and Supporting Independence and Resource Referral**

Strategies to support independence while minimizing harm to others will be informed by the specific deficits at hand. These may include training caregivers in the social reinforcement of rules and expectations, simplifying the residential environment, restricting access to finances, and, in some carefully considered cases, pharmacologic treatment. These efforts will benefit from interdisciplinary collaborations among family, caretakers, and clinical specialists. Referral to a behavioral neurologist or geriatric psychiatrist may be useful for more complex diagnostic and pharmacologic management questions. Involvement of a lawyer or adult protective services may be warranted to establish conservatorship if the patient requires a proxy to prevent persistent behaviors endangering his or her own legal interests.

### **Protecting Others and Preventing Harm**

Finally, clinicians have an ethical stake in the protection of potential victims and the prevention of harmful behaviors. As noted above, informing caregivers and family of the potential for these behaviors heightens awareness, encourages the development of preventive strategies, and likely minimizes harm. In this context, there are no mandatory legal requirements to report the potential for harmful behaviors. In cases of high risk for such behavior, professional consensus guidelines to specify monitoring paradigms and conditions for elective reporting to the state would be helpful. Beyond the aforementioned strategies of social reinforcement, environmental alterations, financial restriction, and pharmacologic treatment, patients may additionally require supervisory measures and restricted access to places or certain individuals to protect those at risk for harm.

### **CONCLUSION**

The purpose of this paper was to review our present understanding of how neurodegenerative processes can lead to harmful behaviors, to

discuss the morally relevant implications of these behaviors, and to provide practical guidelines on the clinician's role and ethical obligations in this context. As we continue to learn more about the neural mechanisms contributing to moral decision making and the specific impairments caused by neurodegenerative diseases, clinicians will be faced with new opportunities to translate these insights into safer and more compassionate plans of care.

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## *Learning to Talk to Surrogates about Shifting to Comfort Measures Only in a Neurologically Devastated Patient*

Richard T. Benson, MD, PhD, and the Editorial Group of the John J. Lynch MD Center for Ethics

An 87-year-old woman, Ms. T, was helicoptered into your hospital's Neurologic Intensive Care Unit (NeuroICU) a week ago from a small community hospital in a rural part of the state. The patient has suffered a devastating left internal carotid artery territory infarction with hemorrhagic transformation, midline shift and herniation. The destruction is so severe that her clinical neurologic evaluation is negative for any cortical brain function, and she is not anticipated to recover neurologically. The patient's past medical history includes a coronary artery bypass surgery (CABG) six years ago with worsening congestive heart failure (CHF) in the last year, diabetes, and a chronic yet stable creatinine of 2.6. At baseline, the patient was reported to have moderate dementia but was still ambulatory with assistance at home, which has been provided by her eldest daughter and son-in-law.

On rounds during the last several mornings, after the necessary medical presentation, the attending physician has shifted the substance of the conversation to the "big picture." That is, this patient is now medically and hemodynamically stable, despite being intubated and off sedation. The family continues to insist that everything be done. However, none of the professionals want to trach and peg this patient, knowing that the facilities to which this patient could safely be discharged are only going to return her to the hospital in worse shape than she is now. The

family reluctantly agreed that the patient should not be resuscitated if she were to have a cardiac arrest and so a do-not-resuscitate order (DNR) has been entered into the patient's electronic medical record (EMR). This limitation to the potential use of "life-extending" technology was a significant negotiation in and of itself and only came after several days without any improvement in the patient's condition.

For the past day or two, however, as the team has begun working towards setting up another conversation about goals of care, the family has been saying that they see her getting better and want to give her more time. The medical team, meanwhile, does not see their patient getting any better; the team does not see her changed in any way from when she arrived. Some of the nurses and physicians have understood the discrepancy from a psychological perspective. That is, many of the medical team have been attributing the family's insistence that Ms. T is improving to a collectively sustained state of denial.

Denial is a powerful psychological concept, understood as a mental state that acts as a defense mechanism when an individual is faced with a set of facts so uncomfortable and anxiety provoking that he or she simply does not believe they can be true, even when there may be overwhelming evidence to the contrary. Here, the overwhelming evidence points to the irreversibility and gravity

of the brain insult. Nevertheless, family members are focused on reporting that she is squeezing their hands, moving her feet, and puckering her lips when they speak into her ear or kiss her on the cheek.

Because many on the team think the family is in denial, the nurses and residents have been trying to refute what the family is saying. Some team members have expressed that if the patient is moving or seeming to respond, these are simply residual, reflexive, neurological impulses; an explanation the family has found to be dismissive. Some of the team have even suggested to the daughter that Ms. T is suffering and that the family should be shifting to comfort care. These inconsistent and confusing comments have produced resistance in the family, who have only become more entrenched in their determined belief that Ms. T can get better.

Today on rounds there is a new attending physician. She is not only the new attending for the current week, but she is also the new unit chief, and so everyone who could attend rounds has done so. After a resident presents and reviews Ms. T's conditions and explains the problem of the

reasonable balance in her disposition, responded that physiologically the intern was not so far off. Although, clearly, using that sort of imagery with the family would be less than appropriate. This family is in crisis, and the team is going to have to be particularly careful not to say anything that could be considered insensitive.

"But," she says with another amused smile, "following that scientific line of thinking, 'who knows something about newborn rooting and grasp reflexes?'"

A resident who has recently had her first child speaks up, describing what these are. "The rooting reflex," she explains, "is a motor response triggered when the corner of the baby's mouth is touched. The baby puckers its lips and turns in the direction of the touch, which helps the baby begin feeding. This reflex disappears at about 4 months of age. As for the grasp reflex, this is when stroking the palm of a newborn causes the baby to close his or her fingers in a grasp. This reflex disappears at about 5 to 6 months of age."

The chief picks up the discussion, posing to the group that this patient may well be displaying these type of reflexes, which can appear after a

*Some team members have expressed that if the patient is moving or seeming to respond, these are simply residual, reflexive, neurological impulses; an explanation the family has found to be dismissive.*

family's unrealistic demands in terms of denial, the new chief asks why the team members think this to be the case. Another resident responds that during his examinations he has not seen a change since the patient arrived. She will occasionally move her foot or open one eye, but she is essentially unchanged since she's been in the unit. The patient's nurse says that the family has become increasingly distrustful and refuses to listen to anyone who doesn't understand these to be signs of improvement.

One of the interns contributes that he grew up on a farm and the situation reminds him of a chicken with its head cut off. Although his intention was to point to a comparable neurological phenomenon in a different organism, the comment garnered a few laughs. The chief, striking a

stroke. Rather than being in what we might assume is a state of denial, the family may genuinely perceive these reflexes as meaningful behavior. The chief also notes for the record that when the nurses and physicians tell the family, "it's just reflexes," the family feels they have been disrespected. Without explaining or taking the time to educate them about what reflexes they may be eliciting from the patient, it's easy to see why the family might feel that their concerns are being ignored or devalued.

The chief lets the implications of this information sink in. A few seconds into the silence, one of the medical students ventures, "So we're sort of wrong here, right? We're attributing what the family is saying to denial, a psychological defense mechanism, when they really may be seeing physical movement in the form of regressive primitive

reflexes. A layperson might reasonably interpret these reflexes as meaningful behavior, and thus a sign of improvement.” The chief agreed, and went on to say she understands why everyone is so distressed at the notion of traching and pegging this patient. “Instead,” the chief went on, “it seems rather selfish to do things to Ms. T that will not make her better and that likely will leave her in a state where she will ultimately die of sepsis from wounds related to anticipatable skin breakdown.” To most clinicians, simply extending this patient’s

sustain persons close to death and/or stable, but in a coma or persistent vegetative state (VS) in nursing facilities for indeterminate periods of time. Because the necessary resources in the U.S. exist to do so, for persons who can be made stable to discharge, it is a family decision. That is, on the ethical basis that those closest to the patient can best speak on behalf of the patient as to what kind of life would be worth living, physicians are no longer, ethically, the arbiters of a patient death if that patient can be made stable to discharge.

*To most clinicians, simply extending this patient’s dying process is inconsistent with the pursuit of virtuous medicine or nursing.*

dying process is inconsistent with the pursuit of virtuous medicine or nursing.

The chief took a couple more minutes, however, to sharpen the conceptual understanding of the house staff’s knowledge of end-of-life care planning. She began by correcting an inaccuracy that had been brought up previously; this patient likely was not suffering. Because the neurology team believed that the patient had no cortical function, she could not be having the conscious experience of suffering. Then the chief explained the ethical difference between a patient who is actively dying and one who is well along on his or her death trajectory but stable enough to discharge. If a patient in a NeuroICU is so unstable that he or she cannot be discharged from the unit, it is likely that the patient is actively dying. If the patient is in fact actively dying, it is ordinarily ethically appropriate for physicians to start limiting life-extending interventions as each is evaluated to no longer be indicated; a medical intervention being indicated when it provides meaningful clinical benefit such as increased function and/or comfort. Deciding what intervention is medically indicated, after taking a family’s or other surrogate’s express preferences into account to the greatest degree medically reasonable, remains a medical decision.

If the patient can be made stable enough to discharge, however, unlike many other countries around the world, in the United States we have not come to consensus about whether we should

Almost dead but stable is not synonymous with actively, imminently dying. Nonetheless, physicians are responsible for making strong recommendations about what they think is in the best interest of their patients. If they do not think a respirator is a good recommendation, they should not make it. Nevertheless, they do have to describe it as an alternative to comfort care, not a treatment, nor something from which the patient is likely to recover. If they think it not to be a better alternative, if they can communicate the facts to the surrogate(s) in a way that the surrogate(s) find their marshalling of the facts compelling, that is perfectly fair. That is, in fact, their job; to marshal the facts in an honest and nonmanipulative way that speaks to what’s medically indicated and what isn’t and why.

Finally, the chief indicated that the group needed to move on to the next patient, but first asked the social worker to set up a family meeting for 3 PM that afternoon and invited as many of the house staff as was available. She also asked that the fellow, whom she expected to be at the family meeting, to have one of the neurologists be available to attend and to come 15 minutes early for the pre-family meeting.

**PRE-FAMILY MEETING (2:45 PM)**

**Chief:** Thank you for coming.

**Fellow:** You’re welcome. Dr. Smith, our attending asked me to extend his apologies but he

had to be out of the hospital today.

**Chief:** That's ok. I assume you've familiarized yourself with the case?

**Fellow:** Yes, I have.

**Chief:** Good, because I want us all to be able to provide the family the same message if that's possible. If not, I want to know where the differences of opinion or uncertainties are so we can address them, transparently. Before the meeting begins, I'm going to quickly go over where I think we are, and where I think we should be going.

Fortunately, the neuro ICU team and the neurosurgical team both agree that this patient is not expected to recover any clinically meaningful function and that the neurological devastation is pervasive, leaving only her brain stem intact. They agree to load the MRI (magnetic resonance imaging) pictures of the patient's brain next to a healthy brain. They will have the CT (computer tomography) scans of the patient to show the technological difference between CT and MRI depictions, just in case the conversation calls for it.

The chief indicates that she will lead and facilitate the meeting, and said she wanted the patient's fellow, residents, intern, and medical student present in the room. In addition, that she would like the patient's bedside and resource nurse present, if possible.

### **FAMILY MEETING (3 PM)**

The chief and all the relevant team members, as preplanned, were already in the room when the social worker and patient's nurse brought the family. The chief and the physicians stood when the family came in and stayed standing until the family was settled in their chairs. As soon as all were seated, the chief took gentle control of the meeting:

**Chief:** Hello to everyone. Before we get started on introductions, I just want to say how sorry we are that Ms. T is not doing well. We know how hard this has been on all of you. The purpose of this meeting is to review the main issues that have brought us here and to move forward with decisions regarding our next steps in her care. So now, let's go around the room and introduce ourselves. Each of you, please, give us your name and how you are related to Ms. T. . . .

With introductions finished, the chief turns to the family.

**Chief:** Before we give you an update on how we see Ms. T doing and hear from you about your questions and concerns, I just want to say, on behalf of the team, that we are concerned about making as certain as we can that we are all focused, together, on figuring out what the next best steps are for your mother/sister/aunt. OK. I'd like to stop talking now and hear from you.

**Daughter:** We think she is getting better. When we squeeze her hand, she grasps it. When we kiss her or stroke her face, she tries to kiss us. We know you and the rest of the doctors and nurses don't believe us. But we see it. We know you just want us to stop everything. But we don't want to; we want her to have more time. We want you to keep doing everything.

**Chief:** I'm very sorry if we have given you the impression that we don't believe you. I've just come on service, so I'm not sure what has been previously communicated, but this morning on rounds we were discussing together how you very well might be seeing the behaviors you have described. I believe you and I am confident that the team does, as well. We want you to know that we, too, want to do everything for Ms. T that is going to help her.

With that, there is again a pause, but this time the chief picks up the conversation before anyone else can step in.

**Chief:** So now we want to go on and talk about what has brought us to this point. As I understand what happened, and please correct me if I have anything wrong, Ms. T was at home with you and you saw her slump over in her chair. You called 911. When the ambulance arrived, they intubated her in your home and then transported her to your local hospital. From there, she was transported here by helicopter. Do I have the story correct so far?

Some of the family members don't move, but the ones who had been in the house give the chief restrained, but positive, body language.

**Chief:** We understand that you want us to give her more time before we have to have the conversation about whether we're going to surgically place a different kind of breathing machine in her trachea and a tube to artificially feed and hydrate Ms. T, or if we're going to shift our plan of care to only those interventions that

provide her comfort. Therefore, we are going to give her more time. We want to give her time to show us more of what you are seeing, and for us to help you appreciate all the things that we don't think she will ever be able to do again. I am so sorry to have to focus us on these problems, but for us all, together, to make the best decisions for Ms. T, it's important that we are all on the same page as much as we can be. So what I really want to focus on today, related to Ms. T's medical condition, is how her brain is doing and what other organs may be sick as well. Brian, our fellow, is loading an MRI picture, a magnetic resonance imaging scan, of Ms. T's brain.

As you can see from these images, her brain is bright and pushed to one side by this dark material. The bright area is the brain tissue permanently damaged by the stroke. The dark area is the blood pushing her brain to the other side. The pressure from the blood and swelling have damaged other areas of her brain. This is not a picture we like to see. Now, look at this MRI from a healthy brain. . . . As you can see, there is a big difference between the two. Unfortunately, Ms. T had such a devastating stroke that the areas of her brain that are responsible for her ability to speak, understand, see, think, or communicate her emotions, feelings, and thoughts with the outside world have all been irreversibly damaged."

**Sister:** But this can't be the only picture you have of her brain. I think she might be getting better; that her brain is recovering. We see her trying to move and squeezing our hand.

**Chief:** You are absolutely right. We have many pictures of Ms. T's brain. Brian, please leave the most recent MRI up where it is and show us the first MRI we did the morning after she arrived. As you can see, the pictures look exactly alike.

We also have other kinds of pictures. Like most hospitals, we have CT scans, which are computed tomography scans. Brian, can you please bring up the most recent CT scan and the first CT that was taken? You can see that these scans are quite different from the MRI scans. The CT scans are a completely different kind of picture. But the pictures of her brain on these CT scans, too, show terrible brain devastation. In a patient whose brain is so damaged as to be irreversibly impaired, before making the kind of decision that we are facing with

Ms. T, we like to compare all of these images to be as certain as medicine can be that things are not going to get better.

The Fellow then loads side-to-side pictures of Ms. T's MRI next to the MRI of a healthy brain.

**Chief:** Which brings us to where we need to be today. I want all of you to join with us as we work to agree on what is and is not what we term "meaningful" movement. The rest of the team and I know that for you any movement can be considered meaningful, because your hopes are for her improvement. However, what we mean when we say "meaningful" is a behavior that is generated consciously. The question is whether Ms. T is acting in response to external stimuli of which she is consciously aware in a way that demonstrates her brain is processing information and working well enough for her to willfully respond. Please be assured that just like you, her improvement is our hope as well. We always want to give our patients the best shot they have at turning that corner that will tell us there is a possibility that they might improve, and that's what we're going to do with Ms. T over the next two days.

For the next two days, I want you to try to elicit the behaviors you are telling us you see. Every time you see a behavior that you believe is willful, call one of the nurses or doctors so they can document what you say you saw. Then, with them there, I want you to do whatever you had just done and see if you can get Ms. T to produce the behavior again. In addition, please, let's all make sure the clinicians document everything.

I know that you've told us already you have seen Ms. T do things that appear meaningful. I understand that you have been upset by hearing various clinicians tell you that these are likely reflexive. It's very important that we all know the difference, you and us, and that we can document these movements so we can decide what's what. Earlier today, and toward this end, we were talking about the kinds of reflexes that can appear in a patient whose brain has been as severely damaged as Ms. T's. Dr. Johnson, our intern, explained it perfectly on rounds this morning, so Sandra, will you repeat the information you provided everyone this morning, please?

**Intern:** When babies are born and their palms are touched, they are likely to grip



your finger. That's called a grasp reflex. When stroked or kissed near the corners of their mouth or even when a breath of air is felt in the corner of a baby's mouth, the baby will turn toward the touch or the feel. This is called the "rooting" reflex. This reflex helps the baby find the nipple and begin feeding. Infants demonstrate such reflexes until they are about 4 to 6 months of age. As the central nervous system continues to develop, other mechanisms take over and this particular reflex fades away or is 'overridden' by conscious decision making in relation to the stimuli. In short, the person begins to "decide whether to grasp or turn their head, and so on.

**Chief:** It is not uncommon for patients with the kind of brain damage that Ms. T has suffered, but who have been left with the part of the brain that remains involved in reflexive or autonomic body functions like digesting the food Ms. T is getting through the tube in her nose, to show reflexes that had been lost since her brain developed in infancy. Therefore, we're afraid that the behaviors you are seeing, as opposed to signaling an improvement, may be a sign that her brain is getting worse. Its activity may be mainly these primitive, reflexive functions rather than the kinds of willful acts we would need to see that would tell us that her overall brain function is improving. We have not seen any of those movements at all, but we would love to see them. Let's take the next two days to look for them together. Let's come back together 2 days from now at the same time, which will be this Thursday at 3 PM. We'll talk about how the two days have gone. We'll come back prepared to make a decision about whether we put the new breathing machine in her throat and the feeding tube in her stomach, a process that sets her up for dying of infection, often from the development of bed sores, given we know the artificial nutrition is never good enough to prevent skin breakdown. Or, whether we are going to make the hard decision to allow her to die comfortably here, in our hands.

If that were to happen, you can be certain that she will be comfortable throughout the process. You can be here with her, or if that's too hard, you can say your good-byes and we will let you know just as soon as she dies. Some family members often want to stay, others don't. There isn't one right way; the question of how you would want to say

your good-byes is whatever is right for you. In addition, I encourage you, over these next couple of days, to tell anyone you think should come in to do so and say their own good-byes, just in case things quickly destabilize. She's "stable" now, but this is also the kind of term that doesn't have the same meaning in the ICU that it does in everyday conversation. Ms. T is stable in the context of being critically ill. Things can change at any time. But we'll think good thoughts, and see where we are on Thursday.

The chief looks around the room and asks if anyone on the hospital team has anything to add. She then turns back to the family.

**Chief:** Now, before we close this meeting, do any of you have anything you would like to ask or say?

A pause is allowed to go on until family members start turning toward each other and shifting around in their seats.

**Chief:** Ok. If not, perhaps you all would like to sit in here and talk together without us. I know this has been a lot to go over today. Feel free to stay in here as long as you'd like.

Thank you for having organized your schedules to come in this afternoon on short notice. I hope the next two days go smoothly.

In this kind of family meeting, one in which everyone from the hospital was focused and present, the chief was able to build trust and rapport and even apologized for any additional anxiety that had been created by the differences in opinion between the team and the family. This helped diffuse the family's hostility and resistance. The chief then demonstrated by way of the relevant technology what has led the medical team to their present assessment. This allowed the team to convey important information about Ms. T's condition in a way that was clear and could be understood significantly better than from the fragmented and sometimes confusing remarks of several busy clinicians.

Making clear the goal of the meeting slowed down a process that was going too fast for the family. Well-trained clinical bioethicists often call this pressing the "pause" button. Rather than being pressured by yet another group of people, many of whom are just a stream of constantly

changing faces, the chief took responsibility for the team and set concrete goals to be achieved in a specific amount of time by having the family and the clinicians act as true partners without asking them to make any life or death decisions. The chief emphasized how critical the circumstances were by telling the family to bring in others to say their good-byes, and reminded the family members that they need not be present if it's simply too much to handle. Finally, the chief showed respectfulness by acknowledging that the family members, too, have busy schedules, and will hold off on discussing hospice or moving Ms. T to the hospital floor for whatever time necessary after being taken off her vent.

During Thursday's meeting, the daughter tells the chief that they have come to a decision as a family and don't believe their mom/sister/aunt would want to be kept alive on machines. The chief assures the family that the medical team supports their decision. The next day the vent is removed and all interventions are shifted to comfort measures only. After about 4 hours without a ventilator, Ms. T is transferred to a private room where she dies two days later with her family surrounding her.

#### Author

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## CASE 1

# Traumatic Brain Injury and Behavior: Understanding the Personal Affront as Not Personal

The Editorial Group of the John J. Lynch MD Center for Ethics

Complexity: 1 2 3 4

## PRESENTATION

*Mrs. J is a 72-year-old woman who was admitted after having a massive stroke. Her husband saw her collapse from the kitchen window as she was gardening. He called 911 as he ran to help her. He reported “pushing on her chest” until the ambulance arrived and the emergency medical technicians (EMTs) took over. The EMTs regained a pulse while on route to the hospital. Mrs. J has no relevant history of stroke nor is it a prevalent occurrence within her extended family. However, for quite some time she has been taking large doses of nonprescription anti-inflammatory medications to help manage her migraine headaches.*

Once in the Emergency Department (ED), Mrs. J was intubated, stabilized, and a noncontrast computed tomography scan (CT) was performed, that revealed a severe hemorrhage centered in the ventromedial prefrontal cortex (VMPFC). Soon after, she was transferred to the Neurologic Intensive Care Unit (NeuroICU). For the first few days, the patient wasn't waking up. However, by the end of the first week, she was beginning to be alert to her husband calling her name. At this time, Mrs. J has been here for three weeks and is now doing remarkably well. She passed her swallowing test, has been following commands, and was successfully extubated two days ago.

Communication with Mrs. J has been fragmented and frustrating. As is often the case with

stroke patients, Mrs. J has experienced problems regaining her ability to speak clearly. She often nods her head seemingly appropriately when asked even fairly complex questions, but is neither able to cognitively find nor articulate the appropriate words. What seems to be even more disturbing to the patient's husband and adult children is that, intermittently, she seems to not want to see them. Although often she is smiling and appears genuinely glad to see others, she can suddenly turn quite hostile to having anyone near her bed or reaching out to touch her. Further, she seems not to be concerned for the welfare of others when attempting to push away those who come near her.

Her husband and adult children have expressed that this is not who their wife and mother

was. They describe her as someone who is kind and conscientious, and whom happily devoted her life to her family and home. Their stories of her paint a picture of a consistently gentle and reasoned woman who enjoyed a relatively private family life but who was always alert to the well-being of others. Her children are struggling to comprehend her behavior without the feeling that something is terribly and maybe permanently wrong with their mother. Mrs. J's husband is at a loss as to how to deal with her and becomes emotional each time his wife of 40 years lashes out

neurologic recovery in terms of capability, to no recovery in relation to the person Mrs. J was known to be. He calls a bioethics consult so he can discuss the ethical implications of the case with someone in the hospital who is likely to be more interested than his neurology colleagues.

#### ETHICAL ISSUES

If Dr. Smithe is right about Mrs. J's clinical picture, then what his partners are attributing to passing secondary symptomatology may be an irreversible neurological problem for Mrs. J, her family, and her

### *Damage to the region of Mrs. J's brain in which the vascular accident occurred has been traditionally associated with permanent changes in relational attitudes and executive functioning.*

uncharacteristically and unexpectedly towards him. The nursing staff is becoming increasingly distressed at their inability to provide what they consider appropriate care, and the assigned social worker is getting nervous because the patient's increasingly hostile behavior may have negative implications for her rehabilitation placement.

Despite Mrs. J's family's consistently describing her as a mild-mannered person who always demonstrated a cooperative attitude in her relationships, including those with physicians, most of the neurologists in the group simply believe that her behavior is due to the frustration generated by her present cognitive difficulty, and her hostile disposition therefore likely a temporary symptom of an altered mental status resulting from the hemorrhage. However, there is one among the neurology group, Dr. Smithe, who is not so sure. He notes that although the tissue damage was not caused by the penetration of an external object as was famously the case with Phineas Gage,<sup>1</sup> nevertheless, damage to the region of Mrs. J's brain in which the vascular accident occurred has been traditionally associated with permanent changes in relational attitudes and executive functioning.<sup>2</sup> Dr. Smithe's concern is that brain injuries of this sort have resulted in permanent changes to what we understand to be the *person*, in which case the nature of conversation to be had with Mrs. J's family changes from one about slow, rehab-dependent

caregivers. If that is the case, the degree to which individuals and medical interventions are forced on the patient will have to do with whether the patient ever regains decision-making capacity. If she does not, a host of protections falls from that, such as being clear that Mrs. J's husband continues to be her medical decision maker. If, for example, her husband were to die suddenly, who among his children would take over? If Mrs. J has alienated either her husband or any of her children, that may have implications for who might be the best surrogate for the patient. If, however, the patient does regain her medical decision-making capacity but continues to be hostile and off-putting to her husband, other family members, and caregivers, should she be allowed to make decisions that may not be in her *medical* best interest if her decisions are knowing, understanding, appreciating, consistent and voluntary, albeit uncaring and indifferent?

Concerning placement, where would be a safe place for the patient to go for rehabilitation if her behavior is uncaring and hostile to others as to render their care ineffective, substandard, and dangerous to them? If no rehab facility will take her, can she be safely taken home?

What if the patient recovers her motor capacities, becomes ambulatory, and perhaps is even able to manage the activities of daily living (ADLs) and recovers enough speech function to clearly demonstrate to Dr. Smithe's partners that the behav-

iors is not some fleeting reaction to her previous incapacities, but likely represents an irreversible change? If this becomes the patient's and family's reality, the relevant ethical question becomes how to best assist the new Mrs. J to live a rich and fulfilling life while managing her behaviors so they pose the least threat to herself and the quality of the relationships with and the physical safety of those around her.

### RECOMMENDATIONS

1. While Mrs. J remains in the hospital, have the patient's psychiatrist meet regularly with the husband and other family members to help them understand that her behavior is not a personal affront, although it may feel that way. Explaining why this is the case from a neurological perspective could help the family understand and prevent the patient's unwelcoming behavior from causing anger and hostility for her family and caregivers.
2. Assist the staff in caring for this patient by conducting regular moral distress debriefings.

### REASONING

Today, the literature on attempting to identify possible neurobiological correlates to morally relevant behaviors is vast.<sup>3-7</sup> Clinically, Mrs. J is in many ways no different from any other patient, insofar as it is incumbent on the physician and other clinicians to keep up with scientific literature relevant to their fields, so they may work toward practicing evidence-based medicine. The difference here is that associated claims, in light of many neuroscientific findings, often involve a challenge to our sense of moral agency. Whatever such findings may suggest about the microphysical causes of morally significant behavior pushes each of us—clinicians and family members—to evaluate what are often lifelong assumptions about the causes of our own behavior.

The ethical challenge to deeply held assumptions about human behavior and moral decision-making in the clinical setting involves developing an ability to look at the stroke patient who starts acting “strangely” (ie, out of character for the *person* previously known by family and friends) and consider the possibility that such abrupt behavioral changes are the psychological symptoms of the brain injury. At the very least, helping the patient's husband, other family members, as well as the medical staff, to not take such manifestations personally will be an important part of gradually incorporating what we may, one day, be more fully

able to appreciate about the behavioral effects of certain neurologic injuries.

### QUESTIONS FOR DISCUSSION

1. As the lead clinical ethicist on the case, how do you address the different long-term assessments across the various neurologists? Does this difference of opinion make any difference in how the patient and family receive care while in the hospital?
2. How would you provide the support suggested by these recommendations if you are at a hospital without the psychiatric resources assumed in this case?
3. In the “Reasoning” section we write that, “The difference here is that associated claims in light of many neuroscientific findings often involve a challenge to our sense of moral agency.” Do you think this is true? Why?

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## CASE 2

# Deep Brain Stimulation and Chronic Parasuicidal Depression: Neurologic Research and Clinical Care

The Editorial Group of the John J. Lynch MD Center for Ethics

Complexity: 1 2 3 4

## PRESENTATION

*Ms. P is a 37-year-old female in the hospital's surgical intensive care unit (SICU), s/p (status post) surgical repair of several broken bones resulting from being struck by a bus during a suicide attempt. She is ventilated and sedated but able to follow commands. Her kidneys are intact and she is producing urine. She is breathing over the vent and has a gag reflex. The team is planning to attempt extubating within the next 48 hours.*

Ms. P's community social worker, whose contact information was found on the patient at the scene of the accident, informs the team that the patient has a long psychiatric history. Reportedly, Ms. P was a happy, healthy child until she fell off her bicycle and hit her head at the age of 14. The patient's mother states that Ms. P knocked herself unconscious but not for very long. By the time the ambulance arrived at the hospital, she had regained consciousness and seemed fine. However, within a few months, Ms. P seemed to become increasingly unhappy. Her performance as a student, as well as her social life, began to suffer. During this time, her parents simply attributed the behavior to the hormonal and social changes that typically accompany puberty and adolescence. Ms. P's depression seemed to worsen, however, at which point her pediatrician suggested a prescription for antidepressants.

Ms. P's depression seemed to improve, but according to the patient's history, during this period is when the suicide attempts began. The first few manifestations of her suicidal ideation began as merely parasuicidal gestures. Since then, the patient has made many such gestures, but has also begun to make serious suicide attempts. To date, Ms. P has committed seven suicide attempts, or parasuicides, several of which have come very close to killing her and have left her with damaged organs, fractured bones, unilateral blindness, and impaired hearing. Today, at 37, Ms. P has trouble walking and has received numerous surgeries to address what damage has occurred. Her condition is the result of several attempts to be hit by oncoming vehicle traffic or to step off cliffs while hiking in the mountains.

Ms. P has undergone years of inconsistent and unsuccessful electroconvulsive therapy (ECT).

Also present is a measurable decline in cognitive function related to higher order decision making post parasuicidal events. This will occasionally result in obvious but temporary decisional impairment. In most cases, Ms. P has regained sufficient capacity once the acute event and its sequelae (eg ventilator support) are over. She, nevertheless, depends on her social worker to navigate through the complexities of the healthcare system.

For this reason, although Ms. P has a court-appointed community social worker, she has never had a guardian.<sup>1</sup> Her mother cares about her greatly and talks with her often, but is said by the clinical team to be clearly suffering from caretaker fatigue. This, and the fact that she resides in another state, have contributed to her inability to continue to be a part of her daughter's daily life. Ms. P receives Social Security disability payments, which she manages with the help of her social worker. Her attempts at completing an academic career have been marginally successful, but she has had difficulty retaining a job.

Ms. P has been intermittently institutionalized, treated with every indicated neuropharmacological and/or psychotherapeutic intervention since her first antidepressant prescription. None of these interventions has proven to assist Ms. P's chronic parasuicidal depression. Now, with the SICU team moving toward extubation, the neuro intensivist on the team suggests deep brain stimulation (DBS). The technology has not been approved by the U.S. Food and Drug Administration (FDA) to treat Ms. P's psychiatric condition, but has shown promise in studies for severe, chronic depression. The team knows that it is, however, FDA-approved and widely used in Parkinson's Disease. The SICU team is unsure about making this recommendation given that the use of such a technology to attempt to treat major depressive disorders is merely in the trial stage. The attending intensivist requests that a bioethicist join the conversation.

#### ETHICAL ISSUES

DBS has been approved by the FDA to treat neurological symptoms associated with Parkinson's disease, as well as behavioral issues associated with a psychological diagnosis of obsessive-compulsive disorder (OCD). Clinical trials are just now producing data for a proper evaluation of its use in depression.

Does Ms. P's depression/suicidality make her chronically incapable of such a decision and / or is her neurological condition of the kind that would respond to DBS in the way intended? Al-

though her decision-making capacity (DMC) has not been an issue in the past, before researchers are even contacted, this needs to be assessed. Whether DBS trials are clinically appropriate, or if she is not a candidate because her "depression" is caused by a structural injury to the brain and thus will likely not respond to electrochemical treatments intended to work on intact neurology, is an assessment the research team needs to make. That is, evaluating depression, as a psychological disorder, does not point us to a specific, micro-physical (neurological) cause in every case. For example, often-depressed persons will respond in some way to serotonin-based treatments, but Ms. P did not demonstrate any improvements when antidepressants were attempted. If DBS for depression is appropriate for clinical trials in light of the electrochemical reaction that occurs from its physiological introduction, and the depressive behavior is somehow linked to her accident at the age of 14, then it may be reasonable to suspect (as the general consensus amongst her careproviders has been) that the cause in this case is associated with a change in neurological structure having possibly resulted from the injury, and not chemically caused, in which case DBS may be of no benefit at all.

Thinking about assisting Ms. P to apply for study eligibility raises additional ethical questions. These include:

1. Ought the SICU team assist this patient in getting into a DBS trial in the area?
2. What is the SICU team's scope of responsibility related to assisting a patient in seeking eligibility screening (eg potential problems in assuring that Ms. P consistently participates, as opposed to repeating the fragmented commitment of her previously attempted programs of care, such as with ECT)?
3. Is Ms. P fully aware of the nature of any potential participation in DBS trials as purely that of a neurological *research subject* and not of a patient receiving prescribed treatment?
4. Is DBS appropriate, even in a clinical trial setting, for someone in Ms. P's *neurological* condition?
5. If considered fully decisionally capacitated, what about assisting Ms. P in a successful suicide?

Presently, there is no tension amongst values that have been espoused in relation to the patient's care plan. Ms. P is improving and is expected to be removed from the ventilator and to begin communicating, at which point she will be assigned a

sitter by hospital policy. Moreover, her suicidality will be frequently assessed. If she is not immediately suicidal, and she no longer requires intensive care, she will be moved to the floor (out of intensive care), and will continue to be monitored (many hospitals implement policies that require any patient who has been deemed suicidal during admission to be assigned a sitter throughout his or her stay, to both protect the patient's safety and limit the hospital's liability). If Ms. P *does* appear immediately suicidal and meets certain evaluative

1. The patient's team should do enough research to find relevant studies in DBS in depression to provide the patient and her community social worker prior to discharge.
2. If the patient seems at all interested, a physician on the SICU team should take enough time to explain to her the basic differences between neurological research and clinical care.

#### REASONING

In the face of Ms. P's certain death by suicide at some point in the future, the clinical team natu-

*When the situation is as dire as it is for this patient,  
the risk/benefit analysis is obvious.*

criteria, she will either be admitted on a voluntary or involuntary basis to a neighboring hospital's psychiatric unit, and won't be discharged until her care team believes she is able to function on her own as well as she did prior to her most recent parasuicide. (She could not stay at the hospital where she is now and be involuntarily committed; there are jurisdictional rules against it. Also, conflicts of interest could easily arise). However, nobody is sanguine; she is bound to try again.

#### RECOMMENDATIONS

Clinicians are more likely to know about research on the developing use of DBS technology than patients are. Since there is no reason to suspect that Ms. P will not regain her decisional capacity, once she does, informing her of existing DBS trials, whether one expects a direct potential benefit or not, is not only ethically permissible, but ethically optimal. When the situation is as dire as it is for this patient, the risk/benefit analysis is obvious. Communicating to Ms. P about neuroscientific research trials seeking subjects is nothing but giving a capacitated, self-determining patient important and relevant information that she can put to good use, regardless of her subsequent decision.

With the need for continued intervention for a mentally ill patient post-discharge, when it comes to a kind of neuroscientific research being the only medical intervention not yet tried, an evenhanded approach to both provision of research information and encouragement of acting on that research information is ethically appropriate.

rally feels concerned about discharging her. This patient is in a perilous condition and likely to die by way of her psychological disease if some beneficial intervention is not found. Although her future suicidality is not the direct responsibility of the SICU team, even with the input of the psychiatry department, the prospect of having their patient heal from her somatic injuries, be psychopharmacologically treated sufficiently to regain capacity, be discharged, and then succeed at killing herself the next time, makes everyone on the team deeply disturbed.

So the reasoning here, like much ethical decision making in medicine, is one of weighing risks and benefits. When a patient is being discharged from a hospital and there is a variety of FDA-approved interventions still to try, there is no need to contemplate whether physicians in the clinical setting ought to be reaching into the research world for assistance. In the case of Ms. P, there is nothing left in the clinical medicine world she has not tried and has found wanting. Because of the potential lethality of her parasuicidal events, the situation calls for thinking outside the normal boundaries of what might be expected of physicians in the clinical setting for coming up with something beyond the hospital's walls that might help this patient.

DBS, like many neuroscientific technologies, is coming into frequent use in the clinical setting. Today the beneficial outcomes for Parkinson's patients of DBS is well established.<sup>2,3</sup> There are a variety of neuromodulatory techniques on the horizon.<sup>4-6</sup> Already DBS is FDA-approved for OCD,



although the use of DBS in depression is still medically and ethically controversial, with use mostly restricted to the research setting.<sup>7-10</sup>

Therefore, as long as the physicians in this case are evenhanded in their presentation of the possibility of entering a neuroscientific clinical trial in DBS and depression, this seems in many ways no different from physicians with no other interventions to offer any other dying patient. Given this patient's history, it is quite likely that, if left untreated, she could be dead of her suicidality in 6 to 12 months. The desperation one feels points towards a risk/benefit analysis for DBS in a patient that is tipped in favor of her trying the neurotechnology, even as a research subject. If it is available, even if merely in the research setting, it seems worthwhile not only to provide the information, but also to encourage the patient to consider it.

#### QUESTIONS FOR DISCUSSION

1. How far ought the care provided by the treating team extend in response to the patient's likely future suicidality?
2. In what ways ought the provision of research information differ, if at all, from provision of information about alternative treatments that are already FDA-approved and in well-established use?
3. Given that this patient's decision-making capacity is frequently in question, what levels of guardianship might be best recommended for this particular patient?
4. How ought an ethicist to approach, if at all, matters related to the *clinical* appropriateness of a research trial, when she/he notices an important distinction in relation to the patient's eligibility and about which the medical team appears unaware?

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### CASE 3

# Hypersexuality and Neuropharmacology: Kluver-Bucy Syndrome

The Editorial Group of the John J. Lynch MD Center for Ethics

Complexity: 1 2 3 4

## PRESENTATION

*The patient, Mr. B, is a 46-year-old male. Over a year ago, Mr. B began demonstrating a cluster of symptoms associated with Kluver-Bucy syndrome (KBS), a rare neurological disorder thought to be caused by bilateral lesions to the medial temporal lobe and manifested in a rare combination of behavioral symptoms including profound memory loss, dietary changes, distractibility, hypersexuality, and recurrent unprovoked seizures.*

On this admission, Mr. B presented to the Emergency Department because of problems taking his anti-seizure medications. The patient reports that he does not like to take his medications because they make him “foggy.” While hospitalized, Mr. B has seized several times, after which, he has made several inappropriate sexual advances toward several female nurses on the floor. When the advances cease and the behavior is addressed with the patient, he becomes placid and appears shamed and remorseful. It has now been discovered that he has experienced post-ictal episodes of hypersexuality at home, during which he has forced sexual intercourse on his wife. The wife is now expressing fear of taking the patient home without his agreement to continue to take his anti-seizure medication. This is of special concern to both Mr. B and his

wife, as they fear the behavior could begin to turn toward their two teenage daughters.

Psychiatry has been called to assess the patient and he has been determined to be decisionally capacitated, even if unable to manage these symptoms while they are occurring. Social work has said that the patient does not qualify for long-term care and the patient and his wife want him to be able to live at home. A family meeting with the patient, his wife, and the neurologists caring for him both in the hospital and as an outpatient, has been scheduled and the neurologists have requested that a bioethicist be involved.

## ETHICAL ISSUES

The ethical issues center on how to allow the patient to be at home, taking the lowest dose of

medications feasible while controlling the seizures and thus any post-ictal or otherwise episodes of hypersexuality. Ethically, it is important to support this capacitated patient's autonomous wish to be at home while balancing what situation can be arranged that is in the patient's best interest related to the need for safety for him, his wife, and their daughters, as well as the nurses while he is in the hospital.

### RECOMMENDATIONS

1. With treatment, Mr. B's symptoms may slowly decline, therefore, it is important to set up a tightly managed outpatient regimen of symptomatic and supportive care. This will include whatever is the drug regimen, as well as whatever psychotherapy can be arranged for the patient and his wife.
2. Prior to discharge, social work should make a home visit to evaluate with the intention of creating a safe environment for the patient, his wife, and daughters. This could include separate sleeping quarters for the husband and wife, with locks on bedroom doors so the wife and/or daughters can lock themselves in if needed.
3. While the patient is still in the hospital, psychiatry should establish a relationship with the patient that is to be continued on an outpatient basis.
4. While still in the hospital, if the patient begins to act inappropriately towards any nurse, the nurse should walk out of the room. If the patient requires a nurse at that moment, a call should immediately be made for someone else to enter the room to help manage the patient's behavior.

### REASONING

Kluver-Bucy Syndrome is a rare neurobehavioral condition in humans.<sup>1,2</sup> The condition was first described in 1937 as an experimental neurobehavioral syndrome in monkeys with bitemporal brain lesions<sup>3</sup> as an impairment that is associated with damage to both of the anterior temporal lobes of the brain. A hallmark symptom is hypersexuality, including a report in the literature of forced spousal intercourse.<sup>4</sup>

Although not life threatening, a patient with this condition can be difficult to treat and manage. Prognosis is variable but may not be permanent.<sup>5,6</sup> There is an increasing group of drugs that have shown efficacy in treating this condition. Even though little is understood about the disorder and its treatment, it has been long reported that carbamazepine can be useful.<sup>7-9</sup> Various cocktails of carbamazepine, clonidine, quetiapine, and

methylphenidate have demonstrated treatment utility.<sup>10,11</sup>

Because there is growing evidence of treatability, it will be important for the neurologists treating Mr. B to find the drug combination that works best for the patient. In light of the fact that he came into the hospital complaining that his present drug regimen was unsatisfactory and because of the need to protect others from his hypersexuality, close monitoring and medication adjustments will be important elements of his care.

Further, it has been reported<sup>12</sup> that social stimulation is a critical component of post-injury healing in Kluver-Bucy Syndrome, and a social worker's home visit may help the patient and his wife arrange their living environment to maximize meeting this need. Although a home visit by a social worker is certainly out of the ordinary in today's hospital care, in this rare case it seems reasonable when considering how to best employ an interdisciplinary team in the patient's best interest.

Finally, staff safety has to be fully addressed. Although the patient's hypersexual behavior towards the nurses is a symptom associated with his syndrome and not considered vicious behavior, the safety of clinical staff should be prioritized. Additional and especially capable personnel may be required in his room during post-ictal periods until the neurology team has determined a better dosing regimen. Nevertheless, nurses should not be subjected to inappropriate behavior. Unless there is an emergency, if the behavior starts, then they should walk out of the patient's room. Whenever possible, two nurses should attend to the patient when nursing is required.

### QUESTIONS FOR DISCUSSION

1. If a patient exhibits behaviors that are threatening and such behaviors can be medically addressed, does that patient have a responsibility to adhere to his treatment regimen, regardless of its noxious side-effects?
2. The case and recommendations call for the patient's adherence to the prescribed regimen to be "tightly monitored." Is this constraint reasonable?
3. How far should the hospital go to protect the patient's nurses from his inappropriate behavior?

4. What are your thoughts on the implementation of hospital policies designed to both understand and better address the safety of similarly neurologically injured patients and their caregivers?

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## John J. “Jack” Lynch, 1929-2016

Dear *JOHE* Readers,

It is with great sadness that I inform you of the death of John J. “Jack” Lynch, MD, Associate Director, Cancer Institute, Emeritus and Medical Director, Emeritus, Center for Ethics, MedStar Washington Hospital Center. Jack, an oncologist, bioethicist, and leading voice on clinical ethics in the Washington, DC, community, died on January 18, 2016, of natural causes; he was 87 years old. We are grateful to report he died quickly and did not suffer.

Jack, whose father was a physician and whose mother was the daughter of a pharmacist, was the first medical oncologist in Washington. He worked for over 50 years with MedStar Washington Hospital Center (MWHC). His vision of comprehensive cancer treatment led to the creation of the MedStar Washington Cancer Institute. “It’s here because of his vision,” according to Brian McCagh, a former vice president of Oncology Services at the institute. It is now DC’s largest cancer care provider.

Jack established the ethics committee in 1982, out of which the Center for Ethics was established soon thereafter. It is so true that those of us who had the honor of working with Jack or learning from him are better for it. I had the privilege of both for 30 years. My time with Jack started when a DC-specific group was convened by Joan Lewis, then of the DC Hospital Association, a project that was largely due to Jack. I had the opportunity to get to know Jack through these quarterly programs

while I was still at the National Institutes of Health (NIH). When my NIH research ethics fellowship was over, I moved to the Center for Ethics. That was 18 years ago. Moreover, if today I know anything about the medical side of clinical ethics, it is mostly because of Jack.

Jack epitomized the virtuous physician. In training residents and medical students how to become physicians of sound ethical judgement and integrity, he was tireless. Up to 36 hours before he died, he was doing what we all had known him to love doing for all those years; he was sitting with us, at the Center for Ethics, talking together so we could collaboratively try to figure out how best to assist a patient, his family, and the clinicians who were caring for him. Every day, when I come into the Center, where he sat is what I see first. There is not a day that goes by that one of us does not ask, “What might Jack have thought?” By all accounts, he was exemplary in every way and his legacy is vast. A jewel in that crown is the Center for Ethics. We at the Center are committed to carrying on his work. His death has left a huge hole in our hearts.

We do have some good news: the Center has been named the John J. Lynch MD Center for Ethics at MedStar Washington Hospital Center. Better still, Jack knew this was in the works before he died. We look forward to the changes the naming will bring. In addition to all the wonderful things I have already told you about Jack, he was a devoted

and superior medical editor who loved his work on this journal. He is, and will continue to be, sorely missed.

Sincerely,

A handwritten signature in black ink, appearing to read "Evan". The signature is fluid and cursive, with a long horizontal stroke extending to the right.

Evan  
Evan G. DeRenzo, PhD  
Editor-in-Chief

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## education & awards

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**The Clinical Ethics Immersion** is the original experiential and simulation-based education program in clinical bioethics. This program is held biannually and is hosted and directed by the faculty and staff of the John J. Lynch MD Center for Ethics. This four-day course focuses on the institutional development of bioethics programming and practical reasoning in clinical ethics consultation. Participants round with senior clinical ethicists in intensive care units, respond to case consultation requests, and engage in discussion with invited lecturers and resident instructors. In addition, participants engage in simulated consultations with trained actors in MedStar's state-of-the-art Simulation Training Environment Laboratory.

**The Ethics and Clinical Social Work (ECSW) program** is hosted and directed by the John J. Lynch MD Center for Ethics, and accredited by the National Association of Social Work for bioethics continuing education credits. The ECSW trains social workers to recognize the ethical significance of complexities that arise in the care of hospital patients, develop an understanding of ethical concepts as they relate to social work, and identify opportunities to work collaboratively with clinical ethicists. Combined case study and lecture allow participants to develop skills in ethical analysis.

**The John J. Lynch MD Moral Courage Awards**, named after the founder and Medical Director of the Center for Ethics, is a biennial program in recognition of individuals who have demonstrated courage when acting against difficult and ethically challenging circumstances. Established in 2010, this program was designed as an opportunity for hospital leaders to model through exemplification the virtues they consider central to creating and sustaining an ethically sound climate in the hospital. For more information, contact the program director, Kahlia Kéita at [kahlia.t.keita@medstar.net](mailto:kahlia.t.keita@medstar.net)



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