

Edmund G. Howe, "Do We Undervalue Feelings in Patients Who Are Cognitively Impaired?" *The Journal of Clinical Ethics* 17, no. 4 (Winter 2006): 291-301.

## Do We Undervalue Feelings in Patients Who Are Cognitively Impaired?

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In this issue of *The Journal of Clinical Ethics*, the Harvard Ethics Consortium presents the agonizing dilemma it faced in the case of "Margaret," a patient with early dementia. Margaret became chronically agitated and aggressive as her illness worsened; she hit and bit, and, at one point, even punched her teen and young adult children. When her agitation and aggression didn't respond to psychotropic drugs or electroconvulsive treatments, her careproviders considered trying low doses of methadone. They feared, however, that even low doses of the drug could contribute to her dying prematurely.

It may have. They gave her the methadone, and it did give her the virtually miraculous relief they hoped for. Yet she died from aspiration pneumonia just 10 days later. This decision was highly controversial — the care team was sharply divided. The core ethical question in the case is what divided the team: Should Margaret's careproviders, under these conditions, have given her methadone? If this decision was the right one, it should be applicable to similar patients, and criteria could then be developed for deciding when, in circumstances like this, careproviders should take this risk.<sup>1</sup>

If the treatment decision was appropriate, then a more far-reaching question comes to the fore: that is, why did some of the team find it controversial? An improved understanding of their concern could benefit other patients with the same illness, facing the same treatment decisions, and perhaps patients with other illnesses as well.

Consequently, in this discussion, I will begin by asking whether what Margaret's careproviders did for her was right. I will present why I believe that Margaret's careproviders, without question, made the best choice for her, and then ask why the treatment was so controversial. I will suggest that careproviders, for the best of reasons — such as protecting vulnerable patients from inadvertent discrimination — may unknowingly over-generalize. They may apply a sound ethical position, but allow it to go too far, so that they fail to establish critical exceptions.

I shall use examples involving patients with traumatic brain injury (TBI), in minimally conscious states (MCS), and in persistent vegetative states (PVS) to illustrate specifically how careproviders might see distinctions and then establish exceptions that would offer more benefit to patients like Margaret in the longer run.

Given this, Margaret's experience may lead to further reflection in two directions. First, for patients who lack cognitive capacity, when should an exception be made, such that careproviders take greater risks, including

that of precipitating death prematurely? Second, should careproviders ever exert greater effort to maintain a patient's life, despite a total lack of cognitive capacity, so long as the patient can relate meaningfully in some way to loved ones?

## MARGARET'S INNER EXPERIENCE

Should Margaret's careproviders have given her methadone in the low doses they did? Often, an initial, optimal approach to answering such an ethical question involving an individual patient is to ask what the patient's experience may have been like. This is difficult to infer when a patient can't express her or his inner experience with words. Still, the extent of Margaret's suffering, whatever its source, as her loved ones and careproviders describe it, is almost palpable.

Persons who have dementia that is deteriorating, such as Margaret's, may suffer in ways that aren't commonly understood. To allow a better understanding of patients' possible inner experience and, perhaps, suffering, I will describe five less well-known sources of suffering that patients may experience.

### 1. PATIENTS MAY KNOW THAT THEY CAN'T "KNOW"

Patients with Alzheimer's disease (AD) may lose the capacity to understand what they are experiencing. The exceptional suffering this lack of capacity may cause was recognized most notably in a court case involving Joseph Saikewicz.<sup>2</sup> Mr. Saikewicz had been greatly mentally retarded since birth; as an adult, he had an IQ of 10 and a mental age of only three. At age 67, he acquired acute, myeloblastic, monocytic leukemia, and his careproviders faced the question of whether they should give him chemotherapy.

The court reasoned that this would cause Mr. Saikewicz unacceptable, exorbitant distress, particularly because the chemotherapy would have bad side-effects, and the patient wouldn't be able to understand why he was having them. He would, the court reasoned, have no comprehension of the reasons for the severe disruption of his formerly secure and stable environment occasioned by the chemotherapy.<sup>3</sup> In the Harvard Ethics Consortium case, Margaret felt fear: as Julieta B. Holman and David H. Brendel describe in their article about Margaret, "A Problem with Palliative Care in a Psychiatric Hospital," Margaret thought that she saw terrorists and called 911 after 11 September 2001. Patients with AD differ from patients like Mr. Saikewicz, as they aren't born with such deficits, and, at least for some time, remain aware of what they are losing. The emotional pain of patients like Margaret who acquire dementia is, for this reason, additionally excruciating.

Both of these sources of increased suffering — not comprehending and knowing of the loss of comprehension — are commonly acknowledged. A greater source of suffering may not be. What may cause patients greater anguish is to suddenly or gradually realize that, in time, they may not only feel more confused — the time may come that they will no longer know *why*. The emotional devastation that patients may experience when they first learn this may be difficult to overestimate. The effect this may have was described by a psychiatric patient named "Jay," who wrote in a previous issue of *JCE*.<sup>4</sup> Jay learned from a psychiatrist he had been seeing for quite some time that he might be incapable of understanding why others responded to him as they did.<sup>5</sup> Jay wrote, "I reacted with horror and dismay [when I learned that I might not be able to accurately perceive] social cues. Worse yet, I was incapable of realizing it. I was blind to my own blindness. . . . Instantly I lost all trust in my ability to judge how well I was actually functioning. How would I know how [others] actually felt? . . . I couldn't accurately judge, even if they told me. I left feeling completely worthless and distrusted any of my own responses."<sup>6</sup>

Such a response to this type of new awareness is not limited to persons with psychiatric illness; it also was experienced and described, for example, by the philosopher Bertrand Russell. Russell had an encounter with Ludwig Wittgenstein, who was at that time one of his students. Russell writes, "I showed him a crucial part of what I had been writing. He said it was all wrong . . . that he had tried my view and knew it couldn't work. I couldn't understand his objection. . . . If I could see it too I shouldn't mind, but, as it is, it is worrying and has rather destroyed the pleasure in my writing."<sup>7</sup>

Ironically, Wittgenstein may himself have experienced the same feeling in response to mathematician

Kurt Godel. Godel wrote in a letter to an acquaintance, regarding his key theory, "it is clear that Wittgenstein did not understand. . . . [What he] interprets . . . in fact is just the opposite. . . . [His response] seems nonsense to me."<sup>8</sup>

Wittgenstein later ridiculed and belittled Godel's contributions to mathematics as "little artifices or conjuring tricks," apparently responding in a wholly different way than Jay or Russell did to not being able to comprehend; he apparently simply became angry — which may have been more like the response that Margaret showed.<sup>9</sup>

Russell's and (particularly in this case) Wittgenstein's reactions are important because they illustrate that such responses to not knowing are universal, rather than experienced only by those with emotional illness. Russell's reaction shows that this is a reaction to which we may all be prone; Wittgenstein's response illustrates that, in response to this awareness, even persons who do not have AD may respond with anger.

Knowing that patients with AD may respond in this way may help us understand them. Imagining that persons such as Russell and Wittgenstein might respond in this way may help us to avoid marginalizing patients with AD as being persons who are emotionally different than we are. Having this awareness may enable us to continue to respond to patients longer as persons who are like us, even after they have lost some or all of their capacity for cognition. This may help prevent us — and the greater society — from responding to patients as if they were socially dead.<sup>10</sup>

What may patients with AD who gain this awareness fear most? They may fear becoming like one of my patients: I asked her what, if anything, her husband did that annoyed her. She said, "He bugs me about my taking my medicine. I am a big girl." The tragedy in the anecdote is that my patient made that statement repeatedly during the session: "I am a big girl, now," she angrily said — over and over. She was not aware that when she said it, she had said the same thing moments before, which was just what she did with her medication.

## **2. PATIENTS MAY LACK RELIEF FROM EMOTIONAL PAIN**

Many patients, even those with great physical pain, may still find meaning, if not joy, in their lives, especially with others. Even if they have extreme pain, they may desperately want to remain alive so that they can continue to interact with their loved ones. When patients have profoundly painful emotions, such as the chronic feelings of agitation and aggression that Margaret had, this may not be possible. Ever-present feelings of fear or depression, or obsessions, or compulsions, may replace all other feelings and leave no space for positive emotions.

These patients may suffer every minute, literally, that they are awake. As one writer wrote, "the lives of persons who have such obsessions have been hijacked by anxiety."<sup>11</sup> A lack of capacity to feel more than one emotion at any one time may be biologically based; for example, persons may not be *able* to feel tenderness toward a loved one when they feel, at the same time, anger or fear. Patients with dementia may be particularly vulnerable to this. They may be, for instance, unduly prone to experiencing obsessions.<sup>12</sup> Their exaggerated worries may saturate their awareness and preoccupy them every moment of their lives. Obsessions and similar feelings may be unlike physical pain, in that they may never stop and may keep patients from ever having other, positive feelings. If this occurs, as it may have with Margaret, it may suggest a different ethical priority from the usual: it may suggest that emotional suffering may be greater than that of even the most painful physical illnesses, because physical pain may not be as constant, and/or patients in pain may still be able to experience positive feelings. If this is so, on this ground at least, careproviders may have as great or a greater moral obligation to try to relieve patients' emotional pain.

## **3. PATIENTS MAY LACK CAPACITY TO DISTRACT THEMSELVES**

Patients with AD may not only be more prone to having obsessions and other feelings with similar wholly destructive effects; they may be wholly unable to gain relief by distracting themselves. Patients with intact cognitive capacities may be able to obtain significant, periodic relief by distracting themselves or thinking of other things — wittingly or unwittingly. Patients who are cognitively intact may be able, for

instance, to obtain relief unwittingly when they talk with others. Patients with AD cannot.

Persons' capacity to reduce their suffering in this way may be entirely biologically based; experiences of pain and of suffering, it appears, involve different parts of the brain. Persons whose cognitive capacities are intact may be able to "shut off" parts of the brain that cause them to obsess (and so to suffer), by "turning on" another part of the brain, as by talking to another or, in fact, just thinking. Patients may be able to actually learn how to relieve their suffering in this way, while at the same time being able to register and report the presence and extent of physical or emotional pain. This possibility is perhaps best illustrated by a response some patients have shown after they have had part of their brain surgically cut in an attempt to relieve intractable pain due to head or neck cancer. Teo Dagi, MD, a neurosurgeon, described this phenomenon in an issue of *JCE* more than a decade ago. "Patients report that their pain is no different; it just 'doesn't matter'," he states. "The operation. . . effectively separates pain and suffering. After surgery, patients hurt but they no longer suffer."<sup>13</sup>

How might patients with intact cognitive capacities be able to learn this skill? As John Astin notes, by adopting a "detached stance," these patients may "cause an uncoupling . . . of the sensory dimension of their pain experience from the affective evaluation alarm reaction." This uncoupling, over time, "may result in a deconditioning of the alarm reactivity to primary sensations such as physical pain."<sup>14</sup>

The capacity to distract oneself can be taught, and the result is a state referred to as mindfulness.<sup>15</sup> Many chronic pain patients can experience, for example, moderate to great improvement even after only eight weeks of such training.<sup>16</sup> That is, patients in pain may be able to disconnect the stressful component from the sensory input that they receive. Jon Kabat-Zin and colleagues write, "moment-to-moment mindfulness may be the principal coping mechanism" for patients who acquire success in dealing with chronic pain.<sup>17</sup>

Mindfulness is also wholly distinct from mere physiological relaxation.<sup>18</sup> Patients with AD may be able, to a degree, to relax their bodies, but, may lack the capacity to use mindfulness consciously or unconsciously to reduce or relieve their physical or emotional pain.

#### **4. PATIENTS MAY LACK CAPACITY TO OFFSET PAINFUL EMOTIONS**

Patients with AD may be worse-off than those who have physical pain and have intact cognition because they may lack a capacity to experience a sense of meaning in their lives — which might otherwise help offset their pain or enable them to better tolerate it. Some patients who have even the most severe physical pain may be able to find meaning that significantly offsets their pain. For example, patients may find meaning during their last days, months, or years in the goal of leaving their loved ones with positive memories of them; they may wish to maintain grace and dignity as they die. This goal may help offset their suffering and make it bearable.

In the case of Mr. Saikewicz described above, the court raised this as an additional ground for not giving Mr. Saikewicz chemotherapy. The court declared that he would experience fear without the understanding from which other patients may derive strength.<sup>19</sup>

#### **5. PATIENTS MAY KNOW THEY HURT LOVED ONES, BUT CAN'T STOP**

Persons with AD may not be able to control their aggression. Due to their illness, they may be especially prone to responding abruptly and with anger, much as it appears that Margaret did.<sup>20</sup> The angry outbursts may be disproportionate to what provoked them. Moreover, the outbursts are more likely to occur during intimate interactions with others, such as when loved ones bathe or dress the person with dementia.<sup>21</sup>

Worse still, in the last stage of the illness, patients may remain partially, if not fully, aware of how they affect others. As this is the case, if and when they harm someone near them, the awareness may be exceedingly painful, particularly when they hurt those they most love. This awareness is illustrated by the following report from a caregiver of her visit with "Helen," a much-loved friend with AD. Ruth Dickinson writes, "During my third visit, Helen set her mind on getting me out of her house. . . . I spoke in low tones, . . . but it didn't help . . . she grabbed my fingers hard and tried to bite them. Gently disengaging my hands, I continued talking quietly, acknowledging her anger. . . . Finally she'd had enough . . . she said, 'You're too nice. You shouldn't be.'"<sup>22</sup>

## THE ETHICAL AND CLINICAL IMPLICATIONS

The five possibilities just described — patients may know that they can't "know," may lack relief from emotional pain, may lack capacity to distract themselves, may lack capacity to offset painful emotions, may know they hurt loved ones — as well as the more general loss of cognition, identity, and life, must be among the worst experiences a person can undergo. In the Harvard case, Margaret's behavior indicated virtually unequivocally that she was in constant pain. For many patients, such pain may justify risking death when it prevents them from being able to interact meaningfully with loved ones. Clearly, Margaret had reached this point. Further, her condition, without a trial of methadone, was irreversible. Worse still, since her disease was progressive, it could only be expected that it would only worsen over time — as she may have known. If there is any state in which careproviders would be justified in trying to relieve a patient's pain — even at some risk of prematurely ending life — it would seem to be this.

How beneficence would apply is self-evident. G.E. Moore, in *Principia Ethica*, commented, "Great intrinsic evils consist of [in addition to other evils] . . . the consciousness of pain."<sup>23</sup> Holman and Brendel, the ethics consultants in Margaret's case, state that there must be zero tolerance for pain. Presumably, Moore would agree. As I suggested above, it may be the *consciousness of pain* that is most dreadful in what patients like Margaret experience — not as a cognitive experience, but what they *feel*.

The principle of justice also applies. Obviously, patients who are competent can choose pain relief, even if it risks prematurely ending their lives, but the principle of justice could be applied in a way that urges careproviders to give highest priority to preserving patients' lives, above all else, in all cases. In fact, I will argue at the end of this article that such a priority is warranted — more than it may be now — for patients who have traumatic brain injury (TBI), in its most severe form, and who are in minimally conscious states (MCS).

Surely when patients have AD and can continue to find meaning in relationships with their loved ones (or others), there is no question that all efforts must be made to extend their lives and enhance their joy to the extent possible. This may be a goal that will never be reached, for society or for patients' loved ones, as society must come to more fully value the emotional capacities that these patients retain.

Thomas Kitwood, for example, called for a change of culture in dementia care; the old culture of care, he argued, was " 'paradigmatically wrong' . . . the prime concern has been with cognition . . . while emotion has been grossly neglected."<sup>24</sup> The task for loved ones is no less daunting; they must grieve the loss of patients with AD as they were, and acquire a new capacity to find as much — or more — meaning in the different persons the patients become. This is possible, but most of us can't achieve this quickly — or even over many years. It may be most easily accomplished by children and younger people, as illustrated by the following case. Meg Rowley, from Louisiana, was only 17 when she wrote the following.

Before my grandma moved to a retirement home, she'd babysit me, and I'd bike to visit her. Then she began greeting me with blank stares and incoherent conversations. . . .

So I took a part-time job as a waitress there. That way, I could help care for her. My first day, I gave her a hug and said, "Hey, Grandma." She responded by vehemently denying she was my grandma. . . .

Eventually, I learned to serve her like any other resident and not be hurt if she treated me like a stranger.

After a while, I didn't need a "Hello, Meg" or even a look of recognition. Instead, I'd tell her how pretty she looked in her pink dress. I was glad just to bring her a little happiness. It seems strange, but my grandmother's condition brought me closer to her.<sup>25</sup>

This kind of adaptation may be accomplished by adults; I think of a Abigail Thomas, whose husband lost most of his cognitive capacity in an accident. She reported experiencing this, many years later: "Rich and I sit together, we hold hands, we are warm-blooded creatures in a quiet space, and that is all the communication we need."<sup>26</sup>

When patients have pain that is as severe as Margaret's, whether it is physical or emotional, it deprives them of the capacity to relate meaningfully to others (assuming that they want this), and when their condition is irreversible (or will get worse), it makes sense for careproviders to consider seeing a distinction, and to make an exception in what they might normally do. When patients are in much less severe states of pain than experienced by patients like Margaret, the principle of justice should be applied; but the pain Margaret presented with provides us with a starting place to determine what is optimal care for patients in her position.

Physical and emotional pain now can be objectively assessed with considerable reliability. It is possible, for example, to use a scale that involves observing patients and rating even nonverbal cues such as vocalizations, facial expressions, and body posture.<sup>27</sup> A pain-assessment measure has been developed specifically for patients with AD, although at this time it requires further testing.<sup>28</sup> When patients have dementia, feelings such as anxiety and fear may drive suffering behaviors such as grimacing, sighing, and restlessness, even though, in cognitively intact persons, these same behaviors may reflect physical pain.<sup>29</sup> It is more difficult to make these physical and emotional assessments with patients with AD. It requires arriving at a balance between imputing too much meaning to the sparse and unclear cues of patients who have more-severe dementia, and ignoring the possibility that there is some meaning to be interpreted.<sup>30</sup> Recognition of the meaning of emotion in the faces of patients with AD progressively decreases, making accurate inferences about what patients feel more difficult as the disease progresses.<sup>31</sup>

Making these distinctions may be very difficult, especially when the treatment considered may, as it did with Margaret, risk bringing about the patient's premature death. This requires careproviders to act in the face of ambiguity, and they may be understandably reluctant to make the same distinctions and to intervene as Margaret's careproviders did. Careproviders who oppose taking such risks do this, no doubt, to protect the patients.<sup>32</sup> These careproviders may alter their position when they consider when, if ever, they might make an exception to it.<sup>33</sup> In the next section, I will offer some examples in which this may be the case.

## **PATIENTS FOR WHOM NEW DISTINCTIONS MIGHT BE INDICATED**

In the above discussion, I suggested that when patients like Margaret totally and irreversibly lose their capacity to experience meaning with their loved ones or to find meaning in any other experience that they value, careproviders should consider taking greater risks in treatment — even those that may hasten death — to try to help patients regain this capacity. This has an obverse implication: that careproviders should seek, as rigorously as possible, to preserve the lives of patients who retain a capacity to experience such meaning in their lives. If these patients could speak, this might be what most or many would want. The key question this obverse implication begs is, *What should count as sufficient meaning?*

The possibility I raise in the clinical examples that follow suggest that this meaning does not need to include being cognitive or primarily cognitive, as some would propose, but may need to include only emotional experience. This is the same kind of transformation, from valuing cognition in patients with AD to valuing emotion, as described above in the case of Meg, who was happy to spend time with her grandmother even when her grandmother no longer recognized her. In considering the obverse implications of Margaret's case, perhaps careproviders should value most fully patients' capacity to relate to others, even when their cognition is greatly impaired. This may include patients with brain impairment due to causes other than AD, that leave them with a capacity to continue to find meaning and joy in their lives and, particularly, to relate emotionally with their loved ones or others. The examples I shall use are patients with TBI and MCS — and perhaps even patients in permanent vegetative states (PVS).

## **A FINER DISTINCTION FOR PATIENTS WITH VERY SEVERE TBI**

At the most recent meeting of the American Society for Bioethics and Humanities (ASBH) in October 2006, Sunil Kothari, MD, an expert in rehabilitation medicine, reported a research finding as surprising and counter-intuitive as it is clinically profound. He reported that patients with severe brain injuries may end up as satisfied with their lives as those with more moderate and mild injuries — and even more so.<sup>34</sup> This may

be because the patients have less insight regarding their deficits. How they fare may depend on many other factors, such as on the extent to which they have ongoing, strong psychosocial support. Kothari also reported another important clinical finding: careproviders may tend to believe that patients with severe brain injuries have worse prognoses, overall, than the patients actually have.<sup>35</sup> This may be because not all careproviders know that patients with severe traumatic brain injury may become more satisfied with their lives than might logically be expected. Further, careproviders may use categories to distinguish between patients who have mild, moderate, or severe illness that don't correlate well, or accurately predict, the degree to which the patients will later be satisfied with their lives. Since these patients, apparently, may often do better than careproviders might predict, careproviders should consider making a new, finer distinction: to try to delineate between the patients in this category who are less likely to do well and those who have a greater chance of doing better. This may help us to judge with greater clarity how patients might or might not benefit from continued life-sustaining care.

A further distinction we might consider making is whether patients with TBI have suffered an injury in a more traditional manner, such as from a blunt instrument or in a car wreck, or from a blast injury, as now occurs with many service persons in Iraq.<sup>36</sup> The damage that patients are most likely to sustain from blast injuries may differ; patients may appear wholly coherent and rational, but they may have serious brain deficits.<sup>37</sup> These deficits may be evident only through formal, comprehensive, neuropsychological testing, which takes hours to carry out.<sup>38</sup> The deficits that are more likely after blasts pose two ethical questions in particular: How should careproviders obtain patients' consent when treating them clinically? and What standards should be used when patients want to be participants in clinical research?

The first of these questions may arise, for example, when patients who have severe leg wounds, suffered in Iraq, later refuse a lifesaving limb amputation. Under the standards of mental capacity usually applied, careproviders probably would conclude that the patients have sufficient cognitive capacity to make this choice. If, however, the same patients have substantial deficits found through formal testing, it may be that a more rigorous standard should be applied. Alternatively, a sliding scale for determining capacity could be used. The measure utilized could depend on the severity of the patients' outcomes, for example, relative to each other.

The end result of either new approach could allow these decisions to be made, in part, by surrogate decision makers, which might leave the patients feeling stigmatized. It could also cause patients to learn too abruptly that they have deficits they didn't know about. This could result in their experiencing the same feelings of despair that "Jay," the psychiatric patient described at the beginning of this article, experienced. Anticipating this result and adopting a more strict, or sliding standard, may result in saving more of these patients' lives.

A second ethical dilemma that patients who have TBI due to blast injury present is what standards to use when they want to participate in clinical research. In research, the standards for determining competency in this group are less certain. The requirements aren't yet definite, as they are for other vulnerable groups, such as prisoners and children. In the near future, however, it is likely that this will change.<sup>39</sup>

Perhaps members of institutional review boards (IRBs) could make a distinction between patients with TBI due to a blast injury and others. As mentioned above in another context, careproviders may opt to protect vulnerable patients more, but this may stigmatize patients more. In this instance, patients may want to participate in research so that they can benefit others, particularly those who have the same kind of injury. One question that members of IRBs who make this kind of distinction in this context would raise, therefore, is the extent to which supporting patients' altruism should be taken into account. An approach that might best meet all of these concerns is for IRB members to consider the risks posed on a study-by-study basis, rather than adopting one policy for all patients as a group. IRBs could then vary the requirements for participants, on a sliding scale, much as they do when research participants are children.

A final ethical issue that IRBs could address is the extent to which such a policy, whether formal or informal, should be well-publicized. Making this policy too widely known could unnecessarily result in

some participants experiencing stigma and despair, for the same reasons I alluded to just above. Inadequately publicizing this policy could be ethically problematic, as the approach wouldn't be adequately transparent.

### **SHOULD WE VALUE WHAT PATIENTS FEEL OR THEIR COGNITION?**

At the same ASBH meeting, James P. Kelly, MD, a neurologist, reiterated an aspect of reality that is always acknowledged, infrequently addressed, but nonetheless of considerable clinical importance. He stated that although current diagnostic techniques, such as the most sophisticated imaging techniques available today, can identify what parts of the brain can and can't do, they can't and may never be able to tell us what patients actually experience.<sup>40</sup> The potential relevance of this limitation for patients in an MCS, or perhaps even in a PVS, is far-reaching. For example, patients may retain the capacity to feel — and if they can feel, they may still respond to the voice and/or the touch of loved ones and others. Some persons have become more concerned about these possibilities recently, because recent empirical findings suggest more strongly than before that when the brain loses some capacities, it tends to "try" to restore them.<sup>41</sup> Our brains also may retain a capacity for plasticity, even late in our lives. Even if a person is in an MCS or PVS, it may be possible that a part of the brain may "take over" a function such as sensing another's voice or touch. Persons in an MCS or PVS may possibly know when loved ones speak to them or touch them, although we may never know whether this is the case. Should careproviders seek to preserve the lives of these patients as much as they would others, even when the patients' capacity to communicate with loved ones is unknown, and, in any case, only one-way? Or is the distinction between having and not having some capacity for cognition the more important clinical distinction to be made?

Joseph Fins, MD, has suggested, in response to recent greater empirical and normative uncertainty in this area, that when patients are in an MCS, the capacity to process language may be most important.<sup>42</sup> Some disagree; they believe that patients' capacity to feel and respond to others is most important.<sup>43</sup> In regard to the question of which of these should prevail — having cognitive capacity or emotional capacity — I think of a woman in her early thirties who went every day, for years, to speak and touch her husband as he survived traumatic brain injury in a coma. She did this until he died. She told me that she found these years by far the most meaningful in her life. She knew that he might not be experiencing, at any level of consciousness, either her voice or her touch. Yet she also knew that he might.

### **CONCLUSION**

I have wanted here to emphasize, above all else, two presuppositions. First, since most of us live mostly for the relationships we have with others, when careproviders must make difficult decisions, whether patients still have the capacity to have relationships may warrant the greatest moral weight. I imagine in this regard that many persons would believe that the most painful event in the Russian author Fyodor Dostoyevsky's life was when he thought he would be shot by a firing squad, which turned out, at the last moment, to be a mock. But I would argue that his most painful moment may have been when his wife Maria died in 1864. He continued to write after she died, on the same table on which she lay dead before him for days, as was the custom at that time. He was writing his novel *Notes from the Underground*, composed as a diary. In the well-known ending, the woman the diarist loves leaves his house and leaves him behind. He runs out, crying out for her desperately, to no avail, in the dark and the snow. The diarist writes, "Never before had I endured so much suffering. . . . I stopped by my table, . . . and stared senselessly before me."<sup>44</sup>

Of the two — the risk of death or the loss of the capacity to relate meaningfully with loved ones — the latter may be worse, for most of us. This presupposition is one of the two that should most underlie the decision of Margaret's careproviders to give her possibly life-threatening medication. The pain that Margaret experienced was worse than either of these, however: not only could she not relate with her loved ones; sometimes she even did them harm. Her pain may well have been caused, more than anything, by still being aware of all she did.

I think in this regard of Abigail Thomas, the woman whose husband had a severe TBI and was in a coma. Thomas had bought some "outsider art" at a rehabilitation hospital — works by patients with brain injury. She bought a note that a man who had a brain injury had written, that suggests what Margaret's experience might have been like. Thomas describes it: "I bought the message of a man who suffers from left neglect, a condition in which brain injury has rendered invisible the left side of everything. His words start in the middle of the page, and go off to the right, writing over and over until there is nothing but a black unreadable mass. The only parts still legible are the . . . words FORGIVE ME."<sup>45</sup>

## NOTES

1. Julieta B. Holman and David H. Brendel state in "A Problem with Palliative Care in a Psychiatric Hospital," in this issues of *JCE*, that the number of patients with dementia is growing, and patients like Margaret may be unable to be cared for appropriately at home or in nursing homes. If they are right, patients like Margaret for whom this same question may arise may be many.

2. *Superintendent of Belchertown v. Saikewicz*, NE Rep, 2nd Ser, 370 (November 28, 1977): 417-35 (Massachusetts Supreme Judicial Court, Hampshire).

3. P. Ramsey, "The Saikewicz Precedent: What's Good for an Incompetent Patient?" *Hastings Center Report* 8, no. 6 (December 1978): 36-42, 40.

4. J. Carter, "Looking Into a Distorted Mirror," *The Journal of Clinical Ethics* 14, no. 1-2 (Spring-Summer 2003): 95-100.

5. The psychiatrist in this case was David H. Brendel, the same doctor who was the chair of the Ethics Committee in Margaret's case. See note 1.

6. Carter, see note 4 above, p. 97.

7. R. Goldstein, *Incompleteness: The Proof and Paradox of Kurt Godel* (New York: W.W. Norton & Company, 2005), 94.

8. *Ibid.*, 118.

9. *Ibid.*, 117.

10. For elaboration of this concept, see K. Charmaz, *The Social Reality of Death* (New York: Random House, 1980), 83.

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12. M.F. Mendez et al., "Compulsive Behaviors as Presenting Symptoms of Frontotemporal Dementia," *Journal of Geriatric Psychiatry and Neurology* 10, no. 4 (October 1997): 154-7.

13. T.F. Dagi, "Compassion, Consensus, and Conflict: Should Caregivers' Needs Influence the Ethical Dialectic?" *The Journal of Clinical Ethics* 3, no. 3 (1992): 214-8, 218, note 2.

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18. Astin, see note 14 above, p. 30.

19. Ramsey, see note 3 above, p. 40.

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27. L. Volicer, "Management of Severe Alzheimer's Disease and End-of-Life Issues," *Clinics in Geriatric Medicine* 17, no. 2 (May 2001): 377-391, 384.

28. K.Y. Kim, P.A. Yeaman, and R.L. Keene, "End-of Life Care for Persons With Alzheimer's Disease," *Psychiatric Services* 56, no. 2 (February 2005): 139-41, 140.

29. R. Schulz, D. Weiner, and L. Martire, "Correspondence: End-of Life Care for Patients with Dementia," *New England Journal of Medicine* 350, no. 7 (12 February 2004): 734.

30. K. Asplund, L. Jansson, and A. Norberg, "Facial Expressions of Patients with Dementia: A Comparison of Two Methods of Interpretation," *International Geriatrics* 7, no. 4 (1995): 527-34, 532.

31. I. Lavenu and F. Pasquier, "Perception of Emotion on Faces in Frontotemporal Dementia and Alzheimer's Disease: A Longitudinal Study," *Dementia and Geriatric Cognitive Disorders* 19 (2005): 37-41.

32. Holman and Brendel speculate that psychiatric personnel who were involved opposed the use of methadone mostly because they had a conditioned predisposition to preventing suicide.

33. The use of broad categories may be highly adaptive; see i.e., S. Pinker, *How the Mind Works* (New York: W.W. Norton & Company, 1997), 128-9.

34. S. Kothari, "Severe Brain Injury: Facts, Fiction, and Faith," (panel presentation at the American Society for Bioethics and Humanities Eighth Annual Meeting, Denver, 26 October 2006).

35. Ibid.. See also C. Hukkelhoven et al., "Some Prognostic Models for Traumatic Brain Injury Were Not Valid," *Journal of Clinical Epidemiology* 59 (2006):132-43.

36. D.L. Warden, "Military TBI During the Iraq and Afghanistan Wars," *Journal of Head Trauma Rehabilitation* 21, no. 5 (September/October 2006): 398-402.

37. K.H. Tauber, D.L. Warden, and R.A. Hurley, "Blast-Related Injury: What Is Known?" *Journal of Neuropsychiatry and Clinical Neurosciences* 18 (May 2006): 141-5.

38. M. Mouratidis, "Informed Consent in Patients with Traumatic Brain Injury," (2006 National Naval Medical Center Bioethics Symposium, Bethesda, Md., 25 April 2006).

39. P. Appelbaum, "Reviewing Research Involving Adults with Impaired Decision-Making Capacity (Including a SACHRP Update)," (paper presented at the 2006 Annual Human Research Protection Program Conference, Washington, D.C., 16 November 2006); see also T. L. Pape et al., "Unresolved Legal and Ethical Issues in Research of Adults with Severe Traumatic Brain Injury: An Analysis of an Ongoing Protocol," *Journal of Rehabilitation Research & Development* 41, no. 2 (March/April 2004): 155-74.

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41. H. Voss et al., "Possible Axonal Regrowth in Late Recovery from the Minimally Conscious State," *Journal of Clinical Investigation* 116, no. 7 (2006): 2005-11.

42. J.J. Fins, "Affirming the Right to Care, Preserving the Right to Die: Disorders of Consciousness and Neuroethics After Schiavo," *Palliative and Supportive Care* 4, no. 2 (2006): 169-78.

43. See, especially, A.M. Owen et al., "Detecting Awareness in the Vegetative State," *Science* 313 (8 September 2006): 140; and L. Naccahe et al., "Psychology: Is She Conscious?" *Science* 313 (8 September 2006): 1395-6.

I think in this regard of a patient who was in a coma, whose husband had melted chocolate on the tip of his finger, and placed it into her mouth. She smiled for the first time in months.

44. F. Dostoyevsky, *Notes from the Underground*, trans. R. Pevear and L. Volokhonsky (New York: Alfred A. Knopf, 1993), 116.

45. Thomas, see note 26 above, p. 147.