

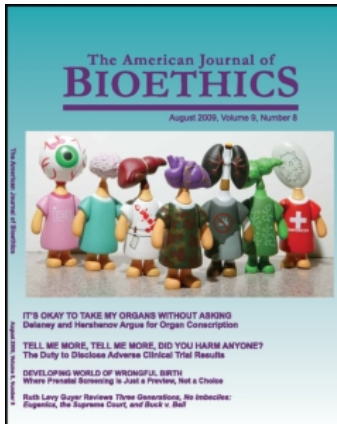
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### Transferring Emerging Neuroscience to the Clinical Ethics Bedside

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(or neurology)? The problem of dementia suggests that it might. The standard way to view dementia (or at least one that comports with a common representationalist view of the mind) is that dementia is the progressive loss of contents of the mind. One talks of dementia in terms of losing certain mental contents (e. g., beliefs, memories), critical connections between these mental contents (e. g., a sense of a familiar face and the belief, 'This person is my wife'), and the ability to generate new mental contents (e. g., new memories). This view has a certain intuitive appeal. We spend our lives filling the mind in various ways and dementia seems to be the slow reversal of this process. As the contents of the mind thin and the connections between those remaining contents come apart, symptoms emerge. Confusion in the grocery store. The front door left open at night. A family member mistaken for another. Without the necessary contents of the mind, persons with dementia lack the mental furniture to be who they once were.

This received view of dementia has limitations given how dementia is experienced and clinically encountered. Dementia first comes to attention when someone cannot perform in ways that used to be easy. Getting lost on the way home from church. Following an uncomplicated conversation at the dinner table. Missing a doctor's appointment. Most diagnostic tests for dementia target certain abilities—for language, for calculation, for visual manipulation, for short-term memory formation. These are requisite abilities for getting about in their daily lives. While it is not impossible to characterize failures in these abilities in terms of lost mental contents, at the clinical level this becomes a bit of a contortion. The phenomenological experience of the person with dementia is that of slowly losing successful ways of coping with the world. One loses skills of conversation, skills of solving problems, skills of relating to familiar objects. Or put more aptly, persons with dementia experience the slow unraveling of their most fundamental life skills. This description of dementia is more true to the phenomenology of the disease and thus represents a better starting point for addressing the philosophical problems that surround the disease (e. g., identity, capacity, moral status). A starting point that makes sense and carries intuitive

appeal across the divide in neuroscience lends some hope to the possibility of bridging it.

Gillett (2009) is motivated by a worry that ought to be our worry as well. Unless there is a way to bridge the gap generated by the different approaches to neuroscience, the understandings of ourselves that each afford threaten to spin independently of each other and leave the most vexing questions before us unanswered. The language of skill ultimately may or may not be a key to providing this bridge but it is at least a promising resource that should not be overlooked. ■

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# Transferring Emerging Neuroscience to the Clinical Ethics Bedside

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In the target article, Grant Gillett (2009) has taken an important step toward greater synthesis of neuroethics,

philosophy, and neuroscience. In his neo-Aristotelian account, Gillett posits a necessary link between neurological

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functioning and a person's subjective "place in the human life-world" (5) and notes the commensurate uniqueness of neuroimaging profiles to human identity. From this introduction the discussion turns to specific aspects of the relationship between neuroscience and human experience, through an analysis of locked-in syndrome (LiS), minimally conscious state (MCS), and permanent vegetative state (PVS). As a practicing clinical ethicist, my comments will focus on the implications of Gillett's analysis of the evolving dimensions of these neurological terms for making decisions in complex particular cases, drawing on some of my own work and that of a few others.

It makes sense to begin with the condition generally identified as having the least potential for human consciousness among these three states—PVS. The Multi-Society Task Force (1994) on PVS defines it as "a clinical condition of complete unawareness of the self and the environment . . ." (1499). In Gillett's (2009) analysis, the term *PVS* refers to a situation in which there is no longer sufficient brain capacity to "do the associational, exploratory, and cognitive interconnection based work of meaningful conscious experience and being-with-others" (5). Hence, the neo-Aristotelian account may employ neuroscience to aid a determination whether, and to what degree, consciousness exists. Recent work on MCS has complicated the traditional concept of PVS by identifying a different, but related, state where an incapacitated brain may enable a person to have some responsiveness to events but prevents anything consistently resembling usual everyday human interactions with the world. Instead, the patient in MCS may experience a fragmented, ephemeral consciousness, which as yet remains variable and ill defined. In sharp contrast, LiS describes a condition notable for severed communication between the patient and the world; the patient in LiS retains full awareness of surroundings but has lost control of his or her body, thus making 'outgoing' communication impossible. Gillett (2009) notes the existential agony that such "apparently unresponsive witness[ing]" (5) imposes on the typical person.

Once the definition and diagnosis of PVS was firmly established in neuroscience, the clinical ethicist could confidently rely on that concept to mediate decisions about many severely brain-injured persons. Now, however, advances in neuroimaging plus new diagnostic categories and assessment scales are facilitating a "new diagnostic nosology about disorders of consciousness," which is expected to improve prognostic accuracy and suggest new therapies (Fins 2008, 46). The additional ethical complications presented by these changes for complex clinical cases of brain injury should not be underestimated. One ongoing theme of my research (conducted with colleagues) has focused on decision making for critically ill patients, especially how physicians' perceptions of constraints on their clinical practice influence interactions with the families of impaired patients and other health care professionals. The types of constraints studied include perceived risk of civil or criminal litigation, anticipation of possible conflict with patients' family members, de-

gree of family consensus, self-reported physician attitudes about medical futility, and physician characteristics such as gender, religious participation, and reported uncertainty about the distinction between efficacy and benefit of treatments (McCrary et al. 1992; 2006; Swanson, and McCrary 1994; 1996). The research has both qualitative and quantitative components, but underlying much of it is a working premise that brain injured patients' diagnoses, while subject to ongoing increased precision, are unlikely to change in dramatic shifts. The emergence of more precise diagnostic categories and tests for conditions like MCS holds potential to alter this analysis in significant ways. These developments suggest the wisdom of moving away from a relatively straightforward principles-based approach during ethics consultations, and toward a more nuanced analysis.

One constraint on decisions that has special potential to become more salient under this new clinical picture is physicians' anticipation of conflict. It seems plausible that as the range of possible neurological impairments grows, early clinical uncertainty in such diagnoses may increase physicians' sensitivity to anticipation of conflict with family members. It is to be hoped that greater diagnostic certainty will emerge as neuroscience research progresses, but during the interim these developments may stimulate greater numbers of ethics consultations on such cases and require ethics consultants to be especially sensitive to the complexities of particular cases. An increased incidence of ideologically charged obstacles in clinical consultations, exemplified by the Theresa Schiavo case, also seems possible as neuroethics advances. As Joseph Fins (2006) has noted, the goals in such cases are to "strive to both *preserve the right to die* for those who are beyond hope while *affirming the right to care* to those who might benefit from coming advances in neuroscience" (169). Achieving a fragile balance between these twin goals will be one of the genuine challenges of future clinical ethics consultations in the area of impaired consciousness.

To meet this challenge, Gillett (2009) (correctly, in my view) draws extensively on the work of Ronald Carson (1997). In response to the standard bioethics approach to moral deadlock in clinical cases—appealing either to the law as trump or to lexically ordered principles—Carson instead proposes a move "beyond calculative decisionmaking to engaged moral inquiry" which he further articulates as "reflective practice" (182). Carson recognizes that cases of ethical conflict are not met by "abstracting from experiences of illness and practices of care but by delving more deeply into them" with practical moral reflection (184). Such a practice is rich enough to encompass not only an approach to clinical ethics cases but, much more broadly, a lived response to Gillett's (2009) question "Who am I, the embodied subject?" (5). This response understands that human identity depends not only on brain function *per se* but how we attempt through the brain to construct a personal world full of "things that contribute the energy and worthwhileness to life" (5). The importance of the challenge of neuroethics is thus made clear. Here, Gillett returns again to his neo-Aristotelian roots by noting the value of the practical virtue

*phronesis* to guide human endeavor and shape identity. Fins (2008) has observed that “humility not hubris should be the virtue that guides the ethical conduct of research and practice” in neuroscience (46). So, too, humility and a supple moral imagination are touchstones of reflective clinical ethics practice in this realm. ■

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# Subjectivity, the Brain, Life Narratives and the Ethical Treatment of Persons With Alzheimer’s Disease

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Grant Gillett’s (2009) welcome and extremely thought-provoking target article addresses many complex issues of such far-ranging consequence that it seems impossible to provide a commentary worthy of his efforts in this space. I must, therefore, confine my remarks to a discussion of “the subjective brain” (5), and the importance of a narrative view of subjectivity as it applies to ethical issues in connection with people with Alzheimer’s disease (AD).

## THE SUBJECTIVE BRAIN

Although I agree substantially with Gillett’s (2009) assertion that “. . . one’s neurocognitive structure is constantly reconfiguring itself so that it develops and changes over time” (5), and with the final statement in the Adequacy Requirement, “A conception [of an embryo] based on present physical properties is inadequate” (5), I believe that saying that the brain is subjective is to beg the question and to be engaging in what Bennett and colleagues (2003) refer to as the “mereological fallacy”: the fallacious ascription “to the

constituent *parts* of an animal attributes that logically apply only to the *whole* animal” (22). They go on to say that,

human beings, but not their brains, can be said to be thoughtful or thoughtless; animals, but not their brains, let alone the hemispheres of their brains, can be said to see, hear, smell and taste things; people, but not their brains, can be said to make decisions or to be indecisive (22).

To say that the brain, rather than the person, is “subjective” is a belief that is not supported, and is perhaps unsupported in principle, by any scientific findings. The unfortunate outcome of presenting a belief as if it were a fact confuses the meaning of personhood by reducing persons to brains and this, in turn, leads us to the slippery slope of deciding arbitrarily how much and what kind of brain function is required in order to justify the ethical treatment of the person of whose brain we are speaking. I do not think that it is necessary to assert (questionably) that the brain is subjective in order to apprehend and respect Gillett’s (2009)

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